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Missy Ziegler

Elizabethtown College, zieglerm1@etown.edu

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The Impact of Fall Prevention Education for Individuals with Parkinson's Disease

Missy Ziegler

Elizabethtown College

## Abstract

**Objective:** The purpose of this study is to explore the relationship between an individual with Parkinson's Disease (PD) perceptions of why falls happen and if receiving fall prevention education is beneficial to reducing falls.

**Methods:** An anonymous survey was developed by the researcher in order to learn more about individuals' personal experiences relating to falls, fear of falling, and fall prevention education. Surveys were used to identify if participants have ever experienced a fall and subsequently examine the relationships between falls and fall education. Semi-structured interviews were conducted to supplement survey results and gain greater insight into the experiences of an individual with PD. Survey and interview responses were both analyzed for common trends.

**Results:** Participants reported receiving fall prevention education after experiencing a fall and not when first diagnosed with PD. All participants who received education about falls perceived the information to be beneficial. In addition, participants reported a fear of falling, but it did not prevent individuals from leaving their home to attend their exercise group, suggesting that this group provides individuals with PD motivation, peer support, and the opportunity to improve their PD symptoms.

**Conclusion:** Fall prevention education should be provided earlier to individuals with PD and this education should be ongoing throughout their disease progression. Occupational therapists are well suited to run a fall prevention education class, which could potentially prevent future hospitalizations due to falls by educating clients on how to manage their PD in their everyday routines.

## **Introduction**

Parkinson's disease (PD) is a chronic, neurological disease that impacts approximately 60,000 Americans each year and more than ten million worldwide (Parkinson's Foundation, 2019). Individuals with PD are at a high risk of falls due to the variety of motor and non-motor symptoms (Foster, Bedekar, & Tickle-Degnen, 2014). Falls not only have large financial implications for healthcare but also contribute to an increased fear of falling, which in turn can lead to multiple activity limitations and participation restrictions (Foster et al., 2014).

Fall prevention education is an important aspect of treatment for individuals with PD. While there is a variety of literature describing fall education after rehabilitation, little is known about the timing of fall education or the effectiveness of it in relation to the PD population. In addition, there is limited research about whether individuals with PD are aware that they are at a high risk for falls. This is of concern to healthcare professionals, including occupational therapists (OT), due to the variety of complications that can occur because of falls. Having a better understanding of client perceptions of the effectiveness of fall prevention education may help healthcare professionals curtail rehospitalizations due to falls. Overall, understanding the effectiveness of fall prevention education could improve the quality of life for individuals with PD.

## **Parkinson's Disease**

Parkinson's disease is a progressive, neurological disorder that affects predominately dopamine-producing neurons, which are in a specific part of the brain called the substantia nigra (Parkinson's Foundation, 2019). Dopamine is responsible for smooth and controlled movements of the body (Gatschet & Drinnen, 2017). PD is caused by the deterioration of these dopamine cells and when 80% of the dopamine cells are lost and die off, causing motor symptoms such as

tremors, rigidity, bradykinesia, and postural instability (Carranza, Davenport Shaw, Snyder, & Zesiewicz, 2013).

PD is a progressive disease meaning the condition worsens over time and results in a gradual degradation of function and increased disability due to motor and non-motor symptoms (Kader et al., 2016). The progression of symptoms looks different for each individual due to the diversity of the disease, but usually symptoms develop slowly over the years when first diagnosed (Parkinson's Foundation, 2019).

### **Symptoms of Parkinson's Disease**

Parkinson's disease can be highly debilitating over time and can create not only motoric dysfunction, as seen in problems walking and with fine motor coordination impairments, but also non-motor related symptoms. Frequently the non-motor problems with depression, flat affect and cognitive declines can be equally, if not more, impactful in the lives of the patient and the caregiver.

#### **Motor Symptoms**

In the early stages of the disease, an individual with PD might present with a few motor symptoms such as rigidity and tremors (Foster et al., 2014). Motor symptoms are related to movement and are a direct cause of the loss or impaired dopamine neurons (Parkinson's Foundation, 2019). Common motor symptoms of PD are tremors, rigidity, bradykinesia, loss of postural reflexes, flexed posture, and freezing (Gatschet & Drinnen, 2017).

Tremors include involuntary shaking of the hands, arms, legs, jaw, or tongue and most are resting tremors meaning the uncontrollable shaking lessens during sleep and when the body part is actively in use (Parkinson's Foundation, 2019). Tremors can interfere with routine activities especially involving fine motor coordination such as dressing or writing. The symptom

of rigidity might be present, which implies stiffness of the arms and legs (Parkinson's Foundation, 2019). Another symptom of PD is bradykinesia, which is the slowness of movement, which means taking smaller steps and taking a longer time to walk (Carranza et al., 2013). Motor symptoms such as loss postural reflexes and flexed posture implies individuals with PD might have impaired balance and explains their tendency to fall easily (Parkinson's Foundation, 2019). The motor symptom of freezing implies the temporary, involuntary inability to move and increases individuals' risk of falling (Parkinson's Foundation, 2019). As debilitating as motoric symptoms can be, so too are the emotional, cognitive and psychosocial effects of the disease process on patients and their loved ones.

### **Non-Motor Symptoms**

Non-motor symptoms are those that are unrelated to movement (Parkinson's Foundation, 2019), and may be brought on by long term use of antiparkinsonian medications individuals use to manage their PD (Foster et al., 2014). Another cause of non-motor symptoms is connected to the effects PD has on the autonomic nervous system (ANS), which controls functions like heart rate and blood pressure (Davis Phinney Foundation, 2017). Non-motor symptoms can also appear years before motor symptoms, which are identified as pre-motor symptoms including symptoms of loss of smell and mood changes (Davis Phinney Foundation, 2017). Examples of non-motor symptoms that are caused by changes to the ANS are sexual dysfunction, incontinence, constipation, and excessive salivation and perspiration (Davis Phinney Foundation, 2017).

Examples of non-motor symptoms include, but are not limited to cognitive deficits, depression, anxiety, sleep disorders, and sensory impairments (Foster et al., 2014). While cognitive functions are typically not impacted until the later stages of the disease (Foster et al.,

2014), some individuals with PD experience mild cognitive impairments, which may make it difficult to maintain or shift attention, plan and completing tasks, and remember information or find the right words to say (Parkinson's Foundation, 2019).

Additional non-motor symptoms can include visual changes, which can include blurry vision, diplopia, and eye movement disorders that can impact a variety of daily tasks, including reading (Parkinson's Foundation, 2019). In addition, individuals with PD may also experience dysphagia, or difficulty swallowing, and communication deficits such as rapid speech, slur or repeat their words, hesitation when speaking, or talking too softly (Schechter & Cram, 2016). These specific non-motor symptoms can make individuals with PD frustrated or embarrassed, causing them to isolate themselves from social activities and reducing quality of life (Schechter & Cram, 2016). Most participants with PD believe their non-motor symptoms to be more detrimental to their quality of life than their motor symptoms (Schechter & Cram, 2016). Overall, both motor and non-motor symptoms of PD can lead to a variety of activity limitations and participation restrictions, which in turn can lead to an increased need for caregiver support and may compromise their involvement in meaningful roles (Foster et al., 2014).

