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Fatigue in Parkinson's Disease:

A Qualitative Descriptive Study Exploring the Individual's Perspective

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ABSTRACT

Fatigue in Parkinson's Disease: A Qualitative Descriptive Study Exploring the Individual's Perspective

by Amy E. Bruno

Fatigue in Parkinson's disease (PD) is a major cause of disability and lower quality of life. It is often under-assessed by health care providers and under-recognized by individuals with PD as being part of their neurological disorder. A comprehensive literature review revealed that there is a lack of descriptive research from the individual's perspective regarding fatigue definitions in PD, self-management strategies, and its impact on quality of life. The aim of this study was to uncover how individuals with PD define this symptom, the effect it has on one's quality of life, self-management strategies to lessen fatigue, and how individuals perceive their health care providers recognize and manage their PD-related fatigue. The study utilized a qualitative descriptive design with responsive interviewing as developed by Rubin and Rubin. In-depth interviews were conducted to gain a rich description of the experience of PD-related fatigue. The sample of eight participants included six males and two females. Participants were recruited from local PD support groups using purposive and snowballing sampling techniques. Strategies from Schatzman and Strauss' field research were used to guide data collection and analysis of the transcripts.

Five themes were revealed through data analysis and included: the Symptom Experience, What Fatigue is Not, Accommodation, Loss, and Mental Fortitude. These main themes were consistent in the data across several research questions and for the majority of the participants. Each main theme was further analyzed. The Symptom

Experience included sub-themes of: symptom identification, daily and pervasive symptom, involvement over time, and seeking validation. What Fatigue Is Not consisted of the sub-themes: tiredness, sleepiness, and depression. Accommodation encompassed alteration in daily routine, engagement in activities, and conservation of self. The theme of Loss was expressed as role loss, loss of activities, and changing sense of self. Mental fortitude included the sub-themes of taking control/perseverance, acceptance, and positive attitude. Participants described the significant effect of fatigue on their quality of life, as well as self-management strategies that decreased fatigue. Half of the participants did not discuss fatigue with their health care providers because they did not bring it up during office visits or the provider did not assess for it. Implications of this research for practice include the importance of assessing for fatigue at every office visit and teaching about self-management strategies. Future research may focus on the development of an intervention study to examine the effect of exercise on fatigue and the exploration of fatigue as part of a symptom cluster with other non-motor symptoms of PD.

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CHAPTER ONE

Introduction

Parkinson's disease (PD) is a chronic neurodegenerative condition that affects more than one million people in the United States (Abrantes et al., 2012). It typically affects older adults and the incidence is projected to double by 2030 due to the aging of the American population (Dorsey et al., 2007; Kowal, Dall, Chakrabarti, Storm, & Jain, 2013). Parkinson's disease includes both motor and non-motor symptoms (NMS). Fatigue, one of the most prevalent NMS, is estimated to affect approximately 58% of individuals with PD and is reported to be a major cause of disability and reduced quality of life (QOL) (Friedman, 2009; Friedman et al., 2010). Despite its prevalence, fatigue is often not assessed in office visits, and is under-recognized as a symptom of PD by individuals themselves (Bonnet, Jutras, Czernecki, Corvol, & Vidailhet, 2012; Gallagher, Lees, & Schrag, 2010). Typically, individuals with PD have difficulty describing fatigue and attribute it to other conditions such as depression (Brown, Dittner, Findley, & Wessely, 2005). Further, there has been very little research to date examining the significance of this symptom from the perspective of the individual with PD.

This qualitative descriptive study was undertaken to uncover how individuals with PD describe the fatigue they experience, the effect fatigue has on their QOL, what self-management strategies they use, and how they feel their health care providers manage their fatigue. One goal was to learn more about the subjective experience of fatigue in individuals with PD, which can inform practicing nurses, other health care providers, educators, and researchers about the importance of fatigue and the impact it has on a person's life.

Background and Significance

Fatigue in PD was first recognized in the literature in 1993 by Friedman and Friedman, who found fatigue to be more common in individuals with PD ($n = 58$) versus controls ($n = 58$) who did not have PD or a similar condition. One-third of the respondents cited fatigue as their most incapacitating symptom. Fatigue was also correlated with the presence of depression (Friedman & Friedman, 1993). Karlsen, Larsen, Tandberg, and Jorgensen (1999) found fatigue to be reported by 44% of participants with PD ($N = 233$). The researchers discovered that fatigue was prevalent for sample participants both with and without depression. Karlsen et al. (1999) concluded that given the subjectivity of fatigue, it is a difficult symptom to measure and further exploration was warranted. The occurrence of fatigue as a distressing NMS has continued to be reported in the literature (Friedman, Abrantes, & Sweet, 2011; Lou, 2009).

One of the ongoing challenges with research in PD-related fatigue is that fatigue is largely a subjective experience and there is no universal definition. Individuals with PD often have difficulty describing their fatigue and may not be certain that is what they are experiencing (Friedman et al., 2007; Friedman, 2009). Types of fatigue that have been described are peripheral, central, physical, and mental (Friedman et al., 2011). These definitions vary in the literature and when compared to anecdotal descriptions of fatigue by individuals, there is a discrepancy between what is defined by researchers versus what individuals actually experience. In addition, researchers assessing for fatigue in PD studies often do not even offer a definition; there is no explicit consensus on what the term means (Friedman et al., 2011).

Olsson, Stafstrom, and Soderberg (2013) conducted a study utilizing a phenomenological hermeneutic interpretation to examine the meaning of fatigue in women with PD ($N = 11$). Participants reported that they viewed the “body as a burden” (p. 744) due to their fatigue. The presence of PD-related fatigue also changed their familiar everyday life and their bodies created a barrier for them to complete daily tasks and activities. Participants reported fatigue was felt as a “whole-body experience” and created a feeling of being paralyzed (Olsson et al., 2013, p. 744), which gave meaning to the experience of PD-related fatigue.

Brown et al. (2005) conducted a multi-step study to develop and evaluate the Parkinson Fatigue Scale (PFS), a new instrument to measure fatigue in PD. Initially, focus groups ($n = 39$) were held to gather comments from individuals with PD to determine how they perceived and experienced fatigue. Descriptions of PD-related fatigue were limited but included the following terms: “heavy, drained, tiredness, lack of energy, exhaustion” (Brown et al., 2005, p. 50). The most common concept that arose was “abnormal tiredness” (p. 50).

Fatigue in PD has been shown to negatively affect QOL (Elbers, van Wegen, Verhoef, & Kwakkel, 2014; Martinez-Martin, Rodriguez-Blazquez, Kurtis, & Chaudhuri, 2011; Miwa & Miwa, 2011). These three studies utilized quantitative methodologies and did not include any patient input regarding how fatigue negatively affected their lives. Elbers et al. (2014) indicated that the presence of depression and anxiety might worsen fatigue. However, descriptive data on fatigue, depression, and anxiety, and its impact on QOL is lacking in the literature. These studies did not include any definitions of fatigue.

To date, no published research describes how individuals cope with PD-related fatigue or what self-management strategies they use to reduce or assist them to live with this symptom. However, Kralik, Telford, Price, and Koch (2005) conducted a study ($n = 30$) to determine how women give meaning to and live with fatigue within the context of a chronic illness. One of the major themes identified by the participants was “accountability for self-care” (p. 377). Participants believed that self-care helped reduce the negative impact fatigue had on their lives. They reported several activities to manage fatigue in their daily lives, such as: allowing periods of rest and time for healing, shifting of home responsibilities to other family members, and pacing daily activities (Kralik et al., 2005). Recognizing that self-care is an important mechanism for living with fatigue in other chronic illnesses may provide insight into how PD-related fatigue can be managed by individuals in their home environment.

Another area of research that has received limited attention relates to the perceptions of individuals of how health care providers assess and manage PD-related fatigue. Martinez-Martin et al. (2011) revealed many NMS, including fatigue, are often under-assessed and not recognized by health care providers during patient visits. Similarly, Gallagher et al. (2010) found many NMS, including fatigue, were not documented in clinic notes. Abudi, Bar-Tal, Ziv, and Fish (1997) emphasized the inconsistency between health care providers’ perceptions of individuals living with PD versus what symptoms individuals reported to be bothersome. In order for health care providers to recognize that fatigue is a common, distressful symptom of PD, they need to be aware of the significant impact that fatigue has on a patient’s daily life.

The chronic and progressive nature of PD poses challenges in all aspects of a patient's life. The multitude of symptoms makes it difficult for individuals to fulfill role responsibilities and activities of daily living. Individuals with PD confront many losses living with this disease including: loss of independence to complete activities of daily living, loss of gross and fine motor control, and loss of self and positive body image (Abudi et al., 1997). Nurses have an important role in supporting individuals to learn to live with the disabling effects of PD. It is essential for nurses to increase their knowledge about the complex symptomatology of PD and the effect motor and NMS have on one's life. This understanding will in turn help the nurse assist persons with PD to live a more meaningful life within the context of this chronic and progressive illness.

Problem Statement

There is a lack of qualitative data in nursing describing the experience of fatigue in PD, how individuals describe this concept, the effect fatigue has on a person's quality of life, what self-management strategies individuals utilize to lessen and/or live with their fatigue, and how individuals perceive health care providers recognize and manage their PD-related fatigue. There is a need in nursing research to qualitatively examine this non-motor symptom in individuals with PD in order to gain greater understanding of the experience of PD-related fatigue.

Purpose

This study utilized a qualitative descriptive design to explore how individuals with PD describe their fatigue, the effect of fatigue on quality of life, self-management strategies individuals may use to reduce their fatigue, and experiences with health care providers managing their fatigue. By uncovering patient experiences regarding PD-

related fatigue, knowledge will be generated. Findings provide essential knowledge that nurses can use to assess, address, and assist individuals managing PD-related fatigue. Improved understanding of fatigue can help to more clearly define the concept, which in turn can improve its measurement and assist nurses to develop nursing interventions to lessen fatigue.

Research Questions

This research was undertaken to increase knowledge and understanding of fatigue in PD, from the individual's perspective. The following questions guided the study:

1. How do individuals with Parkinson's disease describe the fatigue they experience?
2. What effect does fatigue in Parkinson's disease have on an individual's quality of life?
3. What self-management strategies do individuals with Parkinson's disease employ to decrease and/or live with their fatigue and to what extent are these strategies effective?
4. How do individuals describe their experiences with health care providers in addressing their concerns about managing fatigue and its effect on their lives?

Summary of Method

The study utilized a qualitative descriptive design as described by Sandelowski (2000). Qualitative description was an appropriate methodology because the study sought to describe a specific phenomenon, fatigue, from the individual's perspective. The method provided a rich and direct description of an event or an experience

(Neergaard, Olesen, Andersen, & Sondergaard, 2009; Sandelowski, 2000). Findings increase understanding and enhance nursing knowledge regarding fatigue in PD.

In-depth interviews using open-ended questions were used as the primary method of data collection. Responsive interviewing (Rubin & Rubin, 2012) was the guiding framework to conduct audio-recorded interviews of individuals with PD. A total of eight participants were interviewed. Field notes were written after each interview using a style described by Schatzman and Strauss (1973). Qualitative content analysis was used to organize and analyze the interview data (Sandelowski, 2000). Data collection began in July 2015 and lasted for six months, at which time it was determined that data saturation was achieved and no new insights were gained from the interviews.

Significance of the Study

The findings of the study fill a gap in the nursing literature and provide a rich description of fatigue, its effect on QOL of individuals with PD, offer insight into how individuals believe their health care providers assess and assist them in managing their fatigue, and describe self-management strategies individuals implement to lessen this symptom. There is a scarcity of qualitative research about PD-related fatigue; findings of this study provide information on one of the most common, distressing NMS from the perspective of the individual living with PD. The results benefit nursing practice by increasing awareness about fatigue in PD. Nurses who know how to assess for fatigue will benefit those individuals they care for by being knowledgeable about their patients' symptom experiences.

Further, findings from this study benefit nursing research by providing definitional clarification of fatigue from the patient viewpoint. Having a clearer

definition of fatigue may make this concept easier to objectively measure, which is essential for developing intervention studies to reduce fatigue in the PD population.

In 2011, the Neuroscience Nursing Foundation (NNF) made recommendations for future research topics needed in the field of neuroscience nursing. These include: interventions to manage symptoms, adaption to living with a neurologic disorder, self-management of neurological conditions, and interventions to promote QOL in people diagnosed with a neurological illness (Dilorio et al., 2011). This research study fulfills several of these recommendations to advance neuroscience nursing research. Findings provide insight for nurses about how individuals believe their health care providers are managing their fatigue and what self-management strategies they report are effective. Knowledge derived from this study can be used to educate practicing nurses and students about fatigue in PD and the importance of symptom assessment, recognition, and management.

Overview of Study

Chapter 1 introduces the concept of fatigue in PD, and describes its significance to nursing research and practice. Chapter 2 is a comprehensive literature review that identifies existing descriptions and definitions of fatigue in PD, the effect of PD-related fatigue and its effect on QOL, individuals' experiences of health care providers' management of PD-related fatigue, and self-management strategies or interventions described in the literature to manage fatigue in PD. Chapter 3 provides a detailed description of qualitative descriptive methodology and includes the research design, method, setting, and participant information. Chapter 4 discusses the study's findings and includes a description of the conversational partners and main themes and subthemes

that emerged from data collection and analysis. Chapter 5 details the study's conclusions and implications for research, integration and interpretation of the findings, and study limitations. Chapter 5 also examines recommendations for theory, education, research, practice, and policy.

CHAPTER TWO

Literature Review

In this chapter, qualitative and quantitative literature examining PD-related fatigue is discussed. The review includes research from the fields of nursing, medicine, physical therapy, psychiatry, and pharmacology. Attention is given to the concept of fatigue and how it has been defined in PD as well as in other chronic neurological diseases. A review of studies detailing the emergence of fatigue as a prevalent and important NMS is addressed, and literature exploring the effect PD-related fatigue has on QOL is analyzed. Self-management strategies to reduce or lessen fatigue in chronic neurologic illnesses are examined and patients' experiences with health care providers managing fatigue are reviewed. Finally, the chapter concludes with a discussion of the challenges in fatigue research including gaps found in the literature.

Overview

Parkinson's disease is the second most common neurodegenerative disease in the United States (US), estimated to affect approximately one million Americans (Abrantes et al., 2012). The incidence of the disease is projected to double by 2030 given the rapidly growing aging population in the US (Boland & Stacy, 2012; O'Brien, Ward, Michels, Tzivelekis, & Brandt, 2009). Parkinson's disease is typically diagnosed by the presence of three main motor symptoms: bradykinesia, rigidity, and tremor. The motor aspect of PD is widely studied and research has led to improvements in clinical diagnosis and treatments (Chaudhuri, Healy, & Schapira, 2006). Non-motor symptoms (NMS) in PD were recognized by James Parkinson in 1817 when he discussed the occurrence of sleep dysfunction, constipation, dysphonia, dysphagia, dysarthria, hypersalivation, and

urinary incontinence along with the classic motor features in his “Essay on the Shaking Palsy” (Mehndiratta, Garg, & Pandey, 2011, p. 59; Todorova, Jenner, & Chaudhuri, 2014).

NMS have been recognized in the literature as prevalent in the disease and associated with higher disability and lower QOL (Chaudhuri et al., 2006; Chaudhuri et al., 2010; Gallagher et al., 2010; Martinez-Martin et al., 2011). Chaudhuri et al. (2006) describe NMS using a systematic approach by classifying symptoms as neuropsychiatric, sleep disorders, autonomic, gastrointestinal, sensory, and “other.” Shulman, Taback, Bean, and Weiner (2001) conducted a study examining the comorbidity of common NMS including fatigue, sensory symptoms, anxiety, depression, and sleep disturbance. Results of this study indicate that almost 60% of participants ($N = 118$) reported two or more NMS, with the symptoms increasing as the disease progresses (Shulman et al., 2001). Despite the high prevalence of NMS, patients may not recognize these symptoms as part of their neurologic condition (Chaudhuri et al., 2010). In addition, health care providers often do not assess for the presence of NMS during office visits (Todorova et al., 2014). When compared to motor symptoms, Martinez-Martin et al. (2011) found NMS to have a greater effect on health-related quality of life (HRQoL).

Fatigue: Non-motor Symptom in Parkinson’s Disease

PD-related fatigue research began with prevalence studies. Friedman and Friedman (1993) conducted one of the first studies investigating PD-related fatigue. This study compares PD patients ($n = 58$) to a control group ($n = 58$) to assess for fatigue and depression. Patients with PD were found to be more fatigued and depressed than the controls and one-third of respondents scored fatigue as their most incapacitating

symptom. Fatigue correlated with depression but patients who were not depressed were also found to have significant fatigue (Friedman & Friedman, 1993). In a nine-year follow up study, Friedman and Friedman (2001) found fatigue to be a persistent symptom ($N = 26$). The researchers concluded that fatigue in PD occurs early, remains a prevalent symptom, and needs further characterization in future studies. Similarly, Karlsen et al. (1999) found fatigue to be a common and independent symptom in PD. Patients with PD ($n = 233$) and matched controls ($n = 100$) were assessed for the presence of fatigue and 44% of the PD group was found to have fatigue. Researchers in this study also report fatigue to be a commonly occurring symptom in PD that needs further exploration (Karlsen et al., 1999).

Once fatigue was established as a common NMS in PD, researchers began to focus on the impact of fatigue on well-being and quality of life. In several studies it was determined that fatigue decreased overall well being, and negatively affected QOL (Friedman et al., 2011; Herlofson & Larsen, 2003). A study of patients with PD applying for Social Security Disability Insurance (SSDI) revealed that the primary incapacitating symptom that contributes to work disability is fatigue (Zesiewicz, Patel-Larson, Hauser, & Sullivan, 2007). However, despite the known incidence of PD-related fatigue and its associated impact on QOL, PD researchers still encounter challenges. To begin with, there is no universal definition of fatigue, which makes it difficult for researchers to measure a concept that has not been clearly defined. The mechanisms that underlie fatigue in neurologic illness are poorly understood (Kluger, Krupp, & Enoka, 2013), and there are few qualitative studies that have explored the symptom experience of fatigue from the patient perspective.

Fatigue Definitions

Fatigue in General

Fatigue is a broadly used term that has multiple meanings depending on the context in which it is used. Healthy and ill individuals can both experience fatigue. In the healthy person, fatigue is a normal physiologic response to intense activity. This type of fatigue is relieved by rest and does not disrupt one's life (Finsterer & Mahjoub, 2014). The dictionary definition of fatigue is described as "weariness or exhaustion from labor, exertion, or stress" (Mish, 1994, p. 424). Whereas fatigue experienced within illness is described much differently than physiologic fatigue (Finsterer & Mahjoub, 2014). The medical literature refers to this as "pathologic" fatigue (Scruggs, 2009) and it is unrelieved by proper rest, sleep, nutrition, and stress reduction. Pathologic fatigue tends to be associated with disease or illness (Scruggs, 2009) and negatively affects one's psychosocial and occupational functioning and lowers quality of life (Finsterer & Mahjoub, 2014). Pathologic fatigue also has a significant impact on public health and is estimated that "workers with fatigue cost employers \$136.4 billion annually in lost productivity" (Bower, 2012, p. 1220).

Ream and Richardson (1996) examine the definition of fatigue through a conceptual analysis. While they did not examine chronic fatigue, their definition proposes: "Fatigue is a subjective, unpleasant symptom which incorporates total body feelings ranging from tiredness to exhaustion creating an unrelenting overall condition which interferes with individuals' abilit[ies] to function to their normal capacity" (p. 527). This description is more general and does not capture chronic fatigue within an illness.

The definition of chronic fatigue was advanced through the work of Jorgensen (2008). Through the use of the evolutionary concept analysis method, the author determines that chronic fatigue is defined as abnormal and severe lasting at least six months or greater. It is experienced much differently than fatigue previously felt prior to the diagnosis of a chronic illness. Chronic fatigue incorporates the whole body, is disabling, and inexplicable. Antecedents of chronic fatigue include physical disease, coexisting psychopathology, and abuse history. Female gender is considered a risk factor for developing chronic fatigue. Chronic fatigue has many consequences including: stigmatization, social withdrawal and isolation, concurrent psychiatric illness, and decreased quality of life (Jorgensen, 2008).

Fatigue in PD and in the Nursing Literature

There is no established definition of PD-related fatigue (Lou, 2009) used in the literature. The pathology and mechanisms that cause fatigue in PD are poorly understood (Yoshii, Takahashi, Kumazawa, & Kobori, 2006), and patients often have difficulty describing their fatigue (Friedman, 2009) thus leading to a lack of conceptual clarity. Two studies include descriptions of fatigue from the patient perspective (Brown et al., 2005; Olsson et al., 2013). Olsson et al. (2013) was the only study found in the nursing literature and the aim was not to specifically address definitional concerns, rather, the researchers conducted a phenomenological study to examine the meaning of fatigue for women with PD. Descriptions of PD-related fatigue, however, did emerge from that study. Brown et al. (2005) conducted a mixed method study to develop the PFS, an instrument to measure fatigue specifically in PD. The first part of this study gathered information from focus groups to obtain description about fatigue.

Olsson et al. (2013) conducted interviews with women diagnosed with PD ($N = 11$) utilizing a phenomenological hermeneutic interpretation describing the experience of living with PD-related fatigue. The researchers' aim was to increase knowledge and gain insight into how women with PD "experience fatigue in their everyday lives" (Olsson et al., 2013, p. 742). Several themes and findings emerged. The participants reported fatigue had essentially taken over their lives, was "inescapable," and disrupted existing roles and relationships. One major theme, "the body as a burden," describes how fatigue overtook their physical bodies (Olsson et al., 2013, p. 744).

Fatigue was experienced as a constant presence, difficult to describe, resting did not relieve it, and it created a sense of isolation (Olsson et al., 2013). Participants also report that it was difficult for others to understand their experience living with PD-related fatigue. The women describe the sensation of fatigue as "feeling paralyzed," "embedded in a feeling of inertia," "gluey, stuck in a vacuum, weakness, feeling feeble, and lacking the power to move limbs" (p. 744). Fatigue also creates a sense of inner anxiety, shakiness, and their bodies become unpredictable (Olsson et al., 2013).

The effect of fatigue on everyday life was also described. Participants have difficulty managing everyday activities such as household tasks, personal care, and engaging in social activities. Fatigue made the women feel changed from the person they had been previous to their diagnosis (Olsson et al., 2013). Fatigue also affects their cognition and participants discuss that it has become difficult to express their thoughts, causes increased distractibility, and interferes with their ability to make choices (Olsson et al., 2013).

Brown et al. (2005) lead focus groups ($N = 39$) to gather description regarding how PD-related fatigue is described and experienced. The language used to describe fatigue was limited and included the following terms: “heavy, drained, tiredness, lack of energy, exhaustion” (p. 50). The most common descriptive term that emerged was “abnormal tiredness” that was felt to be different than tiredness due to activity or lack of rest (Brown et al., 2005, p. 50).

Despite the lack of descriptive research in PD-related fatigue, several key qualities of the concept have been identified. According to Friedman (2009) PD-related fatigue is remarkably severe when compared to fatigue experienced pre-diagnosis, is not usually related to activity and is an uncomfortable sensation. Stress appears to worsen PD-related fatigue and causes limitations in activity (Friedman, 2009). Anecdotal descriptions provided by patients during office visits include terms such as “debilitating, waking up from anesthesia, or walking through a viscous medium” (Friedman, 2009, p. 187). Fatigue is not defined in early prevalence studies (Friedman & Friedman, 1993; 2001).

