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Occupational Therapy's Involvement with the YMCA in Developing a Program to Address Activities of Daily Living in Those with Parkinson's Disease

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**OCCUPATIONAL THERAPY'S INVOLVEMENT WITH THE YMCA IN
DEVELOPING A PROGRAM TO ADDRESS ACTIVITIES OF DAILY LIVING
IN THOSE WITH PARKINSON'S DISEASE**

By

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A Scholarly Project

Submitted to the Occupational Therapy Department

Of the

University of North Dakota

In partial fulfillment of the requirements for the degree of

Master's of Occupational Therapy

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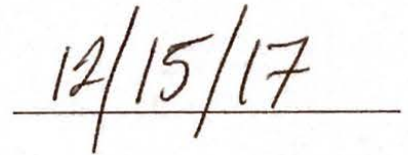
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Approval Page

This Scholarly Project Paper, submitted by Michaela Johnson and Emilea Berhow in partial fulfillment of the requirement for the Degree of Master's of Occupational Therapy from the University of North Dakota, has been read by the Faculty Advisor under whom the work has been done and is hereby approved.

A handwritten signature in black ink, appearing to be 'M. M. G.', written over a horizontal line.

Faculty Advisor

A handwritten date '12/15/17' written over a horizontal line.

Date

PERMISSION

Title: Occupational Therapy's involvement with the YMCA in developing a program to address Activities of Daily Living in those with Parkinson's Disease.

Department: Occupational Therapy

Degree: Master's of Occupational Therapy

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ABSTRACT

The purpose of Occupational Therapy's involvement with the YMCA in Developing a Program to Address Activities of Daily Living in Those with Parkinson's Disease was to create a protocol that addresses the needs of those with Parkinson's Disease (PD), specifically focusing on the area of activities of daily living (ADL). Through the use of occupational therapy perspectives and techniques, this program focuses on increasing and/or maintaining independence and safety during daily tasks in those with PD.

This program was influenced by the Person-Environment-Occupation model due to the transactional approach towards occupational performance. This model focuses on finding the best "fit" between personal, environmental, and occupational factors that lead to performance in everyday activity (Hinojosa, Kramer, Royeen, 2017). This program is designed for the local YMCA in Grand Forks ND and occupational therapists that work with the population of people with mild to moderate PD. Current programs at the YMCA do not include occupational therapy and ADL training. Because of this, the program will compliment current programs. The goal of this program is to provide education and training to individuals with PD in order to allow for them to be as independent as possible and remain in the home environment as well as providing education to caregivers to assist with this process.

This program is to be used by occupational therapists to provide education and ADL training through the use of interventions. These interventions include: mobility and

safety within the home during all ADL tasks, meal preparation, dressing, grooming, bathroom mobility, and equipment maintenance.

CHAPTER I

INTRODUCTION

Rationale

Up to one million people in the U.S. have Parkinson's Disease (PD) with 60,000 new cases diagnosed each year (Florida Hospital, 2017). PD can be defined as a degenerative central nervous system disorder characterized by insoluble fibrils forming in Lewy bodies in the brain (Reed, 2014). There are no other known causes of PD (Reed, 2014). PD is classified under neurodegenerative disorders, is progressive, may have an unknown cause, and is incurable (Abesman, Lieberman & Berlanstein, 2014). PD is characterized by a progressive decline in speed, flexibility, fluidity and coordination of fine and gross motor function throughout the body including the person's extremities, trunk, face and muscles of the voice (Foster, Bedekar and Tickle-Degnen, 2014). These limitations occur early in the disease and progress over time resulting in an increased need for support and making it more challenging for individuals to participate in valued activities and roles (Foster, Bedekar & Tickle-Degnen, 2014).

Muscle weakness, fatigue and decrease in postural stability can lead to an increase in falls which increases the person's fear of falling (FOF). Falling (FOF) are common in those with PD which can cause a person to restrict the activities of daily living (ADL) in which he or she engages in and increase social isolation because of activity avoidance (Nilsson, Drake & Hagell, 2010). Individuals with PD require more help with ADL and Instrumental Activities of Daily Living (IADL) tasks than individuals of other disability

populations (Terriff, Williams, Pattern, Lavorato & Bulloch, 2012). Difficulty engaging in ADLs is correlated with the motor stage of the disease, gait speed, cognitive impairment, and dexterity (Benge & Balsis, 2016). The person's ability to carry out everyday tasks or ADL's is likely more important to the person than how severe the disease has progressed (Hobson, Edwards & Meara, 2001).

Not only does having PD impact a person physically, it also has psychological effects. Common psychological symptoms of PD include depression, anxiety, apathy, agitation, and hallucinations. Of these symptoms, depression is among the most common (Laatu, Karrasch, Maritkainen & Marttila, 2013). These symptoms lead to a decrease in overall quality of life and an increase in caregiver support.

Based on these findings, this scholarly project focuses on increasing confidence in those with PD and teaching compensatory strategies to increase participation in ADL's and IADL's with as much independence as possible.

Statement of Problem

The current local programs available for PD only focus on improving physical and brain functionality so that people with PD can get better and stay better longer. The group that currently exists is at the local YMCA. The program offered is the YMCA Parkinson Wellness Recovery Program and is focused on improving the lives of people with PD by improving physical and brain functionality to help people with PD get better and stay better (YMCA, 2017). Typically, participants spend 30 minutes completing activities and playing games that challenge the thought process and stimulate brain activity to optimize their brain health. Approximately 50-60 minutes of physical activity follow, including a variety of basic progressive and functional whole body movement

exercises, to improve overall physical performance and ability (YMCA, 2017). This program currently includes speech therapy, music therapy, physical therapy and volunteers from occupational therapy. Coverage of education on ADL performance and completion of everyday tasks is very limited.

Currently there is no OT involvement with this program. Individuals with PD report that that specific tasks related to daily activities have become harder as the disease has progressed. These areas include brushing teeth and fastening buttons, dressing and undressing (Hariz & Forsgren, 2010). FOF, decreased coordination, balance, and motor skills are also effects of PD that lead to an overall decrease or fear of completing daily activities (Hariz & Forsgren, 2010; Skinner, Lee, Roemmich, Amano, & Hoss, 2015).

Scope of OT

Occupational therapists help people with PD to plan for changes that occur with the progression of the disease, by recommending home modifications, teaching and demonstrating strategies on how to continue participating in their meaningful occupations, help develop medication management routines, and provide caregiver education (Waite, 2014). Occupational therapists are trained to assist clients with self-management skills, address cognitive skills and impairments, and engagement in social situations. Occupational therapists work hard to promote and maintain quality of life throughout the progression of the disease. Some examples of how OT can provide assistance with cognitive impairments is through organizing daily routines, safety judgments, providing guidance for successfully completing multitasking. Occupational therapists also address and teach ways to adapt tasks, roles, and environments to facilitate engagement as the disease progresses. In addition, occupational therapists address

depression and social participation in this population (Waite, 2014). One way to ensure a therapist is addressing the person's tasks, roles and environments is through the use of models. For this specific product, the use of a model that includes personal factors, environmental factors and occupational performance factors is best suited.

Importance of the Product

This scholarly project will provide education sessions or modules that will address areas of need for the PD population. The current program in place at the local YMCA incorporates games to optimize brain health and uses physical activity using whole body movements to impact physical performance and ability (YMCA, 2017). Areas of ADL performance and everyday activities are not included in the current program. We will focus on mobility, grooming strategies, bathing/toileting mobility and compensatory strategies, dressing, feeding, and equipment maintenance in an effort to meet further needs of this population. An introduction and review session will also be developed for better understanding and transferability. Throughout the sessions, caregivers will be encouraged to attend and participate in order to gain knowledge about this population and their needs in order to help these individuals successfully perform their ADL's in all environments. These education sessions will provide occupational therapists a baseline tool to use when creating and implementing intervention plans for individuals with PD. It is anticipated that through incorporation of these modules, individuals with PD will report less difficulty when completing activities of daily living, an improvement in overall quality of life, and an increase in the duration of independence.

Theoretical Framework

The model that best fits this population and program is the Person-Environment-Occupation (PEO) model. This model was selected because it uses a transactional approach towards occupational performance (Hinojosa, Kramer, Royeen, 2017). The transaction involves the person, environment, and occupation which then leads to occupational “fit”, or optimal occupational performance. The “fit” between the three components is a direct correlation, meaning when the “fit” is at its best, so is the individual's occupational performance, and if the “fit” is decreased, the individual’s occupational performance is decreased (Hinojosa, Kramer, Royeen, 2017). This model identifies person as physical self, cognitive and affective self, and spiritual self, the environment as what surrounds the person, and occupation as different across individuals but is the sense of what the person is accomplishing (Hinojosa, Kramer, Royeen, 2017).

The PEO model applies to the topic of ADL completion in individuals with PD by addressing the interactions between the person, environment, and occupation and the transactions leading to occupational performance. The personal factors are addressed by looking at the individual needs of each person and symptoms that have an effect on the completion of ADL tasks. The environment is impacted through the interaction between the person and environment. The environment may be impacted by personal factors and symptoms of the disease, especially on the physical and social environments.

Compensatory strategies are alternative techniques that assist a person navigate his or her environment due to a decrease in personal skills and abilities. The environmental factors are addressed through the provision of home modification techniques and assistive devices. The occupational factors include the person’s ability to complete occupational

tasks and activities. The person factors have an impact on occupation through limiting and increasing difficulty in completion of occupational tasks.

CHAPTER II

REVIEW OF LITERATURE

Introduction to Parkinson's Disease

Up to one million people in the U.S. have Parkinson's Disease (PD) with 60,000 new cases diagnosed each year (Florida Hospital, 2017). PD can be defined as a degenerative central nervous system disorder characterized by insoluble fibrils forming in Lewy bodies in the brain (Reed, 2014). This degenerative disease is not necessarily due to a genetic factor, as only 15 to 20 percent of people who are diagnosed with PD have a family history of PD. There are no other known causes of PD (Reed, 2014). A neurodegenerative disorder is a condition where pathology results in a degeneration to part or all of the CNS, is progressive, may have an unknown cause, and is incurable (Abesman, Lieberman & Berlanstein, 2014). The brain is affected by the loss of brain cells in the substantia nigra, the locus coeruleus, and the brainstem (Reed, 2014). PD is characterized by a progressive decline in speed, flexibility, fluidity and coordination of fine and gross motor function throughout the body including the person's extremities, trunk, face and muscles of the voice (Foster, Bedekar and Tickle-Degnen, 2014). The degeneration of brain cells causes several symptoms, but the four main symptoms of PD are tremors while at rest, slow and decrease movement, rigidity, and loss of postural reflexes (Jankovic, 2008; Reed, 2014). With these symptoms come activity limitations. These limitations occur early in the disease and progress over time resulting in an

increased need for support and making it more challenging for individuals to participate in valued activities and roles (Foster, Bedekar & Tickle-Degnen, 2014).

The stages of PD are described by the Hoehn and Yahr (HY) Scale, which ranges from stage 1 to stage 5 (Reed, 2014). In stage 1, the person often has a resting tremor and unilateral symptoms that cause no functional issues. The stages progress until stage 5 when the person is confined to a wheelchair or bed unless otherwise assisted (Reed, 2014). The treatment that a person with PD receives can include dopaminergic therapy, deep brain stimulation, and in some exploratory cases other nuclei is targeted for deep brain stimulation as a potential surgical treatment for gait difficulties and postural instability (Jankovic, 2008). Along with the different stages of PD there are also 2 different subtypes: tremor dominant (TD) and postural instability and gait difficulty (PIGD). Tremor dominant is described as having a severe tremor at rest, during mobility, and during activities of daily living (Jankovic et al., 1990). PIGD is defined when the individual has more issues with falling, freezing, difficulty walking, and gait or postural instability (Jankovic et al., 1990). The symptoms of Parkinson's disease have the potential to greatly impact all areas of occupation.

Hess and Hallet (2017) assessed information from multiple sources that detailed the common symptoms of PD in more detail. Akinesia, or loss of willed movements, is a symptom of PD that may be correlated with bradykinesia, a pause in automatic or voluntary movements (Hess & Hallet, 2017). Even though the individual is able to correctly select the muscle group to engage the body part in movement, the body is unable to adequately energize the muscle to make the appropriate joint move (Hess & Hallet, 2017). This impairment of internal generation of movement has been linked to the

decrease in ability to increase the excitability of the motor cortex to produce a motor command to produce movement (Hess & Hallet, 2017).

Postural instability is also a cardinal motor symptom of PD and as the disease progresses, protective reflexes decrease (Hess & Hallet, 2017). In the early stages of the disease, patients often report that there is an increase in tripping which leads to an increased focus while walking on uneven surfaces (Hess & Hallet, 2017). As the disease progresses into the later stages, it is reported that individuals tend to lean or fall backwards more easily. Having this postural instability can increase anxiety and fear of falling (Hess & Hallet, 2017).

The next symptom that is commonly seen in those with PD is a resting tremor. A resting tremor usually occurs on one side of the body at the distal portion of the upper extremity (Hess & Hallet, 2017). Even though this is the most common area, there can also be tremors in the legs, chin, lips, and jaw (Hess & Hallet, 2017). There are many different variations of a tremor. The different variations include: flexion and extension, pronation and supination, and flexing of the fingers (Hess & Hallet, 2017).

No test has been developed that can definitively diagnose PD, so diagnosis is based off of the presence of these four main symptoms (Jankovic, 2008). Other motor symptoms that are occasionally present in people with PD include flat affect, difficulty swallowing, and a shuffling gait pattern. Hess and Hallet (2017) explain that gait patterns in those with PD are one of the most richly described and researched phenomena specific to PD. In the early stages, patients tend to notice a decrease in walking speed, often reported as lagging behind others. As the disease progresses, the individual develops a flexed and stooped posture, along with a slow shuffling movement with their feet and a

decrease in stride-length (Hess & Hallet, 2017). This flexed and stooped posture is often referred to as festination (Hess & Hallet, 2017). Festination refers to when the stooped posture and step size change. When a person's posture changes, so does their center of gravity. The shift in the center of gravity forces the individual to stop on the front part of their foot, instead of the heel. This gait pattern throws the upper body momentum forward making the individual more prone to falling forward (Hess & Hallet, 2017).