### **Falls within the Parkinson's Population**

With the prevalence of PD increasing, falls are expected to have a large impact on health care systems (Kalilani et al., 2016). Falls which result in fractures can lead to more hospitalizations and rehabilitation for individuals with PD contributing to a public health burden and increased healthcare spending (Kalilani et al., 2016). People with PD have an increased risk for falling as compared to others of the same age (Kader et al., 2016). From a study comparing the incidence of falls in PD patients in the United States, 60.5% of patients with PD have experienced at least one fall since being diagnosed and 39% have had multiple falls (Kalilani et

al., 2016). Falls can lead to decreased independence, increased supported care and stress on caregivers, and reduced quality of life (Morris et al., 2017).

Symptoms of PD are one of the primary factors that contribute to an increased risk of falls within this population. Motor symptoms that have been linked to falls include postural instability, dyskinesia, decreased coordination, balance, and freezing gait (Schrag, Choudhury, Kaski, & Gallagher, 2015). Additionally, non-motor symptoms, such as cognitive deficits and others potentially caused by medication side effects, can also contribute to fall risk (Foster et al, 2014). Not one type of symptom places individuals with PD at a higher risk for falls, but a combination of all these symptoms leads to more falls within this population (Foster et al., 2014).

Fear of falling is another factor that can impact an individual's quality of life. For example, in a qualitative study by Kader et al. (2016), individuals with PD were interviewed. Researchers found that individuals with PD's fear of falling can predict falls or near falls as well as recurrent falls. The authors found that having a history of falls and a fear of falling causes fall-related activity avoidance (Kader et al., 2016). By interviewing individuals with PD, findings demonstrated that the two most frequently avoided activities due to a fear of falling are going out when it is slippery and going to a place with crowds. Overall, the study's main finding was that a fear of falling can negatively affect activities of daily living (ADLs), level of physical activity, and cause participation restrictions of meaningful activities for individuals with PD (Kader et al., 2016).

### **Interventions for Parkinson's Disease**

There is a variety of interventions for individuals with Parkinson's disease including medications, surgical options, and therapeutic interventions to help manage and improve motor and nonmotor symptoms that can manifest with this specific disease.



**Interdisciplinary Team**

Since PD is a degenerative disease, the gradual decline of the condition can be slowed down by a variety of interventions (Foster et al., 2014). PD is addressed by multiple healthcare disciplines due to the numerous and diverse symptoms of the disease. The multidisciplinary team could include a doctor, neurologist, occupational therapist, physical therapist, speech language pathologist, and a pharmacist to work on improving motor and non-motor symptoms individuals might be experiencing due to PD (Foster et al., 2014). A well designed, multidisciplinary team, and quality of life interventions have been shown to address complex issues of living with PD (Foster et al., 2014).

**Medications**

The first health professional an individual with PD might encounter after being diagnosed would be a pharmacist to implement and educate them about their medications. Involving a pharmacist on the interdisciplinary team can help implement medication therapy management (MTM) to monitor the patient's treatment and ensure the treatment's effectiveness, safety, and convenience to thereby improve their overall quality of life (Foppa et al., 2016).

Medications are implemented after diagnosis to address dopamine production and symptom management (Lee, Dallapiazza, De Vloo, & Lozano, 2018). For example, some common types of medication used for PD are levodopa, dopamine agonists, and monoamine oxidase inhibitors (Lee et al., 2018). Medication management becomes a part of their daily routine due to the complexity of PD and requires extensive pharmaceutical care to manage their prescriptions through the course of the disease (Henrichsmann & Hempel, 2016). In addition, when symptoms of PD worsen it can lead to dosage increase and the need for new medication (Foppa et al., 2016).

Individuals with PD need to be consistent with their medications every day to manage their complex symptoms, but unfortunately a major problem is non-adherence to prescribed treatment plan (Foppa et al., 2016). Non-adherence is very prevalent in individuals with PD due to the number of medications that they must take throughout the day (Daley, O'Leary Deane, Gray, Hill, & Myint, 2015). More than half of PD patients take two to four anti-parkinsonian drugs, three to four times daily (Daley et al., 2015).

Another reason an individual may not be taking their medications is due to poor health literacy. Most individuals do not understand why they are taking the medication and for what it is prescribed to treat (Daley et al., 2015). Non-adherence to medication could occur due to a lack of medication management and could potentially be ameliorated with individualized patient education about their medications, possible side effects, and the consequences if they do not adhere to their medications.

### **Surgical Options**

Some medications such as the antiparkinsonian drugs, levodopa can cause negative long-term effects such as more motor complications like dyskinesia, which increases the demand of care and cost for the patient, leading to more extreme invasive procedures such as deep brain stimulation (DBS) (Foppa et al., 2016). DBS is the most common surgical option for PD and involves the use of electrodes on a targeted area of the brain using magnetic resonance imaging (MRI) and recording brain cell activity during the procedure (Lee et al., 2018, Parkinson's Foundation, 2019). The second procedure of DBS involves implanting an impulse generator battery (IPG) either under the collarbone or in the abdomen (Parkinson's Foundation, 2019). The IPG provides an electrical impulse to the brain that is specifically involved in motor control and

individuals with PD who receive the DBS surgery, are given a controller to turn the IPG on and off (Parkinson's Foundation, 2019).

Additionally, DBS can help improve symptoms of PD including bradykinesia, rigidity, and tremors, thus leading to a decreased risk of falls (Lee et al., 2018). DBS can also help with gait disturbances and postural instability as well as non-motor symptoms such as cognitive decline, problems with sleep, or swallowing and speech difficulties (Lee et al., 2018). Even though DBS seems to improve the negative symptoms of PD, it is a last resort for most individuals due to it being an expensive and invasive procedure (Lee et al., 2018).

### **Therapeutic Interventions**

Besides medications and surgical treatments, most individuals manage their PD with therapeutic interventions. Medications, surgical approaches, and brain stimulation focus on movement deficit restitution (Nolen & Shah, 2006). Therapeutic interventions focus on improving both motor and non-motor symptoms brought on by PD to maintain independence in activities of daily living (ADLs), reduce caregiver burden, and improve quality of life (Nolan & Shah, 2006).

**Exercise.** Exercise has been shown to help improve motor symptoms of PD as well as reduce falls in the older population (Crizzle & Newhouse, 2012; Sherrington et al., 2016). One study established that exercise interventions in community-dwelling older people has reduced the rate of falls and the risk of falling (Sherrington et al., 2016). It has been shown that physical activity has improved or maintained physical performance skills in individuals with PD (Foster et al., 2014). Exercise may also improve cognitive skills such as executive function, working memory, and communication (Crizzle & Newhouse, 2012). Overall, exercise can improve

symptoms of PD and consequently, may place individuals with PD at a lower risk for falls simultaneously.

