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Improving Quality of Life in Individuals Diagnosed with Parkinson's Disease and Their Caregivers

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Under the direction of the faculty capstone advisor:

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A Capstone Project Entitled

Improving Quality of Life in Individuals Diagnosed with Parkinson's Disease and Their
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Submitted to the School of Occupational Therapy at University of Indianapolis in partial fulfillment for the requirements of the Doctor of Occupational Therapy degree.

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Abstract

The purpose of this doctoral capstone project was to provide education and resources regarding the role of occupational therapy (OT) with Parkinson's disease (PD), coping skills, self-management, wellness, and fall prevention in order to improve overall quality of life (QoL) of individuals diagnosed with PD and their caregivers. Many individuals are diagnosed with PD each year and face a multitude of challenges that can affect performance in daily occupations. Individuals diagnosed with PD can experience difficulties with coping with this progressive illness, health and wellness, self-management of symptoms, and falls. This author conducted a needs assessment with staff of the Indiana Parkinson Foundation (IPF) to discover areas of interests and needs of the organization. Intervention consisted of three educational presentations to the participants of The Climb, an exercise program designed for individuals with PD, sponsored by IPF. This author presented material on what was found in needs assessment, such as the role of OT with PD, coping skills, self-management, The Seven Dimensions of Wellness, and fall prevention/Durable Medical Equipment (DME). Results included an increase in scores as measured by post-session surveys across multiple locations where Climb classes are held, as well as excellent feedback from participants with PD and their caregivers. Additionally, this author gained advocacy, leadership, and communication skills as well as advanced knowledge in the area of Parkinson's disease. Overall, this experience provided a great opportunity for an occupational therapy doctoral student to advocate for the role of OT in a community-based setting.

Improving Quality of Life in Individuals Diagnosed with Parkinson's Disease and Their Caregivers

An estimated 60,000 Americans are diagnosed with PD each year (Parkinson's Foundation, 2018). Parkinson's disease is a chronic, neurological condition with no cure (Parkinson's Foundation, 2018). About 4% of individuals diagnosed with PD receive their diagnosis before the age of 50 (Parkinson's Foundation, 2018). The symptoms of PD consist of motor and non-motor symptoms that are progressive in nature (Parkinson's Foundation, 2018). In a recent study, researchers discovered that persons with PD demonstrated reduced cognitive performance and had increased symptoms of depression, apathy, and anxiety (D'Iorio et al., 2017). Individuals diagnosed with PD progress through five stages, which can result in decreased independence in occupations, especially activities of daily living (ADLs) (Meek et al., 2010). In addition, caregivers can experience increased stress when assisting their loved one in everyday activities (Navarta-Sánchez et al., 2017). Based on this literature, there is a need for education and resources directed at helping individuals with a PD diagnosis and their caregivers.

Review of Literature

As Parkinson's disease is considered to be a chronic condition, it is important to recognize the role that occupational therapy (OT) can play within this population (American Parkinson's disease Association [APDA], 2019; American Occupational Therapy Association [AOTA], 2015). Occupational therapy practitioners can educate and train individuals diagnosed with Parkinson's disease in the skill of self-management (AOTA, 2015). Self-management is defined as, "the decisions and behaviors that patients with chronic illness engage in that affect their health" (Improving Chronic Illness Care, 2019, para. 1). PD may be difficult to manage due to the mental, emotional, and physical effects it has on the individual and the caregiver (Waite,

2014). Occupational therapists can teach individuals diagnosed with PD and their caregivers strategies related to energy conservation and work simplification, safety within the home environment, as well as ways to cope with the psychosocial challenges, such as anxiety and depression (AOTA, 2015).

Occupational Therapy Intervention

Multiple researchers have discovered the effectiveness of occupational therapy interventions with individuals diagnosed with PD (Chapman & Nelson, 2014; Meek et al., 2010; Sturkenboom et al., 2014). Sturkenboom et al. (2014) conducted a randomized controlled trial to assess the efficacy of home health occupational therapy with individuals diagnosed with PD. Participants were assigned to an OT intervention group that consisted of ten weeks of home health OT or to a control group (Sturkenboom et al., 2014). Researchers concluded that home health OT resulted in increased self-perceptions of occupational performance in daily activities, as measured by improvements on the Canadian Occupational Performance Measure (Sturkenboom et al., 2014). In a similar study, researchers completed a case study on a 78-year-old man diagnosed with PD in order to investigate the effects of home health occupational therapy (Chapman & Nelson, 2014). The OT intervention consisted of self-care training, fall prevention, yardwork, leisure pursuits, and religious participation over a six-week period (Chapman & Nelson, 2014). The researchers found improvements in mobility and functional transfers, increased independence with ADLs, an increase in quality of life, decreased fear of falling, and increased interest and participation in leisure activities (Chapman & Nelson, 2014).