Another symptom that has some association with festination is freezing of gait (FOG). FOG refers to a sudden and quick episode of not being able to produce or generate effective stepping, initiate, or continue walking when intended (Hess & Hallet, 2017). FOG can often show as a delayed or failed gait initiation showing a sudden halt in forward motion. Frequently, a jittery stance and alternating weight between legs while trying to initiate stepping accompanies this issue (Hess & Hallet, 2017). There are common triggers that are associated with FOG. These include narrow doorways, busy walking areas, turning while walking, and preparing to sit in a chair. These are often triggered because of the stress, distraction, and the need for dual-tasking (Hess & Hallet, 2017).

In addition to these motor symptoms, people with PD often experience non-motor symptoms including autonomic dysfunction, trouble sleeping, mental health issues, and decrease in the ability to perform dual-tasks (Jankovic, 2008; Hess & Hallet, 2017). Performing activities that require both cognitive and motor activities or multiple motor activities at once can be compromised. These activities include talking while walking and balancing carried objects while walking (Hess & Hallet, 2017). It has been found that those with PD often have to use more attention-focused motor control to successfully

complete tasks (Hess & Hallet, 2017). This need for more focused attention can present as bradykinesia because of the amount of cognitive attention required to generate movement (Hess & Hallet, 2017). Bimanual movements are troublesome for those with PD. When performing bimanual movements, overflow movements on the opposite side of the body are often present (Hess & Hallet, 2017).

Koerts, Beilen, Tucha, Leenders, and Brouwer (2011) found that nonmotor symptoms are present in PD in addition to typical motor symptoms. These authors found that nonmotor symptoms have an effect on executive functioning both in the early and late stage of the disease. It was noted that individuals with PD showed significantly lower scores on multitasking, quality of the plan measures, and psychomotor speed than healthy participants. It was also determined that individuals who have PD had a longer duration of time to take impairments into consideration when planning the execution of different tasks (Koerts, Beilen, Tucha, Leenders, & Brouwer, 2011).

Psychological Effects of Parkinson's Disease

Not only does having PD impact a person physically, it also has psychological effects. According to Laatu, Karrasch, Martikainen, and Marttila (2013), common psychological symptoms of PD include depression, anxiety, apathy, agitation, and hallucinations. Of these symptoms, depression was among the most common. Laatu et al. (2013) determined that many clients who had depression also had apathy. Other less common symptoms included aberrant motor behavior, delusions, euphoria, and disinhibition. Garlovsky, Overton, and Simpson (2016) noted that focusing on emotional coping skills was beneficial. It was also found that addressing thoughts about their

illness, how much a person identifies with their illness, and their belief in their control of the illness were all important in sustaining the client's mental health.

Artigas, Striebel, Hilbig, and Rieder (2015) conducted a study assessing the quality of life (QoL) of those with PD who attend a patient support group (PSG). This study also compared cognitive and motor capacities, prevalence of depression, anxiety, and social phobia in those who attended PSG and those who did not (nPSG). The study found that those who participated in the PSG had better QoL, lower depression, anxiety, and social phobia than those of the control group (Artigas, Striebel, Hilbig, Rieder, 2015). These findings suggest that those who join a PSG, gather more information about their condition and have contact with others who are suffering from the same illness which can help them realize that they are not alone (Artigas, Striebel, Hilbig, Rieder, 2015). The more social supports a person has, the greater the improvement seen in both psychological and physical well-being (Garlovsky et al. 2016). This also helps with overcoming feelings of anxiety towards the disease and their limitations that come along with PD (Artigas, Striebel, Hilbig, Rieder, 2015). It is important to assess the factors or barriers that are contributing to these symptoms in order to increase QoL and lower scores of anxiety, depression, and social phobia. (Artigas, Striebel, Hilbig, Rieder, 2015).

Psychological factors may have an impact on socialization both in public and at home. Benharoch and Wiseman (2004) created a qualitative study that interviewed persons about PD and how it has affected in their social well-being. The results showed that individuals experienced feelings of embarrassment when completing daily occupations in a public setting, such as cutting up and eating food (Benharoch & Wiseman, 2004). Poor motor function, body discomfort and pain are a few of many

consequences that lead to social isolation and depression (Lawrence et al., 2014). In general, those with PD felt self-conscious about their symptoms, and which limited their participation in various occupations while around other people (Benharoch & Wiseman, 2004). Hobson, Edwards and Meara (2001) found that lower self-perception of activities of daily living (ADL) tasks was associated with decreased social interaction in people with PD (Hobson, Edwards & Meara, 2001).

In a study conducted by Lawrence et. al. (2014), 42% of individuals with PD reported depressive symptoms that impact the person's health related QoL and ability to complete ADLs to non-motor symptoms (Lawrence et al, 2014). 62% of decreased QoL was accounted for by the presence of depression in people with PD, showing individuals with depression scored significantly lower scores on ADL measures than those who were not depressed (Lawrence et al, 2014). These findings support that as depressive symptoms become more severe, people with PD experience an increase in difficulty with ADLs regardless of the severity of the person's motor symptoms (Lawrence et al, 2014). Similar to Lawrence et al. (2017), Hariz and Forsgren (2010) found that those who were classified in the PIGD subtype scored themselves lower on the QoL scale due to physical dysfunction that affected mobility, communication, ADL completion, and body comfort (Hariz & Forsgren, 2010). These findings show a connection between the person's ability to engage in ADL's and depression suggesting that people who experience depression have a decrease in ADL performance.

Activities of Daily Living Affected

Individuals with PD require more help with ADL and Instrumental Activities of Daily Living (IADL) tasks than individuals of other disability populations (Terriff,

Williams, Pattern, Lavorato & Bulloch, 2012). Respondents of this study reported a higher frequency of hearing, communication, mobility, pain, memory, learning and seeing limitations than other populations (Terriff, Williams, Pattern, Lavorato, & Bulloch, 2012). Throughout the aging process, it is important to maintain healthy muscle functionality so that in the event one does experience a neurodegenerative disorder later in life, such as PD, they are able to maintain a positive QoL throughout the process (Skinner, Lee, Roemmich, Amano, & Hoss, 2015). Difficulty engaging in ADLs is correlated with the motor stage of the disease, gait speed, cognitive impairment, and dexterity (Benge & Balsis, 2016). Benge and Balsis (2016) also found that financial management, personal belonging responsibility, driving, household management, and food preparation were other common difficulties found in those with PD. These IADL's were affected by both physical and cognitive impairments (Benge & Balsis, 2016). Hobson, Edwards and Meara (2001) determined that the amount of interference from the disease in a person's daily functioning is likely to be more important to the person than the disease severity meaning that the person's ability to carry out everyday tasks or ADLs is likely more important to the person than how severe the disease has progressed (Hobson, Edwards & Meara, 2001).

Skinner, Lee, Roemmich, Amano, and Hoss (2015), explain that there is a combination of aging, degeneration and disuse among those with PD that leads to a decrease in postural stability, abnormal muscle activation, decrease in moment generation, variability in production of force in muscles, and increased muscle fatigue. Muscle weakness is a symptom that is commonly reported by those with PD. (Hess & Hallet, 2017). This muscle weakness, fatigue and decrease in postural stability can lead to

an increase in falls which increases the person's fear of falling. Falling, and fear of falling (FOF) is common in those with PD and can be defined as having ongoing concern about falling, a loss of balance confidence, a low fall-related efficacy or activity avoidance (Nilsson, Drake & Hagell, 2010). One factor that affects falling is the person's balance and confidence in his or her balance.

Foongsathaporn, Panyakaew, Jitkriksadakul, and Bhidayasiri (2016) conducted a study that asked those affected with PD about their confidence in their balance. In this study, it was determined that people with PD had a higher self-perception of gait problems and episodes of falls than those not affected by PD (Foongsathaporn, Panyakaew, Jitkriksadakul, & Bhidayasiri, 2016). People with PD that were higher on the HY stage scale that assesses balance confidence and estimates the falling and fear of falling, scored lower on the Activities – Specific Balance Confidence Scale – 16 (ABC - 16). As the HY stages increased, the confidence scores decreased, which is solely based on the increase in falls (Foongsathaporn, Panyakaew, Jitkriksadakul, & Bhidayasiri, 2016). Similarly to these findings, Nilsson, Drake and Hagell (2010) noted that experiencing falls, unsteadiness while turning, and FOF were associated with decreased fall-related self-efficacy and increased activity avoidance. This fear of falling is more common and pronounced among individuals who experience falls and can cause the person to restrict the ADLs in which he or she engages in and increase social isolation because of activity avoidance (Nilsson, Drake & Hagell, 2010).

According to Nilsson, Drake and Hagell (2010), fear of falling is a significant predictor of future falls, and therefore, should be included in balance performance tests. The researchers also noted that factors such as an increased duration of PD, having

limitations in ADL functioning, and more severe motor symptoms can contribute to the risk of falling in people with PD (Nilsson, Drake & Hagell, 2010). Decreased confidence in one's balance and increased FOF are more common among people with PD than other populations and are other factors that can increase a person's FOF (Nilsson, Drake & Hagell, 2010).

Wressle, Engstrand, and Granerus (2007), examined how functional deficits, fatigue, and complexity of living are affected by PD. The most common functional deficits that were reported were decreased balance, fumbling, slowness, affected speech and problems with memory, writing, and reading (Wressle, Engstrand, & Granerus, 2007). Frequent rest breaks throughout the day prevented individuals from partaking in leisure activity, doing household chores, and shopping. There was also a concern for being able to lift and carry heavier objects, due to decreased strength and a fear of falling or slipping (Wressle, Engstrand, & Granerus, 2007).

Habit change and decreased socialization are two other areas that were considered. Individuals reported that changing their habits was the hardest part about having PD. These individuals stated that it took longer to complete activities and it often became frustrating. Benharoch and Wiseman (2004) explained that participants with PD reported that getting ready for the day was difficult. Specific tasks mentioned included brushing teeth and fastening buttons. Other individuals struggled with the ability to dress and undress, which requires coordination, balance, and motor skills (Hariz & Forsgren, 2010). This also impacts their opportunities for socialization. In general, the participants felt self-conscious about their symptoms, and this limited participation in various social occupations while around other people (Benharoch & Wiseman, 2004). Not only was it

mentally exhausting and challenging to partake in a social outing for those with PD but it was also physically exhausting. Wressle, Engstrand, and Granerus (2007), explained that individuals with PD make an effort to avoid going out in public or having people over. Because these activities require a great amount of energy to complete, engagement in social activities are greatly reduced (Wressle, Engstrand, & Granerus, 2007).

The person's ability to engage in ADLs has a significant indirect effect on the depression and health-related QoL relationship meaning that people with PD who experience depressive symptoms also experience difficulty completing ADL's which results in a decreased health related QoL (Lawrence et al, 2014). This shows the importance in addressing ADL functioning and other non-motor symptoms in individuals with PD. There is evidence to support that increased education on PD can decrease levels of depression, increase health related QoL and improve management of symptoms (Lawrence et al, 2014).

Benharoch and Wiseman (2004) determined that it very useful for participants in a study to rely on others for occupational needs in order to conserve energy. The role of caregivers is very important to those with PD. The caregivers report that they have taken over roles that once belonged to the patient. Terriff, Williams, Pattern, Lavorato, & Bulloch, (2012) explored the needs, disability and QoL in people with PD. Their findings suggest that as the disease progresses, it decreases the person's health related QoL and increases the need for caregivers. The number of people with PD who have at least one caregiver is significantly higher than populations of other diagnoses. Many caregivers to people with PD are family members, especially significant others. These people provide physical, emotional, and economic support.

Because many family members feel overwhelmed by the vast needs of their family member with PD, many ADL and IADL needs are left unmet. Many people with PD do not receive adequate help. According to Terriff, Williams, pattern, Lavarato and Bulloch (2012), 9.6% of people with PD report needing more help than they receive and 14% report needing help but do not receive it. PD has a significant impact on the people and their families. As the disease progresses, so does the severity creating an increased need for care and demand on caregivers. In comparison with other populations, people with PD experience more negative outcomes including pain, vision problems, and communication difficulties (Terriff, Williams, Pattern, Lavarato, & Bulloch, 2012). In terms of areas in which caregivers had to adapt, habit changes were the largest. The caretakers explained that their habits had changed due to the higher time requirement that is needed to complete all activities. Additionally, it was important for the relatives to respect the patient's dignity and not become too overprotective of their loved ones (Wressle, Engstrand, & Granerus, 2007). Wressle, Engstrand, and Granerus, (2007), concluded that daily life activities are greatly impacted in both the individual affected by PD and the relatives who interact and care for those individuals.

Occupational Therapy Role and Interventions

Occupational therapy (OT) has been found to play a large role in the treatment of individuals with PD. One way in which OT can be used with PD is through addressing early symptoms. Addressing early symptoms of PD may identify future risks that impact individuals with PD. Through the use of objective, performance-based measures, therapists are able to gain a full understanding of the person's function in IADL performance specifically to those with PD (Foster, 2014). This will also help with

identifying early changes which will then help with implementing intervention (Foster, 2014). Occupational therapists use these strategies to improve and maintain occupational performance through addressing self-care skills, giving practical advice, and providing assistive devices and adaptation to occupational tasks and environment. They also teach coping skills and provide support and education for these individuals and caregivers so they are able to engage in meaningful occupations (Wressle, Engstrand and Granerus, 2007).

