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THE IMPACT OF AN OCCUPATION BASED PARKINSON CAREGIVER PROGRAM ON
CAREGIVER'S QUALITY OF LIFE

Presented in Partial Fulfillment of the
Requirements for the Degree of
Doctor of Occupational Therapy

Eastern Kentucky University
College of Health Sciences
Department of Occupational Science and Occupational Therapy

Jennifer Labonte
2019

**EASTERN KENTUCKY UNIVERSITY
COLLEGE OF HEALTH SCIENCES
DEPARTMENT OF OCCUPATIONAL SCIENCE AND OCCUPATIONAL
THERAPY**

This project, written by Jennifer Labonte under direction of Casey Humphrey Faculty Mentor, and approved by members of the project committee, has been presented and accepted in partial fulfillment of requirements for the degree of

DOCTOR OF OCCUPATIONAL THERAPY

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Certification

We hereby certify that this Capstone project, submitted by Jennifer Labonte conforms to acceptable standards and is fully adequate in scope and quality to fulfill the project requirement for the Doctor of Occupational Therapy degree.

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Executive Summary

Background: Many people with Parkinson Disease (PD) rely on unpaid and untrained caregivers, typically their spouse, to meet their mobility and self-care needs as their disease progresses. Occupational therapists have the knowledge, skills, and resources to ensure that unpaid caregivers can provide quality care and promote aging in place for the person with Parkinson disease all while maintaining quality of life indicators.

Purpose: The Occupation Based Parkinson Caregiver Program (OBPCP) overarching goal is to enhance the PD patient's caregiver's ability to provide quality care to meet the ever changing needs of a neurodegenerative medical condition along with enhancing quality of life indicators of the caregiver. The OCPCP experimental theory is that quality of life reports of PD caregivers will be enhanced through an occupation based educational program.

Theoretical Framework. The theories that shaped this project are the Ecology of Human Performance, Malcom Knowles principles of andragogy, anthropology learning in communities of practice, the humanist framework, and the constructivist orientation theory.

Methods. The project design was an experimental one group pre and posttest design. The outcome measurement tool was the Parkinson Caregiver Quality of Life Index. Data was analyzed utilizing a paired t-test for individual questions and the total score on the Parkinson Caregiver Quality of Life Scale.

Results. No statistical significance was found between pretest and posttest scores. However, positive improvements were noted on specific components of the scale. Additionally, caregivers self-reported that the course provided valuable and insightful information that will aid both the caregiver and the person with PD.

Conclusions: Occupational therapists should continue to engage in developing research and methods that serve as a guide on best practices to meet the ever changing burdens and demands placed onto the PD caregiver. Further research is required to determine how to best meet the gap in present health disparities experienced by the PD caregiver.

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THERAPY

CERTIFICATION OF AUTHORSHIP

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Certification of Authorship: I hereby certify that I am the author of this document and that any assistance I received in its preparation is fully acknowledged and disclosed in the document. I have also cited all sources from which I obtained data, ideas, or words that are copied directly or paraphrased in the document. Sources are properly credited according to accepted standards for professional publications. I also certify that this paper was prepared by me for this purpose.

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Date of Submission: 5-2-2019

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Section 1: Nature of Project and Problem Identification

Introduction

Parkinson's disease is the second largest neurological degenerative disease affecting the American population (Miller & O'Callaghan, 2015). While there are many resources available for the caregiver, such as support groups, respite stays, and adult day care sites, caregivers continue to have unmet needs. The American Parkinson's Association (APA) and National Parkinson's Foundation have a wide assortment of resources for Parkinson's patients and their support system however, education and training on successful engagement in the occupation and role of caregiving is insufficient to meet most caregiver needs (American Parkinson Disease Association, 2018; Parkinson Foundation, 2018). Health professionals that come in contact with a caregiver caring for a person with a terminal illness often fail at identifying caregiver needs as they are not the client. Rather, the healthcare professional focuses on maintaining the terminally ill person's physical and mental outlook (Bhimani, 2014; Levine, Halper, Peist, & Gould, 2010).

Levin, Halper, Peist, and Gould (2010) indicate that informal caregivers, that is the patient's spouse, child, and other family members, account for \$375 billion per year of unpaid labor costs. These unpaid labor costs have significantly reduced the overall financial burden that has been placed on the Medicare and Medicaid programs. Lageman, Mickens, and Cash (2015) found that 41% of study participants, informal caregivers, remained employed while providing care. In addition, employed caregivers reported missed work on average 3.22 days within a 7 days period due to their caregiving role. Missed employment has a financial implication which impacts both employer and employee. Thus, while

informal caregivers play a key role in healthcare cost containment there is a reverse burden placed on the caregiver and the family's economic self-sufficiency.

Several researchers have identified Parkinson's Disease (PD) caregiver needs, the impact on the unmet needs of the PD caregiver, and the relationship to quality of life and well-being of the PD caregiver (A'Campo, Spliethoff-Kamminga, Macht, & Roos, 2010; Mott, Kenrick, Dixon, & Bird, 2005; Habermann & Davis, 2005). A'Campo, et al. (2010) work in particular, analyzed a PD caregiver education program schooled by psychologists. While the program aided in the enhancement of psychosocial skill growth, it lacked the occupation-based training required to meet the physical demands placed on informal caregivers. Mott et al. (2005) found that education and training in day to day techniques for the PD caregiver enhanced their sense of control, decreased emotional distress, and increased coping mechanisms. While, Habermann and Davis (2005) found that caregiver education that supported self-care, health, and wellbeing was important to the PD caregivers. These studies along with others, have identified a need that can be met by occupational therapists that will enhance the quality of life of caregivers in a more holistic manner.

Caregivers of people with PD often have multiple unmet needs. Housngaard, Pedersen, and Wagner (2011) interviewed female PD caregivers and found that caregiver distress was often a result of PD cognitive changes and changes in personal relationship with the person with PD. In addition, the researchers found that caregivers' quality of life was reduced as they set their own needs aside while providing care. Martinez-Martin, et al. (2007) research into caregiver burden and PD showed that caregiver burden was impacted by caregiver strain, time spent providing care, caregiver psychosocial

wellbeing, their ability to adapt to aspects of the changing disease process, and the person with PD mood. Martinez-Martin, et al. (2008) research into PD caregiver burden, perceived health status and mood, found caregiver depression was linked to disease severity, caregiver quality of life deteriorates with PD disease severity, and social support and self-reported sleep impacted PD caregiver burden of care. Research into PD caregivers clearly demonstrates that caregivers have specific needs related to the occupation of caregiving and role the PD disease process plays into their ability to provide quality care.

Occupational therapists provide a wide variety of services to people with PD in a variety of settings. These care settings can include acute care hospitals, outpatient, home health, and skilled nursing facilities. The services provided to people with PD can include activities of daily living retraining, balance retraining, instrumental activities of daily living training, fine and gross motor training, and PD disease symptom management. Foster, Bedekar, and Tickle-Degnen (2014) systematic review of occupational therapy interventions with people with PD suggests that occupational therapists should assist the person with PD to engage in meaningful activities including physical exercise. They further suggest, that treatments should be tailored to the client and their environment to promote engagement in occupations, maintain engagement in valued activities and roles, and provision of cues and supports for the person with PD and their caregiver in order to regulate physical performance during daily tasks. Occupational therapists are best suited to implement an educational program for the PD caregiver as they have the knowledge and expertise in promotion of engagement in meaningful tasks, adaptations that enhance

engagement in meaningful occupations, and tailor their interventions based on specific needs of a person or group.