Educational Interventions

Numerous researchers have examined the efficacy of educational interventions for PD (Cohen et al., 2016; Guo, Jiang, Yatsuya, Yoshida, & Sakamoto, 2009; Poyner-Del Vento, Goy,

Baddeley, & Libet, 2018). Educational interventions with caregivers have resulted in decreased psychological distress (Poyner-Del Vento et al., 2018). Similarly, educating health professionals in PD and team roles improved clinicians' knowledge and attitudes regarding working with the health care team in the care of PD patients (Cohen et al., 2016). Finally, educational interventions with PD patients have resulted in improvements in health-related quality of life (HRQoL), increased performance with ADLs and movement, and improved mood (Guo et al., 2009).

Self-Management Interventions

Multiple researchers have studied the effects of self-management interventions for PD (Advocat et al., 2016; Hellqvist, Dizdar, Hagell, Bertero, & Sund-Levander 2018; Navarta-Sánchez et al., 2017; Pickut et al., 2015). Self-management techniques that have demonstrated efficacy in the literature have included cognitive-behavioral therapy (Hellqvist et al., 2018), mindfulness training (Advocat et al., 2016; Pickut et al., 2015), and coping skills (Navarta-Sánchez et al., 2017). These interventions have resulted in significant improvements when conducted in group settings (Advocat et al., 2016; Hellqvist et al., 2018; Navarta-Sánchez et al., 2017; Pickut et al., 2015).

Based on the results of literature, it is evident how education and self-management interventions, such as mindfulness and the development of coping skills, can help individuals with PD self-manage their symptoms (Advocat et al., 2016; Cohen et al., 2016; Guo et al., 2009; Hellqvist et al., 2018; Navarta-Sánchez et al., 2017; Pickut et al., 2015; Poyner-Del Vento et al., 2018).

Theoretical Framework

The frameworks for this project were the social cognitive theory of self-regulation and the Health Belief Model (HBM). Based on the literature regarding PD, this author deemed education as the primary focus for this project. Bonnel & Smith (2018) recommend cognitive and behavioral theories for education, and the HBM for new programs. For this project, education regarding self-management of PD, the role of occupational therapy with PD, coping skills, health and wellness, and fall prevention and home safety were provided to clients, in order to help individuals and caregivers of PD manage their chronic condition and improve their overall quality of life.

The social cognitive theory has a large focus on interpersonal factors, behavior, and the environment (Lyons, 2003). Lyons (2003) discussed how this theory can be a beneficial framework for the development of self-management programs, especially within this population. The social cognitive theory suggests that individuals can develop skills to overcome obstacles by practicing self-examination, assess what is happening, and respond with problem-solving behaviors, otherwise known as self-regulation (Lyons, 2003). This theory provides beneficial guidelines for this author, as the goal was to educate the clients on looking internally and externally at themselves, observe their symptoms and feelings towards PD, and change or modify their behavior in a positive way that will help them self-manage their condition, and in turn, improve their quality of life.

The HBM has a large focus on personal health beliefs and health behaviors (Scaffa, Reitz, & Pizzi, 2010). According to the model, perceived susceptibility, perceived severity, perceived benefits, and perceived barriers are the beliefs that influence health behavior (Rosenstock, 1966, 1974; Scaffa, Reitz, & Pizzi, 2010). For this project, all of the clients had

already been diagnosed with PD or were a caregiver for a loved one with PD, the component of perceived resusceptibility, which includes the belief in the certainty and acknowledgement of the diagnosis, was also used as a guideline (Becker, 1974; Rosenstock, Strecher, & Becker, 1994; Scaffa, Reitz, & Pizzi, 2010).