Dixon et al. (2007) conducted a systematic review addressing the efficacy and effectiveness of OT in those with PD. Two random control trials (RCT) were found examining the efficacy of OT in those with PD by comparing intervention to a control group (Dixon et al. 2007). The review concluded that Gauthier 1987's study showed that those with OT were able to maintain their Barthel Index score, which assesses geriatric patients' ability to perform self-care activities, over 1 year whereas the control group did not. Fiorani (1997) found that those who received OT were able to increase their ADL score on the Brown ADL score, which assesses gross mobility and fine motor coordination, by 6.5 points and increase their QoL score by 2.5 points (Dixon et al. 2007). These findings suggest that the use of OT in individuals with PD can be a very beneficial and effective treatment.

Treatment and intervention strategies have been shown to be more effective when they are individualized and client-centered (Strukenboom, Graff, Hendriks, Veenhuizen, Munneke, Bloem, & Nijhuis-van der Sanden, 2014; Wressle, Engstrand, & Granerus, 2007). Making the goals individualized continues to be the gold standard of care because it addresses the needs and wishes of the individual with PD (Clarke et al. 2016).

Abbruzzese, Marchese, Avanzino, and Pelosin (2016) wrote an article focusing on the issues of the present and future of rehabilitation for Parkinson's Disease. It was found that currently the most common types of rehabilitation interventions that have an influence on the improvement of symptoms in PD include physical therapy (PT), OT, and treadmill training which is performed by a physical therapist (Abbruzzese, Marchese, Avanzino & Pelosin, 2016). Such rehabilitation interventions are associated with cueing and attentional strategies towards motor movements. External cueing is used to help with the decrease of internal signals to perform movements (Abbruzzese, Marchese, Avanzino & Pelosin, 2016). Increasing external cueing may increase the ability to facilitate the initiation of motor movements (Abbruzzese, Marchese, Avanzino & Pelosin, 2016). Non-conventional strategies such as dance, music, and martial arts have been also used to improve postural control, which in turn will decrease the chance of falling (Abbruzzese, Marchese, Avanzino & Pelosin, 2016). Even though there is not enough evidence to show that these types of interventions are effective, it has been shown to be more enjoyable and to favor social engagement (Abbruzzese, Marchese, Avanzino & Pelosin, 2016).

Through the use of individualized interventions, the occupational therapist addresses the person's physical and occupational performance. This can be done through the use of physical activity, the provision of environmental cues for physical performance, and education on self-management and cognitive-behavioral strategies that can be used in the person's everyday life (Foster, Bedekar, & Tickel-Degnen, 2014). When used in combination with a home-based approach, these methods of intervention lead to improvement in the person's perceived performance in meaningful daily activities and have a positive effect on the person's satisfaction with daily and instrumental

activities (Strukenboom, Graff, Hendriks, Veenhuizen, Munneke, Bloem, & Nijhuis-van der Sanden, 2014). Some findings suggest that it may be possible that those with mild to moderate PD may not respond to therapy as strongly as those who have progressed further in the disease (Clarke et al. 2016). The findings of Lawrence et al. (2014) suggest that the combination of ADL functioning and depression have a greater impact together on health related QoL than separately. This suggests that the use of cognitive behavioral therapy (CBT) strategies used for depression may be beneficial for individuals with PD experiencing ADL difficulties.

Guo, Jiang, Yatsuya and Yoshida (2014) used an interdisciplinary team of neurologists, occupational therapists, physical therapists, and dieticians to conduct group lectures focusing on the person's meal, mood and moving in a group setting for rehabilitation of idiopathic PD. Treatment included individual training with visual, auditory, and tactile cues or feedback; treadmill training with body weight support; balance training; high intensity resistance training; and active music therapy (Guo, Jiang, Yatsuya & Yoshida, 2014). Results of the study suggested patients feeling stronger and having increased confidence in the future, elevated mood, and a feeling of improvement in personal skills to overcome the inconvenience of PD (Guo, Jiang, Yatsuya & Yoshida, 2014). The findings of this study suggest that the combination of group education and personal rehabilitation programs can be a beneficial and practical intervention complements medical treatment. These interventions can help people adjust skills in daily life, promote guidance and training for people and caregivers, and can promote self-help and family care to delay and prevent deterioration (Guo, Jiang, Yatsuya & Yoshida, 2014).

In OT, home adaptation is another area in which people with PD could use assistance. Just as occupational therapists perform assessments in the clinic that help determine personal challenges, they also perform assessments in the home. These assessments are geared towards barriers that could be contributing to a decline in accessibility, completion of daily tasks, and overall safety (AOTA). As 80% of falls occur in the person's home, the use of home environmental adaptation (HEA) is needed in the PD population (Bihidayasiri et al, 2014). The purpose of HEA is to improve a person's ADLs and improve housing accessibility and usability by removing physical barriers and making changes to improve home safety (Bihidayasiri et al, 2014). At the conclusion of an in-home evaluation, occupational therapists are easily able to recommend and provide equipment and changes in the home that will maximize safety and independence in the home (AOTA). Some examples of home adaptations can include but are not limited to: adaptive equipment, increased amount of lighting, training of family members or caregivers, and/or remodeling of the home (AOTA). Thus, challenges in accessibility and usability in a person's home should be taken into consideration for individuals with PD (Bihidayasiri et al, 2014).

Both physical performance skills and occupational performance can be addressed in several ways. Interventions to address these include physical activity, provision of environmental cues or support, and the use of cognitive strategies for integrating performance patterns into daily life (Foster, Bedekar & Tickel-Degnen, 2014). E. F. Foster (2014) determined that clinical care must consider the degenerative nature of these diseases in order to maximize function and QoL. E.F. Foster's (2014) study suggests that exercise has positive effects on health and well-being and should be encouraged in

individuals with neurodegenerative diseases as this population has a lower adherence to exercise than the general public. The findings of this study suggest that some of the most effective interventions include OT as a component of multidisciplinary care in this population but there is a lack of outcome measurement at the level of occupation (E. F. Foster, 2014).

One way in which education and training can be provided for people with PD is through the use of group interventions. Foster, Bedekar and Tickle-Degnen (2014) concluded that receiving intervention in a group context may be particularly beneficial to people with PD as they are at an increased risk of daily life and health care stigmatization and social isolation (Foster, Bedekar & Tickle-Degnen, 2014). Social interactions and supports are found to be motivators for people with PD to participate in interactions and should be used in intervention (Foster, Bedekar & Tickle-Degnen, 2014). Sensory-perceptual skills can be addressed through multi-session, repetitive physical exercise tasks and activity training (Foster, Bedekar & Tickle-Degnen, 2014).

Butterfield et al. (2017) developed a behavioral activation-based program to reduce levels of apathy in non-demented individuals with PD called The Parkinson's Active Living (PAL) program (Butterfield, et al 2017). The PAL program encourages participants to create their own goals. The coaches help educate and guide the participants to set goals that are realistic, measurable, attainable, specific, and have the ability to be reached in a certain time frame (Butterfield et al. 2017). In collaboration, the therapist and participant set five goals based on the information gathered from the baseline assessment to be used during the six week intervention period (Butterfield et al. 2017). Since individuals with PD have issues with self-initiating, the PAL program

incorporates different aspects that assist with external cueing such as a weekly calendar, goal checklist, and automated reminder calls (Butterfield et al. 2017). The participant is given a calendar that outlines each activity, the times of day, days the activity should be completed, and a plan for possible interruptions (Butterfield et al. 2017). At the end of each week the coach calls each participant to talk about their week, how they are progressing towards their goal, and about anything that interfered with meeting the goals. (Butterfield et al. 2017). This program has been shown to decrease depression, apathy, and increase self-rated QoL (Butterfield et al. 2017).

Future outlook on rehabilitation for PD includes motor imagery (MI) which helps improve motor skills by increasing the proprioceptive signals during movement, and action observation therapy (AOT) which combines observation of actions with repetitive movement (Abbruzzese, Marchese, Avanzino & Pelosin, 2016). Both MI and AOT are used by directly connecting the imagined or observed action with their internal thoughts about the movement. This may assist in increasing the person's ability to learn a new task, increasing motor performance (Abbruzzese, Marchese, Avanzino & Pelosin, 2016). Virtual reality and robotic rehabilitation are two more interventions for future rehabilitation. In virtual reality interventions, the individual interacts with a virtual environment to increase motor learning. The use of robotic rehabilitation interventions is another area of growth, but currently there is little research regarding this type of intervention (Abbruzzese, Marchese, Avanzino & Pelosin, 2016).

Arbesman, Lieberman and Berlanstein (2014) conducted a systematic review to evaluate common interventions used with people with neurodegenerative diseases, specifically PD, Amyotrophic Lateral Sclerosis (ALS), Multiple Sclerosis (MS) and

Transverse Myelitis (TM). The researchers determined that rehabilitation takes place on a continuum of care in which the care changes as the person's needs change. In this study, interventions for PD were found to focus on improving occupational performance and QoL through exercise or physical activity, environmental cues, stimuli and objects, and integration of self-management and cognitive behavioral strategies (Arbesman, Lieberman & Berlanstein, 2014). Overall, interventions that are well-designed, multidisciplinary, and address QoL are needed to encompass the wide range of issues experienced by a person with PD (Foster, Bedekar & Tickel-Degnen, 2014). This evidence can be used to expand the focus of interventions from strictly motor dysfunction and its effect on basic self-care ADLs to include cognitive and psychosocial issues and their impacts on complex areas of occupation (Foster, Bedekar & Tickel-Degnen, 2014).

To further enhance the involvement of occupational therapists, the product presented in later chapters is done in conjunction with the local YMCA. The local hospital, Altru Health System, currently offers a Parkinson's Wellness Recovery Program held at the local YMCA. Its goal is to improve the lives of people living with PD. This program is based off the Parkinson's Wellness Recovery (PWR!) and Exercise4BrainChange™ curriculums. The program currently only focuses on improving physical and brain functionality so that people with PD can get better and stay better longer. Participants spend 30 minutes completing activities and playing games that challenge the thought process and stimulate brain activity to optimize their brain health. Approximately 50-60 minutes of physical activity follow, including a variety of basic progressive and functional whole body movement exercises, to improve overall physical performance and ability (YMCA, 2017).

Currently there is no OT involvement within this specific program. It is important to assess the needs outside of exercise and movement in those with PD. Individuals with PD often report that specific tasks such as brushing teeth, dressing and undressing, and fastening buttons become more difficult as the disease progresses (Hariz & Forsgren, 2010). As discussed throughout the literature review, by addressing the needs of both the caregiver and individual with PD, occupational therapists are able to develop and implement interventions that will assist with remaining independent as long as possible throughout the progression of PD.

Conclusion

Up to one million people nationwide are diagnosed with Parkinson's Disease (PD) each year (Florida Hospital, 2017). Parkinson's disease is a degenerative disease within the CNS that causes a decline in speed and coordination, which in turn leads to a decline in participation in everyday activities. The most common factors associated with PD are tremors, slow movements, shuffling gait, and stooped posture. Motor symptoms are not the only factors limiting participation in everyday activities. Cognitive decline also occurs in those with PD. Executive functioning and multi-tasking diminish as the disease progress (Koerts, Beilen, Tucha, Leenders, & Brouwer, 2011). Self-image, anxiety, and a decrease in confidence about activity performance can lead to isolation and depression in those with PD. Being a part of social groups that help those with the disease find more information about PD and bond with others who also have the disease has been shown to increase the acceptability of this disease (Garlovsky et al. 2016; Artigas, Striebel, Hilbig, Rieder, 2015). It has been shown that those with an increased number of social supports helps with self-confidence and ability to perform successfully. It has been

shown that individuals with PD may require more help with ADL and IADL tasks compared to those with other chronic diseases (Terriff, Williams, Pattern, Lavorato & Bulloch, 2012).

The progression of this disease has an effect on the person's balance, fear of falling, QoL, depression, muscle functioning, and on the role of caregivers. Overall, ADL's are an important area of focus for intervention with PD as the person's ability to carry out everyday tasks or ADLs is likely more important to the person than how severe the disease has progressed. Addressing a person's ADL's can be done by using individualized and client-centered interventions (Strukenboom, Graff, Hendriks, Veenhuizen, Munneke, Bloem, & Nijhuis-van der Sanden, 2014; Wressle, Engstrand, & Granerus, 2007). Current interventions strive to provide client centered care that meets the needs of the person. This can include home adaptation, education and training, the use of group contexts, physical activity, environmental cues and support, use of cognitive strategies for integrating performance patterns into daily life (Foster, Bedekar & Tickel-Degnen, 2014). The future outlook for intervention with PD includes all aspects of a person. The use of a well-designed multidisciplinary team that addresses the person's QoL is the most effective (Foster, Bedekar & Tickel-Degnen, 2014).

Through using these interventions and strategies, the use of OT in individuals with PD can be a very beneficial and effective treatment (Dixon et al., 2007). There are limited findings supporting the effectiveness of OT with this population suggesting a need for further research. One study found, addressed the efficacy and effectiveness of OT in those with PD. The study concluded that those who received OT were able to maintain their scores on the Barthel Index and Browns ADL assessment over 1 year and

increase their ADL scores and QoL (Dixon et al., 2007). With limited information available on the role of OT interventions that target ADL's in PD, there is a need for OT evaluation and development of plans that further target ADL's in this population.

One way in which OT can improve in the evaluation and development of plans is through research and implementation of program plans to increase the success in ADL performance in those with PD. This program plan will address the ADLs that PD affects in everyday life, and is aimed at improving overall physical and mental health in this population. This will be done by creating group protocols that focus on compensation techniques, new strategies, and will provide education and training to family members/caregivers in all areas of ADL's. The goal of this program plan is to improve the performance and duration of independence in activities of daily living in people with PD. These protocols will be developed to provide occupational therapists with a baseline tool that will assist with developing interventions that focus on aiding individuals with PD in successful completion of ADL tasks. The development of these protocols will provide solid background information to enable therapists to adapt and use in multiple areas of practice.