Types of PD-related Fatigue Identified

Two major types of fatigue are recognized and described in PD, peripheral and central. Peripheral and central fatigue are described in several informative articles about PD-related fatigue that are not research studies and these definitions are largely based on neurologists’ perspectives and not from patient accounts. Peripheral fatigue also occurs in myasthenia gravis and congestive heart failure and central fatigue has been characterized as a major type of fatigue in MS and post-polio syndrome (Chaudhuri &

Behan, 2000). Central fatigue contains two subtypes: physical and mental (Friedman et al., 2011).

Peripheral Fatigue

Peripheral fatigue is defined as a physiological process in which a “muscle loses strength with repeated contractions” (Friedman et al., 2011, p. 2000). O’Connell and Stokes (2007) describe peripheral fatigue as akin to “muscle soreness” (p. 315) and reduced muscle strength which is caused by exertion and is a result of reduced effectiveness of muscle fiber activation. The underlying mechanisms of peripheral fatigue are neuromuscular transmission failure, metabolic flaws in muscle tissues, or peripheral circulatory failure (Chaudhuri & Behan, 2000).

Other terms such as “muscle fatigue” and “physical fatigability” are used interchangeably to describe peripheral fatigue (Friedman, 2009; Lou, 2009). The term peripheral fatigue is misleading as it is caused by central nervous system dysfunction but is experienced locally in the muscles versus as a more systemic process (Friedman, 2009). It is a physical form of fatigue versus mental (Chaudhuri & Behan, 2000).

The presence of bradykinesia and tremors may cause power loss in muscles due to repeated contractions and lead to peripheral fatigue (Friedman et al., 2011). This type of fatigue, in contrast to central fatigue, is objective and can be quantitatively measured using a motor task or force generation, such as finger tapping. In the clinical environment, patients are asked to tap the index finger to the thumb and the speed is used as a measure of bradykinesia. In research trials, this is typically measured using an electronic keyboard that assesses change in tapping speed over time (Lou, 2009).

Peripheral fatigue may be measured by a progressive loss of maximal voluntary contraction during task performance (Finsterer & Mahjoub, 2014).

Central Fatigue

Central fatigue, also prevalent in PD, is found in other disorders such as chronic fatigue syndrome and depression (Chaudhuri & Behan, 2000) and is attributed to subcortical dysfunction (Smith & Hale, 2007) and physical and mental factors (Yoshii et al., 2006). Several neurological disorders are associated with this type of fatigue including: cerebral palsy, migraine, motor neuron disease, multiple system atrophy, myotonic dystrophy, and posterior head injury (Chaudhuri & Behan, 2004). Chaudhuri and Behan (2000) define central fatigue as the “failure to initiate and /or sustain attentional tasks (mental fatigue) and physical activities (physical fatigue) requiring self motivation” (p. 35). Central fatigue occurs when there is no observable cognitive failure or motor weakness (Chaudhuri & Behan, 2000). The pathophysiological mechanism behind this type of fatigue is believed to be a failure within the structure of the basal ganglia that affects non-motor function (Chaudhuri & Behan, 2000).

O’Connell and Stokes (2007) use the terms “tiredness, weakness, languor, or sleepiness” as descriptors of this type of fatigue (p. 315). Central fatigue is thought to be subjective in nature and is further divided into two types: physical and mental fatigue (Friedman et al., 2007). Lou, Kearns, Oken, Sexton, and Nutt (2001) state fatigue in PD has both physical and mental components and conducted a descriptive correlational study to further characterize these types of fatigue in PD ($n = 39$) against age matched controls ($n = 32$). The Multidimensional Fatigue Inventory (MFI) was used because this instrument assesses for both physical and mental components of fatigue. Results

revealed that the PD group had increased physical and mental fatigue as compared to the control group. These two types of fatigue were found to be independent of each other, suggesting both types need to be assessed separately. Lou et al. (2001) demonstrate that multiple types of fatigue are present in PD but do not offer additional definitions of physical and mental fatigue.

Physical fatigue occurs by generating force through motor tasks (Friedman, 2009, Lou, 2009, Friedman et al., 2011). It encompasses a feeling of physical exhaustion and decreased energy to perform physical tasks or activities. However, the person experiencing physical fatigue may still have the capability and drive to perform desired tasks (Friedman et al., 2011). This is felt to be a subjective type of fatigue common in people diagnosed with PD, but is currently without an available objective measure (Friedman et al., 2011).

Mental fatigue is described as the “effort one must put forth to pay attention to tasks” (Lou, 2009, p. 197). Friedman (2009) elaborates on this definition by explaining that it is the struggle one experiences in starting and sustaining mental tasks. Finsterer and Mahjoub (2014) describe mental fatigue as a subjective perception of being “cognitively fatigued” (p. 2) following challenging mental activities that require concentration. Mental fatigue can affect both speech and memory (Beiske & Svensson, 2010).

Fatigue in Other Chronic Neurologic Illnesses and Conditions

Due to the lack of descriptive research in PD-related fatigue, other chronic neurologic illnesses were reviewed for definitions and similar themes. Examining fatigue in other illnesses may give insight into how individuals with chronic neurological

conditions describe fatigue and how it affects their lives and could possibly apply to individuals with PD-related fatigue. Kralik et al. (2005) conducted a qualitative study of women diagnosed with chronic illnesses and chronic neurologic conditions to explore the meaning of fatigue. The women described cognitive and physical dimensions of fatigue and report that it felt like a sensation of “fog” in the brain and being unable to move. Two studies examined the experience of fatigue following a spinal cord injury (SCI). Participants felt this was a hindering symptom with cognitive, emotional, and physical aspects (Hammell, Miller, Forwell, Forman, & Jacobsen, 2009a; 2009b). The cognitive domain is described as being overwhelmed and drained, whereas emotional fatigue is expressed through frustrations with their inability to complete tasks and daily activities. One participant states, “it takes me forever to get going” (p. 46). This finding also correlates with feelings of depression. Participants describe the physical domain of fatigue as a feeling of weakness and unpleasant sensations (Hammell et al., 2009a).

Researchers also examined fatigue in the ankylosing spondylitis (AS) patient population. AS is typically classified as a chronic rheumatologic disease, but there are associated neurological conditions such as myelopathy, radiculopathy, and cauda equine syndrome that may be present in individuals diagnosed with this illness (Khedr, Rashad, Hamed, El-Zharaa, & Abdalla, 2009). Similar to the SCI literature, AS patients reported physical and mental components to fatigue. One participant summarizes the description of fatigue as, “it feels as if I have lead bands on my hands and ankles; I struggle to get going, I lack enthusiasm to do things that I normally do and it’s difficult to concentrate sometimes” (Farren, Goodacre, & Stigant, 2013, p. 41.). Respondents also point out that this is different from tiredness and notes it is a very draining sensation and involves poor

concentration that affects cognitive ability to perform mental tasks (Davies et al., 2013; Farren et al., 2013).

Fatigue is widely experienced in post-stroke patients and has several descriptions identified by patients in the literature. Mental fatigue, similar to what is experienced in patients with a SCI, is mentioned but participants expressed difficulty in describing this phenomenon and likened it to their brains being tired and an inability to handle loud external stimuli (Kirkevold, Christensen, Andersen, Johansen, & Harder, 2012). A key finding in post-stroke fatigue is the inability of participants to describe their fatigue in detail (Flinn & Stube, 2010). However in the majority of reviewed studies, researchers reported that this symptom is highly prevalent, distressing, and a new sensation different from previous degrees of tiredness or exhaustion (Eilertsen, Ormstad, & Kirkevold, 2013). These findings are similar to what had been described by Friedman (2009) regarding characteristics of PD-related fatigue.

Fatigue in MS has long been recognized as a prevalent symptom (Moriya & Kutsumi, 2010). Participants across studies describe MS fatigue in varying ways including the sensation that fatigue is “stuck fast to the body” (Moriya & Kutsumi, 2010, p. 423); loss of energy and strength (Flensner, Ek, & Soderhamn, 2003; Stuifbergen & Rogers, 1997); the body as being heavy (Olsson et al., 2005) and diminished power (Olsson et al., 2005). Fatigue in MS is also depicted as a sensation of being paralyzed (Stuifbergen & Rogers, 1997). Mills and Young (2008) conducted a mixed-methods study to define fatigue in MS patients in order to create a single taxonomy to further advance MS-related fatigue research. The researchers found MS-related fatigue contains elements of cognitive and motor impairment, decreased motivation, and is induced by

mental or physical activities; or can occur spontaneously. Mills and Young (2008) report that rest or sleep can relieve fatigue, which is contradictory to previously described characteristics of fatigue by Scruggs (2009). Mills and Young (2008) also discuss that MS-related fatigue typically has “greater severity than any premorbid fatigue” (p. 57), which is similar to what is found in the post-stroke fatigue literature (Eilertsen et al., 2013) and the concept analysis by Jorgensen (2008).

When looking across PD and other chronic neurologic illness studies, several definitional similarities are found. PD-related fatigue, similar to descriptions of MS-related fatigue (Olsson et al., 2005; Stuifbergen & Rogers, 1997), create a feeling of being paralyzed and involve the whole body. According to participants in Olsson et al.’s PD study (2013), fatigue is described as feeling “gluey...like being in a vacuum and like they had a lid on them...they could not manage to hold their bodies up straight” (p. 744). PD-related fatigue affects attention and concentration and creates a feeling of being distracted and unorganized (Olsson et al., 2013) and these descriptions of fatigue are comparable to what is explained by patients with AS and MS (Farren et al., 2013; Mills & Young, 2008).

Limitations and Gaps in Fatigue Definition Literature

Fatigue research is complicated by the lack of a universally accepted definition. Across studies, fatigue may be defined differently or not defined at all (Kluger et al., 2013). Definitions of central, peripheral, mental, and physical fatigue vary within the literature and research studies (Finsterer & Mahjoub, 2014; Kluger et al., 2013). Specific to PD literature, no studies provide a working definition of fatigue. There are anecdotal descriptions of fatigue reported but only one qualitative study provides a description of

fatigue. Additional research is needed to further describe fatigue to gain an understanding about the meaning and experience of fatigue from the individual's perspective.

Fatigue and Related Variables

Excessive Daytime Sleepiness and Depression

It is important to differentiate PD-related fatigue from excessive daytime sleepiness (EDS), depression, and apathy as fatigue may be confounded by these NMS. EDS is a commonly occurring NMS distinct from fatigue but often these two symptoms overlap and can create conceptual confusion (Friedman et al., 2007; Knie, Mitra, Logishetty, & Chaudhuri, 2011). Fatigue and EDS can occur simultaneously or separately in PD. EDS is defined as an “inappropriate and undesirable sleepiness during waking hours” (Knie et al., 2011, p. 203) and it is estimated to affect approximately 50% of patients with PD. Unlike PD-related fatigue in which no one major cause has been established, the pathophysiologic mechanisms for EDS are known (Knie et al., 2011; Yoshii et al., 2006). The cause of EDS is likely a combination of side effects from dopaminergic medications, nocturnal sleep disturbance, and neurodegenerative dopamine degeneration (Knie et al., 2011). Walker, Hand, Cookey, and Gray (2011) conducted a prevalence study of sleep problems among participants with PD ($N = 75$) and investigated the relationship to QOL. Like PD-related fatigue, EDS was found to be present in 26.7% of participants and associated with greater disease progression, lower quality of life, and increased depression.

Depression and fatigue are strongly linked, as fatigue is one of the DSM diagnostic criteria for this psychiatric disorder (Friedman et al., 2011). Several studies

show fatigue to be higher in patients with depression (Friedman et al, 2007) but fatigue is also prevalent in patients without depression (Friedman, 2009). Depression, like fatigue, is associated with lower quality of life. PD patients with depression often have worse motor function and difficulty performing activities of daily living (ADLs) (Reijnders, Ehrt, Weber, Aarsland, & Leentjens, 2008). Prevalence rates of depression in PD vary in the literature with wide ranges reported between “2.7-90%” (Reijnders et al., 2008). Reijnders et al. (2008) conducted a systematic review to ascertain the average prevalence of depression in PD. Thirty-six studies were included in this review and researchers found that depressive disorders were present in 17% of patients (Reijnders et al., 2008).

While fatigue correlates with depression (Friedman & Friedman, 1993), other studies show these symptoms do occur independently (Friedman & Friedman, 2001; Karlsen et al., 1999). Karlsen et al. (1999) conducted a prevalence study in PD patients ($n = 233$), comparing with a healthy control group ($n = 100$), to assess for the presence of fatigue and determine if fatigue is an independent symptom in the disease. Individuals with a diagnosis of depression were excluded (Karlsen et al., 1999) due to its known correlation to fatigue (Friedman & Friedman, 1993). Researchers identified that fatigue occurs independently in PD, even though a correlation with depressive symptoms was established (Karlsen et al., 1999).

Alves, Wentzel-Larsen, and Larsen (2004) conducted a prospective, longitudinal study to evaluate if mental fatigue is a symptom that occurs independently of other non-motor issues in patients with PD ($N = 233$). Patients with higher fatigue scores, as measured by the Fatigue Severity Scale (FSS), have higher scores on depression scales and higher EDS scores on the Epworth Sleepiness Scale (ESS). To assess if fatigue

occurs in the absence of depression and EDS, researchers examined patients without these symptoms during the study period and found a high prevalence rate of fatigue. Similar to Karlsen et al. (1999) and Friedman and Friedman (2001), the authors conclude that fatigue could not be explained by depression or EDS and was an independent symptom of PD. Alves et al. (2004) note fatigue assessment is problematic given its' subjective nature and declare that medications may skew participants' awareness of their fatigue. Another limitation the authors cite is the potential overlap of other NMS that can lead to an overestimation of fatigue due to low specificity of evaluation tools used to assess fatigue in the study.

Havlikova et al. (2008b) used a cross sectional design ($N = 78$) to examine if fatigue is related to sleepiness and depression. In contrast to the study conducted by Alves et al. (2004), EDS was not related to fatigue but there was a strong association between fatigue and depression. Patients who report a high degree of fatigue on measurement tests had higher rates of depression. Havlikova et al. (2008b) report since fatigue is part of the diagnostic criteria for depression, this may affect the results. Part of the exclusion criteria for the study was disease duration greater than 15 years therefore; these results may not be generalizable to patients with later stage PD (Havlikova et al., 2008b). An important implication from this study suggests proper identification and management of depression in PD may mitigate fatigue (Havlikova et al., 2008b).

Whereas Valko et al. (2010) conducted a prospective PD study ($N = 88$) aiming to further characterize fatigue and EDS and its association to motor and NMS, including depression. Results reveal no relationship between depression and EDS. The occurrence of depression was found to be significantly associated with fatigue and these findings are

echoed across other studies (Friedman & Friedman, 2001, Havlikova et al, 2008b; Karlsen et al, 1999). Valko et al. (2010) note results must be interpreted with caution because fatigue is also present in non-depressed patients in the study sample.

Apathy

Apathy is a common NMS estimated to occur in the PD population at a varying rate of 17%-54% (Saez-Francas, Hernandez-Vara, Corominas Roso, Alegre Martin, & Casas Brugue, 2013). This symptom is referred to as a motivation disorder within a chronic illness (Saez-Francas et al., 2013). It is characterized as a reduction in an individual's motivation, reduced emotionality, and loss of interest in goal directed behaviors as compared to their previous state (Marin, 1991). Apathy is commonly linked to depression (Skorvanek et al., 2015) and also occurs in other neurodegenerative disorders such as Alzheimer's, frontotemporal lobe dementia (Rives Bogart, 2011) and Huntington's disease (Simpson, McMillan, Leroi, & Murray, 2015). Apathy can occur in depressive disorders, which may also cause fatigue, but apathy as a symptom is currently not well understood (Rives Bogart, 2011). Fatigue is associated with apathy and possibly may increase fatigue severity (Saez-Francas et al., 2013). Components of apathy are similar to physical and mental fatigue and can create conceptual confusion between these two NMS.

Saez-Francas et al. (2013) conducted a cross-sectional study to determine the relationship between characteristics of apathy and central fatigue in PD patients ($N = 90$). Researchers assessed for fatigue, apathy, depression, and anxiety using existing measurement tools. A linear regression model was used to investigate the relationship between apathy and fatigue. Results indicate fatigue does have a relationship with

features of apathy including depression and anxiety. Patients who have higher levels of fatigue have higher scores for depression, anxiety, and apathy. Participants who have a high degree of apathy also have higher fatigue scores versus those without apathy (Saez-Francas et al., 2013).

Previous studies examining fatigue and apathy have not used a specific apathy scale, which the authors state may create bias and point out this study may be the first to examine central fatigue and its relationship to apathy (Saez-Francas et al., 2013).

However, further conceptual confusion exists between measurement instruments as the fatigue and apathy scales used contain measures such as “lack of effort or energy” which are present in both these NMS and may create overlap that affect study results (p. 241).

This study excludes individuals with dementia, a condition where apathy has been reported to be high. Saez-Francas et al. (2013) advise this is a limitation and apathy may very well be underrepresented in the study. Participants in the study sample were recruited from a tertiary hospital where greater PD severity is more likely and this in turn may have created bias due to having a non-representative sample (Saez-Francas et al., 2013). The researchers acknowledge that the pathophysiological mechanisms of fatigue and apathy are not well known, which further complicates understanding their relationship. Saez-Francas et al. (2013) recommend future studies evaluate these two NMS together to improve understanding of how they are experienced in PD.

Apathy, fatigue and depression are also examined in another study. Skorvanek et al. (2015) conducted a cross sectional study ($N = 151$) to describe the concurrence of apathy with fatigue domains and compared this to individuals with and without depression. Researchers in this study designated fatigue as either primary or secondary.

Primary fatigue occurs in individuals who do not have a mood disorder or EDS while secondary fatigue is present in those with EDS or a mood disorder (Skorvanek et al., 2015). Researchers report that 78.8% of the sample was fatigued and 47% of participants were apathetic. Apathy without depression was present in 13% of participants and depression alone was found in 23% of individuals. Apathy, depression, and fatigue have many overlapping qualities and this study to date was the first to demonstrate that these NMS can be distinguished from each other and can occur independently of one another (Skorvanek et al., 2015). In contrast, Cochrane et al. (2015) conducted a study to investigate the occurrence and severity of fatigue and apathy in patients with MS ($n = 73$) and PD ($n = 89$) and determine the association between these two NMS. In the PD group, 64% of the participants experienced fatigue and 39% experienced apathy compared to 74% (fatigue) and 41% (apathy) in the MS group. Only 6% of the PD participants who were apathetic, were also not severely fatigued. This study confirms a new finding that fatigue and apathy may be strongly associated with each other. The authors surmise that these two NMS may be an overlapping syndrome (Cochrane et al., 2015).

Fatigue and Quality of Life in PD

Several factors affect QOL in PD including motor symptoms such as tremors, falls, freezing of gait, medication side effects, and NMS (Rahman, Griffin, Quinn, & Jahanshahi, 2008). PD-related fatigue negatively affects QOL across several studies. Herlofson and Larsen (2003) conducted the first study exploring the correlation between fatigue and health-related quality of life (HRQol). This Norwegian study ($N = 66$) assessed for the presence of fatigue with the Fatigue Severity Scale (FSS) and HRQol

was measured by the Parkinson's Disease Questionnaire (PDQ-39). The PDQ-39 is a self-completed tool that contains thirty-nine items measuring: mobility, activities of daily living (ADLs), emotions, stigma, social support, cognitions, communication, and bodily discomfort (Herlofson & Larsen, 2003). Results indicate 50% of the participants have significant fatigue and these high fatigue scores correlate with higher PDQ-39 index. Participants with fatigue specifically report increased distress within the areas of emotional well being and physical mobility. Fatigue also had a negative impact on ADLs and social functioning.

Herlofson and Larsen's study (2003) did exclude individuals with depression and dementia. Researchers state patients with cognitive impairment were excluded to ensure validity on questionnaire response. Depression often has fatigue as one of its diagnostic criteria; therefore, to avoid symptom overlap, patients with this psychiatric condition were excluded. This represents a strength of this study as it reveals that fatigue alone is a prevalent and significant symptom in PD that negatively affects HRQoL.

Herlofson and Larsen's study (2003) had limitations that included a small sample size and the fact that the participants did not have advanced PD based on Hoehn and Yahr staging. Data was quantitative and gathered from valid tools but this methodology did not include descriptive information from patients living with PD-related fatigue. Furthermore, the researchers did not provide a definition of fatigue and the FSS measurement instrument does not define fatigue (Friedman et al., 2010).

Havlikova et al. (2008a) conducted a cross-sectional study with Slovakian participants ($N = 175$) to examine the effect certain fatigue features have on QOL in PD patients. Like Herlofson and Larsen (2003), researchers used the PDQ-39 index but

assessed fatigue using the MFI. The MFI does measure aspects of both physical and mental fatigue (Havlikova et al., 2008a), which are common in PD, but like the FSS, does not define fatigue. Havlikova et al. (2008a) also did not define fatigue in their study. Across all QOL domains measured by the PDQ-39, fatigue had a negative impact on all domains especially emotional well-being, mobility, and bodily discomfort. Mental fatigue was a predictor for the following domains on the PDQ-39: emotional well-being, stigma, social support, cognition, and communication (Havlikova et al., 2008a). Physical fatigue was a predictor for PDQ-39 domains of mobility, ADLs, and stigma (Havlikova et al., 2008a).

Limitations include sample characteristics whereas most participants did not have advanced PD and were well enough to engage in the study. The researchers make the assumption that non-responders perhaps had worse functional status and the sample may not be reflective of the PD population in their geographical location (Havlikova et al., 2008a). Similar to Herlofson and Larsen (2003), this study excludes fatigue co-morbidities including depression and sleep issues due to symptom overlap (Havlikova et al., 2008a). There was no formal assessment of depression or EDS and the co-occurrence of these NMS may affect results.

Barone et al. (2009) also conducted a study that assessed for the incidence of NMS and its impact on QOL. In this Italian study ($N = 1,072$) fatigue and anxiety were reported to be the most common NMS. Fatigue was reported in 58% of the participants and highly correlated with lower QOL scores. Apathy was actually found to be associated with the worst QOL score (Barone et al., 2009). While researchers did not exclusively examine fatigue, it may be the largest study to date to examine the

relationship of NMS and QOL and further establishes the significant impact NMS have on individuals with PD. Barone et al. (2009) discuss the lack of a control group as a limitation and the sample studied was mainly in the earlier stages of the disease, which is comparable to previous studies. In a similar study conducted in the United Kingdom (UK), 59% of participants ($N = 94$) reported the presence of fatigue and this NMS was again associated with lower QOL scores, following depression (Gallagher et al., 2010). Researchers found fatigue to be a common negative contributor to QOL in both early stage PD (<5 years) and advanced stage. While this study included patients in the later stages of PD, patients with significant cognitive impairment were likely excluded given the multiple surveys required for study completion. The researchers make the assumption that patients with significant apathy and/or cognitive impairment do not participate and the sample may not be representative of the PD population in the area (Gallagher et al., 2010).

A related longitudinal study by Elbers et al. (2014) from the Netherlands, also examined the relationship between fatigue and health-related quality of life. The participants ($N = 153$) were assessed at baseline, three, six, and twelve weeks respectively. Similar to other studies, results indicate that patients with fatigue report lower levels of quality of life. The longitudinal component of the study was confounded by anxiety and depression and researchers suggest these NMS overlap with fatigue (Elbers et al., 2014). However, when researchers control for these variables, a relationship between fatigue and lower HRQol was still found. This study further clarifies that fatigue is an independent factor in predicting lower HRQol scores.