**Lee Silverman voice treatment.** One intervention that involves exercise which is specific to the PD population is the Lee Silverman Voice Treatment (LSVT) Big, which focuses on intensive exercising of large amplitude movements to help overcome symptoms of PD such as bradykinesia and hypokinesia (Janssens et al., 2014). This treatment is derived from LSVT Loud, which aims to improve speech deficits including hypophonia (Isaacson, O'Brien, Lazaro, Ray, & Fluet, 2018). LSVT Big can begin in inpatient or outpatient rehabilitation, but it is more of an independent home training program because individuals are instructed to complete the exercises at home as well (Janssens et al., 2014). LSVT Big has been shown to improve gait speed and mobility and continuing with this program at home could overall improve the symptoms of PD (Janssens et al., 2014).

**Parkinson wellness recovery.** Parkinson Wellness Recovery (PWR) was founded in 2010 by Dr. Becky Farly, who is also the developer of LSVT Big (Gatschet & Drinnen, 2017). This program promotes neuroplasticity through motor learning principles, exercise, and additional activities involving non-motor and medication management (Parkinson Wellness Recovery, 2019). This exercise program works to counteract PD symptoms and integrates the most up to date research of PD and rehabilitation (Parkinson Wellness Recovery, 2019). Compared to LSVT Big, PWR has a patient centered protocol, which is adaptable to make the program individualized and implemented across all levels of severity of PD (Gatschet & Drinnen, 2017).

**Dance and music therapy.** In addition to exercise, other forms of physical activity have been found to be effective in preventing risk factors for falls of the elderly with PD, who are at a

higher risk for falls (Listewnik & Ossowski, 2018). Improvement in speed and quality of gait can be addressed through therapeutic activities such as dance (Listewnik & Ossowski, 2018). Dance therapy has been found to improve mobility, have social benefits, and is a form of physical activity for individuals with PD to stay active (Listewnik & Ossowski, 2018).

Another way music can help individuals with PD is through rhythmic auditory stimulation (RAS) gait training. RAS is a technique that coordinates gait movements to predictable time cues such as metronome click-embedded music (Thaut et al., 2019). Research in RAS has demonstrated a reduction in freezing episodes, reduction in temporal instability, and improved kinematic stability to reduce the risk and fear of falling (Thaut et al., 2019). Patient education is another important way that those with PD can benefit.

**Patient education.** Patient education can be provided in a variety of formats including verbally through a handout, or in conjunction with an intervention. For example, a randomized controlled study conducted a home program for individuals with PD focusing on strength and movement strategy training while incorporating patient education throughout the program (Morris et al., 2017). Fall education included risk factors of falling, medication management, proper footwear, keeping active, and home safety. The researchers of the study did not state who implemented the falls education directly to the participants, but this study demonstrates how fall prevention education can be implemented with a home program for individuals with PD.

Additionally, research has shown that patients who are more informed about their own health have better outcomes, but it is difficult to find ways to support patients to become informed about their own medical condition (Papadakos et al., 2014). Barriers to individuals receiving patient education are low health literacy, lack of healthcare training and time constraints.

Low healthy literacy may affect why individuals with PD might not be receiving or understanding patient education given to them by a healthcare professional. Health literacy is defined as “the degree to which individuals have the capacity to obtain, process, and understand basic health information needed to make appropriate health decisions” (Jager & Wynia, 2012, p. 294). One group who is at risk for having low health literacy are senior citizens (Papadakos et al., 2014). Most individuals with PD symptoms get worse as they get older and they fall into the category of senior citizens. Overall, low health literacy leads to poorer outcomes including falls and makes individuals susceptible to greater health risks including poor management of chronic diseases (Papadakos et al., 2014).

Additionally, there is a gap in research regarding who initiates fall prevention education and when patients with PD should receive the education. The question as to who should be providing education about falls to the patient remains. In addition, having no training for healthcare professionals in patient education about falls might be another reason why it is difficult to identify who should be implementing fall education (Papadakos et al., 2014). This lack of training for healthcare professional could explain why individuals with PD are receiving fall prevention education after they have experienced a fall.

### **Occupational Therapist’s Role with Parkinson’s Disease**

Occupational therapists (OTs) can be an important member of the interdisciplinary team and are well suited to lead interventions with individuals with PD in their homes and community due to being highly trained in the aging process, role performance and participation, and physical and psychological adaptations to disability (Foster et al., 2014). Despite being highly trained to help people with this condition, individuals with PD are not usually referred to OT at the early stages of the disease (Foster et al., 2014). Therefore, OTs generally see individuals with PD

when the condition has worsened. Thus, the OT takes on a role to compensate or adapt the individual's activities of daily living (ADLs) and their environment to remain independent as much as possible. (Nolan & Shah, 2006).

In addition, there has been research showing an emerging role for OTs in disease modification and prevention, specifically in chronic progressive diseases. Studies have demonstrated that implementing OT interventions in daily routines of independently living older adults improves their independence and prevents their overall loss of function (Rao, 2014). Occupational therapy-based interventions can potentially have significant disease modifying benefits and overall individuals with PD who are referred to OT once diagnosed could possibly delay their loss of function from the progressive disease (Rao, 2014). Additionally, OTs could have a role in providing fall prevention education to individuals with PD as another intervention for preventing falls in the home.

### **Problem Statement and Research Questions**

Individuals with PD are at a high risk for falls due to motor symptoms such as rigidity, bradykinesia, and postural instability as well as non-motor symptoms such as cognitive deficits brought on by the gradual progression of the disease (Foster et al., 2014). Initiating timely patient education on fall prevention is critical to preventing individuals with PD from experiencing falls and allaying an individual's fear of falling in the home and community.

OTs and other healthcare professionals are well suited to incorporate fall prevention education; however, there is currently a lack of research describing the most effective and current educational methods, as well as the most appropriate time to implement them. Having a better understanding of client perceptions of the effectiveness of fall prevention education may

help healthcare professionals, including OTs, to provide effective and meaningful education to optimally prevent falls and promote quality of life.

The purpose of this study is to explore the relationship between an individual's perceptions of why falls happen and if receiving fall prevention education is beneficial to reducing falls. This study will address the following research questions:

1. What is the impact of falls on an individual with PD daily activities?
2. What types of education have individuals with PD received from a health care professional and when did they receive this information?
3. Was the education perceived to be beneficial to the individual?

### **Methods**

This qualitative study utilized multiple modes of data collection including field observations, surveys, and semi-structured interviews. Survey research is defined as a method to collect data using structured questions to receive self-reported information from a sample of individuals and is beneficial because it can be implemented in numerous ways (Taylor, 2017).