By using the social cognitive theory and HBM, the author aimed to educate consumers and staff associated with Indiana Parkinson Foundation (IPF) on the role of OT with PD, coping skills, self-management, wellness, and fall prevention in order to inform the consumers on the importance of examining their personal health beliefs and behaviors and to promote positive behavior change. As a secondary focus, this author provided resources to the site regarding the above topics that can be administered to future consumers of the organization.

Screening & Evaluation

The Indiana Parkinson Foundation is a non-profit, community-based organization that aims to “improve the daily lives of people with Parkinson’s disease, by providing research-based exercise programs and support systems” (Indiana Parkinson Foundation, 2019). In order to thoroughly assess the needs of IPF, this author developed and conducted a needs assessment and a Strengths, Weaknesses, Opportunities, and Threats (SWOT) analysis (Bonnell & Smith, 2018; Scaffa, Reitz, & Pizzi, 2010). This author conducted informal interviews with the program director, leaders of the support groups, and the volunteer coordinator in order to gain insight into the needs of the organization. Several themes developed from the needs assessment. The consumers of the IPF were lacking knowledge on a variety of topics, such as the role of occupational therapy, and medication and sleep. The site mentor reported that there was difficulty in obtaining feedback from the support groups as well as decreased attendance at the support groups. The staff of IPF expressed a desire for more education and resources regarding

the role of OT with PD, coping skills, wellness, self-management of PD, fall prevention and durable medical equipment (DME) resources. Please see Appendix A for the needs assessment questionnaire.

This author and the program director at the site collaboratively decided to hold educational sessions regarding the above topics, in order to increase knowledge of the consumers. This author and the program director of IPF decided to plan the educational sessions after The Climb classes, which offer research-based exercises in a group format, targeted towards slowing the progression of PD symptoms. The findings from the needs assessment correlated to what was discovered in the literature. According to the literature, persons with PD are more likely to have difficulty coping with their chronic illness, have decreased HR-QoL, are at an increased risk for falls, and have a need for self-managing their symptoms (Advocat et al., 2016; Chapman & Nelson, 2014; D'Iorio et al., 2017; Hellqvist et al., 2018; Navarta-Sánchez et al., 2017). Therefore, the author deemed these topics to be important to address with the consumers of the organization.

The service delivery model of this project differs in comparison to other practice areas. The screening and evaluation for this project took place in a community-based setting that is focused on health and wellness of individuals with PD. These types of settings are considered to be *emerging practice areas* (O'Brien & Hussey, 2012). This author used a consultative model of service but was not able to bill for services due to a licensed occupational therapist not being on site. This differs in comparison to more traditional settings, such as acute care or subacute care, which would typically bill for services directly, rather than using a consultative model (O'Brien & Hussey, 2012). The main difference between this emerging practice area and an existing practice area is the method of service delivery and ability to bill for services.

Despite the differences across practice settings, the subject matter of the planned interventions would likely be similar to that in a traditional setting. Occupational therapists working with individuals with PD in the medical model of practice, would likely address similar topics, such as fall prevention and education on self-management, due to the evidence in OT literature (Chapman & Nelson, 2014; Sturkenboom et al., 2014). Further research should be completed in order to examine the precise similarities and differences across practice areas for efficacious interventions for treating individuals with PD.

Implementation Phase

For the implementation phase of this project, this author examined the results of the needs assessment and SWOT analysis in order to develop goals for reaching the needs of IPF. The needs and expressed desires of IPF consisted of more education regarding the role of occupational therapy with PD, coping skills, wellness, self-management of PD, fall prevention and DME resources. Other expressed needs from IPF consisted of wanting more education and resources regarding medication and sleep, as well a way to obtain feedback from caregiver support groups and a way to address decreased attendance at caregiver support groups. This author then developed educational sessions that consisted of a presentation and handouts based on current, evidence-based practice. Please see Table 1 for the expressed needs and DCE student goals.

Three educational presentations were prepared and presented at two of the locations where The Climb classes are held, Greenwood and Noblesville, Indiana. Two topics were discussed within each presentation. The material in session 1 consisted of education and advocacy for the role of occupational therapy with Parkinson's disease, as well as coping skills. The material in session 2 consisted of education on The 7 Dimensions of Wellness and the skill

of self-management. The material in session 3 consisted of education and resources on fall prevention, home safety, and DME. Objectives for each presentation were developed based on the content of each presentation. Please see Table 2 for the specific objectives for each educational session.