The MFI was used to assess for fatigue presence and severity and similar to Havlikova et al. (2008a) results indicate that mental fatigue is highly linked to cognitive aspects of the PDQ-39 (Elbers et al., 2014). The Elbers et al. (2014) study is the first longitudinal study completed that examines the connection of fatigue to HRQoL over a period of time. The authors do note that given the subjective nature of fatigue and QOL, these concepts are difficult to measure and evaluate (Elbers et al., 2014). The researchers also did not control for sleep disorders such as EDS and apathy. These concepts may be related to fatigue and lack of assessment for these variables may have altered results (Elbers et al., 2014). Previous research however, has shown apathy, EDS, and fatigue can occur independently of one another (Alves et al., 2004; Skorvanek et al., 2015).

Limitations Across PD-Related Fatigue and QOL Studies

Existing research has established a relationship between PD-related fatigue and its effect on QOL. The aforementioned studies do not define fatigue and measurement instruments utilized do not include descriptions of fatigue. Fatigue was shown to affect several mental and physical domains on the PDQ-39. The majority of studies examined for this review excluded patients in advanced stages of PD and those with cognitive impairment thus limiting generalizability. No studies were identified that looked at how fatigue changes over the course of the illness. While Elbers et al. (2014) performed a longitudinal study; it was only over three-month period, which is not lengthy enough to observe how fatigue affects individuals with PD across stages of the illness. It is also unknown if fatigue is experienced differently in those individuals with cognitive impairment.

The majority of these studies did not control for depression, EDS, or apathy, all of which may overlap with fatigue. However, Alves et al. (2004) and Skorvanek et al. (2015) performed studies concluding these NMS can occur separately. There is no qualitative literature to date that specifically examines fatigue and QOL from the perspective of the patient. The study conducted by Olsson et al. (2013) reports descriptions on how fatigue is experienced in everyday life by women with PD but the aim of that study was to uncover the meaning of the experience. More descriptive data is needed to explore the concept of fatigue from the patient's perspective to better understand how fatigue affects an individual's QOL.

Self-management of Fatigue in PD and Chronic Neurological Illnesses

Few studies have found successful interventions to treat PD-related fatigue (Friedman et al., 2011). Franssen, Winward, Collett, Wade, and Dawes (2014) conducted a systematic review and meta-analysis of completed randomized controlled trials (RCTs) that examined interventions to treat PD-related fatigue. Fourteen studies were included in the review with inclusion criteria of fatigue as a measurement outcome. Eleven articles studied pharmacological interventions; one assessed an online fatigue self-management program; one study explored caffeine as a treatment; and the last article used an exercise program as an intervention. Medications used in the various RCTs included: pergolide, pramipexole, acute tryptophan depletion, modafinil, methylphenidate, memantine, rasagiline, Carbidopa-levodopa, and doxepin (Franssen et al., 2014).

There was inadequate evidence found to support the use of pharmacological treatments to reduce PD-related fatigue. Non-pharmacological interventions reviewed

did not show any treatment effect or significant reduction in fatigue. The researchers only included studies done in English and Dutch, which is a limitation and this review may not be representative of all current RCTs to treat fatigue in PD. Across studies examined, fatigue measurement instruments varied and no clear definition of fatigue was established by any of the authors (Franssen et al., 2014).

In a double blind placebo controlled trial, Mendonca, Menezes, and Jog (2007) evaluated the effect of 10 mg of methylphenidate three times a day on fatigue measured with the FSS and the MFI in PD patients ($N = 36$). Seventeen patients received the pharmacological intervention while nineteen received a placebo. There was a significant reduction in mean fatigue scores in the control group at six weeks when compared to baseline but not when compared to placebo. Franssen et al. (2014) reviews the Mendonca et al. (2007) study and acknowledges that a treatment effect was found but when results were pooled with other studies investigating the use of amphetamines, it was not felt to be statistically significant.

No research is published that explores how patients self-manage PD-related fatigue and there have been few successful intervention studies identified to treat PD-related fatigue. Similarities between fatigue in other neurological conditions and PD-related fatigue are established in the literature (Olsson et al., 2005; Stuifbergen & Rogers, 1997). Self-management strategies of fatigue in other chronic neurological illnesses including MS, AS, and post-stroke are described in numerous studies and these findings may help to inform researchers and providers on how to manage PD-related fatigue.

Patients with MS, AS, and post-stroke fatigue all noted having a positive attitude, keeping active, resting and taking short naps helped them cope with fatigue (Davies et al.,

2013; Farren et al., 2013; Flensner et al., 2003; Moriya & Kutsumi, 2010; Stuifbergen & Rogers, 1997; Young, Mills, Gibbons, & Thornton, 2013). In a study with MS patients, positive attitude helped participants complete daily goals and provided a sense of achievement that gave them a feeling of control over fatigue (Young et al., 2013). Implementing “pacing techniques” included: setting and prioritizing goals, budgeting energy, distracting techniques, and remaining employed. These pacing techniques are helpful in managing fatigue among some of the AS group (Farren et al., 2013, p. 46). One of the key themes identified across the MS literature was the notion that conserving energy and planning rest or naps is essential to manage fatigue. Participants note they limit social activities and will essentially increase rest times before events (Flensner et al., 2003; Moriya & Kutsumi, 2010; Stuifbergen & Rogers, 1997).

Post-stroke patients utilize “altered expectations” where over time, once fatigue is accepted; the participants adjust their schedule and prior life perspective accordingly in order to live with this symptom (White et al., 2012, p. 1382). This strategy assists participants to be more motivated, improve coping strategies, and maximize daily functioning. Kirkevold et al. (2012) reveal a similar theme described as “being on a mission” to gain strength and maintain mental energy. This was described as an ongoing daily process where the fatigue causes the participants to constantly re-evaluate daily goals to be successful with tasks and individual accomplishments. Re-ordering priorities are noted across studies to assist persons with post-stroke fatigue to manage this symptom and develop their own personal new normal (Eilertsen et al., 2013).

Medication interventions are reported only among those participants with AS. Amitriptyline is a treatment for fatigue associated with AS but respondents were mixed in

their opinions regarding its' effectiveness. Most stopped this medication secondary to side effects, opting for complementary therapies such as meditation, acupuncture, and breathing exercises (Davies et al., 2013; Farren et al., 2013).

Social support including suggestions from friends and attending support groups are additional keys to self-management in fatigue. Having a supportive family is cited as an important factor in being successful in handling this symptom. Asking family and friends to assist with daily tasks when needed is imperative to cope with fatigue (Flensner et al., 2003; Moriya & Kutsumi, 2010; Stuifbergen & Rogers, 1997). Physical activity is noted to improve fatigue in some cases. However, reports by patients did not specify any particular regimen or type of exercise (Davies et al., 2013; Farren et al., 2013; Flensner et al., 2003; Moriya & Kutsumi, 2010; Stuifbergen & Rogers, 1997; Young et al., 2013).

Health Care Providers' Assessment of Fatigue

In Chronic Neurological Illnesses

The under-recognition of fatigue in other chronic conditions has been explored in the literature. Kralik et al. (2005) conducted a study with female participants ($N = 30$) to examine the meaning of fatigue for women living with a chronic illness. Utilizing a participatory action approach, the researchers collected data by e-mail conversations. One of the major themes identified was "seeking medical validation" (p. 375). Participants report that providers seldom mention fatigue during visits and do not identify it as a significant symptom as part of their illness. They express reluctance to bring up fatigue on their own, as they feel their concerns would be dismissed. This also creates lack of confidence in their providers' medical knowledge because they do not validate their experience of fatigue being a distressing and important symptom in their lives.

Participants feel their providers devalue their experiences with fatigue, which causes some women to internalize their fatigue and creates feelings of isolation.

Flinn and Stube (2010) conducted a qualitative study utilizing focus groups to examine the experience of fatigue and impact on QOL on participants ($N = 19$) with post-stroke fatigue. The researchers were trained occupational therapists that conducted semi-structured interviews using interview guide questions. The researchers explored patients' experiences with health care providers by asking the following question: "Did you feel the others (i.e. family, physicians, therapist, or other health professional) understood your issues with fatigue?" (p. 84). Participants felt they were not prepared and not provided education about post-stroke fatigue from health care providers. Similar to the study done by Kralik et al. (2005) these post-stroke patients sought validation from providers in order to legitimize their experiences with post-stroke fatigue as being a real part of their neurological condition. Participants note that providers fail to mention that fatigue might be a symptom they could experience chronically following a stroke (Flinn & Stube, 2010).

White et al. (2012) conducted a prospective qualitative study using semi-structured interviews to uncover the experience of fatigue in post-stroke patients ($N = 23$). Similar to Flinn and Stube (2010), a major theme that emerged was "knowledge." The patients in this study report they were unprepared for the toll fatigue had on their lives post-stroke. Only one participant received advice about fatigue following discharge from the hospital. The remainder informed researchers that months following their stroke, they sought guidance from health care professionals to discuss their experiences and gather understanding about their ongoing fatigue. They report receiving inadequate

answers from health care professionals and some subjects felt their concerns about fatigue were dismissed: “my specialist wiped it off and didn’t answer me” (White et al., 2012, p. 382). Participants cope with post-stroke fatigue by eventually learning how to self-manage their own symptoms as they did not gain answers from their providers.

Health Care Providers’ Assessment of Fatigue in PD

To date, there are no studies identified which examine only fatigue as an overlooked NMS, rather, the identified studies have examined NMS as a whole to determine if these symptoms are assessed by clinicians during patient encounters. NMS in PD are often overlooked by clinicians and not assessed in office visits (Todorova et al., 2014). This may be due in part to limited consultation time that providers have per office visit (Mehndiratta et al., 2011). Patients with PD are sometimes not even aware that the NMS they experience are part of their neurological condition (Bonnet et al., 2012; Chaudhuri et al., 2010). Shulman, Taback, Rabinstein, and Weiner (2002) conducted a prospective evaluation of patients with PD ($N = 101$) at a movement disorders center to ascertain the presence of certain NMS and to then evaluate if these symptoms were identified by the patient’s treating neurologist. Among the participants, 42% reported a problem with fatigue; however, the neurologist clinically diagnosed this in only 14% of the participants. The diagnostic accuracy of the physician in diagnosing fatigue was 25% (Shulman et al., 2002). In this study physicians were least likely to recognize fatigue, followed by depression and anxiety. One recommendation from this study is utilizing validated screening tools during routine office visits to assess for the presence and severity of fatigue and other NMS (Shulman et al., 2002).

The under-recognition of fatigue as a distressing and commonly occurring symptom in PD and other chronic neurological illnesses has been well-established in the literature. While quantitative studies have shown that fatigue in PD is often not assessed in office visits, there were no identified qualitative studies describing the patient experience of having fatigue recognized and managed during health care provider interactions.

Summary

PD-related fatigue is a prevalent and important NMS that has an adverse effect on an individual's quality of life. Fatigue has no universal definition and existing definitions provided in the literature vary. The subjectivity of fatigue further complicates definition development. PD-related fatigue includes peripheral, central, physical, and mental fatigue. Fatigue is often confounded by other NMS common in PD such as apathy, depression, and EDS. Although these symptoms may overlap, research has shown that fatigue is a distinct and independent NMS in PD.

PD-related fatigue has a negative impact on QOL and HRQoL affecting many dimensions including: physical mobility, emotional well-being, interference with performing ADLs, and bodily discomfort. Research done on QOL in PD is mostly quantitative and there are few descriptive studies that specifically examine the patient experience of living with PD-related fatigue. Furthermore, instruments used to assess fatigue in QOL studies do not include definitions of fatigue and researchers do not define fatigue in their studies. Further description of fatigue is needed in order to understand from the individual's perspective how they experience fatigue and its' effect on QOL.

There has been few intervention studies completed with statistically significant effects at reducing fatigue in PD. Examining self-management strategies of individuals with other chronic neurological illness can help inform providers about how to assist individuals to manage PD-related fatigue. Assessing self-management strategies of patients living with PD-related fatigue can assist providers in gaining insight on how patients live with this NMS.

Fatigue is often not recognized by individuals as being a NMS of their illness. Fatigue is often overlooked and not assessed by providers during health care visits. This may result in poorer health outcomes given fatigue's association with decreased QOL. There is no existing descriptive literature exploring individuals' experience with health care providers assessing for and managing PD-related fatigue. To advance the science of fatigue research and improve patient outcomes, it is essential to gain greater insight on how individuals characterize the fatigue they experience from their own perspective. This will assist to fulfill identified gaps in the literature regarding the definition of PD-related fatigue. Qualitative descriptive data can assist to gather the meaning PD-related fatigue has in an individual's life.

CHAPTER THREE

Methodology

The literature review has revealed that there is a lack of qualitative studies with participants who have PD, which has led to a limited understanding of the experience of PD-related fatigue for these patients. Most extant literature consists of quantitative studies that have not delved into the individual's experience of living with fatigue. Therefore exploring fatigue with an inductive, descriptive and exploratory design allows better understanding of the patient's viewpoint, increases understanding of this common NMS, PD, and provides findings to fill the gap in the literature.

The general aim of this qualitative study was to describe and explore the experience of fatigue in individuals living with PD. The following research questions guided the study:

1. How do individuals with Parkinson's disease describe the fatigue they experience?
2. What effect does fatigue in Parkinson's disease have on an individual's quality of life?
3. What self-management strategies do individuals with Parkinson's disease employ to decrease or live with their fatigue and to what extent are these strategies effective?
4. How do individuals describe their experiences with health care providers in addressing their concerns about managing fatigue and its effect on their lives?

The study included in-depth interviews with eight participants using the responsive interviewing method described by Rubin and Rubin (2005, 2012). Details regarding the research paradigm and methodology are fully described in this chapter.

The process of responsive interviewing is discussed including the role of the researcher and conversational partners. Participant selection, inclusion criteria, sampling technique, and procedures for contacting participants are presented. This chapter includes a comprehensive description about data collection, data analysis, data verification and trustworthiness procedures, ethical considerations, and study limitations.

Research Paradigm

This study was conceptualized in the constructionist/naturalistic paradigm, which allows the research to occur in a natural setting and permits individuals to describe and interpret their experiences (Appleton & King, 2002; Rubin & Rubin, 2012). A guiding assumption of constructionism is that the input and perspectives of participants are vital to understanding the selected phenomena of interest (Polit & Beck, 2012). Constructivist inquiry occurs as a subjective interaction between researcher and participants and study findings are the product of this communication (Appleton & King, 2002; Polit & Beck, 2012). Through the research questions, the researcher sought to explore how individuals describe and live with PD-related fatigue. These questions reflect an inductive process, which is typically guided by qualitative methodology (Polit & Beck, 2012).

In contrast to constructionism, the positivist worldview seeks to find a single reality using objective measures to create theories that are typically generalizable (Polit & Beck, 2012; Rubin & Rubin, 2012). Positivism was eliminated as a paradigm to address the research questions because the aim of the study was to learn how individuals with PD describe their fatigue and related experiences. To obtain this knowledge, the distance between the participants and researcher must be minimized which aligns with constructivist assumptions, not positivist ones (Polit & Beck, 2012; Rubin & Rubin,

2012). This researcher sought to gather rich description from individuals with PD to explore their experience with fatigue and was successful in this regard. The level of descriptive inquiry needed for the study was achieved through qualitative design guided by constructivist principles.

Research Design and Method

This study used a qualitative descriptive design utilizing responsive interviewing techniques as developed by Rubin and Rubin (2005, 2012) to gather data from participants. Qualitative descriptive design is guided by constructivist inquiry and the methods used to gather data are diverse (Polit & Beck, 2012). The use of this method allowed participants to describe PD-related fatigue in their own everyday language, its effect on their QOL, self-management strategies, and how they describe their interactions with health care providers in discussing fatigue. Qualitative descriptive design seeks straight accounts of phenomena (Sandelowski, 2000) and was an appropriate method to answer the research questions. Data collection was aimed at uncovering the “who, what, and where of events and experiences” (Sandelowski, 2000, p. 338). Data analysis strategies included qualitative content analysis using coding systems (Neergaard et al., 2009; Sandelowski, 2000) and is described more fully later in this chapter. Findings are presented in Chapter 4.

Phenomenology was considered as an alternative method, as the aim was to understand the experience of PD-related fatigue from the individual’s perspective. However, phenomenology attempts to understand the lived experience of individuals and seeks to interpret meaning of those experiences (Polit & Beck, 2012; Sandelowski, 2000). Interpretation was not the focus of this study. Qualitative descriptive research allowed

the data to be presented using everyday language and kept the researcher close to the data (Sandelowski, 2000).

Responsive Interviewing

The study utilized the responsive interviewing technique as developed by Rubin and Rubin (2005, 2012). This method aligns well with constructionism as responsive interviewing permits the researcher to understand participants' experiences through their own interpretations to create meaning (Hunter Revell, 2013; Rubin & Rubin, 2005, 2012). Responsive interviewing is a flexible design that allows the interviewer to modify questions in response to answers from participants. The main goal of responsive interviewing is to develop a deep shared understanding of the research topic grounded in the perceptions and experiences of the participants (Rubin & Rubin, 2012).

Responsive interviewing is guided by the philosophical underpinnings of critical theory and interpretative constructionist theory and is grounded in the naturalistic paradigm. Critical theory stresses the significance of discovering and remedying societal issues (Rubin & Rubin, 2005). Critical theorists believe knowledge is subjective and this type of research typically aims to empower oppressed groups (Rubin & Rubin, 2005). Interpretive constructionists also believe in subjective knowledge and how a person views an event and the meaning they assign to it is what is valuable. Responsive interviewing depends on interpretive constructionist philosophy, blended with critical theory; a meaningful relationship is formed through conducting interviews (Rubin & Rubin, 2005). This method recognizes that each participant has a unique interpretation of his or her experience, which adds to the understanding of an event or cultural issue of a

particular group. The outcome of using the responsive interview method is a synthesis of understanding based on all the interviews combined (Rubin & Rubin, 2005).

Responsive interviewing stresses the importance of trust between interviewer and interviewee; participants are partners in the research and are thus called conversational partners (CPs) (Rubin & Rubin, 2012). Rubin and Rubin (2005) use the term conversational partner as it connotes an active role of the research participant in shaping and guiding the interview process. The conversational partner, along with the interviewer, work together to achieve a shared understanding of a specific phenomenon (Rubin & Rubin, 2005). The term conversational partner also stresses that each individual is unique and possesses distinct knowledge to interact with the interviewer in his or her own way (Rubin & Rubin, 2005). Each conversational partner has their own communication style; questions and the interview approach were adapted accordingly to each CP (Rubin & Rubin, 2005).

Responsive interviewing is defined by four main characteristics: searching for “context and richness” in a complex and uncertain world; the impact of questioning on the life worlds of the conversational partner and interviewer; having an exchange that occurs within a meaningful relationship; and a flexible design (Rubin & Rubin, 2012, p. 38). These qualities are an appropriate fit to answer the research questions and gain a rich description of the experience of PD-related fatigue.

The relationship formed between the interviewer and the CP is mutual and recognizes the individuality between the two participants (Rubin & Rubin, 2005). Despite the temporary nature of the relationship, the responsive interviewing method creates a meaningful exchange that promotes an improved understanding of the CPs

experiences. It is assumed the participants are the experts in regard to their PD symptomatology and creating a partnership with them allows for a deeper understanding of their experience. The interviewer must respect this personal relationship by maintaining ethical obligations to protect private and sensitive information and avoid bringing personal views and opinions into the interview (Rubin & Rubin, 2005). In this study, the researcher initially guided the interview but this process was iterative; responses changed and shaped the focus of the interviews (Rubin & Rubin, 2012). Learning about what is significant to the CPs is essential to understanding the topic being investigated (Rubin & Rubin, 2005).

The main objective in responsive interviewing is to gain a solid and thorough understanding of the phenomena of interest (Rubin & Rubin, 2005). Depth is achieved during the interview process by pursuing context; handling and organizing multiple similar and conflicting themes; and listening carefully “to the specifics of meanings, situations, and history” (Rubin & Rubin, 2005, p. 35). Strategies to achieve depth during the interview process include: asking pertinent follow up questions, maintaining a flexible research design, and creating future questions based on past interview experiences. Data analysis was concurrent with the interviews and interview questions were modified as new and relevant information was discovered (Rubin & Rubin, 2005).

Role of the Researcher

The role of the researcher was to design the study, develop research questions, recruit participants, and maintain trust and confidentiality with conversational partners. The researcher interpreted and analyzed the data gathered from the interviews. For the study, it was imperative to develop trust with participants. Prior to engaging in

responsive interviewing, the researcher identified her personal attitudes, beliefs, and biases that might have influenced interactions with participants (Rubin & Rubin, 2012). This increased awareness of preconceptions during the interview process, and questions were formulated to reduce or eliminate bias (Rubin & Rubin, 2012). The researcher was an active listener and kept the conversation flexible. The responsive interviewing method requires that the conversational partner's responses shape the interaction and probes were used to uncover meaning (Rubin & Rubin, 2012).

Establishing the nurse researcher role.

The researcher was aware that her presence may affect interactions with the conversational partners. As a nurse practitioner with a specialization in neurology, she was aware that her role might influence the interactions with conversational partners and present role conflict (Jack, 2008). A contingency plan was in place if the need to intervene clinically arose during an interview (Jack, 2008), although this did not happen. The researcher is knowledgeable of community and clinical resources and provided these to the participants prior to the interviews and in the informed consent. An open, honest approach was communicated at the start of each interview and that her role was purely to conduct research and was not to function as a nurse in a clinical capacity.

Active listening.

Active listening goes beyond what individuals typically do in everyday life and conversation (Seidman, 2013). Interviewers must listen to what participants are saying and to simultaneously concentrate on the substance of the interview to ensure understanding (Seidman, 2013). This allows internalization of the interview content and helps shape the interview questions to flow from earlier listening (Seidman, 2013). The

researcher must also be cognizant of hearing a participant's "inner voice" (Seidman, 2013, p. 81) versus a public, or outer voice. The outer or public voice, reflect that the individual is guarded and aware of his or her audience (Seidman, 2013). The researcher can ask for clarification if the participant's language is suggestive of a public voice but must remain sensitive and encouraging during the process (Seidman, 2013).

The researcher remains actively aware during the interview regarding time and content covered and pays attention to verbal and non-verbal cues to keep the interview moving forward. The researcher must suppress the normal instinct to talk in order to encourage an active listening process. Audio recording and taking notes during interviews can facilitate active listening as this prevents the researcher from interrupting participants (Seidman, 2013).

Role of the Conversational Partner

The role of the conversational partner is to provide a description of their experience. The CPs are experts regarding PD-related fatigue as they live with this symptom on a daily basis. They were active participants in the data collection process and their answers to interview questions provided in-depth description and insight into the phenomenon being studied (Rubin & Rubin, 2012). The interview flow was directed by answers and perceptions the conversational partners provided during interactions with the researcher (Rubin & Rubin, 2012).

Managing Data Analysis

Data analysis occurred concurrently with the interviews and began by reviewing interview notes and pertinent field notes. When the interviews were transcribed, formal analysis began and codes and themes were identified. The dissertation chair reviewed

transcribed interviews to provide a double check for accuracy. During initial analysis, themes emerged which prompted additional questions for subsequent interviews (Rubin & Rubin, 2005). Each interview transcript was analyzed prior to the next interview.

Determining Content for Interviews

Interview questions were developed from the research questions which were derived from information gathered from clinical practice and a comprehensive literature search. The researcher used a conversational guide to provide direction for the interview utilizing the prepping strategy detailed by Rubin and Rubin (2005).