Problem Statement

Parkinson disease caregivers receive little to no formalized training that prepares them and/or provides them with ongoing guidance on how to deliver the Parkinson patient with assistance in their daily care needs and mobility challenges (Parrish, Giunta, & Adams, 2003). In addition, PD caregivers receive little to no support for mental health challenges commonly experienced by caregivers of neurodegenerative diseases (Fernandez, Tabamo, David, & Friedman, 2001). Lack of formalized training and absence of ongoing guidance can lead to caregiver injury with new onset of a chronic illness and/or disease, delayed medical treatment or delayed management of new or worsening PD symptoms, and increased caregiver mental health illness (Lagemam, Mickens, & Cash, 2015; Turney & Kushner, 2017; Wressle, Engstrand, & Granerus, 2007). Chronic and/or acute illness and injury along with mental health burnout frequently leads to PD patients' need to transition into skilled nursing care and prevents them from aging in place. No current studies have been located that address PD caregiver needs from an occupation based client centered approach. A study that provides direction and support for programming for PD caregiver needs will impact a growing population demand. The proposed capstone project objective is to address the identified missing needs by providing PD caregivers the tools, education, and resources required to successfully engage in the occupation and/or role of caregiving.

Purpose of Project

The Occupation Based Parkinson Caregiver Program (OBPCP) overarching goal is to enhance the PD patient's caregiver's ability to provide quality care to meet the ever changing needs of a neurodegenerative medical condition along with enhancing quality of life indicators of the caregiver. The purpose of the OCPCP experimental study is to test the theory that quality of life reports of PD caregivers will be enhanced through an occupation based educational program. The independent variable within this research study is defined as the "educational program" which, will consist of seven modules and skill practicum sessions. The dependent variable is defined as "quality of life" which can best be described as how an individual perceives their overall sense of well-being. Quality of life will be measured through a Parkinson Caregiver Quality of Life Scale.

Project Objectives

The research study utilized a quantitative pretest posttest approach to examine whether an occupation based, client centered educational and skill practicum program will impact the quality of life reports of the PD caregiver. Educational modules within the research study contain individualized learner objectives specific to each learning module and are referenced in the Appendix. The learning outcomes for the learning modules are aligned with Finks' (2003) categories of foundational knowledge, application, integration, human dimension, caring, and learning how to learn.

The educational objectives of the Occupation Based Parkinson Caregiver Program are to provide knowledge, experience, and resources to reduce the overall burden of care placed on the caregiver, enhance their quality of life, and overall general well-being.

Theoretical Framework

Multiple theories have influenced the design of the Parkinson's caregiver educational project. These include, The Ecology of Human Performance, Malcom Knowles principles of andragogy, anthropology learning in communities of practice, the humanist framework, and the constructivist orientation theory. Theories are instruments that an instructor utilizes to guide the method of delivery of information and skill obtainment. The selection of which theory will guide an instructional model is dependent on both the instructor and the learner. For the purpose of this capstone project, influences were drawn from multiple theories and will be discussed and analyzed below.

Ecology of Human Performance (EHP) examines the relationship between the person, the context, occupations, performances, roles, and the environment. EHP takes into consideration the impact of the individual's unique experiences and personal context during the completion of the occupation in real life (Dunn, Brown, & McGuigan, 1994). Each individual with PD and their caregiver experiences are unique and shape their interactions, not only with each other but with the caregiver's ability to successfully engage in the occupation of caregiving. The role of the occupational therapist within this project is to alter, adapt, prevent, and create situations in which the caregiver can enrich the meaning behind their caregiving roles, successfully engage in the occupation of caregiving, and create an environment for all participants.

Kaufman (2003) discusses Malcolm Knowles adult learning theory and the principles that guide his theory. In particular, establishment of a learning environment in which the learner feels confident conveying their educational needs and participation of learners in the shared planning of content. An initial needs assessment was conducted for

verification of educational opportunity necessities. The findings of the needs assessment confirmed the author's personal experiences regarding the topic areas in addition to literature review findings. The location of the learning environment selected for this educational project will be conducted at a current site utilized by local support groups of which the participants are familiar. The Knowles adult learning theory thus, are one of four that are framing the course outline and learning activities.

Anthropology of situated learning in community practice learning theory is a thought process in which the learner learns through practice and within a context (University of California Berkley, 2016). Occupational therapists frequently "practice" new learned techniques with clients to assist in the acquisition of new skills. When developing this educational project, the goal was for the participant to be provided the opportunity to practice the taught techniques for two primary reasons. First, to help carry over learned material as discussed in the anthropology of situated learning. Second, to begin the development of critical problem solving that may be required when new situations are encountered related to environmental, activities of daily living, or mobility challenges. An example of this would be - when encountering a bathroom that is not handicap assessable - how the caregiver and the person with PD can successfully complete the toilet task. Situated learning will aid the caregiver in development of the tools required to support aging in place.

The next learning theory which has influenced this educational project is the humanist framework. Torre, Daley, Sebastian, and Elnicki (2006) express this learning theory as an internal force which stimulates the individual to achieve their full possibilities. The educator role is to facilitate the growth of the learner. Caregivers,

whether formal or informal, want to provide the best possible care to the person with PD. As the facilitator of this educational design, the material presentation format and additional tools and resources provided will aid the participant in achieving success as a caregiver to a person with PD. The humanist theory will enhance the caregiver's skill knowledge to prevent injury to both the person with PD and caregiver and allow for aging in place.

Finally, the constructivist orientation learning theory is the last theory that has shaped this educational design project. Under this model, participants gain knowledge and skill attainment through the incorporation of tasks and experiences (University of California Berkley, 2016). Each learning module has both a lecture component and a skill practicum component in which participants will be able to actively engage and develop skills needed to successfully allow the person with PD to remain in their own home. During the skill practicum session, participants will be asked to reflect back on personal experiences and knowledge shared during the current experience to facilitate a deepened understanding into the subject materials. Self-reflection will aid the caregiver in additional identification of needs thus reducing caregiver burden to allow the person with PD to continue to reside in their home.

Significance of Study

Informal caregivers provide a significant amount of unpaid care to the person with Parkinson's disease. In addition, many do not receive any formalized training on how to manage and cope with changes in participation in occupations throughout the neurodegenerative disease process. This study will provide critical training, tools, and resources to the PD caregiver that will enhance their ability to provide care, enhance their

ability to engage in the occupation of caregiving, and enhance the ability of the person with PD to age in their own home for the duration of the disease process that are not present within the current healthcare system. Furthermore, successful engagement in occupations can reduce the risk of new onsets of chronic injury which have the potential to lessen the current burdens within our healthcare system. This study will create a potential new area of community practice for occupational therapists that highlights how the occupational therapy profession can provide enhanced healthcare outcomes to a population. Finally, this study has the potential to become a national recognized program that becomes a standard in healthcare delivery.

The occupation based client centered Parkinson caregiver program is designed to develop and enrich the lives of the PD caregiver and the person with PD to allow successful engagement in occupations and promote aging in place. This program provides a vital link that is currently missing within the healthcare system. Caregivers are only successful when they have the essential tools and resources. Occupational therapy's scope of practice and unique skill set are the perfect match to provide this training.

Section 2: Literature Review

Parkinson's disease, like other neurodegenerative diseases, impacts both the person with the disease and the individual who provides care as the condition worsens. The literature surrounding Parkinson's disease and the PD caregiver can be summarized into the following categories: Parkinson's disease in general, Caregiving in general and the healthcare system, PD caregivers perspectives, PD caregivers needs, PD caregiver burden, Quality of life in PD caregivers, stress management and caregivers, Parkinson's disease and cognition, PD and sleep disorders, PD psychological impacts, and PD caregiver programs. A summary of the literature surrounding this capstone project will be discussed below.