In addition, field observations were chosen, specifically participant observation to gain an insider's view of individuals with PD in the exercise group and gain an understanding of what the participants experience in the group was like (Taylor, 2017). Semi-structured interviews were also chosen to provide some structure to open-ended questions, but also allowing flexibility for the researcher for which questions would be asked to the participant based off their survey responses (Taylor, 2017). Prior to participant recruitment and data collection, this study was approved as exempt by the Elizabethtown College Institutional Review Board (IRB).

### **Participant Recruitment**



Purposive sampling, which indicates that there is a specific selection of individuals by the researcher based on predetermined criteria (Taylor, 2017), was used to recruit participants for this study. Inclusion criteria for this study included individuals with PD who participated in a local community exercise group and were able to provide informed consent.

### **Data Collection**

This exploratory study utilized field observations, surveys, and semi-structured interviews to explore the relationship between falls and fall prevention education and to address the research questions of this study.

**Field observations.** Observations of the community exercise group occurred to become more familiar with the individuals in the group and build rapport with the participants (Taylor, 2017). As a researcher, observing the group afforded insight into the purpose and values of the group. By attending the group, I was also able to explain the purpose of the study in person and allow for any questions or concerns to be answered immediately there at the site (Appendix A).

**Surveys.** An anonymous survey was developed by the researcher in order to learn more about individuals with PD personal experiences relating to falls, fear of falling, and fall prevention education. Survey questions were created based on an extensive review of the literature in order to answer the research questions. The survey was categorized into four sections: demographics, fear of falling, history of falling, and fall prevention education. The survey included a variety of question types, including open-ended, closed, and Likert scale. The demographics section was designed to get to know the individual better by asking about how long individuals have had PD, their living status, and if individuals are receiving other forms of therapy besides the exercise group. The fear of falling section of the survey was to explore how a person's fear of falling might impact their daily activities.

The history of falling section focused on whether the individual had ever experienced a fall or multiple falls and asked questions about when, where, and what time of day did it occur, and what activity the individual was doing when they experienced the fall. The fall prevention education section asked if the individual had ever received education about falls and if it was beneficial to the person. This section focused on who they received the information from and how they received it, either verbally, in a handout, or in another format (Appendix B).

The survey was administered by the researcher and offered three times at the community exercise group. At the end of each group session, the researcher explained the purpose of the research project and sought volunteers. Participants provided informed consent prior to participating in the survey (Appendix C). All surveys were completed and collected at the site and if participants were unable to fill out the survey themselves, their caregiver assisted by asking the individual the questions verbally and writing down their responses.

**Semi-structured interviews.** As an additional way to supplement survey responses, participants who completed the survey had the opportunity to provide their contact information in order to engage in a brief semi-structured phone interview with the researcher. While general interview prompts were created by the researcher, these were modified as needed, based on the participant's survey responses and were used to gain more insight into the experiences of the individual with PD. Phone interviews occurred approximately two weeks after the surveys were completed. Interviews were only completed with participants who volunteered and provided their contact information on the survey. Phone interviews were conducted secondary due to time restraints at the site and the researcher (Appendix D).

## **Data Analysis**

Surveys were anonymous, and each participant was assigned a unique identifier. Paper surveys were kept in a secure location and were only accessible by the researcher and were shredded at the conclusion of the study. Data was organized using an excel spread sheet on a secure computer accessible by only the researcher. Descriptive statistics were used to describe participant demographics, and frequency distributions were calculated for Likert scale and closed survey responses and displayed as percentages (Taylor, 2017). Open ended survey questions were reviewed for common trends.

### **Results**

Survey and semi-structured interview responses were collected and analyzed at the end of the study. The results of the survey were categorized into participant demographics, fear of falling, history of falling, and fall prevention education.

#### **Participants**

In total, twelve individuals participated in the survey. Table 1 demonstrates 41.7% of participants had PD for more than 15 years. Ninety one percent of participants lived with others, including their spouses, children, and grandchildren. Fifty eight percent of participants stated that they received other forms of therapy than the community exercise group, including other forms of exercise, physical therapy, and speech language pathology.

Table 1

*Participant Characteristics*

		N	%
Number of Years with PD	< 5	3	25.0%
	5 - 10	2	16.7%
	11 - 15	2	16.7%
	> 15	5	41.7%
Living Status	Alone	1	8.3%
	With Others	11	91.7%
Who Participants Live With	Spouse	8	66.7%
	Children	1	8.3%
	Parents	0	0.0%
	Spouse, Children, & Grandchildren	1	8.3%
	Did not respond	1	8.3%
	Lives independently	1	8.3%
Received Other Forms of Therapy	Yes	7	58.3%
	No	5	41.7%
Types of Therapy Received	PT only	2	16.7%
	SLP and PT	2	16.7%
	Exercise	2	16.7%
	Exercise and SPL	1	8.3%
	None	5	41.7%

*Note.* N= number of participants; PT= physical therapy; SLP: speech language pathology

**Survey Results**

**Fear of falling.** The fear of falling section of the survey results reveal that 58.3% of participants strongly agreed or agreed that they have a fear of falling (Figures 1a and 1b). Greater than 50% of participants believe that their PD symptoms increase their own fear of falling through most individuals selecting strongly agree or agree. Eighty three percent of participants strongly disagreed or disagreed to not leaving their house due to their fear of falling (Figure 1c). Conversely, 33.3% of participants agree that they avoid certain activities due to their fear of falling, but also displays 41.6% of participants strongly disagreed or disagreed with avoiding activities due to a fear of falling (Figure 1d). Activities that participants reported avoiding due to

their fear of falling included walking, fishing, bike riding, climbing stairs, exercise, standing on their own, and working on a ladder.