Participants

Participants were adults who had been diagnosed with Parkinson's disease, who identified fatigue as a significant symptom in their everyday life, and who were willing to share their experiences. This study utilized purposeful sampling, specifically maximum variation sampling, which attempts to ensure a sample with diverse backgrounds and perspectives (Polit & Beck, 2012). Purposeful sampling assists the researcher to select participants who will best address the research questions (Polit & Beck, 2012). The goal of qualitative descriptive research is to obtain information-rich data and using maximum variation sampling helps explore phenomenon among participants with varied demographic backgrounds (Sandelowski, 2000). Inclusion criteria for the study were:

1. Individuals over the age of 18 who have been diagnosed with Parkinson's disease and identify fatigue as a significant symptom in their everyday life. The researcher used the United Kingdom (UK) Parkinson's Disease Society Brain Bank Clinical Diagnostic Criteria (Hugh, Daniel, Kilford, & Lees, 1992, p. 182) to exclude participants who may have PD caused by a secondary condition:

- History of repeated strokes with stepwise progression of parkinsonian features
- History of repeated head injury
- History of definite encephalitis
- Neuroleptic treatment at onset of symptoms
- More than one affected relative
- Early severe dementia with disturbances of memory, language, and praxis
- Presence of cerebral tumour or communicating hydrocephalus on CT scan
- MPTP (1-methyl-4-phenyl-1,2,3,6-tetrahydropyridine) exposure

2. English speaking.

3. No co-diagnosis of significant cardiac disease (congestive heart failure, cardiomyopathy), active cancer, anemia, or chronic obstructive pulmonary disease. These comorbidities are also associated with significant fatigue and it would be difficult to determine if the fatigue they experienced is PD-related or due to another coexisting condition.

The researcher collected and analyzed data until data saturation occurred (Polit & Beck, 2012). The final sample consisted of eight participants.

Progression of Research Study

The study was reviewed and approved by the Institutional Review Board (IRB) at the University of Massachusetts Dartmouth. In addition, verbal and written (Appendix A) permission was obtained from the director of the Rhode Island (RI) Chapter of the American Parkinson Disease Association (APDA) to recruit participants through that

organization. Working with the director of the RI APDA, participants were identified through support groups, and invited to join the study. All participants signed an informed consent form prior to beginning the interview process.

Recruitment/Setting

Participants were recruited by posting a research recruitment flyer (Appendix B) on the RI APDA chapter's Facebook page and posting information about the study on the chapter's website. In addition, the researcher attended local support groups to recruit potential participants. The researcher asked study participants to refer other individuals with PD who may be interested in participating in the study. This technique is termed "snowballing" and offered a convenient and time saving method (Polit & Beck, 2012) to recruit participants. Another advantage of snowball sampling is that trust may be more readily established as the referral person has already met and established a relationship with the researcher (Polit & Beck, 2012). Three CPs were recruited from support groups, two from the posting on the RI APDA website, and three were referred by other study participants.

Potential study participants contacted the researcher by phone or email and, a series of pre-screening questions were then asked (Appendix C) to ensure eligibility to take part in the study. Eligible participants were scheduled for an interview at a mutually agreed upon time and location. Interview locations varied based on availability and the geographical location of the participant and included the participant's home and the local public library.

Data Collection

Data collection occurred from July 2015 through December 2015. At each interview, demographic data was collected (Appendix D): age, gender, race, ethnicity, marital status, level of education, number of years diagnosed with PD, and other medical diagnoses. The IRB-approved informed consent form (Appendix E) was reviewed with each participant and signed. Participants were provided with a copy of this document. The researcher reviewed the study purpose in detail with each participant. Participants were assigned a code that was determined by the order of the interviews. The first participant interviewed was CP-1, followed by CP-2, etc.

The responsive interviewing technique developed by Rubin and Rubin (2005, 2012) was used to collect data. The interviews were audio recorded and guided by a list of general questions to provide a flexible format to follow during each interview. The questions helped to maintain a direction for the interview, but the researcher was aware that they might change with each subsequent CP. The interview questions were derived from the researcher's professional experience in working with individuals with PD and were developed after performing a comprehensive literature search regarding PD-related fatigue. Each interview was transcribed verbatim by a trained transcriptionist who signed a confidentiality agreement (Appendix G). The researcher ensured accuracy by double-checking the transcribed interviews. Confidentiality was maintained in several ways. The audio recordings and transcribed interview documents were kept in the researcher's home in a locked file cabinet and in a password-protected file; these will be maintained for 3 years per the university's IRB regulations. Conversational partner names were not written on any documentation; pseudonyms were used in the presentation of findings

(Chapter 4). A master list with corresponding identifiers (i.e. CP-1, CP-2, etc.) is kept in a locked file cabinet separate from the audio recordings and transcribed documents.

During the interviews, the researcher referred to each CP by his or her first name only.

The researcher sought rich descriptions about PD-related fatigue and how this NMS affects QOL, how individuals self manage fatigue (if at all), and individuals' experiences with health care providers assessing and managing fatigue. The researcher collected data using open-ended interview questions to elicit this information and description from the CPs. Responsive interviewing allows conversational partners to answer questions in a flexible manner and encourages the exchange to evolve during the interaction (Rubin & Rubin, 2012). This technique enables the CP to guide the flow of the interview (Rubin & Rubin, 2012). Questions were prepared in the form of a conversational guide, which is an outline that gives the researcher direction on what questions to ask (Rubin & Rubin, 2005, 2012) (see Appendix F). The conversational guide includes main and follow up type questions (Rubin & Rubin, 2012). Main questions reflect the study's research questions and aims (Rubin & Rubin, 2005) and present information in a less abstract way for easier understanding. Based on responses, the researcher used appropriate follow-up questions to gather more depth and detail and further explore themes and concepts (Rubin & Rubin, 2005). Probes are also used by the researcher to assist in managing the conversation, for elaboration, and clarification if needed (Rubin & Rubin, 2012).

The interviews took place in either the conversational partner's home or a meeting room of the local public library. Each interview lasted approximately 60-75 minutes. Interviews were spaced out by at least seven days between each participant. This allowed

the researcher to absorb the content of each interview prior to the next and begin initial data analysis.

Conversational partners were reassured that if any discomfort occurred during the interview, he or she could stop the interview and withdraw from the study any time with no impact on their relationship with the RI APDA. Participants were provided the name and contact information of individual(s) they could contact if they experienced any distress from being involved in the study. This information was identified in the informed consent. The researcher informed participants that there are no right or wrong answers and emphasized that the purpose of the study was to gather individuals' perspectives and experiences of PD-related fatigue. None of the CPs withdrew from the study and no one expressed that they experienced any distress from participating in the study.

The researcher was an active listener during each interview and recorded key words and phrases used by the conversational partner. Following each interview, field notes were written to record observations and interpretations. Field notes assist the researcher to recall certain key information during the interview process, record non-verbal behavior by the conversational partner that may be important in data analysis, and cue the researcher into key words or phrases important to the study findings (Polit & Beck, 2012; Schatzman & Strauss, 1973). The researcher kept the field notes in a separate journal. Field notes were reviewed by the dissertation chair for thoroughness.

Schatzman and Strauss (1973) describe three types of field notes: observational, theoretical, and methodological. Observational notes are the "Who, What, When, Where, and How of human activity" (Schatzman & Strauss, 1973, p. 100) and are mainly

statements based on watching and listening to the participant. There is little interpretation on the part of the researcher when taking observational notes. In contrast, theoretical notes attempt to derive meaning from observational notes and are the beginning attempts to analyze the data. Theoretical notes assist the researcher to interpret data to develop concepts and identify linkages with previously obtained data (Schatzman & Strauss, 1973). Methodological notes assist the researcher to self-critique and are observational notes on the researcher (Hunter Revell, 2013; Schatzman & Strauss, 1973). Methodological notes can help cue the researcher during subsequent interviews in regards to approach, timing, and setting the stage (Schatzman & Strauss, 1973). All three types of notes were recorded in the research journal.

Procedures for Analysis

Qualitative content analysis was used to analyze the data. This method of analysis is preferred in qualitative descriptive studies as it is a dynamic process that uses verbal and visual data to summarize content (Sandelowski, 2000). The analysis is data driven and codes to analyze the data are directly derived from the information gathered in each interview (Sandelowski, 2000).

A trained transcriptionist transcribed each interview verbatim (Rubin & Rubin, 2012). Each interview was thoroughly read by the researcher to obtain a general summary of the interaction. The researcher identified and coded statements, words, and excerpts that related to each research question (Rubin & Rubin, 2012; Sandelowski, 2000), which begins the process of identifying concepts and themes generated from the interviews. Field notes written immediately after each interview were analyzed simultaneously with each interview transcript to summarize codes related to each

research question. Once each interview and corresponding field notes were individually analyzed, data across interviews and participants were compared. Final data analysis identified similarities and differences to combine concepts and themes. The codes identified during data analysis produced a rich description to address each research question. The interview transcripts were also reviewed for themes and codes by the dissertation chair.

Procedures for Data Verification

Qualitative interviewing produces data that are highly credible but the researcher must take steps to ensure reliability and validity (Rubin & Rubin, 2012). For this study, Rubin and Rubin's (2005) criteria for credibility were used. Credibility was heightened by choosing conversational partners who were experienced and knowledgeable about the phenomena of interest and had first hand experience with the research problem (Rubin & Rubin, 2005). Findings should aim toward a complementary understanding to provide a complete picture of PD-related fatigue. Additional measures to confirm reliability and validity include: ensuring each conversational partner is very clear about the study's aims, the nature of the study, data collection procedures, keeping detailed and accurate notes, and having field notes and transcribed interviews reviewed by another researcher (Brink, 1993).

Credibility is also achieved through thoroughness, accuracy, believability, and redundancy (Rubin & Rubin, 2005). Thoroughness refers to fact checking, investigating discrepancies and new discoveries, and preparing appropriate follow up questions as needed (Rubin & Rubin, 2005). Accuracy requires careful and detailed record keeping during the interviews in order to represent what each CP stated (Rubin & Rubin, 2005).

This was achieved by verbatim transcription of each interview and the subsequent and careful review of each transcript to double check for accuracy. The field notes kept by the researcher provide a double check system to maintain that transcribed data reflected what took place during each interview. Accuracy also requires that the interviewer does not substitute what was said in the interview or use any of his her own words, opinions, or experiences in place of what the conversational partner said. Member checks are undertaken to help confirm accuracy and credibility. The researcher shares feedback with participants regarding developing themes (Brink, 1993; Polit & Beck, 2012).

Believability means showing what the conversational partners have stated is accurate and without deception. Rubin and Rubin (2005) stress that in conversational partnerships lies are not common and the norm is an open and honest relationship. Steps to safeguard believability include: informing each CP that the research is voluntary, developing a trusting relationship, designing research questions that minimize distortions, calculated omissions, and overstatements (Rubin & Rubin, 2005). Building redundancy into the study design also can increase believability (Rubin & Rubin, 2005) and was achieved by asking the same questions in different ways and comparing findings with different sources, such as published literature. The researcher examined inconsistencies that arose but took care not to embarrass or upset the conversational partner when bringing this up (Rubin & Rubin, 2005).

Validity was addressed through representativeness and transparency. Transparency implies that one who reads the research study is able to see the exact steps taken in data collection and analysis (Rubin & Rubin, 2005). The research study should allow the reader to assess the completeness of the study and biases of the researcher

should be apparent (Rubin & Rubin, 2005). The researcher has the transcribed interviews and field notes readily available for review for data verification and to ensure transparency. A record detailing the codes and themes identified and how they were analyzed is readily available (Rubin & Rubin, 2005). Keeping a journal detailing the research project also serves to make biases and reactions transparent (Rubin & Rubin, 2005). Transparency encourages the researcher to stay close to the data, which is an essential part of qualitative research (Rubin & Rubin, 2005).

Ethical Considerations

The researcher took several measures to display ethical behavior towards the conversational partners. Participation in the study was completely voluntary and no coercive pressure from the researcher was demonstrated. Participants had the option to withdraw from the study at any time with no adverse effect on their relationship with the researcher, UMASS Dartmouth, or with the RI APDA, although none did. The researcher made every effort to conduct the study according to ethical standards set forth by the IRB at UMASS Dartmouth. Any concern regarding the participants' rights would have been brought to the attention of the dissertation chair, the institutional compliance officer, and the director of the RI APDA, although this did not occur.

The researcher was transparent in all aspects of the study and followed guidelines developed by the university's IRB. Each conversational partner was provided with a copy of the informed consent. The researcher assured participants that their anonymity and confidentiality would be maintained. Respect was demonstrated by being courteous during interactions, keeping appointments, arriving on time, and offering to provide the results of the study (Rubin & Rubin, 2012). The researcher intends to inform the

conversational partners if the study is to be published. All forms and study materials including demographic data, informed consent, transcribed interviews, and field notes are kept in a locked file cabinet and only the researcher, dissertation chair, and committee have access if needed. Audio recordings are stored on the researcher's home computer using a password-protected file for each recording. After three years and completion of the study, this information will be destroyed.

Limitations and Delimitations

This is a qualitative descriptive study that aims to provide rich description of a concept. A major limitation of this research approach is the results are not generalizable to the population of people with Parkinson's disease as a whole (Neergaard et al., 2009). Sample size is small and may not be reflective of the PD population in the United States or the local community. Recruiting from support groups may have led to a biased sample, as individuals who attend these groups may not be representative of persons with PD who do not attend support groups. Interviewing may also increase the risk of social desirability bias where participants may try to present themselves in a favorable light or try to impress the researcher (Brink, 1993). Participation in this study is voluntary which also can create a biased sample. Additional study limitations will be discussed further in Chapter 5.

CHAPTER FOUR

Findings

This qualitative study was undertaken to describe how individuals with PD describe fatigue, how it effects their QOL, what self-management strategies lessen their fatigue, and how fatigue is assessed and managed by their health care providers. A presentation of the findings includes participant descriptions that arose during the in-depth interviews and from data analysis described in Chapter 3 in response to the four research questions. The research questions are:

1. How do individuals with Parkinson's disease describe the fatigue they experience?
2. What effect does fatigue in Parkinson's disease have on an individual's quality of life?
3. What self-management strategies do individuals with Parkinson's disease employ to decrease and/or live with their fatigue and to what extent are these strategies effective?
4. How do individuals describe their experiences with health care providers in addressing their concerns about managing fatigue and its' effects on their lives?

This chapter includes a detailed description of each CP along with descriptive statistics. Conversational partners are introduced chronologically in the order in which they were interviewed. Following the introduction of CPs, themes and subthemes related to each research question are discussed. The content includes a mixture of themes identified by the researcher and descriptive terms provided by the CPs. Terms and phrases used by the CPs will be put in quotation marks. Words or phrases used across

participants will be indicated in italics. Themes identified and named by the researcher are indicated in bolded text.

Following the presentation of each CP, there is a discussion of how participants describe the fatigue they experience, beginning with a dialogue on fatigue onset and symptom identification. Words and phrases used by the CPs to label fatigue are presented. In the next section, the effect of fatigue on QOL is discussed with emerging themes. Then self-management strategies used by CPs to lessen fatigue are detailed. This discussion includes how participants accommodate their daily schedules to live with fatigue. The last section highlights how health care providers assess PD-related fatigue and recommendations given by providers to decrease or live with fatigue.

Conversational Partners (CPs)

The study included a sample of eight individuals. The majority of the CPs ($n = 5$) volunteered to participate after learning about the study at local PD support groups. The remaining participants were recruited through snowball sampling. Demographic characteristics of the conversational partners are detailed in Table 1. Pseudonyms are used to protect the identity of the conversational partners. In addition, names of specific places and geographical locations have been changed to further provide anonymity and ensure confidentiality. Descriptive statistics are discussed as well as detailed descriptions of each CP.

Table 1

Demographic Characteristics of Conversational Partners

CP	Gender	Age	Highest Level of Education	Marital Status	Race	# Years Living with PD	Employment Status
1 Carl	Male	73	PhD	Married	White	9	Retired
2 Rod	Male	58	PhD	Married	White	6	Working full-time
3 Mary	Female	66	BS	Married	White	6	Retired
4 Dean	Male	64	MS	Married	White	5	Retired
5 Fred	Male	66	AD	Divorced	White	4	Retired
6 Bill	Male	57	Some college	Married	White	8	Semi-retired
7 Neil	Male	78	High school diploma	Married	White	4	Retired
8 Pat	Female	60	Bachelor's	Divorced	White	2	Working full-time

The age range of the sample was 57-78 years old with an average age of 65.25 years. The number of years living with PD ranged from 2-9 years with an average of 5.5 years. Six participants were male and two were female. It was a homogenous sample with all eight participants identified as white, while six were married and held a college degree. The majority of the sample reported that they were retired, with only three of participants currently working.

CP1: Carl.

Carl is a 73-year-old white married male who lives with his wife in a suburban town in Southern New England. He was diagnosed with PD in 2006. He is a former college professor who holds a MBA and PhD and taught computer science at a local university until retiring in 2008. His children and grandchildren live nearby and he sees them regularly.

Carl was interviewed at his home with his wife present. His wife used a device similar to a gait belt to help Carl out of his chair when needed. He also used a cane at times when he arose from his chair. He had difficulty answering questions due to hypophonia and frequent dozing during the interview. Carl volunteered to participate in the study after reading about it on the local APDA website. He is under the care of a movement disorder specialist.

CP2: Rod.

Rod is a 58-year-old white married male who lives with his wife in a suburban town in Southern New England. He was diagnosed with PD in 2009. He currently works as a full-time college professor in New England and his highest degree earned is a PhD. Rod was interviewed alone at a community library in a private meeting room. He had no

speech difficulties and did not use assistive devices. Rod volunteered to participate in the study after learning about it through another research participant. He is under the care of a movement disorder specialist.

CP3: Mary.

Mary is a 66-year-old white, married female who lives with her husband in a suburb in the southern part of New England. She was diagnosed with PD in 2009. She is a retired graphic designer and has a Bachelor's degree. Mary continues to paint and is very active in the local PD community and attends support groups and events hosted by the local APDA chapter. She plays card games with a social group on most days and also attends several exercise classes during the week.

Mary was interviewed in her home and her husband was not present. Her house is handicapped accessible and she has an electric stair chair leading to the basement level and second floor of the home. She has a raised toilet seat in bathroom and a reclining lift chair in the living room. Mary uses a walker at times but ambulated without any assistive devices during the interview. Mary does have mild hypophonia but this did not affect the interview. Mary volunteered for the study after she saw the information posted on the APDA Facebook page. She is under the care of a movement disorder specialist.

CP4: Dean.

Dean is a 64-year-old married male who lives with his wife in Southern New England. He is a retired counselor, holds a Master's degree, and previously worked professionally as a chef. He is an avid home chef, cyclist, and exerciser. He attends several fitness classes per week including Zumba and "BIG" classes. Dean was

diagnosed with PD in 2010 and had to stop working in 2011 due to his PD symptoms, which have left him disabled.

The interview took place at a private meeting room in a local library. Dean did not use any assistive devices and had mild hypophonia but this did not affect his ability to engage in conversation. Dean volunteered for the study after learning about it from attending a PD support group. He regularly sees a movement disorder specialist.

CP5: Fred.

Fred is a 66-year-old divorced white male who lives alone in a rural community in Southern New England. He was diagnosed with PD in 2011. He is a retired respiratory therapist with a specialization in neonatology. Fred is a United States veteran and former helicopter pilot. He is an avid kayaker and enjoys walking and running around the lake he lives near. He picks his grandchildren up from school every day and enjoys spending time with them.

Fred does not use any assistive devices and has no speech impairment. Fred volunteered for the study after attending a PD support group presentation. The interview was conducted in a private meeting room at the local town library. A movement disorder specialist treats his PD.

CP6: Bill.

Bill is a 57-year-old white married male who resides in Southern New England with his wife. He was diagnosed with PD in 2007. He is semi-retired and continues to engage in consulting work. Bill is very active in the PD community and serves on the board of a local PD organization. He also helps newly diagnosed people with PD deal

with their diagnosis and provides personal guidance to several people each week on how to live with PD. He is an avid boxer and enjoys sailing.

The interview with Bill took place in a private meeting room of a local city library. He does not use any assistive devices and did not have significant speech abnormalities. Bill volunteered for the study after reading the advertisement posted on the local APDA Facebook page. He is under the care of a movement disorder specialist.

CP7: Neil.

Neil is a 78-year-old white married male who lives with his wife in a suburban neighborhood in Southern New England. He was diagnosed with PD in 2011. Neil does not use any assistive devices but did state that he typically stays on the first floor of his two-story house since he has some difficulty with climbing stairs

He was interviewed in his home, with his wife present. He has mild hypophonia but was easy to understand in conversation. At times Neil would lose his train of thought during the interview but was easy to redirect. He often sought guidance from his wife during these occasions. Neil offered to volunteer for the study after a presentation was given at a local support group. A general neurologist treats his PD.

CP8: Pat.

Pat is a 60-year-old divorced female who lives alone in Southern New England. She was diagnosed with PD in 2013. She continues to work full-time in a human resources department at a local college. Her daughter is a registered nurse who informed her of the study. Pat was interviewed in her two-level house and she uses a cane to ambulate for an unsteady gait. A movement disorder specialist manages her PD.

Research Question 1: Description of Fatigue

This research question was designed to explore how people with PD describe the fatigue they experience and the language they use to label it. An introductory statement asked when conversational partners first started to notice fatigue and how long they have been living with this symptom in relation to their PD. CPs were asked to describe a day when they experienced fatigue and probes were used to gather more data about fatigue such as physical and mental characteristics.

As the interviews progressed and themes emerged, the researcher added additional probes to clarify concepts learned from previous CPs regarding varying levels or types of fatigue and if sleepiness was also experienced. Two main themes were identified through this research question, *symptom experience* (TH1) and *what fatigue is not* (TH2). Subthemes for TH1 include: symptom identification, daily and pervasive symptom and evolvment over time. For TH2, the subthemes revealed are tiredness, sleepiness, and depression.

Symptom Experience (TH1)

Symptom identification.

The majority of the CPs report they first recognized fatigue following their official diagnosis of PD. The timeframe of symptom onset and identification varied among participants with most reporting 1-2 years after diagnosis. Carl and Mary could not pinpoint when they became aware of fatigue as a bothersome symptom, but noted that now it was a symptom that was very present and debilitating. Mary was able to convey that in her initial phase following PD diagnosis, she experienced sleep disturbance, which has progressed to what she calls fatigue. She noted that the two are separate entities.

Mary also reports that once she ceased working, she noticed the symptom. “Prior to...when I was working, I think I was busy. My mind was engaged...but my mind's not engaged, you know, you notice these things more.”

Similarly, Dean reports that he used to identify fatigue as being “really tired” and noted this has worsened over time to become what he now refers to as fatigue. Dean states that his fatigue was worse now and much more pervasive as compared to earlier in his diagnosis. Rod also expresses that fatigue while prevalent for a few years, has really come to the forefront of his illness experience and is now his dominant symptom of PD. Only Dean and Bill identified symptoms of fatigue prior to PD diagnosis. For Bill, fatigue is the primary presenting symptom which led him to seek medical care and to his eventual PD diagnosis.

I noticed it before I was diagnosed. I saw my primary care physician for about 18 to 24 months before...I was officially diagnosed, and my comment to him was, I was experiencing symptoms similar to the day before you have a full-blown flu. You're just lethargic, you're tired, you can't move. That's the best description I can give you. That was my primary complaint (Bill).

Neil's experience regarding symptom identification is unlike the other participants. He started experiencing fatigue about two years after PD diagnosis but describes the sensations as a pain between his shoulder blades and a feeling of “weakness in strength.” In his case, pain occurs first like an aura and then he experiences more bodily sensations that he identified as fatigue. Pat also had a unique experience regarding symptom labeling. She reports her fatigue has become much more noticeable over the last year but that it was directly correlated with medication administration and timing.

Pat reports that she has fatigue about one to two hours after taking her PD medication. Although she has other periods of fatigue, she relates the sensations she notices after taking her medications to what she calls fatigue and that this has been a prevalent and bothersome symptom in her life.