Parkinson's Disease and Caregiving

Hirsch, Jette, Frolkis, Steeves, and Pringsham's (2016) meta-analysis examined the incidence of Parkinson's disease and its relationship to the aging population. Based on their study, men between the ages of 60-79 were more likely to be diagnosed with PD than women. In addition, the incidence of diagnosis of PD increased with age varying from 2.94/100,000 starting at age 40 to 132.72/100,000 between the age of 70 to 79. The authors report an overall PD diagnosis incident rate of 17 per 100,000 in the general population. As the population ages, the occurrence of PD is expected to increase in conjunction with the population thus, a program focused on the PD caregiver to enhance aging in place will be of benefit to communities.

Research by Donelan et al. (2002) indicates that one in four individuals are currently engaged in the role of a caregiver for an adult with, 79% being either the spouse or child of the person with an illness/injury. In addition, 52% are employed full time and

11% are employed part time in an outside career/job. Fifty four percent of caregivers reported that they are helping with a majority of ADL activities which included bathing, dressing, and toileting tasks. On average, the caregivers reported spending 8 to more than 41plus hours per week in their caregiving role. Finally, 21% reported caregiver health worsening since the onset of the caregiving role. Donelan and colleagues' (2002) research provides the healthcare community with a portrait of additional trials caregivers encounter in the daily routines and supports the need to aid in reducing their burden of care.

Levine, Halper, Peist, and Gould's (2010) research specified that caregivers need experienced clinicians to develop trainings that enhance their quality of care provided by the caregiver for both the chronic and long term care needs to the care recipient. In addition, caregivers required the tools and resources to successfully manage the recipient's needs, understand the healthcare system in order to be an advocate, and independently manage the stressors associated with engagement in the occupation of caregiving. This research provides evidence that an educational program designed to meet the needs of PD caregivers is desired within this population.

Caregiver Needs

Whether the person receiving care is a child or an adult, the caregiver in many instances, provides both physical and emotional support to the individual. Providing care to an individual with a neurodegenerative condition such as Dementia, Parkinson's, Multiple Sclerosis, or even ALS, creates a new set of physical and emotional demands on the caregiver. Neurodegenerative conditions change, often deteriorating, with time placing more of the care requirements onto the caregiver and increasing their burden of

care. Increased burden of care can lead to increased rates of institutionalized care needs, caregiver burnout, and caregiver injury and illness.

Mott, Kenrick, Dixon, and Bird's (2005) study revealed that caregivers of Parkinson's disease patients reported loneliness, sleep disturbances, emotional stress, and anger/frustration. In addition, Mott et al. (2005) found that as PD progresses caregivers' stress levels and the burden of care can become overwhelming. The research concluded that support and training on daily management of Parkinson's disease enhanced the caregiver's sense of control and perceptions surrounding the disease unknowns.

Research by Habermann and Davis (2005) looked into the needs and challenges faced by caregivers of Parkinson's disease and revealed the demand for caregivers to have knowledge and skill training in self-care components, providing optimal care, and management of their own health and well-being while fulfilling the role of a caregiver. Habermann and Davis's (2005) research compared caregivers of Parkinson's disease to caregivers of Alzheimer's disease. Their data indicated that Parkinson's caregivers had a greater number of self-care components that they found difficult when compared to the Alzheimer's caregivers. From an occupational therapy lens, this makes sense due to the increased motor challenges faced by Parkinson's patients throughout their disease process.

Aoun, Kristjanson, and Oldham's (2006) research looked at the unmet needs of caregivers of people with neurodegenerative conditions and found that caregivers' ability to provide care in the home depended on the carer's ability to cope both mentally and physically with the role of caregiving. In addition, caregivers and the person with the neurodegenerative condition preferred to age in place and required improved training to

successfully remain in their home throughout the disease course. Finally, caregivers and person with the medical condition reported a need for enhanced information and coordination of services from all healthcare providers. An occupation based caregiver educational program has the ability to provide caregivers with the tools and resources required to allow greater numbers of individuals to successfully age in place.

Work by Wressle, Engstrand, and Granerus (2007) found that people with PD experienced restrictions in their activities of daily living, changes in previously established habits, decreased socialization, and increased worry and fear of falling. While the caregivers reported, changes in roles and responsibilities, decreased socialization, increased worry over the future, changes in habits, and relationship constraints. Both the caregiver and person with PD indicated that psychological support was important along with enhanced coping strategies, and accessibility to healthcare providers. This research aids in supporting the need for caregiver education and training in psychosocial management and client centered engagement in activities of daily living.

Houngaard, Pedersen, and Wagner (2011) interviews with informal PD caregivers found four central themes in their interviews. First, the caregiver needed to learn how to live with a person with a neurodegenerative condition that impacts both physical abilities and cognitive abilities over time. Second, that contact with healthcare providers on medication administration was a critical element to enhance function due to the timing of medication activation with the PD person's body. Third, control of power shifted throughout the progression of the disease impacting both the carer and the person with PD sense of helplessness and enhanced feelings of anxiety. Finally, a change in self-management was reported. This consisted not only of the person with PD declining ADL

needs, but also the increased burden of care placed on the carer. Hounsgaard and colleagues' (2011) research aids in identifying a need for caregiver training in management of clients factors which impact the occupation of caregiving.

Turney and Kushner (2017) found in their research that PD spouse caregivers experienced strong sense of commitment to the role of caregiving. In addition, many found that while they had support systems in place for respite services, challenges faced at end stages such as frequent falls, incontinence, and behaviors had a significant impact on the person with PD ability to age in place. The authors suggested that, based on their findings, healthcare practitioners should discuss options in the PD advanced stages, provide additional support and resources for mental stressors faced by the population, and provide resources to enhance social interactions for the PD caregiver. Lageman, Mickens, and Cash (2015) examined PD caregiver's needs and barriers to services. The researchers found that caregiver stress is impacted by the person with PD functional level for ADL and mobility. In addition, the PD caregivers identified a need for services and/or training in coping with lifestyle changes associated with PD, wellness strategies, stress management, emotional changes associated with PD, and managing personality and cognitive changes associated with PD. Turney and Kushner (2017) and Lageman and colleagues (2015) research supports the need for caregivers to have training in the PD disease process, participation in activities of daily living, and instruction in management of client factors which impact activities of daily living.

Pasetti et al. (2003) study indicated that Parkinson's caregivers would like to have greater knowledge of the disease process. In addition, the caregivers would like to have greater support from both their communities and families to assist them in their

caregiving role. The work by Pasetti et al. (2003) suggests that caregivers would benefit from tools and access to resources that provide aid for the caregiving role along with education on disease process and progression management.

The work of Parrish, Giunta, and Adams (2003) reveals that Parkinson's caregivers reported a higher rate of prevalence of depression, high blood pressure, and arthritis. The study results suggested that Parkinson's caregivers have a need for respite care, training on behavior management, and emotional support. Parrish, Giunta, and Adams (2003) suggested that educational trainings and written materials for the caregiver on topics such as behavior management and wellness would be beneficial to the Parkinson's caregiver. In addition, they identified 16 self-care areas that were upsetting to the caregivers. These included bathing, toilet use, mobility, supervision for safety, and incontinence. Therefore, an education program that incorporates management of functional tasks, behaviors, and wellness would be valuable to the Parkinson's caregiver and should be considered as potential topic areas for presentation materials.