CHAPTER III

METHODOLOGY

The product, *Activities of Daily Living with Parkinson's Disease*, was created to assist occupational therapists in providing education to both those with PD and their caregivers about ways to increase independence and safety for as long as possible. To develop this product there were different phases that were completed. The first phase was an in-depth literature review that focused on: Parkinson's disease, neurodegenerative diseases, progression and stages of PD, interventions used with PD, the role of OT, and psychological or psychosocial aspects of the disease. The research engines used to complete this literature review included: AOTA, PubMed, PsychInfo, Google Scholar, CINAHL, AJOT. Additional information was found in textbooks and educational websites regarding home modifications. Textbooks were used to complete session outlines, online websites were used to locate and assist with development of activities and handouts to include for references and expert input from the Parkinson's program director at the local YMCA was used to assist with development of sessions. Pictures were obtained from Word ClipArt and the website Pixabay.com which features pictures that have creative commons rights.

Next, seven, one-hour sessions were developed using *Cole's Seven Steps* to assist with facilitation of the ADL groups. The sessions were developed from the information found in the literature about the most problematic areas for those with PD. The group leader will introduce each session with an introduction to the group and the objectives that are to be met. The program interventions include: mobility and safety within the home and community, grooming strategies and techniques, bathroom mobility, meal

preparation and feeding, upper and lower body dressing, and equipment maintenance. Each group will address various learning styles by providing paper handouts, lecture material, and kinesthetic activities with the caregiver. Each group member will be encouraged to ask questions throughout the session. At the end of each session, members will be asked to come prepared with questions regarding the next sessions. The education sessions will be described further in the following section.

As the progression of PD has an effect on the person's environment, engagement in occupation, and individual traits and abilities, the model of Person-Environment-Occupation was chosen for this product. The Person-Environment-Occupation model was used to develop the sessions for this program. This model was selected because it incorporates personal factors, environmental factors and occupational engagement in relation to Activities of Daily Living and focuses on the transaction between these three domains (Hinojosa, Kramer, Royeen, 2017).

CHAPTER IV

PRODUCT

OCCUPATIONAL THERAPY'S
INVOLVEMENT WITH THE YMCA IN
DEVELOPING A PROGRAM TO ADDRESS
ACTIVITIES OF DAILY LIVING IN
THOSE WITH PARKINSON'S DISEASE.



Michaela Johnson, MOTS
Emilea Berhow, MOTS

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LIST OF MATERIALS

Session 1 Materials:

- Folder
- Stickers
- Markers

Session 2 Materials:

- Safety Discussion PowerPoint
- Handout
- Adaptive Equipment
 - Walker
 - Walker tray
 - Canes
 - Wheel chairs
 - Walker basket

Session 3 Materials:

- PowerPoint on Energy Conservation
- Handout for Energy Conservation
- Adaptive tools
 - Brushes
 - Blow dryers
 - Make up brushes
 - Tooth brushes
 - Weighted sleeves
 - Built up handles
 - Electric shavers and personal tools

Session 4 Materials:

- Ice breaker questions
- Bathroom equipment
 - Shower chair
 - Shower bench
 - Reacher
 - Grab bars
 - Walker
- Handout on Tips & Tricks and bathroom modifications

Session 5 Materials:

- List of Stretching Activities
- Handout
- Videos showing dressing with adaptive equipment
- Adaptive equipment
 - Dressing stick
 - Reacher
 - Sock aid
 - Velcro
 - Shoe horn
 - Leg lifter
 - Button hook
 - Elastic waistband
 - Elastic shoelaces

Session 6 Materials:

- Paper, pencils
- Kitchen Safety Handout
- Ingredients for a simple desert (brownies, cookies, etc.)
- Baking supplies (pans, spatula, bowls, spoons, oven mitt, etc.)
- Adaptive equipment:
 - Built up handles

Session 7 Materials:

- Paper
- Masking tape
- Adaptive equipment
 - Walker
 - Cane
 - Wheel chair
 - Other personal adaptive equipment
- Tools (wrench, screw drivers, etc.)

SESSION 1

“Introduction to Parkinson’s ADL Group”

Introduction: *Introduce the activity*

- Introduce self to group and explain the purpose of the group and what will be covered.
 - Overall introduction:
 - Therapist leads the session for getting to know one another.
 - Overview of the program, sharing experiences of challenges and areas to work on, and discussing the topics that will be covered through the group.
 - Therapist will provide individuals a packet of the overall program/sessions to bring to each session for caregiver or individual to take notes or to use for reference.
 - **Overall Goal:**
 - Upon completion of this program plan, individuals with PD will report less difficulty when completing activities of daily living to improve quality of life.
- Participants will receive a folder during the first session.
- Handouts will be provided during or following each session summarizing the information covered in each session. Participants will add information to the folder to have a reference at home.
- **Warm Up:** “Decoration of Folders”
 - Craft supplies and folders will be provided. Members are to decorate the folders however they like. This activity will take 10 minutes. If individuals need assistance with this activity, caregivers are encouraged to assist.

- **Rationale:**

- Individuals with PD that engage in personal support groups have better quality of life, lower depression, anxiety and social phobia than individuals that were not involved in personal support groups increasing information about their condition and contact with others with PD (Artigas, Striebel, Hilbig & Rieder, 2015).
- Having a higher number of social supports has a greater positive impact on psychological and physical well-being than having no social supports (Garlovsky et al., 2016) which assists in overcoming feelings of anxiety and limitations with PD (Artigas, Striebel, Hilbig, Rieder, 2015).
- A goal of the session is to educate caregivers on the importance of support and assisting loved ones to remain as independent as possible.
- The presence of a caregiver can make a large impact. Many people with PD do not receive adequate help (Terriff, Williams, Pattern, Lavarato, Bulloch, 2012).
 - 9.6% report that needing more help than they receive (Terriff, Williams, Pattern, Lavarato, Bulloch, 2012).
 - 14.6% report needing help but do not actually receive any (Terriff, Williams, Pattern, Lavarato, Bulloch, 2012).



Objectives:

- Understand the overall purpose of the group.
- Understand the goals/activities that are being addressed and why.
- Feel more comfortable with the impairments/barriers that come along with PD.

Activity, Sharing, and Processing:

- Provide an overview of how PD effects ADL performance using the article (Johnson, 2017) provided on p. 51.
- This is done to provide support and education on the effects that PD has on a person and his or her ability to complete daily tasks.
 - Hand out FAQ's Sheet (Goodwater & Yutrzenka, 2017) for group members on p. 44.
- Discussion:
 - What was surprising to you about this article?
 - What specific ideas pertain to you and your ability to complete daily activities?
 - What did you find helpful about this article?
 - What experiences do you have that are the same or different from the article?
 - What do you wish the article would have talked about?
 - Share personal experiences about difficulties with ADLs and ideas/strategies that have helped completing these tasks.
 - Discuss/share areas that are of difficulty that weren't included in the article.
- Discuss future group sessions and topics for future sessions.
 - Ask what topics would be important to cover and topics of increased interest.
 - If topics to be addressed later, reassure them of the topics.

- If a new topic is brought up:
 - Make a note of the topic and address topics as they apply to other sessions
 - Address topics during the final session to wrap up the educational experience.
- Provide brief overview of sessions to come.
- Future Session Topics:
 - Mobility
 - Grooming
 - Bathroom mobility and transfers
 - Dressing
 - Meal preparation
 - Feeding
 - An overview of equipment maintenance and use
- Discuss future group sessions and ways to improve daily activities.
- Encourage individuals to share their difficulty areas and what they would like to know more about/practice more
 - Confidentiality: provide blank paper and a box for topics for future sessions.
- Encourage caregiver participation and attendance to future sessions.

Application: *Help the group understand how they can use these skills they learned in the sessions in real life*

- Ask if presented topic areas are areas in which they would like to improve.
- Ask members if they are willing to participate in these group sessions to increase their ability to complete ADLs.

Homework:

- Explain the next group session titled, “*Let’s Get Moving*”
- Ask members to prepare for next session by thinking of 2-3 questions or examples of specific tasks that pose difficulty to mobility within his or her environment.
- Be prepared to share these questions and examples with the group.
- Have members of the group be prepared to discuss these examples and questions during the next session.



Model Application

- **Person:**
 - Factors may vary from person to person but the physical and cognitive impacts and symptoms of PD will be addressed and how they affect ADL performance and participation. Throughout this session the therapists will help decrease anxiety and provide comfort in attending the future ADL sessions

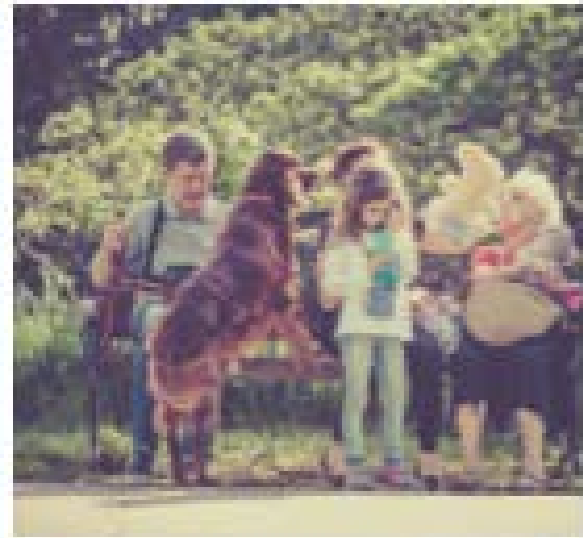
- **Environment:**
 - Environmental factors may vary from person to person but environmental adaptations and modifications will be addressed to increase performance and participation in ADL's. Throughout this session the therapists will help provide comfort and confidence in talking about environmental issues that impact participation and performance in occupations.

- **Occupation:**
 - Occupations may vary from person to person but the meaningful occupations of each group member will be the main focus of their session. Throughout this session the therapists will help provide comfort and confidence in talking about issues with participation and performance issues in occupations.

- **Transactions:**
 - Due to working with a varying population of individuals with PD, the transactions between the person, environment and occupation will be different for each individual group member. In regard to goodness or poorness fit between the three components, this will also vary depending on each group member; therefore, the interaction will be unknown. The components of each transaction will be individualized and evaluated further upon interaction with group members.

Notes

Parkinson's Disease



Answers to common questions for people who have or may have Parkinson's

What you will learn

- What Parkinson's Disease is
- Symptoms
- How many people have Parkinson's
- Diagnosis
- Treatment

Information retrieved from Parkinson's Disease Foundation.
Please visit www.pdf.org for more information.

What is Parkinson's Disease?

Parkinson's disease (PD) is a lifelong disorder that affects movement. PD causes damage over time.

It is caused by death of brain cells. These cells make chemicals that help your coordination and movement.

When the cells die, your movements are affected.



Information retrieved from Parkinson's Disease Foundation.
Please visit www.pdf.org for more information.

What are the symptoms of Parkinson's?

The most common signs are:

- Shaking in your hands, arms, legs, or jaw
- Stiff muscles and arms/legs
- Slow movements
- Poor balance and coordination

Other signs are:

- Pain
- Confusion
- Poor sleep
- Being tired
- Depression
- Anxiety
- Change in thinking skills, such as
- memory and attention



Information retrieved from Parkinson's Disease Foundation.
Please visit www.pdf.org for more information.

How many people have Parkinson's?

About 10 million people in the world live with Parkinson's.

In the United States, about 1 million people live with Parkinson's.

Information retrieved from Parkinson's Disease Foundation.
Please visit www.pdf.org for more information.



**It is more
common in men
than women**

How will I know if I have Parkinson's?

There is no test to know for sure if someone has Parkinson's. A doctor will test to check for other diseases.

Doctors will look at symptoms and rule out other diseases before they diagnose you.

Information retrieved from Parkinson's Disease Foundation.
Please visit www.pdf.org for more information.

How is Parkinson's treated?



- Currently, there is no cure for Parkinson's.
- However, it can be treated with medications.
- Symptoms can also be treated with surgery.

(Parkinson's Disease Foundation, 2016)

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Activities of Daily Living and Parkinson's Disease

Michaela Johnson

Parkinson's Disease is a progressive disorder that effects motor planning or ability to plan movements correctly. Those with Parkinson's Disease see a decline in fine and large motor coordination, balance, walking ability and cognitive function (Foster, Bedekar and Tickle-Degnen, 2014). With a decline in these areas, individuals with Parkinson's Disease also see a decline in their ability to perform daily activities successfully. Since Parkinson's Disease is a progressive disease, there are many different stages and difficulties people have when performing daily tasks. Some of the most common tasks that individuals struggle include dressing, grooming, financial management, driving, and household management such as cleaning, cooking and laundry (Benge & Balsis, 2016).