Six of the participants were able to relay when they identified the onset of fatigue. For two of the conversational partners this was more difficult. Throughout data collection, it also became apparent that many participants had difficulty describing fatigue and took quite some time to come up with descriptive terms. At times the CPs were unsure if what they were experiencing was truly fatigue and questioned their own descriptions. Many participants also felt they had varying levels or degrees of fatigue.

Table 2 provides a list words, phrases, and terms the CPs used to describe their fatigue. Descriptions are characterized as general, physical, and mental. During data collection, several participants reported having physical sensations, as well as cognitive or mental components, that were part of their fatigue experience. Table 2 illustrates similarities and differences across participants.

Table 2

Descriptive Terminology of Fatigue

CP	General	Physical	Mental
1 Carl	Feels like I have no control	Clumsy	Not thinking as fast
2 Rod	Overwhelming Wave of low energy Tiredness/exhaustion Difficulty initiating/ maintaining mental/ physical activity	Physically tired	Mentally tired
3 Mary	Absolutely drained/I crash I can't function/energy gone	I can't physically move I just have to lie down	I can't think straight.
4 Dean	I'm not sure I can put it into words...normal tired is when you exert yourself and you have to take a rest...I have to dialogue with myself to start an activity	Feels heavy and slows	My brainpower is slipping I can't pay attention The pathway for that train of thought just disappears
5 Fred	Fatigue is different from tired Overwhelming sensation Need to lie down	I find that I move a little bit slower getting in and out of a car	You feel like you can't think straight Brain feels a little like...you're in a fog
6 Bill	Boot camp tired	I need to get horizontal quick [when fatigue hits]. Similar to the day before you have a full-blown flu	You get what I call a brain fog It's a hangover without the headache
7 Neil	You just plain feel washed out	Weakness in muscles Your strength goes Pain between shoulder blades It's hard to walk Physical fatigue	Forgetfulness at times
8 Pat	Overwhelming Difficult to describe Tiredness I've never felt before	Fatigue includes episodes of falling asleep Bone numbing fatigue	Affects short-term memory Decreases concentration

All conversational partners describe a physical component to fatigue and use terms and phrases to depict actual bodily sensations they experience. For three of the conversational partners, their descriptions are consistent and the fatigue was so overwhelming that they would need to lie down.

Fred: The fatigue, the best way I can describe is, that every so often, I have this overwhelming sensation that I need to lie down...no matter what I'm doing. I could be enjoying my company with friends or relatives and I'll feel like I really need to lie down and rest even if it's only for a half hour. I only lie down when it's that overwhelming urge that I feel like I can't do anything else.

AB: Okay. Do you...do your...does your body feel a certain way...like a...

Fred: Yeah. I guess the best way to describe it is, you know, let's say you're watching a favorite movie at night and it's getting late. The movie's not over yet but you want to see the ending and you're trying to fight to stay awake. That would be the overwhelming fatigue.

Bill and Mary also give similar descriptions of the physical aspect of fatigue they experience. Severe fatigue is described as being so overpowering that they need to either sit or lie down because their bodies could not physically be engaged in standing or any other activity. Like Fred, Mary explains that when she has periods of intense fatigue she will need to lie down quickly and notes "it's not that I have to sleep, the energy is gone (Mary)." For Mary when this occurs, she is very uncomfortable and reclining in her chair helps alleviate the discomfort associated with the fatigue sensation. According to Bill, he needs to "get horizontal quick" when severe fatigue strikes as it is a matter of safety

especially if he is driving or engaging in activities with power tools. He reports that the severe fatigue could be so intense that like Mary and Fred, he cannot really function and needs to take a break. Bill equates his fatigue with the same level of exhaustion he experienced during boot camp and uses the term “boot camp tired.”

I call it boot camp tired. That's the best description I can give you...when your eyelashes are tired and when your eyelashes hurt and you know you're about ready to fall down. You actually dream of being in bed, being horizontal even on a tile floor, that's how tired you are in boot camp (Bill).

Bill further describes his fatigue experience, comparing it to boot camp.

The only thing I've ever experienced like this is boot camp where you're up for 48 hours straight, 8-mile marches, 10-mile marches, that's the only thing that comes close to it. You actually fantasize about being in bed lying down on the floor. You fall asleep standing up. That's the only thing that compares to it (Bill).

Many participants talked about physical symptoms related to fatigue. Carl notes that his balance worsens and he may fall while both Mary and Pat feel their speech becomes softer. Neil is the only CP who used the word “pain” when explaining his experience, stating that he feels actual physical pain during a fatigue episode. Several CPs also report that fatigue encompasses an inability to complete tasks because of slowed movements with the accompanying feelings of being *drained* or *exhausted*. Dean offers this vivid description of how he experiences and describes fatigue.

AB: I know I kind of keep asking you the same question...how do you feel it in your body?

Dean: Okay, because I ride a bike a lot I experience traveling with the wind...and turning into the wind. The fatigue that I experience when doing activities is like turning into the wind when it's not blowing. So it's just doing fine, doing fine, doing fine and all of a sudden, I just kind of get, just feel physically like everything gets, feels heavy, and slows.

The experience of physical fatigue varies across participants. Fatigue is consistently hard to describe and overwhelming at times. The conversational partners use similar words to define fatigue including: *low energy, heaviness, slowness, and weakness*. A common occurrence was the need to lie down when fatigue set in due to an overall inability to function. Several CPs struggled to come up with words to describe their fatigue and the researcher used various probes to obtain rich description. These included phrases such as “tell me more about how your body feels when you are fatigued” and “what happens to your body when you are fatigued?” Dean sums up how difficult it is to put his symptom experience into words. “You know, I just see everything. So, it’s hard for me...to box things up (Dean).” CPs also discuss how fatigue affects their cognitive or mental state.

All participants discuss having some sort of cognitive issues that they related to their fatigue. Several report periods where they have decreased attention, concentration, motivation, and impaired thinking. At times these symptoms come with the onset of physical fatigue but for many, mental fatigue occurs independently. A common thread among the CPs is that mental fatigue creates an increased effort to initiate and finish tasks that are deemed cognitively challenging such as: completing taxes, preparing documents for work, and doing the household budget. Pat, Neil, and Dean all report that mental

fatigue consists of short-term memory loss or forgetfulness. Dean states that his “brain power is just slipping.”

Both Bill and Fred use the term “fog” to describe the effect fatigue has on their brains. Bill reports “it actually affects your brain” and his brain would become “tired...you get what I call a brain fog. It’s a hangover without the headache.” Similarly, Fred states, “Your brain feels a little, uh, like...you’re in a fog.” Fred elaborates by providing this vivid description.

It’s like...let’s say when you’ve been sick for a little while with the flu or something like that and you do...do a lot of sleeping and you are kind of in a slumber situation. That’s the best way to describe it (Fred).

As previously discussed, both Mary and Pat spoke about speech changes when they experience fatigue. This includes physical changes like hypophonia, speech hesitancy, stuttering, and word-finding difficulties that they feel is part of their fatigue experience. Dean and Neil also report trouble with word finding and attribute this to fatigue.

Mental fatigue is a theme identified by all participants. Specific manifestations varied but they felt that fatigue also affects their cognitive realm. Physical and mental fatigue impacts each conversational partner on a daily basis. The findings reveal that fatigue is a daily and pervasive symptom and this was identified as the next sub-theme.

Daily and pervasive symptom.

All of the conversational partners experience fatigue on a daily basis at varying levels and intensity. For four of the participants, fatigue is the most problematic symptom of their PD and is present throughout the day. Fatigue is “overwhelming” and

all consuming causing them to schedule their daily activities around their fatigue symptoms. Even though fatigue is constant and overpowering, most of the CPs still have a desire to engage in activities. Dean offers a compelling description of this.

Um, fatigue...let me just say the way that I talk about my experience of being fatigued or overtired, whatever it is, I tell my doctors that I want to go dancing and take a nap at the exact same time, all day long (Dean).

Many of the participants experience levels of fatigue. These levels range from mild to extreme, and in the latter case the CPs could not complete either physical or mental tasks. For some, this is predictable or cyclical and related to specific activities or events; and for others, fatigue severity is erratic.

Three conversational partners report the daily presence of fatigue but also describe having periods when the fatigue becomes so intense, that they can no longer participate in activities of daily living (ADLs) and need to lie down (Mary, Bill, Fred). For Mary, her daytime fatigue is not predictable and she notes, "During the day, I have no idea how I'm going to feel." Whereas nighttime fatigue occurs on a regular basis every evening at approximately 7:00 PM and she has to be in her recliner by this time, noting "I just have to be horizontal." Mary further explains that when this severe fatigue starts, she feels very "uncomfortable" and the only way to relieve this is to lie down and rest her head. The daytime fatigue does not come with any warning or prodromal signs, but at night, Mary reports having a sense of extreme tiredness and knowing when she needs to stop any activity she is engaged in.

In contrast, Fred's daytime fatigue is always present but he can "work through it" and it does not prevent him from performing ADLs or participating in social or

recreational events. When his daily, less severe fatigue hits, he reports feeling “slower” but his cognitive status is unaffected. Approximately 2-3 times per week, he will experience more intense episodes of fatigue that he defines as “overwhelming” and all consuming and he must lie down. He states, “You fight to stay awake.” According to Fred, this intense fatigue is a more severe and debilitating type of fatigue that requires him to stop what he is doing and nap in order to work through it. There is no pattern to his severe fatigue and it can surface at any time.

Similarly, Bill reports varying levels of daytime fatigue that typically has no effect on completing ADLs or work-related activities. However, periods of severe fatigue are noted to be erratic and at times can last up to four to five days out of the week. This severe fatigue is what Bill terms *boot camp tired* and requires him to lie down due to the severity and effect on physical and mental functioning. He explains, “I need to get horizontal quick” in that he feels his overall safety could be affected if he is not in a resting position. Prior to the onset of this, he would experience a severe feeling of tiredness (like Mary) and at times would experience double vision. These symptoms occur with his severe fatigue, but not the daily less significant fatigue.

Five of the participants report that while fatigue is a dominant daytime symptom, it is likely to be less bothersome in the morning and increases as the day progresses. Most of the CPs schedule activities and appointments in the morning or early afternoon, when they feel their best. For some, participating in household chores increases the intensity of fatigue and they correlate symptom onset following these activities. Both Rod and Bill report that once fatigue sets in later in the day, it becomes more difficult to “garner” or “marshal” the energy to engage in activities or work responsibilities. When

asked to elaborate on these descriptions both gave similar explanations stating that more energy is available earlier in the day to complete tasks. Fatigue seems to set in later in the day and have a more significant impact on functioning.

Only one participant, Pat, connects the onset of fatigue symptoms with timing of taking her medications. She reports that her pattern of fatigue, while daily and also “overwhelming,” is linked to medication timing. Approximately 1-2 hours after taking her PD medications, she begins to feel very fatigued and “sleepy.” These symptoms can then last all day but are more severe during the period following drug administration. She also describes experiencing fatigue if she is sitting and not engaged in activity. She recognizes excessive yawning as a warning sign that a fatigue episode is coming. She reports experiencing a “bone-numbing fatigue” that she has difficulty describing and notes accompanied symptoms of feeling very “sleepy.” While she has a feeling of generalized fatigue that is present all day, it does not seem to interfere with her ADLs. She reports that daily fatigue is more “being tired from doing simple tasks.” Pat is able to discern that the severe fatigue episodes are related to medication timing and more noticeable during periods of inactivity.

All of the participants experience fatigue on a daily basis that is at times, very bothersome, and interferes with ADLs and social and occupational responsibilities. For many of the CPs, there are two types of fatigue: daily with little impact on functioning and severe, which has a significant influence on daily life. All of the participants report more energy during the day with fatigue becoming more prevalent and bothersome in the afternoon or evening. Only one participant notes the onset of problematic fatigue after taking medications and describes the bodily sensations as having a component of

sleepiness. Sleepiness and fatigue were mentioned as separate entities by other participants and will be discussed later in this chapter. The sub-theme of evolution of fatigue over time is explored next.

Evolution over time.

For two of the CPs, fatigue preceded the diagnosis of PD but for the majority of the participants it is a symptom they identified after receiving the official diagnosis. Six of the CPs reported that fatigue worsened over the course of their diagnosis and was identified on average 2-3 years after diagnosis. As previously discussed, fatigue can be daily and mild or more severe and debilitating and this experience changed for some of the participants during the course of their illness.

Bill and Dean are the only conversational partners to identify fatigue as occurring prior to PD diagnosis. For Bill, fatigue is his primary presenting symptom and he sought a medical evaluation because of it. His fatigue was present for 18-24 months prior to diagnosis. Dean also reported feeling extremely tired prior to PD diagnosis but unlike Bill, he has the accompanying symptom of imbalance.

Several participants note a difference in PD-related fatigue versus fatigue experienced prior to diagnosis. Mary reports she never had fatigue prior to PD, whereas Dean felt the experiences are quite different. Below is an excerpt of the conversation with Dean on the difference.

AB: So, going back to this feeling you had before you were diagnosed, you know, when you were younger and you got tired, is this different from like years ago? Is it a different feeling for you?

Dean: Yeah, I think it is, I'm not sure if I can put it into words, but yeah, normal tired is, you know, when you exert yourself and you just need to take a rest. I have to have a dialogue with myself to start an activity.

Dean describes PD-related fatigue as becoming a constant force in his life, unlike previous tiredness or fatigue he would experience before. He also reports that fatigue has become more severe and a significant symptom since his initial PD diagnosis.

Prior to PD diagnosis, Rod stated there was more “bounce back” in regard to fatigue experience where he was able to recoup his energy and return to a previous level of functioning. With PD-related fatigue, he reports “the reserves are not as deep and wide as I had hoped” meaning after an episode of severe fatigue, he does not return to baseline and over time feels the cumulative effect of fatigue. Rod discusses that resting can help the fatigue but naps typically do not lessen the sensation whereas prior to his PD diagnosis they would. Mary shares that even when she lies down when severe fatigue hits, sleeping or napping have no effect on fatigue. Fred reports that even with a full night’s sleep, fatigue is still present. However, napping helps to reduce the intermittent, severe fatigue episodes he experiences. Prior to PD, Neil talked about being “normal tired” that would go away on its own and was pain free. While Pat states that the fatigue that she had prior to her diagnosis did not involve the “sleepiness” that she experiences now.

Several participants made the distinction that PD-related fatigue is different from pre-disease state. Fatigue previously was something that resolved on its own and did not interfere with ADLs. PD-related fatigue is described as more severe and its presence increases over the course of the disease. The CPs report fatigue occurs with overlapping

elements of sleepiness and depression. This cross-concept comparison led to the identification of the second theme in the study. A discussion follows.

What Fatigue is Not (TH 2)

It was challenging for all of the participants to describe their fatigue. It is problematic and a common symptom but many struggled to come up with the language to define it. Four of the CPs began the description dialogue with how they felt when they were initially diagnosed with PD. Once they identified their presenting symptoms of PD during the interviews, they discussed how they began to notice an abnormal tiredness that interfered with daily activities and language used to label fatigue was then associated. *Tiredness* and *sleepiness* are terms the CPs used as examples to differentiate from fatigue. Two CPs also discuss *depression* and wanted to make the clear distinction that their fatigue was not a form or symptom of depression.

Tiredness.

Fred distinguishes PD-related fatigue from tiredness by explaining that, to him, tiredness is how he would feel after working a double-shift. He would get home and essentially have to sleep for only a few hours and then start the workday over again. Fred states that this is much different from what he experiences now, “An overwhelming sensation that I need to lay down.” For him, tiredness was something that resolved without much action while PD-related fatigue requires an intervention. Pat describes that her PD-related fatigue is a “tiredness I’ve never felt before” and notes that the fatigue she experiences now is much more severe than “regular tiredness.”

Sleepiness.

Rod uses the term sleepiness and states, “it’s not the same thing as sleepiness. I get sleepy too, but I don’t have the daytime sleepiness.” Rod has prior knowledge about different NMS of PD and brought this up during the interview and explicitly stated that his fatigue is very different from sleepiness. For this CP, the two were contrasting concepts as fatigue involves physical and mental characteristics and does not consist of episodes of falling asleep. Mary also made this distinction. She reports that for her being sleepy was a relatively new symptom along with the fatigue. These symptoms were both different with sleepiness described as sudden onset sleep, even in the middle of an activity. Mary describes fatigue as an overwhelming and uncomfortable sensation that causes her to rest. She does not fall asleep during fatigue episodes.

AB: Anything else you want to say about the fatigue that you can think of?

Mary: Just to have people understand it's not being sleepy. It's different than sleepy. You just feel like you're drained...and totally drained, you can't do anything.

In contrast, Dean feels sleepiness is part of the fatigue experience but is able to describe the two as different. Sleepiness is falling asleep somewhat suddenly, similar to what Mary describes, and fatigue is more the physical and mental sensations she experiences (see Table 2). Sleep disturbance can lead to episodes of sleepiness but fatigue is not dependent on a good night’s sleep. Neil also reports that he experiences sleepiness as a separate entity from fatigue.

Neil: I...I don't know whether sleepiness during the daytime enters into this fatigue business.

AB: Do you find the sleepiness is different than the weakness in your muscles that you feel?

Neil: Yes, it's different.

AB: Okay. So, there's kind of two different things you...you feel...this kind of physical feeling in the muscles.

Neil: Yeah.

AB: What's the sleepiness?

Neil: Well, it's under control right now with Ritalin.

AB: Okay.

Neil: I've just been on Ritalin for about a month now, but what would happen is I...I'd sleep nine hours a night, get up and have breakfast, sit down in the chair, and fall asleep for an hour...

Neil went on to explain that he falls asleep often if he is just sitting in his chair reading or watching television. Like Mary, he feels fatigue consists of different bodily sensations including "muscle weakness, tiredness, and pain." However, when further asked if he felt sleepiness and fatigue are different, Neil did admit he is not quite sure.

AB: Okay. So...because...this is...this is interesting...so, for you, fatigue is...is something you feel in your muscles where you're weak and you kind of lose your power?

Neil: Physical...physical fatigue.

AB: Physical...but sleepiness to you is sleepiness...that's not what you feel fatigue is? Is that...is that accurate?

Neil: Well, I'm not sure.

AB: (Laughs)

Neil: I was asking more than...more than stating a fact. I don't know...

AB: Yeah.

Neil: ...whether they're related or not.

This exchange illustrates how conceptually confusing describing fatigue can be for participants. As the interview progresses with Neil, it becomes apparent that episodes of sleepiness and fatigue are different and occur at different times of the day. Sleepiness is responsive to Ritalin and fatigue is not.

Pat describes her fatigue using the word *sleepiness* but when asked for more description on this, she elaborates and reports fatigue is more than the “sleepiness sensation.”

AB: ...so, for you, that fatigue is the falling asleep...that sleepiness?

Pat: It's...it's...it's bone-numbing fatigue. It's so overwhelming, and I'm not a person that sleeps easily. I'm one of those, like, you know, checking out the ceiling at midnight and at 1 and at 2, so, to have this thing, like, put me down like that is so out of the ordinary for me. I'd walk up and down the halls at work to try to wake myself up.

AB: Okay. So, you feel it in your whole body?

Pat: Um...I can't say that. It's just tiredness like I've never felt. It's so different from anything I had ever felt before.

Pat experiences both sleepiness and fatigue and is able to state the difference and detail that fatigue is not just sleepiness.

Depression.

Depression, like fatigue, is a prevalent NMS in PD. Often times, the two can be confused, as fatigue is a symptom of depression. Bill reports that he has a past medical history of depression that was treated several years ago. He conveyed during the interview, “I’m not clinically depressed.” Due to his prior history of depression he is aware that many people diagnosed with PD have depression. He feels fatigue can cause depression in PD because it is “relentless.” Bill shares that while the symptoms are similar and both occur in people with PD, he was absolutely not experiencing depression, just fatigue. Neil also carries a diagnosis of depression and discusses that it creates more difficulty for him in attending social events, whereas fatigue does not affect this.

Tiredness, sleepiness, and depression all occur in PD and have many overlapping characteristics with PD-related fatigue. Several conversational partners spoke to this and also gave rich description differentiating these symptoms. Clarifying the concept of fatigue is difficult as evidenced by conversations with the participants. In the next section a discussion of how fatigue has affected each conversational partner’s quality of life follows.

Research Question 2: Fatigue and Quality of Life (QOL)

The second research question was designed to gather information about how fatigue affects QOL. The researcher began this dialogue with each conversational partner by using the following introductory statement. “I’m interested in learning about how fatigue impacts your life.” Probes were then used during the interview to inquire how fatigue affected the ability to care for oneself, its impact on relationships with family and friends, ability to engage in hobbies, social and occupational activities, and if fatigue

changed the individual's daily schedule. CPs were also asked to describe a day where fatigue had a negative impact on them.

Two main themes emerged from the data analysis: accommodation (TH3) and loss (TH4). A sub-theme identified in TH3 is alteration in daily routine and for TH4 sub-themes include role loss, loss of activities, and changing sense of self.

Accommodation (TH 3)

"I'm planning my life around it. I have changed everything...to accommodate it" (Pat).

All of the CPs, with the exception of Fred, have rearranged their lives and made adaptations to their daily schedules in order to live with fatigue. Six of the participants report that fatigue is more problematic later in the afternoon and in the evening, so they schedule appointments and activities in the morning or early afternoon. Scheduling activities around fatigue also creates disruptions in social life and role changes. Many CPs feel bothered and upset by having to rearrange their life to live with this symptom and used terms like *frustrated* and *disappointed* when discussing how schedule changes make them feel.

Bill, Rod, and Pat are all employed and spoke about how fatigue affects their work life. Pat shares that she carefully plans her medications around the time she has to be at work. Since her fatigue is directly related to medication timing, she only takes one dose while she is at work and has adapted to fatigue by using strategies to minimize it. Despite having to rearrange her day due to fatigue, the experience has not been particularly bothersome to her. Pat states, "it's just what I need to do." Bill had to reschedule client meetings due to fatigue but does not see this as a negative stating, "I try to find the positive aspect of a bad situation." Rod adjusts his workday due to fatigue and

makes certain his courses are scheduled later in the afternoon or early evening when he feels his best. He also negotiated to have the location of his classes closer to his office to help conserve energy and make living with fatigue easier. Making these accommodations does not necessarily bother Bill, and similar to Pat, he feels it was what he needed to do to “conserve his energy.”

In contrast, Mary reports great frustration with having to change her schedule because of her fatigue. The severity and timing of her fatigue episodes prevented her from going out at night. She shares, “I have to miss out. It’s frustrating.” The schedule change also affects outings with her husband and confides that she worries that this bothers him.

Despite fatigue severity and schedule modifications, all of the conversational partners state that they still engage in activities. As fatigue evolves over the course of their illnesses, many participants continue to modify their daily lives around this symptom.

Mary speaks about the need for continuous modification in her experience with attending choir practice, a meaningful and enjoyable activity in her life. She shares that practice has always been in the evening but was able to persuade the other choir members to schedule some afternoon practices so that she could attend. Bill also discusses having to continuously modify his schedule to incorporate rest periods for energy conservation. Having this flexibility in his routine allows him to continue with activities he loves like woodworking and counseling newly diagnosed individuals with PD. Bill does not view these modifications negatively, but rather as a challenge to have to “continuously ratchet it down.” He further describes what he means by this phrase by explaining his need to

balance his own wants and needs with the fatigue. He feels this is an ongoing process during his illness course calling it “continuous modification.”

Fred reports that while he needs to avoid riding his motorcycle when he has a severe fatigue episode, fatigue has no impact on any ADL, social event, or other hobby and he does not have to accommodate his schedule in order to live with this symptom. He states, “I haven’t missed out on anything really” (Fred). He is the only participant to note this as all other CPs have some activity they missed out on and they did report schedule changes due to fatigue.