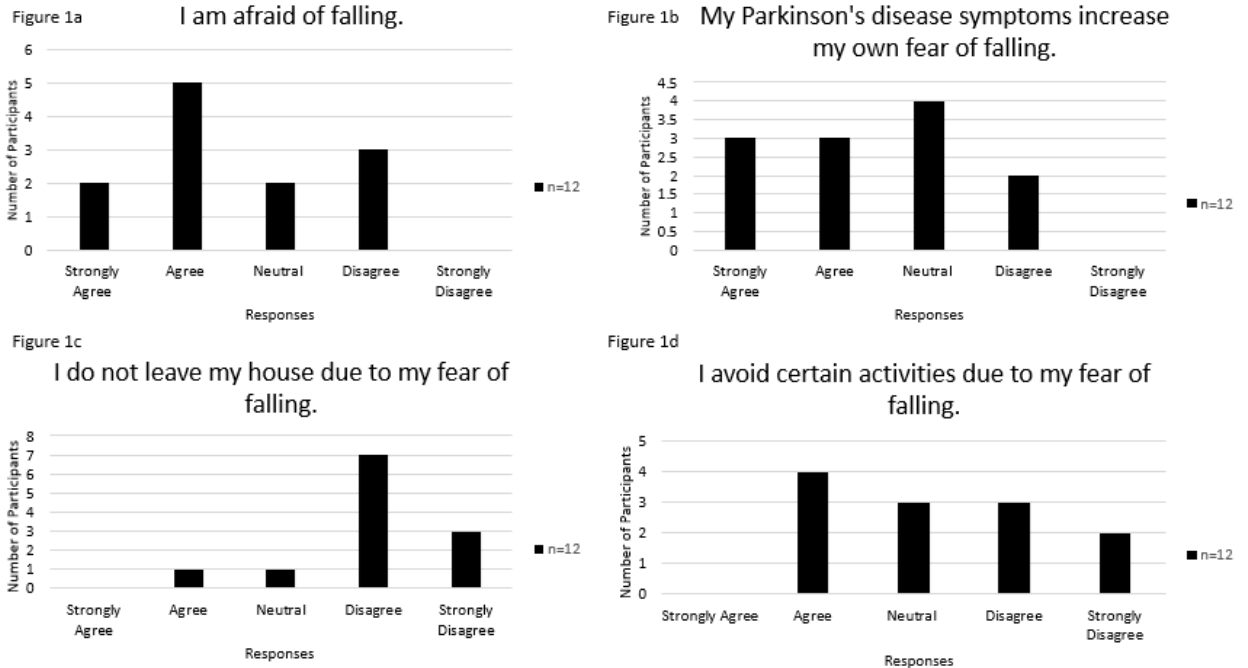


Figure 1a-1d. Fear of falling

**History of falling.** Seventy five percent of participants have experienced a fall and 33.3% of participants have experienced multiple falls (Figure 2a). The history of falling characteristics illustrate that 66.6% of participants who have experienced a fall reported their most recent fall occurred a month ago (Table 2). One participant stated their most recent fall was only three days ago and other participants stated their most recent fall happened a year or more ago. All the participants’ falls occurred in the home and in the afternoon, except one whose fall occurred at night. There were a variety of activities participants were performing when they experienced their most recent fall including mobility activities, activities of daily living (ADLs), and instrumental activities of daily living (IADLs). Mobility activities included walking, getting

up from a chair, using stairs, and turning around. ADLs included getting dressed and IADLs were taking out trash and using a ladder for home management.

Table 2

*History of Falling Characteristics*

		N	%
When the Most Recent Fall Occurred	A week ago	0	0%
	Last month	6	67%
	3 months ago	0	0%
	A year ago	0	0%
	Other	3	33%
Where the Most Recent Fall Occurred	Home	8	89%
	Community	0	0%
	Other	0	0%
	Did not respond	1	11%
Time of Day the Most Recent Fall Occurred	Morning	0	0%
	Afternoon	7	78%
	Night	1	11%
	Did not respond	1	11%
Activity Being Performed During Most Recent Fall	Mobility	5	56%
	ADLs	1	11%
	IADLs	2	22%
	Did not respond	1	11%

*Note.* ADLs = Activities of Daily Living; IADLs = Instrumental Activities of Daily Living

**Fall prevention education.** Sixty seven percent of participants have received education about preventing falls prior to this survey and more than 50% of participants reported that they believe the information was beneficial (Figure 2b). Participants reported receiving the fall prevention education from a variety of sources, including their doctor, therapist, caregiver, or through reading. They also reported receiving the education in a variety of formats including through a class, a handout, and verbally (Figure 2c). Interestingly, 41.6% of participants who received education about falls received the education after they experienced a fall. In addition, only one individual received fall education immediately after being diagnosed. Additionally,

participants who have never received any education about falls would like to receive information and seventy five percent of the participants stated through a class (Figure 2d).

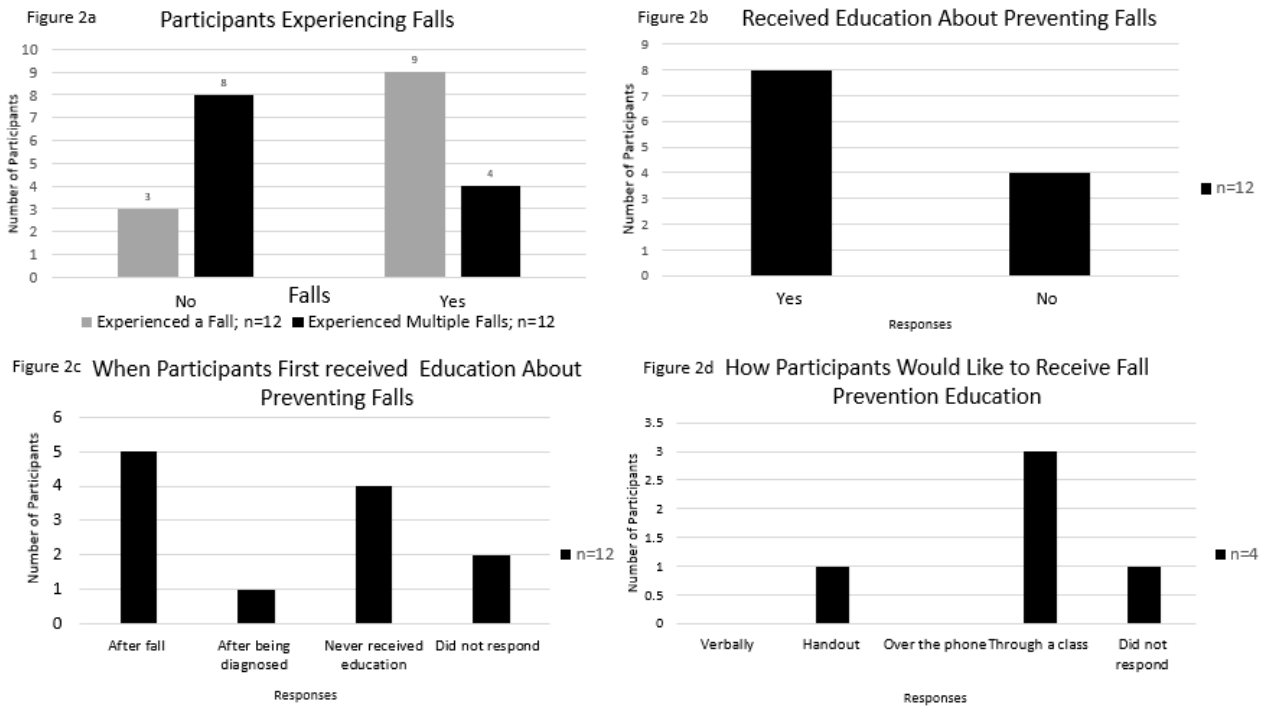


Figure 2a-2d. History of falling and fall prevention education

### Semi-Structured Interview Results

While several participants expressed interest in completing phone interviews by providing their contact information on the survey, only one phone inquiry was completed secondary due to time constraints of both the participants and the researcher. Participant 11 was interviewed over the phone two weeks after the survey was administered and had not experienced a fall, attributing this to a variety of factors, including the accessibility of his house and participation in the community exercise group. During the interview, Participant 11 discussed the importance of peer support regarding fall prevention education. He shared, “It is important to be around people who understand you, like in a class.” Participant 11 also shared

advice for individuals newly diagnosed with PD: “Take your time, don’t be in such a hurry that you are not conscious of your surroundings.” The implications of these findings are discussed in more detail, specifically about the fear of falling, implementation of fall prevention education, the need for peer support, and how OT could get more involved with this population.