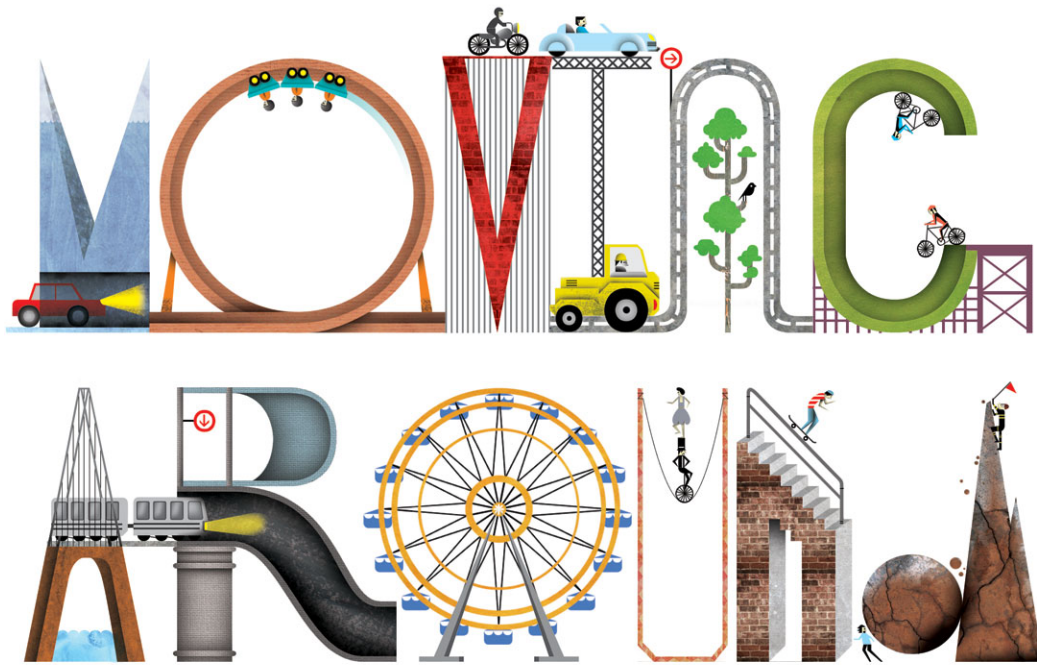
There are many ways in which those with Parkinson's Disease can increase their independence with everyday tasks. Occupational Therapy (OT) is an example of this service. Occupational Therapy is a profession that helps those across the lifespan engage in things that the person needs and wants to do. OT helps individuals live life to the fullest by providing individual services that focusing on prevention, modification and establishing or regaining skills that will help the individual be successful in everyday life (AOTA). Occupational therapy (OT) has been found to play a large role in the treatment and intervention of individuals with PD. One way in which OT can be used with Parkinson's Disease is through addressing early symptoms of the disease. Addressing symptoms of Parkinson's Disease early will predict future risks that may pose issues for individuals with Parkinson's. By using evaluations, therapists can gain a full understanding of the person's function performance in their activities of daily living (Foster, 2014). By understanding the individual, the therapist will be able to design and provide individualized treatment focusing on specific issues to help increase independence and engagement in everyday activities.

There are current interventions used in OT that have been proven to be effective. This can include all of the following interventions. Home adaptation such as modifying the bathroom to accommodate for a walker or wheelchair. Education and training on strategies and techniques to successfully complete dressing, grooming or cooking. The use of group activities to increase social interaction and cognitive function. Physical activity to help with balance and strengthening. Environmental cues and support such as calendar for memory, family members assisting with shopping, or simple alarms to remember medications. The use of a well-designed multidisciplinary team that addresses the person's quality of life and their independence is shown to be the most effective in treating Parkinson's Disease (Foster, Bedekar & Tickle-Degnen, 2014).

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SESSION 2



“Movin and Groovin” Moving From Place to Place

SESSION 2

“Movin and Groovin”

Moving From Place to Place

Introduction:

- Welcome PD individuals and caregivers/family members to today’s group.
- Explain the purpose of the group:
 - Increase safety in mobility around the house and within the community
- Address questions/concerns in homework tasks from previous session
 - Members were to come prepared with 2-3 questions or examples of tasks that pose difficulty to mobility within his or her environment.
 - Have members share questions and examples.
 - Be prepared to discuss examples provided
- Warm Up:
 - Go around the room starting with one group member and circulating around the room.
 - Have each group member state his or her name
 - Have each group member share with the rest of the group one to two favorite hobbies.



● Rationale:

- Postural instability is a cardinal motor symptom of PD. As the disease progresses, protective reflexes decrease (Hess & Hallet, 2017).
- In the early stages of the disease, there is an increase in tripping which leads to an increased focus while walking on uneven surfaces (Hess & Hallet, 2017).
- As the disease progresses, individuals tend to lean or fall backwards more easily (Hess & Hallet, 2017).
- This postural instability can increase anxiety and fear of falling (Hess & Hallet, 2017).
- As the disease progresses, the individual develops:
 - A flexed and stooped posture
 - A slow shuffling movement with their feet
 - A decrease in stride-length (Hess & Hallet, 2017)
- When a person's posture changes, so does their center of gravity. The shift in the center of gravity forces the individual to stop on the front part of their foot, instead of the heel.
- This gait pattern throws the upper body momentum forward making the individual more prone to falling forward (Hess & Hallet, 2017).

Objectives:

- Learn 2-3 strategies to decrease falling risks and increase mobility safely
- Demonstrate or discuss 2-3 safe strategies for mobility
- Understanding of mobility equipment

Activity: *Introduce the activity*

- Lecture: Safety discussion PowerPoint located on p. 62.
 - Present information about safety tips to do in the home to decrease amount of falls.
 - Tools and environmental changes that can be done to increase safety with mobility within home.
 - Safety in the community.
 - Distribute handout to follow along during session and to keep for future use located on p 61.
- Demonstration
 - Instructor will demonstrate in front of large group before splitting up into groups of two:
 - Proper kitchen mobility
 - Walker and wheelchair placement
 - Tools to use in kitchen for mobility of food with use of:
 - Trays
 - Baskets
 - Sliding techniques
 - After demonstration, group members will split up into pairs:
 - Individual and caregiver
 - Individual and therapist

- Once in groups, individuals will practice mobility techniques.
- Therapists will be available for answering questions and giving advice about techniques.

Sharing: *Have group members share their thoughts about the activity.*

- What did you think of the activity?
- What did you like/dislike about the activity?
- What did you find most helpful?

Processing: *Have the group share and process through their feelings about the session*

- Overall, how do you feel about this activity and your experience?
- How did you feel about having your caregiver/family member here with you? Did it change the experience for you?

Application: *Help the group understand how they can use these skills they learned in the sessions in real life*

- Why is important to be aware of how to declutter or keep your house clean to prevent falls?
- How will your caregiver/family member help you complete these tasks?
- How will you remember to use these strategies to complete safe mobility throughout the home and community?

Homework:

- Explain the next group session: Grooming
- Members are to come prepared with 2-3 questions or areas of difficulty in completing grooming tasks and bring equipment.



Model Application

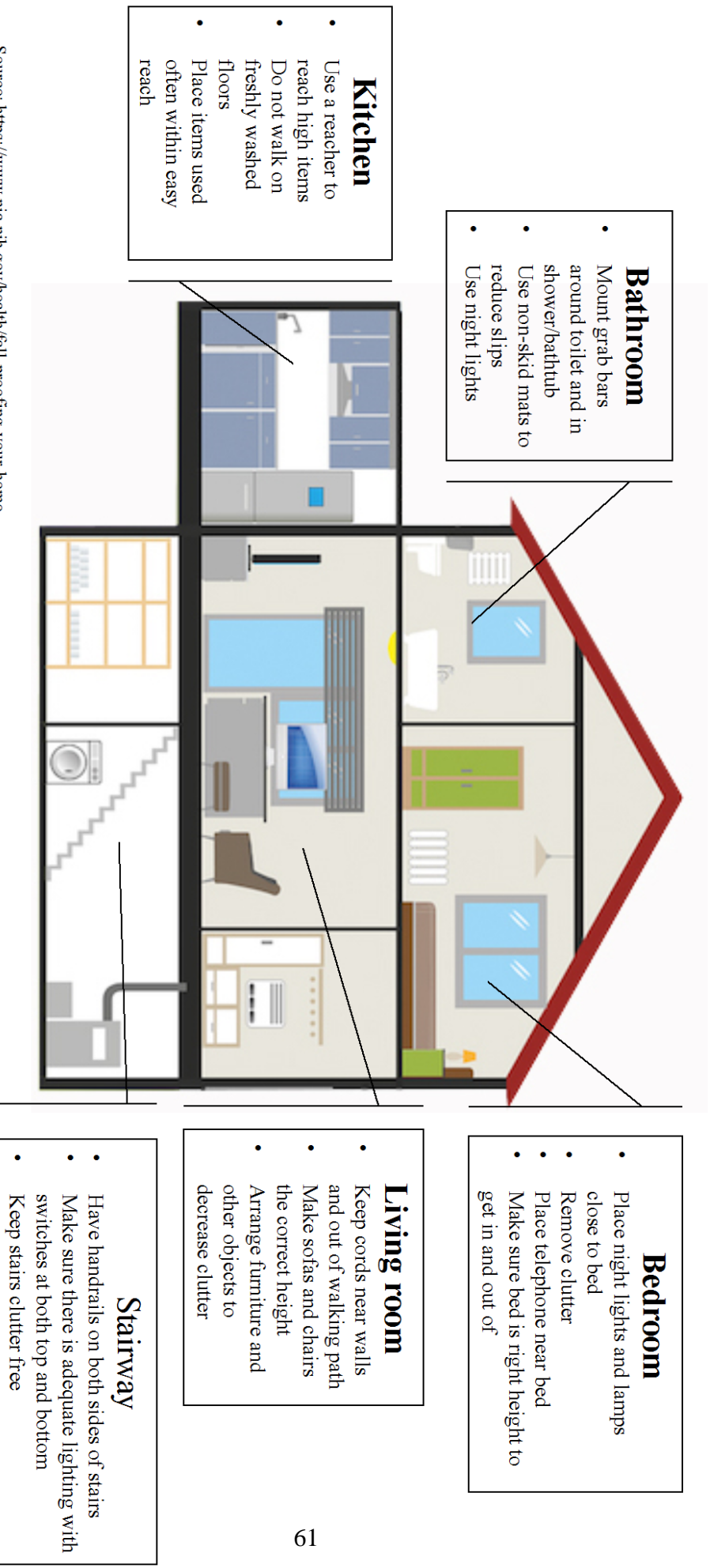
- **Person:** Factors may vary from person to person but will include the following aspects.
 - **Physical:** Physical impacts and symptoms within the progression/stage of PD.
 - **Cognitive:** Cognitive impacts, impairments and symptoms of the progression/stage of PD.
 - **Affective:** address possible social isolation and increase mood with education on ability to complete daily activities safely, completed in group context.
 - **Spiritual:** independence in ability to complete meaningful occupations.
- **Environment:** Factors may vary from person to person but will include the following aspects.
 - **Physical Environment:** Tools and environmental changes are provided to the group members that can be done to increase safety with mobility.
 - Safety in the community
 - Safety within home
 - **Cultural Environment:** Adaptations to the environment are done in a way so individuals are able to maintain cultural values and beliefs of independence by allowing people to make modifications in a discreet way.
 - **Social Environment:** Address isolation issues, decrease in prior meaningful occupations outside or inside of the home.
- **Occupation:** Factors may vary from person to person but will include the following aspects
 - **Self-Care:** will address person's ability to move around the physical environment for completion of self-care tasks.
 - **Productivity:** will address person's ability to complete daily ADL tasks with or without assistance, and person's satisfaction in completion of these activities.
 - **Leisure:** will address the person's ability to complete prior activities and how the disease has impacted engagement in these activities.

- Leaving the house.
- Safely maneuvering the physical environment inside and outside the home.
- **Transactions:** Due to working with a varying population of individuals with PD, the transactions between the person, environment and occupation will be different for each individual group member. In regard to goodness or poorness fit between the three components, this will also vary depending on each group member; therefore, the interaction will be unknown. The components of each transaction will be individualized and evaluated further upon interaction with group member.

Notes

Safety First!

Falls Prevention guide for Parkinson's Disease



Source: <https://www.nia.nih.gov/health/fall-proofing-your-home>

“MOVIN AND GROOVIN”

Safety within the home and community

Throughout the home

- Non-skid surfaces
- Stable furniture
- Good lighting throughout home
- Wide hallways to accommodate adaptive equipment
- Railings on stairways
- Remove throw rugs
- Remove access clutter to reduce falls

In the bedroom

- Make sure feet can touch the floor while seated on bed
- Utilize a bedrail or pole to assist with bed mobility
- Use light sheets on the bed for easy bed mobility
- Make lighting easily accessible
- Place a bedside commode for nighttime
- Rearrange closets and dressers for easier access

In the bathroom

- Install grab bars by toilet and in and around tub/shower
- Use toilet riser and arm rests or grab bars to easily mobility
- Utilize a sturdy bath bench or chair with back for support
- Keep floor clutter free

In the kitchen

- Store commonly used items in lower and easily accessible drawers
- Place items used for cooking in a safe place around the stove for ease of accessibility to decrease reaching
- Use a reacher to reach light items off higher shelves

In the stairway

- Ensure for adequate lighting
- Steps should be non-slip surfaces
- Install railings on both sides of the stairway if permitted
- If unable to use adaptive equipment on the stairs, place equipment both at top and bottom of stairs
- Install ramp if possible or can not manipulate stairs
- Keep steps clutter free
- Place bright colored tape on bottom and top stairs for easier view of steps

Community Mobility - Driving

- **If still able to drive**
 - Eliminate driving distractions
 - Avoid night time driving
 - Choose familiar and comfortable routes
 - Take a defensive driving course
- **If unable to drive**
 - Consider taking public transportation (bus, Dial-a-Ride, Taxi)
- **Handicap accessible**
 - Ask family and friends to drive
 - Volunteer drivers from church or assistive housing

Community mobility – Going out to dinner

- **Choosing a restaurant**
 - Table service to reduce trying to walk and hold a tray, dinner plate and/or drink
 - Time the dinner when energy is at its peak to reduce issues with mobility or cognitive problems
 - Arrive early to restaurant to ensure for optimal seating selection and faster food service
- **Call ahead**
 - Confirm that restaurant is handicap accessible (parking and seating options)
 - Ask the restaurant if they are willing to accommodate for needs

SESSION 3



“Keep Calm and Groom On”

Brushing Your Teeth/Washing Face/Applying Makeup/shaving

SESSION 3

“Keep Calm and Groom On”

Brushing Your Teeth/Washing Face/Applying Makeup/shaving

Introduction:

- Therapist leads the session for basic grooming tasks.
- Therapist will go over each area and provide strategies on how to safely and properly perform each task.
- Therapist will then let individuals perform each task with the strategies with as much assistance as needed.
- Address questions/concerns in homework tasks
 - Group members were to come prepared with 2-3 questions or areas that pose difficulty to performing this task to share
 - Group members were encouraged to bring adaptive equipment to this session.
- Warm-Up: Holiday Season
 - What is your favorite holiday and why?
 - What are the most stressful parts about this holiday besides preparing the meal?