Many of the participants note changes in normal roles and responsibilities due to fatigue. Despite these changes, all of the participants discuss a supportive network of family and friends. Fatigue does not have a negative effect on family relationships and social support is important for each conversational partner to cope with fatigue. Mary does mention concern that her inability to participate in evening activities may bother her husband but was quick to note, “He mostly is very, uh, caring and accepts it” (Mary). Dean is the only conversational partner to say that he feels his wife does not see fatigue “as a big problem for me” (Dean). He believes this because his wife sees that he gets an incredible amount of work done around the house. This change in family roles is often due to accommodating for fatigue and needing to reprioritize activities and responsibilities. Fatigue creates loss in the lives of the CPs. Loss is identified as the fourth main theme of the study and a discussion is presented next.

Loss (TH 4)

Role loss.

Five participants report having to give up certain responsibilities due to PD-related fatigue. The change in responsibilities results in a range of outcomes including complete role loss such as losing a job and role change such as altering or sharing responsibilities that were once solely theirs. The conversational partners respond to this role adjustment with feelings of being slightly bothered to others feeling “disappointment” and “like a burden” to their loved ones.

Bill shares that due to his experience with fatigue he has had to semi-retire. However, he does not perceive this role adjustment as a negative event in his life. He shares his perspective.

You focus on what you have because you'll never have everything you want. You will never be content by focusing on what you don't have because you'll never have everything. Focus on what you do have and exploit those (Bill).

Mary had to stop working entirely due to her PD-related fatigue and while she does not elaborate on how this makes her feel, she does talk freely about the loss of other roles including teaching and volunteering. Mary is an artist and used to quite enjoy volunteering at senior centers to teach art classes. Teaching is something she deeply values and has to stop due to her severe fatigue episodes. She shares how this role loss has made her feel. “I can't even volunteer to be a volunteer because I don't know if I'm going to be able to show up. People can't count on me” (Mary). She goes on to talk about how much she misses teaching these classes because she felt like she was

contributing. This is one of the areas in Mary's life where fatigue has had a significant negative impact.

Prior to the adverse effects of PD-related fatigue, Carl was responsible for taking care of the budget and general household maintenance in his family. Since fatigue has set in, he has had to let go of this role due to his health. Carl said that his wife has had to take on the "burden of running a household," however his family is very supportive. Fatigue affects his ability to carry out mentally demanding tasks at work, with increased mistakes and longer time to accomplish tasks as a result. Carl blames this on "fatigue and stress." While fatigue is not the primary symptom that led to his retirement, it has contributed to his inability to fully complete his work responsibilities.

Rod changed his role as a college professor secondary to his fatigue experience. He shares that he stopped teaching summer courses and chose not to participate in committees in order to conserve his energy. While he initially expressed feelings of guilt in regard to letting go of some of his work duties, he feels that he has come to terms with his decision. He notes that some work tasks take "more conscious effort." Rod describes an example. "I can do what I need to do pretty much the way I need to do it as far as I can tell. I will delay responding to emails that require thought...I'll delay making phone calls (Rod)." Rod does not believe his overall work performance has suffered due to PD-related fatigue. He also shares feelings of guilt about not being able to help out with housework and describes feeling "lousy about it."

She's accepted the fact that [there are] certain things that I'm not going to do.

She adjusts her requests and expectations to what she thinks I'm capable of doing

but will also suggest, you know, “let’s try to do this,” or that kind of stuff and be encouraging (Rod).

In contrast, three other CPs (Fred, Neil, Pat) describe no experience of role loss or change during their interviews. Fred and Neil do not feel they experience any sort of role loss or change. Due to the adjustments Pat made in her life to live with fatigue, she reports no role loss or change during the interview. She feels she has adapted the best she can at her workplace and is still performing most duties to the best of her ability.

Loss of activities.

“It causes me to edit my engagement in things” (Rod).

Seven of the conversational partners state that fatigue impacts their social life and engagement in activities. A main contributing factor in this disruption is timing. Schedule changes that are made to live with fatigue become the very culprit of them not being able to participate in social events. In conversation with Mary, this theme becomes apparent. Mary’s fatigue is debilitating in the evening, and therefore she has to miss choir practices and performances, as well as nighttime theatre events. She stated that fatigue “ruins my life” (Mary). In order to manage her fatigue, she has to consciously “force” herself to go out and do errands. She also confides that she worries about the effect these limitations have on her relationship with her husband. However she does note that he is always supportive and empathetic.

Carl also speaks about “forcing” himself to go out and engage socially. He shares that this has been very difficult for him and he feels “disappointed in myself” (Carl). Similarly, Neil and Dean report their social activities are planned around fatigue and they typically go out in the morning. Needing to make this social adjustment does not bother

Dean. Despite his fatigue he continues to engage in social activities, but acknowledges that it takes extraordinary effort to leave the house. Both Dean and Mary self-identified as active people who continue to be very social.

Neil brings up another perspective regarding changes in social life. While he does not feel fatigue has caused him to miss much, he has fears about going out with family and friends.

I'm afraid I'm going to get wiped out. It's the concern of making everybody wait for me while I'm trying to finish my dinner...it makes me feel disappointed in myself. And you know, concerned about how...how bad it's going to get (Neil).

Neil went on to discuss how his depression may also play a role in how he feels during social interactions but he did clarify that fatigue made him feel "slower" and this was his concern when he does go out. Despite this, he does not avoid social engagements.

Rod, like Mary, is more cognizant to schedule social engagements and notes even with friends, "we've got to schedule our phone calls" (Rod). Fatigue has caused him to edit his socializing in order to conserve energy for other responsibilities he needs to carry out. This editing has not been distressing to him as he states, "For the most part, I've been okay with it" (Rod). He does miss spontaneity in regard to making plans, but this aspect does not have a negative effect on his life. Similarly, Bill also describes needing to frequently reschedule social events.

In contrast, Pat reports that she is unable to go out with her work colleagues anymore due to the fatigue, which has been "a little isolating" (Pat). She talks about missing out on going with them to football games and tail gaiting and states, "I feel bad

about it because it seems like a lot of fun” (Pat). Her fatigue makes it difficult for her to go to the movies and she does not do this anymore. This change in her social routine does not necessarily bother her. She reports being more upset about not being able to socialize with her work friends. “They don’t even ask me anymore” (Pat). For Pat, this is a big loss that she has difficulty coping with. On the contrary, she never misses family outings and holiday gatherings and pushes herself to go to those. “Family means everything to me” (Pat).

Several conversational partners describe activities that fatigue has interfered with and for some, they have had to stop beloved hobbies or decrease participation in household duties. Both Carl and Fred report a love for riding motorcycles. Carl has had to stop driving altogether and this creates a “loss of control” for him and is upsetting. Carl also has cognitive and balance symptoms that led to the loss of driving, but he does describe fatigue as a contributing factor. Whereas Fred will only avoid riding his motorcycle on days where he has the more severe and “overwhelming” fatigue. This does not bother him and he does not consider this a loss since there are plenty of days where he can ride without issue.

Mary’s fatigue has a negative effect on several activities. She no longer teaches art classes because “I just can’t tell how I’m going to feel...I can’t tell from one minute to the next...whether you’re going to be good or not” (Mary). She also shares her difficulty with completing errands such as picking up prescriptions. Sometimes she has to stop at a family member’s house to rest before she can complete the task. Despite this, Mary remains very social and is able to participate in most of the activities she wants to. Rod shares that he is unable to take long car trips anymore. He used to drive to visit family

out of state but fatigue interferes with this. He discusses that he and his wife now tend to fly more often. Extended driving became “too taxing...too hard to stay focused” (Rod). Even with his wife driving the majority of the time, fatigue would still be present and made the trips uncomfortable.

One interview that highlights the impact of loss of activities on a participant occurred in conversation with Bill. He was very emotional when talking about how fatigue interfered with his ability to read. He used to be a voracious reader and feels PD-related fatigue robbed him of this.

When I read...you know, you go into a fantasy world and your brain is operating in color. Now it's black and white and a scratchy picture. It's foggy and it's tedious...it's not enjoyable...it's work to read. It's a loss.

Bill became visibly upset as he talked about this loss during the interview. It is one of the things he has had a difficult time coping with since being diagnosed with PD. The loss of reading has had a significant impact on his QOL. He has a very active life and is an avid woodworker, does part-time consulting work, and is involved in the local PD community as an advocate. He did discuss during the interview that sometimes fatigue does interfere with his advocacy work and this disappoints him because he does not like to let people down. He is less bothered by missing consulting work or having to stop woodworking projects.

Changing sense of self.

Two of the participants discussed the effect of PD-related fatigue on their personhood. Rod describes how fatigue made him see himself.

So fatigue is one of those things where it makes a lot of the, first of all, it affects the way I think about myself. It is truly one of those symptoms that you can't ignore and when you try to punch through it, I can get so far but only so far and it's probably the symptom that causes me the greatest concern for my...the longevity of my career (Rod).

Rod is one of two participants who continued to work full-time and during the interview process it was apparent that his career was very meaningful to him. Rod did tear up during this part of the interview when he discussed the effect fatigue has had on his career.

In conversation with Dean, he reveals that a part of his fatigue experience is the feeling that he can no longer experience joy.

Dean: I don't consider myself depressed, but I have this feeling of not being able to enjoy, that's really the key for me, is the part of my brain or the part of my being that experiences joy is pretty much gone. I can do things that make me smile and laugh but the inward feeling, you know, that resonates with your heart and your soul it, that's just missing. You know, it's like the volume control on the TV doesn't work. You can read the lips and know what's going on but you just don't feel it.

AB: Does that have anything to do with the tiredness or the fatigue? Do you think that they're linked?

Dean: Yeah, I think so.

For him, fatigue changed the way he experiences the ability to enjoy what is around him.

Research Question 3: Self-management of Fatigue

The aim of this research question was to uncover how individuals with PD self-manage their fatigue and what strategies they use to reduce or live with fatigue. Participants were asked about the types of activities they engage in that help their fatigue. To gain a rich description, the CPs were asked to elaborate on why they thought certain activities or interventions reduce their fatigue and how it makes them feel. Probes included if any alternative treatments were utilized and if medications reduce fatigue. The researcher attempted to uncover how specific interventions affect mental and physical fatigue. As the data collection unfolded, CPs were asked about strategies that they had tried that were not effective at diminishing fatigue but were mentioned by other participants as being helpful.

Accommodation (TH3) surfaced again in the data for this research question and a fifth theme, mental fortitude (TH5), emerged as well. Engagement in activities and conservation of self are subthemes discovered within TH3. Subthemes identified in TH5 include: taking control/perseverance, acceptance, and positive attitude. The major strategies identified by the CPs to manage fatigue are listed in Table 3. Effective and ineffective strategies are included for comparison purposes.

Table 3

Effective and Ineffective Strategies to Reduce PD-Related Fatigue

Conversational Partner	Effective Strategies	Ineffective Strategies
Carl	Naps	Exercise
Rod	Schedule change Rest periods Acceptance Exercise	Naps
Mary	Schedule change Rest periods Artwork	Exercise Naps
Dean	Exercise (Zumba, bicycling) Positive attitude, Perseverance Naps Spirituality Taking control	–
Fred	Exercise (kayaking, walking, jogging) Rest periods Positive attitude, Perseverance	–
Bill	Exercise (boxing, yoga) Sailing Positive attitude, Perseverance Rest periods Naps Schedule changes Medication (mental fatigue)	–
Neil	Exercise (boxing) Perseverance Medication	–
Pat	Schedule change Rest periods Exercise (walking)	Medication

Note. Empty cells indicate the CP did not provide any information regarding ineffective strategies to reduce fatigue.

Accommodation (TH3)

Conservation of self.

Accommodation surfaced as a common theme participants used to manage and decrease their fatigue. CPs rearranged their schedules and made modifications to be more productive. They planned activities at times of the day when they experienced less fatigue. Pat and Rod continue to work full time which requires them to make adjustments at work in order to conserve energy and complete work responsibilities. For Pat, self-management means only taking one dose of her medication at work to reduce the fatigue side effect. When fatigue happens at work, she stops what she is doing and goes for a walk. Pat notes that sometimes she cannot accomplish all work-related tasks in a day but gives herself permission to complete work that is less of a priority the next day.

Rod makes many numerous modifications to his work schedule to accommodate fatigue. His self-management strategies include: shutting the door to his office to rest or nap, eating regularly because skipping meals reduces energy levels, not teaching summer classes, requesting earlier class times and decreasing committee work. Neither Rod nor Pat expresses any issues at work due to fatigue accommodations.

Mary plans activities for the morning or early afternoon due to the severe fatigue she often experiences at night. She describes this as frustrating but knows it is a necessary step in managing and living with fatigue. Bill also “pre-arrange[s] [his] day around plain fatigue.” At times he has to miss work meetings and events, and while this is disappointing it does not bother him to accommodate his schedule. Furthermore, none of the participants experience negative reactions from family, friends, or co-workers regarding schedule changes due to fatigue.

Three of the conversational partners (Bill, Fred, Mary) discuss the need to lie down during periods of severe fatigue. For Bill and Fred, this self-management strategy has a significant impact on reducing fatigue, while Mary notes that napping does not improve the symptom. She states, “[Naps] wouldn’t make any difference.” However, reclining relieves the uncomfortable sensations she experiences during periods of physical fatigue. According to Mary, she does not need to actually sleep when reclined, but the *positioning* helps her to conserve energy. Conversely, Fred and Bill share that napping is another self-management strategy that alleviates the severe fatigue they experience a few times a week. According to Fred napping helps to “recoup some energy and then I [can] get on with the rest of my day again.” He feels “rejuvenated” after an hour-long nap and this effect can last the rest of the day. Whereas, both Carl and Dean report short-term relief of fatigue with napping, but no long lasting effects. Dean states that as soon as he starts to engage in another physical or mental activity, the fatigue returns. The following exchange with Bill highlights how he feels naps reduced fatigue.

AB: Okay...when you take the naps, does it have an effect on the physical or the brain fatigue?

Bill: Big time. Even if it's only 20 minutes...huge difference.

AB: Can you tell me what happens afterwards? Like, how do you feel in your body?

Bill: 200% better. You go from being a 3/10 to a relative term 8 or 9/10. It's a big difference.

Bill states this effect can last all day and gives him the energy to complete other tasks and responsibilities that need to get done. None of the participants schedule regular

naps or have any kind of prescribed nap or rest routine. The degree of fatigue seems to be the precipitating factor in deciding whether or not to take a nap, and is largely done on an as needed basis.

Engagement in activities.

“Boxing is better than the drugs” (Bill).

Several of the conversational partners cite exercise as one of the most effective strategies to decrease fatigue. The type of exercise varied and includes: boxing, Zumba, bicycling, exercise classes specifically designed for people with PD, kayaking, walking, yoga, and using home gym equipment such as the treadmill or a rowing machine. One of the major findings that emerged from discussing exercise regimens and hobbies with the CPs is that fatigue is completely alleviated when engaging in certain physical activities or specific hobbies. Five of the participants (Pat, Mary, Neil, Dean, Bill) speak to this during their interviews. The term engagement came up several times when discussing feelings of fatigue. The CPs explain that when they are “engaged” in a specific activity, fatigue is not noticeable to them and the symptom abates. *Fatigue alleviation* was identified as an outcome that was experienced by the CPs.

Six of the participants (Neil, Rod, Dean, Fred, Bill, Pat) report exercise to have a positive effect on fatigue and use it as a self-management strategy. Neil and Bill identify boxing as an activity that diminishes fatigue and increases their overall well-being. Neil shares that benefits of his boxing class include reduced fatigue, improved walking, and improved mood. He speaks highly of this exercise class stating that it is specifically designed for people with PD.

I think I walk a little better [after boxing]. It's mind over matter I guess. You feel emotionally pumped up which makes you a little bit more ambitious and...re-energized and it lessens it a little bit (Neil).

Bill also reports feeling “energized” during and after boxing class. He notices that these classes eliminate his “brain fog” or mental fatigue.

Boxing is better than the drugs. It's just as simple as that...and...and not to get off on a tangent, but the camaraderie you have there is unlike anything I've seen since boot camp. On all but one occasion, of the 100 days I've boxed in the last year and a half, all but one day, I felt much better when I left than when I went in. I go in dragging myself in the door. Like, "I don't want to be here” and 15 minutes later, the brain fog is gone and you're energized (Bill).

Bill shares that yoga was another form of exercise which reduces fatigue, but does note, “it helps, but not as much as boxing.” He explains that overall any form of exercise has a positive impact on fatigue and decreases the symptom. Boxing is the activity that has the greatest impact on fatigue reduction. Neil complements his boxing by doing home exercises and notes he “feels better” after stretching, using the treadmill, and workout bench. When asked to elaborate, he reflects that exercise does not worsen the muscle weakness (physical fatigue) and he feels “more energized.”

Energized is a term used by Dean, Fred, and Rod to discuss the impact that physical activity had on PD-related fatigue. Fred is an avid kayaker, who walks regularly and occasionally jogs. He explains that exercise does not make him feel fatigued afterwards, but rather it has positive effects.

The more I exercise, the more I realize I can work through this. So, it's a psychological, it has a good psychological impact being active. You know, one would think you're, after working out for an hour, especially kayaking, that you'd be tired. Well, I actually feel good. I find that it rejuvenates me to exercise. I don't feel tired (Fred).

For Rod, fatigue has become one of his most problematic symptoms and he recently started an exercise plan for self-management. Rod utilizes home exercise equipment including a rowing machine and weights. During the interview he shares that since starting a regular exercise regimen, he is sleeping better, has less fatigue, and more energy.

I'm tired after workouts but I feel good that I was able to do it. I'll still experience fatigue and tiredness during the day, but it will be less frequent and take longer to hit. It gives me more of a reserve that I can draw on (Rod).

Similarly Dean reports feeling tired after his workouts, but also energized post-workout despite the initial tiredness. He states that even in the presence of severe fatigue, he forces himself to exercise because it makes him feel better and "like I'm taking control again." Dean is a very active person and takes weekly Zumba classes, daily PD exercise classes, and rides either his outdoor or indoor bicycle on most days. He reflects on the benefits for his mood stating, "it gives me a boost" and feels "stronger and more accomplished" with these feelings often lasting the rest of the day. Three other conversational partners (Fred, Rod, Bill) also note their energized feelings lasted either all day following a workout to 1-2 days later. Pat experiences similar feelings when she is walking. Pat shares that when she feels fatigue coming on, she gets up and walks

around stating, “It wakes me up” and reduces the sleepiness sensation that comes with the onset of fatigue.

In contrast, Carl does not find exercise to be effective and said it could actually worsen fatigue and often times would prevent him from completing his workout. He becomes “too tired” to finish his PD-tailored exercise videos and has no post-exercise benefits. Likewise, Mary also experiences tiredness during exercise sessions. She works with a trainer once a week, participates in warm water fitness classes, and attends PD group exercise classes. Mary describes uncomfortable physical sensations during and after exercising. Despite this challenge she states, “I push through it” which is different than Carl’s perspective. Mary’s experience with exercise and fatigue is captured in the following statement.

I usually feel tired but I’m glad I did it. I need a little downtime [after exercising] before I go onto my next activity, playing cards. I seem to be able to get through those [exercises] but sometimes after I finish, sometimes often it...my whole body starts shaking like it’s overtired or something and that happens right after doing the exercise (Mary).

Overall, exercise has a very positive effect on both mental and physical fatigue for the majority of the participants. Even though some of the CPs report no improvement in fatigue, and others have increased tiredness, all engaged in daily exercise. Across participants exercise is something that they feel is beneficial in managing not just fatigue, but PD in general.

Three of the CPs discuss specific hobbies that are used as self-management strategies to lessen fatigue. Mary talks about how being engaged in her artwork is

energizing, noting that while painting, drawing, or doing graphic design she does not experience fatigue. For Bill, a devoted sailor, he shares that while sailing his brain fog completely abates. Sailing also has a lasting effect on his fatigue symptom. He notes that on the days he sails, the fatigue is less prevalent with decreased intensity. Fred uses the words “very energizing” when talking about spending time with his grandchildren or out in nature, stating that he does not seem to notice fatigue.

Several CPs discuss having complete alleviation of fatigue while engaged in activities. Pat notes, “any time I’m active, I don’t get it.” As long as she is *engaged* in either work, household chores, walking, or during social events, she does not experience fatigue episodes. Pat reports that while the episodes of fatigue are cyclical and occur in relation to medication, she can alleviate the symptoms by starting an activity. The activity might be mental such as completing important paperwork at her job, or physical, like walking. Bill provides another example of fatigue alleviation when he speaks about boxing.

It’s a magic elixir. The fog goes away within fifteen minutes. I concentrate on hitting the bag and the fog goes. The fatigue might stay, but the fog goes away.

That’s half the battle. The fatigue usually goes. The fog always goes (Bill).

Boxing has had a significant impact on Bill’s mental fatigue. When asked to describe why he thought this was the case, he was not sure but felt perhaps it was because he was “engaged” in physical activity. He has a similar experience when he goes sailing and describes how he feels in the following exchange.

AB: What about the sailing?

Bill: My symptoms go away...whether it's tremor, rigidity, brain fog, um, anything, the symptoms go away completely. You're fully engaged, and it's...it's, uh, second nature. I mean, I love being on the open ocean. The best way I can describe it is...I don't know if you've ever seen...saw Lesley Stahl interviewing Michael J. Fox...

AB: Probably...yeah...yeah.

Bill: ...and he was very symptomatic with the bradykinesia and they took him to, um, the, uh, ice-skating rink in New York and he was a hockey player when he was young. They had him strap on a pair of skates, grab a hockey stick, and a puck, and the symptoms instantly went away and he handled the puck almost flawlessly...but no symptoms at all. That same thing happens to me when I'm boating.

AB: When you're boating...okay...and the fatigue as well?

Bill: The fatigue comes but the brain fog is usually gone, and the fatigue is later and less intense.

Bill gives a very compelling description of how he feels during sailing, one of his favorite pastimes. It is similar to his experience boxing and even though he is not sure why his symptoms abate during these activities, he does speculate that finding his passion has been very helpful at reducing the problematic brain fog.

Neil also experiences fatigue alleviation when he attends boxing class. He states that when he is concentrating on the exercises “the fatigue doesn’t seem to enter into it.” Benefits include improved strength, greater energy during class, and no fatigue when engaged in boxing. While Dean does not box, he reports a similar experience while

exercising. “As soon as I jump into my exercises, I don’t experience any of the symptoms when I start my exercises.” Like Neil and Bill, he is not certain why this occurred but noted that exercising draws attention away from his symptoms and wonders if it is a form of *distraction* from the fatigue he experienced daily.

Mary speaks about her artwork and its effect on eliminating fatigue. She finds engaging in her art creates feelings of euphoria and is energizing. She also notes that creating art gives her a purpose and makes her feel good about herself. Mary has donated proceeds from her art to local PD organizations. She does not notice her fatigue when working on a project.

When I’m engaged in my artwork, time just flies. I don’t notice what’s bothering me. I could be lying in bed and doing this so, it was so energizing and I kept working and being busy, busy and didn’t notice anything. No aches, no pain, no fatigue (Mary).

Fatigue alleviation occurs when the participants are engaged in various activities. Five CPs do not notice fatigue and other PD symptoms when occupied with a hobby or exercise they really enjoyed. Three participants feel being *engaged* was the reason for this, while others are not sure why symptoms improve or abate during the activity.

Mental Fortitude (TH5)

Positive attitude.

Fred, Dean, and Bill all cite a “positive attitude” and optimism as a means of living with PD-related fatigue. They believe that having a positive outlook is essential to deal with the effects of fatigue. They do not want their illness to take control of their

lives and one of the ways they gained control was “trying to find the bright side” and stay positive. Dean discusses how spirituality influenced his ability to stay positive.