The sessions took place once a month at each location, from January to April 2019. In order to promote effective implementation of the education and resources, this author consulted occupational therapy textbooks and current research articles to develop each of the educational sessions. Additionally, this author included pre and post surveys which allowed for attendees to give feedback, as well as the ability for this author to measure the effectiveness of the educational sessions. Likert rating scales were used for the pre and post surveys for the consumers to rate the effectiveness of each presentation. The pre and post surveys each contained 5 questions in which participants could rate their knowledge on a scale of 1 to 5 on the given topics before and after each presentation. Furthermore, the surveys had a designated space for consumers to write comments or suggestions regarding the presentation.

Throughout the implementation phase of this project, this author incorporated various leadership skills within each presentation. This author used effective communication in order to deliver the educational pieces through a presentation format, followed by an opportunity for attendees to ask questions. This author also rehearsed each of the presentations several times to ensure effective delivery. In addition, this author had the opportunity to present the materials and lead discussions at the caregiver support groups, which required effective communication, time-management, and organization skills. These skills also aided in the development of the staff. Some staff members were unfamiliar with a few pieces of the educational material and resources that this author provided, which further increased their knowledge and ability to coach

and support their clients, specifically resources regarding wellness and fall prevention. Additionally, this author had the opportunity to develop a fall prevention handout that will be added to training manuals of IPF for future trainers, in order to promote further staff development. Toward the end of the DCE rotation, this author was given the opportunity to travel with the site mentor to educate Climb trainers at different locations across Indianapolis on the educational pieces that the DCE student developed. This was another example of how leadership, communication, and planning promoted staff development across multiple Climb locations.

Discontinuation and Outcome Phase

The first educational sessions took place in Noblesville and Greenwood, IN. The role of occupational therapy with PD and coping skills were presented to the consumers. Thirteen consumers were present at Noblesville and 14 consumers were present at Greenwood. Consumers consisted of individuals diagnosed with PD, their caregivers, Climb trainers, and Climb volunteers. This author discovered a 1.5 increase in scores from the pre and post, 5-item Likert scale, survey in Noblesville and a 1.2 increase in scores in Greenwood. Many consumers wrote positive comments and feedback on the surveys. Some comments ranged from “interesting”, “the positive coping skills were especially helpful”, to describing this author as “perceptive, interesting, caring, and knowledgeable”.

The second educational sessions also took place in Noblesville and Greenwood, IN. The Seven Dimensions of Wellness and the skill of self-management were presented to the consumers. Fifteen consumers were present at Noblesville and 11 consumers were present at Greenwood. This author discovered a 1.7 increase in scores from the pre and post, 5-item Likert scale, survey in Noblesville and a 1.3 increase in scores in Greenwood. Feedback for this author

consisted of many positive comments. One individual wrote “This was very informative and beneficial. I feel as though I can provide better care to my wife. Thanks”.

This author presented the third educational sessions at Noblesville and Greenwood and educated the consumers about fall prevention, home safety, and DME. Eleven consumers were present at Noblesville and 15 were present at Greenwood. This author discovered a 1.7 increase in scores from the pre and post, 5-item Likert scale, survey in Noblesville and a 1.5 increase in scores in Greenwood. Various of the attendees wrote in feedback for this author, such as “Presentation was well done”, “I am now much better informed to be a good caregiver”, and “Covered material in a timely manner”.

In order to ensure quality improvement and ongoing education for The Climb trainers, this author provided electronic and paper copies of all handouts, resources, and materials for IPF to pass along to staff members and trainers, so the consumers of The Climb at all locations can continue to be served and educated in an effective manner. Additionally, this author provided the program director with a list of possible projects or programs that future DCE students could complete in order to serve IPF and ensure further quality improvement. Due to the large number of individuals diagnosed with PD in today's society, and the number of deficits that can be associated with PD, such as difficulty coping with and self-managing the illness, an increased fall risk, and decreased health-related quality of life, this author was able to effectively meet the needs of this Indiana organization by providing quality, evidence-based materials. The materials presented effectively met the needs of IPF, based on what this author discovered in the needs assessment, and how the consumers' knowledge increased after observing each presentation.