● Rationale:

- Bimanual movements are troublesome for those with PD. When performing bimanual movements, overflow movements on the opposite side of the body are often present (Hess & Hallet, 2017).
- Individuals with PD often have difficulty engaging in ADL's.
- Difficulty in this area of occupation is correlated with:
 - The motor stage of the disease
 - Cognitive impairments
 - Dexterity (Benge & Balsis, 2016)
- Individuals with PD take longer to complete activities and often became frustrated.
- Benharoch and Wiseman (2004) explained that those with PD reported that getting ready for the day was difficult.
 - A specific task mentioned was brushing teeth.
- Therapists can provide compensatory strategies and techniques to assist with completing everyday tasks by addressing:
 - Decreased bimanual skills
 - Overflow movements
 - Decreased dexterity
 - Motor movements

Objectives:

- Learn 2-3 strategies to increase ability to complete grooming tasks.
- Understand compensatory strategies and how they can be helpful.
- Understand how your caregiver/family member can assist in this step of your daily routine.

Activity: *Introduce the activity*

- In large group, have members discuss current ways they perform grooming tasks and what barriers are present that interfere with completing grooming tasks.
- After discussion, present and discuss energy conservation tips with large group.
 - Provide handout of Energy Conservation tips to follow along on p. 74.
- Present and discuss adaptive tools and techniques to use when performing grooming tasks
 - Physical demonstration
- Demonstration and Practice:
 - After demonstration, have group members split up into pairs:
 - Individual and caregiver
 - Individual and therapist
 - Have individuals practice seated grooming, energy conservation techniques, weighted tools (toothbrush, makeup brushes), built-up handles, electric shavers or personal tools.

Sharing: *Have group members share their thoughts about the activity.*

- What are overall thoughts on this activity?
- Was it helpful?
- What did you like/dislike?

Processing: *Have the group share and process through their feelings about the session*

- Overall, what did you learn from this session?
- What can be changed for the next session?
- How has this information helped you?

Application: *Help the group understand how they can use these skills they learned in the sessions in real life*

- What are some changes you could make in your home set-up to help with completing your morning routine?
- From this session, how will you generalize these strategies/techniques to other parts of your day?



Homework:

- Explain the next group session.
- Ask for members to come prepared with 2-3 questions or areas that pose difficulty to performing this task to share.

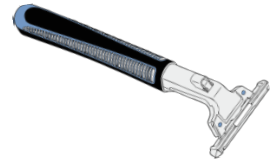
Model Application

- **Person:** Factors may vary from person to person but will include the following aspects.
 - **Physical:** Physical impacts and symptoms within the progression/stage of PD.
 - **Cognitive:** Cognitive impacts, impairments and symptoms of the progression/stage of PD.
 - **Affective:**
 - Address possible decrease in confidence due to inability to complete grooming tasks independently.
 - Address possible decrease in self-esteem, self-worth, or overall self-confidence due to inability to complete grooming tasks as effectively.
 - **Spiritual:** Independence in ability to complete grooming tasks effectively.
- **Environment:** Factors may vary from person to person but will include the following aspects.
 - **Physical Environment:** Tools and environmental changes are provided to the group members that can be done to increase ability to perform grooming tasks with as much independence as possible.
 - **Cultural Environment:**
 - Adaptations to the environment are done in a way so individuals are able to maintain cultural values and beliefs of independence.
 - Techniques that assist with grooming techniques to remain independent as possible.
 - **Social Environment:** Address possible isolation, depression, and decrease in involvement in social activities due to appearance.
- **Occupation:** Factors may vary from person to person but will include the following aspects.
 - **Self-Care:** Address individual's ability physically and mentally complete self-care tasks.

- **Productivity:** will address person's ability to complete daily grooming tasks with or without assistance, and person's satisfaction in completion of these activities.
- **Leisure:** Address the person's ability to complete grooming tasks in preparing for leisure activities and leisure activities related to grooming.
- **Transactions:** Due to working with a varying population of individuals with PD, the transactions between the person, environment and occupation will be different for each individual group member. In regard to goodness or poorness fit between the three components, this will also vary depending on each group member; therefore, the interaction will be unknown. The components of each transaction will be individualized and evaluated further upon interaction with group member.

Notes

Energy Conservation Tips and Tricks for Grooming



Symptoms of Parkinson's Disease, such as rigidity and tremors may pose difficulty in completing grooming tasks. Grooming may also become tiresome and hard to complete efficiently.

The following are tips that may help:

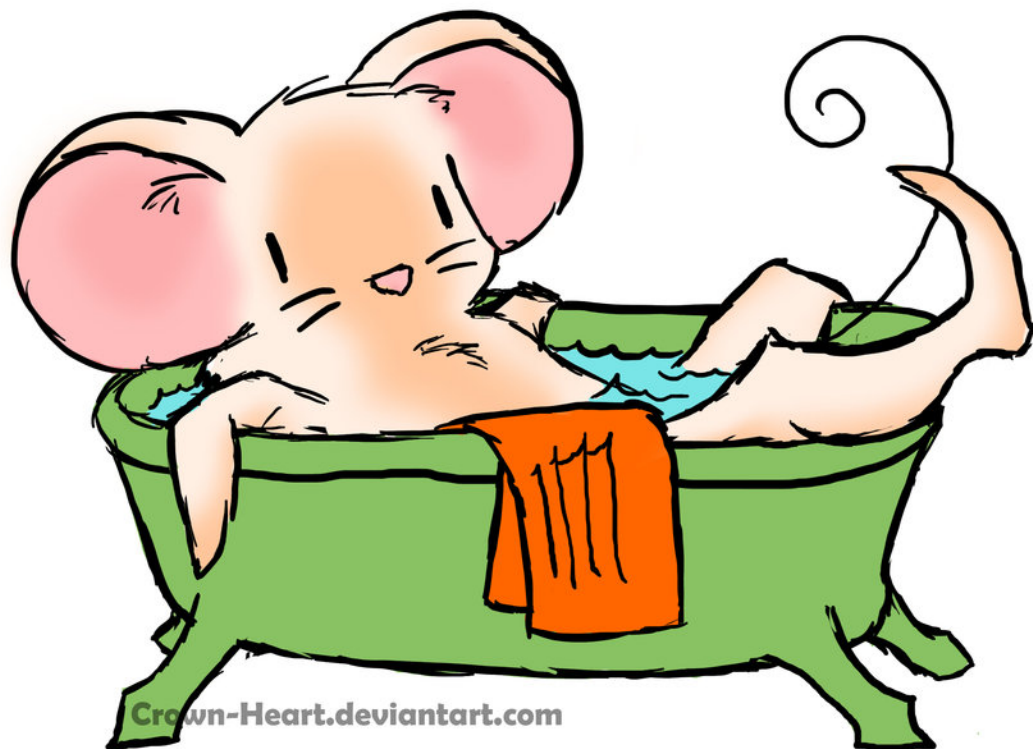
- Sit down on a chair with a back when brushing your hair, teeth, or any activity that requires standing for an extended amount of time
- Use built up handles, cuffs, or finger loops to assist with handling of grooming tools
- Prop elbows on vanity when performing grooming tasks to decrease tiredness and symptoms

- Use an electric shaver to decrease amount of time and movements required to perform shaving
- Purchase an electric toothbrush to assist with energy conservation
- Use a hands-free technique for drying hair by mounting hairdryer either on wall or vanity
- Perform activities at time of day where energy is higher or medication is effective
- Ask family member or care giver for assistance if feeling tired or low on energy
- Break up grooming tasks or simplify grooming tasks
- Do not perform activities if feeling uncertain or unsafe
- Have walker, wheelchair, or chair close to grooming area in case a break is needed

For more information about energy conservation techniques that could work for you, consult with your occupational therapist.

Source: <http://www.parkinson.org/Living-with-Parkinsons/Managing-Parkinsons/Activities-of-Daily-Living/Bathing-and-Grooming>

SESSION 4



“Scrub a Dub Dub, Getting In & Out of the Tub”

Bathroom Mobility and Compensatory Strategies for Bathing, Showering, and Toileting

SESSION 4

“Scrub a Dub Dub, Getting In & Out of the Tub”

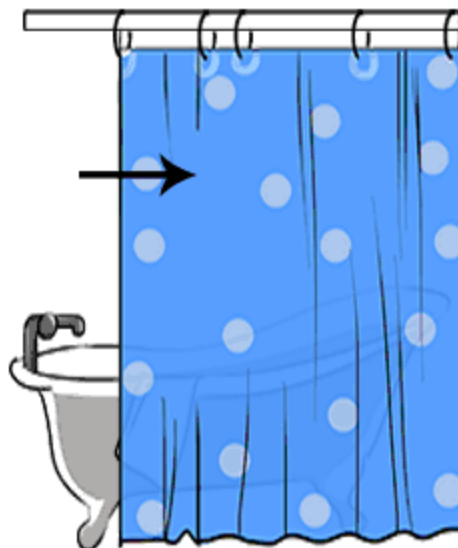
Bathroom Mobility and Compensatory Strategies for Bathing, Showering, and Toileting

Introduction:

- Therapist introduces the topic of mobility and completion of bathroom tasks.
 - Therapist will go over safe mobility procedures for bathroom mobility including:
 - Getting in and out of the bathtub/shower.
 - Getting on and off the toilet.
 - Moving around within the bathroom.
 - Use of safety equipment to assist with bathroom tasks.
 - Therapist will be on standby to provide tips and answer questions throughout session to ensure strategies are completed properly and safely.
- Address questions and concerns from previous session.
- Address questions and concerns from assigned homework tasks.
 - Group members were to come to session with 2-3 questions about bathroom mobility.
- Warm Up: “Icebreaker Cards”
 - Therapist will utilize ice breaker questions located on p. 87.
 - Each participant will draw a card from the deck until all members have participated.

- **Rationale:**

- In the early stages of the PD, there is an increase in tripping leading to the person trying to focus more while walking on uneven surfaces (Hess & Hallet, 2017). This takes away the person's attention from the task at hand.
- In certain environments, such as the bathroom, there are other factors that increase a person's chance of falling and overall fear of falling including:
 - Wet surfaces
 - Objects to maneuver around
 - Having to stabilize oneself while entering and exiting the shower for hygiene tasks
- As the disease progresses, individuals tend to lean or fall backwards more easily.
- Having postural instability can increase anxiety and fear of falling (Hess & Hallet, 2017).
- In this environment, it is very important to address the person's fear of falling and provide him or her with the tools necessary to safely maneuver the bathroom environment.



Objectives:

- Understand importance of bathroom safety.
- Learn 2-3 compensatory strategies to use in the bathroom.
- Understand the importance of assistance when needed with use of equipment or assistance from a caregiver.

Activity: *Introduce the activity*

- Therapist will provide the group members with information pertaining to:
 - bathroom equipment
 - movement strategies for use within the bathroom
 - caregiver assistance suggestions
 - modifications to the bathroom environment to increase ease of mobility
- Therapist will provide group members with a handout showing pictures and helpful tips on bathroom mobility and environmental adaptations to make while completing these tasks located on p. 84.
- The therapist and caregiver will assist the group members in walking through safe bathroom mobility techniques for entering and exiting the shower/tub.
- The therapist and caregiver will assist the group members in completing safe bathroom mobility for getting on and off the toilet.
- Demonstration and Practice:
 - Therapist will identify, and teach compensatory strategies for bathing, showering, and toileting.
 - Therapist will let individuals explore the different strategies.
 - Therapist will be on standby to provide tips and answer questions throughout session to make sure strategies are used properly.
 - Session will incorporate safety and energy conservation throughout.

Sharing/Processing: *Have group members share their thoughts and process their feelings about the activity.*

- What did you learn from this activity?
- What was the most stressful/frustrating part of the session?
- What was helpful to you?
- What did you like/dislike from this activity?
- How did it feel about having your caregiver/family member present today?
 - Did it change the experience for you?
- What was the hardest part about completing these tasks?

Application: *Help the group understand how they can use these skills they learned in the sessions in real life*

- Identify 2 compensatory strategies that you can use in the bathroom?
- What are ways you can use these strategies in other areas of your home?
- How will you ask caregivers to assist with bathroom mobility tasks?

Homework:

- Explain the next group session and ask for members to come prepared with 2-3 questions or areas that pose difficulty to performing this task to share

Model Application

- **Person:** Factors may vary from person to person but will include the following aspects.
 - **Physical:** Physical impacts and symptoms within the progression/stage of PD.
 - **Cognitive:** Cognitive impacts, impairments and symptoms of the progression/stage of PD.
 - **Affective:**
 - Address possible decrease in confidence due to inability to complete bathing tasks independently.
 - Address possible decrease in self-esteem, self-worth, or overall self-confidence due to inability to complete bathing tasks as effectively.
 - **Spiritual:** Independence in completing bathing tasks effectively and thoroughly.
- **Environment:** Factors may vary from person to person but will include the following aspects.
 - **Physical Environment:** Tools and environmental changes are provided to the members to ensure safety and effective mobility in and out of the shower/bathtub or on and off the toilet.
 - **Cultural Environment:** Adaptations to assist with remaining independent in the bathroom environment while showering/bathing and/or toileting.
 - **Social Environment:** adaptations to assist when accessing public facilities (i.e. gym, pool, other friends or family).
- **Occupation:** Factors may vary from person to person but will include the following aspects.
 - **Self-Care:** Address group member's ability to shower or bathe and toilet effectively and safely.
 - **Productivity:** Address member's ability to safely move in and around the bathroom, complete transfers in and out of the shower/bathtub, and on/off the toilet.