### **Discussion**

The results of this study illustrate that individuals with PD have a fear of falling and it causes people with PD to avoid daily activities. This is consistent with previous studies which stated falls contribute to an increased fear of falling, which leads to activity limitations and participation restrictions (Foster et al., 2014). Studies have also shown that having a history of falls and a fear of falling causes fall-related activity avoidance (Kader et al., 2016).

While previous studies have suggested that individuals with PD who have experienced a fall typically do not leave their home due to a fear of falling (Kader et al., 2016), the participants of this study did not appear to follow this trend. All the participants reported leaving their home to attend the community exercise group, suggesting that the exercise group provided them with motivation, social support, and opportunity to improve their PD symptoms.

In regard to fall prevention education, the majority of participants stated they would like to receive the information through a class. This is not surprising since the participants are currently involved in a local community exercise class and like to be around their peers. Participant 11 revealed throughout the interview that individuals with PD want to be around others who understand what they are going through to help each other and be supportive of one another. This suggests that peer support might be an important factor to motivate individuals with PD to attend fall prevention education classes. Fall prevention education classes that



encourage peer support could give individuals with PD the opportunity to learn from others with similar experiences.

In addition to the format of fall prevention education, the timing of education must also be considered. The majority of participants in this study did not receive fall prevention education until after they experienced a fall. Individuals with PD are considered to be at a high risk for falls due to the variety of motor and non-motor symptoms that can occur (Foster et al, 2014), and this delayed education provision might further contribute to this risk. Falls have a large impact on healthcare and can cause multiple complications, including a loss of independence and a reduced quality of life (Morris et al., 2017), so it is imperative that prevention education be provided in a timely manner.

Additionally, occupational therapists are not usually seen by individuals with PD at the early stages of their disease and are often not referred to OT until their condition has worsened (Foster et al., 2014), if referred at all. While literature suggests that OT services are beneficial for individuals with PD, none of the participants in this study, including those who had experienced a fall, were currently receiving OT services. Participants were engaging in physical therapy, speech language pathology, and other forms of exercise. This suggests that individuals with PD are not being referred to OT services even if they are experiencing falls. The problem could possibly be that primary care physicians are not aware of the role of OT and how OTs can make environmental modifications and adapt daily routines for individuals with PD.

Overall, OTs should be incorporated in the multidisciplinary team early on by primary care physicians by referring newly diagnosed patients with PD to OT services in their early stages of their diagnosis. OTs would be well suited to run fall prevention education classes for individuals with PD as OTs are trained to adapt daily routines to enhance functional abilities are

equipped to address environmental modifications to help reduce falls in the home (Jansa & Aragon, 2015).

### **Limitations**

The study had a small sample size of only twelve participants and participants only represented one community exercise group. Future research with a larger sample size and participants from multiple PD groups should be completed to gain a more comprehensive understanding about how falls impact individuals with PD's daily activities and if individuals are receiving fall prevention education. Another limitation was small numbers of semi-structured interviews completed due to time constraints and difficulty coordinating schedules with participants. For future research, more interviews should be conducted to further supplement survey responses and provide a better understanding of individuals' personal experiences with PD and experiencing falls.

### **Conclusion**

Overall, fall prevention education should be provided earlier to individuals with PD and this education should be ongoing throughout their disease progression. Fall prevention education classes should include peer support and a variety of education modalities based on individuals' personal learning styles. OTs could help to prevent further hospitalizations due to falls for individuals with PD by educating clients on how to manage their PD in their everyday routines through fall prevention education classes.

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## Tables

Table 1

*Participant Characteristics*

		N	%
Number of Years with PD	< 5	3	25.0%
	5 - 10	2	16.7%
	11 - 15	2	16.7%
	> 15	5	41.7%
Living Status	Alone	1	8.3%
	With Others	11	91.7%
Who Participants Live With	Spouse	8	66.7%
	Children	1	8.3%
	Parents	0	0.0%
	Spouse, Children, & Grandchildren	1	8.3%
	Did not respond	1	8.3%
	Lives independently	1	8.3%
Received Other Forms of Therapy	Yes	7	58.3%
	No	5	41.7%
Types of Therapy Received	PT only	2	16.7%
	SLP and PT	2	16.7%
	Exercise	2	16.7%
	Exercise and SPL	1	8.3%
	None	5	41.7%

*Note.* N= number of participants; PT= physical therapy; SLP: speech language pathology

Table 2

*History of Falling Characteristics*

		N	%
When the Most Recent Fall Occurred	A week ago	0	0%
	Last month	6	67%
	3 months ago	0	0%
	A year ago	0	0%
	Other	3	33%
Where the Most Recent Fall Occurred	Home	8	89%
	Community	0	0%
	Other	0	0%
	Did not respond	1	11%
Time of Day the Most Recent Fall Occurred	Morning	0	0%
	Afternoon	7	78%
	Night	1	11%
	Did not respond	1	11%
Activity Being Performed During Most Recent Fall	Mobility	5	56%
	ADLs	1	11%
	IADLs	2	22%
	Did not respond	1	11%

*Note.* ADLs = Activities of Daily Living; IADLs = Instrumental Activities of Daily Living



Figures

Figure 1a I am afraid of falling.

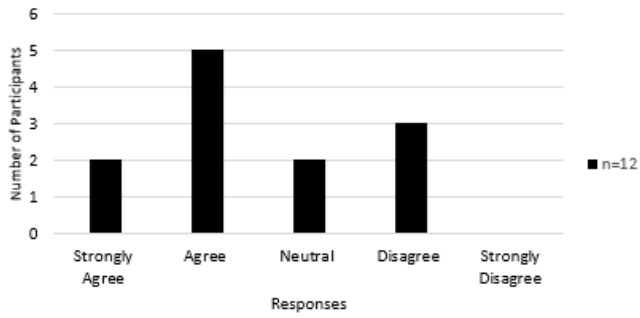


Figure 1b My Parkinson's disease symptoms increase my own fear of falling.

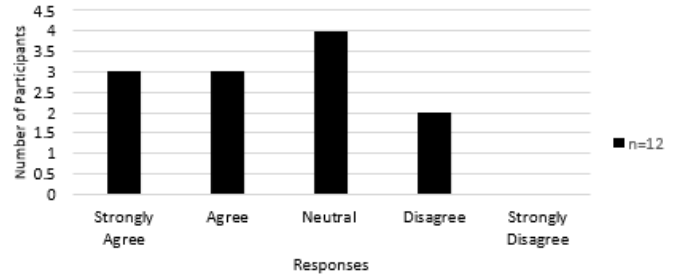


Figure 1c I do not leave my house due to my fear of falling.