Finally, research by Ferreria, Coriolano, and Lins (2016) into PD caregiver needs found that interpersonal family relationships was critical to assisting with coping with the changes associated with the disease process. The researchers also found that knowledge about PD was important for enhanced quality of life for both the person with PD and their caregiver. In addition, improved caregiver support on disease management can lead to enhanced healthcare solutions. Furthermore, the authors stated that training programs that enable caregivers to increase information and awareness on the disease process can enhance quality of life. This research, in addition to the others presented above, validates the need programming for the caregiver.

Caregiver Burden and Quality of Life

Caregiver burden and quality of life are indicators that reflect how the caregiver is feeling and coping with the demands of the caregiving role. Developing an understanding into the caregiver burden and quality of life indicators allows healthcare professions to provide treatment and resources to meet this population needs. Numerous research studies were located that examined the relationship between the PD caregiver and burden of care and/or quality of life perceptions. Below is a summary of current literature findings on caregiver burden of care and quality of life.

Bhimani (2014) completed a literature review to better understand the burden on caregivers with PD. Bhimani's work found that caregivers often report feelings of being overwhelmed by the physical demands of caregiving and are unprepared to care for the person at home. In addition, caregivers of PD distress was directly linked to the level of impairment the person with PD displays. The person with PD sleep disturbances can directly impact the caregivers sleep patterns leading to increased feelings of distress. People with PD whom have impulse control issues and apathy behaviors also lead to increase distress for the PD caregiver. Caregivers of PD often experience social isolation due to changing roles and spousal relationships. Caregivers of PD also feel anxiety secondary to the financial strain that is placed on the familial unit due to time away from work and/or inability to work due to the demands of caregiving. Bhimani's literature review supports the need for a program that addresses client factors along with participation of activities of daily living in PD caregivers.

Cifu et al. (2006) found that caregiver burden was significantly associated with performance of the person with PD ADL status and motor impairments. In addition, the

researchers found an association between caregiver burden and the person with PD's mood, behaviors, and cognitive status. Finally, self-reported hours of sleep by the PD caregiver was also correlated to the caregiver burden and overall health status. Tokunago, Washio, Miyabayashi, Fortin, Shin, and Arai's (2009) research found that PD caregivers experienced depression at a higher rate than caregivers of frail elderly and/or individuals with Dementia. The researchers suggested that mental support on reducing depression and increasing resources for future needs of the PD person are essential for the caregiver. These research studies inform healthcare personnel that caregivers' burden of care perceptions are linked directly to the overall functional ability and mood of the person they are providing care to. An educational and skill practicum course designed to help manage the challenges associated with caregiving can therefore help to reduce burden of care perceptions.

The work of Martinez-Martin, et al. (2008) and Martinez-Martin, et al. (2007) focused on Parkinson's caregiver's burden, health status, and mood. The studies by Martinez-Martin and colleagues (2007; 2008) established that caregiver mood, specifically depression and anxiety, were related to disease severity, burden of care, and caregiver variables such as social support and education level. Moreover, Martinez-Martin and colleagues (2007; 2008) determined that caregiver burden was associated with both amount of time devoted to caregiving and need for safety supervision. Furthermore, a link between caregiver burden and perceived health status of the caregiver was found to be significant. Finally, Martinez-Martin and colleagues (2007; 2008) found Parkinson's patient's depression, agitation, behaviors, and delusions were also related to caregiver burden and reported distress. The results of the work by Martinez-Martin and

colleagues (2007; 2008) suggested that programming, tools, and resources for the caregiver on mood management and reduction of caregiver burden would increase the quality of life and health status of the caregiver.

Ho, Collins, Davis, and Doty's (2005) research into the role of caregiving and its relationship to employment, health concerns and support found that 1/3 of working caregivers missed at least one week of work per year related to caregiving responsibilities. In addition, caregivers reported personal chronic conditions twice as often as non-caregivers and reported increased financial costs associated with medical bills than non-caregivers. The researchers concluded that while caregivers take the financial burden off the healthcare system by providing unpaid labor, they face additional challenges of worsening personal health and personal financial debt placing additional burdens on the family unit. Therefore, an educational program designed to reduce physical burden of care placed on the caregiver will aid in enhanced outcomes for the caregiver and person with a neurodegenerative condition.

Pinquart and Sorensen's (2003) research into the psychological impacts of caregiving found that caregivers had increased stress, increased rates of depression, lower reports of well-being, and impaired physical health when compared to non-caregivers. While many caregivers reported an enhanced personal connection to the person they were providing care to, caregiving had a negative impact on their ability to cope with changes in their roles and responsibilities which placed a greater burden of care on the caregiver and resulted in increased reports of stress and depression. Pinquart and Sorensen (2003) concluded that by providing caregivers with the time and resources to gain more control over the caregiving experience by means of learning how to manage challenging

behaviors, enhanced problem solving, and self-management techniques that caregivers' reports of stress, depression, personal well-being, and physical health was improved.

Kelly and colleagues (2012) analyzed the relationship between quality of life and strain in PD caregivers in Australia. Kelly and colleagues (2012) stated that caregivers of people with advanced PD have increased incidence of depression, decreased reports of quality of life, reduced reports of physical and mental health, and reduced financial circumstances. Their research further found a correlation between self-reports of quality of life in the person with PD and the amount of strain reported by the PD caregiver. Consistent with these findings, high levels of quality of life coincided with low levels of reported caregiver strain. Finally, their research found that caregivers of people with PD in poor health had higher reports of strain. Lyons, Stewart, Archbold, Carter, and Perrin's (2004) research linked length of time providing care to worsening caregiver health and wellness. Their study found that both depression and physical health declined in relationship to attitudes of pessimism, decreased coping mechanisms, and poor habit choices. While this study only looked at changes over a ten year period, it is important to note that caregiver health and wellness was linked to length of time providing care. As the healthcare system moves further away from institutional care, it is important to consider what tools and resources caregivers require in order to allow them to continue to provide care in their homes. Lyons and colleagues' (2004) and Kelly and colleagues' (2012) research brings to light the need for caregivers to have the skills and resources needed to effectively cope with challenges of providing care to a person with PD and improve their mental health outlook.

The work by Tew, Naismith, Pereira, and Lewis (2013) on the contribution of personality traits and quality of life in PD caregivers found that lower levels of reports of quality of life by caregivers was associated with greater PD disease duration, advancement of disease stage, and length of time the person with PD required daily care. From a personality perspective, the researchers found that enhanced quality of life reports in caregivers were associated with higher levels of conscientiousness, openness, and extroversion. In addition, the researchers found that depression was associated with the caregiver's ability to maintain and engage in social relationships outside the role of caregiving. Martinez-Martin and colleagues (2005) assessed the impact of PD on informal caregivers and caregivers' strain. Their research found that PD stage and level of disability were predictors of caregiver burden. Specifically, the functional ADL level of the person with PD was a predictor of the caregiver psychosocial burden and related reports of quality of life. Finally, the person with PD reports of quality of life was directly related to the caregiver's report of quality of life. These literature results indicate that the PD caregiver would benefit from tools and resources that enrich their ability to engage in their occupations of choice while managing the client factors that impact their caregiving roles.

Navarta-Sanchez et al. (2016) examined psychosocial adjustment and quality of life determinants in people with PD and their caregivers. Their research found a relationship between disease severity and coping responses. Positive coping responses was related to the caregivers' ability to adjust to the psychosocial challenges encountered as a caregiver. In addition, PD caregiver's ability to psychosocially adjust was a predictor of quality of life reports. The researchers indicated that enhancing caregivers coping

abilities will enable the caregiver to meet challenges faced during the PD disease process and enhance reports of quality of life.