- **Leisure:** Address using public facilities when participating in leisure activities in the community or other individuals homes
- **Transactions:** Due to working with a varying population of individuals with PD, the transactions between the person, environment and occupation will be different for each individual group member. In regard to goodness or poorness fit between the three components, this will also vary depending on each group member. Therefore, the interaction will be unknown. The components of each transaction will be individualized and evaluated further upon interaction with group member.

Notes

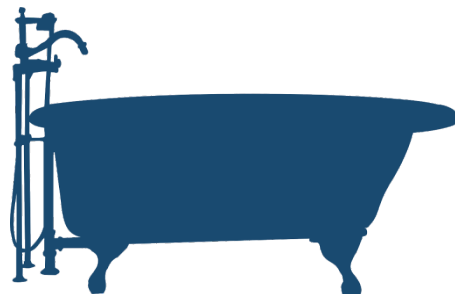
Bathing and Showering: *Energy Conservation and Safety*

The symptoms associated with Parkinson's Disease can make showering tiresome, unsafe, and challenging. The following tips will help make this daily task safer, easier, and more successful:

- Professionally install 1-2 grab bars in and around shower stall to assist with entering and exiting shower.
 - *DO NOT* use towel racks, soap dishes or facets as a device to help with mobility or stabilization
- Use a shower bench or chair with a back while showering
- Keep shower water at a lower temperature to help maintain energy levels
- Use pump soap and wash cloth or loofa on a stick instead of bar soap
- Use a handheld showerhead when seated in shower
- Install a shelf in shower to place items to reduce having to bend down to pick up items

- Place life-alert or telephone close to shower in case of an emergency
- Place non-skid rugs outside of shower or bathtub to reduce slippery, wet floors
- Place non-skid mat on floor of bathtub or shower
- If using a bathtub, install a tub rail to help with safety entering or exiting bathtub
- Ask for assistance or supervision when entering, exiting, or during shower if you feel unsafe
- Perform shower or bathing when energy is high or medication is active
- Do not perform if you feel weak or unsafe. Do not feel afraid to ask for assistance if needed

If you are unsure of any techniques, equipment, or have general questions, ask your occupational therapist for further information



Source: <http://www.parkinson.org/Living-with-Parkinsons/Managing-Parkinsons/Activities-of-Daily-Living/Bathing-and-Grooming>

Ice Breaker Activity Cards

<p>If you were a dog, what kind would you be?</p>	<p>If you could live anywhere on the planet, where would you choose to live?</p>
<p>Are you a sunrise, daylight, twilight, or night? Why?</p>	<p>If you could be in the movie of your choice, what movie would you choose and what character would you play?</p>
<p>What are your 3 favorite foods?</p>	<p>What is your favorite season? Winter, Spring, Summer, Fall</p>
<p>What is your ideal vacation destination? Why?</p>	<p>Pick something out of your pocket or purse and tell why it is important to you.</p>
<p>If you were to start a new hobby, what would it be?</p>	<p>What is the best thing that has happened to you this week?</p>
<p>What was your favorite birthday or Christmas present?</p>	<p>Would you like to go to a tropical island or the Arctic more?</p>
<p>If you could invite 3 famous people to dinner, who would you invite?</p>	<p>Which time period would you like to visit in history?</p>
<p>What is your favorite sport or physical activity?</p>	<p>What is/was your most recent job?</p>

SESSION 5



“Dressed to the Nines”

SESSION 5

“Dressed to the Nines”

Introduction:

- Therapist will identify, and teach strategies associated with independent dressing.
- Therapist will provide compensatory devices and education on use of devices that can assist with dressing.
- Therapist will be present and available for group members to provide tips and answer questions throughout session to ensure safety and proper use of equipment and strategies.
- Address questions/concerns in homework tasks.
 - Group members were to prepare 2-3 questions or areas that pose difficulty to performing dressing tasks to share.
 - Have each group member share.
- Warm Up: Stretching activities and full body movements
 - Complete the following activities for 15-30 seconds each (can be completed in sitting or standing):
 - Reach above your head
 - Reach out to both sides (make a T with your arms)
 - Reach across chest to opposite side of body
 - Twist your trunk (waist) from side to side
 - Lift knees alternating (marching)
 - Move ankles in a circular motion going both directions

- **Rationale:**

- Difficulty engaging in ADL's is correlated with the motor stage of the disease, cognitive impairments, and dexterity (Benge & Balsis, 2016).
- Individuals with PD stated it took longer to complete activities and often became frustrating.
- Benharoch and Wiseman (2004) explained that those with PD reported that getting ready for the day was difficult.
- A specific task mentioned was fastening buttons.
- Other individuals struggled with the ability to dress and undress, which requires coordination, balance, and motor skills (Hariz & Forsgren, 2010).
- Addressing the functional levels of each individual and their ability to complete such tasks is important in retaining and continuing to be independent with daily occupations or routines.



Objectives:

- Participants will be able to identify 2-3 dressing techniques.
- Understand 2-3 strategies to increase ability in independent dressing.
- Feel comfort in adaptive techniques and ability to complete dressing tasks.
- Identify 2 kinds of adaptive equipment for dressing.

Activity: *Introduce the activity*

- In large group, therapist will present information through demonstration, overview of handout, and videos to show:
 - Upper body and lower body dressing techniques.
 - Adaptive equipment to assist with dressing.
 - Energy conservation.
- Provide handout that states and explains multiple energy conservation tips and strategies for dressing located on p. 97.
- Discuss handout in more detail with large and provide examples if strategy is unclear.
- Demonstration and Practice:
 - After demonstration, have group members split up into groups of two including individual and caregiver/therapist.
 - Extra clothing will be provided to practice dressing techniques and use of equipment.
 - Sock aid
 - Reacher
 - Shoe horn
 - Leg lifter
 - Dressing stick
 - Button hook

- Velcro
 - Elastic waistband
 - Elastic shoelaces
- Have individuals practice energy conservation techniques while dressing.

Sharing: *Have group members share their thoughts about the activity.*

- What was the most stressful/frustrating part of the session?
- How did the hands on practice with the equipment make you feel?
- Does the use of dressing techniques seem to assist with energy levels?
- Did you find this activity helpful?

Processing: *Have the group share and process through their feelings about the session*

- What did you like most helpful with this session?
- What did you not like about this session?
- How did it make you feel that your caregiver was here learning with you?
 - Did it make you feel more comfortable, confident, incompetent, frustrated?

Application: *Help the group understand how they can use these skills they learned in the sessions in real life.*

- How will you structure your dressing routine to accompany these techniques?
- How will you overcome stressful aspects of dressing?
- What specific dressing techniques can you incorporate into your daily life?

Homework:

- Explain the next group session.
- Ask for members to come prepared with 2-3 questions or areas that pose difficulty to performing meal preparation and self-feeding tasks to share with the group.

Model Application

- **Person:** Factors may vary from person to person but will include the following aspects.
 - **Physical:** Physical impacts and symptoms within the progression/stage of PD.
 - **Cognitive:** Cognitive impacts, impairments and symptoms of the progression/stage of PD.
 - **Affective:**
 - Address possible decrease in confidence due to inability to complete dressing tasks independently.
 - Address possible decrease in self-esteem, self-worth, or overall self-confidence due to inability to complete dressing tasks as effectively.
 - **Spiritual:** Independence in completing dressing tasks effectively and thoroughly.
- **Environment:** Factors may vary from person to person but will include the following aspects.
 - **Physical Environment:** tools and environmental changes provided for the participant to safely engage in dressing tasks and have an understanding of dressing equipment.
 - **Cultural Environment:** Facilitate independence with dressing tasks to maintain quality of life and allow individuals to complete tasks by him or herself.
 - **Social Environment:** adaptations and assistive techniques for dressing in public place, engaging individuals and caregivers in dressing techniques together and allowing for “typical” social environment during dressing tasks.
- **Occupation:** Factors may vary from person to person but will include the following aspects.
 - **Self-Care:** completing self-care tasks of dressing as independent as possible or with assistance of caregivers.

- **Productivity:** ability for person to complete dressing tasks as independently as possible and in appropriate amount of time across contexts.
- **Leisure:** address completion of dressing tasks before and after leisure activities and while in public places
 - Dressing rooms
 - Locker rooms
 - Other people's houses
- **Transactions:** Due to working with a varying population of individuals with PD, the transactions between the person, environment and occupation will be different for each individual group member. In regard to goodness or poorness fit between the three components, this will also vary depending on each group member; therefore, the interaction will be unknown. The components of each transaction will be individualized and evaluated further upon interaction with group member.

Notes



Dressing:

Tips and Tricks to be successful

The symptoms of Parkinson's Disease may make it difficult to complete dressing tasks. Dressing tasks or routines may become more challenging and time consuming which may lead to frustration and decreased success. The following tips and tricks will assist with greater success:

Dressing tips:

- Allow more time to complete dressing. Rushing through tasks may increase symptoms and ultimately increase stress and frustration.
- Complete dressing tasks when energy levels are high or medication is active
- Do a few stretches or mobility activities before dressing to help warm up your muscles

- If muscles in one arm or leg are stiffer than the other, place those in clothing first
- When dressing, sit down in a chair with supportive arms and back.
 - DO NOT sit on edge of bed. This may cause you to lose balance and fall
- When putting on socks and shoes, use a footstool, reacher, or long handled shoe horn to decrease need to bend or energy used
- For dressing, use dressing stick or reacher to assist with putting on lower extremity clothing
- Gather all clothing at once to decrease multiple and unnecessary trips back and forth

What to wear to make dressing easier:

- Choose fabrics and clothing styles to make dressing easier
- Choose clothing that is soft and stretchy, especially if stiffness is an issue
- Wear non-skid socks while dressing to decrease chance of falling

- Avoid socks with tight elastic bands around the ankles
- Wear light yet supportive shoes with Velcro or elastic laces
- If possible, either buy clothing with Velcro or replace buttons on clothing with Velcro to decrease little finger movements
- Choose jackets, coats, and mittens/gloves that are oversized to assist with ease of putting on

Source: <http://www.parkinson.org/Living-with-Parkinsons/Managing-Parkinsons/Activities-of-Daily-Living/Getting-Dressed>

SESSION 6



“What’s Cooking?”

Meal Preparation and Feeding Yourself

SESSION 6

“What’s Cooking?”

Meal Preparation and Feeding Yourself

Introduction:

- Therapist will provide, identify, and teach individuals about strategies and equipment that would help decrease the challenges while preparing meals and self-feeding.
 - Therapist will allow individuals to try out these strategies during the session to find what works best for them.
 - Therapist will be present to provide tips and answer questions throughout session to ensure safety and that strategies are used properly.
- Address questions and concerns in homework tasks.
 - Answer questions on areas that pose difficulty to performing meal preparation tasks to share.
 - Have all members share.
- **Warm Up Activity:** 2 Truths and a Lie
 - Rules: write 3 items down on a piece of paper including two truths and one lie. Do not write your name on this paper.
 - Participants will be directed not to share which item is a lie to other group members.
 - Other members will be directed to identify which item is the lie for each group member. This process will be completed until all members have participated in the warm-up activity.
 - Similarities and differences in the truths will be identified and will be related to the task of cooking, meal preparation, and feeding.

- **Rationale:**

- The level of difficulty in completing ADL tasks is related to the person's motor stage, gait speed, cognitive impairment, and dexterity (Benge & Balsis, 2016).
- Areas of common difficulty:
 - Financial management
 - Personal belonging responsibility
 - Driving
 - Household management
 - Food preparation (Benge & Balsis, 2016)
- Most commonly, individuals reported decreased balance, fumbling, slowness, affected speech, problems with memory, writing and reading and concern lifting and carrying heavier objects (Wressle, Engstrand & Granerus, 2007).
- Because of this, meal preparation and feeding are difficult to complete for individuals with PD. Although it is based on progression of disease and current ability, it is an issue that is frequently identified by individuals with PD.
- Individuals with PD experience a resting tremor on one side of the body at the distal portion of the upper extremity (Hess & Hallet, 2017).
 - Even though this is the most common area, there can also be tremors in the legs, chin, lips, and jaw (Hess & Hallet, 2017).
- These tremors increase difficulty with completing meal preparation and feeding tasks.

Objectives:

- Identify equipment to use while completing meal preparation tasks.
- Understand the importance of energy conservation in the kitchen.
- Complete cooking task with adaptive equipment and energy conservation techniques.

Activity: *Introduce the activity*

- This activity will include an educational portion teaching group members on topics including:
 - Proper kitchen set up
 - Tools for cooking/adaptive equipment
 - Safety while moving in the kitchen
 - Working with hot food and appliances
 - Use of energy conservation for meal preparation and activity in the kitchen
- The beginning of the session will be an overview of information regarding kitchen safety and adaptive utensils that can be used for PD. Handout on p. 108.
 - A handout will be provided.
- Demonstration and Practice:
 - Individuals of the group will get to practice using different kinds of adaptive equipment available through making a dessert.
 - Individuals of the group will be assigned to a specific task for this activity and will be encouraged to use adaptive strategies and devices to complete making the dessert.

Sharing: *Have group members share their thoughts about the activity.*

- What are some activities that are more challenging for you during meal preparation?

- What do you do to make these activities easier to complete?
- What is the most frustrating part about meal preparation and feeding yourself?
- What is the most enjoyable part about meal preparation and feeding yourself?

Processing: *Have the group share and process through their feelings about the session*

- What did you learn from this session?
- What did you like about the topic today?
- What did you dislike about the topic today?
- How do you feel this session has helped you?

Application: *Help the group understand how they can use these skills they learned in the sessions in real life*

- What are some adaptations you would be able to make in your home for meal preparation?
- How will caregivers/family members assist you in use of these skills during completion of meal preparation tasks?
- How can you generalize these ideas to other areas of your life?