Overall Learning

Through the doctoral capstone experience, this student demonstrated excellent leadership and advocacy skills. The first educational session advocated for the role of occupational therapy when working with individuals with PD and their caregivers. In addition, when attending meetings and networking events, this author educated others on the purpose of the DCE project, as well as advocated for the occupational therapy profession as a whole. This author demonstrated effective leadership skills by constructing a needs assessment and developing educational materials that were pertinent for IPF.

Through the DCE experience, this author was able to gain in-depth knowledge about Parkinson's disease, through the participation and observation of The Climb exercise classes, conference calls with larger organizations, support groups, assessments, and guest speakers' presentations. Additionally, this author demonstrated effective communication and exceptional time-management skills by completing projects in a timely manner and taking the time to get to know the consumers of IPF. This author had the opportunity to meet many individuals, caregivers, healthcare professionals and non-healthcare professionals, and learn from them while also educating about various topics in the OT profession. Overall, this experience was a great way for this author to gain advanced knowledge in the area of Parkinson's disease as well as improve the knowledge of others' through education and advocacy.

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Table 1

Expressed need from organization and correlating DCE Student Goals

Expressed Need	DCE Student Goal
Knowledge on role of occupational therapy	Provide education and handouts on role of occupational therapy to participants, caregivers, and trainers through a presentation format.
Resources and information on medication	Out of DCE student's scope.
Information on healthy sleep habits	Provide a handout of tips to improve sleep hygiene.
Lacking feedback from support groups	Provide an attendance sheet after each meeting to site mentor who can use it to send satisfaction surveys to participants that attended
Decreased attendance at support groups	Out of DCE student's scope.
Coping Skills	Provide education and handouts on coping skills for participants, caregivers, and trainers through a presentation format.
Wellness	Provide education and handouts on The 7 Dimensions of Wellness for participants, caregivers, and trainers through a presentation format.
Self-Management	Provide education and handouts on self-management strategies for participants, caregivers, and trainers through a presentation format.
Fall Prevention/DME	Provide education and handouts on practical steps to help prevent falls and DME that can be used to help prevent falls to participants, caregivers, and trainers through a presentation format.

Table 2

Educational Session Objectives

Education Session	Objectives
<p>Session 1: Role of Occupational Therapy with PD; Coping Skills</p>	<ul style="list-style-type: none"> ● The purpose of this session is to better understand the role of occupational therapy (OT) and how it can help you or your loved one with PD. ● By the end of this session, you will be able to recognize how OT can be beneficial before something happens, such as a fall or a complication of Parkinson’s Disease. ● By the end of the session, you will be able to understand how positive coping skills can help you or your loved one manage symptoms of Parkinson’s disease.
<p>Session 2: The Seven Dimensions of Wellness; Self-Management</p>	<ul style="list-style-type: none"> ● By the end of this session, you will have a better understanding of each of the seven dimensions of wellness. ● By the end of the session, you will have a list of practical steps that you can use to enhance each of the areas of wellness in your life. ● By the end of the session, you will have a better understanding of how to self-manage your symptoms of PD and your overall health. ● By the end of the session, you will be educated on free resources available from the national Parkinson’s Foundation that you can use in your daily life.
<p>Session 3: Fall Prevention; Durable Medical Equipment</p>	<ul style="list-style-type: none"> ● By the end of this session, you will have a better understanding of some of the causes of falls. ● By the end of the session, you will have some general advice on how to prevent falls.

	<ul style="list-style-type: none">● By the end of the session, you will be educated on proper durable medical equipment that can help prevent falls while completing activities of daily living.
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Appendix A
Needs Assessment

What are the biggest strengths of your programs?

What are the biggest areas for improvement?

What are some of IPF's short and long-term goals?

How do you incorporate mental health/wellbeing into your programs?

Are there any topics/areas that the participants of your programs have asked to be addressed more often? If so, what are they?

Which topics are you most interested in? Check all that apply.

_____ The role of occupational therapy with Parkinson's Disease

_____ Preventing falls within the home environment

_____ Durable medical equipment (grab bars, bathroom equipment, etc.)

_____ Coping Skills

_____ Tips on self-managing Parkinson's Disease

_____ Resources on wellness

_____ Other (Please specify):