Fernandez, Tabamo, David, and Friedman's (2001) research sought to determine the predictors of depression symptoms in the PD caregiver. Their research found that the amount of time a person had PD was associated with caregiver's level of depression. In addition, the presence of sleep disturbance in the person with PD was found to be a strong contributor to the caregivers' rates of depression. The researchers suggested that by identifying caregiver stressors the potential to avoid institutional care and increase aging in place will be enhanced. In addition, identification and treatment of caregiver stressors will enhance the quality of care provided to the person with PD.

Parkinson's Disease and Sleep

Prolonged periods of sleep allows the human body to restore, repair, and regenerate itself. Our sleep patterns are impacted by many sources including but not limited to age, the ability to cope and manage stress, medication side effects, and disease. Sleep disturbances commonly found in PD patients can consist of difficulties with sleep initiation and maintenance, parasomnia, restless leg syndrome, fragmented sleep, and other sleep disorders (Suddick & Chamber, 2010). In addition, Suddick and Chambers (2010) reported prevalence rates of sleep disorders in people with PD at 60 to 90%. Sleep disturbances in people with Parkinson's disease can impact both the person and their caregiver depending on the type and/or form of sleep disturbance that is present.

Happe and Berger (2002) studied the relationship between sleep disturbances and Parkinson's caregivers. Their research found that sleep disturbances increased in response to the amount of assistance provided to the Parkinson's patient. In addition, the

sleep disturbances of the Parkinson's patient and the severity of their motor impairment were directly linked to caregiver sleep disturbances.

Fernandez, Rowena, Tabamo, David, and Friedman (2001) also studied sleep disturbances and found a correlation between the duration of the Parkinson's disease and the caregiver's sleep disturbances. Furthermore, a correlation was determined between the Parkinson's patient's severity of illness and caregiver's level of depression. Finally, their study verified that sleep disturbances were a strong contributor to caregiver depression. This research, in addition to the work by Happe and Berger (2002), provides evidence that education and tools on improving quality sleep would be beneficial for the Parkinson caregivers.

Parkinson's Disease and Cognition

Cognitive declines, especially in areas of executive function skills, are a common deficit experienced by people with PD. In addition, declining levels of cognitive impairment can be found as the disease progresses. Yang, Tang, and Guo (2016) discussed Parkinson's disease and the related cognitive impairments. The authors reported that 25 to 50% of people with PD may experience mild cognitive impairments (MCI) to profound dementia like cognitive impairments. Common cognitive impairments in the PD person consist of executive function impairments and visuospatial dysfunctions. Yang, Tang, and Guo (2016) reported that cholinesterase inhibitors, partial NMDA receptor antagonists, and noradrenergic reuptake inhibitors have shown promise in helping to diminish the impact of cognitive related decline in the person with PD. With the risk of PD diagnosis increasing with age, the risk for age related cognitive impairments along with PD cognitive impairments is of concern and should be addressed

to prepare the PD caregiver for additional challenges that maybe encountered during the neurodegenerative disease process.

Leroi, McDonald, Pantula, and Harbishetter (2012) analyzed the relationship between Parkinson's disease patients' cognitive impairments and its impact on quality of life and caregiver burden. The results of their study indicated that severity of cognitive impairment in Parkinson's patients has a direct impact on the quality of life of the caregiver. In addition, the researchers confirmed that level of disability was higher in the cognitively impaired Parkinson's patient than the non-cognitively impairment Parkinson's patient with the same level of motor impairments together with a higher rate of burden of care provided by the caregiver. The authors suggested that by providing caregivers with education and training on how to manage the cognitive changes associated with Parkinson's disease, the quality of life of the caregiver could be preserved and reduce the need for institutionalization.

Pena et al. (2014) examined an integrative cognitive training program to enhance cognitive function and disability in people with PD. The authors found that people with PD following a cognitive training program demonstrated enhanced visual memory, visual learning, and cognitive processing speed. The authors also found that the cognitive training program resulted in improved functional disability. These research articles provide evidence that caregivers would benefit from training and support on best methods and approaches to help manage, prevent, and slow the rates of cognitive decline associated with PD.

The literature clearly has established PD caregiver physical and mental needs along with the burdens that they face when providing care to a person with PD. The

current healthcare system design is focused around the person with PD. In addition, many organizations exist that provide support for the person with PD and their caregiver. However, little research and evidence is present to support what forms of support best match the needs of the PD caregiver.

Parkinson's Caregiver Programs

A'Campo, Spliethoff-Kamminga, Macht, the EduPark Consortium, and Roos (2010) study examined a standardized program for Parkinson caregiver education. Session topics included, general information, self-monitoring, health promotion, stress management, social competence, management of anxiety and depression, social support, and the evaluation. The results indicated that study participants found the information helpful however, would have liked increased practice in the session topics. The participants stated it was too difficult to incorporate into daily life. It is important to note that most of the session's topics were taught by Psychologists. An occupation based approach may have been more meaningful and useful to the caregivers. In addition, a more hands on, real life simulation of tasks would have provided the caregivers with the skills and confidence to apply the knowledge immediately to their unique situations. The work by A'Campo and colleagues (2010) provided a baseline for the design of the Occupation Based Client Centered Parkinson's Disease Caregiver Program. By reviewing the literature on caregiver's needs, the results of a PD caregiver needs assessment, and the results of the A'Campo et al. (2010) findings, the incorporation of skill practicum sessions, ADL management, and mobility challenges were added to provide a well-rounded program to meet the physical and mental demands placed on the PD caregiver. It is the goal of this program to enhance the quality of life of the PD caregiver by

providing them with the education and resources needed to successfully manage the changing demands of the neurodegenerative PD process.

Section 3: Methods

Project Design

The purpose of this project was to provide education and skill training on successful engagement in the role of caregiving that will enhance the caregiver's quality of life. The project was conducted in four education module sessions each lasting two hours in length. Each session consisted of educational materials, skill application, and resource tools. Thus, a quantitative pre-experimental one group pre and posttest research design was selected utilizing an outcome measure of quality of life. The pre-experimental one group pre and posttest design was selected because the research project will be studying one population group, caregivers of Parkinson's disease, to determine if an educational program will improve their quality of life (Creswell, 2014). The population group will serve as their own control group. In addition to pre and post testing data, at the end of each learning module an education feedback form will be provided to participants to ensure materials delivered were in a format that they were able to comprehend. The educational research project was completed in collaboration with the American Parkinson's Association of Madison, Wisconsin.

Setting

Educational modules were conducted in a community based location located in Madison, Wisconsin that is currently utilized by the Madison, Wisconsin chapter of the American Parkinson's Disease Association for a caregiver support group. The community based site was selected based on availability of public transportation and availability to accommodate the number of attendees. Furthermore, the community based

site was selected as these sites are familiar with the intended audience and within easy access of the surrounding area.

Inclusion/Exclusion Criteria

Inclusion criteria for the research study consisted of being a caregiver of a person with Parkinson's disease, able to attend all educational modules, and residing within a 30 mile radius of the city center of Madison, Wisconsin. No exclusion criteria will be present. Prior and additional co-morbidities of the caregiver and person with PD are not expected to impact the educational design and therefore, no exclusion criteria is required.

Participant Data

According to Thomas and Sweetnam (2002), PD caregivers are characteristically the spouse or partner of the person with PD. In addition, 60% of the PD caregivers are over the age of 65. Hirsch, Jette, Frolkis, Steeves, and Pringsham's (2016) research indicated that men have a higher rate of PD diagnosis, thereby resulting in the female spouse as the primary caretaker. It is expected, based on the literature review, that the study participants are a mix of both male and female, with more women than men. The average age of the study participant will likely be over 65 years of age.