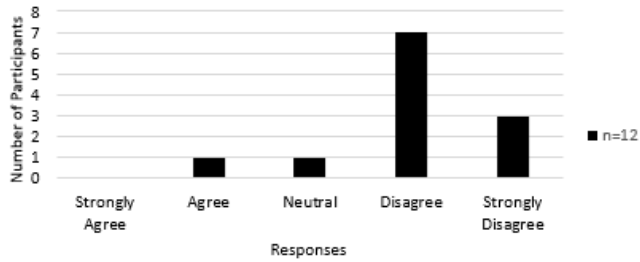


Figure 1d I avoid certain activities due to my fear of falling.

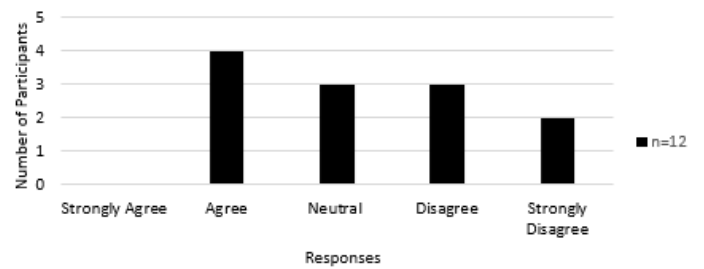


Figure 1a-1d. Fear of falling

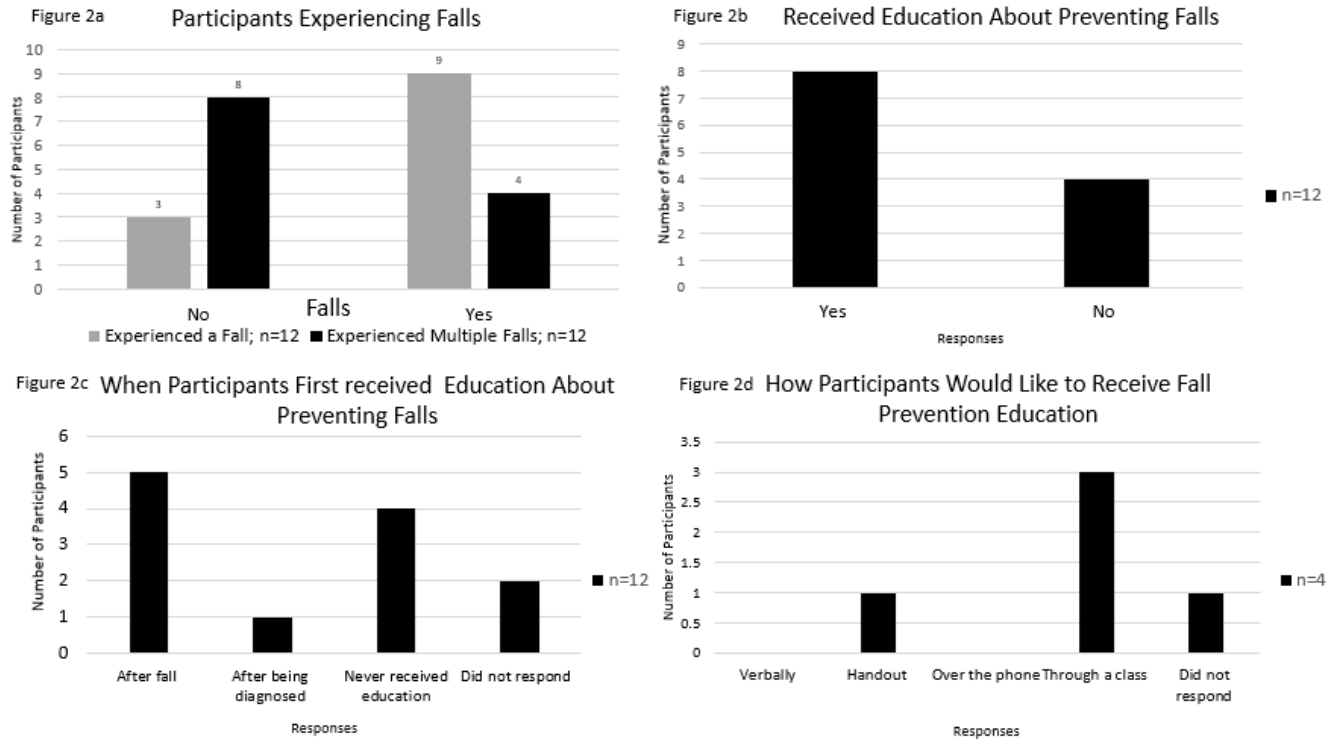


Figure 2a-2d. History of falling and fall prevention education

## Appendix A

## Script for Introduction to Parkinson's Exercise Group

Title of Research: The Impact of Fall Prevention Education for Individuals with Parkinson's Disease

Principle Investigator(s): Missy Ziegler OTS and Gina Fox OTD, OTR/L

Script:

## First Visit to the site:

Hi, my name is Missy Ziegler. I am a senior occupational therapy major at Elizabethtown College. I am completing an undergraduate research project this year about individuals with Parkinson's disease and their experiences with falls. I am interested in learning more about what causes falls in this population and how do falls impact their daily activities. I am also interested to see if receiving fall prevention education was beneficial to reducing falls depending on when and how you receive the education.

Today, on my first visit, I am here to simply observe and familiarize myself with the group. Thank you for allowing me the opportunity to observe your group and learn more about your experiences with Parkinson's disease. On my next couple of visits, I will have paper surveys asking questions about your experiences with Parkinson's disease and falls.

## Second Visit to the site:

As we talked about last time, I am interested in learning about your experiences with Parkinson's disease and falls. I am interested in learning about what causes falls with this population and overall how falls may impact your daily activities. I also want to learn more about fall prevention education and if the information you receive is beneficial to reducing falls depending on when and how you received the education.

If you are interested in participating in my research project, you can volunteer to fill out a short participant consent form that I will go over with you and complete the paper survey. The paper survey will be anonymous unless you leave your name and contact information at the bottom of the survey. At the bottom of the survey, there is a section asking if you are interested in participating in a short interview to answer more in-depth questions about your survey responses and your experiences with falls. If interested and want to volunteer for a short survey, either in person or over the phone, simply leave your name, phone number, and email address if you have one and I will contact you in two weeks. If you have any questions at any time, let me know.

Appendix B

**Survey Questions**

These survey questions are designed to help the researchers better understand your experiences with Parkinson’s disease and falls. Please answer the questions honestly and to the best of your ability. If there is a question that you do not feel comfortable answering, you may skip it.