We as human beings are co-creators with God or spirit to create your...the life you have, or change the life you have into something more positive. And it really fits for me and my wife because we're pretty optimistic, and we work really hard to have the life that we... want (Dean).

Dean feels that being positive and optimistic has made it easier for him to live with PD-related fatigue and not let the symptom control his life. Fred and Bill discuss the relationship between optimism and control and feel positivity helps them take the control away from fatigue.

Taking control/perseverance.

“The worst thing in the world is just to sit in that chair and let it get worse by itself (Neil).

Four conversational partners discuss how they force, push, or muscle their way through fatigue episodes and continue on with their daily lives, activities, and responsibilities despite the presence of bothersome or significant fatigue. Taking control and persevering are self-management strategies identified by several of the participants. Fred states, “I refuse to quit,” and acknowledged that he will continue to engage in responsibilities even when he is fatigued. Fred has learned to persevere by incorporating naps when severe fatigue hits, and then he will get up and continue his day and force himself to do his daily tasks. Neil reports that he pushes himself and this allows him to feel *gratified* because he is then “not giving in” to the fatigue. Neil notes persevering

despite the fatigue also improves his mood when he is able to complete a workout or household task.

Dean uses the term “muscle through it” to describe forcing himself to engage in activities despite fatigue. Like Neil and Fred, he does not want to give in to the fatigue.

I feel like I’m taking control again. I’m somewhat compulsive in terms of if something needs to be done I’m going to do it. Even though I have this dialogue in my head...‘you can do this’...I just kind of do my best...I don’t want to give fatigue or tiredness their own power (Dean).

“Taking control” over fatigue, persevering, and not giving in empowered many of the CPs to live comfortably with fatigue. Pat reports that the only time she gives in to fatigue is when she is home and can rest if needed. Despite Mary’s severe fatigue episodes, she also shares that if she has to go somewhere or has a social engagement, she pushes herself. The ability to live with PD-related fatigue by taking control is a powerful self-management strategy used by several of the participants.

Acceptance.

Acceptance is also cited by four of the CPs as a self-management strategy for living with fatigue. Once the conversational partners accepted that fatigue was part of their lives, they were then able to make the necessary accommodations in their roles and daily schedules. This in turn created a sense of peace. From Rod, “I’ve come to the realization this summer that I don’t have to do it (certain work responsibilities, teaching summer classes) to feel like a worthwhile person.” Letting go of the once was and accepting his current situation was very therapeutic for Rod. Bill, Dean, and Fred also

discuss how accepting fatigue as part of their daily lives in a sense gives them permission to adjust their responsibilities and expectations.

The conversational partners utilize various strategies to self-manage and live with fatigue. Many of these strategies overlapped, whereas others were unique to an individual. Across participants it is apparent that all of the CPs sought ways to alleviate and better manage fatigue. Some activities like boxing, exercise, and artwork completely alleviated fatigue for participants while they were engaged in the activity. Fatigue benefits lasted a variable amount of time but consistently improved the participants overall sense of well-being. The next section discusses how fatigue has been assessed and addressed by the participants' health care providers (HCPs) and includes recommendations made by HCPs aimed at reducing PD-related fatigue.

Research Question 4: Health Care Provider's Recognition, Assessment, and Management of Fatigue

This research question was asked with the purpose of exploring if HCPs assessed or recognized the presence of PD-related fatigue during office visits. If fatigue was assessed, the conversational partners were asked about the interactions they had with their providers to elicit information about how fatigue was discussed during the visit. During the interview, the participants were initially asked if they spoke to their doctors about fatigue and to describe those interactions. CPs were then asked to describe the interaction and discuss interventions or treatments that the HCPs advised them to use to manage fatigue. Two of the five main themes emerged in the data for this research question. Symptom experience (TH1), with a new subtheme of seeking validation, and mental fortitude (TH5) with the subtheme of taking control/perseverance.

Symptom Experience (TH 1)

Four of the CPs did not discuss fatigue with their HCPs or could not recall their physicians bringing up the topic therefore, little data was gathered from these participants. Both Carl and Mary state that their movement disorder specialist physicians have never talked to them about fatigue. However, Mary does plan to talk about fatigue at her next office visit since the severity of her daytime fatigue is worsening. Conversely, Fred also sees a movement disorder specialist physician who has asked him about fatigue. Fred shares that he and his physician talk about strategies he uses to manage his fatigue, but he did not offer any additional guidance.

Dean is another conversational partner that has not brought up fatigue with his movement disorder specialist physician. He reflects that it is difficult to address all of his PD-related concerns during an office visit, but also that he does not like to portray himself as someone that is not doing well due to his PD. Dean recalls telling his physician that exercise improves PD symptoms, not just fatigue, to which his physician replied ‘keep it up.’

I’m not complaining. I’m describing symptoms...but the medical profession looks at it as complaints. I’m a person who wants to put my best foot forward. He doesn’t have a clear picture of what’s going on with me...I’m trying to get everything into that short time span (Dean).

Dean feels the way the health care system is set up, that it is impossible to have everything addressed. He has no additional plans to address fatigue with his HCP and feels he is self-managing this symptom adequately.

Seeking validation.

Neil did not talk about fatigue with his general neurologist; he instead discussed sleepiness he was experiencing. His physician had not brought up fatigue or assessed for this symptom in past office visits. Neil's episodes of sudden sleepiness occur after getting up in the morning often when he is sitting and not engaged in any particular activity. Neil was prescribed Ritalin, which helped him become more alert and less sleepy. He also experiences more ambition since starting the medication but this has had no effect on the physical symptoms of his fatigue, pain, or muscle weakness.

Rod reveals he had a recent conversation with his movement disorder specialist physician regarding fatigue. While Rod was the first to bring up fatigue, he states that "it's part of his routine ask" meaning his HCP would ask if this was a bothersome or prevalent symptom. Rod states that his physician researches NMS and "has written on fatigue." Rod's HCP is very aware that fatigue is common in PD. His fatigue has significantly worsened over the last year and when he initially brought up this complaint, he was advised to start a regular exercise routine. Rod was also prescribed Ritalin, but he decided not to start the medication, as he wanted to commit to exercise first. At the time of the interview, Rod reports that exercise has reduced his fatigue and is having a significant positive effect on this symptom. Rod plans to discuss the positive effects with his physician at his next office visit and stresses he was not ready to add another medication at this time.

Mental Fortitude (TH 5)

Taking control/perseverance.

Similar to Rod, Bill has discussed fatigue with his HCP multiple times. Bill's story is unique because fatigue has been his most bothersome symptom. It is fatigue that initially led him to seek medical care, which resulted in his eventual PD diagnosis. His movement disorder specialist physician diagnosed him with PD during his initial visit. He had discussed fatigue multiple times with his HCP who has endorsed ongoing physical activity. Like Neil, Bill is also on a stimulant to help with fatigue. He takes amphetamine salts and notes that they reduce the brain fog, but not the severe episodes of fatigue.

They do not cause a buzz...they seem to help the brain fog. I tried going off them last month and the brain fog came back in a vicious way. The brain fog makes you tired, so we get rid of the brain fog...you're less tired (Bill).

Bill also discusses how therapeutic boxing has been for him, not just at reducing fatigue but improving his overall well-being. He reports that his HCP is now referring his patients to the boxing gym, "he's a believer." According to Bill, "half the new boxers have come from his office."

Pat is the only participant to research fatigue on her own and then approach her movement disorder specialist physician about this symptom. Initially, due to the severe sleepiness she was experiencing after taking her PD medications, she brought the subject up with her physician after she fell asleep driving and hit a curb. An initial intervention was to take Pat off Pramipexole, a PD medication. She notes, "They didn't seem to indicate that there was fatigue associated with Parkinson's." Pat was then switched to

Carbidopa-Levodopa and had the “same fatigue reaction.” At this point she decided to self-manage her fatigue and changed the timing of the medication to coincide administration when she was mostly at home. Pat recalls that there was again no mention of fatigue by her HCP as being a side effect of the medication or part of PD. Even though her fatigue episodes were more severe after taking her medication, she also had a baseline level of what she called *bone-numbing fatigue*. Her fatigue continued to be pervasive which led her to do her own research online. She describes how she came to find out that fatigue could be part of the symptomatology of PD.

Pat: ...and so, I know the first time I told her about it...she never told me that there was any association between either my medicine or Parkinson's. I was, um, what did I do? I went up on YouTube, and there was a neurologist talking about Parkinson's and the top 10 most difficult things for a Parkinson's patient to deal with and #1 was fatigue and that was the first time that I had heard it. So, I mean, I know that's crazy.

AB: How did you get to that YouTube video?

Pat: I know. I don't...

AB: I wonder...(Laughs)

Pat: ...you know, I think I Googled, like, just Parkinson's and he just went through them, like 10, you know, he did like a David Letterman thing. You know, it was like 10, 9, 8 and it was really interesting, and, uh, he...he seemed credentialed...(laughs)...you know. But anyway, I wrote them down just so that I could look at them and go, "Crap, why hasn't this ever come up before?" and then, when I was listening to one of the Michael J. Fox webinars that was not about

fatigue, they started talking about fatigue and so, that's when I went back into the doctor and said, "Okay, so, is it the Parkinson's or is it the medicines doing this to me?"

Pat is unable to remember exactly how her doctor responded when she discussed her findings. During the interview, she struggled to recall exactly what transpired next. She did note that even though she continued to complain of severe fatigue episodes, she was kept on her medication, Pramipexole. Pat's fatigue continued and when she went back for an office visit to report ongoing fatigue, her HCP started Nuvigil, a stimulant medication. This medication caused insomnia and nausea. At that point in time, her HCP did not offer any other suggestions regarding fatigue management and Pat had already decided to continue her own self-management strategies.

AB: So, did she have another suggestion?

Pat: (Sighs) No. I just said to her, "I'd rather deal with the fatigue" because I know what to do to deal with it you know, I've put all these things in place, checks and balances, in place.

AB: Like you said...you've rearranged your schedule....yeah.

Pat: I have changed everything to accommodate it.

While approximately half of the CPs did not discuss fatigue with their HCPs, the other half did report discussions they had about fatigue and recommendations made by physicians. Only one physician, a movement disorder specialist, advised exercise as an intervention to decrease fatigue. Stimulants were also recommended but appeared to offer limited symptom relief. Even though most of the participants were under the care of a movement disorder specialist, fatigue was not always assessed at office visits. Pat

gives a very vivid description that details how she came to find out that fatigue was PD-related and how she sought answers and treatment recommendations from her HCP.

Five major themes were identified during data analysis. Table 4 summarizes the major themes and subthemes across research questions. The individual experience and perspective of living with PD-related fatigue encompasses five major themes: *symptom experience*, *what fatigue is not*, *accommodation*, *loss*, and *mental fortitude*. Individuals with PD experience the process of symptom identification as they seek to describe what they are experiencing. PD-related fatigue is a daily and pervasive symptom and tends to worsen as the disease progresses. This progression is described as evolution over time. Individuals experience *accommodation* and *loss* as fatigue affects their daily lives. Role loss, loss of activities, and changing sense of self occur as the individual lives with PD-related fatigue. Alteration in daily activities was identified as a subtheme of accommodation and the conversational partners felt their daily lives had to be restructured around fatigue. *Accommodation* also arose out of the data analysis as a self-management strategy to reduce fatigue with engagement in activities and conservation of self noted as subthemes. *Mental fortitude* included the subthemes: taking control/perseverance, acceptance, and positive attitude. These strategies helped the CPs live with fatigue. The symptom experience led individuals to pursue advice from their HCP and at times, participants were seeking validation regarding their fatigue. *Mental fortitude* was also revealed as a characteristic that prompted individuals to ask about fatigue at office visits.

Table 4

Themes and Subthemes Across Research Questions

Theme	RQ1	RQ2	RQ3	RQ4
Symptom Experience (TH1)	TH1 Symptom identification Daily & pervasive Sx Evolution over time	-	-	TH1 Seeking validation
What Fatigue is Not (TH2)	TH2 Tiredness Sleepiness Depression	-	-	-
Accommodation (TH3)	-	TH3 Alteration in daily routine	TH3 Engagement in activities Conservation of self	-
Loss (TH4)	-	TH4 Role loss Loss of activities Changing sense of self	-	-
Mental fortitude (TH5)	-	-	TH5 Taking control/perseverance Acceptance Positive attitude	TH5 Taking control/perseverance

Note. Subthemes are listed below each major theme. TH = major theme

Summary of Findings

Fatigue is a common and distressing symptom of PD that has both physical and mental aspects. The majority of participants had difficulty describing fatigue and commonalities found included using language such as: tiredness, overwhelming, draining, lack of energy, and brain fog. All CPs had some component of mental and physical fatigue. Fatigue was typically more severe and pervasive post-PD diagnosis versus pre-PD diagnosis and typically worsened over the illness course. The timing and intensity of fatigue varied among participants. Most experienced increased fatigue later in the afternoon and evening and felt they had more energy earlier in the day. All of the conversational partners had some level of fatigue daily and for several of them; there were periods of severe fatigue, which required an immediate self-management strategy such as lying down. Some of the CPs also had coexisting sleepiness and depression but were able to articulate that these symptoms were different from fatigue.

Fatigue had a significant impact on quality of life and CPs had to re-arrange their schedules and decrease engagement in certain activities in order to live with this symptom. Many participants noted role loss due to fatigue and this included losing their job or restructuring their role at work, giving up certain positions they once held, and adjusting how much they could help with household tasks. Some had to give up certain activities like teaching summer classes or volunteer work due to the fatigue. All the participants reported having a positive social network and no adverse effects of their fatigue experience on their relationships with family and friends. Fatigue caused negative self-image in three participants, but for another, there was no negative effect of fatigue on QOL.

Several self-management strategies were utilized including: boxing, exercise classes, home workouts, walking, sailing, and artwork. All of these strategies were successful in reducing fatigue. Engagement in activities, conservation of self, taking control, perseverance, acceptance and having a positive attitude were all identified as strategies that helped reduce fatigue and promoted an ability to live more comfortably with fatigue. HCPs often did not assess or ask about fatigue during office visits. Recommendations offered by HCPs included: exercise and stimulant medications. Seven of the CPs were under the care of a movement disorder specialist physician, however four participants did not talk about fatigue with their provider. The next chapter discusses the findings in comparison to the literature. Implications for practice, education, research, and policy are made.

CHAPTER FIVE

Discussion, Conclusions, and Recommendations

This research study was conducted to explore how individuals with PD describe fatigue, how it affects their QOL, what self-management strategies lessen their fatigue, and how fatigue is assessed and managed by their health care providers. Chapter five includes a summary of the findings organized by themes, followed by integration and interpretation of the findings as informed by relevant literature. Conclusions consist of a discussion of implications and limitations of the research. Recommendations for theory, education, research, practice and policy are offered.

The Symptom Experience (TH 1) emerged as a theme across research questions one and two. Subthemes identified under TH1 include: symptom identification, daily and pervasive symptom, evolvment over time, and seeking validation. Fatigue was identified by all of the participants as a problematic symptom that caused distress. While fatigue was often difficult to describe for the majority of CPs, all of them were able to assign terms that explained how they experienced the symptom. Two participants noted that they experienced fatigue prior to receiving a diagnosis of PD and this prompted one CP to seek out the advice of his HCP, which eventually led to diagnosis. PD-related fatigue has physical and mental components, occurred daily, and tended to worsen from time of initial PD diagnosis. Fatigue was worse in the morning for most of the participants. When fatigue became more noticeable and interfered with daily life, participants brought up the symptom experience with their HCPs. One participant self-identified as having PD-related fatigue and sought validation from her HCP when she realized what she was experiencing. Her HCP did not confirm that her fatigue was part

of PD and the CP continued to manage it on her own. Two other participants discussed fatigue with their HCPs in order to get advice on how to manage the symptom.

Participants discussed additional symptoms that at times overlapped with fatigue. What Fatigue is Not (TH 2) arose as a theme when CPs described fatigue and the symptoms that were seen as different experiences. The three subthemes are tiredness, sleepiness, and depression. Five of the CPs describe these other symptoms as being prevalent in their lives but noted that they were not the same thing as what they labeled PD-related fatigue. Unlike fatigue, tiredness was not as severe and experienced before PD diagnosis. Fatigue was felt to be a more “extreme” version of tiredness and CPs felt it was harder to manage than “regular” tiredness. Five CPs experienced sleepiness and this was differentiated from fatigue during interviews. One CP had a history of depression and noted that while he was aware that depression and fatigue had similar symptoms, he was clear that his fatigue was not depression.

Accommodation (TH 3) was a major theme noted in research questions two and three. The conversational partners used accommodation as a self-management strategy but it was also found as a major factor affecting QOL. Subthemes identified include: alteration in daily routine, engagement in activities, and conservation of self. CPs had to change their daily schedule in order to live comfortably with fatigue. Strategies consisted of rearranging events, appointments, and planning their day around fatigue. Most of the CPs had worsening fatigue in the afternoon and evening so life was structured around times they felt their best. For some, this created significant distress, as they had to miss out on events or activities.

In regard to self-management of fatigue, engagement in activities such as exercise and beloved hobbies reduced fatigue. Conservation of self was also achieved through accommodation, as CPs discussed that planning life around fatigue allowed them to conserve energy in order to enjoy activities they valued. Rest periods and naps were other strategies used to help the CPs live more comfortably with fatigue.

Loss (TH 4) was a major theme identified in the data from research question two. The impact of fatigue on QOL was marked, and included subthemes of role loss, loss of activities, and changing sense of self. Fatigue led to the loss of occupation for two participants and another had to give up some work responsibilities. Fatigue caused CPs to transfer household tasks to their spouses and forego hobbies and nighttime activities. Participants who expressed that fatigue changed them as a person were seen as having a changing sense of self. One CP felt fatigue made her unreliable because she never knew when she would need to break a commitment due to her symptom. Another CP, whose identity was steeply grounded in his career, feared fatigue would eventually cause him to stop working. One participant discussed how he has a hard time experiencing joy and the part of him that enjoys activity is gone. He attributed this to fatigue.

Mental fortitude (TH 5) was discussed as a self-management strategy (RQ 3) and was present when participants described their experiences with seeking advice from HCPs (RQ 4). Three subthemes include: taking control/perseverance, acceptance, and positive attitude. These subthemes assisted the CPs to manage their fatigue. CPs learned to live with fatigue and accept that it was part of their lives. A positive attitude was identified as something that provided strength and power over fatigue. When approaching their health care providers, four CPs discussed how they wanted to learn

more about this symptom and how to reduce it. They took control over their symptom experience.

Integration and Interpretation of the Findings

Study findings indicate that fatigue is a prevalent and disabling symptom that has a negative impact on one's QOL (TH 1, TH 4). This is consistent with past research studies, which conclude that fatigue is a commonly occurring symptom of PD and can reduce QOL (Friedman & Friedman, 2001; Herlofson & Larsen, 2003; Karlsen et al., 1999). Olsson et al. (2013) to date has conducted the only other qualitative study examining PD-related fatigue in women. Findings from the Olsson et al. (2013) study demonstrate that PD-related fatigue disrupts roles, creates feelings of isolation, and is a constant symptom for the female participants. Similar to the CPs in this study, fatigue is also difficult for participants to describe and left them feeling an overall sense of weakness, loss of strength, and interfered with cognitive function (Olsson et al., 2013). In addition, fatigue also causes difficulty with completing household tasks and engaging in social activities, which is consistent with the findings of the current study (TH 3) (Olsson et al., 2013).

Brown et al. (2005) reports that participants in a focus group used the following terms to describe fatigue: "heavy, drained, tiredness, lack of energy, and exhaustion" (p. 50) and notes fatigue was different from tiredness felt after activity or lack of rest. Findings from the present study also reveal that the CPs used the same terminology to describe their fatigue and some of the CPs remarked on the difference between tiredness and PD-related fatigue (TH 2). Previous literature findings also note that fatigue experienced prior to the diagnosis of PD is different from post-PD diagnosis (TH 1)

(Friedman, 2009). The current study and past literature both uncovered similar findings in that fatigue pre-diagnosis is less severe, more likely to be relieved by naps or rest and is also not felt to be daily or as pervasive (Friedman, 2009).

Two main types of central fatigue in PD, known as physical and mental, detailed in previous literature were also described by the CPs in this study (TH 1). Physical fatigue is explained by the CPs who used terms such as “exhaustion” and “decreased energy,” which is consistent with the literature (Friedman, 2009; Lou, 2009). Friedman et al. (2011) report that even with physical fatigue present, individuals might still be capable and able to perform tasks. The CPs in this current study did acknowledge that they were able to engage in various physical, social, and occupational related tasks even when they felt physically fatigued.

Mental fatigue includes feelings of being “cognitively fatigued” after activities (Finsterer & Mahjoub, 2014, p. 2) or having difficulty in initiating and sustaining mental tasks (Friedman, 2009). Mental fatigue can also affect speech and memory (Beiske & Svensson, 2010). This research study revealed that all CPs experienced some form of mental fatigue with varying descriptions similar to the previous literature. Two of the CPs describe “brain fog”, which has been used to describe mental fatigue in other neurological and chronic conditions (Kralik et al., 2005). Other participants reported decreased attention, slowed thinking, worsening of short-term memory, forgetfulness, and difficulty in sustaining and initiating tasks which is similar to descriptions of mental fatigue not only found in PD, but other chronic neurological illnesses as well (Davies et al., 2013; Farren et al., 2013; Olsson et. al., 2005, 2013).

Fatigue can often be confused with excessive daytime sleepiness, depression, and apathy as these NMS have many characteristics that overlap (Friedman et al., 2007). Some of the CPs report concurrent depression in addition to the presence of fatigue but are able to differentiate these symptoms as separate entities (TH 2). Sleepiness occurred for three participants and while the CPs did struggle to describe these symptoms separately, they all feel that sleepiness is a different symptom from fatigue (TH 2). The CPs with sleepiness ($n = 3$) gave descriptions that are similar to what is reported in the literature regarding excessive daytime sleepiness (EDS). EDS is excessive and undesirable sleepiness typically felt during the waking hours (Knie et al., 2011). The CPs who experience sleepiness felt bothered by this symptom, noting that it occurred during times of very little stimulation, and causes disruption in the ability to complete ADLs, which is consistent with the literature (Knie et al., 2011).

Previous studies conducted on fatigue and its effect on QOL have largely been quantitative. This is the first qualitative study to explore how PD-related fatigue affects QOL. The Olsson et al. (2013) study examined the meaning of fatigue in women with PD, but did not primarily seek to address fatigue's effect on QOL. Researchers in their study uncovered that fatigue does interfere with daily tasks, chores, and social outings, much like in the present study. Accommodation is a theme revealed with the participants in the current study (TH 3). This theme describes how participants have to change their daily lives and schedules in order to live comfortably with fatigue. This finding is similar to Olsson et al. (2013) as the participants noted "you get used to it, or you adjust yourself to the situation..." (p. 745).

Herlofson and Larsen (2003) found fatigue to have a negative impact on ADLs and social functioning, which parallels this study's findings (TH 4). Havlikova et al. (2008a) report that fatigue has a negative effect on cognitive functioning. These findings are echoed by the CPs in the present study who report that mental fatigue consists of decreased attention, concentration, and memory difficulties (TH 1).

There are no previous studies which examined how individuals self manage PD-related fatigue. Intervention studies have explored the effect of medication and exercise on fatigue. Franssen et al. (2014) performed a systematic review and meta-analysis of randomized control trials that examined interventions to treat fatigue including medications such as stimulants and exercise. Inadequate evidence was found to support the use of medications to treat PD-related fatigue and the exercise intervention did not produce a statistically significant effect (Franssen et al., 2014). Several of the CPs in the study report exercise to have a positive effect on their fatigue, which is in contrast to previous studies (TH 3). Exercise improves both physical and mental fatigue and has an energizing effect. Two of the participants report using stimulants. One was on amphetamine salts and the other was taking methylphenidate. The CP who has been taking Methylphenidate reported it helped his sleepiness but not the fatigue he was experiencing. Methylphenidate has not been shown to reduce fatigue when compared to a placebo group (Mendonca et al., 2007). Amphetamine salts have not been previously studied in relation to PD-related fatigue, but in the present study one CP reports that this medication reduced mental fatigue or brain fog significantly.