Participants were recruited through the Wisconsin chapter of the American Parkinson Association (APA), a PD caregiver support group, and local Neurologists that specialize in the treatment of Parkinson's disease. Flyers were distributed and made available at the local APA chapter's caregiver support group meeting sites and physician offices. In addition, an advertisement of the flyer was posted on the Wisconsin Chapter of the APA website and sent via email to the APA's PD database subscribers.

Project Methods

Data collection in the pre-experimental one group pre and posttest research design was collected prior to the start of the first educational module and following the final educational module. A pretest posttest design allowed for testing of the hypothesis that an educational series will enhance the quality of life of the Parkinson caregiver. Study participants completed pre and posttest measure via pen/paper and were asked not to supply their name on the scale for confidentiality purposes.

The data obtained from the pre and posttest measurement tool was analyzed utilizing a paired t-test. The paired t-test was selected as a single variable (quality of life) and will be assessed at two different points in time which will allow for comparison of the study participants' scores following the intervention. The paired t-test will consequently provide data that will support or dispute the hypothesis that an educational program will enhance Parkinson's caregiver's quality of life.

Outcome Measures

The outcome measurement tool employed was the Parkinson Caregiver Quality of Life Scale. Dimenas, Dahlof, Jern, and Wiklunk (1990) define quality of life as a term that describes how an individual perceives their overall sense of well-being. Quality of life (QOL) takes into consideration then, an individual or groups satisfaction with their physical and mental health, family unit, employment and wealth status, safety and sense of security, and religious beliefs. Quality of life was selected as the outcome measure as the goal of the research project is to provide the Parkinson caregiver with educational tools that will enhance their ability and satisfaction to participate in the occupation of caregiving.

The Parkinson Caregiver Quality of Life scale was specifically developed for this research as a means to measure the particular population's quality of life. The Parkinson Caregiver Quality of Life scale is an 18 item questionnaire consisting of various quality of life questions. Participants will be asked to rate their satisfaction on how often an item occurs between never (1) to always (5). The score of all 18 items will be totaled and then compared pre and post test to determine if a change in quality of life perceptions was achieved following the educational modules. Refer to table 9 in the appendix for the Parkinson Caregiver Quality of Life Scale.

Reliability and validity of measurements tools aid in supporting the significance of a research findings. The Parkinson Caregiver Quality of Life Scale was specifically developed for this research study and at this time no data is present to support the reliability or validity of the scale. The Parkinson's Quality of Life Scale was based on two previously published quality of life scales, the WHOQOL BREF (Gholami, Moosavi Jahromi, Zarei, & Azizallah Dehghan ,2013) and the Caregiver Quality of Life Index – Cancer (CQOLC) (Weitzner, Jacobsen, Wagner Jr., Friedland, & Cox, 1999). Future research will need to be conducted to obtain the reliability and validity of the scale for the patient population and its ability to predict quality of life outcomes.

Ethical Considerations

As with any project and/or program, risk is an inherent quality. Potential risks in the OBPCP project consisted of physical injury due to unforeseen accidents or unknown participant chronic condition exacerbation in the skill practicum component of each educational module. For example, a participant could trip over a chair leg while self-transferring from a sitting to a standing position or during the skill practicum the

participant with a “bad back” could self-inflict a muscle strain while practicing a floor to sit transfer. Participation in the study, including the skill practicum components, are voluntary and the participant could decline to partake at any time. In addition, these risks are no greater than what the PD caregiver may already be experiencing within their home and/or work environment. In order to mitigate these risks, the community based site and all equipment was reviewed prior to protect participants from injury and harm. Informed consent was obtained prior to the initiation of the first education session to ensure all participants were fully informed of the research project and objectives. Education on body mechanics was provided to participants to reduce the risk of injury associated with providing care to another individual and to reduce risk of injury during practice skill sessions. Invasion of privacy is a potential risk. Since the program was designed in a group setting, participants may overhear personal conversations between other participants that were unintended. This was controlled by asking all individuals to refrain from sharing personal information that was not intended for the group.

In addition to the above stated ethical considerations, the following will also be accounted for. One, the location of the study was not associated with Eastern Kentucky University or the primary researcher. Two, site consent was obtained to ensure the property owner is in agreement with research occurring in their building. Third, study participant’s culture, religious beliefs, and gender differences will be respected at all times. Finally, study participants were offered the opportunity, should they wish, to obtain the study results after data analysis has been completed.

Timeline of Project

The research project was conducted in four weekly consecutive sessions, each lasting approximately two hours in length. Table 1 outlines the educational series. The “lecture” consisted of a PowerPoint presentation on each specific topic area and handouts were provided to allow participants to take notes on the materials presented. The “experience” is defined as the hands on skill practicum sessions that occurred and were directly related to the topic area. The experience consisted of introduction and hands on application of adaptive equipment for self-care and mobility, transfer training on varied surfaces, utilization of various relaxation techniques to manage stress, and training on techniques to manage cognitive and behavioral challenges commonly encountered. The “reflection” is a time when the group of participants regrouped, reviewed any additional questions that had arisen on the topic area, allowed for sharing of experiences and challenges, and reflected on additional educational opportunities utilizing the Shape up method. Feedback was provided to the primary researcher via an educational module feedback form and through a shape up activity during the reflection period to allow for adjustment to enhance learning opportunities. Shape up (Suskie, 2000) is an educational assessment method in which participants are asked the following questions; what squares up with what I know?, what are three important points I learned?, and what keeps going around in my head?.

Table 1: Timeline outline

	Module 1	Module 2	Module 3	Module 4
Educational Topics	PD Overview Sleep Cognition	Self-Care	Mobility	Psych Health 101 Health Promotion
Total Time	120 minutes	120 minutes	120 minutes	120 minutes
Learning Activities	Lecture Experience Reflection	Lecture Experience Reflection	Lecture Experience Reflection	Lecture Experience Reflection
Additional Resources	Yes	Yes	Yes	Yes
Feedback	Shape Up feedback form	Shape up feedback form	Shape Up feedback form	Shape Up feedback form

Section 4: Results

Participant Demographics

Eight study participants completed four educational and skill practicum learning modules over a four week time period.. The data for quality of life perceptions was collected utilizing the Parkinson Caregiver Quality of Life Scale. Due to weather related challenges, weekly makeup modules were offered for any participant that missed the previous week's materials due to the incremental weather. Thus, all eight PD caregivers completed all modules and all were included in the pre and post test data collection results.

The gender of the PD caregivers consisted of seven females and one male. During the modules, seven of the PD caregivers self-reported that their spouse was the person with PD and one of the PD caregivers reported that her son was the person with PD. In addition, all PD caregivers reported that the person with PD was actively engaged in part time and/or full time employment during this study.