**Demographics**

**The following questions are designed to get to know you better.**

1. How long have you had Parkinson’s disease? \_\_\_\_\_
2. Do you live by yourself?  
Yes **OR** No
3. If **No**, who do you live with? \_\_\_\_\_
4. Are you currently receiving other forms of therapy other than this group?  
Yes **OR** No
5. If **Yes**, what forms of therapy are you currently receiving? \_\_\_\_\_

**Fear of Falling**

**The following questions will ask about fear of falling and how it impacts daily activities.**

**Within each question focus on the words in bold.**

6. I am **afraid** of falling.  
Strongly Agree    Agree    Neutral    Disagree    Strongly Disagree
7. My Parkinson’s disease symptoms **increase** my own fear of falling.  
Strongly Agree    Agree    Neutral    Disagree    Strongly Disagree
8. I **do not** leave my house due to my fear of falling.  
Strongly Agree    Agree    Neutral    Disagree    Strongly Disagree

9. I **avoid** certain activities due to the fear of falling.

Strongly Agree   Agree   Neutral   Disagree   Strongly Disagree

10. If you circled **strongly agree or agree**, what activities do you avoid the most due to your fear of falling? \_\_\_\_\_

### History of Falling

The following questions focus on if you have ever experienced a fall. If you have **never** experienced a fall, you can skip to the next section, Fall Prevention Education.

11. Have you ever experienced a fall?

Yes **OR** No

12. Have you experienced multiple falls?

Yes **OR** No

13. When was your most recent fall?

A week ago   Last month   3 months ago   A year ago   Other? \_\_\_\_\_

14. **Where** did your **most recent** fall occur?

Home   Community   Other? \_\_\_\_\_

15. What **time of day** did your **most recent** fall occur?

Morning   Afternoon   Night

16. What **activity** were you doing when you experienced your **most recent** fall?

\_\_\_\_\_

### Fall Prevention Education

The following questions will focus on if you have ever received fall prevention education.

17. Have you received any education about preventing falls previously?

Yes **OR** No

18. If **Yes**, who did you receive that information from?

Doctor      Therapist      Caregiver      Other? \_\_\_\_\_

19. If **Yes**, when did you first receive education about preventing falls?

After you were diagnosed      After you fell      Other? \_\_\_\_\_

20. If **Yes**, how did you receive the education about falls? Circle all that apply.

Verbally    Handout      Over the phone      Through a class      Other? \_\_\_\_\_

21. If you have **received** fall prevention education previously, do you believe it was **beneficial** to you?

Yes **OR** No

22. If you have **never** received any education about falls, how would you like to receive it?

Circle all that apply.

Verbally    Handout      Over the phone      Through a class      Other? \_\_\_\_\_

**I am looking to further conduct short interviews, in person or over the phone to learn more about how Parkinson’s disease has impacted your daily routines and your experiences with falls. If interested, please leave your contact information below and I will be contacting you in 2 weeks.**

**Name:** \_\_\_\_\_

**Phone number:** \_\_\_\_\_

**Email Address:** \_\_\_\_\_

## Appendix C

**Consent Form**

Title of Research: The Impact of Fall Prevention Education for Individuals with Parkinson's Disease

Principal Investigator(s): Missy Ziegler, OTS and Gina Fox, OTD, OTR/L

Purpose of Research:

The purpose of this study is to determine if individuals with Parkinson's Disease have experienced any falls and whether they have received education about falls after being diagnosed. By doing this study, we hope to learn about the personal experiences of individuals with Parkinson's disease related to falls, including the impact of falls on their daily lives and the types of education they received regarding fall prevention. We also want to learn if receiving fall prevention education is beneficial and prevents falls from happening in the home and community.

Procedures:

As a participant, I will fill out an anonymous survey about my experience with Parkinson's disease and falls. If I am comfortable giving my name and contact information, I may be asked to participate in a brief interview, either in person or over the phone, to further discuss my survey answers as well as my experience with falls.

Risks and Discomforts

I understand that there are minimal to no risks or discomforts anticipated from my participation in this study. I might feel slightly uncomfortable at times when discussing my personal experiences with falls and Parkinson's disease; however, I understand that all my responses will be kept confidential.

Benefits

I understand that this study will have no direct benefits to me; however, the information I provide may, in the future, help other healthcare professionals to become more knowledgeable about falls and fall prevention education within the Parkinson's disease population.

Compensation

I understand that I will not receive any compensation for participating in this study.

Confidentiality

All surveys will be anonymous unless I choose to list my name and contact information for a short interview. The information gathered during this study will remain confidential with all records to be kept private and locked in a file during the study. Only the researchers listed on this form will have access to the study data and information. The results of the research will be published in the form of an undergraduate paper and may be published in a professional journal or presented at professional meetings. In any report or publication, the researcher will not provide any information that would make it possible to identify me.

Withdrawal without Prejudice

My participation in this study is strictly voluntary; refusal to participate will involve no penalty. If I initially decide to participate, I am still free to withdraw at any time. If I decide to not participate in this study, it will not impact my participation with this group.

Contacts and Questions

If I have any questions concerning the research project, I may contact Missy Ziegler at (267)795-7050 or Gina Fox at (717)891-7670. Should I have any questions about my participant rights involved in this research I may contact the Elizabethtown College Institutional Review Board Submission Coordinator, Pat Blough at (717)361-1133 or via email at bloughp@etown.edu.

**Statement of Consent:**

- I am 18 years of age or older.
- I have read the above information. I have asked questions and received answers.
- A copy of this consent form has been provided to me.

Participant Signature \_\_\_\_\_ Date \_\_\_\_\_

Investigator Signature \_\_\_\_\_ Date \_\_\_\_\_



## Appendix D

**Phone Interview Questions**

- If the participant answered **agree or strongly agree** to questions in the fear of falling section.
  1. When did you notice your fear of falling?
  2. Name some of your Parkinson's symptoms that you believe contribute to your fear of falling?
- If the participant answers **yes** to question 11: have you ever experienced a fall?
  3. After the fall happened, what did you do?
  4. Since your first fall, how has that fall impacted your daily activities?
- If the participant answers **yes** to question 12: have you experienced multiple falls?
  5. How many times have you fell since being diagnosed with Parkinson's disease?
  6. Have all your falls occurred in the same place around the same time?
- If the participant **never** received fall prevention education:
  7. Would you like to receive fall prevention education and why did you pick to receive the information in that specific method (verbal, handout, class, over the phone, etc.)
- If the participant **has received** fall prevention education:
  8. Why was the fall prevention education either beneficial or not beneficial to you?
  9. Is there another method you would have liked to receive the fall prevention education? (either verbal, handout, over the phone, through a class, etc.)
- **General questions:**
  10. Do you think any of the interventions you have previously received have helped you prevent falls?

11. What do you think healthcare providers should tell individuals with Parkinson's disease about falls?
12. What kind of advice would you give someone who was recently diagnosed with Parkinson's disease about preventing falls?