While there is no previous research on PD-related fatigue self-management, this concept has been explored in other chronic neurological conditions where fatigue was

found to be a prevalent symptom. In these parallel studies, fatigue is described in a similar way to the present study. Patients with MS, AS, and post-stroke fatigue note positive attitude, planning naps or rest periods, and limiting social activities help them manage this symptom (Farren et al., 2013; Flesner et al., 2003; Moriya & Kutsumi, 2010; Stuifbergen & Rogers, 1997; Young et al., 2013). White et al. (2012) report that participants with post-stroke fatigue adjusted their schedule to live more comfortably with fatigue; a finding also revealed in this study and termed accommodating fatigue (TH 3, 5).

Young et al. (2013) report that patients with MS took control over fatigue by completing daily goals and maintaining a positive attitude, which is consistent with this study's findings. Kirkevold et al. (2015) found post-stroke patients went through the process of "being on a mission" (p. 667) to regain energy and take control over their fatigue. They participated in physical and mental activities to increase strength and lessen fatigue. Like the CPs in this study, they continued to restructure how to manage their lives in the presence of daily and pervasive fatigue (TH 3, 5). Olsson et al. (2013) report that women with PD-related fatigue describe that they "struggled against it" by "striving to endure" and live their daily lives (p. 745). These findings parallel how the CPs in this study persevered despite the presence of daily and bothersome fatigue (TH5).

There are no prior studies that have examined how health care providers assess and manage PD-related fatigue. The current study reveals that for the majority of CPs, their HCP did not assess for fatigue at office visits and many participants did not bring fatigue up during their visits, even though it was a problematic symptom. Previous studies performed suggest that NMS are often under-assessed and under-recognized by

providers during office visits (Todorova et al., 2014). Patients also are not aware that some of their symptoms, including fatigue, are part of their neurological condition (Bonnet et al., 2012; Chaudhuri et al., 2010) and this was found to be consistent with at least one conversational partner's experience (TH 1). Until the CP researched PD-related fatigue on her own, she was unfamiliar that this was a common NMS in PD. When she then brought up her new understanding of fatigue with her HCP, her physician did not confirm that fatigue was common in PD. Kralik et al. (2005) identify the theme "seeking medical validation" (p. 375) in a study that examined the experience of fatigue in women with chronic illness, which included neurological disorders. This is consistent with one of the subthemes identified in this study (TH 1).

No previous research has examined treatment recommendations offered by HCPs to manage PD-related fatigue. In the present study, one HCP advised the use of exercise and stimulant medication. Medication and exercise, as a treatment is mostly anecdotal, as current exercise and drug intervention studies have not had a statistically significant effect on fatigue (Franssen et al., 2014).

Conclusions and Implications of the Research

Fatigue is a prevalent and disabling NMS in PD. This study served to fill a gap in the literature and provide qualitative data on how individuals with PD-related fatigue describe their symptom, the effect fatigue has on QOL, self-management strategies utilized, and how health care providers assess and manage fatigue during routine office visits. To date, this is the first qualitative study to examine these elements with the exception of Olsson et al. (2013) who explored the meaning of fatigue in women with PD. The present study however, also included the perspective of men. While previous

researchers have begun to characterize fatigue, this is the first qualitative study that sought to examine how individuals describe fatigue from their own perspective. The rich descriptions provided by the CPs are consistent with previous research findings.

Defining fatigue continues to be a challenge as this is largely a subjective symptom. The researcher's goal was not to provide a universal definition of fatigue, but rather to explore how individuals describe and experience PD-related fatigue. The descriptions obtained in the study add to the existing definitions in the literature. Future definition work may focus on a concept analysis of fatigue that includes both physical and mental aspects.

The study provides rich data on how fatigue affects the individual's QOL and gives a first-person account of how participants self-manage fatigue. The majority of CPs who engaged in regular physical activity felt it had a positive effect on their fatigue. To date, no qualitative studies have examined the benefits of physical activity. While previous quantitative studies have been done, researchers did not find statistically significant effects of exercise on fatigue. A compelling discovery in the current study was the notion of fatigue alleviation when participants engaged in certain activities such as boxing, artwork, and sailing. The concept of fatigue alleviation should be explored in future qualitative studies to gain a better understanding of this phenomenon. The current study also provided a roadmap for future intervention studies. Boxing offered significant relief not only in terms of fatigue but also with other PD-related symptoms. A study examining the effect of boxing on PD-related fatigue could provide support for an exercise intervention that reduces fatigue. In addition, results showed that stimulant medication reduced mental fatigue. Future studies should be undertaken to examine the effects of these drugs on physical versus mental fatigue.

Findings reinforce previous literature, which states that non-motor symptoms like fatigue are typically not assessed in office visits and may not be recognized as being part of PD. No qualitative study has explored the assessment of PD-related fatigue by HCPs. Current findings provide an increased awareness regarding the under-recognition of this symptom, give insight into the types of recommendations made by HCPs to reduce fatigue, and offer intervention suggestions for providers to use in practice. Study findings, similar to previous research, revealed that individuals with fatigue related to chronic neurological illness often do not bring up their problematic symptoms with their HCPs and time constraints were cited as a hindrance (Mehndiratta et al., 2011). Future fatigue research can explore measures to facilitate the assessment and recognition of fatigue during office visits without disrupting provider productivity.

While study findings have important implications for individuals with PD and their treating HCPs, the results also advance the field of neuroscience nursing in the areas of research, policy, and advocacy. In 2011, the Neuroscience Nursing Foundation (NNF) published research recommendations to advance the field of neuroscience research. The NNF advised nurses to engage in research across neurological disorders and specific areas to address included: interventions to manage symptoms, adaption to living with a neurologic disorder, self-management of neurological conditions, and interventions to promote QOL in people diagnosed with a neurological illness (Dilorio et al., 2011). The current research study fulfilled several of these recommendations to advance neuroscience nursing.

Limitations of Research

This is a qualitative descriptive study and the results are not meant to be generalizable. Findings may not be representative of all individuals who live with PD-related fatigue. Limitations of the research include a small and homogenous sample. The sample was all white and most had a college education. The homogeneity of the sample may be indicative of the types of individuals with PD who attended support groups or were interested in participating in the study. The average age of participants was 65 and this also presents a limitation as fatigue may be experienced differently in those with younger onset and more advanced PD. Including minorities and those of diverse educational backgrounds and different age ranges may provide a fuller picture of the fatigue experience in PD. This sample also reflected a population who had access to available community exercise and social activities. The sample as a whole reported they had positive social support. These factors may have led to this population being more motivated and having greater opportunities to engage in activities that led to reduction in their fatigue. Including individuals in varying socioeconomic groups and those with limited social support may produce more diverse findings.

Another limitation of the study is that the interviewer was a novice and early in the data collection phase, there were times that not enough rich description was elicited. It is possible that this may have limited the fullness of the conversational partner's stories. Qualitative descriptive design may be seen as a limitation when working with a chronic neurodegenerative population. Many persons living with PD, including some of this study's participants, have concurrent speech and memory deficits. These challenges often made it difficult for some of the conversational partners to express their thoughts

and recall information. The researcher also relied on the participants' memory and ability to provide a rich description of fatigue and their experiences. This may be a limitation in that memory is not always reliable.

While part of the study's exclusion criteria was dementia, this was based on self-report and not on objective data due to the qualitative nature of the research. It is possible that some of the CPs had cognitive issues that had not been formally diagnosed and could potentially interfere with their ability to describe experiences. The method itself may have been a hindrance to gather rich descriptive data in these circumstances.

The study design relied on participants to self-identify that they had fatigue. Fatigue is a subjective and complicated symptom to understand and can be confused with other symptoms of PD including excessive daily sleepiness and depression. Conceptual confusion may have interfered with the ability of the CPs to fully describe and differentiate their symptom experiences.

Recommendations

Recommendations for theory, education, research, practice and policy are addressed in this section.

Theory

Findings of the study have implications for future theory development in the field of symptom management and symptom clusters. Results revealed that some of the participants experienced both fatigue and sleepiness, which are two distinct NMS in PD. Participants had difficulty differentiating these symptoms but with probing, were able to discern fatigue and sleepiness as different experiences.

Symptom clusters have been widely researched in the cancer literature (Barsevick, Whitmer, Nail, Beck, & Dudley, 2006) but not in PD. Many NMS in PD occur together including fatigue, apathy, and sleepiness and may produce increased disease disability (Knie et al., 2011). A symptom cluster in PD can be developed from the research findings and further developed into a middle-range theory. To further understand the similarities and differences of these NMS, the Theory of Symptom Management (Dodd et al., 2001) may be utilized to investigate the individual symptom experience and guide future management strategies.

Education

Recommendations for education include making curricula changes in undergraduate and graduate nursing programs to include more comprehensive information about PD-related fatigue and other NMS of PD. Many current nursing textbooks include limited information about fatigue in PD. Given its high prevalence and significant impact on QOL, it would be beneficial to educate nurses about the multiple complex symptoms of PD. Specific to advanced practice education, the findings of this study can help future nurse practitioners and physicians assess for this symptom in clinical practice.

Research

Several implications for future PD-related fatigue research are recommended and are highlighted in the following strategies.

1. Concept analysis of PD-related fatigue to develop an operational definition of the symptom.

2. Development of an intervention study examining the effect of boxing on PD-related fatigue.
3. Evaluate the utilization of a fatigue scale during routine office visits help to identify the presence of this PD symptom and improve overall disease management.
4. Further examination of NMS clusters in PD: Are fatigue, EDS, and apathy more likely to occur together in a symptom cluster and does the presence of all three of these NMS produce greater disease disability?
5. Does mental fatigue in PD represent a form of cognitive dysfunction or is it solely a form of PD-related fatigue?
6. Does the implementation of a PD-centric curriculum improve nurses' knowledge about caring for individuals with PD?
7. What are the factors that increase resilience in learning to live with PD?
8. Is the fatigue experience described similarly by caregivers or partners of those with PD?

Practice

This study has several implications for practicing nurses. First, it established that fatigue is a common and disabling symptom in PD and can have a negative effect on one's life. For advanced practice nurses and physicians who care for patients with PD, assessing for fatigue at office visits is important to establish the presence of this symptom as it often is overlooked and not brought up by the patients. The participants in this study noted exercise to be beneficial, and moving forward nurses can encourage individuals with PD-related fatigue to engage in programs that may reduce their symptoms. Finally, the findings of the study suggest that fatigue interferes with daily activities and if this

symptom is present, nurses can assist patients to develop strategies to manage fatigue and provide referrals to services as needed.

Policy

Exercise was shown to reduce fatigue and have a positive effect on the CPs' lives. Most health insurance companies, including traditional Medicare, do not pay for gym memberships. Nurses can help develop policy changes within large health care organizations to reduce costs of participating in exercise programs and make these programs more accessible for patients with PD-related fatigue.

Nurses can also advocate for individuals with PD at the national level to increase knowledge of PD-related fatigue. The Parkinson's Disease Foundation (PDF) through its Community Choice Research Award asks individuals and families living with PD to identify priority research areas using survey data. In 2014, PD-related fatigue was identified by the survey participants as an under recognized symptom that required more research to advance its understanding and treatment (Friedman et al., 2015). A panel sponsored by the PDF concluded that more interventions for treating fatigue are needed. The results of this study confirm that exercise and being engaged in enjoyable hobbies can reduce fatigue. Nurses can utilize this information and recommendations from the PDF panel to further PD-related fatigue research by working with local and national PD organizations and engaging in ongoing research.

Summary

Fatigue is a common NMS in PD and occurs in more than half of all individuals with this condition (Friedman, 2009). Fatigue is highly associated with increased disability and decreased QOL (Friedman, 2009; Friedman et al., 2010). Very little qualitative research has been conducted examining this NMS. This study served to fill a gap in the existing literature by providing descriptions of PD-related fatigue from the individual's perspective and examining the effect of fatigue on QOL. This study was the first to explore self-management strategies to reduce PD-related fatigue and examine if HCPs assess for this symptom and offer recommendations for treatment. This research contributes to the knowledge of PD-related fatigue, as experienced by the individual, and identifies implications within nursing for theory, practice, education, policy and future research.

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APPENDIX A

Permission Letter

May 5, 2015

Amy Bruno, ANP-C, PhD(c)

Dear Ms Bruno,

I will be happy to help with recruitment for your dissertation study once you have IRB approval. Our RI Chapter of the American Parkinson Disease Association (RI APDA) will:

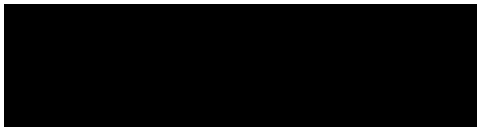
- Promote your study using your flyer on our RI APDA website at: www.riapda.com
- Promote your study using your flyer on our RI APDA Facebook page at: RIAPDA
- We will distribute your study flyer to all our affiliated support groups and at RI APDA functions
- We would invite you to all support groups to discuss your study with our members.

We thank researchers like yourself whose thoughtful investigation will improve the quality of treatment and as such, the lives of our PD families.

Please let me know if you need anything

additional.

Sincerely,



Mary Ellen Thibodeau, RN
APDA Information & Referral Center (www.riapda.org)
Kent Hospital - Parkinson's Center
455 Tollgate Rd.
Bldg 2C
Warwick, RI
02886



APPENDIX B

Study Flyer

Have you been diagnosed with Parkinson's disease?

Do you suffer from fatigue on a daily basis?



Needed: Adults diagnosed with Parkinson's disease who suffer from fatigue on a daily basis.

Why:

- To understand how individuals with Parkinson's disease describe their fatigue and how it affects their life.
- To understand how individuals with Parkinson's disease manage their fatigue.
- To understand how fatigue in Parkinson's disease is treated by health care providers.

Fatigue is a common symptom in Parkinson's disease and can have a significant and negative impact on one's life. By sharing your experience, you can assist nurses in better managing fatigue in Parkinson's disease and you may gain insight on your own fatigue.

Contact: Amy Bruno, ANP-BC, PhD(c) at [REDACTED] or [REDACTED]

APPENDIX C

Pre-screening Questionnaire

1. Do you have any of the following conditions? **Please circle yes or no.**
 - Chronic obstructive pulmonary disease (COPD) **YES NO**
 - Congestive heart failure **YES NO**
 - Anemia **YES NO**
 - Cardiomyopathy **YES NO**
 - Active cancer (are you actively undergoing treatment for cancer?) **YES NO**

2. Do you have a history of any of the following conditions? **Please circle yes or no.**
 - Repeated strokes **YES NO**
 - Multiple head injuries **YES NO**
 - Encephalitis **YES NO**
 - Brain tumor **YES NO**
 - Long-term use of dopamine blocking medications (e. g. anti-psychotic medications or medications used for nausea) **YES NO**
 - Exposure to MPTP **YES NO**
 - Diagnosis of early onset dementia **YES NO**
 - More than one relative diagnosed with Parkinson's disease **YES NO**

3. If you answered yes to any of the conditions in question 2, is your Parkinson's disease thought to be caused/due to that condition? _____

APPENDIX D

Demographic Data Sheet

Thank you for agreeing to participate in this study. Please complete the following questionnaire.

CODE NUMBER: _____

1. Gender: Female _____ Male _____

2. Age: _____

3. With what racial group do you identify?

- White _____
- African American or Black _____
- American Indian or Alaska Native _____
- Asian _____
- Pacific Islander/Hawaiian _____
- Other _____

4. With what ethnic group do you identify?

- Hispanic/Latino _____
- Non-Hispanic/non-Latino

5. Please select one of the following:

- Single _____
- Married _____
- In a domestic partnership
- In a long-term relationship not living together _____
- Divorced _____

- Widowed _____

6. What is your highest level of education? _____

7. When were you diagnosed with Parkinson's disease? _____

8. Do you have any other medical or psychiatric conditions?

APPENDIX E

Informed Consent

Fatigue in Parkinson's Disease: A Qualitative Descriptive Study Exploring the Individual's Perspective

Conducted By: Amy Bruno, ANP-BC, PhD(c) of the University of Massachusetts Dartmouth, College of Nursing; [REDACTED]

Faculty Advisor: Dr. Susan Hunter Revell; [REDACTED], [REDACTED] - [REDACTED]

CONSENT FORM FOR RESEARCH

You are being asked to participate in a research study. This form provides you with information about the study. The person in charge of this research will also describe this study to you and answer all of your questions. Please read the information below and ask any questions you might have before deciding whether or not to take part. Your participation is entirely voluntary. You can refuse to participate without penalty or loss of benefits to which you are otherwise entitled. You can stop your participation at any time and your refusal will not impact current or future relationships with UMass Dartmouth or participating sites. To do so simply tell the researcher you wish to stop participation. The researcher will provide you with a copy of this consent for your records.

I have been asked to participate in a research study described below. The researcher, Amy Bruno, ANP-BC, PhD(c) will explain the project to me in detail. I should feel free to ask any questions. If I have more questions later, Amy Bruno, the principal investigator on this study, will discuss them with me and can be contacted at [REDACTED].

Purpose of this Study

The purpose of this study is to explore fatigue in Parkinson's disease in order to better understand this symptom and how it affects an individual's life. I have been asked to participate in this study because I have a diagnosis of Parkinson's disease and I experience fatigue on a daily basis.

If I agree to participate in this study, the following procedures will take place:

- The researcher will meet with me in an interview at a time to be arranged for our mutual convenience. The location will also be mutually agreed upon and will be a quiet and convenient location.
- The interview will last approximately one to one and a half hours and it is expected this will take place during one meeting. If necessary, the interview may need to be completed in a second interview.
- During the interview, the researcher will ask me to describe the fatigue I live with, how it affects my daily life, what I do to manage my fatigue, and how fatigue is managed by my health care provider, if applicable.
- All interviews with the researcher will be audio recorded.
- The researcher may ask to call or email me for further questions and clarification after the interview is complete.
- I may decline to answer any question during the interview.
- The researcher may share general findings of the study with me and allow me time to provide additional information.

The total estimated time to participate in this study is one to one and a half hours.

Risks or discomfort of being in this study

This is a minimal risk study. This means that this study's risks are no greater than those of everyday life. However, if talking about a particular issue causes me any emotional discomfort or distress, I may choose not to discuss this further, or terminate participation in the study. If I choose to terminate the interview for any reason, I will give the researcher permission to use the information obtained during the partial interview. If I wish to have further assistance in dealing with my feelings, I will be referred to my health care provider or support person.

Benefits of being in this study

Although the results of this study may not be of immediate benefit to me, the information obtained from this study has important implications for individuals with Parkinson's disease. Fatigue is a common and disabling symptom in Parkinson's and has been shown in various studies to have a negative effect on an individual's quality of life. By participating in this study, you will provide important information about fatigue to nurse researchers and provide greater awareness about fatigue in Parkinson's disease.

Compensation

You will be given a 25\$ gift card to Target© as compensation for participating in this study.

Confidentiality

The information that I provide will be used for research purposes only, including teaching and publication. My participation in this study is confidential. My name will not be identified. All records, including notes and transcribed interviews, will not identify me by name and will be kept in a locked file in the researcher's home. All audio recordings will be kept secure by using a password protected file for each audio file. My name will not appear on the label of the recording. I will be identified by a unique code, assigned by the researcher, which will appear on the recording label. Records will be kept secure by the researcher for a period of three years upon conclusion of the study.

Confidentiality and Privacy Protections

- None of the information collected will identify me by name. Numbers will be used in place of names for the demographic information, interview transcripts and audio recordings so that no personally identifying information is visible on them.
- Researcher notes and audio recordings will be kept in a locked file cabinet or on a password protected file in the researcher's home. Only the researcher will have access to them.
- Audio recordings will be heard only for research purposes by the transcriptionist and researcher. The transcriptionist has signed a confidentiality agreement. To make future analysis possible, the researcher will retain the audio recordings in a password-protected file for a period of up to three years, and then destroy the audio recordings.
- It is anticipated that findings from this study will be submitted in a manuscript for publication. In that event, data will be summarized and be treated in such a manner that no individual's data, including mine will be identifiable.
- In the event the researcher suspects elder abuse and/or neglect, or feels that I am living in an unsafe environment, confidentiality will be broken in order to provide assistance.

The records of this study will be stored securely and kept confidential. Authorized persons from the University of Massachusetts Dartmouth, members of the Institutional Review Board, and (study sponsors, if any) have the legal right to review my research records and will protect the confidentiality of those records to the extent permitted by law. All publications will exclude any information that will make it possible to identify me as a subject. Throughout the study, the researchers will notify me of new information that may become available and that might affect my decision to remain in the study.

APPENDIX F

Conversational Guide

Introductory Statement

- **Tell me how long you have had fatigue.**
 - The introductory statement will set the tone for the interview and focus the CP specifically on his or her fatigue. It will give the researcher a general sense of how long the CP has been living with this symptom.

Main Question #1: Tell me about a day you experienced fatigue.

- This question will address how fatigue affects one's every day life.
- Additional probes may be necessary to guide the conversational partner and these may include:
 - When thinking about a bad day with fatigue, how would you describe:
 - That physical feeling?
 - That emotional feeling?
 - What is a good day with fatigue like for you? Describe how you feel physically, emotionally.
 - In what ways does fatigue affect how you take care of yourself?
 - Your relationships with family and friends. Tell me about how fatigue affects these relationships.
 - Your ability to take part in social activities. How does fatigue affect these experiences?

Main Question #2: I'm interested in learning about how fatigue impacts your life.

Describe for me how you feel when fatigue limits:

- your ability to take care of yourself
- your ability to spend time with family/friends
- your ability to do the things you want to do
- Is there a word that comes to mind when you think about what you miss out on because of your fatigue?
- How do you feel your family and friends perceive your fatigue?
- If the CP uses a specific word to discuss fatigue, the researcher will ask about that word when it is convenient in the conversation. This is to help gather rich data about how the CP is describing his or her fatigue.

Main Question #3: I would like to understand what is helpful in making your fatigue better. Can you tell me about any strategies you use?

- Tell me more about how that helps.
- Alternative therapies: do you use any of these to help with fatigue?
- Your medicine. Tell me about your experience with them to help your fatigue.

Main Question #4: I would like to learn more about your experiences with your doctor. Do you talk to your doctor about your fatigue?

- How does your doctor respond?
- Tell me more about what your doctor has said about fatigue.
- Can you describe for me how he (she) helps you manage your fatigue

Wrap-up:

- What has been the greatest challenge for you in having Parkinson's related fatigue?
- Is there anything else that we haven't covered in this interview about your experience with fatigue that you would like to talk about?

APPENDIX G

Confidentiality Agreement

In the performance of my duties as transcriber for this research study, I understand that I will have contact with confidential information. I understand that participants have received commitments of anonymity and confidentiality in exchange for their participation. I recognize that it is critical that each individual's privacy is respected and that any and all information that I may have access to as a result of transcribing for this study may not be disclosed to any other persons except the principal investigator.

I therefore agree that:

- I will not discuss or disclose in any manner any information identifying any individual participating in this study ("identifying information") except in the performance of job-related duties.
- I will conduct conversations and telephone calls involving identifying information in such a way that the confidentiality of that information is safeguarded against eavesdropping or other disclosure to unauthorized or unintended recipients.
- I will keep all recordings, documents and computer files involving or containing identifying information secure against unauthorized access or reading.

Signature and Date

Printed Name