Results

De Winter (2013) recommends that for small sample size research studies a paired t-test is an effective method to test for significance. Final data analysis was completed utilizing a paired t test to compare pre and posttest data for significance of improvement in quality of life perceptions following an educational program. The primary researcher input pre and post test data into an Excel document for analysis. A mean pre and post score was computed for each individual question on the Parkinson Caregiver Quality of Life Scale. In addition, a total score for each subject was calculated along with the total mean score. The Excel data analysis tool was utilized to calculate the p value for each

question along with the total score. The p value for significance was set at $p = .05$. The Parkinson Caregiver Quality of Life Scale overall pretest mean score was 56.5 with a posttest mean score of 57 ($p = .45$). The total possible score on the Parkinson Caregiver Quality of Life Scale was 90. Table 2 summarizes the pre and posttest mean scores for each individual question of the Parkinson Caregiver Quality of Life Scale along with their corresponding p values. Based on the data analysis, no statistical significance was found following the implementation of the Occupation Based PD Caregiver Program in quality of life perceptions amongst the study participants. Although statistical significant was not found in the paired t test results for the total score nor the individual questions, a positive change in pre-test and posttest scores was noted in fifteen of the eighteen questions on the Parkinson Caregiver Quality of Life Scale.

Although not collected for data analysis, study participants reported that the program content was “helpful”, “learned so much”, “ wish I had this information last year”, “ no one ever told me this”, and “great information” following the completion of the educational modules via the educational module feedback form, refer to Table 3. The Shape Up reflection was completed and discussed orally as a group following the end of each module and was not documented in any manner.

Table 2: Data Analysis Results of the Parkinson Caregiver Quality of Life Scale

Question Number	Pretest Score Mean	Posttest Score Mean	p
1	3.5	3.5	0.5
2	3.625	3.5	0.400
3	3.5	3.625	0.413
4	2.375	3	0.175
5	3	3.125	0.413
6	2.375	2.25	0.413
7	3.625	3	0.108
8	2.375	2.625	0.299
9	3.75	3.625	0.392

10	4	4	0.5
11	3	3.125	0.417
12	2	3	0.077
13	2.75	2.875	0.421
14	3.25	2.625	0.152
15	4	3.75	0.175
16	2.875	3.25	0.322
17	3	3	0.5
18	3.5	3.125	0.237
Total	56.5	57	0.457

Table 3: Shape Up Results

Question	Module One		Module Two		Module Three		Module Four	
	Yes	No	Yes	No	Yes	No	Yes	No
1	8		8		8		8	
2	8		8		8		8	
3	8		8		8		8	
4		8		8		8		8
5	no comments		no comments		no comments		no comments	
Comments	unable to hear speaker, great information, will share this information with my husband he will find it so helpful, thank you for the information		learned so much, great, thank you for the hands on experience		no one ever told me this, great information		wish I had this last year, so helpful, are you going to be doing this for others?	

Discussion

Current and previous research on caregiver needs and burdens have clearly identified the presence of health disparities within the PD population (Martinez-Martin et al, 2008, 2007, 2005; Mott et al., 2005). Caregiver needs and burden often go unchecked by healthcare professionals. While support groups offer caregivers an avenue to gain knowledge, find support services, and provide a venue to express their thoughts and

concerns, they often have insufficient resources and knowledge to provide the caregiver with the tools required to successfully engage in the role of caregiving. Occupational therapists have the knowledge, tools, and resources to provide the caregiver with the skills required to successfully engage in the occupation of caregiving for sustained periods of time.

The available literature on PD caregiver programs demonstrates a gap in how healthcare providers support the individuals providing care to those with degenerative conditions. There are only a few studies, such as A'Campo et al. (2010), that have begun to investigate the best method of practice to reduce this health disparity. The research by A'Campo et al. (2010) utilized a team of psychologists to provide education on mindfulness, health promotion of the caregiver, stress management, management of anxiety and depression, and social competence. At the time of this study, no additional research was available on other PD caregiver programs. While some aspects of this research study are based on A'Campo's design, this study is unique in that it utilized a client centered occupational therapy approach to meet the knowledge gap on how to impact PD caregiver quality of life perceptions and generate best practices to ensure a healthy population of caregivers.

While the study did not demonstrate statistical significance in improvement of overall quality of life perceptions, the caregivers attending the educational sessions did self-report that the information was helpful, informative, and that they learned techniques that will enhance their ability to provide care to their loved one. In addition, both total data scores along with all but three individual question scores indicated a positive change at the time of posttest collection. Question 12 of the Parkinson Caregiver Quality of Life

scale, “do you feel guilt”, came the closest to obtaining statistical significance with a p value of .077. Questions four, seven, fourteen, and fifteen also came close to obtaining statistical significance. Table 2 references specific questions and associated p values. Changes noted in data scores from pretest to posttest along with participant verbalization suggest that the Occupation Based PD Caregiver program did have a positive impact on the lives of the participants.

Guilt is an emotion that is often sensed by individuals providing care to a friend or loved one whom is chronically ill. Guilt can also be a component of depression and anxiety that is experienced by the PD caregiver (Martinez-Martin et al., 2007). Question 12, “do you feel guilt?”, showed a positive change between pretest/posttest scores. Gallego-Alberto, Losada, Márquez-González, Romero-Moreno, and Vara’s (2017) research indicated that negative guilt feelings are often associated with the commitment to caregiving and specifically with the element of behavioral changes. Within the cognitive learning module and Psychosocial 101 module, the goal was to provide the caregiver with the tools to successfully manage both cognitive related changes, behaviors that may manifest, and enhance their coping mechanisms. Behaviors place additional strains and burdens on caregivers and are often one of the main reasons for admission to a skilled nursing facility for long term placement. The change in pretest to posttest score could be related to the educational tools and resources that were provided to the PD caregiver to aid them in the management of these secondary disease complications.

Sadness, like guilt, is a common emotion felt by caregivers. Fernandez, Tabamo, David, and Friedman (2001) and Bhimani (2004) both found that depression is not only present in PD caregivers but that it is also correlated with quality of life, burden, and the

person with PD physical and emotional stages. Question 4, “do you feel sadness”, had a positive change from pretest to posttest reporting. The change in score could have been related to a multitude of factors. These factors could have been the content within the educational modules in addition to the group conversations related to depression, anxiety, and coping that were actively discussed throughout the educational modules. As previously discussed, PD caregiver research clearly has established a link between depression and quality life. Therefore, it is reasonable to consider that that addressing these components within the educational modules could be associated with the positive improvements in caregiver quality of life associated with question 4. Thus, health professionals have an obligation to continue to address this component in the services we provide.

Throughout the educational modules, community resource lists were provided along with the general educational topics. The change in pretest/posttest score of question 15, “how often do you have the tools to provide care to your loved one”, may have been a direct result of the modules and resources. This aligns with Ferreira, Wanderley de Sales Coriolano, and Lins’s (2016) research which found that caregivers require valuable information in order to provide quality care. The educational modules were specifically designed to provide information on ways to enhance quality care related to self-care, mobility, and psychosocial health. The caregiver comments throughout the educational program reflected the value of the educational modules to the PD caregiver along with the change in scores for question 15.

Martinez-Martin et al. (2005) research found that both the disease duration and the cognitive and emotional status influenced PD caregiver burden. Question 7, “how

satisfied are you with your quality of life”, in the Parkinson Caregiver Quality of Life scale also showed a positive change in pre and posttest scores. The two educational modules, Cognition and Psychosocial Health 101, could have directly influenced this change. These modules provided education and skill practice on approaches to reduce caregiver burden related to changes in the person with PD’s cognitive level and means to ensure the PD caregiver could self-manage stress and improve coping mechanisms.

A’Campo and colleagues’ (2010) PD caregiver program utilized the Parkinson Disease Questionnaire and the EuroQOL five dimension questionnaire as a measurement outcome tool for PD Caregiver quality of life. Their study was also unable to find statistical significance in PD caregiver quality of life which mirrored this study’s findings. A’Campo and colleagues (2010) suggests that quality of life perceptions change over time which, could impact the ability to obtain statistical significance. In addition, they suggest that the instrument tools were also not sensitive enough to capture the small changes reported by participants. Based on A’Campo et al. (2010) findings and the results of this study, the argument to utilize qualitative data versus quantitative outcome data in further research studies should be considered as quality of life perceptions is both exclusive and unique to each individual.