Homework:

- Ask for members to come prepared with questions and areas for further information, clarification, or practice.



Model Application

- **Person:** Factors may vary from person to person but will include the following aspects.
 - **Physical:** Physical impacts and symptoms within the progression/stage of PD.
 - **Cognitive:** Cognitive impacts, impairments and symptoms of the progression/stage of PD.
 - **Affective:**
 - Address possible decrease in confidence due to inability to complete cooking tasks independently.
 - Address possible decrease in self-esteem, self-worth, or overall self-confidence due to inability to complete cooking tasks as effectively as possible.
 - **Spiritual:** Independence in completing meal preparation tasks effectively and thoroughly.
- **Environment:** Factors may vary from person to person but will include the following aspects.
 - **Physical Environment:** address adaptive strategies, techniques and equipment to be used in the kitchen during meal preparation to increase ability to complete tasks in kitchen environment.
 - **Cultural Environment:** address person's ability to complete household roles or responsibilities related to meal preparation and remains as independent as possible.
 - **Social Environment:** address completion of meal preparation tasks independently and with assistance of caregiver during holiday season and with assistance of others to maintain social environment.
- **Occupation:** Factors may vary from person to person but will include the following aspects.
 - **Self-Care:** address the person's ability to engage in meal preparation and eat/feed independently in order to increase independence and allow for self-care.

- **Productivity:** address use of adaptive equipment and strategies for use in the kitchen during meal preparation tasks.
- **Leisure:** address person's ability to engage in meal preparation for leisure or participate in other leisure activities that require meal preparation or eating. Address use of adaptive equipment for feeding and meal preparation with independence.
- **Transactions:** Due to working with a varying population of individuals with PD, the transactions between the person, environment and occupation will be different for each individual group member. In regard to goodness or poorness fit between the three components, this will also vary depending on each group member; therefore, the interaction will be unknown. The components of each transaction will be individualized and evaluated further upon interaction with group member.



Notes

Mealtime:

Tips to become successful with cooking



The progression of Parkinson's Disease symptoms may cause challenges in the kitchen. By adapting techniques and introducing equipment may increase success when cooking. The following are tips to remain successful, safe, and independent in the kitchen

General Meal Preparation Tips:

- Remove rugs and decrease clutter to decrease chance of falls while gathering materials
- If rugs are needed, use rugs with a non-slip backing and low to the ground to decrease chance of falls

- Use a cart or tray to transfer objects around the kitchen
- Gather all utensils and materials before beginning to cook to decrease unnecessary trips to help save energy
- Tremors may pose safety issues in the kitchen. Using adaptive equipment will increase safety while cooking. This includes:
 - Using adaptive cutting boards with built-up sides and non-slip backing
 - Using weighted knives while cutting
 - Using electric knives to conserve energy
- Built up handles will assist with grasping utensils both during meal preparation and eating.
 - One easy fix includes pipe insulation which can be found in hardware stores

Cooking Environment

- Position appliances and equipment in a place that is safe and easy to reach

- Place commonly used tools, food, and dishware in an easy to reach place to decrease chance of falls and to conserve energy
 - DO NOT use a footstool or chair with wheels, use a sturdy footstool with railings for stability
 - Ask for supervision or assistance if object is high or out of reach
- If possible, equipment may need to be raised or lowered to a more comfortable height and to conserve energy
- To decrease clutter and increase kitchen efficiency, keep counter space free of extra tools or clutter

Washing dishes

- If washing dishes by hand, purchase a dishwashing brush that has soap in the handle to increase ease of use
- Use a wash mitt to conserve energy
- If loading the dishwasher, use the higher shelf to place items. If needed, ask for assistance to load lower shelf if it becomes difficult to bend down

Dining

- Use stable surfaces when dining
- Use built up handles on utensils to assist with grasp
- Use weighted utensils to help decrease effects of tremors
- Place a non-slip material under place to keep it from moving around.
 - Dycem can be purchased to assist with this
- Place a plate guard around the plate to assist with keeping food on the plate
- Ask for assistance if needed to cut food or pour liquids into glass
- Drinking smaller amounts at a time or using larger cups may be used to decrease spilling while drinking liquids

Source: <http://www.parkinson.org/Living-with-Parkinsons/Managing-Parkinsons/Activities-of-Daily-Living/Mealtime>

SESSION 7



“Can We Fix It?... Yes We Can!”
Equipment Maintenance and Review of Information

SESSION 7

Can We Fix It?... Yes We Can!

Equipment Maintenance and Review of Information

Introduction:

- Therapist will provide education on maintenance of equipment.
 - Education on strategies and resources available for assistance in maintaining personal equipment will be provided.
 - A review of the education provided throughout this Parkinson's ADL Group will be completed during this time to promote carryover.
- Address questions/concerns in homework tasks from previous session.
 - Group members were asked to come prepared with any questions, clarifications, or areas for increased practice.
- **Warm Up Activity:** Paper Tower
 - Paper and masking tape will be provided to each group member and caregiver pair.
 - Groups will be directed to create a tower using the materials in front of him or her.
 - Have group members work with caregivers to build a paper and tape tower.
 - Ask individuals the hardest part of the activity and most enjoyable part of the activity.
 - Once completed, the topic of equipment maintenance will be applied to maintaining personal equipment.
 - Introduce today's topic of equipment maintenance and overall review of information throughout the progression of the sessions.

Objectives:

- Understand how to properly care for equipment and where to take it or who to contact if assistance is needed.
- Feel confident in performing activities that were presented in sessions.

Activity: *Introduce the activity*

- Provide participants and caregivers with education on use of personal equipment and maintenance of mobility equipment including:
 - Walkers
 - Canes
 - Wheelchairs
 - Other adaptive equipment
- Provide participants and caregivers with handout on available community resources for equipment maintenance and local places to purchase equipment located on p. 119.
- Demonstration and Practice
 - Participants will practice ideas talked about in the session today on maintenance and use of assistive devices.
 - Individuals will be asked for further questions or concerns they have on topics that may or may not have been addressed in the group.
 - Remaining time will be used to go over topics of concern brought up by participants.



Sharing/Processing: *Have group members share their thoughts and process their feelings about the activity.*

- What would you want to work on more?
- What would you like more practice with?
- What did you find most beneficial about these sessions?
- What would you change about the sessions?
- How did it feel with your caregiver present?
- With your caregiver present, did you feel it was more of a positive or negative experience?
 - Explain

Application: *Help the group understand how they can use these skills they learned in the sessions in real life*

- What did you learn from this session today?
- What did you like/dislike?
- What overall did you feel was the most beneficial from this program?
- What of these strategies will you be applying to your daily life?
- How will your family member/caregiver assist you in using strategies from this program?
- What strategies have you used at home?
 - What was proven to be useful? Not useful?
- Overall, how has this program helped you?
- Would you recommend this course to others?

Model Application

- **Person:** Factors may vary from person to person but will include the following aspects.
 - **Physical:** Physical impacts and symptoms within the progression/stage of PD.
 - **Cognitive:** Cognitive impacts, impairments and symptoms of the progression/stage of PD.
 - **Affective:**
 - Address possible decrease in confidence due to inability to complete tasks associated with equipment maintenance independently.
 - Address possible decrease in self-esteem, self-worth, or overall self-confidence due to inability to complete personal equipment maintenance as effectively as possible.
 - **Spiritual:** Independence in completing personal equipment maintenance effectively and thoroughly and meaning to the person when completing personal equipment maintenance tasks.
- **Environment:** Factors may vary from person to person but will include the following aspects.
 - **Physical Environment:** address use of and knowledge of tools, available resources, and equipment needed for personal equipment maintenance.
 - **Cultural Environment:** facilitate independence in ability to complete equipment maintenance and bring forth an understanding of the importance of equipment.
 - **Social Environment:** address knowledge of facilities and places in which to bring equipment for maintenance following social norms and understandings.
- **Occupation:** Factors may vary from person to person but will include the following aspects.
 - **Self-Care:** facilitate independence in person's ability to complete equipment maintenance and understand places in which to utilize equipment maintenance. Allow for the person to complete self-care tasks with use of personal equipment.

- **Productivity:** complete maintenance tasks in timely fashion and be able to engage in all ADL tasks with use of personal equipment.
- **Leisure:** Address engagement of maintenance of personal equipment as leisure tasks; assist the person in participating in leisure tasks because of use of personal equipment.
- **Transactions:** Due to working with a varying population of individuals with PD, the transactions between the person, environment and occupation will be different for each individual group member. In regard to goodness or poorness fit between the three components, this will also vary depending on each group member; therefore, the interaction will be unknown. The components of each transaction will be individualized and evaluated further upon interaction with group member.



Notes

Grand Forks Area Community Resources for Equipment and Equipment Maintenance



The following are stores in the Greater Grand Forks area that carry and assist with purchasing medical equipment needs. These include: assistive tools and utensils, grab bars, reachers, bath benches and chairs, canes, walkers, etc. These places may also assist with medical equipment maintenance.

Skip's Budget Drug - Pharmacy

2015 Library Cir. Grand Forks, ND 58201
(701) 772-4805

Lincare

2100 S Columbia Rd Suite 110 Grand Forks, ND 58201
(701) 775-3965

Yorhom Medical Essentials

4350 S Washington St Grand Forks, ND 58201
(701) 780-2500

Sanford Health HealthCare Accessories

621 Demers Ave East Grand Forks, MN 56721
(218) 773-5840

Wall's Medicine & Health Center

708 S Washington St Grand Forks, ND 58201
(701) 746-0497

Embrace Pharmacy

2424 32nd Ave S Suite 101b Grand Forks, ND 58201
(701) 757-1552

Altru Health System

4350 S Washington St Grand Forks, ND 58201
(701) 780-2500

Innovative Products Inc.

830 S 48th St Grand Forks, ND 58201
(701) 772-5185

Walmart Supercenter

2551 32nd Ave S Grand Forks, ND 58201
(701) 746-7225
5755 Gateway Dr. Grand Forks, ND 58203
(701) 620 - 6003

Lowe's Home Improvement

4001 32nd Ave S, Grand Forks, ND 58201

(701) 765 – 9000

Menards

3550 32nd Ave S, Grand Forks, ND 58201

(701) 775 - 6204

CHAPTER V

SUMMARY

The purpose of Occupational Therapy's Involvement With the YMCA in Developing a Program to Address Activities of Daily Living in Those with Parkinson's Disease was to develop a protocol that addresses the unmet needs of those with Parkinson's Disease (PD), specifically focusing on the area of activities of daily living (ADL). Through the use of occupational therapy perspectives and techniques, this program focuses on increasing and/or maintaining independence and safety during daily tasks in those with PD.

After an extensive literature review and discussion with the local YMCA about the needs of those with PD and the interventions currently used with this population, it became evident that there was a lack of programming targeting activities of daily living implemented at the local YMCA. Findings in the literature review supported that individuals with PD require more help with ADL and Instrumental Activities of Daily Living (IADL) tasks than individuals of other disability populations (Terriff, Williams, Pattern, Lavorato & Bulloch, 2012). It was found that individuals with PD require more assistance due to the correlation between difficulty performing tasks and the person's motor stage of the disease, gait speed, cognitive impairment, and dexterity as the disease progresses (Benge & Balsis, 2016). Overall, the person's ability to carry out everyday

tasks or ADLs is found to be more important to the person than how severe the disease has progressed (Hobson, Edwards & Meara, 2001). As a way to guide this product in line with the needs of the population found in the literature review, the Person-Environment-Occupation Model was chosen. The Person-Environment-Occupation Model was used for this program due to the transactional approach towards occupational performance. This model focuses on finding the best “fit” between personal, environmental, and occupational factors that lead to performance in everyday activity (Hinojosa, Kramer, Royeen, 2017).

Throughout the development of this product, various limitations came up. This product is focused on a specific population, individuals with mild to moderate PD. This limits the amount of people that can utilize this program and implementation with other populations. However, with minor changes to this program, it could be adapted and modified for use with other populations of neurodegenerative disorders as many of the personal factors, environmental factors, and occupational factors for populations of individuals with neurodegenerative disorders are similar. Another limitation to this product is the limited information found in the literature review pertaining to PD and mobility. There was limited information available on specific interventions and mobility suggestions for individuals with PD. Therefore, the information in the literature review focuses on information that is generalized to all populations instead of specific to individuals with PD. This allows for more transferability to other populations should it be modified or adapted for other use. A third limitation is focus on the use of this product in Grand Forks Area only. This allows for greater detail for the needs of individuals in this area but limits use in other areas. With minor adaptations to handouts pertaining to

available resources for equipment, this product could be utilized in other areas. Further studies and literature reviews may be beneficial to this product to determine effectiveness and satisfaction with the population in completion of ADL tasks.

This program is designed for the local YMCA and occupational therapists that work with the population of people with mild to moderate PD. Current programs at the YMCA do not include occupational therapy and ADL training. Because of this, the program will compliment current programs. The goal of this program and the developers is to provide education and training to individuals with PD in order to allow for them to be as independent as possible and remain in the home environment as well as providing education to caregivers to assist with this process. Through continual contact with the local YMCA, it was apparent that this program would be highly valued and would work in conjunction with the current programming offered. Because this product is highly valued, both an electronic copy and paper copy could be provided to those interested in the implementation of this product. Because this product does not have a mandatory sequential order, therapists are encouraged to complete sessions in the order in which meets the needs of his or her specific group. Due to the structure of this program, a thorough evaluation of the individual at the beginning of the program is not necessary, but knowledge of diagnosis and current performance is greatly needed.

In summary, through the review of literature and discussion with the local YMCA about the needs and current programs available in the community, the developers anticipate that this program will increase the safety, satisfaction of ADL performance, and knowledge in those with PD and their caregivers.

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