Limitations

Subsequent post reflection of the study presented the author with potential limitations that may have impacted the outcome of the lack of significance found during data analysis. First, the amount of time between pre and post test data collection was roughly four weeks with a single intervention provided each week. Quality of life perceptions may not significantly be altered within this time frame. It is suggested then,

that future research would benefit from posttest data being collected at two points in time following the final educational module to determine if a long term impact on caregiver quality of life is achieved and sustained over time

Second, a single assessment tool was utilized to capture quality of life. A single assessment tool may not be sensitive enough to capture small changes in quality of life perceptions or encompassing enough to capture all quality of life indicators. Additionally, quality of life perceptions can significantly vary depending on outside environmental influences and the subjective experience of the caregiver. These factors were not controlled for within this study and could have influenced the statistical significance. Further studies are also warranted to investigate the reliability and validity of the Parkinson Caregiver Quality of Life Scale in its accuracy to capture the quality of life perceptions of the PD Caregiver. Furthermore, the inclusion of qualitative data would be of benefit for future research in order to obtain additional data to describe and define the PD caregivers' quality of life perceptions following the educational project.

In addition, the relatively small sample size of the project may have impacted the statistical significance as it created an increased risk of a Type II error and thus the not revealed the variance in pretest to posttest scores. Nelson, Kielhofner, and Taylor (2017) discuss approaches to protect against a Type II error such as an increase sample size. The project was implemented and scheduled midweek during a midday time. This could have limited the number of available participants as many caregivers were engaged in the occupation of work. Further research should consider the date and time offerings to increase the availability of greater subjects and reduce the risk of a Type II error.

Finally, all the caregivers of the person with PD in this study self-reported that their loved one was currently employed in some capacity. This suggests that the person with PD is functioning at a level that requires little to no assistance from the caregiver. Lageman et al, 2015 research suggests that caregiver burden and related quality of life in the PD caregiver is generally lower with higher functioning people with PD. Thus, the participants level of caregiver burden may have been less than other potential PD caregivers. Recommendations to modify inclusion and exclusion criteria to ensure subjects are equally represent for all PD stages should be considered for future research.

Conclusion

Martinez-Martin et al. (2005) research discusses the need for professionals to equally identify factors that influence PD caregiver burden but also their quality of life in order to reduce the impact of Parkinson disease. Caregiver burdens and demands are expected to grow as our population ages and chronic conditions are medically managed for longer periods of time. Martinez-Martin et al. (2007) suggests that PD caregiver burden can be predicted based on the psychological well-being of the caregiver in addition to their perceived quality of life. It is essential, that as a healthcare professional, occupational therapists continue to engage in developing research and methods that serve as a guide on best practices to meet the ever changing burdens and demands placed onto the caregiver. In addition, occupational therapists working with people with PD and the caregivers of PD have the opportunity to enhance participation in activity of daily living activities, reduce health disparities, and promote quality of life. Further occupational research is required to determine how to best meet the gap in present health disparities experienced by the PD caregiver. Finally, further research on how the profession of

occupational therapy can assist in the enrichment of quality of life perceptions of the PD caregiver should be conducted.

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Appendix

ADL Learning Module Objectives

1. Develop an understanding of what activities of daily living (ADL) are.
2. Develop an understanding on what ADL adaptive equipment is and to develop and understanding on what incontinence is and how it's related to PD.
3. Develop an understanding on best methods to provide assistance to the person with PD as it relates to ADL's, to develop and understanding on how to utilize adaptive equipment, and to develop an understanding on how to carry out an incontinence program to promote continence.
4. Develop an understanding on analyzing an ADL routine to determine the best approach for success.
5. Develop an understanding on effective means of communication with the person with PD during an ADL task and developing an understanding on how to best approach an ADL challenge in a public place.
6. Develop an understanding on setting boundaries to assist the person in maintaining their independence and developing an understanding of how, when, and where to provide assistance with ADL to decrease caregiver burden and decrease risk of fall and injuries.
7. Develop foundational understanding of ADL's and needs throughout the PD disease process.
8. Develop an understanding on how to best assist the person with PD without undue burden or injury for the caregiver.

9. Develop an understanding of how to provide assistance in a public place when the environment is not ideally situated.

Mobility Learning Module Objectives

1. Develop an understanding of mobility and mobility devices.
2. Develop an understanding of potential mobility challenges encountered by people with PD and their caregivers within their home and community and how to effectively manage them.
3. Develop an understanding on best communications methods during mobility challenges with the person with PD.
4. Develop an understanding in the role of Physical and Occupational Therapy in relationship to mobility and PD.

Sleep Learning Module Objectives

1. Develop an understanding of the normal sleep components.
2. Develop an understanding of the common sleep disorders commonly found with people with PD.
3. Develop an understanding into sleep hygiene measures that may improve quality of sleep.

Psychosocial Learning Module Objectives

1. Increase the caregiver's awareness of common emotional challenges encountered by a caregiver and create a plan to alleviate the psychological burden placed on the caregiver.

2. Develop an understanding on ways to manage stress and develop an understanding on methods to effectively cope with the changing role requirements of a PD caregiver.
3. Develop an understanding on how changes associated with the person with PD can impact the caregiver's engagement in meaningful activities.

Health and Wellness Learning Module Objectives

1. Understand the connection between health and physical mobility for the person with PD and the caregiver.
2. Understand the connection between health and the mental abilities for both the person with PD and the caregiver.
3. Understand the connection between health and mood for both the person with PD and the caregiver.

Cognition Learning Modules Objectives

1. Develop an understanding on providing practical solutions to managing the potential cognitive decline experiences by the person with PD to reduce burden of care.
2. Develop an understanding about the common cognitive impairments that may be experienced by people with PD.
3. Develop an understanding how to manage and adapt to changes in cognition to reduce caregiver stress.

Parkinson's Disease Learning Module Objectives

1. To develop an understanding of Parkinson's disease etiology and the signs and symptoms of PD throughout the neurodegenerative process.

2. To develop an understanding of the roles of the healthcare team for the person with PD and to develop an understanding on the role of the PD caregiver.

Parkinson Caregiver Quality of Life Scale Questions

1	How satisfied are you with you sleep pattern?
2	How satisfied are you with your daily routine?
3	Do you have worries or stress?
4	How often do you feel sad?
5	How often do you feel you have stress or have difficulty coping?
6	Are your finances a concern?
7	Are you satisfied with your quality of life?
8	Is your health impacting your ability to participate in daily life?
9	How often do you find enjoyment in your life?
10	Do you consider your life meaningful?
11	Do you feel frustrated with life and/or your life situations?
12	Do you feel guilty?
13	Is being a caregiver prevented you from doing things you enjoy?
14	How often do you receive the support you need from your family and/or friends?
15	How often do you feel you have the tools to provide care to your loved one?
16	Do you feel overwhelmed with the role of caregiving?
17	How often has your relationship changed with your loved as a result of providing care to them?
18	How often you are able to participate in the activities you enjoy?

Shape Up Educational Module Feedback Form

1. Did the content of today’s course match the descriptions provided?

Yes No

2. Were you able to understand the materials presented in today’s course?

Yes No

3. Was the information presented today applicable to the care you are providing or will provide? Yes No

4. Is there another teaching method that will help you learn?

5. If you were to make a change in the information what would you want included or removed?

Comments:
