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## The lived experiences of pain and fatigue in persons living with neurological conditions: A phenomenological study

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A thesis submitted in partial fulfillment of the requirements for the Master of Science degree in Health and Rehabilitation Sciences

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## Abstract

*Purpose:* The aim of the study was to understand the experiences and impact of pain and fatigue and to further explore the relationship between participants' descriptions of their lived experiences with these phenomena within and across multiple sclerosis, Parkinson's disease, and cerebral palsy. *Methods:* Semi-structured interviews were used to interview nine participants about their experiences of living with pain and fatigue in their respective conditions. A new phenomenological approach was adopted, and data was analyzed inductively using interpretive phenomenological analysis. *Results:* Three final themes including a lack of understanding, negative perceptions of pain and fatigue, and coping strategies used to manage these phenomena within and across conditions. Across conditions, pain and fatigue negatively impacted the biopsychosocial aspects of these persons' lives, reducing their quality of life and overall well-being. *Conclusion:* Future researchers and clinicians should focus on emphasizing their patients' lived experiences as essential in advancing research and healthcare in this field.

## Keywords

Pain, fatigue, multiple sclerosis, cerebral palsy, Parkinson's disease, biological pain, biological fatigue, physical pain, physical fatigue, mental fatigue, emotional pain, emotional fatigue, cognitive pain, cognitive fatigue, social experience, biopsychosocial experience, biopsychosocial model

## Summary for Lay Audience

Pain and fatigue in multiple sclerosis (MS), Parkinson's disease (PD), and cerebral palsy (CP) are reported as the most common and disabling symptoms and are often under-emphasized and poorly understood within daily life and healthcare settings. Due to the individual experiences of pain and fatigue in persons living with neurological conditions, these symptoms are described as being personal and complex in nature. Pain and fatigue have been shown to negatively affect functionality, mobility, quality of life (QoL), and the overall well-being of adults with these conditions. The aim of this study was to understand the experiences of pain and fatigue within and across these neurological conditions and explore the similarities and differences between the experiences of these symptoms from the descriptions provided by participants. Nine participants participated in semi-structured interviews centered on the physical, cognitive, emotional, and social aspects that may influence a person's lived experience with pain and fatigue across conditions. The study found a lack of understanding, negative perceptions of pain and fatigue, and coping strategies used to manage these symptoms across conditions to be the most prevalent topics discussed by participants throughout their interviews. Pain and fatigue were found to negatively impact the physical, cognitive, emotional, and social aspects of persons experiencing pain and fatigue across conditions, further resulting in a poorer QoL and overall well-being. Future research should emphasize using qualitative research methods to further explore and understand the lived experiences of pain and fatigue within and across neurological conditions, and the impact biopsychosocial factors have on this experience. This research may help clinicians and caregivers caring for people with MS, PD, and CP to develop a more informed and personalized approach to improve the current management and intervention plans.

## Co-Authorship Statement

The study objectives, research questions, and study design were developed by Lauren Kane and Dr. Laura Brunton. The final semi-structured interview guide was developed by Lauren Kane, Dr. Laura Brunton, Dr. Janelle Unger, and Dr. David Walton. Data collection and analysis processes were completed first by Lauren Kane and then with consultation with Dr. Laura Brunton. All manuscript writing was completed by Lauren Kane, with revisions, suggestions, and feedback of all chapters made by Dr. Laura Brunton. All references and additional sources are appropriately referenced in the final manuscript.

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## List of Abbreviations

|       |  |
|-------|--|
| MS    | Multiple sclerosis                       |
| CP    | Cerebral palsy                           |
| PD    | Parkinson's disease                      |
| QoL   | Quality of life                          |
| HRQoL | Health-related quality of life           |
| MSRP  | MS-related pain                          |
| MSRF  | MS-related fatigue                       |
| CNS   | Central nervous system                   |
| CIS   | Clinically isolated syndrome             |
| RRMS  | Relapsing-remitting multiple sclerosis   |
| PPMS  | Primary-progressive multiple sclerosis   |
| SPMS  | Secondary-progressive multiple sclerosis |
| IPA   | Interpretive phenomenological analysis   |
| PAR   | Participatory action research            |

# 1 Introduction and Background

## 1.1 Statement of the problem

Multiple sclerosis (MS) and Parkinson's disease (PD) are progressive neurodegenerative disorders characterized by degeneration of the central and peripheral nervous systems (Ayache & Chalah, 2017; Ayano, 2016; Bruno & Sethares, 2015; Sadowska, Sarecka-Hujar & Kopyta, 2020), with MS further presenting as an autoimmune inflammatory condition due to its indeterminate disease course (Newton, Griffith & Soundy, 2020; Oh, Vidal-Jordana & Montalban, 2018). Cerebral palsy (CP) is defined as a group of permanent disorders of movement and posture characterized by non-progressive disturbances in the developing fetal or infant brain (Rosenbaum et al., 2007). However, changes in the manifestation, appearance, and consequences of CP may occur with age (Brunton & Bartlett, 2013). Pain and fatigue are among a wide array of clinical symptoms affecting those with MS, PD, and CP; and have been reported as the most common and disabling non-motor symptoms within and across these neurological conditions (Newton, Griffith & Soundy, 2020; Flensner, Ek & Söderhamn, 2003; Charvet, Serafin & Krupp, 2014; Graham et al., 2016; Del Sorbo & Albanese, 2012). Pain and fatigue are subjective in nature and are highly dependent upon an individual's perceptions and personal experience (Raja et al., 2020; Ream & Richardson, 1996). The updated consensus definition of pain states it is an unpleasant experience with sensory and emotional components resembling that associated with actual or potential tissue damage (Raja et al., 2020). The definition of fatigue authored by Ream & Richardson (1996) is widely used across disciplines and defines fatigue as a subjective, unpleasant, and unrelenting



condition interfering with one's ability to function to their normal capacity due to extensive feelings from tiredness to exhaustion.

Pain and fatigue have been shown to negatively affect motor function (Ayano, 2016; Charvet, Serafin & Krupp, 2014; Rosenbaum et al., 2007; Mills & Young, 2008; Pradhan & Srivastava, 2020), quality of life (QoL), and overall well-being (Bruno & Sethares, 2015; Del Sorbo & Albanese, 2012; Brunton, McPhee & Gorter, 2021; Gromisch, Kerns & Beauvais, 2019; Skogar et al., 2012; Truini, Frontoni & Cruccu, 2013) of adults with these conditions. The consequences of these non-motor symptoms impact the daily life and greater life course of individuals with MS, PD, and CP to a greater degree than in the general population. These symptoms are identified as multidimensional, complex, and subjective and are influenced by biopsychosocial (biological, psychological, and social) factors (Flensner, Ek & Söderhamn, 2003; Raja et al., 2020). It is due to the multidimensionality and subjectivity of these phenomena that relying on objective measurements and quantitative approaches of assessment has been viewed as inappropriate when attempting to understand meaning and experience (Ream & Richardson, 1996).

Research and clinical experts under-emphasize the patient perspective of experiences with pain and fatigue by focusing on the visible and measurable effects these symptoms present (Newton, Griffith & Soundy, 2020; Del Sorbo & Albanese, 2012; Flensner, Ek & Söderhamn, 2003; Olsson, Lexell & Söderberg, 2008), underestimating the importance of the subjective experience of pain and fatigue as lived by the patient. In addition, researchers, clinical experts, and others are unable to understand the meaning of these experiences (Flensner, Ek & Söderhamn, 2003), making clinical management and

treatment challenging (Newton, Griffith & Soundy, 2020). Reasons for this lack of understanding can include, (1) a lack of consideration of the “how” or “why” these phenomena affect an individual; (2) studying the association of symptoms and experiences versus the “how” or “why” that experience occurs (Newton, Griffith & Soundy, 2020); (3) difficulty in grasping the meaning of pain and fatigue due to the invisibility of these phenomena to others; and (4) different views and perspectives between involved parties in a clinical encounter (Flensner, Ek & Söderhamn, 2003). The devaluation of lived experiences in our healthcare system and research can negatively impact the quality of healthcare available to patients.

The importance of understanding the phenomena of pain and fatigue through lived experiences is underpinned by the need to respect a person’s report of their experience (Raja et al., 2020), outlining the need for a voice to be given to those experiencing pain and fatigue as a part of their condition. Research has been centered on studying pain and fatigue *within* condition specific silo’s (i.e. solely MS) creating a lack of research and understanding *across* conditions. For example, a greater amount of research on pain and fatigue has been studied specifically in MS as opposed to PD and CP. Therefore, this shows us that the existing knowledge of the experience of pain and fatigue within MS may be leveraged to enhance the understanding in PD and CP; and allows us to explore and understand if similarities exist between the lived experiences of these phenomena *across* conditions, and/or if differences between the lived experiences exist *within and across* these conditions. This has created a need to expand our research focus to study these phenomena beyond the condition specific silo’s in these neurological conditions. Furthermore, knowledge on the lived experiences and meaning of pain and

fatigue from the patient perspective is insufficient and needed to enhance the overall well-being of individuals with the specified conditions. Furthermore, these experiences could inform education, create supportive coping strategies and enhance understanding and awareness of these symptoms by clinicians responsible for assessing and treating these conditions with the overall goal of advancing care for adults with MS, PD and CP.

## 1.2 Literature Review

### 1.2.1 Current knowledge of pain and fatigue

The consensus definition of pain was first defined in 1979 by the International Association for the Study of Pain (IASP) as “an unpleasant sensory and emotional experience associated with actual or potential tissue damage or described in terms of such damage” (Raja et al., 2020, p. 1976-1977). Due to advances in our understanding of pain, for the first time since 1979, this definition has undergone revisions and the new 2020 definition is “an unpleasant sensory or emotional experience associated with, or resembling that associated with, actual or potential tissue damage” (Raja et al., 2020, p. 1976-1977, International Association for the Study of Pain [IASP], 2020). This revised definition was intended to be more inclusive of the individual experiences of pain while continually recognizing its diverse and complex association with biological, psychological, and social factors (Raja et al., 2020; IASP, 2020; Sonneborn & Williams, 2020). The IASP expanded upon their most recent definition by adding several key notes. One of these key notes is that the concept of pain can be learned from lived experiences (IASP, 2020; Raja et al., 2020). This note aids in affirming that we can seek to understand the meaning of this phenomenon through participant narratives of their experiences with pain and fatigue.

Ream & Richardson (1996) provided a definition of fatigue which was proposed for nursing use, stating that “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’ ability to function to their normal capacity” (p. 527). This definition places a focus on the fact that objective measures may not be appropriate in the study of a phenomenon such as fatigue, due to its multidimensional and subjective nature (Ream & Richardson, 1996).

### 1.2.2 Multiple Sclerosis

Multiple sclerosis is defined as a chronic, inflammatory, and progressive autoimmune disease of the central nervous system (CNS), characterized by demyelination and axonal degeneration (Oh et al., 2018). There are four distinct clinical disease courses of MS including clinically isolated syndrome (CIS), relapsing-remitting MS (RRMS), primary progressive MS (PPMS), and secondary progressive MS (SPMS) (Dobson & Giovannoni, 2019). CIS is the initial clinical event preceding MS in approximately 85% of patients (Kuhle et al., 2015; Piri Cinar & Ozakbas, 2018). Similarly, approximately 85% of patients experience a relapse leading to RRMS, and of those ~75% experience SPMS as a progression of their RRMS. The clinical course of these types of MS is characterized by relapses and disease progression with the transition from RRMS to SPMS remains unclear due to the varying pathology (Kamm, Uitdehaag & Polman, 2014; Dobson & Giovannoni, 2019; Oh et al., 2018). Finally, 15% of patients are known to have PPMS (Kamm, Uitdehaag & Polman, 2014) involving direct progression of the condition (Dobson & Giovannoni, 2019). The age of onset of MS is typically between 20 to 40 years of age (Oh et al., 2018), with RRMS and SPMS

occurring around the age of 30 years and PPMS occurring at approximately 40 years of age (Mills & Young, 2008).

There is significant variation in the prevalence of MS worldwide, however, the current global median prevalence is 33 cases per 100,000 people; with the global incidence of MS continually increasing (Oh et al., 2018). Disease activity and progression create an extremely variable disease course, causing prognosis to be difficult (Oh et al., 2018). Clinical presentations of MS can typically include: optic neuritis, gait ataxia, paresis, sensory deficits, corticospinal tract and/or cerebellar dysfunction, and spasticity (Kamm, Uitdehaag & Polman, 2014). The clinical diagnosis of MS is made based on the demonstration of lesions in the CNS on clinical and/or magnetic resonance imaging (MRI) findings (Kamm, Uitdehaag & Polman, 2014; Oh et al., 2018). The use of MRI, blood tests, and the presence of oligoclonal bands in cerebrospinal fluid can also be used in diagnosing MS (Oh et al., 2018). Treatment and management of MS can include, (1) disease-modifying therapies (ex. Immunosuppressants and immune reconstitution therapies); (2) symptomatic treatments (ex. Anticholinergics and neuropathic pain medication); and (3) comorbidity treatment (ex. Lifestyle and well-being modifications, aerobic exercise, and healthy eating) (Dobson & Giovannoni, 2019).

### 1.2.2.1 Pain in multiple sclerosis

Pain is a common and disabling symptom that frequently accompanies a diagnosis of MS (Svendson et al., 2005; Ehde et al., 2006; Newton, Griffith & Soundy, 2020; Flensner, Ek & Söderhamn, 2003). The prevalence of MS-related pain (MSRP) ranges from 29% to 86%, with an estimated 72% of the older population (typically 50 years of age or older) being affected (O'Connor et al., 2008). Prevalence rates of MSRP likely

vary due to the methodological variability in sampling methods and methodologies used across studies. The nature of MSRP can be musculoskeletal or neuropathic, acute, or chronic (Ehde et al., 2006) and persons may experience any of these four types of pain during the course of their MS. Persons with MS may experience chronic musculoskeletal or neuropathic pain or acute musculoskeletal or neuropathic pain. The location of the pain can originate from various sites, with severity of the symptom increasing when pain is experienced in more than one location (Ehde et al., 2006; Gromisch, Kerns & Beauvais, 2019). Several risk factors are associated with pain in persons living with MS, including: older age, female sex, a lower level of education, increased healthcare use, longer disease duration, and greater disease severity (Ghajarzadeh et al., 2018; Sharbanian, Duquette & Mayo, 2018). Pain can be either unrelated to or secondary to MS disease processes (see section 1.2.2) (Ehde et al., 2006); and is often characterized as a secondary factor, meaning this phenomenon may exacerbate or cause fatigue, which can lead to deconditioning resulting in further functional impairments (Charvet et al., 2014).

MSRP is reported to lower overall health-related quality-of-life (HRQoL) and can result in poorer mental and general health for people with MS (Ghajarzadeh et al., 2018; Sharbanian, Duquette & Mayo, 2018). Additionally, MSRP can negatively affect an individual's activity levels, their ability to hold employment, participate in social activities and personal relationships, sleep habits, and mental health through increased depression (Gromisch, Kerns & Beauvais, 2019; Sharbanian, Duquette & Mayo, 2018). Interestingly, Sharhrbanian and colleagues (2018) found that persons with MS who did not experience pain were less fatigued and thus reported higher energy and activity levels and were more likely to be employed. However, for those who experience pain as a

symptom of their MS, there are negative associations with the physical and psychological aspects of a person's well-being (Gromisch, Kerns & Beauvais, 2019). Despite knowledge of the significant impact on the physical (biological), psychological, and social aspects of pain in MS, the experience of pain is still vastly under-emphasized and poorly understood by researchers and clinicians.

The underestimation of the effect of MSRP has been suggested to be due to its multidimensional, subjective, and complex nature, and the relationship between pain and fatigue (Shahrbanian et al., 2018). Previous studies on pain in MS, seem to identify this phenomenon as a uni-dimensional outcome or focus on biological dimensions such as intensity and duration; therefore, research is missing across the various dimensions of impact (including the lack of understanding of psychosocial factors). Although the IASP definition of pain was recently changed to acknowledge personal experience, this change is solely recognized in the notes supporting the primary definition. It is clear that MSRP requires an in-depth analysis and consideration of the biopsychosocial factors and how they contribute to the pain experienced by people with MS.

While current literature acknowledges the subjectivity of the phenomenon of pain in MS, a substantial gap exists in studying descriptions of the lived experiences of MSRP from the patient perspective and its impact on the daily life and greater life course of these individuals. This knowledge is required to reduce the negative impact and association of pain on persons with MS and increase the clinical course of management and treatment.

### 1.2.2.2 Fatigue in multiple sclerosis

Fatigue is the most common and disabling symptom of MS, with people considering fatigue to be their most serious or among their worst symptoms (Krupp et al., 1988; Fisk et al., 1994; Flensner, Ek & Söderhamn, 2003). MS-related fatigue (MSRF) is often noted by people as their first symptom of MS which then persisted throughout the course of their condition. People often report the fatigue associated with MS to be different than the fatigue they experienced before (Krupp & Christodoulou, 2001). It has been estimated that between 78% to 87% of persons with MS experience severe fatigue (Krupp et al., 1988). The nature of MSRF can be acute and intermittent or chronic and persistent (Krupp & Christodoulou, 2001). The experience of MSRF is derived from both primary and secondary factors (Charvet, Serafin & Krupp, 2014); primary fatigue relates directly to damage of the CNS, while secondary fatigue is related to comorbid symptoms of MS. Fatigue can be influenced by comorbid disease factors such as: pain, depression, anxiety, sleeplessness, and heat sensitivity (Krupp & Christodoulou, 2001; Charvet, Serafin & Krupp, 2014; Mills & Young, 2008). The risk of fatigue can increase with relapses, further disability, and loss of ambulation (Charvet, Serafin & Krupp, 2014). Pain, in combination with deconditioning, can worsen fatigue over time, contributing to the exacerbation of functional impairments in those with MS (Charvet, Serafin & Krupp, 2014).

MSRF is identified as multidimensional, complex, and highly subjective with increasing evidence of its impact on the biopsychosocial and emotional aspects of a person's life (Ream & Richardson, 1996; Flensner, Ek & Söderhamn, 2003; Smith &



Hale, 2007). Psychosocial factors such as personality, age, gender, beliefs, and prior experience can contribute to the subjective experience of fatigue (Smith & Hale, 2007).

An individual's voice is the most effective descriptor to convey the experience of fatigue. Previous studies have sought to describe the lived experiences of fatigue by exploring this symptom through the patient perspective and narrative. Patient descriptions of MSRF represent multiple dimensions including the physical, cognitive, emotional, and social factors impacting their lives. A lack of or no energy was described as feeling 'drained' and 'empty' (Newton, Griffith & Soundy, 2020; Mills & Young, 2008; Olsson, Lexell & Söderberg, 2005; Stuifbergen & Rogers, 1997). This feeling of being drained of energy was illustrated by this idea of 'discharging a battery' which could happen rapidly (Flensner, Ek & Söderhamn, 2003), and fatigue could come on easily (Krupp et al., 1988). Fatigue has been represented as a feeling of tiredness and exhaustion, distinct from common tiredness and exhaustion in healthy people (Flensner, Ek & Söderhamn, 2003; Olsson, Lexell & Söderberg, 2005; Mills & Young, 2008). Also, a distinction has been made between common tiredness and exhaustion from depression, weakness, or sleepiness (Charvet, Serafin & Krupp, 2014). Sleepiness and sleeplessness were commonly experienced as a result of fatigue; leading to the need to sleep or rest for varying lengths of times to improve and/or manage fatigue (Mills & Young, 2008; Newton, Griffith & Soundy, 2020; Krupp et al., 1988; Stuifbergen & Rogers, 1997).

Persons experiencing MSRF often felt as though their limbs or whole body were heavy and their muscles were weak or lacked muscle strength (Newton, Griffith & Soundy, 2020; Mills & Young, 2008; Olsson, Lexell & Söderberg, 2005; Flensner, Ek & Söderhamn, 2003; Béthoux, 2006). The inability to perform activities of daily living was

often expressed as an impediment or involuntary stop in accomplishing tasks or desired activities (Newton, Griffith & Soundy, 2020; Mills & Young, 2008; Cowan, Pierson & Leggat, 2020). The experience of MSRF was found to restrict familial and social lives, personal commitments, self-care, relationships, and work (Stuifbergen & Rogers, 1997; Flensner, Ek & Söderhamn, 2003; Olsson, Lexell & Söderberg, 2005; Béthoux, 2006). MSRF has been perceived as limiting, interfering with, or preventing intermittent or sustained physical functioning (Krupp et al., 1988; Newton, Griffith & Soundy, 2020).

Opportunities for social participation were generally limited due to fatigue (Cowan, Pierson & Leggat, 2020). One reason for this lack of ability to partake in social activities has been related to the lack of understanding of the experiences of MSRF by others (Newton, Griffith & Soundy, 2020; Olsson, Lexell & Söderberg, 2005). Interestingly, patients have noted how they themselves were limited in their understanding of their own condition (Olsson, Lexell & Söderberg, 2005). Physical and mental MSRF can lead to a loss of independence which causes people to feel ‘trapped’ or the desire to isolate themselves from others (Newton, Griffith & Soundy, 2020; Flensner, Ek & Söderhamn, 2003; Smith & Hale, 2007; Olsson, Lexell & Söderberg, 2005). Additionally, reduced or absent motivation to perform certain tasks or activities has been described as an ongoing challenge for persons with MSRF (Mills & Young, 2008; Krupp et al., 1988). Patients often describe that they now have limited employment opportunities, lack employment, or can no longer work due to MSRF (Cowan, Pierson & Leggat, 2020); and they express feelings of ‘shame’ or ‘guilt’ related to not working (Flensner, Ek & Söderhamn, 2003). They find it hard to live as they did before and may

desire to regain their previous life and capabilities they once had (Olsson, Lexell & Söderberg, 2005).

Depression, stress, and anxiety have been shown to be negatively associated with increasing fatigue levels (Newton, Griffith & Soundy, 2020; Mills & Young, 2008; Krupp & Christodoulou, 2001); with fatigue being a source of depression and vice versa (Béthoux, 2006). Depression, exercise, and the end of a day have been described as factors which aggravate fatigue (Krupp et al., 1988). The emotional hardship for many of these individuals is significant, as many of them expressed feelings of ‘sorrow’, ‘shame’, being ‘worthless’, ‘disappointed’, ‘embarrassed’, ‘fear’, and ‘worry’ (Newton, Griffith & Soundy, 2020; Flensner, Ek & Söderhamn, 2003). Additional feelings described include ‘weariness’, ‘defeat’, ‘anger’, ‘despair’, ‘sadness’, ‘helpless’, ‘overwhelming’, and being ‘uncertain’ (Mills & Young, 2008; Flensner, Ek & Söderhamn, 2003; Olsson, Lexell & Söderberg, 2008). Stuifbergen and Rogers (1997) have suggested that MSRF essentially reduces joy in these persons’ lives.

Stuifbergen and Rogers (1997) and Olsson and colleagues (2005) noted that the experience of MSRF can impair individuals’ capability to make decisions regarding activities and responsibilities regarding work, home, and leisure. Cognitive challenges are shown to be associated with MSRF-related difficulties in the daily lives of those living with this condition, including: poor concentration and attention, increased mental effort, memory and recall issues, and overall problems thinking clearly (Newton, Griffith & Soundy, 2020; Mills & Young, 2008; Olsson, Lexell & Söderberg, 2005; Stuifbergen & Rogers, 1997).

An additional factor influencing MSRF is the weather. Heat, direct sunlight, humidity, and cold are all causal factors that can increase fatigue (Stuifbergen & Rogers, 1997; Krupp et al., 1988). Newton and colleagues (2020) noted that spasticity associated with MS may increase due to the cold, which in turn increases fatigue. Likewise, a rise in temperature may increase fatigue causing an increase in physical symptoms, emotional irritability, and cognitive difficulty (Stuifbergen & Rogers, 1997). When heat is involved, some individuals report using cooling techniques to combat their fatigue (Mills & Young, 2008; Charvet, Serafin & Krupp, 2014).

There are several coping strategies that have been reported as useful in attempt to manage the ongoing challenges that persons with MSRF face in their daily lives. One of the most used coping strategies is rest. Patients expressed how rest can help to improve their fatigue, dependent upon how much rest is required to help plan their day-to-day or deal with the onset of MSRF (Newton, Griffith & Soundy, 2020). Rest may also help to recover their bodies and restore their energy levels (Mills & Young, 2008; Krupp et al. 1988; Stuifbergen & Rogers, 1997; Smith & Hale, 2007). Additional strategies reported include exercise, eating nutritious meals, controlling temperature, positivity, and conserving energy by doing less, working smart, and receiving help from others (Stuifbergen & Rogers, 1997). Flensner and colleagues (2003) and Newton and colleagues (2020) described how persons coped with MSRF by accepting their life as it is. This included accepting their limits and boundaries, framing their lives how they want to live them, focusing on the positive and learning how to accept other aspects of their condition. Persons with MSRF expressed a desire to structure their lives through planning, meal prepping, and prioritizing activities they want to do, which lowered stress

and saved energy (Flensner, Ek & Söderhamn, 2003; Newton, Griffith & Soundy, 2020; Mills & Young, 2008; Olsson, Lexell & Söderberg, 2005). Another way to lower fatigue-related stress was through the creation of environments to meet the physical and psychological needs of those experiencing MSRF (Krupp and Christodoulou, 2001).

In summary, fatigue is an invisible symptom with a significant impact on daily life for those living with MS (Cowan, Pierson & Leggat, 2020; Olsson, Lexell & Söderberg, 2005). It disrupts general well-being (Krupp and Christodoulou, 2001), and is negatively associated with QoL and perceived health status (Béthoux, 2006). In this respect, MSRF is different than transient fatigue experienced by people who are healthy (Krupp et al., 1988). Fatigue in MS is constant, and ongoing, with MSRF being recognized as time-consuming and all-absorbing (Smith & Hale, 2007; Flensner, Ek & Söderhamn, 2003; Stuifbergen & Rogers, 1997; Olsson, Lexell & Söderberg, 2005). Fatigue has been described as an unpredictable ‘paralyzing force/power’ invading the whole body (or numerous parts of it) (Flensner, Ek & Söderhamn, 2003; Newton, Griffith & Soundy, 2020; Smith & Hale, 2007; Stuifbergen & Rogers, 1997); and therefore, MSRF should be recognized as a ‘whole body experience’ (Olsson, Lexell & Söderberg, 2005). This experience of fatigue is perceived as feeling numb and betrayed due to the invasion of MSRF in the body, which led to an increased bodily awareness. To continue to explore the symptom itself and lived experience of MSRF, knowledge regarding the physical, cognitive, emotional, and social aspects impacting daily life and the use of coping strategies to manage the physical and cognitive challenges associated with fatigue is required.

### 1.2.3 Parkinson's Disease

PD is a chronic, progressive neurodegenerative disease (Ayano, 2016) characterized by motor and non-motor symptoms (the former related to dopamine deficiency in the striatum) (Chen & Tsai, 2010) associated with a loss of dopaminergic neurons in the substantia nigra pars compacta (Young Blood et al., 2016). Persons experiencing PD may experience motor fluctuations in their condition known as the on/off phenomenon (Bieske et al., 2009). The prevalence and annual incidence of this condition range from 100 to 200 per 100,000 and 15 per 100,000 people, respectively (Tysnes & Storstein, 2017; Elbaz et al., 2016). The mean age of onset typically occurs around 60 years of age and affects 50% more men than women for unknown reasons (Bruno & Sethares, 2015; Ayano, 2016).

Numerous prognostics factors are useful to understand the progression of PD including timing of disease onset, sex, presence of dementia, cardinal motor symptoms, autonomic failure, poor levodopa response, and comorbidities associated with the condition (Rizek, Kumar & Jog, 2016; Chen & Tsai, 2010). Motor symptoms can include tremor, rigidity, bradykinesia, postural and gait instability; non-motor aspects include sleep disorders, pain, fatigue, cognitive and/or behavioral impairments (Bruno & Sethares, 2015). Subjective complaints have been described in a generalized sense by persons with PD in relation to functional motor impairments as stiffness, slowness in movement, feelings of imbalance, a sense of falling and/or tremors in the arms, head, or legs (de Lau et al., 2006). Diagnosis is made when an individual presents with tremor, rigidity, and bradykinesia (Ayano, 2016). Exclusion criteria is determined through

patients' family and medical history, and a neurological evaluation is performed (Elbaz et al., 2016; Pradhan & Srivastava, 2020; Rizek, Kumar & Jog, 2016).

PD has been reported as the second most common neurodegenerative disease after Alzheimer's disease (Kluger et al., 2016). Increasing age is a risk factor for PD, and it is likely that the aging population is the cause of rising incidence rates of PD in Canada (Ayano, 2016). Additionally, other risk factors associated with PD include exposure to environmental factors (ex. Pesticides, herbicides, and various metals), mutations in the parkin and LRRK2 genes and others, history of brain injury, anti-inflammatory drugs, and increased body mass index (Chen & Tsai, 2010; Elbaz et al., 2016; Pradhan & Srivastava, 2020; Rizek, Kumar & Jog, 2016). Interestingly, physical activity and drinking coffee and/or tea have been found to lower the risk of PD (Chen & Tsai, 2010). PD can be treated using a combination of psychosocial treatment, physiotherapy, speech therapy, dietary intervention, pharmacological management (ex. Levodopa and anticholinergic drugs), and surgery (ex. Deep brain stimulation) (Ayano, 2016; Pradhan & Srivastava, 2020; Rizek, Kumar & Jog, 2016).

### 1.2.3.1 Pain in Parkinson's disease

Pain in PD is characterized as a common pre- and non-motor symptom and is described as a subjective phenomenon which can result in the impairment of QoL (Fil et al., 2013; Truini, Frontini & Criccu, 2013; Twomey, Stuart & Baker, 2018) and negatively impact HRQoL (specifically, bodily pain, general health, and social functioning) (Skogar et al., 2012). Personal to each individual with PD, their pain may be more disabling than their motor symptoms, resulting in a poorer QoL (Del Sorbo & Albanese, 2012). The prevalence of PD-related pain has been shown to vary between

34% to 83% (Young Blood et al., 2016). Approximately 80% of patients with PD are known to experience chronic pain over the course of their disease (Bieske et al., 2009). The variability in prevalence could be due to the assessment of the different types of pain in PD (Del Sorbo & Albanese, 2012), as some studies only look at/assess some of the types of pain in PD, while others may assess all types of pain which would result in increased prevalence; the variation in the methodologies and sample sizes used across studies may also influence prevalence rates.

PD-related pain has been characterized by five different types of pain: musculoskeletal, radicular-neuropathic, dystonic, central neuropathic pain, and akathisia (Ford et al., 2010; Fil et al., 2013; Young Blood et al., 2016). Musculoskeletal pain is associated with rigidity and akinesia along with a lack of mobility and abnormal posture (Ford et al., 2010; Young Blood et al., 2016). The prevalence of persons experiencing this type of PD-related pain is approximately 45% to 74% (Fil et al., 2013). Radicular-neuropathic pain is localized to the affected nerve or nerve root (Ford et al., 2010; Young Blood et al., 2016) with a prevalence of this pain type ranging from 5% to 20% in those with PD (Fil et al., 2013). Dystonia is related to a forceful twisting movement which leads to postural abnormalities and deformities; spasms associated with dystonia create one of the most painful experiences for persons with PD (Ford et al., 2010; Young Blood et al., 2016). The prevalence of pain related to dystonia is approximately 8% to 47% (Fil et al., 2013). Central neuropathic pain originates as a direct cause of PD itself and is not a result of rigidity, bradykinesia, or musculoskeletal cause associated with PD (Ford et al., 2010; Young Blood et al., 2016). An estimated 10% to 12% of persons with PD experience this type of pain (Fil et al., 2013). Akathisia can be a potentially disabling



type of pain in PD as it is associated with a subjective inner restlessness leading to a lack of ability to remain still (Ford et al., 2010; Young Blood et al., 2016). Although not categorized as a type of PD-related pain, restless leg syndrome causes intense sensations in the extremities which improve with movement. The prevalence of this syndrome ranges from 8% to 20% in persons with PD (Fil et al., 2013).

Factors which may potentially affect PD-related pain include: age, gender, severity and duration of disease, depression, and pre-existing disturbances (Fil et al., 2013). The prevalence of pain is known to increase with age, however, the effect of age on pain presence remains controversial across studies (Beiske et al., 2009). Pain is found to affect females more than males, with both sexes reporting pain in different locations of the body (Bieske et al., 2009; Coriolano et al., 2014). PD-related pain is observed to increase with disease severity and duration. The degenerative and progressive nature of the disease may affect pain transmission, reception, and interpretation (Fil et al., 2013). The emotional dimension of pain and the subjective perceptions of pain intensity may be affected due to the involvement of the striatum in PD (Fil et al., 2013). The frequency of pain in PD increases in those experiencing depression. Pre-existing pain from systemic diseases such as diabetes or osteoporosis may continue post-PD diagnosis; noting that post-diagnosis pain may also be related to age instead of the condition itself (Fil et al., 2013). Conversely, Bieske and colleagues (2009) found pain to be independent of demographic and clinical variables such as the duration and severity of PD. An increase in PD-related pain occurs during off-periods (Bieske et al., 2009), where individuals may require more rest, sleep, and less activity to accommodate for the pain.

The presence of pain can heighten the physical, psychological, and social effects of PD (Twomey, Stuart & Baker, 2018); and there is a need to discuss these effects from the patient perspective to understand how PD-related pain affects their day-to-day lives. Descriptions of pain have been remarked by persons with PD as being tiring and troublesome, with the most common descriptors being ‘nagging’, ‘throbbing’, and ‘acute’ (Coriolano et al., 2014; Skogar et al., 2012). Additional descriptors of pain frequently expressed by these individuals include ‘increasing’, ‘strong’, ‘tearing’, ‘radiating’, ‘fearful’, ‘cramping’, ‘burning’, ‘aching’, ‘exhausting’, and ‘debilitating’ (Coriolano et al., 2014). How pain is perceived and further described by persons with PD can be affected by pain intensity. Coriolano and colleagues (2014) discussed how patients described their current pain intensity as ‘distressing’, ‘horrible’, and ‘excruciating’; however, this may be person-dependent varying with each person’s intensity levels of pain. How persons with PD experience pain can differ between sexes with, for example, in the study by Skogar and colleagues (2012) more males than females experienced restless leg syndrome. Further expressions of pain detailed by those experiencing this phenomenon include ‘migrating’, ‘irritating’, ‘worrying’, and ‘suffocating’ (Skogar et al., 2012).

Experiencing such a large number of feelings and emotions associated with pain can negatively impact the psychological state of a human being. Twomey and colleagues (2018) perceived the psychological impact on persons with PD in terms of despair and despondency. These individuals often had negative thoughts causing their mood to lower which caused their pain to increase. Feelings of hopelessness, suffering, depression, and anxiety were described, with PD patients noting that they may use anti-depressants to

control their depression (Twomey, Stuart & Baker, 2018). When the pain was just unbearable, persons with PD made statements regarding suicidal thoughts as they felt they were a victim to the pain.

Pain created a sense of isolation and exclusion, with social isolation resulting in poorer psychological well-being (Twomey, Stuart & Baker, 2018). Having a social life was often a distant thought and perceived as non-existent nor possible to have a relationship with a significant other. Feelings of guilt brought on the feeling they had to hide their painful experience from loved ones as to not be a burden on their carer (Twomey, Stuart & Baker, 2018). Guilt may also result as the persons experiencing PD-related pain may sympathize with their family in relation to the hardship they've placed on their lives. Participation in social events can be difficult due to sleep deprivation, as most people generally receive 3 to 4 hours of sleep a night due to pain (Skogar et al., 2012); therefore, pain generally dictates their daily life and results in reduced participation in life (Twomey, Stuart & Baker, 2018). Acceptance was described in terms of accepting their pain so they could overcome and remain in control of their own life, which was often accomplished by employing coping strategies.

Coping strategies are employed by individuals with PD as a way to live with their pain and attempt to manage it. An inner battle to overcome their pain, accept it and achieve control of their own life was described by those with PD (Twomey, Stuart & Baker, 2018). They often spoke of 'mind over matter' in attempting to control their physical being (Twomey, Stuart & Baker, 2018) which then helped to control the psychosocial aspects of their life. In spite of this, PD-related pain was described as an all-consuming phenomenon, so not everyone could accept their pain and lacked the

motivation to do so as they felt defeated (Twomey, Stuart & Baker, 2018). Exercise and physical activity were described by persons with PD as major factors in managing their pain (Twomey, Stuart & Baker, 2018; Skogar et al., 2012). Exercise was noted as a source of pain relief as well as a distraction from the pain (Twomey, Stuart & Baker, 2018). Those with PD spoke of needing to force themselves to continue activities so they could get this relief. However, there is an evidence gap surrounding the specific dose and style of exercise that should be prescribed to each individual to address their pain (Twomey, Stuart & Baker, 2018). Both heat and cooling of the aching area were recognized as helpful ways of coping with the localized pain (Twomey, Stuart & Baker, 2018; Skogar et al., 2012). Using rest and controlled breathing were described by persons experiencing PD-related pain (Twomey, Stuart & Baker, 2018; Skogar et al., 2012), which helped to relax themselves and continue with their day. The need to be flexible in their day-to-day was required to be able to manage their pain as it could be unpredictable in when it arose. Additional coping strategies included having a bath, acupuncture, massage, transcutaneous nerve stimulation, or sonography. All of the above coping strategies are employed to manage not solely the physical needs of these individuals, but also their psychological and social needs related to pain.

Persons experiencing PD-related pain tended to feel as though they were treated by their clinician as a symptom, rather than as a person with biopsychosocial needs (Twomey, Stuart & Baker, 2018). They felt as though their clinician was not concerned with their psychosocial well-being or their care and lacked the time to discuss their needs. Therefore, a lack of rapport, trust, and understanding between the clinician and their patient, and a lack of understanding of the symptom of pain by the clinician themselves

were often noted (Twomey, Stuart & Baker, 2018). However, individuals with PD acknowledged their lack of understanding of their own pain, which led to them creating their own reasoning as to why PD-related pain was affecting them (Twomey, Stuart & Baker, 2018). This tended to lead to an increased impact on these person's psychological state.

The phenomenon of pain is multidimensional, subjective, and complex in nature (Twomey, Stuart & Baker, 2018), and therefore cannot be reduced to its physical components, but must also encompass biopsychosocial domains. Although pain is known to encompass cognitive and emotional components (Twomey, Stuart & Baker, 2018), clinicians often disregard patient complaints regarding this phenomenon, resulting in underdiagnosis and poor treatment of pain in PD (Del Sorbo & Albanese, 2012). Furthermore, research evidence has primarily focused on the quantifiable aspects of pain in PD including the onset, prevalence, classification, pathophysiology, and treatment outcomes. By solely studying the phenomenon of pain using objective assessments and measures, the patient perspectives of their experiences of pain in PD are undervalued. The exploration of the multidimensional experience is missing from the PD-related pain literature and is required to hear and understand the individual with PD regarding their symptoms, and to overcome a lack of a patient-centered care approach in clinical practice. Twomey and colleagues (2018) described how there is a lack of interplay between external support (medication and symptom management) and internal support (coping and self-management strategies). Future research observing this lack of interplay is required to be able to combine external and internal support in the management and treatment of pain in PD.

### 1.2.3.2 Fatigue in Parkinson's disease

Fatigue has been reported as a common, frequent, and disabling non-motor symptom of PD; and is identified as one of the *most* disabling symptoms among those with PD (Friedman, Abrantes & Sweet, 2011; Friedman et al., 2007; Brown et al., 2005). The prevalence of fatigue in PD ranges between 33% and 70% (Friedman, Abrantes & Sweet, 2011), and has a lifetime prevalence of more than 50% (Mantri et al., 2020). Differences in the prevalence of PD-related fatigue may be seen due to differences in study methodologies and patient populations. The study of fatigue remains challenging due to the lack of understanding of this phenomenon, under-recognition of its importance in everyday life, and due to the lack of a consensus or universally accepted definition of this phenomenon (Del Sorbo & Albanese, 2012; Kluger et al., 2016).

The characterization of PD-related fatigue is split into two subtypes: central and peripheral fatigue. Central fatigue is seen as subjective in nature and may result in reduced muscle recruitment, coordination of motor units, central drive, and joint flexibility due to spasticity (Chou & Ridder, 2016). The terms central fatigue and subjective fatigue have been used interchangeably. Central fatigue can be further divided into physical and mental fatigue. Physical fatigue involves the ability and motivation, but lacks the energy to perform physical tasks, and involves a sense of physical exhaustion (Friedman, Abrantes & Sweet, 2011). Mental fatigue stimulates cognitive effects due to demanding cognitive activities and tasks requiring sustained concentration and mental endurance (Friedman, Abrantes & Sweet, 2011). This may occur during and/or after prolonged periods of these demanding activities. More persons with PD tend to report subjective physical and mental fatigue than their healthy counterparts (Lou, 2009);

however, these types of fatigue were found to be not well correlated in PD (Friedman, 2009). Peripheral fatigue, also known as physical fatigability, is thought to be objective in nature and is often quantifiably measured and does not directly correlate with subjective fatigue (Chou & Ridder, 2016; Bruno & Sethares, 2015). This type of fatigue is described as a muscle losing strength with repeated contractions (Friedman, Abrantes & Sweet, 2011). Recognition of objective fatigability and subjective fatigue as dissociable phenomena is important when studying a complex symptom such as fatigue (Kluger et al., 2016) as the challenges that exist in proposing relevant definitions of fatigue are also reflected in patients having difficulty in describing the phenomenon they experience.

PD-related fatigue is known as a pre-motor symptom as it tends to develop early in and persist and worsen over the disease course (Friedman et al., 2007; Siciliano et al., 2018). This symptom may be influenced by age, but no relation between fatigue and sex was seen in the study by Siciliano and colleagues (2018). This phenomenon can emerge prior to and can be as troublesome as motor symptoms in affecting daily living and is often thought of as a warning sign for the development of PD (Del Sorbo & Albanese, 2012; Chou & Ridder, 2016; Friedman et al., 2016; Friedman, Abrantes & Sweet, 2011). An increase in PD-related fatigue may occur during off-periods, however, the implications are unclear as multiple non-motor symptoms may occur in addition to fatigue during off-periods (Friedman et al., 2016).

Fatigue in PD is of multifactorial etiology which includes depression, daytime sleepiness, additional sleep problems, apathy, and cognitive impairment as additional non-motor symptoms which manifest in this condition (Mantri et al., 2020; Kluger et al., 2016). A significant association with depression but not disease severity was found in

persons experiencing PD-related fatigue (Friedman et al., 2007); individuals reported more depressive symptoms and are at an increased risk of receiving a depression diagnosis along with fatigue (Siciliano et al., 2018). Of interest, Siciliano and colleagues (2018) found depression and fatigue in PD to be distinct entities although some overlap between the two symptoms may be seen. An association was found between longer disease duration and increasing fatigue levels (Siciliano et al., 2018). An increase in daytime sleepiness was found in those experiencing PD-related fatigue compared to those without fatigue; and on average, individuals with fatigue have more severe sleep disturbances (Siciliano et al., 2018). Friedman and colleagues (2011) noted that fatigue is different from daytime sleepiness, however, further investigation into this difference is needed to enhance understanding of this distinction. Siciliano and colleagues (2018) found persons with PD-related fatigue to be moderately more apathetic and anxious than those who do not experience this symptom. These authors additionally highlighted that fatigue is likely not a result of disease progression or cognitive deterioration associated with PD; however, severe cognitive impairment was seen in participants in this study.

Evidence of correlations between fatigue and depression, anxiety, and apathy are supported across studies, however, not all persons with PD may experience these comorbidities (Friedman et al., 2016); if experienced, however, they generally have a negative impact on QoL (Chou & Ridder, 2016; Del Sorbo & Albanese, 2012). PD-related fatigue is a significant contributor to a deterioration in QoL and HRQoL (Chou & Ridder, 2016; Siciliano et al., 2018). Siciliano and colleagues (2018) noted two circumstances where the QoL of individuals with PD-related fatigue are negatively impacted, including when fatigue is experienced in conjunction with other non-motor



symptoms, and when cognitively impaired individuals were included in study analyses. Further study is required to understand the effect of these comorbidities on subjective fatigue in PD (Lou, 2009) and their impact on the QoL of those with PD-related fatigue.

The subjective experience of fatigue is complex and is known to be multidimensional consisting of physical, emotional, and cognitive components (Mantri et al., 2020; Brown et al., 2005; Chou & Ridder, 2016). Feelings of being ‘depleted’, ‘slowing down’, ‘dragging’, and ‘drained’ were perceived by persons with PD (Mantri et al., 2020; Chou & Ridder, 2016; Brown et al., 2005). Fatigue associated with this condition was described as ‘heavy’, ‘debilitating’, ‘utter’, ‘complete’ and a sense of feeling ‘completely shattered’ (Mantri et al., 2020; Chou & Ridder, 2016; Friedman, 2009; Brown et al., 2005). The severity of fatigue was perceived as being ‘extreme’ or ‘total’ (Chou & Ridder, 2016; Friedman, 2009). The experience of fatigue has been subjectively characterized as a lack of energy, tiredness, weakness, and exhaustion (Brown et al., 2005; Del Sorbo & Albanese, 2012; Mantri et al., 2020; Friedman, 2009; Kluger et al., 2016). The Fatigue Assessment Inventory similarly defines fatigue as a sense of tiredness, a lack of energy and total body give out (Friedman et al., 2007). A lack of energy can be due to dyskinesias, and tremors associated with PD creating an increase in the amount of energy needed to perform activities (Friedman, 2009). Tiredness is described by individuals with PD as being ‘abnormal’ and ‘overwhelming’ (Mantri et al., 2020) and is different from fatigue associated with activity, lack of sleep, and daytime sleepiness (somnolence) (Brown et al., 2005). The terms sleepiness, tiredness, and fatigue are often used interchangeably across studies (Friedman et al., 2007), despite fatigue being distinct from sleepiness and tiredness (Kluger et al., 2016).

Persons with PD tend to tire quicker than others without even doing anything (Brown et al., 2005). This perception of weakness and feeling weak was described as a similar feeling to having a long term illness, waking after anesthesia, and walking through a viscous medium (Friedman, 2009). Exhaustion was expressed by many enduring fatigue with special note of cognitive fatigue also causing feelings of being exhausted and weary (Friedman et al., 2016).

Cognitive fatigue is another term for central fatigue focusing on the mental aspect of this phenomenon and its subjective nature (Friedman et al., 2016). The cognitive fatigue experienced with PD is associated with cognitive impairment which can include difficulty concentrating (Brown et al., 2005), a lack of focus (Mantri et al., 2020), reduced attention, and difficulty with memory retrieval (Friedman et al., 2007; Friedman et al., 2016). A lack of clarity (Chou & Ridder, 2016) and a reduced ability to think about complex issues arises with this type of fatigue (Friedman et al., 2016) leading to the need for self-preservation where persons with PD feel the need to wait until they are ‘sharper’ before making decisions (Mantri et al., 2020). Cognitive fatigue can be met by a general feeling of malaise and occurs when the complexity of a task or attentional demands increase (Friedman et al., 2016). Persons with PD describe cognitive fatigue as having a mind of its own and being its own entity where it beholds them (Mantri et al., 2020). An increase in mental effort is needed to combat the cognitive fatigue associated with PD to maintain normal daily performance (Friedman et al., 2016).

Fatigue is a symptom which is experienced daily by those with PD and often worsens as the day continues (Chou & Ridder, 2016). Maintenance of day-to-day life is of utmost importance to those with PD and generally requires an increase in both mental

and physical effort to attempt and accomplish daily activities (Kluger et al., 2016; Brown et al., 2005). The quality of fatigue can vary throughout a day (Mantri et al., 2020), with physical and/or mental qualities being perceived in people with PD (Del Sorbo & Albanese, 2012; Brown et al., 2005). PD-related fatigue may worsen with even mild activities causing individuals to reduce their activities (Del Sorbo & Albanese, 2012) including physical leisure activity and vigorous exercise (Friedman, 2009; Friedman et al., 2007). Less time is spent physically moving each day and less is typically done in a day than persons with PD aim to achieve as it takes them longer to complete daily tasks (Brown et al., 2005; Friedman et al., 2007). This may result in reduced physical function (Friedman, 2009; Friedman et al., 2007) and feeling like their lives are restricted finding it difficult to cope with everyday activities (Brown et al., 2005).

Restriction of daily life in PD can stem from the reluctance to socialize and avoidance of interaction when fatigued (Brown et al., 2005; Chou & Ridder, 2016). This symptom can be unpredictable (Chou & Ridder, 2016) and occur suddenly with individuals noting how fatigue can sneak up on them or just hit them (Mantri et al., 2020). PD-related fatigue was personified as an external force that individuals had little control over and perceived their fatigue to have characteristics resembling human emotions and behaviors (Mantri et al., 2020). Fatigue may influence and impact persons social roles, relationships, and work performance (Friedman et al., 2007). Feelings of ‘worry’, ‘guilt’, and ‘frustration’ may arise with additional feelings of ‘anxiety’ and ‘panic’ occurring in social settings (Brown et al., 2005). Depression may be associated with feelings of frustration, although their depressive state or mood is not driving their fatigue (Kluger et al., 2016). Characterization of the emotional impact of PD-related

fatigue was illustrated using negative and positive motivation. Negative motivation was described in terms of persons feeling isolated and unmotivated, not wanting to do anything, and as though everything in their lives was insurmountable (Mantri et al., 2020). However, Kluger and colleagues (2016) noted how persons with PD *want* to perform tasks and activities, but they lack the energy channeling a lack of motivation, so they do nothing instead. This negative motivation is then met with positive motivation – although the timing of this occurrence may vary based on the individual – as a way of overcoming these negative feelings. People will attempt to work through their fatigue in order to achieve what they aim to in a day and try to feel ahead or on schedule (Mantri et al., 2020). This idea of scheduling is helpful in organizing which tasks and activities are to be done in a day and planning social gatherings or outings with family and friends. Ways of coping and managing fatigue can be very individualized for each person with PD, although some overlap is seen.

The PD-related fatigue is described as different from the fatigue experienced prior to diagnosis of this condition (Friedman et al., 2016; Lou, 2009); and therefore, requires the use of a single or multiple coping strategies or management techniques to overcome the effects and impact that accompany this symptom. Pharmacological interventions including dopamine agonists, anti-depressants, and stimulants (wake-promoting agents) in low doses such as modafinil (mixed results but well-tolerated) and amphetamine (well tolerated but has not been shown to be of aid) and others (ex. Memantine) have been used in managing fatigue (Friedman, 2009; Chou & Ridder, 2016; Friedman, Abrantes & Sweet, 2011). Methylphenidate impacted PD-related fatigue significantly and positively, and rasagiline has proved beneficial in the early stages of PD (Bruno & Sethares, 2015;

Friedman, Abrantes & Sweet, 2011; Del Sorbo & Albanese, 2012). Modafinil and methylphenidate alongside levodopa have been shown to improve physical fatigability (Lou, 2009). Both levodopa and rasagiline have shown small but insignificant benefits in reducing fatigue in PD (Friedman et al., 2016). There is controversial evidence supporting the use of amantadine and its benefit for PD-related fatigue (Friedman, Abrantes & Sweet, 2011), so caution may be implemented prior to use. Due to varying doses of each medication and study sample sizes, the effects of each intervention on fatigue remain controversial (Bruno & Sethares, 2015). Although certain pharmacological interventions may be of use in managing fatigue, persons with PD tend to prefer non-pharmacological or natural coping strategies to reduce the impact of this phenomenon in their lives.

The coping and management strategies that work to manage and/or reduce PD-related fatigue are best known to the individual experiencing this symptom in their daily lives. Persons with PD will plan rest periods during the day and will occasionally need to lie down wherever they are and just stop and do nothing (Mantri et al., 2020; Friedman et al., 2016). This can be helped by pacing their daily activities and scheduling their day (Friedman et al., 2016); rest periods can occur at the same time(s) daily and therefore they may schedule tasks, meetings, and/or activities around these times. However, in attempt to improve nighttime sleeping, it is suggested that those with PD-related fatigue alter their sleep habits by reducing daytime naps (Friedman, 2009). While resting is a well-known coping strategy for many with this condition, they may still feel fatigued after rest instead of feeling refreshed (Friedman et al., 2007). An alternative therapy showed a one-time 30-minute Japanese massage intervention helped to reduce fatigue

(Bruno & Sethares, 2015); however, more evidence is needed to support the use of this intervention in PD. Additional strategies used include acupuncture (Chou & Ridder, 2016) and cognitive behavioral therapy (Chou & Ridder, 2016). Colder climates are preferred as heat is likely to worsen PD-related fatigue, and therefore, temperatures should be regulated to help reduce this symptom (Friedman et al., 2016). Increasing social and mental activity is known to increase peoples' enjoyment, increasing their motivation which helps to reduce their levels of fatigue (Friedman, 2009). Physical exercise is known to improve co-morbid symptoms of depression, anxiety, and sleep disturbances and help individuals regain control in their life (Friedman, Abrantes & Sweet, 2011; Friedman et al., 2016; Chou & Ridder, 2016; Del Sorbo & Albanese, 2012). Additional benefits can be seen with exercise training helping to increase physical function and improve gait (Friedman et al., 2007). Approximately 30 minutes per day or starting at 5 minutes two to three times per day of exercise can greatly benefit these individuals (Friedman, 2009). Overall, exercise is perceived as helpful in improving overall QoL (Friedman, Abrantes & Sweet, 2011; Friedman et al., 2007).

Regarded as one of the most disabling symptoms, fatigue can result in the decline of QoL and is still often underrecognized by clinicians and researchers (Mantri et al., 2020; Chou & Ridder, 2016), and therefore likely undertreated as well. The research literature has focused on the objective measures, pathophysiology, and treatments of fatigue in PD (Bruno & Sethares, 2015) rather than focusing on the patient as central in the elucidation of the lived experience of fatigue. Scales or questionnaires measuring subjective fatigue in PD are often used, however, these measures do not correlate with understanding subjective fatigue based upon individuals' narratives of lived experience

(Friedman et al., 2016). Studies asking persons with PD about how they define fatigue are negligible (Bruno & Sethares, 2015), but are necessary to encapsulate their perception of this phenomenon which may help to develop a clear definition of fatigue. Further study using objective measures alongside subjective complaints of PD-related fatigue is needed to enhance our understanding of this phenomenon (Kluger et al., 2016). Refining the terminology to describe PD-related fatigue is required to factor in the patient's voice in how they experience and describe this phenomenon (Mantri et al., 2020). The patient's perceptions of how fatigue affects their day-to-day lives are undeniably important in understanding the nature of fatigue in PD.

#### 1.2.4 Cerebral Palsy

CP is an umbrella term defined as “a group of permanent disorders of the development of movement and posture, causing activity limitation, that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain.” (Rosenbaum et al., 2007, p. 9). The condition itself is considered non-progressive due to the static injury of the brain; however, the manifestations of the disease can change over time such as the appearance and progression of secondary musculoskeletal conditions (Brunton & Bartlett, 2013).

In 2011 to 2012, the incidence of CP was estimated at 2.6 to 2.9 per 1000 children aged 2 to 17 years (Michael-Asalu et al., 2019). The estimation of prevalence is difficult due to early diagnosis in infancy or childhood and the limited longitudinal follow-up of these individuals after transition from pediatric healthcare. The diagnosis of CP relies heavily on neurologic/neuromotor assessment (ex. General movements assessment and the Hammersmith Infant Neurologic Examination), neuroimaging (ex. MRI), and

recognition of the clinical risk factors (Michael-Asalu et al., 2019; Sadowska et al., 2020). While the diagnosis of CP is mainly clinical, evidence suggests that there may be genetic underpinnings including single gene mutations (ex. KANK1, ADD3, and ITPR1), candidate CP genes (ex. AGAP1 and JHDM1D), copy number variants (ex. GRIK2), and single nucleotide polymorphisms (Michael-Asalu et al., 2019). As a result of the complexity associated with diagnosis, it can be a protracted process and commonly occurs between one to two years of age (Michael-Asalu et al., 2019).

Often the cause of CP remains unknown, largely because it is often multifactorial, and the etiology is complex. Risk factors for the development of CP include: neonatal respiratory distress syndrome, meconium aspiration, instrumental or emergency cesarean section, birth asphyxia, neonatal seizures, hypoglycemia, and neonatal infections (Michael-Asalu et al., 2019). This condition is comprised of three motor subtypes known as spastic, dyskinetic, and ataxic; with unilateral or bilateral topographical distribution aiding in the classification of CP subtype (Rosenbaum et al., 2007). However, the predominant type of motor disorder is ‘mixed’ CP where one specific motor subtype does not always dominate (Rosenbaum et al., 2007). Different genetic underpinnings may lead to each specific subtype of CP. Several interventions can be used in attempt to prevent CP, such as therapeutic hypothermia, caffeine, postnatal corticosteroid avoidance, antenatal steroids, and magnesium (Michael-Asalu et al., 2019). Treatments available to those with CP may differ if an individual has unilateral or bilateral distribution of their impairment; however, generally physical rehabilitation, including neurodevelopmental and reflex locomotion treatments, prescription medications (ex. Baclofen and benzodiazepines), botulinum toxin, and specific orthopedic and neurosurgical operations



(ex. Derotational osteotomy and selective peripheral or dorsal rhizotomy) are possible treatments provided to individuals with CP over their life course (Sadowska et al., 2020).

#### 1.2.4.1 Pain in cerebral palsy

Pain is the most frequent complaint of individuals with CP and often develops into a chronic condition (van der Slot et al., 2012). An estimated prevalence of 24% to 83% of persons with CP experience pain to varying degrees (Malone & Vogtle, 2010; van der Slot et al., 2012; Engel et al., 2005). The prevalence and effects of pain increase with age, such as limitations in social life and employment, which creates significant concern for adults with CP (Vogtle, 2009; Graham et al., 2016). The experience of pain is influenced by cognitive, affective, and behavioral mechanisms and therefore is often studied in accordance with the biopsychosocial model (McKinnon et al., 2020a). However, McKinnon and colleagues (2019) acknowledged that the exclusive use of the biopsychosocial framework limits the understanding of the experiences of pain from persons with CP (McKinnon et al., 2020a).

Patients' self-reported causes of pain in spastic CP have been known to be associated with arthritis, tendonitis, bursitis, hip dysplasia, carpal tunnel, and physical overuse (van der Slot et al., 2012). Within dyskinetic CP, comorbidities known to influence pain include scoliosis, hip displacement, muscle contracture, gastrointestinal disorders and/or the movement disorder itself (McKinnon et al., 2020a). Different manifestations of childhood pain were described by McKinnon and colleagues (2020b) including comorbidities such as dyskinesia, constipation, reflex, headaches, and musculoskeletal problems. Chronic pain syndromes may also result due to the

development of secondary conditions such as joint dislocations, contractures, osteoarthritis, and neuropathy (van der Slot et al., 2021).

An association between the number of body locations with pain and the severity of motor impairment was seen in the study by McKinnon and colleagues (2020a). Specifically, Ostojic and colleagues (2022) discussed how people classified as Gross Motor Function Classification System (GMFCS) levels III and IV tend to have more complex pain experiences. Pain may be triggered depending on the intensity of gross and/or fine motor functions across different body parts. However, conversely, this symptom itself may impair gross motor functions (Ostojic et al., 2022). Pain is relatively consistent in its severity and location (Ostojic et al., 2022); however, it remains individualized dependent on the person experiencing it.

Pain is a personal experience; and it is through life experiences that we may understand this phenomenon (Raja et al., 2020). In the study by Brunton and Bartlett (2013), pain was predominantly described as a feeling of muscle soreness, with some participants additionally describing this symptom as tiredness. One study explored CP-related pain and described it in terms of the *dys-appearing body* and the *not appearing body* (Sandström, 2007). Pain was described as a new experience which was ‘disturbing’ as individuals with CP felt an increased awareness of their body due to the occurrence or *dys-appearance* of pain. Feelings of not recognizing their own body when pain was absent was a part of the *not appearing body* theme (Sandström, 2007). This symptom was perceived as feelings of being ‘annoying’, ‘frustrating’, ‘unpredictable’, ‘erratic in nature’, ‘constant’, ‘and ‘relentless’ (Ostojic et al., 2022; Castle, Imms & Howie, 2007;

McKinnon et al., 202b; Lindsay, 2016). Individuals with CP-related pain felt ‘disappointed’, ‘sad’, ‘lonely’, ‘helpless’, and ‘powerless’.

As a result of CP-related pain, participants reported feeling overwhelmed due to feelings of social isolation and separation (Castle, Imms & Howie, 2007; McKinnon et al., 2020b; Ostojic et al., 2022). This can take a toll on individuals mental health and motivation to participate in daily activities (Ostojic et al., 2022). Individuals experiencing CP-related pain felt it was ‘unfair’ that on top of their condition they had to endure pain; and the question of why they had pain versus determining the cause of their pain was often asked by these people (Castle, Imms & Howie, 2007). People with CP have reported feeling desperate for relief and that search for a cure for pain consumed their thoughts, time, and energy; essentially, overpowering their lives (Castle, Imms & Howie, 2007; McKinnon et al., 2020b). However, it was noted that once individuals accepted that pain was a part of their everyday lives and that they would have to live with it (Bergqvist et al., 2019; McKinnon et al., 2020b; Sandström, 2007), they found it easier to control (Ostojic et al., 2022).

In young people and adults living with CP, pain is negatively associated with QoL, participation, and well-being (Fairhurst et al., 2019; Graham et al., 2016). Pain inhibits individuals’ participation in physical activity; and can be a consequence of strenuous activity and/or the body working near or at its limit (Ostojic et al., 2022). However, people choose to perform activities at their limit because it is important to them to continue to maintain levels of activity (Bergqvist et al., 2019). Additionally, a decrease in person’s ability to participate in activity due to CP-related pain has been shown to be

related to being at school all day (for younger people) and going shopping (Engel et al., 2005).

Pain and fatigue can occur simultaneously, with fatigue exacerbating pain if, for example, an adolescent with CP was up all day without rest (Engel et al., 2005; Sandström, 2007). Experiencing pain everyday leads to severe physical and mental fatigue (Bergqvist et al., 2019). Pain and physical fatigue are known to accompany the deterioration of the body's ability to function and to perform activities throughout the life course (Opheim et al., 2009; Malone & Vogtle, 2010). CP-related pain can additionally lead to functional decline (van der Slot et al., 2021); and the interference of pain on daily activities is greater when pain is experienced more often (Opheim et al., 2009).

Restriction of activity or levels of activity they can accomplish is commonly reported as a limiting factor in daily life by those with CP (Castle, Imms & Howie, 2007). These persons described how they had to stop, not pursue, or completely change an activity to compensate for their pain, in order to remain mobile, and maintain participation in essential activities of daily living (Brunton & Bartlett, 2013; Lindsay, 2016). They occasionally pushed through the pain to be able to participate and prevent it from taking over and interfering in their daily lives (McKinnon et al., 2020b; Castle, Imms & Howie, 2007; Lindsay, 2016). Pain can negatively affect their ability to participate in and cope with certain recreation and leisure activities, as well as overall participation in school (Lindsay, 2016).

A number of coping strategies have been expressed by those with CP-related pain. Rest during activity or resting for different lengths of time was considered a tremendous

help in managing pain (Ostojic et al., 2022; Jensen, Engel & Schwartz, 2006; McKinnon et al., 2020b). Rest could include taking breaks, sitting down, or leaning on someone or something during activity (Brunton & Bartlett, 2013). Planning and making adaptations to activities or other aspects of daily living was described as helpful in, for example, keeping a schedule (Brunton & Bartlett, 2013). Numerous patient descriptions of coping strategies were described in studies which included: breathing, using distractions (ex. TV or music), stretching, relaxing, controlled breathing, massage, heat, or cold packs, repositioning themselves, knowing their limits, and listening to themselves and their body (Ostojic et al., 2022; McKinnon et al., 2020b). Some people used medication and/or physical therapy to help manage their pain. Emotional support was also described as helpful in managing pain (Ostojic et al., 2022); however, support from family was deeply appreciated, but often came with frustration, humiliation, and physical and emotional exhaustion (Castle, Imms & Howie, 2007). Jensen and colleagues (2006) presented primary and secondary coping strategies determined by the frequency they were reported by patients. Primary strategies included asking for help, persisting through tasks, keeping positive, diverting attention, and increasing activity. Secondary strategies included guarding, exercising, social support, stretching, ignoring the pain, and praying or hoping.

Within the current literature, a large focus continues to exist on the clinical assessments and manifestations of pain in CP. Persons with CP felt as though it was impossible to describe the full intensity of their pain to someone who does not experience it or could not understand their unavoidable suffering because they were not living it (Castle, Imms & Howie, 2007). People living with this condition feel as though clinicians need to believe their patients' pain is real before they will ever be able to help them

(Castle, Imms & Howie, 2007). The knowledge and skills needed to address and manage pain are gained through life experiences (Ostojic et al., 2022). Knowledge of the obstacles and challenges these people face in their daily life and throughout their life course remains limited. In addition, clinicians need to trust their patients and explore their experience in greater depth to first understand before attempting to manage, treat, and improve their pain.

#### 1.2.4.2 Fatigue in cerebral palsy

Both adults and children with CP report fatigue as a frequent occurrence in their daily lives (Russchen et al., 2014). The prevalence of fatigue is high, with approximately 40% of adolescents and adults with CP experiencing fatigue (Russchen et al., 2014; van der Slot et al., 2012; McPhee et al., 2017). Furthermore, adults who experience CP-related fatigue are likely to still experience fatigue as a symptom of their condition 3 years later (Oude Lansink et al., 2018), demonstrating the chronic nature of this symptom. High levels of fatigue have been demonstrated in young adults, suggesting that fatigue should be addressed as a potential health issue at this stage of life in persons with CP (Russchen et al., 2014), which could help to improve fatigue levels and overall general health as they age.

People with bilateral CP have reported increased levels of fatigue compared to those with unilateral CP, which could be due to the effect of increased physical strain associated with bilateral CP (Russchen et al., 2014). One study found that 61% of adults with bilateral CP were fatigued, and specifically 41% were severely fatigued (van der Slot et al., 2012). Opheim and colleagues (2009) assert that the origin of fatigue in CP is physical, highlighting the possibility of a relationship between physical strain and fatigue.

To account for this strain, persons with CP may attempt to conserve their energy and prevent fatigue by reducing their daily physical activity levels (Russchen et al., 2014). Conversely, results of a recent study showed that topographical distribution has no significant contribution in determining the location where adults with CP experience fatigue; this determination would need to be studied in a larger sample (Oude Lansink et al., 2018).

Despite being a non-progressive condition, people with CP do experience deterioration of the body's ability to function and to perform activities throughout the life course, and this is often accompanied by an increase in pain and physical fatigue (Opheim et al., 2009; Malone & Vogtle, 2010; McPhee et al., 2017). A variety of factors may play a role in CP-related fatigue, including sleep disorders, behavioral factors, stress, depression, pain, spasticity, or medication (Russchen et al., 2014; Brunton, McPhee & Gorter, 2021). A co-occurrence of chronic pain, fatigue, and depressive symptoms is often seen in persons with this condition (van der Slot et al., 2012; Sandström, 2007).

Limited knowledge on the lived experience of fatigue in CP is available as studies have focused on the physical classification of this symptom and its effects, such that a focus on the subjective nature of fatigue and understanding the experience has been neglected. Nevertheless, the subjective experience of CP-related fatigue can be characterized through patients' narratives of their lived experiences.

Fatigue is often characterized as a multifactorial and variable (Brunton & Bartlett, 2013) symptom including general, physical, and mental aspects (van der Slot et al., 2012; Brunton, 2018). Persons with CP describe fatigue as feelings of being tired and weak, and

a lack of strength, specifically due to fatigue being experienced primarily in the leg muscles (Brunton & Bartlett, 2013). Fatigue was also perceived as a new experience that drained all energy (Sandström, 2007) and a lack of energy (Brunton & Bartlett, 2013). van der Slot and colleagues (2012) reported that fatigue often resulted in a reduction in motivation and the performance of activities. Individuals with CP described reducing the number of activities they performed as fatigue was a major consequence of activity and could be dependent upon the day and level of functional impairment (Brunton & Bartlett, 2013; Brunton, 2018). Functional impairment could also result in a significant reduction in independence and mobility (Brunton, 2018). Interestingly, physical activity was also described as a way of preventing fatigue (Brunton & Bartlett, 2013; Brunton, McPhee & Gorter, 2021), depending on the amount and length of activity.

Fatigue is known to have a negative impact on daily functioning in those with spastic bilateral CP. van der Slot and colleagues (2012) found evidence supporting the notion that the ability of these individuals to cope and accustomize themselves to chronic pain and fatigue may not detrimentally affect functioning. Fatigue was described as unpredictable such that individuals found it difficult to know when symptoms would onset and required time and experience to learn how to recognize the signs of fatigue (Brunton & Bartlett, 2013). Brunton & Bartlett (2013) reflected that increased self-awareness was required to learn to cope with fatigue so that people with CP can function at their peak and live their fullest life. Fatigue may be influenced by responsibilities at work/school or home, social life, and long or full days (Brunton, McPhee & Gorter, 2021). Brunton (2018) noted that those experiencing CP-related fatigue may place



different value on social and physical activities, based on the enjoyment they receive, and the energy required, to participate in these leisure activities.

Many factors can affect fatigue in daily life. External factors contributing to fatigue can include mental health challenges such as stress, anxiety, and mood (Brunton, McPhee & Gorter, 2021). A reciprocal relationship between stress and fatigue was described by Brunton (2018), where stress may lead to an increase in fatigue, and the experience of fatigue itself can be stressful (Brunton, 2018). Additional external factors influencing fatigue can include the weather (pressure changes and temperature) and excessive sensory stimulation (Brunton & Bartlett, 2013; Brunton, McPhee & Gorter, 2021). A lack of and poor quality of sleep and insufficient rest breaks may also lead to heightened levels of fatigue in CP (Brunton, McPhee & Gorter, 2021).

In an attempt to manage and cope with varying levels of fatigue, specific coping strategies (highly specific and individually tailored) used by persons with this condition were described. The most reported strategy was the use of rest and relaxation such as taking breaks, sitting down, leaning on someone or something, reading or listening to music (Brunton & Bartlett, 2013; Brunton, McPhee & Gorter, 2021; Brunton, 2018). Words used to describe rest include needing to 'recharge', 'recuperate', and 'remove pressure' (Brunton & Bartlett, 2013). Sleeping or napping was also a common technique used to restore energy levels. Planning and pacing by restricting, stopping, not pursuing, or decreasing activity were also described as helpful in managing fatigue (Brunton & Bartlett, 2013; Brunton, McPhee & Gorter, 2021); although less than half of participants in the study by Brunton (2018) reported using pacing, and planning was the least commonly used strategy. Physical activities such as yoga, stretching, or swimming were

typical activities used to manage increasing levels of fatigue (Brunton, McPhee & Gorter, 2021). Lastly, modifying or adapting activities in daily life was perceived to be helpful for managing fatigue and could include the use of an alternative type of mobility aid than that which is regularly used or increasing the time available to perform a specific activity (Brunton & Bartlett, 2013; Brunton, McPhee & Gorter, 2021; Brunton, 2018).

Despite knowledge regarding the frequency of fatigue in CP, researchers have rarely conducted studies on patient descriptions of fatigue within this condition (van der Slot et al., 2012; Russchen et al., 2014). Most studies which have sought to study the experience of fatigue in those living with CP, have done so by using subjective assessment tools, as opposed to looking at subjective descriptions of fatigue (Brunton & Bartlett, 2013). Therefore, there is still a significant gap in understanding how fatigue impacts people with CP in their daily lives through their lived experiences. This gap requires further exploration to aid in the future development of enhanced and more appropriate treatment and management strategies for fatigue in CP.

### 1.3 Purpose of the study

The purpose of this study is twofold. The primary aim was to understand and describe the meaning, experience and impact of pain and fatigue in the daily life and greater life course from the perspective of people living with MS, PD, and CP. To achieve this primary purpose, the guiding research question of “how do persons living with multiple sclerosis, Parkinson’s disease, and cerebral palsy experience pain and fatigue?” was applied. The secondary aim was to explore the relationship between experiential accounts of and the concepts of pain and fatigue within and across conditions. The secondary research question of “how are the experiences and concepts of pain and fatigue similar

and how do they differ *within and across* conditions?” was implemented to study this relationship. These study aims were addressed using a new phenomenological approach guided by van Manen’s hermeneutic-phenomenological method (van Manen, 2016). New phenomenology provides insight into the subjective understanding of pain and fatigue and allows for an in-depth understanding of the personal experiences as lived by the individual as they engaged with these phenomena (Caelli, 2000; Dowling, 2007). This is the first study to our knowledge to explore the lived experiences of pain and fatigue within and across MS, PD, and CP to understand any commonalities or differences in the experience of pain and fatigue across neurological conditions with similar prevalence of these symptoms.

Through provision of experiential accounts from the individual, clinicians may develop an increased understanding of the personal impact the non-motor symptoms of pain and fatigue have in the daily lives and life course of their patients. In turn this may enhance current healthcare practices for managing pain and fatigue and improve functional ability, QoL, and overall well-being. Furthermore, the knowledge gained from this study will inform the choice or development of effective management strategies to be used by patients and their healthcare providers. Specifically, the development of better management strategies, interventions (including treatment and prevention) that may provide benefits by reducing the burden of pain and fatigue on the people living with the specified conditions; and attempting to minimize the burden placed on caregivers who aid in managing non-motor symptoms. This study may enhance the knowledge of clinicians surrounding the similarities and differences that exist between these phenomena which may further aid in developing effective management strategies and delivering healthcare.

Lastly, a common theme among the limited literature to date is that patients perceive that clinicians and researchers do not understand their experience of pain and fatigue. The study findings may enhance clinical practice and inform future research by equipping clinicians and researchers with the practical knowledge of adults' experiences to connect with their patients and participants from a new place of understanding.

## 2 Methodology and Research Methods

### 2.1 Methodology

#### 2.1.1 Methodological stance in qualitative inquiry

Due to the complex nature of pain and fatigue in MS, PD, and CP, there is a need to focus on understanding the lived experiences of these symptoms and as such a new phenomenological approach will be adopted, guided by van Manen's hermeneutic-phenomenological method (van Manen, 2016). Alase (2017) asserts that the decision to adopt a qualitative research methodology is about which approach is participant-oriented and flexible enough to get at a research participant's real lived experiences. A new phenomenological approach allows for an in-depth exploration of the experience of pain and fatigue as described by research participants, while also providing insight into obtaining a subjective understanding of the phenomena (Dowling, 2007). Recognizing the limitations of previous inquiry that has suppressed individual's experiences by focusing on the objective reality and descriptions of pain and fatigue, new phenomenology seeks to allow a more robust understanding of the personal experiences of the individual as they engage with the phenomena (Caelli, 2000; Dowling, 2007).

The study seeks to extend beyond the integration of objective descriptions and philosophical underpinnings and concentrate on the lived experiences of pain and/or fatigue within and across included conditions. To accurately reflect and achieve the study's aim, van Manen's hermeneutic-phenomenological method introduces guidelines to support the practical implementation of new phenomenology in attempt to describe how people experience pain and fatigue in their daily lives.

Hermeneutic phenomenology is defined by van Manen as:

“... a method of abstemious reflection on the basic structures of the lived experience of human existence. The term method refers to the way or attitude of approaching a phenomenon. Abstemious means that reflecting on experience aims to abstain from theoretical, polemical, suppositional, and emotional intoxications. Hermeneutic means that reflecting on experience must aim for discursive language and sensitive interpretative devices that make phenomenological analysis, explication, and description possible and intelligible. (van Manen, 2014, p. 26)

van Manen's phenomenology, termed the “phenomenology of practice”, appears under the heading of new phenomenology with its beginning underlying assumptions grounded in both Husserl's transcendental and Heidegger's interpretive phenomenology's (Dowling, 2007). Expanding upon the traditional theory of phenomenology, van Manen focused on the practical orientation of phenomenology (van Manen, 2014; Errasti-Ibbarando et al., 2018). van Manen felt that in order for researchers to use phenomenology across disciplines, it needed to move beyond approaches that sought to discover and draw determinate conclusions of phenomena (van Manen, 2014). Therefore, the phenomenology of practice approach seeks to subjectively explore the lived experience in searching for a subjective meaning of phenomena (Caelli, 1998; Caelli, 2000). van Manen contends that phenomenology is both descriptive and interpretive, and that every description entails an interpretation (van Manen, 2014; van Manen, 2015). Further to this point, Giorgi (2000b) argued that descriptions of an experience are dependent upon the manner in which they are experienced. It is the descriptions from

individuals' experiences as lived, that will provide a more expansive base on which to construct descriptions of the phenomena of interest (Caelli, 2000; Dowling, 2007).

The hermeneutic-phenomenological method is based on reflection and writings on the subject of lived experiences (Errasti-Ibarrando et al., 2018). Although this practice is ascribed as a 'method', van Manen acknowledges that there is no method to phenomenology or hermeneutics (Errasti-Ibarrando et al., 2019). This claim was first introduced by Gadamer in 1975, describing that hermeneutics is concerned with clarifying the conditions where understanding ensues (Caelli, 1998). Gadamer's claim (1975) introduced the path to new phenomenology. By extending the phenomenology of hermeneutics into the new realm, an exploration and understanding of phenomena (in the case of this study, pain, and fatigue) within the lived world can be ascertained (Caelli, 1998). The method to phenomenological hermeneutics is a series of suggestions (or conditions) proposed by van Manen (2015) on which to guide hermeneutic-phenomenological research (Errasti-Ibarrando et al., 2018; Errasti-Ibarrando et al., 2019). The suggestions include: (1) engaging with a phenomenon which interests and commits us to the world; (2) exploring experience as lived rather than how it is conceptualized; (3) reflection upon essential themes which seek to characterize a phenomenon; (4) employing the art of writing and rewriting to describe a phenomenon; (5) fostering a pedagogical relation that is strong and oriented to the phenomenon; and (6) considering the relationship between the parts and whole which balance the research context (Errasti-Ibarrando et al., 2018; Errasti-Ibarrando et al., 2019; van Manen, 2015). The first suggestion is further discussed under section 2.1.4 (role of the researcher) regarding the main motivation behind the study. Secondly, this study seeks to explore the experience of

pain and fatigue as lived by the research participants in their daily lives and greater life course. Suggestion number three informs the rationale as to why interpretive phenomenological analysis (IPA) was the analytical method of choice. During analysis, the researcher can describe how certain elements of the experiences of participants emerge in the co-construction of themes within the specified neurological conditions. The main themes characterizing the phenomena of pain and fatigue were iteratively analyzed throughout the research process and reflected upon by the researcher and research participants. The researcher continually immersed themselves in the data and the process of writing and rewriting. Additionally, the researcher kept reflexive journals to acknowledge and bracket any preunderstandings they had towards the phenomena and neurological conditions explored throughout this study. Lastly, acknowledgement of the parts and the whole are further discussed in section 2.2.5.2 (approach to data analysis) regarding the hermeneutic circle. In summary, a new phenomenological approach guided by van Manen's hermeneutic-phenomenological method provided insight into the lived experiences of pain and fatigue from the perspectives of individuals diagnosed with MS, PD, and CP.

### 2.1.2 Biopsychosocial model

The biopsychosocial model was constructed by George Engel in 1980. This scientific model was created to expand upon the missing dimensions of the model used predominantly in medicine, known as the biomedical model (Engel, 1980). The biomedical model inherently reduces and/or excludes what characterizes the 'whole' of a person and encompasses a reductionistic approach whereby clinicians neither consider psychosocial aspects of the patient and focus their decision making based off of traditions



or customs, rules, common sense, or even self-reference (Engel, 1980). The major criticism of the biomedical model is that although subjective experiences can result from physiological factors, focusing solely on the physiological (or biological) elements that contribute to an experience results in ignoring the patient's psychological, cognitive, and social states that can contribute to and impact their experience (Borrell-Carrió, Suchman & Epstein, 2004). Engel further criticized the narrow outlook of the biomedical model which led clinicians to view patients as objects as opposed to incorporating their subjective experiences into practice and regarding them as human beings (Borrell- Carrió et al., 2004). Therefore, the biopsychosocial model was proposed as a more inclusive, systems-oriented approach which sought to characterize what makes up the 'whole' of a person (Engel, 1980). Engel describes how, with consideration of the biopsychosocial model, the provider-patient relationship (otherwise known as the two-person system) in clinical settings seeks to include the experiences and behavior of the patient (Engel, 1980). For the purposes of this study, the researcher sought to consider not only the observable biological factors, but to also take into consideration the psychological and social components which may impact the participants' experiences with pain and fatigue. To do this, the interview questions were constructed using the biopsychosocial model as a framework.

### 2.1.3 Paradigmatic position in qualitative inquiry

The ability to unpack lived experiences of phenomena such as pain and fatigue requires methodological coherence of the research question, paradigm position and methodological framework (Richards & Morse, 2007). The choice to adopt a constructivist position aligns with the views of the researcher. It is difficult to know

where the line exists between maintaining qualitative coherence of the research process and ensuring that the positionality of the researcher is unwavering with respect to their beliefs and views (see Appendix A for reflexive note from the researcher on post-positivist versus constructivist paradigm). Furthermore, a constructivist paradigm allows for exploration of the phenomena of pain and fatigue as they contribute to the experience of persons living with neurological conditions. Crotty (1996) argues that adopting a constructivist paradigmatic position in new phenomenology opposes the traditional focus of phenomenology which seeks to explore and describe the universal or objective reality of abstract phenomena such as consciousness, being, and perception. However, this argument has been increasingly disputed as new phenomenology espouses a focus on subjective experience creating change in the epistemological stance of phenomenology. The epistemological assumptions of transcendental and hermeneutic phenomenology vary in their understanding of phenomena through description versus interpretation (Caelli, 2000). Considering the interpretive epistemological position of new phenomenology, the change in epistemology increasingly aligns with a constructivist paradigmatic position.

A key component of qualitative research conducted within constructivism is the notion of multiple realities. Schwandt (2000) asserts that no single true reality can exist – no universal meaning of a phenomenon – but rather multiple realities can be constructed. This idea espouses the ontological and epistemological positions of a relativist and subjectivist, respectively. This paradigmatic approach holds that realities are constructed between the researcher and participant and positions the researcher to act as the ‘learner’ in which they are devoted to understanding the participant’s perspectives and the

meaning they attach to an experience (Schwandt, 2000). Therefore, a constructivist does not attach a single objective meaning to a phenomenon, but rather emphasizes the need to understand the experiences of that phenomenon as lived in the world (Ponterotto, 2005). In the case of this study, the researcher and participant collaborated in interpreting the meaning of the experiences of pain and fatigue, while maintaining focus on the individual's narrative accounts of the phenomena and their impact on their daily lives. The ability of the researcher and participant to collaborate in the interpretation of the meaning of pain and fatigue was achieved by the researcher allowing the participant to discuss any and all experiences they wish to share throughout their interview. Below, section 2.2.5.1, describes how the researcher attempted to make sense of the participant making sense of their experiences with pain and fatigue (Smith et al., 2009). This process occurred during the semi-structured interviews, and after throughout the data coding and analysis processes.

#### 2.1.4 Role of the researcher

The moment the researcher first entered the field of their research influenced the entire period of the research study. The researcher had to respect and be courteous in entering the lives of other people while discussing possibly difficult and sensitive topics. The participants who chose to participate in the study reached out directly to a member of the study team via the contact information provided on the recruitment poster and online research portals of the recruitment sites. This marked the point of entry of the researcher. The researcher was the primary point of contact for questions, concerns, or general inquiries of the participants. For people who agreed to participate in the study, the researcher began the interview with open conversation to establish rapport.

From a constructivist perspective, multiple constructed realities can be approximated, through ensuring a reciprocal researcher-participant relationship (Schwandt, 2000). To be able to subjectively understand lived experiences, the researcher worked to establish reciprocity between themselves and participants; this was done through the researcher establishing rapport with the participant through general discussion in getting to know one another. This relationship allowed for an open and honest discussion to occur throughout the research process and ensured that the participant felt comfortable interacting and discussing their experiences with the researcher. The adoption of a constructivist paradigm allowed the researcher to be in a position where they were able to establish such open communication by way of being transparent regarding the aims of the study, what was asked of the participants and why the researcher decided to study this topic.

The main motivation behind conducting research on this topic is personal friends and family of the researcher who have been diagnosed with PD and CP and have experienced pain and fatigue in their day-to-day lives. Then, in discussions with the researcher's supervisor, the decision was made to include MS within this study as the majority of research on the lived experiences of these phenomena has been conducted within this condition. The research team thought it prudent to extend the experiences of pain and fatigue beyond the diagnosis "silo" for each of MS, PD and CP and to provide context of the experience of pain and fatigue across neurological health conditions, as inadequate knowledge on the subjective experiences of pain and fatigue for persons living with these neurological conditions is found in current research literature. In particular, understanding the experiences of pain and fatigue across conditions allowed for an in-

depth exploration of the similarities and differences across patients' descriptions of their lived experiences with pain and fatigue to close the existing gap regarding the inadequate study of cross-condition analyses. This may allow for a new and improved understanding and method for studying these phenomena across multiple neurological conditions.

Therefore, the researcher sought to bridge this gap first identified by individuals important in their life, but then to all individuals with a confirmed diagnosis of one of the three conditions.

## 2.2 Research Methods

### 2.2.1 Description of setting

Participants were recruited from the MS Society of Canada, Parkinson Society Canada and *CanChild* Centre for Childhood Disability Research. The Transitional and Lifelong Care (TLC) program at St. Joseph's Health Care London was included as an initial recruitment site, however, due to difficulties in recruitment, this site did not result in the recruitment of any participants. All successful recruitment took place virtually via online research portals and through posting of the recruitment poster via social media platforms for each recruitment site. The TLC program planned to use in-person recruitment through introduction to the study by a member of their circle of care.

### 2.2.2 Recruitment

Nine participants of either sex and any gender, aged 18 years or older were recruited. Additional inclusion criteria included: a formal diagnosis of MS, PD, or CP as communicated by the participant; self-report of current or past experience of pain and/or fatigue; fluent in English; and had access to an electronic device (computer, phone, tablet,

etc.). Exclusion criteria included individuals with severe cognitive and/or speech impairment and those who were non-fluent in English. Severe cognitive and/or speech impairment was determined informally by the researcher or members of the study team if a research participant could not understand and sign the letter of information (LOI) (see Appendix B) or verbally maintain a conversation online for the purposes of the intended study interviews. One participant was excluded from the study due to a large portion of the audio-recording being unintelligible, preventing complete and successful verbatim transcription of the interview. The unintelligible audio was a result of an inability for the researcher to hear the participant's voice on the audio-recording post-interview when transcribing the data. It should be noted that a reduced voice volume is a common symptom associated with PD. This participant was then replaced with another participant making up the total of nine participants in this study.

To begin, the research participant communicated with a member of the study team upon receiving the contact information of the researcher from one of the three recruitment locations (outlined in section 3.1). The research participant connected with a member of the study team who then assessed the participant's eligibility for study inclusion based on the criteria above; these tasks were all done by email. The sampling method used for informant selection was purposive sampling. This method of sampling allowed the researcher to deliberately choose which participants were to be included in the study by virtue of the knowledge or experience the individual possessed and could offer to the research study (Etikan, Musa & Alkassim, 2016; Smith et al., 2009). Essentially, including participants in the study who provided an in-depth understanding of the central phenomena of pain and fatigue. Furthermore, interested participants were

chosen based upon their initial contact with the researcher (as long as they met the inclusion criteria); and as such, some interested participants were not included in the study due to the limited number of participants in the study and ensuring equal representation across the neurological conditions. As purposive sampling can be an inherently biased method, the researcher decided *a priori* key features or experiences they wanted to sample for and reflected upon and documented their biases within a reflexive journal throughout the sampling process. These *a priori* features included the sex, age, diagnosis, and length of time from diagnosis of the potential participant. Once participants made initial contact with the study team detailing their interest in participating, they were replied to with an email detailing the introduction to the study and the LOI for the participant to review, sign and return to the researcher. An opportunity was also provided for potential participants to ask the researcher questions about the study prior to consenting (via Zoom or email). Once signed informed consent was received, the researcher sent an additional email containing the link, date, and time of the interview.

### 2.2.3 Data Collection

Semi-structured interviews were conducted via Western University's Corporate Zoom platform. The use of a virtual platform such as Zoom enabled the participants to participate in the interviews in an environment where they felt most comfortable, while mitigating the risks associated with in-person data collection amidst the COVID-19 pandemic. Each individual participated in one interview, lasting approximately an hour to an hour and a half. Open-ended questions were posed with follow-up prompts and/or questions asked to ensure that the interview focused on characterizing the lived

experiences of pain and fatigue. Through the use of a semi-structured interview guide (Appendix C), the researcher was able ensure that participant responses were relevant to the phenomena of pain and fatigue, while remaining open and receptive to the stories that participants told when discussing their experiences. The researcher posed additional questions that were not a part of the guide depending on the conversation and the need or desire to delve deeper into specific experiences and stories to co-construct the meaning of pain and fatigue. Any additional interview questions posed were documented in memos and annotations within the data analysis software, NVivo12 (QSR International), in the individual participant transcripts, and were able to be posed in subsequent interviews.

A common criticism of phenomenology is that descriptions of experiences must occur prior to any reflection and therefore must focus on pre-reflective experiences and remove conscious thinking in order to obtain in-depth and immediate narratives (Caelli, 1998; Caelli, 2000). However, new phenomenology is concerned with descriptions of daily lived experiences regardless of if the experience is immediate or has been reflected upon (Caelli, 2000). Prior to the interview, the semi-structured interview guide was emailed to the research participant to allow them to reflect upon the experiences they intended to share or deemed most relevant in response to the pre-determined questions. The interviewer ensured that consent to audio- and video-record the interview was granted prior to the start of the interview; this allowed for interviews to run smoother and for rapport to be further established between the researcher and participant. The entirety of the interviews were audio-recorded and transcribed verbatim. If the participant's video was enabled during the interview, the video recording was immediately deleted upon completion of the interview to maintain their privacy and confidentiality.



The semi-structured interview guide (Appendix C) was used as a framework to conduct the interview between researcher and participant, not to dictate the narrative or direction of the interview (Smith & Osborn, 2008). The role of the participant was primarily to lead the interview in the sharing of their experiences, while the role of the researcher was to use the interview guide to focus/refocus the interview on the phenomena of interest. The interview guide was designed with the knowledge and input of the members of the study team and was based on interview guides used in previous literature. Additionally, the interview guide was created using the biopsychosocial model to explore the biological, psychological, and social factors which may influence the lived experiences of pain and fatigue. The researcher continued to reflect upon the principles of the biopsychosocial model throughout the data collection process to ensure that they were considering the participant as a “whole”.

#### 2.2.4 Data Management

Participant contact (full name, email address, and telephone number) information were stored in a password-protected Microsoft Excel master list and shared with the principal investigator via OneDrive. A study ID number (PF00#) was assigned for each participant to de-identify their data throughout data collection and analysis procedures. Consent forms and online data (including audio-recordings, live transcriptions (using the Live Transcription feature in Zoom), and participant demographic information) were stored in separate password-protected files using study ID numbers for each participant. All files are stored on the Western University OneDrive of graduate student Lauren Kane and Dr. Laura Brunton (PI). All transcripts and participant quotes were attached to and saved via their study ID number. Any identifying information mentioned in an interview

was removed from the transcript and edited to provide context for what was removed (i.e. “[participant name]”). Any unintelligible sections of the audio-recordings were removed from the transcript and edited to provide context for what was removed (i.e. “[unintelligible]”). All collected data will be destroyed after the record retention period of 15 years.

## 2.2.5 Data Analysis

### 2.2.5.1 Approach to Data Analysis

IPA is a qualitative analysis approach that allows for exploration and discovery related to the lived experiences of an individual (Smith, Flowers & Larkin, 2009). IPA is underpinned by three theoretical orientations including phenomenology, hermeneutics and idiography. The orientations underpinning this analytical approach align with new phenomenology and a constructivist paradigm, supporting a hermeneutic phenomenological approach and idiographic nature. Idiography is concerned with maintaining a commitment to the detailed analysis of subjective phenomena while valuing the individuality of human perspective (Noon, 2018; Peat, Rodriguez & Smith, 2019). The overall aim of IPA is to provide in-depth descriptions of the lived experiences of the research participants and explore the phenomena of interest (in the case of this study, pain and fatigue). The ability to make sense of these experiences requires a reflective researcher-participant relationship known as the double hermeneutic approach (or dual position) to analysis (Smith et al., 2009; Peat, Rodriguez & Smith, 2019). Essentially this approach asserts that the researcher is trying to make sense of the participant making sense of the phenomena of interest (Smith et al., 2009). In the context of this study, the researcher bracketed their own assumptions through explicit reflection

on their experiences with pain and fatigue. Bracketing was done prior to commencing data collection and each interview, and continually throughout the process of coding participant data and developing themes to ensure any codes, memos, annotations, and/or emergent and final themes were not solely influenced by the researcher's experiences. This allowed the researcher to focus on the participants experiences in the world through acknowledging where the researcher's biases were influencing the co-creation of the descriptions of pain and fatigue. As a result, the researcher and participant worked together to co-construct the meaning of the lived experiences of pain and fatigue during the interview process, and the researcher continued the co-construction with interpretation during the analysis process. Additionally, the researcher continued to reflect upon the principles of the biopsychosocial model throughout the data analysis process to ensure that they were considering the participant as a "whole".

The co-construction of meaning within IPA is congruent with engaging in the hermeneutic circle (Laverty, 2003; Peat, Rodriguez & Smith, 2019). Application of the hermeneutic circle involved moving from individual participant accounts of experience to looking at the larger accounts, or the integration and interpretation of all participants accounts of the phenomena of interest (Smith et al. 2009; van Manen, 1997). That is not to say that IPA provides an objective meaning of the phenomena, but rather allows for the discovery of meaning through experiential accounts as lived. Additionally, the hermeneutic circle was iterative in nature, which allowed for the researcher to engage in reflexivity throughout the research process and continually interact with and be immersed in the data. Practically, to implement IPA in this study, interviews were transcribed verbatim and integrated the use of memoing and annotating whereby the researcher

interpretively engaged with the text and created analytic comments (Smith & Osborn, 2008). A case-by-case approach was taken to the process of data analysis, meaning that the first participant 'case' was reviewed in detail and then each case subsequently was analyzed.

A step-by-step approach to IPA was adapted from the approaches of both Peat and colleagues (2019) and Smith & Osborn (2008) for the purposes of this study. First, the researcher read and reread the transcript to immerse and familiarize themselves with the experiential accounts provided by the participant. Second, as the researcher continued to read the transcribed interview, they made initial comments through the use of a memo within the transcript. There are no definitive guidelines as to what may be commented on; therefore, the researcher had the freedom to comment on similarities, differences, links, or connections and/or even the language of the participant within individual data across the phenomena as it relates to the other data collected to that point (Smith & Osborn, 2008). Third, emerging themes were documented using another memo based on the initial comments made by the researcher. These emergent themes were used in the construction of final themes which described the meaning of the experience of pain and fatigue. The fourth step to IPA involves two stages. Initially, the researcher chronologically ordered the themes and then the researcher attempted to make connections across themes by clustering them together (Peat et al., 2019; Smith & Osborn, 2008). It is important to note that some themes may appear more prominent at this stage. As IPA is an iterative process, the researcher had to be aware that as they interpret the text, they are reflecting upon their ability to make sense of the participant's narratives (what they actually said in the interview) and that the themes reflected these experiences (Smith & Osborn, 2008).

Furthermore, the researcher created a table of themes identifying the more prominent themes and which sub-themes were contained within them. Prominent themes were identified based upon the number and patterns of codes tailored towards a specific theme, the number of participant references, and the researcher's interpretation of the meaning and importance behind participant narratives. It should be noted that chosen themes were not based solely off the prevalence in which they appeared across the data set. Fifth, the researcher moved on to the next case and repeated steps 1-4 ensuring that they continued to bracket their own assumptions to acknowledge any potential biases which could sway the interpretation of the data from a new case (Peat, Rodriguez & Smith, 2019). These first five steps were undertaken for each participant's case before advancing to the next steps of analysis. In alignment with IPA, as the researcher continued to analyze cases and new information came to light, they reiteratively reviewed earlier transcripts to ensure the continuation of immersion within the data and research process (Smith & Osborn, 2008). Step six included the researcher searching for any patterns across themes, highlighting those which were distinctive across all cases and creating a final table of all prominent themes within the data; presenting the final themes (Peat, Rodriguez & Smith, 2019; Smith & Osborn, 2008). Lastly, the 'writing up' step moves from the interpretation of themes to the elicitation of the deeper meaning of the lived experiences of the phenomena of interest (Peat, Rodriguez & Smith, 2019; Smith & Osborn, 2008). Here, the researcher described the themes which were co-constructed between the researcher's interpretations and the participant's narratives and provided verbatim excerpts from the transcripts to support the themes (see section 3 for results).

### 2.2.5.2 NVivo12 Data Analysis Software

NVivo12 (QSR International) is a data management software used for qualitative and mixed-methods research, that allows researchers to organize and code various types of data. For the purposes of this study, this software was used to code the transcribed data taken from the participant semi-structured interviews and to create annotations and memos during the research analysis process. Individual participant transcripts were imported into the NVivo12 database where they were then individually coded. The process of initial coding and the development of emergent and final themes using the data organized in NVivo12 is described below.

An inductive approach to coding was taken as codes were attached to units of data (participant references) while the transcripts were being analyzed. As the researcher read and re-read each participant transcript, participant references were then coded to existing codes or new codes, if needed, based upon the researcher's interpretation of the meaning behind the text. Initially, each code was represented as a child code under the parent code 'All Codes' so the researcher was not pre-determining or developing possible emergent themes or coding structures prior to completion of coding across all transcripts. Further to this point, this allowed for the researcher to reduce potential biases nor solely relate their own experiences of pain and fatigue to that of the participant.

Once this process of initial coding was completed for all nine participant transcripts, the researcher started to group together child codes to develop emergent themes from the data. One researcher (LK) performed all coding of participants' transcripts. Emergent themes were determined based on how the interpreted relationships between specific child codes, the meaning reflected in certain references across codes,

and the relationship between references discussed across participants. Additionally, the frequency in which the same or similar words were discussed by participants and found in different codes, helped to illustrate possible relationships between codes, which was then used in the determination of potential emergent themes. At this point in the research process, three emergent themes were developed and named.

Compellingly, throughout the iterative part and whole analysis process, the emergent themes were not changed, and thus were finalized. Changes that did occur were changes or additions to the sub-themes which made up each final theme. Final themes were represented as parent codes, while sub-themes were depicted as child codes. These child codes continually changed between the development of emergent themes into final themes, as certain sub-themes were clustered together as the researcher interpreted several codes to have similar meanings. Furthermore, certain themes expressed a similar parent-child relationship as the final themes (parent codes) contained multiple sub-themes (child codes) which aided in supporting the meaning and understanding of the researcher's interpretation of the participants narratives of their lived experiences with pain and fatigue.

### 2.2.6 Methods for maximizing quality

The qualitative criteria proposed by Tracy (2010) were used to increase the rigor, transparency, credibility, and meaningful coherence of this study. Rigor applies the concept of requisite variety noting that the tool used to study the phenomena of interest must be complex, flexible, and multifaceted (Tracy, 2010). As pain and fatigue are complex in nature, complex tools (such as phenomenology and IPA) were required to be able to study and actively interpret lived experiences and the way that an individual

interacts with these symptoms in their daily life. The flexibility of the tool is important as it translated to the need for the chosen research methodology (new phenomenology) to be flexible enough to understand and co-construct lived experiences. Furthermore, the use of a semi-structured interview guide allowed for flexibility of the researcher to pose new questions within an interview and openness within participants responses to questions. Lastly, the multidimensionality of these phenomena required a multifaceted tool that could encompass the notion of pain and fatigue existing within multiple dimensions. Exploring the existence of the multiple dimensions of pain and fatigue was accomplished through the use of phenomenology and IPA; through allowing an in-depth exploration of participants narratives discussing the multiple facets which make up their lived experiences including the physical, emotional, cognitive, and social aspects of experience.

To further increase rigor in this study, the data collection and analysis methods used were carefully chosen to provide an open and flexible approach to studying pain and fatigue considering the multidimensionality and subjectivity of these symptoms. The specific data collection and analysis procedures used throughout the course of the study were carefully detailed here to provide an accurate and in-depth account of (a) the number and length of the interviews, (b) the level of transcription detail, (c) the types of interview questions asked, and (d) the process in which data was transformed and written up (Tracy, 2010). The researcher sought to increase rigor in this study through this detailed methodological transparency associated with comprehensive data collection and analysis processes.



Another form of demonstrating transparency within this qualitative research study included the use of self-reflexivity and memoing. Tracy (2010) discusses how researchers can assess their own motivations and biases prior to beginning a research study. To this point, the researcher provided their motivations behind conducting research on the topic of pain and fatigue in persons living with MS, PD, and CP, (see section 2.1.4) to ensure that this was explicitly known to the reader. Additionally, the researcher reflected upon their own biases, presuppositions, and their motivation behind conducting this research, and bracketed these biases and preconceived thoughts. Bracketing was performed prior to commencing data collection with the assistance of the study's principal investigator as well as prior to each interview and continually throughout the analysis process of coding participant data and the interpretation of themes to ensure any codes, memos, annotations, and/or emergent and final themes were not solely influenced by the researcher's experiences, but reflected true co-construction by merging the researcher and participants experiences and understanding through interpretation. Bracketing helped to understand and acknowledge the potential influence the researcher's experiences may have had on the final themes. The process of reflecting and bracketing ensured that the researcher did not prematurely arrive at a description of the phenomena without accurately considering each participant's narrative of their experience (Errasti-Ibarrando et al., 2018). The concept of bracketing is viewed as consistent with van Manen's hermeneutical approach as well as the analytical process of IPA as the researcher must overcome their own experiences to achieve an openness to and be able to interpret the phenomena being studied in light of their own feelings, preferences, and assumptions, thereby engaging in a cyclic approach to bracketing (Errasti-Ibarrando et al., 2018; Peat

et al., 2019). Lastly, memoing was used throughout the entirety of the research process as the researcher kept annotations in each participant transcript which included the researcher's: interpretations of participant quotes, reflections of personal experiences specific to a quote, and bracketing of any biases (which included the nature of the questions posed in an interview). Reflexive notes were considered throughout the process of IPA in developing final themes and sub-themes to aid in the interpretation and co-construction of the meaning of the lived experiences of pain and fatigue. The concepts of bracketing and memoing aided in increasing transparency of the research process and the researcher through in-depth reflection on study procedures and the researcher.

Credibility applies to the trustworthiness of the research results which can be ascertained through multivocality (Tracy, 2010). Multivocality ensures that the voice of the participant is heard and not drowned out by the researcher. To ensure the participant's voice was recognized in the study, verbatim participant quotes were included in the study findings to support the final themes and sub-themes.

Finally, the aim of the methodology chosen was to produce a research process which acted as a cohesive unit. Meaningfully coherent research studies as denoted by Tracy (2010), are those that use a qualitative methodology, paradigmatic position and data collection and analysis methods which are congruent and cohesive and allow the researcher to achieve their stated objective through purposeful study design. In the current study, the researcher articulated how each chosen element of the research study design was interconnected and appropriately aligned with the aims of the study.

### 2.2.7 Ethical Considerations

Prior to commencing semi-structured interviews, the participant reviewed the LOI and gave informed signed consent. Ethical approval was obtained from the Health Science Research Ethics Review Board at The University of Western Ontario (see appendix D) and the Lawson Health Research Institute (see appendix E).

## 3 Results

### 3.1 Participants

A total of nine participants (n=9) participated in one semi-structured interview each between January to May 2022. Participants represented a heterogeneous group and consisted of six women and three men. Their ages varied from 32 to 78 years. All participants had a self-reported diagnosis of MS, PD, or CP lasting from 2 to 32 years and each presented with a specific sub-type of their respective condition. An overview of their demographic characteristics is presented in Table 1.

**Table 1: Demographic Characteristics of the Participants (n=9)**

| Participant | Sex | Age | Condition | Sub-type              | Pain, Fatigue, or Both | Length of Diagnosis (years) | Employed (Y/N) |
|-------------|-----|-----|-----------|-----------------------|------------------------|-----------------------------|----------------|
| PF001       | F   | 54  | MS        | RRMS                  | B                      | 25                          | Y              |
| PF002       | M   | 61  | MS        | PPMS                  | B                      | 17                          | N              |
| PF003       | F   | 78  | PD        | n/a                   | Minor P and F          | 5                           | N              |
| PF004       | F   | 49  | MS        | Unknown               | B                      | 4                           | Y              |
| PF005       | M   | 67  | PD        | n/a                   | Minor P and F          | Not reported                | N              |
| PF006       | F   | 61  | PD        | n/a                   | B                      | 11                          | N              |
| PF007       | F   | 53  | MS        | Unknown               | B                      | 11                          | Y              |
| PF008       | M   | 58  | PD        | n/a                   | B                      | 2                           | N              |
| PF009       | F   | 32  | CP        | Right side Hemiplegia | B                      | 32                          | Y              |

*F* = female; *M* = male; *MS* = multiple sclerosis; *PD* = Parkinson's disease; *CP* = cerebral palsy; *RRMS* = relapsing-remitting multiple sclerosis; *PPMS* = primary-progressive multiple sclerosis; *P* = pain; *F* = fatigue; *B* = both pain and fatigue; *Y* = yes; *N* = no.

### 3.2 Interpretation of Final Themes

The data analysis process of IPA resulted in three final themes and eleven sub-themes (with additional themes supporting each sub-theme) provided in Table 2. A summary of the final themes and sub-themes are presented below with supporting verbatim excerpts from participants (see Appendix F).

**Table 2: Overview of Final Themes and Sub-themes Co-constructed from the Interpretive Phenomenological Analysis of Participant Semi-Structured Interviews (n=9)**

| Themes                       | Sub-themes                | Tertiary themes                 | Frequency of References Across All Interviews<br>n (%) | Number of Participants Referencing Selected Theme | Condition(s) theme relates to (MS, PD, or CP) | Pain (P), Fatigue (F), or Both (B) |
|------------------------------|---------------------------|---------------------------------|--|---|---|------------------------------------|
| <b>Lack of Understanding</b> |                           |                                 | <b>87 (10.5%)</b>                                      | <b>9 (100%)</b>                                   | <b>MS/PD/CP</b>                               | <b>B</b>                           |
|                              | By Others                 |                                 | 41 (4.9%)  | 8 (88.9%)   | MS/PD/CP                                      | B                                  |
|                              | By Clinicians             |                                 | 30 (3.6%)  | 7 (77.8%)   | MS/PD/CP                                      | B                                  |
|                              | By the Patient Themselves |                                 | 16 (1.9%)  | 8 (88.9%)   | MS/PD/CP                                      | B                                  |
| <b>Negative Perceptions</b>  |                           |                                 | <b>479 (56.5%)</b>                                     | <b>9 (100%)</b>                                   | <b>MS/PD/CP</b>                               | <b>B</b>                           |
|                              | Fatigue as a spectrum     |                                 | 92 (10.9%)   | n/a   | MS/PD/CP                                      | n/a                                |
|                              |                           | A lack of energy                | 23 (2.7%)  | 7 (77.8%)   | MS/PD/CP                                      | B                                  |
|                              |                           | Fatigue distinct from tiredness | 12 (1.4%)  | 7 (77.8%)   | MS/PD/CP                                      | B                                  |
|                              |                           | Fatigue as extreme tiredness    | 28 (3.3%)  | 9 (100%)  | MS/PD/CP                                      | F                                  |
|                              |                           | Exhaustion                      | 29 (3.4%)  | 5 (55.6%)   | MS/PD/CP                                      | F                                  |
|                              | Losing Yourself           |                                 | 121 (14.3%)  | n/a   | n/a   | n/a                                |
|                              |                           | Negativity                      | 28 (3.3%)  | 9 (100%)  | MS/PD   | B                                  |
|                              | All-encompassing          | 23 (2.7%)                       | 8 (88.9%)  | MS/PD/CP  | B   |                                    |
|                              | Limiting                  | 21 (2.5%)                       | 5 (55.6%)  | MS/PD/CP  | B   |                                    |

|                             |                         |             |           |          |              |
|-----------------------------|-------------------------|-------------|-----------|----------|--------------|
|                             | Before and after        | 15 (1.8%)   | 5 (55.6%) | MS/PD    | B            |
|                             | Feeling lesser          | 13 (1.5%)   | 5 (55.6%) | MS/PD    | F            |
|                             | Lack of control         | 10 (1.2%)   | 6 (66.7%) | MS/PD/CP | B            |
|                             | Lack of muscle strength | 7 (0.8%)    | 3 (33.4%) | MS/PD/CP | B            |
|                             | Dependence              | 4 (0.5%)    | 3 (33.4%) | MS/PD    | B            |
| Dealing with Change         |                         | 52 (6.1%)   | n/a       | n/a      | B            |
|                             | Worrying                | 12 (1.4%)   | 4 (44.5%) | MS/PD    | B            |
|                             | Hiding                  | 16 (1.9%)   | 5 (55.6%) | MS/PD    | B            |
|                             | Pushing through         | 24 (2.8%)   | 8 (88.9%) | MS/PD/CP | B            |
| Nature of Phenomena         |                         | 112 (13.2%) | n/a       | n/a      | B            |
|                             | Constant                | 34 (4%)     | 8 (88.9%) | MS/PD/CP | B            |
|                             | Unpredictable           | 20 (2.4%)   | 7 (77.8%) | MS/PD/CP | B            |
|                             | Heaviness               | 17 (2%)     | 6 (66.7%) | MS/PD    | B            |
|                             | Time-consuming          | 15 (1.8%)   | 6 (66.7%) | MS/PD    | B            |
|                             | Intense                 | 14 (1.7%)   | 7 (77.8%) | MS/PD/CP | B            |
|                             | Progressive             | 12 (1.4%)   | 5 (55.6%) | MS/PD/CP | B            |
| Associated Factors          |                         | 85 (10%)    | n/a       | n/a      | B            |
|                             | Cognitive challenges    | 43 (5.1%)   | 7 (77.8%) | MS/PD    | B (mostly F) |
|                             | Impaired sleep          | 18 (2.1%)   | 6 (66.7%) | MS/PD/CP | B            |
|                             | Anxiety & Depression    | 15 (1.8%)   | 5 (55.6%) | MS/PD/CP | B            |
|                             | Weather                 | 9 (1.1%)    | 4 (44.5%) | MS/PD/CP | B            |
| Other Experiential Accounts |                         | 17 (2%)     | n/a       | n/a      | B            |

|                          |                         |                    |                 |                 |              |
|--------------------------|-------------------------|--------------------|-----------------|-----------------|--------------|
|                          | Something that you feel | 16 (1.9%)          | 8 (88.9%)       | MS/PD/CP        | B (mostly P) |
|                          | Fatal                   | 1 (0.1%)           | 1 (11.2%)       | MS              | B            |
| <b>Coping Strategies</b> |                         | <b>282 (26.5%)</b> | <b>9 (100%)</b> | <b>MS/PD/CP</b> | <b>B</b>     |
|                          | Main strategies         | 247 (23.2%)        | n/a             | n/a             | n/a          |
|                          | Support                 | 50 (4.7%)          | 9 (100%)        | MS/PD/CP        | B            |
|                          | Rest to renew           | 46 (4.3%)          | 9 (100%)        | MS/PD/CP        | B            |
|                          | Acceptance              | 32 (3%)            | 8 (88.9%)       | MS/PD/CP        | B            |
|                          | Accommodating           | 29 (2.7%)          | 8 (88.9%)       | MS/PD/CP        | B            |
|                          | Positivity              | 29 (2.7%)          | 6 (66.7%)       | MS/PD           | B            |
|                          | Pain management         | 21 (2%)            | 8 (88.9%)       | MS/PD/CP        | P            |
|                          | Planning                | 20 (1.9%)          | 7 (77.8%)       | MS/PD/CP        | B            |
|                          | Physical activity       | 20 (1.9%)          | 6 (66.7%)       | MS/PD           | B            |
|                          | Other strategies        | 35 (3.3%)          | n/a             | n/a             | B            |
|                          | Relaxation              | 15 (1.4%)          | 6 (66.7%)       | MS/PD/CP        | B            |
|                          | Independence            | 12 (1.1%)          | 5 (55.6%)       | MS/PD           | B            |
|                          | Feeling lucky           | 8 (0.8%)           | 3 (33.4%)       | MS/PD           | B            |

n (%) = The number of references participants discussed in relation to the respective theme and the frequency with which that theme was referred to across all nine semi-structured interviews. A sample calculation is provided in appendix G of the frequency of references across all interviews for the final theme a 'Lack of Understanding'. n/a = unable to conclusively determine the conditions, symptoms, or number of participants who specifically referenced the selected theme. The bold font illustrates the three final themes and their respective frequencies, conditions, and symptoms discussed across all interviews.

### 3.2.1 Interconnectivity across final themes

The final themes including ‘Lack of understanding’, ‘Negative perceptions’, and ‘Coping strategies’ were co-constructed from participant narratives of their lived experiences with pain and fatigue and the researcher’s interpretations of these experiences. A lack of understanding by others (including family, friends, partners, colleagues, strangers), by clinicians, and by the patient themselves was seen as an antecedent to the negative perceptions of pain and fatigue and coping strategies characterized in the daily life and life course of persons living with MS, PD, and CP. The lack of understanding by others often stemmed from their inability to acknowledge, understand, or visually observe the symptoms of pain and fatigue; nor provide support or listen to the individual experiencing these phenomena. Similarly, participants noted that clinicians tried to manage or treat these phenomena without making the time for conversation or to listen to their patients’ experiences. This often led to the patient's experiences and perspective being unacknowledged and undervalued in clinical assessment. An important factor leading to patients lack of understanding is that they were not told by clinicians that pain or fatigue could or would be a symptom of their condition; and therefore, had difficulty making sense of the presence of these phenomena in their lives. Overall, this lack of understanding contributed to negative perceptions of pain and fatigue due to trouble navigating their condition and the symptoms that arose with it (including pain and fatigue).

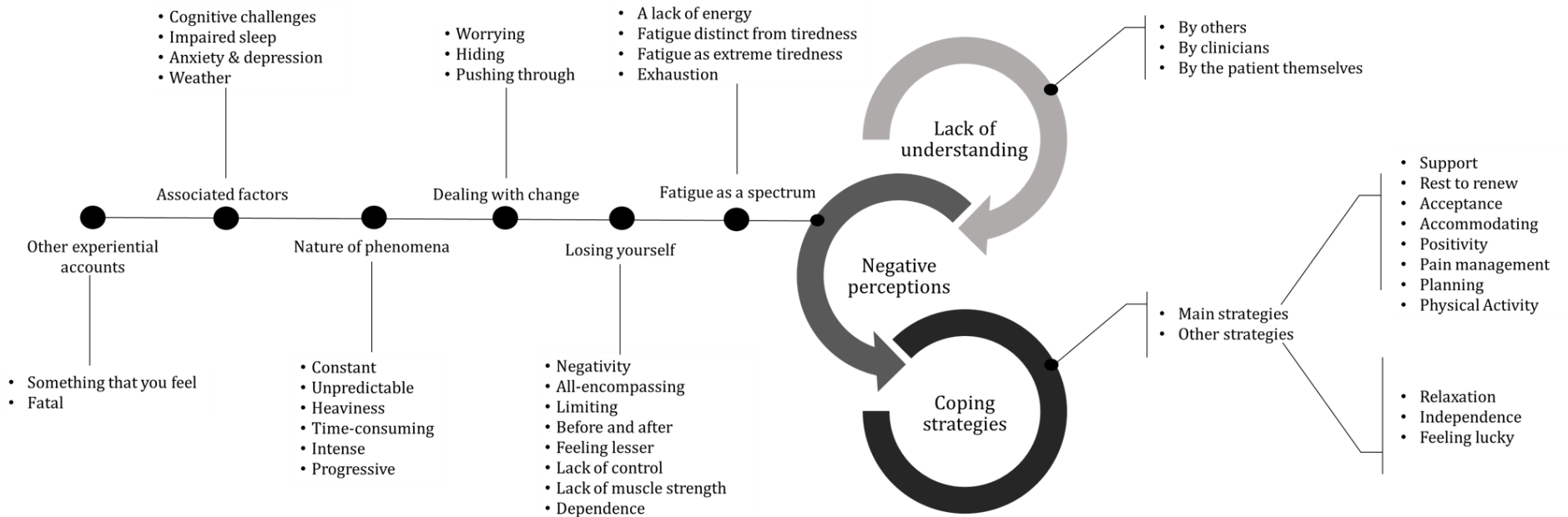
Negative perceptions of pain and fatigue encompass the difficulties and challenges which negatively impact the daily lives and greater life course of individuals who experience pain and fatigue across the specified neurological conditions as elicited from participants’ narrative accounts of their personal experiences. Participants fall along a spectrum of fatigue (some participants also described pain occasionally being associated with the states of this spectrum) including a lack of energy, fatigue distinct from tiredness, fatigue as extreme tiredness, and exhaustion. The subtheme of negativity emphasizes the negative feelings, thoughts, attitudes, state of mind, and lack of positivity that impact and reduce the quality of life of participants. Additionally, cognitive challenges were described by participants as ‘brain fog’, cognitive fatigue, a reduced



ability to absorb information, reduced memory capacity and retrieval, and difficulty concentrating. Pain and fatigue were often constantly present for individuals with these neurological conditions; however, for others, they still were felt to be unpredictable presenting at random times throughout a day or for an extended period. This led to the participant feeling the need to push through the pain and/or fatigue limiting their lives so they could maintain their functional ability and quality of life. These phenomena were described by those with MS, PD, and CP as an all-encompassing experience. Participants reported using a variety of coping strategies to combat these feelings and perceptions of pain and fatigue, to maintain a positive outlook and mindset and to improve their quality of life.

The support from others (including family, friends, support groups, colleagues, neurologists, strangers, etc.) proved immeasurable in helping to manage and cope with the pain and fatigue experienced daily by those living with these conditions. To be able to continue with day-to-day tasks, participants required rest to renew themselves and restore their energy levels, although the amount of rest required varied greatly between participants. Positivity and maintaining a positive outlook towards life through humor, meditation, self-talk, and compartmentalization appeared to be a key feature associated with coping with pain and fatigue. Additional coping strategies described included putting accommodations in place, planning their day around pain and/or fatigue, keeping physically active, and managing the pain (not fatigue) when necessary (ex. therapy or medication). Finally, participants arrived at a certain point where they were able to accept that their condition, the pain, and the fatigue will be an ever-present part of their lives as their new ‘normal’; although this meant they developed and used coping strategies to manage these symptoms of their condition in their daily lives.

It can be seen through the narrative accounts of those living with pain and fatigue associated with MS, PD, and CP, that a lack of understanding by others, clinicians, and the patient themselves, leads to negative perceptions of these symptoms in the daily life and life course of persons living with these conditions. These negative perceptions then result in a need to develop coping strategies to continue to participate in daily life. Figure 1 provides a visual display of the interconnectivity of the final themes.



**Figure 1: The interconnectivity across final themes (lack of understanding, negative perceptions, coping strategies).**

## 3.2.2 Lack of Understanding

### 3.2.2.1 By Others

A lack of understanding by others was perceived as others trying to relate their own experiences of pain and fatigue to those of persons living with these neurological conditions; in essence, marginalizing the individuals experience and dismissing the nature of MS/PD/CP related pain and fatigue. This marginalization occurred from family, friends, and even strangers. One participant described marginalization in terms of others being positive but unrealistic. This was perceived as others (friends) trying to normalize pain in that it happens to everyone; however, for this participant, their pain is constant and so they needed to keep a sense of realism in that their pain likely would not dissipate or completely disappear. They must remain positive but could only allow themselves to be positive to a certain degree.

*They try to marginalize it as a way of being positive. That's all it does, is it marginalizes the effort. That's why it's called toxic positivity because it's positivity at the cost of reality.*  
[PF008]

It was described by participants how other people also lack knowledge surrounding MS, PD, and CP which can add to others lack of understanding and occasionally can lead to ignorance. Some participants described the loss of their partners after diagnosis which can be attributed to the ignorance of their loved one, as they did not want to have to take care of them and wanted to live their own life. Acknowledgement of the fact that it is or would be hard for others to understand the experiences of pain and fatigue without living through it was highlighted. Family, friends, and others want to understand, and they mean well and have good intentions in trying to relate to the persons experiences; however, it is difficult to do so and can therefore result in feelings of annoyance and occasionally anger. This was described as being due to overreacting to the needs of persons living with these conditions by helping them in situations where they are capable of helping themselves and may not require assistance. Due to the invisibility of pain and fatigue, participants described how others may be confused, cannot take them

seriously, or not realize they are in pain because they cannot visually observe these phenomena.

*One wouldn't know or understand, and I would never have understood what it was until I was in it. [PF005]*

*But if you look at me and if the pain parts were a different color, you would see that, okay, I have pain in certain parts of my body. [PF001]*

*I think some people are confused because I don't look like I'm always in pain. So, when I say that I'm having a really bad pain day cause I'm upfront about it, they don't always... it's not they don't believe me, they just don't realize what I mean, and I think a lot of that has to do with just how society handles pain and handles disability as a whole. [PF009]*

### 3.2.2.2 By Clinicians

Participants described a heightened focus on assessing the biological/physical factors which affect pain and fatigue, without discussing the psychological, emotional, cognitive, or social factors which play a part in the patients experience with these symptoms. This can lead to an inability to understand their patient's condition as a whole.

*I kind of feel like a lab rat with my neurologist to tell you the truth. Like I feel like I, you know, I fit in this category, let's try this medication, it's not working. Okay, let's try this. You know? So, I'm more of a character study for my neurologist. [PF001]*

Participants expressed that they wished clinicians would take the time to listen to them and make them feel like their diagnosis is not the end of their life. They wanted to feel like they were heard. Additionally, participants wanted to be able to understand the course that their condition may take, what symptoms may arise, and the next steps recommended to help them manage. One participant described how they had no idea that pain was a possibility with their condition and felt like someone should have told them or a guide should be available to them considering all the possibilities. Furthermore, participants felt that clinicians needed to take the time to consider their patient as a whole and converse with their patient to understand their perspective on what they're feeling.

*Especially again with the physical pain, when you have a neurologist, who again I know their job isn't to like console me, their job is to, you know, say "I gotta take care of the disease, not you as a whole." [PF001]*

The idea of marginalization arose again with clinicians in attempting to tell their patients how they may or are supposed to feel and what they may now be capable of doing. This is not to say that there aren't any clinicians who engage in meaningful conversation with their patients and take the necessary time to treat them. Rather, it highlights what can be done to improve these clinical encounters and how participants feel.

*Like the doctors try to explain to you and I told my neurologist, "You have MS patients, you don't have MS. Don't ever tell me how I'm supposed to feel or what I'm capable of doing." [PF002]*

### 3.2.2.3 By the patient themselves

Participants described how they were not made aware of the fact that pain or fatigue may be a symptom of their condition, which created a major lack of understanding and ability to make sense of the presence of these phenomena in their lives. In fact, individuals spoke about not being able to make sense of why they have been diagnosed with their respective conditions, and why they are affected by pain and fatigue. They expressed a wish to know why this was done to them and why their body responds the way it does.

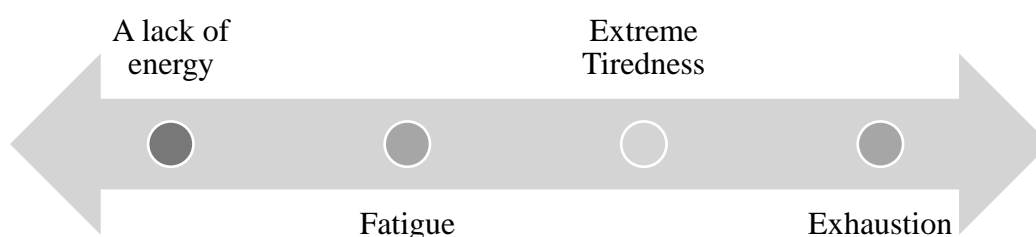
*Well, I go back to making sense of having Parkinson's and there's no sense in it. It's kind of like you think why me? And it has to be somebody I guess and there's no really understanding where it comes from, like who gets it, doesn't get it. Why do some people have some things more severe than others? [PF006]*

*... "why am I in pain?" You know. "Who's done this to me? Why am I like this?" Those sorts of negative thinking. [PF008]*

*That I wish that I knew why my body does what it does. [PF009]*



This feeling of fatigue then progresses to a final state of exhaustion. Fatigue was illustrated as a spectrum from participants' descriptions of fatigue being a fluid movement between these four states affecting their biopsychosocial experiences with this phenomenon. Fatigue was not determined to be solely a linear progression from a lack of energy to exhaustion, but rather they could feel any one of these states at any time. Participants alluded to pain contributing to which fatigue state they were experiencing along this continuum. The spectrum of fatigue is illustrated in Figure 3.



**Figure 3: Fatigue as a spectrum.**

### 3.2.3.1.1 A lack of energy

Participants described how pain, and to a greater effect fatigue caused a lack of energy or having no energy in their daily lives. One participant described how both phenomena played a part in how they were able to express their energy levels; where they may feel like they had a lot of energy, but when in pain and feeling fatigued, they were unable to communicate their energy (verbally or physically). Furthermore, even when passionate about something in their life, for example, a subject in school, they did not have the energy to care to complete associated tasks. Additionally, one participant perceived pain as feeling 'shattered' as they had no energy after short bouts of physical exertion; and felt as though they were sleeping a lot and had a hard time getting out of bed in the morning.

Another participant described how their lack of energy could stem from extroverted situations, as they were an introvert and typically gained energy from being

in small groups when in pain. A lack of energy could impact participants' social life as they felt they could no longer be at a social event or elsewhere when fatigued. One participant described the fatigue as feeling like someone hit them with a hammer because they lacked the energy to continue their day and had to go home.

Participants described how fatigue compromised their energy stores which made them realize how reliant they were on having enough energy for daily tasks. One participant described having two different levels in their life which influenced each other: a fatigue level and an energy level. Occasionally when fatigued, participants' energy could be taken away from them suddenly, leaving them feeling like they needed to fall asleep wherever they were sitting. Other days, participants had higher energy levels where they could not do certain things nor do more in a day than they would have liked. This was usually due to the task being attempted requiring more energy than the participant had. Furthermore, the timing of when tasks are completed could be changed dependent on the day. For example, one participant will not take a shower one day because this task takes a lot of physical and mental energy to perform which could be draining for them.

One participant described their lack of energy associated with fatigue in terms of the spoon theory, the battery theory, and a mixed battery/spoon theory world which they live in. The spoon theory was described in terms of every task taking a different number of spoons. If they were to run out of spoons for one day, they would have to borrow from the next day, which reduced their energy stores for the following day. This same participant noted how they did not fully 'prescribe' to this theory, and more so followed the battery theory where they considered themselves like a rechargeable battery. The downside to this theory was that when the battery came unplugged, it didn't charge. The participant then realized their energy levels in a day slowly drained and they were not necessarily able to charge their energy back up to the same level they had previously or even the day prior. Lastly, this participant lived in a world which closely associated with a combinatory spoon/battery theory. This combined theory bounded their world through constantly checking and balancing their energy levels, determining their priorities in what



needed to be done, had they been done, and which tasks could wait; and how much energy was left to do other things.

*So, for example, for some people sharing takes 3 spoons. So now you've only got 2 more spoons to use for the rest of the day to do other things. [PF009]*

*I prescribe more to the battery theory in terms of I go to sleep, I charge up my body, I charge up my energy. [PF009]*

Participants described fatigue as being an absence of energy, leaving them feeling drained at the start and end of a day. A lack of energy often impacted participants ability to complete tasks any given day and participate in social events. Participants discussed the need to constantly understand the level of energy they had or had used; and communicated how their lack of energy could lead to feelings of tiredness.

*You have to define it [fatigue] by an absence. It's an absence of energy. Its absence of all kinds of energy. So, it's not just the energy to go out on your own, but to get the energy to socialize with friends, it's the energy you need to cook a dinner. [PF006]*

### 3.2.3.1.2 Fatigue distinct from tiredness

Some participants described fatigue as tiredness, although others distinguished fatigue and tiredness as being separate phenomena. Upon initial diagnosis of their condition, one participant was honest in admitting that they were confused as to if they were feeling tired or fatigued; but now, are very clearly able to observe the differences between the two and finding the distinction to be obvious. Participants described how tiredness can be both mental and physical. Mental fatigue was described as different from tiredness by one participant discussing how they became tired from too much mental stimulus and another discussing how they could not focus or maintain focus. Participants differentiated physical tiredness from fatigue when they noticed bags under their eyes or read the same line of a book six or more times. Tiredness was described by participants as 'ordinary tiredness', a result of being in pain, and due to a lack of sleep or needing sleep. Participants additionally described feelings of tiredness as resulting from the weather, living with the challenges brought on by a full day, and generally living their life.

Interestingly, one participant discussed how healthcare professionals view fatigue as different from feeling tired; and this is reflected in their management and treatment approaches of their patients. Another participant noted the difference between fatigue and tiredness through perceiving fatigue as the body's way of telling them they were tired.

*The difficulty to know is, again, how much is fatigue from Parkinson's and how much is fatigue because you just went four kilometers. [PF006]*

### 3.2.3.1.3 Fatigue as extreme tiredness

All participants described how fatigue meant being tired, although some participants still felt it was important to differentiate fatigue and tiredness as different symptoms. As such, participants defined their fatigue as 'extreme', 'disabling', and 'meaningless' tiredness. When fatigue worsened, participants felt apathetic and increasingly tired; and described how they were always tired no matter what they did. Two participants perceived fatigue as tiredness through the metaphor of an iron/heavy theater curtain or garage door which continued to descend without them being able to stop it.

*I know when I'm experiencing fatigue because it's sort of like this meaningless, meaningless tiredness, that is, you know, it's really nothing, but you still feel tired, want to do nothing, and feel negative. [PF003]*

*... like a comparison of like a theater curtain. It's [fatigue] that heavy curtain it's just coming down and coming down and like, there's nothing you can do to stop it. It's just going to close and it's like a veil of tiredness right. [PF004]*

Being tired was perceived to be due to a lack of or having no energy and becoming more tired as their day persisted. For example, one participant discussed how they became increasingly tired every evening after dinner. Additionally, another participant described how the more fatigued and tired they were, the more they had to think about telling their body what to do. They could not do something without having to think about or make an effort to do it.

*Fatigue to me just means being so tired that... being fatigued means being tired period. I mean that's the denotative meaning of it, and that's how I think of fatigue. The fatigue I've got it means being tired enough that it's hard to do something, like to do something I normally do. [PF005]*

Participants described fatigue as being both mentally and physically tiring. How mentally and physically tired a participant was dictated how quickly they would tire from performing an exerting task; one participant described how their body's weariness to participating in life was determined upon how mentally and physically tired they were. This was perceived as meaning the participant was less apt to participate in acts of daily living when tired.

*... my brain needs to stop hearing things. Like sound becomes irritating and annoying and overwhelming, and sensory things become overwhelming when you're that tired... [PF004]*

#### 3.2.3.1.4 Exhaustion

Exhaustion due to fatigue was reported as feeling 'complete', 'endless', and resulted in feeling 'completely drained' (where a task such as blow drying their hair was exhausting). Additionally, feelings of desperation usually resulted due to knowing they had not slept and would crash at some point during the day. A single participant identified the fact that there is a difference between tiredness and exhaustion. Another participant described how exhaustion was their fatigue level and that they had differing levels of exhaustion that they felt. Further discussion into the specific levels of exhaustion was not provided in this study.

*You go to sleep exhausted; you wake up exhausted. You live your life through the day exhausted; and at times you can't even get a statement out or have a conversation with somebody. [PF002]*

Participants described how they felt exhausted when they woke up, they started their day exhausted, and finished their day exhausted. Only one participant noted they did not often experience waking up feeling exhausted. No matter what participants did in a

day, they always ended up feeling exhausted and remained exhausted even when their fatigue dissipated. They recognized that despite their exhaustion they still had to perform as much as they could in a day. This was due to the variability associated with fatigue, where participants could not rely on the fact that they could complete a task or activity the next day because they could never be certain of their energy levels. This left participants needing to be increasingly flexible throughout their days. As discussed in relation to the spoon theory by one participant, they became increasingly exhausted as they had a reduced amount of energy (spoons) in a day or for the next day.

*It [fatigue] hits you. You'll sleep for 10 hours, you get up and you're even more exhausted. You run a 25 kilometer marathon, and then start your day, and then run another 25 marathon. [PF002]*

Exhaustion was also described by participants in terms of psychological (mental) and social (emotional) exhaustion. One participant perceived their fatigue to be a state of mental exhaustion different from that which they experienced before their condition. Participants lacked the emotional ability to communicate with someone due to exhaustion and often felt they needed to be left alone. This was perceived as being due to a mental overload where too many thoughts were occurring in their minds which didn't make sense; and so, they needed to take the time for themselves to recuperate.

*It's [fatigue] like a mental exhaustion, state of mental exhaustion... and it's very different than mental exhaustion I have had before. [PF005]*

### 3.2.3.2 Losing Yourself

#### 3.2.3.2.1 Negativity

Upon initial diagnosis, participants expressed concern regarding what a diagnosis meant for their life. One participant described how when they were first diagnosed, it felt like a death sentence. However, this hardship was not alleviated as the course of MS and PD progressed. Participants often described fatigue as continually getting worse and being the worst of all the negative things occurring in their life. These negative thoughts created

a downward spiral of feeling like there was no end in sight for them which led to feelings of depression and anxiety.

*So, when I was diagnosed, I was like Annette Funicello, she's an actress. Now she can't talk, she can't walk. That's me. That's all you know, that was my focus. That's me, my life is over, you know. [PF001]*

Negativity was perceived as stemming from participants describing fatigue in terms of it being easy to look on the dark side of life as fatigue encouraged dreary and apathetic feelings as though they could not be bothered to do things anymore. Participants recognized the limitations this symptom put on their lives, and how they could no longer do things they could previously do and so they don't do or don't try to do these things at all as it may never be the same. Fatigue did not encourage activity, feeling good about themselves, or joy in life.

*And now I guess I realize there's some things that can't be fixed or they can only be fixed temporarily because that's Parkinson's, it's like this big slow monster moving along that gobbles up everybody in its way, but you've got plenty of time to watch it coming. [PF006]*

In fact, fatigue was regarded as a symptom which robbed them of their lives like a thief. Fatigue was perceived as being a negative symptom with a negative quality which forced participants to have negative thoughts instead of positive ones and remain in a negative state of mind. For one participant, they became irritable when their fatigue was more severe, and they wanted to stay positive but felt they no longer could.

*... it's got a mind of its own and you have to succumb to it... it's a thief. Robs your life. [PF004]*

Pain was negatively associated with MS and PD in the minds of participants as it was perceived as a cost and inconvenience. One participant described it as pain with no benefit afterwards. They did not get any sort of reward, nor did they get to feel good about themselves after going through a painful experience; essentially, it was perceived as living through pain for nothing in the end. Pain and fatigue were described as having a

mind of their own where participants felt like they could not stop these phenomena from happening.

*If I'm too negative, and that does happen, I mean I wouldn't classify myself as a negative person. I think I'm really positive but there are times when I'm down and in those moments my pain often increases. [PF008]*

### 3.2.3.2.2 All-encompassing

The experience of pain and fatigue was all-encompassing consisting of an out-of-body, full-body, and inner-body experience. Fatigue was described as being an out-of-body experience as one participant felt like their soul was being pulled from their physical body. This was interpreted as the participant feeling like they were living their life outside of themselves, outside of their own body when experiencing fatigue.

*It is different. It's a different kind of fatigue. Parkinson's fatigue it saps your soul. It sort of pulls you out of yourself. [PF006]*

The full-body experience of pain and fatigue was all-encompassing in that it consisted of both physical and mental aspects which seized the mind and body. Essentially, appropriating the individual as a whole. The level of effort and mental energy that is required to complete a task such as walking was increased and inherently difficult due to the need to be more in tune with their body; and sometimes, they were not able to complete the task at all. Their cognitive and functional ability and mobility were compromised, as pain and fatigue essentially completed a system wide shut down and they were incapable of doing anything during this time.

*Fatigue becomes almost like a full body starting with my brain... and then it's just, it's all encompassing. [PF001]*

*It's [pain] more the spasticity, it's more when my whole body responds. [PF009]*

The inner body is where the pain supposedly lives. Referencing the notion of pain being invisible to the perceptive eye, participants perceived pain as being inside of them. Participants described this feeling of pain being 'sharp', 'intense', 'in the bone', creating

an ‘internal uproar’, like someone is cutting out or squeezing their muscles, and sticking something inside of them. This latter reference was frequently referred to as a ‘stabbing’ sensation, like a ‘needle’, a ‘heat pick’, or more commonly an ‘icepick’ was being stuck inside of them.

*If you could see inside of me, you wouldn't have the same impressions... There's a lot of our members who you know they'll walk with a limp or things like that, but they're experiencing a lot of internal uproar. [PF002]*

*It's kind of like an ice or a heat pick being driven up through my heel into my calf as far as my knee or my hip. [PF008]*

*I literally compare it [muscle spasm pain] to like a fist, and then letting go is how I compare the pain... it's almost like my muscles are squeezing themselves. [PF009]*

### 3.2.3.2.3 Limiting

Pain and fatigue were described as a limitation and a lifestyle restriction. Participants described how their ability to experience certain things with their family, perform certain activities, or engage in meaningful conversation are compromised due to these phenomena. Participants perceived pain and fatigue to be ‘debilitating’ and ‘a barrier in life’. One participant discussed how inaccessibility and ableism were perceived to be significant barriers in their life, reducing their QoL. This inaccessibility was due to their living accommodations as they lived in a basement apartment which induced pain and fatigue in having to go up and down a high set of stairs. These individuals needed to pick and choose what they could and could not do in order to remain functional and not in a constant state of tiredness or exhaustion. It limited their ability to be who they were, who they are now, and everything they could be if they did not have to live with pain and fatigue.

*Pain to me is a restriction of a healthy lifestyle... It's not a wall, because you can go around walls, you can go through walls. It's a restriction that, you're handcuffed to the pain. No keys to take off your handcuffs. [PF002]*

*Not to be able to experience the same things that your family's experiencing or get the same amount of joy out of it, because you're fighting the demons inside of you. [PF002]*

Tasks which used to be done quicker take longer to complete and must be done over an extended period of time in a day, or in smaller time segments throughout a week. One participant described how their husband now does all the cooking because that task is so physically and mentally exhausting for them that they simply can't do it. There is a cost and inconvenience associated with doing certain tasks, and they had to decide if the cost of accomplishing a task was worth it, something only they could determine for themselves.

*So, I've always done the cleaning in my relationship with my wife from the very beginning, and I enjoy that because it puts order in my life. But that's become challenging at best. I used to be able to clean the house on a weekend. Now it takes all week mostly. [PF008]*

Participants also described a social limitation process where they discussed not being able to spend extended periods of time with people; and so, they limited the time spent at social gatherings. The amount of time was different for each person but essentially, participants must learn and balance the demands and limitations associated with pain and fatigue to preserve their highest QoL.

#### 3.2.3.2.4 Before and after

A challenge living with MS and PD is that these people can compare themselves to the 'me before' and the 'me after' the onset of pain and fatigue associated with their respective condition. This makes them feel as though their experiences now are worse than they were prior to their condition. In a sense they feel robbed of the QoL they could have had if they did not have pain and fatigue as symptoms of their respective neurological condition.

*It was the me before fatigue and the me after fatigue. [PF006]*



*I think fatigue then [before MS] was self-induced. Fatigue now is not self-induced. [PF007]*

*So that's the cost [losing a night's sleep to pain]. So, I don't feel always very good about going into that [cleaning task] and discouraged at times when I can't do what I normally could do. [PF008]*

### 3.2.3.2.5 Feeling lesser

Feeling lesser seemed to be perceived by participants with MS and PD as fatigue causing brain fog and making everything feel bigger than it actually is. The idea of self-deprecation was introduced due to fatigue making them feel 'stupid', 'flustered', 'discouraged', and like a 'bumbling fool'. Ultimately, they felt badly about themselves being unable to achieve the functional ability and goals they wished they could.

*I'm not functioning as a human being. You don't function as a human being. You function as like a broken-down car that's got a couple months left; and it may have 4 flat tires, you can still drive it, but you know you may be burning oil, and you got black smoke coming out of the tail pipe but you're still moving. [PF002]*

### 3.2.3.2.6 Lack of control

Pain and fatigue were described as being beyond the participants' control and made them feel like they were slowly losing or had less control over their bodies. One participant described how when their fatigue was less severe, it was easier to control, and they found it easier to get through a day and perform tasks even when fatigued. Participants described being unable to control their limbs due to spasming or their coordination due to numbness. A mental lack of control also seemed to be at play in feeling like things were bigger and worse than they actually were. This seemed to cause participants to lack control over and at times may not be able to regulate their emotions and emotional response to a situation.

*Honestly, I just feel very flighty. Like not in control, like everything just feels so much bigger and worse than it actually is. [PF001]*

*Like my wife will often take note of when I'm in pain; and she's not cold and not concerned, she makes note of it. But she doesn't comment on it unless I say, "I'm out of control, and I need help." [PF008]*

### 3.2.3.2.7 Lack of muscle strength

A loss and/or lack of muscle strength was characterized as resulting due to pain and fatigue, and the disease course of the condition itself. Participants described how they no longer have the strength to and require an increased amount of effort to perform certain tasks such as typing on a typewriter, lifting weights, or getting out of bed as a result of their fatigue. Some participants described how their affected and thereby weaker side of their body, attributed to their condition, resulted in a lack of or no strength which could cause higher pain in these areas.

*The physical fatigue now... I don't know whether to characterize it as a fatigue, or it's just a loss of muscle strength. [PF005]*

*My pain is mainly on my left side because it's my weaker side, so I have no strength. [PF007]*

### 3.2.3.2.8 Dependence

Participants with MS and PD described feeling vulnerable in moments where they needed to rely on others to help them perform certain activities. One participant realized they needed the help of others as they would not be able to do it on their own, which was a hard realization as they wanted to maintain their independence as much as possible. Generally, participants wished to maintain a certain level of independence in their lives to feel like they could continue functioning themselves.

*... the things where I need their [other people] help more like opening a jar of jam or like cutting something or drawing a knife... Things that I try not to do cause my right hand doesn't work so amazing. Or like pouring hot water, then I'll show my vulnerability more because I have to. [PF004]*

### 3.2.3.3 Dealing with change

#### 3.2.3.3.1 Worrying

Upon initial diagnosis, participants with MS and PD tended to worry about what was going to happen to them. Were they going to experience pain and fatigue? Now that they do experience these symptoms, would they worsen? They demonstrated an increased concern for their well-being and a caution towards pain and fatigue. Additionally, participants expressed a sense of feeling nervous that they may experience more pain and fatigue later in their life which could make it harder to do activities or affect their sleep as their condition and/or these symptoms progress. Lastly, one participant acknowledged worry towards the possibility of needing more care as time goes on and how that affects those around them.

*Fatigue, you think it feels like it's going to go on forever like this. It doesn't, you know. I know intellectually that I'm going to get better, that I'll get some energy again. But that's sort of like this little reptilian brain at the back of your head saying, "no you won't you're going to be like this forever." [PF006]*

#### 3.2.3.3.2 Hiding

Persons living with MS and PD tended to hide their symptoms from others including family and friends, whether in private or social settings. They tried to mask or downplay their pain and fatigue to still be functional and a part of familial or social events. One participant described how they felt 'shame' in having to explain to people they need a moment for themselves, which endorsed feeling like they needed to hide their pain. Participants described how they did not want to be the center of attention and preferred to blend into the background. However, when the pain and fatigue were more intense, participants could not always hide the fact that they were experiencing these symptoms and so they had to share their experiences with others. Only one participant described how their pain was easier to hide than their fatigue because they could not mask the look of their physical tiredness. Hiding was also used as a way of ignoring these phenomena, so they did not have to deal with the negative thoughts or negative aspects associated with the research they found on their condition.

*... so, they're not really aware of my pain. I don't think I really share my pain that much with people. [PF001]*

*... when I'm with others I try to be outgoing, I try to be upbeat, try to not let that [fatigue] show. [PF003]*

*I don't always complain or whine how much I'm in pain because it's just like I look at it's part of life now. So, I hide a lot of it. I don't let a lot of it show. [PF007]*

### 3.2.3.3.3 Pushing through

'You have to do what you have to do'. The constant and relentless characterizations of pain and fatigue led to persons living with these symptoms to feel like they had to push through their bodies physical and/or mental response to continue to function. Participants described how pain and fatigue 'suck' but also that they have to 'suck it up' in order to live the life they want to live. By pushing through and enduring these symptoms, people with these conditions felt as though they were able to remain active, working (for those employed), sociable, and not as if they were constantly going around in circles fighting to survive. Although pushing through tended to aid participants in accomplishing the above, driving through the pain and fatigue could result in a decreased ability to and quality of sleep, and 'paying for it' physically and emotionally the following day.

*You know it's like a racehorse. They got the blinders on, so you don't know what's coming, what's going. You just got to go ahead and do it, and that's all I think about. You know survival is every day, 24/7 and I can't waste my energy on that. I got to spend my energy on what I can do and what I still have to do. [PF002]*

*I really, really try to not so much fight it [fatigue] but live with it; and, you know, continue to push through it and be active, and you know as sociable as I can because those are good things, and they make me feel better. [PF003]*

*So, I gotta keep living my life. I can't always let pain do it for me. [PF009]*

Participants also expressed their desire in not wanting or not being able to push themselves. They did not want to overdo it by depleting their remaining energy and

realized that when their body shuts down, they cannot push past that feeling and have to stop. This could result in feelings of frustration.

*So, the first few times when we visited and I said I had to go he [son] was like “no, no, stay, stay, stay.” So, I was kind of pushing myself and then I realized I can't. Not doing him a favor or me a favor. [PF004]*

### 3.2.3.4 Nature of Phenomena

#### 3.2.3.4.1 Constant

Pain was described by six out of nine participants as being constant, while another two participants experienced intermittent pain. The two participants described their pain as being easier to deal with because it was not constant, and they were unable to imagine what having constant pain would feel like. However, conversely, a statement was made by one participant that they don't know what not having pain means because they are always in a constant state of pain.

*So I'm constantly in pain and I've been that way. I think maybe as a kid, I think I had painless days... But since at least since I was in college just starting at age 18, I don't remember not being in pain. [PF009]*

Pain is very much a state of being. It does not dissipate and is perceived as always being there whether it is minor or major, or on the front or back burner. This idea of the front and back burner was interpreted from participants descriptions in how they felt the need to keep going and move forward in their life because the pain wouldn't stop. So, pain was sometimes put on the back burner in order to be able to continue to do things. Sometimes the pain can come in intense waves, for example, one participant described feeling like their hand was so cold it was like it was in a bucket of ice. This can lead to participants having to do things more than once, for example, in picking up a spoon, it is as if the pain is gripping the spoon. They feel the pain in their hand but cannot actually feel the object; like the pain takes over. The constant pain is in fact perceived as a constant reminder to participants that they have and live with MS, PD, or CP. This is distracting and upsetting and leads to feelings of constant depression and aggravation.

*Since the inception [of pain] my entire left side has been numb, but my right side... I do have severe pain in my legs, in my right leg, and also on both shoulder blades, constant pain and its excruciating... It's extremely uncomfortable and very aggravating. It's a constant non-seizing up pain. It's just constant. [PF002]*

Participants not only experience constant pain, but some also experience constant fatigue. Similarities between how these phenomena are constantly experienced were described by certain individuals. One participant described how their pain and fatigue moved in a constant cyclical motion, so when they aren't experiencing one phenomenon, they experience the other (pain and fatigue were described as being on two opposite ends of a spectrum which feed off each other). Additionally, another participant perceived both pain and fatigue in terms of an electrical system. The constant feeling of pain was observed as clutching a live wire and electrocuting themselves, shocking their system; while fatigue was described as the body constantly short-circuiting itself, like a table lamp flickering or turning on and off. Constant fatigue was defined as being unrelenting (often having no other option than to shut down and sleep) and endless.

*Because fatigue feels like it's almost a cop out word... Fatigue... Something is strong but there's little cracks that are going in it, right. In this thing that's really, really strong and the little cracks are kind of making it crumble a little bit. So, that to me is what fatigue looks like it's just small little pokes that slow you down. [PF001]*

*So how I process the world is very much fatiguing in general, because... So, for me, fatigue and my level of fatigue is very much based off of how much stimulus I can deal with. How much extra work I can put in or not put in. How much navigating of the world I have to do in order to live. So, I'm constantly fatigued. [PF009]*

#### 3.2.3.4.2 Unpredictable

Pain and fatigue were perceived as being unpredictable due to these symptoms presenting seemingly randomly in terms of when in the day they occurred, and further inconsistency around timing across days. Spontaneous waves of sleep were described by participants where one minute they were awake, and the next they were asleep with no warning or precursor to this happening. Certain aspects of the neurological conditions themselves

were described as predictable such as trouble walking or shooting pain, however, the psychosocial aspects associated with symptoms of pain and fatigue seemed to result the most in feelings of unpredictability. For example, participants described pain and fatigue varying with each new day resulting in daily highs and lows and the recognition of some days being better than others for accomplishing tasks.

*So, it's like getting a shortage in your electrical outlets, you see the zapping, that's MS. So, it can happen any time during the day, if you're working, if you're resting. Even if you're just you know, watching TV. You, your body decides to short circuit, that's when you get it [pain]. [PF002]*

*I try to arrange my life so I wouldn't get like that [fatigued], but you don't know how it's going to be, one day you wake up in the morning and the world is wonderful, and the next morning you wake up, you don't want to get out of bed. [PF006]*

*You know those are my targeted times to make sure that I'm paying attention to what's going on with my fatigue; and that's different, because my pain can come out of nowhere anytime, and what... I shouldn't say that my pain is always there, but it can spike at unexpected times. Something seemingly random sometimes. [PF008]*

### 3.2.3.4.3 Heaviness

Heaviness was described by participants with MS and PD as the physical heaviness of limbs and muscles. Participants described feeling 'extra heaviness' in their limbs which resulted when the pain and fatigue were more intense. One participant described how their legs felt heavy after working a five-hour shift, however, even when they were not working, they still experienced this heaviness at a lesser intensity. Heaviness could cause participants to move and perform activities at a slower pace. One participant described how the heaviness of their body was an indicator their body was tired telling them to shut down and rest. Additionally, an emotional heaviness was described by participants as fatigue placing an emotional burden on their lives but feeling lighter in moments their fatigue may have subsided.

*I think that's to me what I liken to fatigue, like my physical fatigue, just heaviness in the body... Like, I'm sitting on the floor here, my legs feel heavy, and they're being supported by the floor, but they feel heavy. Does that make sense, right? Like how can they feel heavy? I'm not holding them. The floor is holding them up, but they feel heavy. [PF001]*

*Oh, I feel, thank goodness it's [fatigue] gone. Thank goodness I feel brighter, I feel lighter. [PF003]*

#### 3.2.3.4.4 Time-consuming

Pain and fatigue were extremely time-consuming in the daily lives of those with MS and PD as it caused them to require various periods of rest throughout a day, taking time away that they could spend with their family or use to perform other tasks. Participants described how it took longer to perform and complete tasks such as cleaning, cooking, or baking, and they may not have been able to complete a task on certain days due to these symptoms. Additionally, fatigue can cause participants to have to engage in longer conversations if they are trying to converse during an “off” time as they are not fully present mentally during this time. Interestingly, one participant described how they have plenty of time to watch their pain coming, but fatigue does not allow them the same courtesy. Another participant described how sometimes the thought of a new cure becoming available for their condition consumed their thoughts and time. The sheer amount of time that pain and fatigue arise in their lives is time-consuming in itself in participants having to deal with the presence of these phenomena.

*So, I always say I can start the race, takes me a little bit longer to finish it, but I'll get there. [PF007]*

*The amount of time and effort exerted in dealing with Parkinson's disease is huge; and I don't know how huge. It's probably just as huge with the other disabilities or the other illnesses, but that's something else that, it's an immense drain physically, mentally, emotionally. [PF008]*



### 3.2.3.4.5 Intense

Pain and fatigue were perceived by participants in terms of mental and physical intensity. Depending on the intensity of the pain and fatigue, participants' responses towards these symptoms varied. The physical and mental fatigue made them feel as though they needed to immediately rest. Participants used the phrases 'shards of glass being thrown at you' and 'intense crushing' and words including 'sharp' and 'searing' to describe their pain, noting that it can also negatively affect their mobility. One participant noted how the intensity of the pain can result in dramatic responses.

*This pain can sometimes be so intense that it takes my breath away. Literally, where it'll make me gasp, or it'll make me throw up, or it'll make me scream and I mean I don't, I sort of yell from time to time when it takes me by surprise, and it causes me to throw up. Sometimes it gives me a massive headache. Sometimes it drops me to my knees. [PF008]*

### 3.2.3.4.6 Progressive

An overall idea of pain and fatigue being progressive was formed through participant narratives across the three neurological conditions describing how these symptoms continue to increase, deteriorate, and worsen over the course of their life since they were diagnosed.

*I experience physical fatigue for sure, and I've started to experience it more worryingly in the last couple of months. My symptoms alone have deteriorated in the last couple of months. [PF005]*

*But in terms of like pain as I got older... I'm having more muscle spasms, or I'm twisting over my ankles more or I'm having days where I have to medicate with medication to help or I've now had to go on medication for spasms. [PF009]*

## 3.2.3.5 Associated Factors

### 3.2.3.5.1 Cognitive challenges

Participants with MS and PD encountered a variety of cognitive challenges associated with their pain and primarily fatigue. The three challenges commonly discussed by

participants included brain fog, physical exertion increasing fatigue, and cognitive impairments. These will be discussed in further detail below. In addition to these challenges, participants described how they could not remember where they were (ex. driving somewhere) and so they had to determine a layout of the places they were going to in a day. Otherwise, the cognitive fatigue was so great it was as if one minute their brain was working and they were present in the moment, and the next it was not and it's as if they were somewhere else. When fatigued, one participant found it very difficult to be able to put themselves in the right frame of mind. Additionally, another participant described how their introverted nature created cognitive challenges in social situations where there were many people as they often felt overwhelmed and had difficulty functioning in a thoughtful, reflective, and/or logical manner.

*... I get my energy from being in small groups, and that's fine. But it's sort of, I liken it to being in like a stadium of people and... it's overwhelming. It causes challenges with focus, the ability to function thoughtfully or reflectively or logically, is sometimes impaired... So that's how I sort of, I wish it would stop but it's more like that crowded room. [PF008]*

Brain fog was described as being more of a mental than a physical fatigue where participants described it as an 'intense thinking fatigue', 'brain fatigue', and having difficulty when doing anything requiring mental capacity or focus. This cognitive fatigue often made participants feel 'stupid' or 'flustered' which often led to feeling frustrated overall. This fatigue itself was described by one participant as being 'huge' and 'debilitating' as they felt they couldn't get rid of or get out of the brain fog which affected what they could do in a day. When participants felt tired or were in pain, their thoughts would begin to jumble affecting their ability to think and caused their brain to shut down. One participant described this as their brain going into 'shut down mode'.

*... but when I'm fatigued, I know I've said the word stupid, but again I feel like I'm just, you know, I'm a baby just learning how to crawl, or walk and find words even sometimes you know. [PF001]*

Participants perceived physical exertion to increase their cognitive fatigue. When physically tired participants felt it affected their brain; however, even when they were not tired, they continued to feel this 'brain fog'. Descriptions of feeling as though they could not think carefully, clearly, or at all would create confused emotions where they could get teary or yell. Participants felt as though they had to think at a slower pace because it took longer to focus on the task or activity they performed.

*I call it sort of hitting the proverbial staying focused, alert, and awake wall. Because what suffers is my concentration, my ability to stay focused, my ability to tune in to all those things, go down the toilet. [PF008]*

When pain was at its most extreme, one participant described feeling completely out of their mind. If fatigue got more intense, the need to immediately lie down or rest was overpowering; and if they did not rest their fatigue would continue to worsen. Another participant described how when fatigue was at its most extreme, they were unable to function, communicate or even work at the same level of 'sharpness' that they wanted to or would be able to if that cognitive fatigue was not there. When feeling not as sharp, participants felt that they were unable or had a reduced ability to retain information, like a sponge that can't absorb anything. Both pain and fatigue were described as symptoms associated with a decrease in mental acuity and processing speeds. Having a conversation with multiple people at one time was found to be very hard to process and absorb what each person was saying. Additionally, a lack of sleep was perceived as being a possible factor in affecting their speed and ability at which participants could process information. Lastly, one participant found they had difficulty concentrating, while another felt they had a reduced capacity for and ability to retrieve memories due to cognitive fatigue.

*It's like you're having a conversation with 20 people at the same time. How much can you, you know absorb? Maybe one, maybe two at the most, but you still got all these other things going on in your head that doesn't make sense. [PF002]*

### 3.2.3.5.2 Impaired sleep

Impairment of sleep was dependent upon the time of day and activity level throughout, spasticity, and being able to sleep at all in a night due to pain and fatigue. One participant described how the busier they were in a day, the harder it was to sleep at night, which participants described as often resulting in tossing and turning, waking up, pacing around, and/or falling asleep while standing. Some participants described how they now have a separate bed and sleep in their own bedroom, separate from their partner, because of their difficulties sleeping. Another participant described how those in their support group typically slept for an approximate maximum of 2 to 3 hours a night. This was because participants continued to wake up throughout this period of time and so it was perceived as taking short naps throughout the night instead of receiving a restful sleep. Impaired sleep at night can result in the need for participants to lie down, nap, or sleep during the following day to compensate for the previous lack of sleep. The ability to sleep was not solely dependent on how many hours one could sleep for but depended on the quality of sleep they received. One participant described how their additional diagnoses impacted their capacity to and quality of sleep at night, plus their body being ready to sleep but their brain was still awake which kept them up.

*And first bedtime lasts somewhere between an hour and an hour and a half, and that might be the only sleep I get that night... Because my pain then wakes me up and then I'm pacing a good deal of the rest of the night. Which involves you know, pacing until I fall asleep on my feet sometimes, which is never good. So, I have to be careful where I go at night... I've fallen into furniture... onto the floor and into a wall... I went through a wall once. [PF008]*

*At night often I have difficulty falling asleep, and it's not because my body isn't ready to sleep, it's because my brain won't shut down. So, my thoughts and everything I'm thinking about are rapid firing still, but my body is ready for bed. My body is ready for sleep. So, that right there tells me I have energy. It's just my body doesn't have the energy. [PF009]*

### 3.2.3.5.3 Anxiety & depression

Anxiety and depression were described as an unfortunate reality for these participants living with pain and fatigue. These co-morbidities generally occurred when a participant was unable to meaningfully engage with their family due to the presence of pain and fatigue, or as a result of them spontaneously falling asleep. Participants described anxiety resulting from trying to complete certain tasks in a day and becoming anxious and stressed when they were unable to achieve these goals. Depression occurred due to symptoms of pain and fatigue being constant, impairing cognitive ability, and feeling like their joy was being taken away. One participant noted how their depression impacts their life to the same degree that their pain does. During times when participants felt they were losing control of their bodies, feelings of ‘aggravation’ and becoming depressed could occur. A relation between anxiety and depression was also described as an increase in anxious feelings resulted in the occurrence of depression or both occurring simultaneously; this was typically seen when pain was present.

*Like when am I going to start feeling better? When can I finally go out? Go for a walk without having to stop because your legs are spasming or your shoulder is like, am I having a heart attack because the pain across my chest is so bad I can't breathe? When is it gonna end? So, you know the depression starts, your anxiety goes up, the pains still there. [PF002]*

*It [fatigue] takes away joy. [PF003]*

### 3.2.3.5.4 Weather

Weather plays a large part in affecting a person's pain and fatigue especially when the weather is consistently changing. Participants described weather forecasts such as pressure changes, the extremes of hot and cold, dampness, rain, and snow resulting in becoming increasingly tired which led to the need for them to rest. However, occasionally individuals experiencing the heat would be unable to sleep and it affected their emotions (ex. ‘grumpy’) and how their body felt. Opposingly, one participant described how the cold affected their feet which was perceived to impact their ability to walk and perform daily activities.

*So, if it's too hot I can't sleep. I don't sleep well. I'll wake up and I'm crabby and tired, and then the weather outside if it's damp, if it rains, or get super cold that affects me. So yeah, I know everyone laughs at me with the barometric pressure. I'm like no I know when it's gonna come cause my body feels it. [PF007]*

### 3.2.3.6 Other experiential accounts

#### 3.2.3.6.1 Something that you feel

Pain was described as being ‘something that you feel’. Participants commonly knew that they were experiencing pain because they felt it; and they could feel their pain at its lowest level and its most extreme. One participant described how through feeling their pain it told them they were alive, which was perceived as a good thing. Participants described how because pain is a constant phenomenon, its relentlessness allows them to, more so than not, always feel their pain. Only two participants said that they knew they also experienced fatigue for the same reason in that they felt it.

*So, this morning I was doing work and I was working on a document, and I could feel myself like not dotting the I's and crossing the T's properly and I thought it's almost time to... my editing skills right now are not good. Like, I'm missing things, it's time to stop working... Like so you can feel it [fogginess, fatigue], like you can really feel it. [PF004]*

*... when you have MS, you have to be like your own like diagnostic, you know, beacon or whatever because no one else is going to see. It's invisible. So much of it you have to feel it [pain], you know. [PF004]*

*You don't have to say why this is pain. You know it's pain because you feel it. [PF005]*

#### 3.2.3.6.2 Fatal

Participant PF002 described how individuals in their MS support group took advantage of medical assistance in dying (MAiD) as they expressed their wish to end their life. This was perceived as being due to their inability to remain functional, wishing they had a condition that would take their life, and not wanting to burden their family any longer.

*It's tough. A lot of them wish they could just take their lives. It's heartbreaking to see that but you can't talk them out of it, and I've seen people trying to talk them out of it, and it's just, you can't talk them out of it, you're not walking in their shoes. Okay, you can express your opinion, you may be against MAiD, you may be against suicide but it's none of your damn business, because you're not living what they're living. [PF002]*

### 3.2.4 Coping Strategies

Coping strategies used to help participants manage their pain and fatigue in their daily life included the main sub-themes of: support, rest to renew, acceptance, accommodating, positivity, pain management, planning, and physical activity. These sub-themes will be discussed in further detail below. The words participants used to describe their main coping strategies plus other strategies are illustrated in Figure 4. The size of each word indicates the frequency with which the word was mentioned across the total of nine participant semi-structured interviews. Additional sub-themes discussed by participants included relaxation techniques, independence, and feeling lucky.



**Figure 4: Word cloud of the final theme: coping strategies.**

#### 3.2.4.1 Main strategies

##### 3.2.4.1.1 Support

Support was described by participants in terms of receiving support from those closest to them, from others, through support groups, and by supporting themselves. Support from family and friends was described by participants as being understanding of the pain and

fatigue participants experienced and understanding when they needed time to themselves. This included participants' husbands, wives, children, and friends who really understand them and helped them to deal with their pain and/or fatigue and look after them if they needed additional help. Friends were also very understanding of participants "on-off" times by asking when participants were available for a social outing or helping to move things that were in their way when out in a different setting. Additional ways their loved ones supported participants included: never making them feel bad they couldn't do something, making sure they had what they needed in any given moment, taking care of one another by checking in, and working together to do things and seeing what they could change to improve.

*I think it helps that I have a great team. I have a great friend support system. [PF007]*

*I had a friend who also has cerebral palsy, but his symptoms exhibit differently. He's like "you put your heart and soul into everything you do. I hope to goodness that on your days off you don't leave your bed unless you have to." [PF009]*

The support from others was described by one participant as their colleague helping them at work during a time they were experiencing 'brain fog' which was greatly appreciated so they could continue on with their day without feeling flustered. Additionally, another participant discussed how people were always there to help; for example, a stranger was extremely sympathetic of their fatigued state and made sure they were okay and offered to take them wherever they needed to go. Participants described how neurologists, healthcare, and support staff, and those with other autoimmune diseases could be extremely understanding of what they were going through and may be able to help them get through tougher times.

Participants discussed the need to support themselves by knowing their limitations and when they needed help to complete certain tasks, and by listening to themselves. Additionally, one participant described how they needed to be upfront with people when out at a social engagement and explain to them that they are exhibiting symptoms of fatigue. This way, people were able to understand why participants felt the way they did instead of being concerned. Wanting to support and understand what others go through –



whether this be others with their condition, a different condition, or healthy people – was expressed by participants so they do not make the mistake of assuming what someone is going through.

Support groups were described as a tremendously important resource for support as the individuals who make up these groups typically understood the experiences that participants went through. People within these groups helped each other by: providing emotional support, calling, or visiting each other, helping with tasks such as cleaning their home or completing funding paperwork for assistive equipment, and reassuring each other there would always be someone there to support them. This helped participants get through their day and learn how to talk about the ways in which they were able to get through their day with others. Participants described how nice it was knowing that there were others who felt the same way as them. Individuals in these support groups accommodated each other's needs as they understood what each other were going through and helped by, for example, sharing coping strategies that worked for them. One participant described helping members of their support group despite most likely paying for it physically and emotionally later in their day because they wanted to help despite the negative implications for their own well-being. This participant described how their support group liked to celebrate the little victories in their lives with other members of the group. This was perceived as being important to them because they still had something to enjoy in their life and were able to share it with other people. For example, members shared victories such as riding the subway with their walker for the first time, going for a walk around the block and enjoying the sunshine (despite being tired), and reading a book and finally understanding what the book said. These 'little' victories were believed to be sweeter to celebrate with members of their support groups because these individuals fully understood the meaning, importance, and magnitude behind these accomplishments.

*... it's like you're seeing your child winning a spelling bee or winning a race, or seeing them with their friends and you're getting enjoyment out of it because your part of their lives. Well, our members are... It's our second family, and it's the only family that truly*

*understands it because they live what you live. They've experienced what you're experiencing. [PF002]*

Talking with someone such as a professional, a family member or friend proved helpful for two participants. One participant described how talking to their general practitioner provided them with a safe space to talk or cry. Additionally, reaching out to someone to talk to was perceived as something they could do to help themselves, which gave them a sense of control. For another participant, talking with someone close to them allowed them to openly discuss their pain and fatigue which helped the person listening develop a newfound or greater understanding of what the participant was going through in their life.

Research was described as a way for participants to be able to deal with their diagnosis and additional challenges which arose at a later time in their lives. It helped one participant to feel more prepared for what was to come and allowed them to end their day feeling okay about themselves and what they accomplished or did not accomplish. It helped them to understand and make sense of their pain validating that the pain was not just in their head. Research also provided a sense of companionship by connecting online with others with the same condition and/or symptoms and receiving verification through seeing and hearing that others felt the same. Lastly, one participant described how with the diagnostic information they read online, they were able to develop a 'clinical lens' for themselves which helped them target their treatments and personal course of action they wanted to take in a day.

#### **3.2.4.1.2 Rest to renew**

Resting was a major coping strategy in managing both pain and fatigue experienced by participants. An employed participant described how they needed to rest prior to a workday as these days were generally more taxing. Participants described how resting prior to activities including physical activity was required. When physically active, one participant described needing longer periods of rest, giving them the time to catch their breath. Rest periods were not only used in times where participants were more physically active but were needed in day-to-day life as well. The time needed to rest in order to

renew themselves varied between participants. Some described needing 5 to 20 minutes or an hour so they could shut down, sleep, and then continue on with their day. Others described how they needed hours – not just minutes – to rest, or it could even take all day before they had enough energy to perform activities. Even taking as little time as 30 seconds to slow down and figure out how they can deal with their pain – whether that be by walking slower or stopping when tired – helped to make participants lives easier and feel calmer in the face of their pain. Interestingly, one participant highlighted how ‘normal’ people only need 5 to 15 minutes to rest before they are able to continue on with their day. Additional ways in which participants could rest included playing with their dog (sitting and throwing a ball), catching up on Netflix, reading a book or the newspaper.

Fatigue created feelings of apathy and tiredness where participants felt they needed to lie down as they could not do anything more. One participant made a distinction between when they can simply nap or lie down, and then they have to fully be asleep in order to get the rest their body demands. For example, this same participant described this in terms of the time of day they needed to sleep, and the level of fatigue they were experiencing. At 1pm and at a level 10 on the fatigue scale, this participant described how they had to sleep as they could no longer handle hearing any external noises or sound. At 5pm and at a level 7 on the fatigue scale, they discussed how they could simply shut their eyes and just lie down without having to sleep. When asleep, the body was at its calmest which helped participants to not feel as tired and reduced their pain.

*It's [rest] up there with eating and bathing and like your nighttime sleep, is that one o'clock sleep and five o'clock [rest periods]. [PF004]*

Pain and fatigue could occur suddenly without notice where the need to lie down, nap, or sleep is so strong they have no other option than to succumb to their body's response. This response could also occur due to mental fatigue where, for example, a participant was driving their car and they had to pullover and sleep in a parking lot because they had no other choice. This intense feeling of needing to rest was described as

being at the point of no return where all of their system lights were flashing and so they needed to stop. Rest was deemed non-negotiable with no other task or activity happening instead of taking the time to renew their mind and body. A majority of participants described how when their brain and body were perceived to no longer be cooperating with each other, their body was telling them they needed to shut down. For example, one participant compared their fatigued body to the ‘rainbow spinning wheel’ (cursor) on a MacBook laptop. When too many buttons on the computer have been pressed and now it won’t do anything, so the wheel is spinning but you can’t do anything more until you power down the laptop and restart. Participants noted how with time, their body learned when it was time to stop, and the participant learned to listen to what their body was telling them and then took the necessary time off before completing the same or a new thing that same or the next day.

*It's when your body is telling you to rest and shut down and recuperate, and let it regenerate. Whereas before fatigue - but before MS - fatigue was annoying. Whereas now, I know it's telling me that my body needs to regenerate. It's used up all its energy that it's had for the day and needs to get it back. [PF007]*

### 3.2.4.1.3 Acceptance

The need for participants to accept that pain and fatigue would always be in their lives was a hard reality. However, participants described that through accepting the presence of these phenomena, their overall well-being improved. Part of this process of acceptance stemmed from the idea that pain and fatigue are experienced by healthy people in their ‘normal’ lives and were experienced by the participants in this study before living with their neurological condition; therefore, pain and fatigue are ‘normal’ phenomena which occur in the everyday life of all people, whether they have a health condition or not.

Acceptance by others was described in terms of family members knowing they cannot help to relieve or extinguish the pain and fatigue in participants’ lives, and they have to accept this. Additionally, one participant who is still employed discussed how a client told them the story of their mother who had an autoimmune disease; and how she was still a great mother to her children and knew her limits and what she was capable of

doing. This story made the participant feel better knowing they could still be a great mom despite the ongoing challenges which pain and fatigue presented in their life. Participants described how they found acceptance through recognizing that their life was different than before, but they can still do things, some of which they did before. Having an ‘aha’ moment was perceived as a moment of realization in understanding what they can and cannot do because of fatigue and how they could handle it. This idea of accepting what their body wanted them to do and the body’s response to pain and fatigue was discussed as a way of dealing with these phenomena.

*You just had the crappy draw of the cards and you're dealt with it, and you got to deal with it. [PF002]*

Participants described how pain and fatigue are a part of who they are and that they will deal with these symptoms despite the fact it may be unfair that they have to endure pain and fatigue in their daily lives. One participant discussed how having pain and fatigue as a part of them allowed them to discover how they can take on the world in a way that is meaningful to them despite these challenges they experience. Another participant described how pain is their way of life and they have to accept this because they do not want the pain to consume them. This individual found themselves feeling proud because they were able to understand their condition and deal with it in their own way. They felt open enough to discuss their condition with others, which helps to enhance the understanding and knowledge of others surrounding their condition.

*I have the attitude, you know, that I got thrown this curveball, I'll deal with this curveball. I'll still do my life. [PF007]*

A part of accepting fatigue in the lives of those with MS and PD was through characterizing this phenomenon as a normal experience for all people. Participants discussed the idea of ‘self-induced fatigue’ whereby a ‘normal’ person brings on fatigue through their daily activities. This could occur by: going to bed too late, doing something (ex. schoolwork) too much or too late in a night that they lose sleep, training in jujitsu for 4 hours, or working a double shift causing them to be tired and exhausted. One participant discussed how ‘normal’ people can also get tired from doing things they

aren't used to doing. People tend to overexert themselves which naturally leads to fatigue and being tired.

*The quantity rather than quality I think. I think it's just that I have a lot more fatigue....  
Everyone has fatigue. Everybody I know has fatigue. I just have more of it, that's all.  
[PF003]*

Pain as 'normal' was understood through the existence of pain associated with everyday living before MS, PD, and CP. For participants with MS and PD, it was difficult to understand and distinguish the pain which they had dealt with throughout their entire life before their diagnosis ('normal'), and the pain after their diagnosis (condition-related). Pain was described by those with MS and PD as being something that was known through previous experiences. For example, one participant had migraines since the age of 12, while another had aches and pains which moved up their legs over the course of their life. Furthermore, another participant described experiencing pain in jujitsu from being punched or hit as a part of their training; and likened what was a pinched nerve to being everyday pain associated with this activity, when in fact it was found to be a precursor to their MS. Additional examples of pain being a normal circumstance of life included pain due to women's menstruation or periods causing cramping or low back problems, and stress-related pain from carrying everyday stress in the head, neck or shoulders. Participants described feeling like they could take the pain associated with their condition because they developed high pain tolerances due to the pain they experienced before. For the participant with CP, they had experienced pain throughout their entire life due to the nature of the condition which was perceived as their 'normal' pain; and their condition-related pain was considered the pain which progressed and worsened throughout the course of their life. As an example, this participant discussed how they had a broken bone chip in their ankle and yet they were still fully weight bearing and walking (all be it hobbling); they reported this as being a 'normal case' for them as they were used to having to keep going despite any obstacles which obstructed their path.

*Well I've had pain all my life off and on as everyone does; everyone has pain sometimes.  
[PF005]*

*I guess its just, it is part of being normal, everybody experiences pain from time to time. [PF006]*

*To the point where I've had doctors go, "So explain your pain scale." I'm like "what pain scale do you want? Mine or yours?" ... If I'm using your regular 1 to 10, mine's like off your chart... Right? Because my one is like non-existent like I don't know what one feels like on the chart... Like my one is I'm a functional human being. I can go up and downstairs. I'm not tripping over my feet, like that's a one, or even like a 3, depending on the day. [PF009]*

#### 3.2.4.1.4 Accommodating

Various forms of accommodation were used by participants to manage their pain and fatigue. Accommodations put in place to help with the pain and fatigue which arose due to physical actions were described. One participant described how they used visual cues as a technique which aided them in helping to perform physical motions when in pain or fatigued. For example, when they tried to pick up something with a numb hand, by visually looking at the motion being performed, this helped to complete the action as they no longer had to solely rely on the physical sensation of their hand. Through modifying forms of contact, one participant was able to interact with others in a way which reduced their pain and fatigue. As typing was described as an 'excruciating' and 'hellish' task, this participant told others that they have to call instead of email if they wanted to talk. Additionally, one participant discussed how they received accommodations during school such as sitting on a bench in assemblies because they had an ankle foot orthosis; or how they had talked to the Dean of their university about a professor who was talking too loudly and setting off their startle reflex during class. Another participant described how they will accommodate for the amount of movement they perform in a day by doing either fewer or more activities dependent upon their energy levels which helped to reduce their pain.

*Well, it's a warning... you shouldn't really work through pain. You should figure out what's happening, and turn down your activities to try and accommodate it. That's not always easy. [PF006]*

*So, if I do something I really have a mindset to do it and just focus like you know there is an end in sight, and I do it. [PF007]*

Participants described needing to watch themselves so that they were able to recognize the fatigue so that it didn't hit them suddenly. When able to recognize the fatigue, this made their lives easier because they didn't need to worry about dropping everything and resting, as they could then do tasks at a slower pace or in moderation. Furthermore, participants could then actively decide to remove themselves from a situation before the fatigue set in, which allowed them to not have to abruptly leave social outings. One participant described how they prioritized the things that matter to them including working, socializing, being a good family member, and exercise. It was noted that what participants prioritized differed from month to month, for example, sometimes work was more important and other times exercise was depending on what was happening at that time in their life. Additional accommodations could include using adaptive methods such as sitting instead of standing to perform a task, delegating tasks, and engaging in different ways with others. One participant noted how it is important to know what accommodations to use in a situation and when to ask for and use them. Their self-care was essentially determined by how they were able to accommodate their life environment.

*Because I don't take naps during the day on purpose to try to enhance my sleep hygiene. [PF008]*

*A lot of my coping strategies are more like accommodations. So, for example, my niece knows on a bad day that I'm likely not going to chase her around the house or run around a lot, but that there's other ways to play. We can read books, I will do crafts, I'll engage with her in different ways. She's learned that there are certain times of day that I do better than others. I tend to be better in the mornings before noon usually. [PF009]*

Awareness was perceived as an accommodation as participants described this management technique in terms of being aware of the effect pain and fatigue, or the condition itself had on their lives. One participant described how they were only able to understand the impact pain, fatigue, and their neurological condition had on their life



because they were the one living through it. Furthermore, another participant described how other disabled individuals are more aware and understanding of what they were going through; whereas someone who is non-disabled would not have this same level of understanding. Intrinsically, awareness of a condition and its associated symptoms equated understanding. Furthermore, one participant discussed how someone without a neurological condition perceived their life to be so bad, when the participant would have given anything to trade places with them.

*So like yes I would love more people to know or see or not, you know, make assumptions or whatever but like I'm sure I'm guilty of so many of them that I don't even know about, you know. That I don't even know I'm doing it or that it's happening because I make, we all make assumptions, you know. Right, like that's human. [PF004]*

Awareness of the condition-related fatigue by the participant themselves and others were described. One participant described how they became aware of their fatigue in the beginning because they became nervous about the travel associated with work and the work itself. Additionally, one participant described how they became more aware of the effect their condition had on their mood; while opposingly, another discussed how they were not always aware of their mood changing; however, their family was. Their family could realize when they became fatigued and started to get 'snippy'. Participants realized that recognizing signs of when their mood changed and being aware of the symptoms associated with their condition was an ongoing process.

*So, pain is supposed to be a warning system for your body, but it's not in my case... Well, I can't step onto hot pavement or hot sand when bare feet, cause I'll burn my foot and I won't know... the pain will register differently like less, so I don't know necessarily if my foot's burning... Or conversely being frozen. I walk outside to get stuff in the winter in my bare feet, and it drives my wife mad. [PF008]*

One participant described the necessity for awareness between medical professionals and the individual experiencing pain and fatigue; awareness of how these persons experience these symptoms in social situations; and awareness of these phenomena and conditions in the general populace.

### 3.2.4.1.5 Positivity

An essential method of coping with the negativity experienced in the daily lives of participants with MS and PD was through maintaining a positive outlook on life. Two participants noted the importance of positivity in helping them combat their pain. One participant described how they kept their pain monster (described in section on negativity) back using a wall of positivity; while the other, showed how pain itself can actually be a positive phenomenon because it tells them they are still alive and moving.

To remain positive in the face of fatigue, participants tried to work on being more 'up' by approaching the day with a positive mindset, doing the best they can, and using positive thinking and reframing efforts. Furthermore, one participant tried to positively reframe their previous experiences with this phenomenon in an attempt to be better prepared the next time a bout of fatigue occurred. This same individual used journaling and writing as ways of dealing with their frustration that accompanied recurring fatigue. Additional strategies included deep breathing and reminding themselves it was okay to stop every now and again. When and if fatigue ever dissipated, feelings of being grateful and making the most of the time they had without this symptom were expressed.

*Just simple things like "this is going to be a good day," you know, "come on, get up, move around, go get your breakfast, make a pot of coffee." Approaching the day with working on doing it with that... I have to tell you it doesn't come naturally some days, you know, you don't feel like that. You get up and you're slow to get around... But usually that's how I work on it. [PF003]*

*I don't regret the fact that I happen to have these things. They shape who you are and often make you a better person. [PF008]*

One participant discussed how they used compartmentalization as a coping strategy. One way of doing this was by giving pain a persona which helped to fight off the pain and keep it in a position where it was not dominating their life. This allowed the participant to move forward with their life instead of remaining in a constant negative state of mind.

*So, dealing with it [pain], I either have to compartmentalize it, in essence sending it to a different room in my party house to fuss on their own; and you know, whatever they do in that room is whatever they do in that room, and I just try to, you know compartmentalize it off in that direction. [PF008]*

The use of humor was described by two participants as a way of keeping positive when experiencing fatigue. Strategies surrounding humor included making jokes and laughing about the fatigue in order to move forward with their life. One participant received enjoyment from making others laugh which was perceived as important to them and allowed them to face life's adversity in a more positive manner.

*Humor is huge in my life. I like to be funny. I like to laugh. I like to, well I don't like to be funny I just seem to make people laugh a lot more... I enjoy making people laugh. So, humor is important. [PF008]*

Meditation (including tai chi) and self-talk were both described as ways of dealing with pain. Meditation was perceived as a way of helping two participants to keep positive in their day-to-day lives and situated in the real world. One participant described the process of improving their personal self-talk as a continuous learning process where there was always room for self-improvement. While taking a minute to care for themselves, one participant took this time to tell themselves it was okay to relax and reset. Resetting was interpreted as resetting their energy levels, and ability to take on physical, emotional, and social activities.

*I'm not against being positive but it also needs to be real... So, I've been learning to improve my own personal self-talk. Learning how to meditate, which has been very useful. [PF008]*

### 3.2.4.1.6 Pain management

Persons living with these neurological conditions described preferences for natural management techniques (ex. turmeric as an anti-inflammatory) that do not involve the use of pain medication; however, others have learned to use medication such as ibuprofen or creams to work through their pain. One participant described the use of water therapy

(hot tub, pool, or the ocean) as a way to manage their pain. As pain is a constant phenomenon, water therapy allowed them to feel nothing and free for even the slightest fragment of time.

*I feel like we also are taught to run away from pain, which we shouldn't. We should learn how to manage it. [PF001]*

*I feel like moving in water... you're like a newborn baby in the embryotic sac and you're free. There's nothing... I feel nothing. [PF001]*

*Knowing that the treatments are imperfect, in terms of targeting pain, and it's often a cocktail of treatments that you need to work on your specific pain environment or your pain landscape. [PF008]*

*Coping strategies is also knowing when to take the medication. [PF009]*

Pain management can also include the use of medication, steroids, or additional medication not described in participant narratives in this study. One participant described how levodopa is 'worthless' for their physical and mental symptoms. The individual's role in deciding whether or not to receive and/or take medication (ex. pills or steroids) can place a burden on them, specifically during the decision-making process. This decision is entirely their own as the individualized response to the medication must be assessed by the individual to determine if they do not wish to continue with the medication. If they do not wish to continue, they can then enter a conversation with their physician to discuss changing the medication or starting an alternative or new course of treatment.

*It's [steroids] difficult and hard on your system and hard on your aura, for me it is. It's in a lot of people it makes you like worse coping skills, and it makes you hyper and like hard to sleep at night. So, there was lots of big decisions to make and that I had to make myself. [PF004]*

### 3.2.4.1.7 Planning

Different techniques were used by participants in order to plan their time in the most effective and appropriate manner to fit their needs. Participants reported scheduling their time around pain and fatigue for meetings (for those employed), appointments, activities, exercising, and sleeping. They also scheduled their time as a way of increasing their social life by being open about the time they needed to rest and the times they would most likely be available to go out with friends or visit their family.

*That I have to say, “whoa, whoa, whoa” like I need to build in a time where I’m lying down from 5 to 5:30. Still have time to freshen up and get dressed and ready, and I can’t meet you guys until 7 or 6:30 or and then on the back end of that I also can’t stay up late. [PF004]*

While it was perceived as an initial and ongoing challenge to learn the times their bodies required rest (“off” times) versus the times they would be free for meetings, appointments, or social gatherings (“on” times), participants learned these times and worked around them to plan their day-to-day activities. An additional way to help plan their day was described through setting a goal and working towards achieving it as a way to complete a task or activity.

*Yeah, it's a bit of a tightrope, but that's okay. It's all about having a goal and trying to get to it. [PF008]*

To conserve their time and energy stores, participants prepped meals for the week that they could then ‘grab and go’; and to conserve their cognitive ability, they mapped out their travel routes so if exhaustion set in, they could still get to their final destination. Similarly, one participant discussed how they brought their cane with them on longer walks on the occasion that it may be required to assist them in getting back home.

*On the weekends I would cook big batches of pasta or cook up something in the crockpot that I could freeze in portions. So that through the week, when I had no energy, I could just thaw, grab and go. Or I'd have things that I could easily just shove in the oven, and it*

*would heat up, and I didn't have to really think about anything other than, did I press the timer? Is it the right temperature? [PF009]*

Despite using these planning methods to cope with pain and fatigue, participants noted that they sometimes failed, due to the unpredictable nature of these symptoms which often resulted in participants needing to alter or completely change their plans if pain or fatigue completely consumed their mind and/or body.

### 3.2.4.1.8 Physical activity

Participants described how physical activity granted benefits but provided limitations in managing their pain and fatigue. Participants with MS and PD were aware that the level of exercise they could accomplish prior to their condition was no longer attainable; however, they still wished to try to remain physically active to keep mobile and functional. Participants described needing to exercise caution in the amount of physical activity they did because otherwise it could negatively affect their overall mobility and functional abilities. Yoga and stretching were described as less strenuous methods of coping with these phenomena, although specific poses and exercises were not discussed. Additional physical activities participants described included strength training, boxing, cycling, and walking. Participants discussed how overall exercise makes them generally 'feel better' and 'useful' throughout a day, and they enjoy doing it.

*I do workout at home with weights and stuff like that; but we're very conscientious of what I used to be able to do before what I can do now. [PF002]*

*So, an excessive amount of physical activity usually triggers that [pain]. [PF008]*

### 3.2.4.2 Other strategies

#### 3.2.4.2.1 Relaxation

Participants sometimes needed a relaxation day which could include having a hot bath, using heating pads and massage units, getting additional sleep, and watching television shows to distract their mind. One participant used horseback riding as their main coping strategy until they could no longer ride due to personal reasons. Additional forms of

relaxation consisted of journaling, deep breathing, and the participants listening to themselves and their bodies response to pain and fatigue.

*For the next day I woke up, and I was in pain... my leg was sore and tight and so today's gonna be more of a relax day. So, I had a foot bath... soak my feet, use heating pads and stuff... basically with the pain I had more of a quiet day and took care of it. Listen to it. Dealt with it. [PF007]*

### 3.2.4.2.2 Independence

Individuals with MS and PD expressed the value of maintaining a sense of independence as highly important in their lives. Independence was characterized as learning how to and being able to care for themselves, feeling like they could make decisions for themselves, and maintaining focus and the ability to function in a day when faced with pain. Overall, participants felt like they needed to be able to deal with their condition and all associated symptoms by themselves with as minimal help from others as possible. However, participants were still extraordinarily appreciative and grateful for the support they received from others.

*That's the person I am. I'm not one of those people like "oh feel sorry for me" type people... I think it kind of makes light that you know what I was given this disease because they knew I could deal with it without whining. [PF007]*

### 3.2.4.2.3 Feeling lucky

Participants with MS and PD felt lucky for the support that others provided them whether that be their family, friends, other people with their condition, or strangers. Additionally, two participants reflected on the fact that they currently do not have constant pain or fatigue in their lives and felt extremely lucky for this as they recognized that others experiencing these symptoms with their condition were not as fortunate.

*And I'm lucky, in that there are people with Parkinson's who have constant pain; whether it's a low level or a high level but it's constant and I can't imagine what it would be like. Every so often I get to bed, and I think well I only had one pain today or I didn't have any pain today, and it's like, well, I'm lucky, because a lot of people don't have that. [PF006]*

### 3.2.5 Pain and fatigue across conditions

Participants across conditions described similarities and differences between pain and fatigue. Pain and fatigue were described as separate phenomena that influence each other where an increase in pain can cause an increase in fatigue; with special note of one participant noting an increase in physical pain may result in an increase in mental fatigue. Pain and fatigue must be managed together, as participants perceived that if they dealt with their pain but not their fatigue, they would be stuck in this continuous loop where they lose sleep causing them to be overtired and eventually, lose control over their mind and bodies. One participant perceived these symptoms to exacerbate one another. Participants described how pain and fatigue can both occur suddenly although some overlap may be seen when both phenomena are experienced at the same time. Words used by participants with MS and PD to describe both pain and fatigue included ‘debilitating’, ‘unwelcome’, ‘unwanted’, ‘distracting’, and ‘annoying’. Table 3 outlines the most common descriptors used by participants across conditions to describe their pain and fatigue. Descriptors are the most common words used by participants to describe their pain and fatigue. The percentage is the frequency with which participants reported each descriptor across all nine semi-structured interviews. One participant perceived both pain and fatigue to restrict their lives, movements (could no longer move quickly), and mobility. Another participant perceived these phenomena to compromise their lifestyle, reduced their functional ability to work, maintain or grow relationships, and left them unable to be the person they could be otherwise. Both participants found pain and fatigue impacted their communication levels. One participant perceived this idea of fatigue originating from their pain as the constant pain they experienced was bound to translate into fatigue over time.

*Fatigue is associated to lack of sleep, which is associated with the pain in my body, which ends up being associated with mental fatigue. [PF001]*

*The pain restricts you from moving, so does the fatigue. It restricts your cognitive... It restricts your mobility, your communication levels... they're both very restrictive. It's like having a straight jacket on you but then also with the straight jacket you're being tied to a pole. [PF002]*



*Fatigue is a natural extension of pain. I think. I think when you're in pain all the time fatigue is sort of a given. [PF008]*

Participants described their pain as more of a physical experience whereas fatigue was deemed to be a more mental and emotional experience. Participants found the physical pain to be easier to deal with than the brain fog or cognitive fatigue which was described as harder to live through. The pain was described as a hurtful sensation, whereas fatigue was perceived as tiring and mentally caused negative thoughts. One participant described how their fatigue could be compounded by their pain, but they recognized these phenomena as distinct entities. Fatigue was described by participants as a new experience related to the condition itself with differing manifestations and characterizations of fatigue existing; while the pain was perceived to be a symptom that was known, and they were familiar with. When extremely fatigued, one participant's ability to communicate was impacted, but when in extreme pain, this was not the case despite the above results describing everyday pain and fatigue to both affect communication. One participant described fatigue as being heavy, burdensome, and more troublesome than pain towards the beginning of their journey with their condition. Conversely, another participant described how they are more likely to be in pain than fatigued. They perceived their fatigue to be variable and eventually dissipated, only impacting their mobility when their body suddenly required rest and had to stop all activity. Their pain was described as impacting their mobility, processing speeds, and QoL.

*... I think for me the fatigue was more at the beginning, more cumbersome than the pain. [PF007]*

*Pain is something that I can kind of is more tangible in terms of, it's not fatigue. Like it's not exhaustion. It's not general worn out outness. It's more. [PF009]*

**Table 3: Most common descriptors used by participants across nine semi-structured interviews to describe their pain and fatigue.**

| Descriptors | PF          |             |             |             |             |             |             |             |             | Frequency (%) |
|-------------|-------------|-------------|-------------|-------------|-------------|-------------|-------------|-------------|-------------|---------------|
|             | 001<br>[MS] | 002<br>[MS] | 003<br>[PD] | 004<br>[MS] | 005<br>[PD] | 006<br>[PD] | 007<br>[MS] | 008<br>[PD] | 009<br>[CP] |               |
| Tiring      |             |             |             |             |             |             |             |             |             | 64            |
| Different   |             |             |             |             |             |             |             |             |             | 42            |
| Dealing     |             |             |             |             |             |             |             |             |             | 24            |
| Hard        |             |             |             |             |             |             |             |             |             | 24            |
| Mental      |             |             |             |             |             |             |             |             |             | 23            |
| Physical    |             |             |             |             |             |             |             |             |             | 22            |
| Bad         |             |             |             |             |             |             |             |             |             | 22            |
| Hurting     |             |             |             |             |             |             |             |             |             | 22            |
| Constant    |             |             |             |             |             |             |             |             |             | 20            |
| Exhausting  |             |             |             |             |             |             |             |             |             | 20            |
| Spasming    |             |             |             |             |             |             |             |             |             | 19            |
| Annoying    |             |             |             |             |             |             |             |             |             | 10            |
| Heavy       |             |             |             |             |             |             |             |             |             | 10            |

Each colored (grey) box represents a descriptor used by a participant to describe their pain and fatigue. The frequency (%) reported is the frequency with which that descriptor was referred to across all nine semi-structured interviews.

## 4 Discussion

The current study sought to understand the experiences and impact of living with pain and fatigue and further explore the relationships between participants' descriptive narrative accounts of these phenomena within and across MS, PD, and CP. The three final themes of this study included a lack of understanding, negative perceptions of pain and fatigue, and coping strategies used by participants. Our findings indicate that individuals with these neurological conditions experience physical, emotional, cognitive, and social side effects from pain and fatigue in their everyday lives and life course overall. The discussion is structured such that the similarities across conditions will be presented first, followed by differences across conditions, followed by the similarities between the constructs of pain and fatigue, and finally, the differences between the constructs of pain and fatigue seen across these neurological conditions.

### *Similarities across conditions*

Mantri and colleagues (2020) and Kluger and colleagues (2016) discussed how apathy is a non-motor symptom that manifests due to the multifactorial etiology of PD-related fatigue affecting those with this condition. In the current study, feelings of apathy were pervasive in the experiences of people with MS and PD due to the negative thoughts and state of mind of these individuals. Twomey and colleagues (2018) reported an increase in PD-related pain due to negative thoughts which lowered the mood of persons experiencing this symptom. The current study supported and expanded upon these findings as negative thoughts were seen as a result of pain in MS and PD causing anxiety and depression which ultimately impacts mood. The negativity was typically accompanied by emotional responses when they felt the severity of their fatigue increased where the mind did not allow positive thoughts to enter no matter how hard they tried. Negative thoughts were found to consume the minds of those with MS and PD when fatigued, they described the symptom itself as negative, which forced them to remain in a negative state of mind and robbed them of the QoL they could otherwise have. Feelings of being robbed of the QoL they could have had were also found as the experience of pain and fatigue worsens upon diagnosis of either of these conditions. Studies affirmed

these findings as pain and fatigue were reported to reduce the general well-being, QoL, and HRQoL of people with MS and PD (Ghajarzadeh et al., 2018; Sharbanian, Duquette & Mayo, 2018; Krupp and Christodoulou, 2001; Béthoux, 2006; Fairhurst et al., 2019; Graham et al., 2016; Twomey, Stuart & Baker, 2018; Skogar et al., 2012; Chou & Ridder, 2016; Siciliano et al., 2018).

Participants were self-deprecating when they experienced fatigue and typically felt worse about themselves and their ability to accomplish daily activities as a result of this phenomenon. Individuals with MS and PD experienced strong emotional responses as a result of their fatigue which they did not always share with others. This emphasizes the importance for caregivers or others in supporting roles to be aware of the internal struggle these people may face and the negative psychological impact which may consequently occur.

Pain was perceived as a cost and inconvenience which negatively affected individuals' ability to feel rewarded in their life when they have accomplished even a small task. Participants with MS and PD felt there should be some sort of benefit for having to endure constant pain in their daily lives, however, they often ended their day without the validation or justification they felt was owed after enduring pain. Participants in the current study perceived research as a way of coping with these conditions and the associated pain and fatigue. Participating in research helped to increase the control individuals had over their lives as they felt more prepared for what to expect in a day and over the course of their condition. Research was perceived to provide emotional and social support through connecting to others with similar experiences or those interested in their experiences so that participants were able to experience validation of their feelings.

Participants in the current study discussed that support groups were a tremendous resource for physical, emotional, and social support. Individuals with MS and PD found physical support through these groups as members were eager to help each other with daily physical tasks for those who may have greater difficulty with the physical aspects of their condition. Participants also discussed how being able to talk to other people who completely understand what they are going through and how they were feeling is one of

the greatest levels of emotional support they could receive and provided further validation of their feelings. Although individuals in these groups hope to support each other in any way possible, caution should be exercised in knowing when to stop to preserve their physical and mental functionality and overall well-being.

A lack of interest or feeling like they were unable to partake in tasks or activities they may have previously enjoyed doing was highlighted by participants. Stuifbergen and Rogers (1997) highlighted how the experience of MSRF reduces the joy felt by these persons; however, the current study found that fatigue typically discouraged people with these conditions from participating in activities and reduced the joy they received out of life. A unique finding of this study was the emotional heaviness brought on by fatigue in these two conditions. Emotional heaviness is perceived as the psychological burden associated with fatigue, that makes their lives darker; and is only lifted in moments when their fatigue subsides, where they feel happier and may be able to experience some semblance of joy in their lives. Humor provided those with pain due to MS and PD the ability to maintain a positive outlook and receive joy in their lives. Furthermore, support groups are perceived as increasing the joy these people receive in their lives as they can share the smaller victories in their lives with people who understand them, and the significance associated with these achievements.

Studies discussed how individuals experiencing physical and mental MSRF perceived loss of independence, which could lead to social isolation (Newton, Griffith & Soundy, 2020; Flensner, Ek & Söderhamn, 2003; Smith & Hale, 2007; Olsson, Lexell & Söderberg, 2005). The results of the current study supported these findings as participants felt socially isolated when feeling like they had to do everything on their own; however, independence was used as a coping strategy and perceived to be a significant contributor to maintaining a sense of autonomy and regaining control in life when facing the pain and fatigue associated with their MS and PD, respectively. The support of others was perceived as deeply appreciated, although participants felt more fulfilled when they were able to knowingly perform tasks and activities on their own. The idea of support also entailed a level of family and friends needing to remain flexible in their approach to

providing help as participants may otherwise feel overwhelmed and like they are unable to help themselves.

Stuifbergen and Rogers (1997) discussed how individuals experiencing MSRF are limited in their ability to take care of themselves and make decisions related to work, home, and leisure. However, participants with MS and PD in the current study emphasized that they had adapted to ensure they were able to take care of themselves to preserve their independence and minimize the limitations imposed on their ability to care for themselves. Furthermore, when experiencing MSRF or PD-related pain, participants described how they were able to maintain their focus and functionality throughout the day better when they felt they were independent versus when they had to rely on others.

Hiding their symptoms was perceived as a way for participants with MS and PD to maintain a sense of control in their lives and remain functional. Participants hid or downplayed their symptoms of pain and fatigue from others when at family or social events as they did not want to concern others. Twomey and colleagues (2018) reported feelings of guilt caused from individuals feeling like they needed to hide their PD-related pain from their loved ones as they sympathized with their hardship and so they did not want to be a burden on those caring for them. The current study supported these findings as participants described feelings of guilt that arose when they needed time to themselves and were not able to be near their friends and family. Participants with MS and PD perceived the increased likelihood of becoming a burden to those around them as they required more care, which was a significant worry and further resulted in feelings of guilt.

Worrying about what the future held and if pain and fatigue would affect their lives and worsen over time were expressed as concerns by those with MS and PD. This is a valid concern as studies have shown that pain and fatigue will persist and worsen over the disease course of both conditions (Flensner, Ek & Söderhamn, 2003; Friedman et al., 2007; Siciliano et al., 2018; Bieske et al., 2009). Furthermore, feelings of worry were expressed by individuals with MSRF and PD-related pain and fatigue when experiencing an emotional hardship in their lives (Newton, Griffith & Soundy, 2020; Flensner, Ek &

Söderhamn, 2003; Skogar et al., 2012); and when anxious in social settings (Brown et al., 2005). In the current study, participants expressed a sense of being cautious towards pain and fatigue, showing that they may have heightened awareness and take care to avoid experiencing these symptoms. Del Sorbo and Albanese (2012) highlighted how performing even basic activities can worsen PD-related fatigue causing the person to have to reduce their activity level. The current findings support this statement for pain and fatigue in MS and PD as participants discussed their worry that as these symptoms progressed, they would negatively impact participants' ability to perform activities and increasingly affect their sleep.

Previous studies have discussed how the limbs or whole body of persons experiencing fatigue related to MS and PD were described as heavy; and their muscles were weak or lacked strength (Newton, Griffith & Soundy, 2020; Mills & Young, 2008; Olsson, Lexell & Söderberg, 2005; Flensner, Ek & Söderhamn, 2003; Béthoux, 2006; Chou & Ridder, 2016; Brown et al., 2005). The current study supported these findings with the addition of pain causing similar feelings of physical heaviness in the limbs, muscles, and body. Heaviness is perceived to impact these persons to a greater degree when pain and fatigue are more intense, which can occur when individuals with these conditions are employed and consistently working. de Lau and colleagues (2006) reported how persons with PD typically experience a slowness in their movements due to the functional impairments associated with the pathophysiology of the condition. Participants in the study by Mantri and colleagues (2020) further described how they felt they were slowing down due to their PD-related fatigue. The current study supported the findings of moving and performing activities at a slower pace, however, this was ascribed to the heaviness associated with pain and fatigue in MS and PD. The experience of physical heaviness can be an indicator the body needs to shut down and rest prior to continuing or commencing any activity.

MSRF is recognized as a time-consuming phenomenon (Smith & Hale, 2007; Flensner, Ek & Söderhamn, 2003), with the current study supporting and broadening this finding to include pain and fatigue as being time-consuming phenomena for both MS and PD. Studies show that PD-related fatigue can cause individuals to reduce the amount of

time spent moving, and increase the amount of time it takes to perform activities resulting in less being done in a day (Brown et al., 2005; Friedman et al., 2007). The current study similarly reported that participants with MS and PD occasionally experienced an inability or took longer to perform and complete tasks and required more rest throughout a day to compensate for the level of activity.

Friedman and colleagues (2011) discussed the mental fatigue associated with PD and how it caused cognitive challenges due to the demands of the tasks or activities, requiring sustained concentration and mental endurance. The current study reported brain fog as a specific cognitive challenge discussed by participants expanding the findings of Friedman and colleagues to the MS population. Brain fog was described as causing difficulties with tasks requiring sustained mental capacity or focus in MS and PD. Cognitive fatigue can cause individuals with MS and PD to lack clarity (Newton, Griffith & Soundy, 2020; Chou & Ridder, 2016), and so they wait to make decisions until they feel sharper (Mantri et al., 2020). The current study supported this finding in participants with MS and PD, such that they experienced heightened emotional responses when experiencing brain fog which was perceived as lacking the ability to think clearly or carefully. The inability to think clearly and a lack of sleep due to cognitive fatigue were additionally perceived as causing problems with absorbing information and negatively impacted processing speeds and mental acuity. Difficulties in processing, absorbing, and understanding conversations with more than one person were noted, emphasizing the need for further study on ways to manage multileveled discussions in social settings for these persons.

Studies of individuals experiencing MSRF reported poor concentration and memory and recall problems (Newton, Griffith & Soundy, 2020; Mills & Young, 2008; Olsson, Lexell & Söderberg, 2005; Stuifbergen & Rogers, 1997). Interestingly, the current study found similar findings in participants with PD where cognitive fatigue was described as having difficulty concentrating, memorizing, and recalling their memories. This suggests similarity in the experience of cognitive fatigue across MS and PD, affecting concentration and memory retrieval. Other cognitive impairments were described by participants including the perception of pain and fatigue causing heightened



psychological and emotional responses and an overpowering need to rest in MS and PD. The definition of fatigue by Ream and Richardson (1996) defines this symptom as an unpleasant and unrelenting phenomenon interfering with one's ability to function to their normal capacity. The current study supported and expanded upon this definition as participants with MS and PD perceived they could not function, communicate, or work (if employed) at the capacity they would otherwise be able to if they were not fatigued.

In the current study, participants with MS and PD recognized that there were two different experiences of fatigue: fatigue related to their condition and fatigue experienced before their condition. Participants noted that the quality of the fatigue may be the same, but the quantity of fatigue increases in MS and PD resulting in increased feelings of tiredness. Persons with MS and PD related fatigue reported a difference between the nature of their fatigue (e.g., constant) related to their condition or experiences they had prior to being diagnosed (e.g., not constant) and how they experience more physical and mental fatigue than healthy people would experience (Krupp et al., 1988; Lou, 2009). The inability to make sense of the experiences of pain and fatigue in the current study could stem from difficulty in recognizing these phenomena as related to their condition if they were experiencing these symptoms before their diagnosis like any other healthy individual.

Persons with PD describe physical activity as a significant contributor in managing their pain (Twomey, Stuart & Baker, 2018; Skogar et al., 2012) and it has been proven to lower the risk of this condition (Chen & Tsai, 2010). Furthermore, exercise has been shown to be of aid in managing MSRF (Stuifbergen & Rogers, 1997). Twomey and colleagues (2018) discussed how participants with PD-related pain reported they felt they needed to force themselves to continue to be physically active as it helped with their pain. The current study showed similar findings where, although they occasionally dwelled on the fact they could not accomplish the same level of exercise they could before, participants attempted to remain physically active to improve their function and mobility amidst their pain and fatigue. This was perceived as another way of regaining control in their life, which supports the findings of studies (Friedman, Abrantes & Sweet, 2011; Friedman et al., 2016; Chou & Ridder, 2016; Del Sorbo & Albanese, 2012) on physical

exercise helping to improve depression, anxiety, and sleep disturbances and provides an improved sense of control. In addition, Twomey and colleagues (2018) noted a gap regarding the specific exercise dose each individual should be prescribed to manage their pain. Participants in the current study expressed the same weariness regarding how much physical activity they should do before it would exacerbate their pain or fatigue, impacting their functional abilities and mobility. Further investigation surrounding the dose of physical activity to be prescribed within MS and PD is needed to better manage pain and fatigue.

Individuals experiencing PD-related fatigue may attempt to reframe their previous and/or current experiences with this phenomenon to better prepare themselves for subsequent bouts of fatigue. Interestingly, Flensner and colleagues (2003) and Newton and colleagues (2020) described how persons coped with MSRF by framing their lives how they want to live them; the current study extended these findings to PD, including a variety of framing techniques reported to manage PD-related fatigue. Meditation and self-talk were perceived as coping strategies which were used to calm the mind and body to engage in more physical, emotional, and social activities or on a more regular basis. These strategies can also have a calming effect which helped participants to remain positive and restore energy levels. Perhaps the use of positive mantras could be useful to individuals experiencing pain and fatigue due to neurological conditions by producing a calming effect and providing benefits of relaxation to the body and mind.

The single participant with CP in the current study illustrated their fatigue as a lack of energy in three different ways including the spoon theory, the battery theory, and a combination of both theories. The spoon theory is an approach to life that constantly caused an individual to live with a lack of energy day-to-day and made them increasingly aware of the amount of energy they had used in a day and how much they had left for the following day. Flensner and colleagues (2003) described MSRF as feeling drained of energy and further depicted the lack of energy associated with this phenomenon as resembling a discharged battery. Similarly, the participant with CP in the current study perceived their fatigue to resemble a rechargeable battery that slowly discharged causing them to lose energy and eventually resulted in impaired energy levels where they could

no longer achieve the same level of energy as before. These findings show similarities between MSRF and CP-related fatigue through the subjective characterization of their lack of energy in terms of a discharging battery. This participant additionally theorized a combined spoon and battery theory where they had to constantly work to control and balance their energy levels which helped with the prioritization of daily tasks and enhanced their understanding of the remaining energy they had to use.

Pain and fatigue are negatively associated with QoL, HRQoL, participation, and overall well-being in MS, PD, and CP (Bruno & Sethares, 2015; Del Sorbo & Albanese, 2012; Brunton, McPhee & Gorter, 2021; Gromisch, Kerns & Beauvais, 2019; Skogar et al., 2012; Truini, Frontoni & Cruccu, 2013; Krupp and Christodoulou, 2001; Béthoux, 2006; Fairhurst et al., 2019; Graham et al., 2016; Fil et al., 2013; Twomey, Stuart & Baker, 2018). However, the results of the current study supported these findings solely in MS and PD as the negativity which accompanies pain and fatigue were perceived as affecting all aspects of life; with fatigue being seen as debilitating and reducing QoL and increasing negativity leading to more pain.

Participants with MS and PD discussed how they wanted to maintain their independence to preserve their functional ability. Although this was not discussed by the participant with CP in the current study, Brunton (2018) documented how individuals with CP-related fatigue experience a reduction in their independence and mobility due to their functional impairment. This further shows a possible connection across all three conditions and the negative impact of fatigue on maintaining independence.

Previous studies found evidence suggesting that persons with MS and CP require additional help under certain circumstances creating an increased need to depend on others (Newton, Griffith & Soundy, 2020; Flensner, Ek & Söderhamn, 2003; Smith & Hale, 2007; Olsson, Lexell & Söderberg, 2005) when fatigued, and ask for help and receive emotional and/or social support (Jensen, Engel & Schwartz, 2006; Ostojic et al., 2022) when in pain. Similarly, while the support of others was helpful and appreciated in managing pain in CP, Castle and colleagues (2007) noted how these individuals experienced negative feelings towards the help provided. Even though participants were

appreciative of the help they received, their vulnerability increased during moments they perceived to be losing their independence when fatigued. These findings show a relationship between pain and fatigue across the three conditions in promoting negative emotional responses when mindful of moments they must depend on others instead of themselves.

Studies on CP-related pain reported that by pushing through, the people experiencing this symptom continued to participate and prevented pain from intruding in their daily lives (McKinnon et al., 2020b; Castle, Imms & Howie, 2007; Lindsay, 2016). The current study similarly found that participants across conditions continued to be physically active and sociable when they pushed through their pain and fatigue; however, occasionally this resulted in a poorer quality of sleep and increased physical and emotional challenges the following day. Pushing through was perceived as taking back the control that these phenomena stole from participants and was observed as a way of fighting back.

Castle and colleagues (2007) discussed how individuals with CP-related pain wanted a cure for their pain so badly that it consumed their thoughts and time. Similarities in experience existed between accounts of PD and CP related pain as a participant with PD described how they continued down a blind road hoping for a cure for their condition and the associated pain which consumed the time they could have spent on other things.

Interestingly, Brunton and Bartlett (2013) discussed how the amount and length of physical activity is a source of prevention which can positively or negatively affect fatigue in CP. The current study may have found a similar finding if more CP participants had been recruited; and may have possibly seen these findings with respect to CP-related pain as well. Furthermore, studies have reported stretching and yoga as methods of managing increasing levels of CP-related pain and fatigue, respectively (Ostojic et al., 2022; Jensen, Engel & Schwartz, 2006; Brunton, McPhee & Gorter, 2021); similarly, participants in the current study described stretching and yoga as methods of managing pain and fatigue in MS and PD. The findings of our study suggest yoga and stretching

may be used as non-pharmacological coping strategies to manage pain and fatigue across all three included neurological conditions.

Jensen and colleagues (2006) discussed how people with CP ignored their pain as a way of coping; the findings of the current study suggested that participants with MS and PD also ignored their pain and fatigue as a maladaptive coping strategy to weather these symptoms. Deep or controlled breathing were reported as being effective techniques in managing pain in PD and CP (Twomey, Stuart & Baker, 2018; Skogar et al., 2012; Ostojic et al., 2022; McKinnon et al., 2020b). The current study found deep breathing to be effective in managing PD-related fatigue, along with journaling, writing, and positive reminder to take breaks.

Studies on MSRF and CP-related pain noted the importance of focusing on the positive aspects of life and keeping positive when faced with the daily challenges brought on by these phenomena (Stuifbergen & Rogers, 1997; Newton, Griffith & Soundy, 2020; Flensner, Ek & Söderhamn, 2003; Jensen, Engel & Schwartz, 2006). In the current study, participants with MS and PD perceived positivity as a helpful strategy in combatting and controlling their pain. These findings may be seen in CP, but further study is required to explore the use of positivity in this condition.

Flensner and colleagues (2003) and Newton and colleagues (2020) described a lack of understanding by researchers, clinical experts, and others in the ability to understand the experiences of pain and fatigue in those with MS. It was thought to be related to the invisibility of these phenomena to others as well as difficulty understanding the meaning of pain and fatigue or even why they occur in the first place (Newton, Griffith & Soundy, 2020; Flensner, Ek & Söderhamn, 2003). Within the current study, participants across all three conditions described how others, clinicians, and they themselves lacked the ability to understand the experience of pain and fatigue in their respective condition.

Specifically, participants in the current study described how others didn't understand what they were going through, and the ignorance of others resulted in marginalization of their experiences of pain and fatigue, often by relating it to their own

experiences. People who support individuals with neurological conditions (family, friends, clinicians) should actively listen with a goal to understand their experience and embrace that it may be different than their own experience with these phenomena.

Parker and colleagues (2021) discussed the notion of "invisibility" in how the invisible symptoms of pain and fatigue impacted the lives of those with MS and left them feeling socially isolated, reluctant to seek help, lacking confidence in their perceptions of these symptoms and feeling as if their condition was not "real" because their symptoms were not overtly seen as debilitating in the eyes of other people. Participants in the current study described how the symptoms of pain and fatigue were not always visible or could be hidden, resulting in others being unable to understand the impact or presence of these phenomena, which left participants feeling misunderstood. For others to be able to understand the impact these symptoms have on the lives of those with MS, PD, or CP, they must recognize the invisible qualities intrinsic to these phenomena, including the pain and fatigue occurring inside the body, not visible to the onlooker.

Participants further described how clinicians focused on the physical effects of pain and fatigue as opposed to understanding the condition as a 'whole' and discussing the psychosocial factors impacting their experience with these phenomena. This relates back to the biomedical model which focuses solely on the biological elements of a condition and ignores the psychological, cognitive, and social states that contribute to, and impact, an individual's experience (Borrell-Carrió, Suchman & Epstein, 2004). Engel (1980) proposed the biopsychosocial model to characterize the 'whole' of a person. Participants in the current study described how clinicians (in addition to other people) tried to relate their own experiences of pain or fatigue to their patients which made them feel unheard and left them wanting and needing to be heard; if not by a clinician, then by someone else. Further study on the lack of understanding of healthcare professionals is needed to determine how clinicians understand these conditions and their patients. Newton and colleagues (2020) discussed the need for a greater understanding of MSRF to stop physiotherapists from relating their own experiences of this phenomenon to their patients. Our findings similarly suggest the need for a greater understanding of pain and fatigue related to MS, PD, and CP to reduce marginalization by clinicians. This is not to say that

there aren't clinicians who engage in meaningful conversation with their patients and take the necessary time to understand how these experiences may impact the care provided; rather, it highlights what can be done to validate patient experiences and improve these clinical encounters.

Newton and colleagues (2020) discussed how researchers, clinicians, and others lack consideration of the "how" or "why" fatigue affects an individual with MS and the "how" or "why" an experience with this phenomenon occurs. The findings of the current study show how participants across neurological conditions contemplate these same questions of "how" or "why" pain and fatigue happen and affect them. Being unable to make sense of these experiences with pain and fatigue and how or why they occurred in their lives added to participants' lack of understanding regarding both their condition and its associated symptoms.

In the current study, being honest and direct with their feelings and when and how they exhibited pain and fatigue were perceived as helpful ways participants could help themselves but also increase the understanding of those supporting them and reduce feelings of concern. Participants supported themselves by making a concerted effort to understand what other people go through, so they do not misjudge or presume to know how someone else is feeling as they recognize and know how this feels and do not want to put someone else in this position. This shows how a greater level of understanding and willingly taking the step to understand a person's experience can be beneficial in supporting someone struggling with pain and/or fatigue.

Fatigue was interpreted as a spectrum encompassing a lack of energy, fatigue, extreme tiredness, and exhaustion. The experience of fatigue has been subjectively described as a lack of energy across conditions (Newton, Griffith & Soundy, 2020; Mills & Young, 2008; Olsson, Lexell & Söderberg, 2005; Stuifbergen & Rogers, 1997; Brown et al., 2005; Del Sorbo & Albanese, 2012; Mantri et al., 2020; Friedman, 2009; Kluger et al., 2016; Brunton & Bartlett, 2013). Results of the current study described fatigue, and to a lesser degree pain, as a lack of or no energy, which was perceived to negatively impact

the way people can verbally and physically communicate their energy levels when performing daily activities.

Individuals across conditions realized how much they relied on having energy throughout a day and perceived a lack of energy to impact their daily lives. Participants' described the lack of energy stage on the spectrum as being variable and the unpredictability of this fatigue resulting in fluctuating levels of energy each day which further influenced the functional abilities of participants and the amount of rest they required in a day. In previous studies a lack of energy was described, across conditions, as feelings of being drained (Mills & Young, 2008; Olsson, Lexell & Söderberg, 2005; Stuifbergen & Rogers, 1997; Chou & Ridder, 2016; Brown et al., 2005; Sandström, 2007). Participants in the current study perceived certain tasks or activities to be more draining, highlighting the need to maintain flexibility in daily schedules by adjusting the timing of when these tasks can be performed. The current study found a lack of energy impeded the social lives of these individuals. For introverts, extroverted situations were taxing leading to the need to restore their energy levels once depleted due to pain. Similarly, when fatigued, it was found that they no longer had the physical or mental energy to remain present at social events and had to leave to rest and renew their energy.

Previous studies of fatigue in MS and PD characterize fatigue as distinct from common tiredness, despite the terms fatigue and tiredness being used interchangeably by the general public and some healthcare providers (Flensner, Ek & Söderhamn, 2003; Olsson, Lexell & Söderberg, 2005; Mills & Young, 2008; Charvet, Serafin & Krupp, 2014; Friedman et al., 2007; Kluger et al., 2016). The current study supported these findings as some participants across conditions distinguished fatigue and tiredness as separate phenomena. Further investigation surrounding fatigue and tiredness is required to enhance our understanding of the connection or differences between these phenomena. In the current study, fatigue was perceived as encompassing physical and mental components. The mental fatigue associated with MS, PD, and CP was described as different from common tiredness, instead associated with having to focus for extended periods of time or the mind being unable to deal with an increased amount of mental stimulus. Physical fatigue was perceived as distinct from tiredness by the visible physical



appearance and consequences of fatigue; providing further evidence to support the idea of this phenomenon showing visible characteristics.

As some individuals across conditions characterized fatigue and tiredness as distinct phenomena, others described fatigue using the term tiredness. This could be due to different people experiencing different levels of fatigue, further reinforcing the spectrum of fatigue. For those individuals who described fatigue as tiredness, it was perceived as extreme and disabling tiredness and they struggled to find meaning and reasoning behind why they constantly felt so tired. This level of tiredness was perceived to be associated with heaviness, a lack of control, and a lack of energy in not being able to stop the onset or constant feelings of these phenomena in their daily lives and greater life course. Mental cognizance often accompanies the performance of physical tasks, as these individuals require more thought behind and to carry out actions, suggesting that both physical and mental aspects are at play when experiencing fatigue. The current study reported physical and mental exertion to influence the rate at which persons would tire and impacted their participation in daily life which in turn negatively affected their QoL and overall well-being.

In the current study, exhaustion due to fatigue across conditions was perceived as the end of the fatigue spectrum and caused additional feelings of being drained. Feelings of desperation were common with this level of fatigue and caused participants to lose hope that they would be able to live a day without experiencing exhaustion. Exhaustion was perceived as a separate stage from fatigue. Individuals across conditions noted how their days were always subject to change at a moment's notice when experiencing exhausting fatigue. The current study found that individuals with these neurological conditions need to be flexible in their daily lives in wanting to complete tasks or activities, given that pain and fatigue can occur unexpectedly and impact their ability to function. This evidence supports the findings of Mantri and colleagues (2020) who identified fatigue in PD to occur suddenly without warning; and Twomey and colleagues (2018) who discussed that persons need to maintain flexibility in their daily schedules to manage the pain associated with their PD. Participants reported that occasionally, certain days required more energy based on their activities, resulting in increased feelings of

exhaustion and reduced energy the following day. Fatigue has been described in previous studies in MS and PD as exhaustion (Mills & Young, 2008; Brown et al., 2005; Del Sorbo & Albanese, 2012; Friedman, 2009), with Flensner and colleagues (2003) making special note of MS-related exhaustion as different than exhaustion seen in individuals without chronic conditions. Similarly, Friedman and colleagues (2016) made special mention of PD-related fatigue and cognitive fatigue promoting feelings of exhaustion. Our study expands upon the finding of Flensner and colleagues (2003) to include exhaustion in PD as different from that seen in people without chronic conditions. The current study supported these findings as a participant with PD articulated their fatigue as mental exhaustion, suggesting mental and cognitive aspects of PD-related fatigue may lead to exhaustion.

Together the theme of fatigue as a spectrum should be considered within the context of the definition of fatigue by Ream and Richardson (1996) which identifies fatigue as feelings ranging from tiredness to exhaustion. Given the current study's findings of the importance of representing fatigue as a spectrum, it may be useful to alter the definition of fatigue in neurological conditions to incorporate feelings ranging from a lack of energy to exhaustion; although further study on the acceptability of this spectrum of fatigue associated with MS, PD, and CP would be useful.

The current study found participants across conditions required their own time and environment to retreat to when emotionally exhausted from communicating with others. These findings suggest connections across conditions experiencing emotional exhaustion due to fatigue. Across conditions, the perceptions into the differences between a lack of energy, fatigue, extreme tiredness, and exhaustion may highlight that there is still a need to understand the underlying causal factors (physical, psychological, and/or social) which contribute to people with MS, PD, and CP differentiating these phenomena from one another. Furthermore, healthcare professionals should be aware of the spectrum of fatigue and the various subjective characterizations possible for their patient's fatigue and should individually tailor management or treatment plans accordingly.

The current study found individuals experiencing PD-related fatigue to feel like they are living their lives from the outside looking in, including feeling physically and emotionally outside of their own bodies. Olsson and colleagues (2005) described MSRF as being a “whole-body experience”, the current study corroborates and expands upon these findings by describing pain and fatigue as a full-body experience that seizes the physical body and mental state of individuals across conditions. Cognitive challenges and issues with functionality and mobility due to the body's response to pain and fatigue caused persons with MS, PD, and CP to completely cease whatever they are doing and rest.

Twomey and colleagues (2018) previously described pain as being an “inner battle” for those with PD. This was similarly described by individuals across conditions in the current study with pain creating an internal uproar, emphasizing the psychological effect of pain. Pain was perceived as appropriating those with all three conditions from within and essentially was invisible to others because the pain lived inside of them, further corroborating the invisibility of this symptom. Pain across conditions was described as various objects being stuck into their body suggesting the physical sensations of this symptom may contribute to the possible psychological distress these people experience.

Previous studies described MSRF and MSRP as limiting as they interfered with these persons' functionality and their levels of participation in social and personal activities and relationships (Krupp et al., 1988; Newton, Griffith & Soundy, 2020; Cowan, Pierson & Leggat, 2020; Gromisch, Kerns & Beauvais, 2019; Sharbanian, Duquette & Mayo, 2018). The current study also described pain and fatigue as factors which limit the daily lives of those with MS, PD, and CP, and restrict the lifestyle these individuals want or could have if they did not experience these symptoms. The ability to engage in meaningful conversation and activities with family and others is compromised due to debilitating pain and fatigue acting as barriers restricting the lives of people with these conditions.

Across conditions, pain and fatigue were perceived to cause a lack or loss of control over the physical body and perceived these symptoms as harder to control than anticipated; this resembled the findings of Mantri and colleagues (2020) who described PD-related fatigue as an external force that was hard to control. Participants in the current study also discussed feelings of lacking control on a mental level as they perceived things in their life as worse than they were, which led to an inability to regulate their emotions in different situations. Constant pain and fatigue were also described as being something out of their control which slowly chipped away at their existence. This suggests a possible relationship between the mental and emotional aspects associated with pain and fatigue and should be investigated further. Twomey and colleagues (2018) discussed how for those with PD it became easier to control their physical body when they had the willpower to do so, which helps to control the psychosocial factors which impact their life. Expanding the findings of Twomey and colleagues to the MS and CP population may help these individuals to increase their control over their physical being, and mental and emotional responses.

Dealing with pain and fatigue in the everyday life of a person living with MS, PD, or CP is a lifelong learning process and requires trial and error to recognize what is best for them in that moment, whether to push themselves or not. This finding stemmed from the ‘me before’ and ‘me after’ discussion where participants start to learn when they can push themselves in the way they did before diagnosis or the onset of pain/fatigue, and when this may no longer be possible. Olsson and colleagues (2005) previously discussed the hardship experienced by people with MSRF in not being able to live as they did previously; although the perspectives of participants in the current study suggest that by accepting pain and fatigue, individuals with MS, PD, and CP can preserve some of the life they had “before” pain and fatigue by recognizing their limitations and finding a way around them. Finding a way to accept pain and fatigue may allow these individuals to discover who they are now and gives them a chance to engage in life in a way that they deem meaningful.

Studies have shown MSRF and pain and fatigue in PD and CP to be unpredictable symptoms (Flensner, Ek & Söderhamn, 2003; Newton, Griffith & Soundy, 2020; Smith

& Hale, 2007; Stuifbergen & Rogers, 1997; Ostojic et al., 2022; Brunton & Bartlett, 2013; Chou & Ridder, 2016). The current study supported these findings with MSRP additionally being described as an unpredictable symptom. In essence, these symptoms of pain and fatigue across conditions were identified as being personal and individualized to each person as they can present and progress differently in everyone.

Ostojic and colleagues (2022) described CP-related pain as being erratic in nature; while Brunton (2018) noted how CP-related fatigue is of variable nature encompassing general, physical, and mental factors which may impact these persons lives. Despite the perception of unpredictability, the current study found the physical aspects associated with pain and fatigue across all conditions to be most predictable, suggesting the need for further investigation into management strategies for physical pain and fatigue. Furthermore, the current study found the psychosocial aspects of pain and fatigue across conditions to be the most unpredictable, suggesting the need to explore the mental and social aspects associated with these conditions in further depth to develop effective coping and management strategies.

Participants across conditions described a lack of muscle strength due to pain and fatigue. It was perceived that participants were experiencing what is traditionally defined as peripheral fatigue lacking strength when attempting to accomplish physical tasks associated with repeated muscular contractions (Friedman, Abrantes & Sweet, 2011); This has been well documented in other studies, across all conditions (Newton, Griffith & Soundy, 2020; Mills & Young, 2008; Olsson, Lexell & Söderberg, 2005; Flensner, Ek & Söderhamn, 2003; Béthoux, 2006; Brunton & Bartlett, 2013; Brown et al., 2005; Mantri et al., 2020; Friedman, 2009).

Pain and fatigue across conditions were perceived as being physically and mentally intense resulting in variable responses of the body and mind dependent upon the intensity. Coriolano and colleagues (2014) discussed how the intensity of PD-related pain can affect how people perceive and describe their pain. The current study broadens these findings by recognizing that descriptions of pain and fatigue across MS, PD, and CP can be person-dependent varying with the intensity of these phenomena. Participants'

experiences of pain were perceived to negatively impact their physical, psychological, and emotional states. Physically, participants noted that their mobility was negatively affected when their pain was more intense; and emotionally, their mind and body's response to intense pain was overwhelming. Fil and colleagues (2013) identified how the involvement of the striatum in PD may affect the emotional dimension of pain and the subjective perceptions of pain intensity. Further investigation into the emotional dimension of pain through the subjective descriptions of those living with MS, PD, and CP is needed to understand the true impact of intense pain on these persons; and mixed methods studies would be beneficial to understand the striatum's impact on the emotional response to pain and varying intensity levels in PD.

Pain and fatigue in MS, PD, and CP are known to negatively affect the sleep habits of these persons causing sleepiness and sleeplessness, that can result in sleep deprivation (Gromisch, Kerns & Beauvais, 2019; Sharbanian, Duquette & Mayo, 2018; Mills & Young, 2008; Newton, Griffith & Soundy, 2020; Krupp et al., 1988; Stuifbergen & Rogers, 1997; Russchen et al., 2014; Brunton, McPhee & Gorter, 2021; Siciliano et al., 2018). The current study described how these phenomena impaired persons' sleep across conditions, with special note of further impairment occurring when experiencing spasms or when a person had a busy day. Skogar and colleagues (2012) reported people with PD-related pain attain approximately 3 to 4 hours of sleep a night. The findings of the current study found individuals in an MS support group sleep no more than 2 to 3 hours per night, and this sleep was not described as being restful but was typically a broken sleep. This suggests chronic sleep deprivation across MS and PD related to pain or fatigue, and these findings may also be relevant to individuals with CP.

To compensate for the lack of and reduced quality of sleep, persons with MS required increased amounts of rest during the day which could include lying down, napping, or sleeping (Mills & Young, 2008; Newton, Griffith & Soundy, 2020; Stuifbergen & Rogers, 1997). In the current study, the level of rest the body requires varied between lying down, napping, or having to be completely asleep and were dependent upon external factors and the time of day; although participants noted they felt they were calmest when completely asleep. These findings suggest a connection between

the type of sleep and the calmness of the individual. The participants in the current study discussed that restful sleep was not necessarily dependent on the number of hours slept, but rather the quality of the sleep they received. Further investigation surrounding the quantity and quality of sleep individuals with MS, PD, and CP receive and require is needed.

Groomsich and colleagues (2019) and Shahrbanian and colleagues (2018) found increasing levels of depression to have a negative impact on persons experiencing MSRP. Depression and anxiety are known to be comorbid factors which can negatively influence fatigue in MS, PD, and CP (Newton, Griffith & Soundy, 2020; Krupp & Christodoulou, 2001; Charvet, Serafin & Krupp, 2014; Mills & Young, 2008; Krupp et al., 1988; Brunton, McPhee & Gorter, 2021; Friedman et al., 2016; Friedman et al., 2007; Siciliano et al., 2018). In the current study, when individuals felt as though they were unable to meaningfully participate in familial events due to pain and fatigue, they reported increased feelings of anxiety and depression, which was perceived as a result of being left out of social events, triggering emotional responses such as feelings of guilt, as seen in the study by Brown and colleagues (2005).

Feeling stressed and anxious were perceived to impact a person's ability to complete their daily activities and achieve their goals. The constant sensations and cognitive challenges associated with pain and fatigue often led to participants feeling depressed. The lack of or reduced joy in life was also found to be a factor that influenced the occurrence of depressive symptoms. The current study provides some evidence supporting a connection between pain and depression; and a possible connection between an increase in anxiety influencing the occurrence of depression, where both comorbid symptoms may occur concurrently. Depression was perceived as being triggered through an emotional response to pain and fatigue when participants were increasingly distracted or upset when constantly reminded they had to live with their condition. Overall, feelings of anxiety and depression were linked to experiences with pain and fatigue across conditions and seemed to negatively impact QoL.

Consistent changes in the weather are perceived to play a role in affecting the experience of pain and fatigue across conditions. Brunton and Bartlett (2013) noted how pressure changes can affect those with CP-related fatigue. The current study supported these findings across all three conditions. Heat has previously been found to increase MSRF and PD-related fatigue (Stuifbergen & Rogers, 1997; Friedman et al., 2016), and negatively impact these persons physically, emotionally, and cognitively (Stuifbergen & Rogers, 1997). The current study found heat was related to increased pain and fatigue across these conditions, specifically impairing their sleep, and impacting them emotionally and physically. Newton and colleagues (2020) reported colder climates increased levels of spasticity and fatigue in MS; however, the current study did not find the colder weather to affect spasticity but did find the cold to increase pain and fatigue across conditions. Dampness, rain, and snow may be further forecasts which can affect individuals with these conditions and increase their weariness of the varying effects weather may have on their physical, emotional, and cognitive states.

The experience of pain and fatigue across conditions is known to increase the desire and need to rest for the body to be able to recover and to restore energy levels (Mills & Young, 2008; Krupp et al. 1988; Stuifbergen & Rogers, 1997; Smith & Hale, 2007; Bieske et al., 2009; Twomey, Stuart & Baker, 2018; Brunton & Bartlett, 2013). The current study revealed resting to be a primary strategy for participants in coping with their pain and fatigue. For individuals able to remain employed, rest was typically required the day before a workday as it was perceived to help conserve energy levels and reduce the depletion of energy when working. Previous studies (Mills & Young, 2008; Newton, Griffith & Soundy, 2020; Krupp et al., 1988; Stuifbergen & Rogers, 1997; Ostojic et al., 2022; Jensen, Engel & Schwartz, 2006; McKinnon et al., 2020b) and the current study found the length of time needed to rest to improve or manage MSRF and CP-related pain varied. Rest periods needed across conditions varied in length including seconds, minutes, hours, or all day which allowed individuals across conditions to feel rejuvenated, increased their levels of energy, and had a calming effect on the mind and body when in pain. Finding individualized ways of distracting the mind when in pain or fatigued was perceived as helpful to control the body's physical and mental responses to these phenomena. Feelings of apathy and tiredness were also found in the current study to



enhance the need to rest suggesting a lack of motivation and energy may be indicators of the onset of fatigue across conditions.

The previously discussed unpredictability of pain and fatigue influenced the type of sleep the body required where individuals across conditions had to rest immediately as their bodies shut down and negatively impacted their function and mobility. Mantri and colleagues (2020) and Friedman and colleagues (2016) reported that when experiencing PD-related fatigue these persons needed to immediately lie down and rest. The current study found that cognitive fatigue may additionally influence the need for rest at a moment's notice, which can also be perceived as unsafe in certain situations such as driving if unable to stop. This suggests a possible physical and cognitive connection across conditions which may affect the type of rest required. When fatigued, the mind and body were perceived as responding individually, lacking the ability to coordinate between thoughts and movements, and rest is perceived as the only management strategy available in the moment.

In the current study, once participants accepted the presence of pain and fatigue in their lives, their overall well-being was seen to improve. Participants relayed the difficulty in accepting pain and fatigue as a part of their lives which was perceived as being related to having to accept the reality of their diagnosis. This is particularly important as previous studies have shown that fatigue in MS and pain in PD and CP is easier to control once someone has been able to accept that these phenomena would be present in their daily lives (Newton, Griffith & Soundy, 2020; Flensner, Ek & Söderhamn, 2003; Twomey, Stuart & Baker, 2018; Bergqvist et al., 2019; McKinnon et al., 2020b; Sandström, 2007; Ostojic et al., 2022). In the current study, receiving support from others helped persons to accept their condition and the associated symptoms making them feel as though they can deal with the challenges they may be presented with and work within their limits; this was perceived as helpful in retaining control over their lives.

Various accommodations were described as useful in managing pain and fatigue across conditions in the current study. Accommodations were perceived to increase the functionality and mobility of participants by using visualization techniques and

modifying physical tasks to be easier thereby reducing daily activity levels.

Accommodations were found to positively influence the physical and psychosocial aspects of pain and fatigue across conditions as participants were able to adapt the way they performed activities, get help from others, and were able to engage with people in ways they may not have previously thought to use. The use of different methods of communication helped to increase socialization and allowed people to feel more in control when experiencing pain and fatigue. Further investigations surrounding the use of various forms of contact to make socializing easier and more accessible across conditions are needed. The use of accommodations is highly individualized for each person and relies on each person's life environment. Further evidence should be provided by healthcare professionals on when to ask for and use accommodation in certain situations.

Studies have shown that individuals with MS, PD, and CP find planning and scheduling their time helpful in organizing their daily tasks and activities (Mantri et al., 2020; Friedman et al., 2016; Brunton & Bartlett, 2013). The current study supported these findings, as participants perceived these coping strategies to be effective and helped maintain a sense of control in their lives as they tailored their daily schedule to their wants and needs. Participants in the current study perceived scheduling to increase their ability to partake in social events as it increased the honesty and discussion surrounding pain and fatigue across these conditions, supporting the finding of Mantri and colleagues (2020) in relation to planning and social life. Scheduling social outings allowed participants to reduce feelings of guilt associated with having to cancel when pain or fatigue suddenly occurred.

Mills and Young (2008) discussed how people with MSRF prepare their meals in advance to save energy and reduce stress. Brunton and colleagues (2021) similarly reported how persons with CP-related fatigue can use mobility aids to modify and adapt daily activities thereby decreasing activity levels which can help to manage fatigue in CP. In the current study, alternative ways perceived to help plan their lives included prepping meals, travel routes, and preplanning when to bring assistive equipment which helps to preserve their energy and reduce the amount of time these tasks consume out of their day. Similarly, through scheduling, participants could prioritize specific activities, and this

was perceived as a way for participants to do the things in life they wanted to and found important, which may be an additional way of increasing the joy they experience in their lives.

In the current study participants were also able to learn their “on” and “off” times which facilitated scheduling of their days, including activities and rest, accordingly. These findings were similar to the study by Friedman and colleagues (2016) describing how individuals with PD-related fatigue schedule their lives around their rest periods. Related to this, participants found daily living to be easier when they were able to recognize the onset or presence of pain and fatigue because it provided the insight they needed for them to plan their day accordingly and in advance, as well as to perform activities at a reduced rate than they would otherwise be able to, supporting the findings of Brunton and Bartlett (2013). Finally, goalsetting was perceived to be a useful coping strategy used across conditions which helped to increase motivation to complete activities. Individuals experiencing pain and fatigue across these conditions should proceed with maintaining a flexible schedule while continuing to plan their days due to the unpredictable nature of these phenomena.

The management of pain in neurological conditions can be challenging and complex. The desire to learn new and different pain management techniques across conditions was expressed due to the need for individualized management (as pain can present differently in everybody) and not wanting to be afraid of pain. In the current study, participants varied in their preference to use non-pharmacological 'natural' management or pharmacological interventions to reduce or manage their pain. In a study by Ayano (2016), the use of pharmacological treatments including levodopa and anticholinergic drugs in combination with additional therapies were reported. In the current study participants reported medication including steroids, pain prescriptions or analgesic creams to be of use in managing pain across MS, PD, and CP; however, levodopa was perceived as ‘worthless’ by one participant in managing the physical and mental aspects associated with their PD-related pain. Twomey and colleagues (2018) described how there is a lack of interplay between external support and internal support; and it is highly recommended that individuals, across conditions, regularly communicate

with their healthcare professionals regarding the use and changing of medications or alternative treatments, or if the use of coping strategies in combination with treatment should be used to ensure the best care is received.

### *Differences across conditions*

Specific to MS, the use of MAiD provided a sense of being able to take control over their own lives (or the end of their life) rather than continuing to lack control for the rest of their life. While participants provided their narrative accounts of their experiences with pain and fatigue, MAiD allowed them to control the narrative of their own story.

Although the use of or wish for MAiD was not described by participants with PD or CP, other conditions (even those beyond neurological conditions) may benefit from the discussion of MAiD or other available treatments with respect to pain and fatigue, specifically in discussing one method of control over their own lives. Further research is necessary to understand the reasoning behind why individuals may wish to use MAiD and the effects this may have on caregivers if the process is initiated and followed through.

Newton and colleagues (2020) discussed how individuals with MSRF felt shame when experiencing fatigue; in the current study, one participant felt shame for needing to take time to themselves which supported feeling the need to hide their MSRP. This highlights a connection between MSRP and MSRF as they can both cause feelings of shame and a desire to hide in the background. Flensner and colleagues (2003) reported feelings of shame and guilt when unable to work due to MSRF, although these findings were not found within our study.

Feelings of needing to hide came again here and were also described by one participant with MS discussing how their pain was easier to mask than their fatigue due to the physical tiredness which could be visually seen by others. This extends previous work that has represented pain and fatigue as invisible symptoms, suggesting that fatigue has characteristics observable to the perceptive eye; suggesting the need to further investigate the "invisibility" surrounding fatigue and the accuracy of this perception.

Pain and fatigue in MS were perceived as causing a lack of control, described as their bodies constantly short-circuiting impeding their ability to continue to physically perform. Individuals experiencing MSRP described how they had a lot of time to prepare for the onset of pain, however, knowing the pain was coming consumed their thoughts and reduced the amount of time they had to perform other activities. Similarly, the experience of MSRF was perceived as thought consuming as the onset of this symptom was unpredictable and sudden, but once present, it was constant. Although pain was described as having negative qualities, it was additionally perceived by a participant with MS as a positive phenomenon validating their continual existence in the world, reminding them they are alive.

Participants in the current study found water therapy to be a possible effective method of managing pain in this condition. The decision-making process in whether to take or continue taking medication to manage pain places a burden on the individual experiencing this symptom relating to the idea of an emotional heaviness described in MS.

Within PD, one participant who experienced fatigue described being unable to put themselves in the right frame of mind, causing problems remaining present in their daily life. Difficulties in functioning thoughtfully, reflectively, and logically, as well as feeling overwhelmed were perceived to be associated with one participant with PD's introverted nature creating cognitive challenges in social settings when experiencing pain. Further investigation on how introversion affects the social ability of those with neurological conditions experiencing pain is needed.

In the study by Mantri and colleagues (2020), people experiencing PD-related fatigue personified this phenomenon with human characteristics; the current study also found this, as one participant described compartmentalizing their pain by giving it a persona that they perceived as benefiting their overall well-being.

Specific to the CP participant showed how they were able and had to take control of their own life to accommodate for their physical disabilities; however, they often had to advocate for themselves due to the lack of understanding of others surrounding them.

In the current study, this participant discussed how the process of acquiring and developing ways of dealing with their pain or fatigue, including coping strategies, was also a lifelong learning process as these symptoms progressed throughout their life.

The current study found that poor accessibility and ableism were negative factors experienced by people with CP which affect and reduce the QoL of these individuals. Further evidence on how poor accessibility and ableism negatively impact QoL and increase levels of pain and fatigue in the CP population is required. Castle and colleagues (2007) noted restrictions to the type and level of activities individuals with CP who are experiencing pain and fatigue can perform. The current study supported these findings as the participant with CP discussed needing to recognize which tasks they would complete in a day to remain functional and reduce the likelihood of tiredness or exhaustion.

The participant with CP expressed having always experienced pain related to their condition, and therefore living with CP-related pain was considered their 'normal'. It is necessary to provide information to these individuals on the risk factors and signs of pain and fatigue specifically associated with their neurological condition, but also management strategies to reduce or mitigate the effects, rather than assuming that it is 'normal' and thus that they must live with it.

#### *Similarities between the constructs of pain and fatigue*

Pain and fatigue were perceived to be distinct but directly related entities. Charvet and colleagues (2014) reported how pain is associated with the exacerbation of fatigue, further resulting in the exacerbation of functional impairments within MS. The current study supported these findings as the pain was perceived to exacerbate fatigue and vice versa in MS which may result in a decline in QoL and well-being if these symptoms are not managed. Engel and colleagues (2005) identified the ability of fatigue to exacerbate pain in CP; however, the current study found CP-related pain to worsen and intensify the negative aspects associated with fatigue in this condition. Also of note, the current study found that when people, across conditions, concurrently managed these symptoms, they were able to have better control over their whole body and their lives and reduced feelings of tiredness. These findings also suggest that it may be beneficial for these

individuals to manage their pain and fatigue together as this may help to improve the quantity and possibly the quality of sleep they receive.

Pain and fatigue were perceived as debilitating in the lives of those with MS, PD, and CP and these symptoms may be experienced simultaneously resulting in more debilitation during these times; this was perceived as increasing the need for and the use of coping strategies during these times. Feelings of pain and fatigue, both unwelcome and unwanted, were perceived to cause an inner emotional struggle resulting from the inability of participants across conditions to rid themselves of their constant pain and fatigue typically resulting in negative emotional responses. Individuals should be aware of the possible challenges pain and fatigue may cause in their lives. Participants in the current study perceived these challenges as difficulties with interpersonal relationships, lifestyle restrictions, communicating with others, functional impairments, and mobility-related issues which subsequently may reduce their QoL. The current study found that individuals experiencing only pain should be aware that fatigue may be an inevitable symptom associated with their pain which may affect them later in life.

#### *Differences between the constructs of pain and fatigue*

The current study discovered differences between pain and fatigue with respect to the biopsychosocial factors which influence the experience of these symptoms across conditions. Pain and fatigue were perceived as existing on opposite ends of a spectrum in CP; so, if an individual is not experiencing pain, they are experience fatigue and vice versa due to the constant nature of these phenomena. Further evidence supporting this idea of pain and fatigue existing along the same spectrum is needed specifically within CP and across conditions. Further study on physical pain and mental and emotional fatigue is needed to understand why these experiences differ with pain focusing on the body, and fatigue both the mind and body. The mental aspect associated with fatigue was perceived to increase the negative thoughts of people across conditions, causing them to remain in a negative state of mind more consistently than when in pain. The current study found individuals perceived their lives would be easier if they only had to deal with the pain as opposed to the brain fog associated with fatigue.

Pain is perceived to be a familiar phenomenon as people experienced pain in their life before or apart from their diagnosis. However, fatigue is perceived as a new sensation that accompanies MS, PD, and CP which can be harder to adjust to as fatigue differs in its manifestations throughout the greater life course. This suggests that fatigue may require individuals to be increasingly flexible in their daily lives to accommodate this symptom. In individuals with MS, the intensity of pain and fatigue were perceived to influence the ability of participants to connect and communicate with others; suggesting further investigation on how communication is impacted by different intensity levels of pain and fatigue. The current study found fatigue in MS to be more cumbersome than pain which was perceived as placing additional burden on the lives of those experiencing MSRF. The current study found individuals with PD consistently experience more pain than fatigue, which was perceived as having physical and cognitive effects which impacted their overall QoL.

#### 4.1 Clinical implications

The findings of the current study indicate that the physical, emotional, cognitive, and social aspects which influence the experience of pain and fatigue should be a priority for clinicians and others caring for those with MS, PD, and CP as this may lead to a more informed and tailored approach to management and intervention plans. Clinicians may additionally need to be aware that the experience of pain and fatigue for those living with these conditions can be different from their own personal experiences with these symptoms and should be mindful of this when creating management plans for their patients. Clinicians need to engage in meaningful conversation with their patients during clinical encounters to ensure they understand how participants are feeling and how they are impacted by pain and fatigue. Meaningful conversation is idealized as being an inclusive conversation between the clinician and patient to discuss their feelings and needs and form a management plan together. The findings of this study indicate that clinicians need to be aware of the invisibility of pain and fatigue such that these symptoms may not be visible to the outsider; and so, clinicians should be making note to ask about these symptoms during clinical encounters and act according to the information their patient is providing them.



Many clinicians use quantitative measurement tools such as surveys, questionnaires, numeric rating scales, etc. to assess patient outcomes. Whilst these tools are an adequate form of clinical assessment, they lack the use of qualitative data such as questions on the lived experiences of a phenomenon (such as pain or fatigue) in daily life or the greater life course. One suggestion to improve patient outcome measures in practice is for numeric rating scales assessing pain and fatigue from 0 to 10 or using a visual analog scale to include qualitative follow-up questions or prompts. Prompts could include “Why did you rate that level of pain/fatigue?” and/or “How does a rating of #\_\_ (ex. 4) differ from a rating of #\_\_ (ex. 7)?” which were questions created and used within the current study’s interview guide. As an example, the former question sought to explore and understand how a specific numeric rating affects or impacts an individual’s life from their perspective; while the latter, was intended for the participant to characterize their rating of pain or fatigue and how they understand the meaning of their symptoms in their own life context. The addition of qualitative questions to patient outcome measures may improve care through the integration of patient perspectives of their lived experiences seeking to include the patient as a partner in their care.

As fatigue may present itself later in the course of MS, PD, or CP, clinicians should be aware and appropriately alter their management strategies if or when their patients present with or verbally indicate fatigue is a challenge for them. Participants suggested that a guide outlining the course of each neurological condition, the possible associated signs, risk factors, and symptoms which may arise as a result of the condition, as well as recommendations for management of their condition would be helpful to be better informed and increase their understanding of their own condition. This type of guide should be created as it would benefit individuals across conditions; however, given how variable the disease courses are person-to-person even within a single condition, development of a formal guide might be difficult, therefore, the onus falls to clinicians involved in the care of these individuals to continually assess and coach their clients through their diagnosis and expectations for symptom management.

The current study illustrates how important it is that patients and clinicians work together to concurrently manage pain and fatigue to improve additional co-morbid

symptoms which accompany these phenomena such as depression or anxiety. Furthermore, awareness between clinicians, the individual experiencing pain and/or fatigue, and the general populace may help to bridge the lack of interplay between external and internal support, as described by Twomey and colleagues (2018); and indicates that medical or alternative treatments in combination with non-pharmacological coping strategies may advance the care individuals receive when experiencing pain and/or fatigue due to neurological conditions.

A group program may help persons with neurological conditions experiencing pain and fatigue to understand the effects and impact these symptoms have on their lives, help to improve awareness surrounding comorbidities, and help them to develop and use coping strategies. For example, a group program where a healthcare professional guides a weekly meeting in a structured or flexible format; and individuals discuss a shared issue (e.g. lacking energy, impaired sleep) or specific personal issues (e.g. brain fog) with the group could prove useful. Furthermore, some sessions could focus on providing individual members of the group with information or teaching them coping strategies relevant to their specific problems and challenges. Group programming is flexible in that it can be used to develop coping strategies for all members of the group across conditions but can also allow for tailored individualized programming that is just delivered in the group setting (as coping strategies can be individual and personal to the individual using them). For example, coping strategies may be presented to members within a group as a menu of choices where individuals can sample and choose which strategies work best for them to cope with their daily pain and fatigue. Persons living with a neurological condition may then have the necessary tools to create their own ‘coping strategies toolbox’ which includes self-tailored coping strategies that they can use to help manage their symptoms as required. Additionally, this menu of choices could reflect the strategies currently being recommended by clinicians for managing clinical pain and fatigue and by presenting it to their patients and providing education on how to properly use these coping strategies in a group setting it would create efficiencies in the healthcare system and free up more time in individual clinical appointments for other concerns.

## 4.2 Research Implications

Future research should continue to use qualitative methods to explore the lived experiences of pain and fatigue within and across these conditions to provide further evidence to support the findings, specifically in the CP population due to the underrepresentation of this population in this study. Researchers may broaden their sights to use different types of phenomenology to study lived experiences across various neurological conditions outside of those studied here. Furthermore, future research may continue to use interpretive phenomenological analysis in analyzing a heterogeneous sample of participants to expand the use of this form of analysis across conditions which may help to further study outside of condition specific silos. Future research may also look at developing an educational intervention on how to develop a specifically tailored menu of coping strategies (or a ‘coping strategies toolbox’) to be used by individuals with neurological conditions experiencing pain and fatigue.

The initial design of the current study intended to also study the lived experiences of pain and fatigue in amyotrophic lateral sclerosis, as previous research showed the possibility of similar experiences shared between this condition and MS, PD, and CP. However, due to challenges with recruitment, no individuals with amyotrophic lateral sclerosis were recruited. Therefore, future research should consider studying the lived experiences of pain and fatigue to further understand and explore the meaning and impact of these symptoms in daily life and the greater life course; as well as the similarities and differences of the experience of these phenomena within and across all neurological disorders.

Further use of the biopsychosocial model in research on pain and fatigue is necessary to understand how the biopsychosocial factors affect and impact individual lived experiences placing value on the patient as a co-constructor in their own care. Future research attempting to understand the differentiation of physical pain and mental and emotional fatigue experiences would be of benefit in understanding the impact these symptoms have on the mind and/or body across conditions. Research that would advance our understanding of the psychological and social aspects which may influence the unpredictability and invisibility of pain and fatigue across conditions is recommended.

Furthermore, further research surrounding whether pain and fatigue are truly invisible symptoms is needed as the current study corroborated the invisibility of pain; however, the findings also contradicted the notion of invisibility as fatigue may have visible characteristics which can be seen by others.

Further study on the lived experiences of pain and fatigue within and across neurological conditions may be done using Participatory Action Research (PAR). PAR is an approach which seeks to be more inclusive of all participants as equal stakeholders in the research process, actively engaging and collaborating with researchers to identify issues of concern within their community to address social transformation (Benjamin-Thomas et al., 2018; Gabel, 2002). This approach is useful in studying lived experiences within neurological conditions as PAR fits within the social model of disability by working to establish discussion between researchers and individuals with a disability to empower the latter (Barnes, 1992). Studying the lived experiences of pain and fatigue within and across neurological conditions using PAR will allow researchers and patients to work together to enact social transformation by empowering the voices and experiences of those who are disabled. Using a PAR approach to study the lived experiences of pain and fatigue may expand our understanding of these phenomena within and across neurological conditions beyond our approach informed by the biopsychosocial model in this study. Furthermore, research may become more relevant and impactful to those experiencing neurological conditions and associated comorbidities through integrating patients lived experiences; with the goal of disseminating this research to clinical practice to raise awareness, consciousness, and inform social change at the meso and macro levels.

### 4.3 Limitations

The online mode of communication may have influenced how patients described their pain and fatigue versus the traditional in-person method, in part due to the limited personal connection between the researcher and the participant. The influence of the mode of communication was mitigated by the researcher working to establish and maintain rapport with participants at the beginning, middle, and end of the interviews to mimic the effect of an in-person meeting as much as possible. Additionally, some

sections of audio recordings were unclear, and were unable to be used. Unclear sections of audio were listened to a minimum of 3 times by the researcher, at different time points, and cross-checked with the live transcription provided by Zoom, to determine if the essence of what the participant was discussing could be summarized if not transcribed verbatim. If the researcher could not translate the audio after 3 listening's, that section of audio was deemed unintelligible and therefore not included in the analysis. One participant with PD was removed from the study entirely by the researcher due to multiple unintelligible sections of their interview's audio recording.

Participants engaged in an interpretive phenomenological analysis are usually taken from a homogenous (e.g. MS), not heterogenous (e.g. MS, PD, and CP) sample (Smith & Osborn, 2008). The decision was made to engage a heterogenous sample as the research question was intentionally exploring the experience of fatigue and pain across neurological conditions. Evidence of similarities between the descriptive nature of these phenomena was provided in the literature review to support the reasoning behind studying three different neurological conditions. Finally, purposive sampling was used as a method of finding individuals with experiences of the symptoms of pain and fatigue within and across these specific neurological conditions who provided relevant descriptions to the research problem being addressed. Purposive sampling was deemed effective for recruitment of participants with MS and PD; however, the author cannot attest to the effectiveness of this sampling method in CP as only one participant was recruited.

Recently, the sample sizes used in IPA studies are becoming increasingly smaller (between 1-3 participants), with student research studies recommending no more than 5 or 6 participants due to the limited time available to undertake these types of qualitative studies (Smith & Osborn, 2008). Larger sample sizes are less commonly used within IPA studies; however, they can provide the opportunity for comparison studies examining similarities and differences of one phenomenon from multiple perspectives. As this study had a sample size of 9 participants, it could be deemed that the study resulted in incongruence of the research methods. Smith and Osborn (2008) noted how sample size is dependent upon the degree of commitment to the analysis and reporting of study

findings, the richness of the participants' narratives, and the constraints the researcher is operating under. To support our chosen sample size, the researcher ensured their commitment to the analysis by reading and re-reading participants transcripts to immerse themselves in the data and accurately reported participants' experiences as discussed in the interview to represent their voice. The richness of participants' narratives was determined by purposive sampling of participants to ensure their experiences of pain and fatigue were relevant to the research aims and questions. The total sample size of 9 participants was decided upon in discussion between the researcher and principal investigator as it was believed the researcher would be able to accurately and reflectively collect and analyze the data from this number of participants given the 2-year time frame provided for this study. Furthermore, given the heterogeneity of the sample across the three conditions, a larger sample size was also deemed congruent with the research questions at hand.

Representation of individuals with CP was limited due to challenges with recruitment which may have resulted in the inability to draw meaningful conclusions of the lived experiences of pain and fatigue in this condition. In order to rectify the difficulties with recruitment of CP participants from the TLC program, the research team was able to recruit from the *CanChild* Centre for Childhood Disability Research which resulted in the one participant included in this study; and may have resulted in further participants wanting to be a part of the study if the time available for recruitment was not constrained to the given time frame for completion of the master's thesis.

The study's inclusion criteria required a formal diagnosis of MS, PD, or CP as communicated by the participant, not based upon a confirmed clinical diagnosis by a neurologist or other specialist. Therefore, there is a possibility of differential diagnoses which the participant may not be aware of and therefore may skew the results of the study relating specifically to these neurological conditions. Only one participant discussed the possibility of having a differential diagnosis as they recently had an MRI at the time of the interview and their neurologist was in the process of reviewing the results. However, after the interview this participant confirmed their diagnosis of PD via email, and no other possible differential diagnoses were brought to the researcher's attention.

Persons with severe cognitive and/or speech impairments were excluded from this study, limiting the generalizability of the study findings to persons with these impairments in the specified neurological conditions. The choice to exclude these people was made because of the online interviewing process. Individuals with cognitive and/or speech impairments may not have been able to participate in an interview without the aid of a caregiver. As the study was looking to provide an in-depth exploration and understanding of the experiences of pain and fatigue as lived by the participant themselves, the researcher made the decision to exclude these individuals to respect the study's aims and reduce the possibility of caregivers providing their interpretations or misinterpretations of participants experiences.

Our study only represents a snapshot of the patients' experiences with pain and fatigue. Therefore, future studies are required to explore the long-term experiences of pain and fatigue in MS, PD, and CP. It is recommended that research continue to explore the lived experiences of pain and fatigue within and across these neurological conditions using a follow-up study where researchers repeat these interviews every, for example, 5 years, to explore how pain and fatigue are impacting these persons at different stages in their life (e.g. improved QoL, worsened symptoms).

#### 4.4 Conclusion

In conclusion, the current study provided insight into the lived experiences of pain and fatigue within and across neurological conditions. The study focused on the lack of understanding and negative perceptions of pain and fatigue, and the coping strategies used to manage these symptoms. Pain and fatigue encompass biopsychosocial factors which negatively affect the daily life and greater life course of persons across conditions. These symptoms have deleterious effects on physical function and mobility, induce negative thoughts and cognitive challenges, heightened emotional responses, and cause social isolation that worsens with increasing symptom severity. Pain and fatigue are constant phenomena that may impair sleep and can cause a lack of physical and mental control over the body, accompanied by a reduced ability to control emotions. People across conditions experience lower mood, reduced joy, and guilt as a result of pain and

fatigue. Overall, pain and fatigue collectively reduce the QoL and overall well-being of persons with MS, PD, and CP.

Pain and fatigue are common, complex, multifaceted symptoms which are physically, psychologically, and socially debilitating. Pain and fatigue are highly personal experiences which should be studied based on the experiences of individuals living with these symptoms in their daily lives. Future research should focus on continuing to use qualitative methods and the biopsychosocial model to explore and understand the impact these factors have on the lived experiences of pain and fatigue within and across neurological conditions, whilst giving voice to patients' in co-constructing their own care. Clinicians and caregivers caring for people with MS, PD, and CP should prioritize the biopsychosocial aspects of pain and fatigue helping to develop a more informed and individualized approach to improve on and advance current management and intervention plans.



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## Appendices

### **Appendix A: Reflexive Journal Entry on Post-Positivist versus Constructivist Paradigm**

Maintaining coherence within an entire research process is no simple task. Once I had determined the appropriate methodological framework to be used within this study, I had to ask myself “So now that you’ve chosen your methodology, does my paradigm align this framework with my views, beliefs and values?”. If anyone had asked me two years ago, I would have said that I aligned with the views of a post-positivist, no questions asked. I can say that I believed that there had to always be an answer to the question, a specific path that was taken to get to that answer. Coming from a background in quantitative research, this was always the case. However, once I began to learn and enhance my knowledge on paradigmatic positions, I quickly realized that there is no one true reality, no set ways to think or go about acting and living in the world. This led me to adopting a constructivist paradigm. A constructivist paradigm allows for an open and creative interpretation of experiences as they are perceived through the eyes of those who live through those moments. This allows the researcher the leisure of not having to control every aspect of the research process. Rather, focus can be placed on the experiences of the participants, with the role of the researcher becoming more of a guiding hand and equal partner, then a figure of power.

## Appendix B: Letter of Information and Consent for Research Participants



### Letter of Information and Consent (Research Participant)

**Title of Study:** Conceptualizing the lived experiences of pain and fatigue in persons living with neurological conditions

**Investigators:** Laura Brunton, PT, PhD, Assistant Professor, School of Physical Therapy, Faculty of Health Sciences, Western University

Lauren Kane, MSc Candidate Health and Rehabilitation Sciences Graduate Program, Faculty of Health Sciences, Western University

Janelle Unger, PT, PhD, Assistant Professor, School of Physical Therapy, Faculty of Health Sciences, Western University

David Walton, PhD, Associate Professor, School of Physical Therapy, Faculty of Health Sciences, Western University

#### Background

Pain and fatigue have been reported as the most common and disabling non-motor symptoms in adults living with multiple sclerosis (MS), amyotrophic lateral sclerosis (ALS), cerebral palsy (CP), and Parkinson's disease (PD). People with pain and/or fatigue can have impaired functional and cognitive abilities, a reduced quality of life (QoL), and poorer overall well-being. Although the functional changes that occur as a result of the disease and the disease course of MS, ALS, CP, and PD are different, similarities between descriptions of pain and fatigue suggest that there may be benefits to studying these symptoms across conditions. This will be the first study to provide an in-depth understanding of the experiential accounts of pain and fatigue across conditions in adulthood to provide support for the development of a treatment to prevent and manage these symptoms.

#### Purpose

You are being invited to participate in this research study because:

- you are 18 years of age or older
- you have a confirmed diagnosis of one of the following conditions:
  - Multiple sclerosis
  - Amyotrophic lateral sclerosis
  - Cerebral palsy
  - Parkinson's disease
- you are experiencing pain and/or fatigue as a symptom of MS, ALS, CP, or PD

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Study Title: The lived experiences of pain and fatigue in persons living with neurological conditions  
 PI: Laura Brunton  
 Version number/date: V3/11/23/2021

Participant Initials:





To participate in this study, you must also:

- Be able to read, write, and speak in English
- Have access to an electronic device (computer, phone, tablet, etc.)

Up to 12 adults will participate in this study.

### Requirements for Participation

If you agree to participate in this study, you will partake in one interview using a semi-structured interview guide. The interview will consist of open-ended questions and follow-up prompts being asked on the topics of the biological, psychological, and social factors that may influence your lived experiences with pain and fatigue. You will be provided with a copy of the interview guide via email prior to your scheduled interview to reflect upon the experiences you intend to share or deem most relevant in response to the pre-determined questions and prompts. The interview will last about 1 hour and will be audio-recorded and transcribed. Shortly after your interview, the researcher will provide you with a detailed copy of your data and her analysis to reflect upon and ensure that the researcher's interpretations are consistent with the experiences you discussed in your interview. The researcher will make changes to the data based on your reflections. All interviews and member reflections will take place via Western University's Corporate Zoom (for individuals with MS, ALS, and PD) and Webex (for individuals with CP) to protect the privacy and confidentiality of participants.

### Audio-recording and Live Transcription Permission

The study team is requesting permission to audio-record and use the Live Transcription features throughout your interview to capture study data. The Live Transcription feature takes all audio and speech from a meeting and puts it into text format for everyone to see during the interview. A copy of this text and any audio recorded during the interview will be kept on a secure network drive after the interview is done. Please check one of the below options to indicate your consent to allow the study team to use these features during your interview:

- I provide consent to *both* being audio-recorded and for the Live Transcription feature to be enabled during my interview.
- I provide consent to *only* be audio-recorded during my interview.
- I provide consent to *only* have the Live Transcription feature enabled during my interview.

### Goals of the Study

The primary goal of this study is to develop an understanding of the symptoms of pain and fatigue through the lived experiences of persons living with MS, ALS, CP, and PD. We are



looking to explore the accounts of pain and fatigue within and across conditions and determine if the descriptions of these symptoms differ from one another.

#### **Risks and Harms of Participating**

There is a potential risk that you may become emotionally upset or distressed due to the nature of the interview questions and discussion of your experiences of pain and fatigue. In an attempt to reduce this risk, you may pause or take a break at any point throughout the interview. If the upset or distress is too great, you may stop the interview and choose if you wish to have the interview rescheduled for another date. Additionally, we are collecting and storing personal information online (full name, email address, and telephone number) and descriptive information (sex, gender, and age) and therefore, there is always a risk of a breach in privacy associated with online data storage. We will use best practices to protect your privacy including password-protected files on a secure network service and limiting the amount of people who can see your personal information.

#### **Benefits to Participating**

There are no direct benefits to you from participating in this study. However, the knowledge gained from this study may help develop an increased understanding of the personal impact these symptoms have in the daily lives and life course of patients. In turn, this may enhance current healthcare practices for managing pain and fatigue and improve functional ability, quality of life, and overall well-being in adulthood. This information may provide guidance on effective management strategies and help create treatment strategies to be used by healthcare providers.

Participation in this study is completely voluntary. You may choose not to participate in the study, refuse to answer any questions, or withdraw from the study at any time by contacting the study team, with no effect on your care or relationship with the organization that told you about the study. If interested in participating in this study, please sign the consent form and return it to the study team by uploading the file to the shared OneDrive folder sent to you by the study investigators.

#### **Confidentiality/Privacy**

Your confidentiality will be respected. Your consent forms and online data will be password protected and stored on a secure network drive at Western University. Only those individuals listed as investigators will be able to access all information and files on the network drive. Neither your name nor any additional identifying information (age, gender, sex, diagnosis, email address, and telephone number) will be used when publishing the findings of this study, you will be assigned a study ID number and nickname for all data collection. All collected data will be destroyed after 15 years.

Representatives from the Western University Health Sciences Research Ethics Board may contact you or require access to your study-related records to monitor the conduct of the

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Study Title: The lived experiences of pain and fatigue in persons living with neurological conditions

PI: Laura Brunton

Version number/date: V3/11/23/2021

Participant Initials:



research. In addition, authorized representatives from Lawson's Quality Assurance and Education (QAEP) team may look at your identifiable research records held at Western University for quality assurance purposes. By signing this form you are authorizing such access.

If you have any questions about this study, please contact Dr. Laura Brunton at  or by email at

If you have any questions about your rights as a research participant or the conduct of the study, you may contact The Office of Research Ethics at Western University at (519) 661-3036 or by email at [ethics@uwo.ca](mailto:ethics@uwo.ca)

You do not waive any legal rights by signing this consent form. You may return it to Dr. Laura Brunton at  or graduate student Lauren Kane at  by uploading the file to the shared OneDrive folder sent to you by the study investigators; note that email is not a secure method of data transfer.

**This letter is for you to keep.**

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Study Title: The lived experiences of pain and fatigue in persons living with neurological conditions  
 PI: Laura Brunton  
 Version number/date: V3/11/23/2021

Participant Initials:



**Consent Form (Research Participant)**

**Title of Study:** Conceptualizing the lived experiences of pain and fatigue in persons living with neurological conditions

**Investigators:** Laura Brunton, PT, PhD, Assistant Professor, School of Physical Therapy, Faculty of Health Sciences, Western University

Lauren Kane, MSc Candidate Health and Rehabilitation Sciences Graduate Program, Faculty of Health Sciences, Western University

Janelle Unger, PT, PhD, Assistant Professor, School of Physical Therapy, Faculty of Health Sciences, Western University

David Walton, PhD, Associate Professor, School of Physical Therapy, Faculty of Health Sciences, Western University

I have read the Letter of Information and Consent, have had the nature of the study explained to me and I agree to participate. All questions have been answered to my satisfaction.

|                                    |                          |      |
|------------------------------------|--------------------------|------|
|                                    |                          |      |
| Name of Participant (Please Print) | Signature of Participant | Date |

I have explained to the person named above the nature of the study, answered all questions they had and obtained their consent for participation in this study. They will be provided with a copy of this signed and dated informed consent form.

|                           |      |
|---------------------------|------|
|                           |      |
| Signature of Investigator | Date |

## Appendix C: Interview Guide for Research Participants

Thank you for meeting me today and participating in this study. Please note that at any time during the interview you may pause to reply to or skip any questions. Once you feel comfortable and ready to start the interview, I will begin the audio-recording and enable the live transcription feature [only if consented to on the letter of information signed by the participant] and will stop upon completion of the interview. Should you choose to turn on your camera at this time, please note that a video recording will also take place and will be deleted immediately upon completion of the interview.

### Demographics Questions

1. What is your age? \_\_\_\_\_ [Age criterion met (18+): \_\_\_\_ Yes  
\_\_\_\_ No]
2. What is your sex? \_\_\_\_\_ Male \_\_\_\_\_ Female  
\_\_\_\_\_
3. What is your gender? \_\_\_\_\_
4. Formal diagnosis of MS? \_\_\_\_ Yes \_\_\_\_ No [MS criterion met: \_\_\_\_\_  
Yes \_\_\_\_ No]
5. Formal diagnosis of ALS? \_\_\_\_ Yes \_\_\_\_ No [ALS criterion met:  
\_\_\_\_ Yes \_\_\_\_ No]
6. Formal diagnosis of CP? \_\_\_\_ Yes \_\_\_\_ No [CP criterion met: \_\_\_\_\_  
Yes \_\_\_\_ No]
7. Formal diagnosis of PD? \_\_\_\_ Yes \_\_\_\_ No [PD criterion met: \_\_\_\_\_  
Yes \_\_\_\_ No]
8. How long have you been diagnosed with [MS, ALS, CP, or PD]?

### Questions for Pain

1. Tell me about your experience of pain.
  - a. How does that make you feel?
  - b. How did you make sense of that experience?
2. When did you start experiencing pain in relation to your diagnosis?
3. **For CP patients only:** When did you feel the pain started?
4. Please describe a situation where you experienced pain.
  - a. What were you thinking and/or feeling when that was happening?
  - b. What were you thinking and/or feeling after that happened?
  - c. What do you think others think or feel while you are experiencing pain?
5. When was the last time you experienced pain?
6. What does pain mean to you?
7. How would you describe pain as different from someone who doesn't have [MS, ALS, CP, or PD]?
  - a. From that description, how is your pain different?
8. On a scale of 0-10, rate your level of pain (0 = no pain, 10 = very severe pain)

- a. Why did you rate that level of pain?
- b. How does a rating of # \_\_\_\_\_ differ from a rating of # \_\_\_\_\_?
  - i. This question is asking, for example, if you were to rate your level of pain as a 4, how does this pain level differ from a level 6? How would you explain/describe the differences in ratings?
9. In your own words, can you tell me what pain means to you?
10. How do you define pain?
11. Is there anything else you would like to shared about pain and your experience?

### Questions for Fatigue

1. Tell me about your experience of fatigue.
  - a. How does that make you feel?
  - b. How did you make sense of that experience?
2. When did you start experiencing fatigue in relation to your diagnosis?
3. **For CP patients only:** When did you feel the fatigue started?
4. Please describe a situation where you experienced fatigue.
  - a. What were you thinking and/or feeling *when* that was happening?
  - b. What were you thinking and/or feeling *after* that happened?
  - c. What do you think others think or feel while you are experiencing fatigue?
5. When was the last time you experienced fatigue?
6. What does fatigue mean to you?
7. How would you describe fatigue as different from someone who doesn't have [MS, ALS, CP, or PD]?
  - a. From that description, how is your fatigue different?
8. On a scale of 0-10, rate your level of fatigue (0 = no fatigue, 10 = very severe fatigue)
  - a. Why did you rate that level of fatigue?
  - b. How does a rating of # \_\_\_\_\_ differ from rating of # \_\_\_\_\_?
    - i. This question is asking, for example, if you were to rate your level of fatigue as a 4, how does this fatigue level differ from a level 6? How would you explain/describe the differences in ratings?
9. In your own words, can you tell me what fatigue means to you?
10. How do you define fatigue?
11. Is there anything else you would like to share about fatigue and your experience?

### Questions for Pain and Fatigue

1. How are pain and fatigue the same?
2. How are pain and fatigue different?
3. How do you know you're experiencing one or the other?



## Appendix D: Health Science Research Ethics Review Board (REB) Approval



**Date:** 7 January 2022

**To:** Dr. Laura Brunton

**Project ID:** 119499

**Study Title:** Conceptualizing the lived experiences of pain and fatigue in persons living with neurological conditions

**Application Type:** HSREB Initial Application

**Review Type:** Delegated

**Full Board Reporting Date:** 26/January/2022

**Date Approval Issued:** 07/Jan/2022 07:09

**REB Approval Expiry Date:** 07/Jan/2023

Dear Dr. Laura Brunton

The Western University Health Science Research Ethics Board (HSREB) has reviewed and approved the above mentioned study as described in the WREM application form, as of the HSREB Initial Approval Date noted above. This research study is to be conducted by the investigator noted above. **All other required institutional approvals and mandated training must also be obtained prior to the conduct of the study.**

**Documents Approved:**

| Document Name  | Document Type          | Document Date | Document Version |
|--|------------------------|---------------|------------------|
| Telephone Script   | Telephone Script       | 15/Jul/2021   | 1                |
| Consent form for Research Participant V1 August 1 2021               | Written Consent/Assent | 01/Aug/2021   | 1                |
| Recruitment Poster V2-10-07-2021                                     | Recruitment Materials  | 07/Oct/2021   | 2                |
| Email Recruitment Script for Circle of Care Collaborator             | Email Script           | 08/Oct/2021   | 1                |
| Interview Guide for Research Participants V3-10-21-2021              | Interview Guide        | 21/Oct/2021   | 3                |
| Interview Guide for Researcher V3-10-21-2021                         | Interview Guide        | 21/Oct/2021   | 3                |
| Protocol - Pain and Fatigue in Neurological Conditions V3-12-02-2021 | Protocol               | 02/Dec/2021   | 3                |
| Email Recruitment Script V3-12-01-2021                               | Email Script           | 01/Dec/2021   | 3                |
| Telephone Script V3-12-01-2021                                       | Telephone Script       | 01/Dec/2021   | 3                |
| Fillable_ Consent form for Research Participant V3 November 23 2021  | Written Consent/Assent | 23/Nov/2021   | 3                |

No deviations from, or changes to, the protocol or WREM application should be initiated without prior written approval of an appropriate amendment from Western HSREB, except when necessary to eliminate immediate hazard(s) to study participants or when the change(s) involves only administrative or logistical aspects of the trial.

REB members involved in the research project do not participate in the review, discussion or decision.

The Western University HSREB operates in compliance with, and is constituted in accordance with, the requirements of the TriCouncil Policy Statement: Ethical

Please do not hesitate to contact us if you have any questions. Sincerely,

Ms. Nicola Geoghegan-Morphet, Ethics Officer on behalf of Dr. Philip Jones, HSREB Chair

*Note: This correspondence includes an electronic signature (validation and approval via an online system that is compliant with all regulations).*

## Appendix E: Lawson Health Research Institute Ethics Approval



### LAWSON FINAL APPROVAL NOTICE

**LAWSON APPROVAL NUMBER: R-22-007**

PROJECT TITLE: Conceptualizing the lived experiences of pain and fatigue in persons living with neurological conditions

PRINCIPAL INVESTIGATOR: Laura Brunton

LAWSON APPROVAL DATE: 7/01/2022

ReDA ID: 11187

Overall Study Status: Active

Please be advised that the above project was reviewed by Lawson Administration and the project was approved.

**“COVID-19: Please note that Lawson is continuing to review and approve research studies. However, this does not mean the study can be implemented during the COVID-19 pandemic. Principal Investigators, in consultation with their program leader or Chair/Chief, should use their judgment and consult Lawson’s research directive and guidelines to determine the appropriateness of starting the study. Compliance with hospital, Lawson, and government public health directives and participant and research team safety supersede Lawson Approval.”**

**Please provide your Lawson Approval Number (R#) to the appropriate contact(s) in supporting departments (eg. Lab Services, Diagnostic Imaging, etc.) to inform them that your study is starting. The Lawson Approval Number must be provided each time services are requested.**

**Dr. David Hill  
V.P. Research  
Lawson Health Research Institute**



**Appendix F: Overview of themes and inherent typological structures of meanings of MS-related, PD-related, and CP-related pain and fatigue with quotations from the raw data**

|  |
|--|
| <b>LACK OF UNDERSTANDING</b>   |
| <b>By Others</b>   |
| <p><i>They try to marginalize it as a way of being positive. That's all it does, is it marginalizes the effort. That's why it's called toxic positivity because it's positivity at the cost of reality. [PF008]</i></p> <p><i>One wouldn't know or understand, and I would never have understood what it was until I was in it. [PF005]</i></p> <p><i>But if you look at me and if the pain parts were a different color, you would see that, okay, I have pain in certain parts of my body. [PF001]</i></p> <p><i>I think some people are confused because I don't look like I'm always in pain. So, when I say that I'm having a really bad pain day cause I'm upfront about it, they don't always... it's not they don't believe me, they just don't realize what I mean, and I think a lot of that has to do with just how society handles pain and handles disability as a whole. [PF009]</i></p> |
| <b>By Clinicians</b>   |
| <p><i>I kind of feel like a lab rat with my neurologist to tell you the truth. Like I feel like I, you know, I fit in this category, let's try this medication, it's not working. Okay, let's try this. You know? So, I'm more of a character study for my neurologist. [PF001]</i></p> <p><i>Especially again with the physical pain, when you have a neurologist, who again I know their job isn't to like console me, their job is to, you know, say "I gotta take care of the disease, not you as a whole." [PF001]</i></p> <p><i>Like the doctors try to explain to you and I told my neurologist, "You have MS patients, you don't have MS. Don't ever tell me how I'm supposed to feel or what I'm capable of doing." [PF002]</i></p>   |
| <b>By the Patient Themselves</b>   |
| <p><i>Well, I go back to making sense of having Parkinson's and there's no sense in it. It's kind of like you think why me? And it has to be somebody I guess and there's no really understanding where it comes from, like who gets it, doesn't get it. Why do some people have some things more severe than others? [PF006]</i></p> <p><i>... "why am I in pain?" You know. "Who's done this to me? Why am I like this?" Those sorts of negative thinking. [PF008]</i></p> <p><i>That I wish that I knew why my body does what it does. [PF009]</i></p>  |

*Um, I can't tell you about pain that I know for sure is related to Parkinson's. I could just tell you about pain that I get. It's not any different from pain that I had before. [PF003]*

## **NEGATIVE PERCEPTIONS**

### **Fatigue as a spectrum**

**A lack of energy:** *So, for example, for some people sharing takes 3 spoons. So now you've only got 2 more spoons to use for the rest of the day to do other things. [PF009]*

*I prescribe more to the battery theory in terms of I go to sleep, I charge up my body, I charge up my energy. [PF009]*

*You have to define it [fatigue] by an absence. It's an absence of energy. Its absence of all kinds of energy. So, it's not just the energy to go out on your own, but to get the energy to socialize with friends, it's the energy you need to cook a dinner. [PF006]*

**Fatigue distinct from tiredness:** *The difficulty to know is, again, how much is fatigue from Parkinson's and how much is fatigue because you just went four kilometers. [PF006]*

**Fatigue as extreme tiredness:** *I know when I'm experiencing fatigue because it's sort of like this meaningless, meaningless tiredness, that is, you know, it's really nothing, but you still feel tired, want to do nothing, and feel negative. [PF003]*

*... like a comparison of like a theater curtain. It's [fatigue] that heavy curtain it's just coming down and coming down and like, there's nothing you can do to stop it. It's just going to close and it's like a veil of tiredness right. [PF004]*

*Fatigue to me just means being so tired that... being fatigued means being tired period. I mean that's the denotative meaning of it, and that's how I think of fatigue. The fatigue I've got it means being tired enough that it's hard to do something, like to do something I normally do. [PF005]*

*... my brain needs to stop hearing things. Like sound becomes irritating and annoying and overwhelming, and sensory things become overwhelming when you're that tired... [PF004]*

**Exhaustion:** *You go to sleep exhausted; you wake up exhausted. You live your life through the day exhausted; and at times you can't even get a statement out or have a conversation with somebody. [PF002]*

*It [fatigue] hits you. You'll sleep for 10 hours, you get up and you're even more exhausted. You run a 25 kilometer marathon, and then start your day, and then run another 25 marathon. [PF002]*

*It's [fatigue] like a mental exhaustion, state of mental exhaustion... and it's very different than mental exhaustion I have had before. [PF005]*

## **Losing yourself**

**Negativity:** *So, when I was diagnosed, I was like Annette Funicello, she's an actress. Now she can't talk, she can't walk. That's me. That's all you know, that was my focus. That's me, my life is over, you know. [PF001]*

*And now I guess I realize there's some things that can't be fixed or they can only be fixed temporarily because that's Parkinson's, it's like this big slow monster moving along that gobbles up everybody in its way, but you've got plenty of time to watch it coming. [PF006]*

*... it's got a mind of its own and you have to succumb to it... it's a thief. Robs your life. [PF004]*

*If I'm too negative, and that does happen, I mean I wouldn't classify myself as a negative person. I think I'm really positive but there are times when I'm down and in those moments my pain often increases. [PF008]*

**All-encompassing:** *It is different. It's a different kind of fatigue. Parkinson's fatigue it saps your soul. It sort of pulls you out of yourself. [PF006]*

*Fatigue becomes almost like a full body starting with my brain... and then it's just, it's all encompassing. [PF001]*

*It's [pain] more the spasticity, it's more when my whole body responds. [PF009]*

*If you could see inside of me, you wouldn't have the same impressions... There's a lot of our members who you know they'll walk with a limp or things like that, but they're experiencing a lot of internal uproar. [PF002]*

*It's kind of like an ice or a heat pick being driven up through my heel into my calf as far as my knee or my hip. [PF008]*

*I literally compare it [muscle spasm pain] to like a fist, and then letting go is how I compare the pain... it's almost like my muscles are squeezing themselves. [PF009]*

**Limiting:** *Pain to me is a restriction of a healthy lifestyle... It's not a wall, because you can go around walls, you can go through walls. It's a restriction that, you're handcuffed to the pain. No keys to take off your handcuffs. [PF002]*

*Not to be able to experience the same things that your family's experiencing or get the same amount of joy out of it, because you're fighting the demons inside of you. [PF002]*

*So, I've always done the cleaning in my relationship with my wife from the very beginning, and I enjoy that because it puts order in my life. But that's become*

*challenging at best. I used to be able to clean the house on a weekend. Now it takes all week mostly. [PF008]*

**Before and after:** *It was the me before fatigue and the me after fatigue. [PF006]*

*I think fatigue then [before MS] was self-induced. Fatigue now is not self-induced. [PF007]*

*So that's the cost [losing a night's sleep to pain]. So, I don't feel always very good about going into that [cleaning task] and discouraged at times when I can't do what I normally could do. [PF008]*

**Feeling lesser:** *I'm not functioning as a human being. You don't function as a human being. You function as like a broken-down car that's got a couple months left; and it may have 4 flat tires, you can still drive it, but you know you may be burning oil, and you got black smoke coming out of the tail pipe but you're still moving. [PF002]*

**Lack of control:** *Honestly, I just feel very flighty. Like not in control, like everything just feels so much bigger and worse than it actually is. [PF001]*

*Like my wife will often take note of when I'm in pain; and she's not cold and not concerned, she makes note of it. But she doesn't comment on it unless I say, "I'm out of control, and I need help." [PF008]*

**Lack of muscle strength:** *The physical fatigue now... I don't know whether to characterize it as a fatigue, or it's just a loss of muscle strength. [PF005]*

*My pain is mainly on my left side because it's my weaker side, so I have no strength. [PF007]*

**Dependence:** *... the things where I need their [other people] help more like opening a jar of jam or like cutting something or drawing a knife... Things that I try not to do cause my right hand doesn't work so amazing. Or like pouring hot water, then I'll show my vulnerability more because I have to. [PF004]*

### **Dealing with change**

**Worrying:** *Fatigue, you think it feels like it's going to go on forever like this. It doesn't, you know. I know intellectually that I'm going to get better, that I'll get some energy again. But that's sort of like this little reptilian brain at the back of your head saying, "no you won't you're going to be like this forever." [PF006]*

**Hiding:** *... so, they're not really aware of my pain. I don't think I really share my pain that much with people. [PF001]*

*... when I'm with others I try to be outgoing, I try to be upbeat, try to not let that [fatigue] show. [PF003]*

*I don't always complain or whine how much I'm in pain because it's just like I look at it's part of life now. So, I hide a lot of it. I don't let a lot of it show. [PF007]*

**Pushing through:** *You know it's like a racehorse. They got the blinders on, so you don't know what's coming, what's going. You just got to go ahead and do it, and that's all I think about. You know survival is every day, 24/7 and I can't waste my energy on that. I got to spend my energy on what I can do and what I still have to do. [PF002]*

*I really, really try to not so much fight it [fatigue] but live with it; and, you know, continue to push through it and be active, and you know as sociable as I can because those are good things, and they make me feel better. [PF003]*

*So, I gotta keep living my life. I can't always let pain do it for me. [PF009]*

*So, the first few times when we visited and I said I had to go he [son] was like "no, no, stay, stay, stay." So, I was kind of pushing myself and then I realized I can't. Not doing him a favor or me a favor. [PF004]*

#### **Nature of phenomena**

**Constant:** *So I'm constantly in pain and I've been that way. I think maybe as a kid, I think I had painless days... But since at least since I was in college just starting at age 18, I don't remember not being in pain. [PF009]*

*Since the inception [of pain] my entire left side has been numb, but my right side... I do have severe pain in my legs, in my right leg, and also on both shoulder blades, constant pain and its excruciating... It's extremely uncomfortable and very aggravating. It's a constant non-seizing up pain. It's just constant. [PF002]*

*Because fatigue feels like it's almost a cop out word... Fatigue... Something is strong but there's little cracks that are going in it, right. In this thing that's really, really strong and the little cracks are kind of making it crumble a little bit. So, that to me is what fatigue looks like it's just small little pokes that slow you down. [PF001]*

*So how I process the world is very much fatiguing in general, because... So, for me, fatigue and my level of fatigue is very much based off of how much stimulus I can deal with. How much extra work I can put in or not put in. How much navigating of the world I have to do in order to live. So, I'm constantly fatigued. [PF009]*

**Unpredictable:** *So, it's like getting a shortage in your electrical outlets, you see the zapping, that's MS. So, it can happen any time during the day, if you're working, if you're resting. Even if you're just you know, watching TV. You, your body decides to short circuit, that's when you get it [pain]. [PF002]*

*I try to arrange my life so I wouldn't get like that [fatigued], but you don't know how it's going to be, one day you wake up in the morning and the world is wonderful, and the next morning you wake up, you don't want to get out of bed. [PF006]*

*You know those are my targeted times to make sure that I'm paying attention to what's going on with my fatigue; and that's different, because my pain can come out of nowhere anytime, and what... I shouldn't say that my pain is always there, but it can spike at unexpected times. Something seemingly random sometimes. [PF008]*

**Heaviness:** *I think that's to me what I liken to fatigue, like my physical fatigue, just heaviness in the body... Like, I'm sitting on the floor here, my legs feel heavy, and they're being supported by the floor, but they feel heavy. Does that make sense, right? Like how can they feel heavy? I'm not holding them. The floor is holding them up, but they feel heavy. [PF001]*

*Oh, I feel, thank goodness it's [fatigue] gone. Thank goodness I feel brighter, I feel lighter. [PF003]*

**Time-consuming:** *So, I always say I can start the race, takes me a little bit longer to finish it, but I'll get there. [PF007]*

*The amount of time and effort exerted in dealing with Parkinson's disease is huge; and I don't know how huge. It's probably just as huge with the other disabilities or the other illnesses, but that's something else that, it's an immense drain physically, mentally, emotionally. [PF008]*

**Intense:** *This pain can sometimes be so intense that it takes my breath away. Literally, where it'll make me gasp, or it'll make me throw up, or it'll make me scream and I mean I don't, I sort of yell from time to time when it takes me by surprise, and it causes me to throw up. Sometimes it gives me a massive headache. Sometimes it drops me to my knees. [PF008]*

**Progressive:** *I experience physical fatigue for sure, and I've started to experience it more worryingly in the last couple of months. My symptoms alone have deteriorated in the last couple of months [PF005]*

*But in terms of like pain as I got older... I'm having more muscle spasms, or I'm twisting over my ankles more or I'm having days where I have to medicate with medication to help or I've now had to go on medication for spasms. [PF009]*

#### **Associated factors**

**Cognitive challenges:** *... I get my energy from being in small groups, and that's fine. But it's sort of, I liken it to being in like a stadium of people and... it's overwhelming. It causes challenges with focus, the ability to function thoughtfully or reflectively or logically, is sometimes impaired... So that's how I sort of, I wish it would stop but it's more like that crowded room. [PF008]*

*... but when I'm fatigued, I know I've said the word stupid, but again I feel like I'm just, you know, I'm a baby just learning how to crawl, or walk and find words even sometimes you know. [PF001]*

*I call it sort of hitting the proverbial staying focused, alert, and awake wall. Because what suffers is my concentration, my ability to stay focused, my ability to tune in to all those things, go down the toilet. [PF008]*

*It's like you're having a conversation with 20 people at the same time. How much can you, you know absorb? Maybe one, maybe two at the most, but you still got all these other things going on in your head that doesn't make sense. [PF002]*

**Impaired sleep:** *And first bedtime lasts somewhere between an hour and an hour and a half, and that might be the only sleep I get that night... Because my pain then wakes me up and then I'm pacing a good deal of the rest of the night. Which involves you know, pacing until I fall asleep on my feet sometimes, which is never good. So, I have to be careful where I go at night... I've fallen into furniture... onto the floor and into a wall... I went through a wall once. [PF008]*

*At night often I have difficulty falling asleep, and it's not because my body isn't ready to sleep, it's because my brain won't shut down. So, my thoughts and everything I'm thinking about are rapid firing still, but my body is ready for bed. My body is ready for sleep. So, that right there tells me I have energy. It's just my body doesn't have the energy. [PF009]*

**Anxiety and depression:** *Like when am I going to start feeling better? When can I finally go out? Go for a walk without having to stop because your legs are spasming or your shoulder is like, am I having a heart attack because the pain across my chest is so bad I can't breathe? When is it gonna end? So, you know the depression starts, your anxiety goes up, the pains still there. [PF002]*

*It [fatigue] takes away joy. [PF003]*

**Weather:** *So, if it's too hot I can't sleep. I don't sleep well. I'll wake up and I'm crabby and tired, and then the weather outside if it's damp, if it rains, or get super cold that affects me. So yeah, I know everyone laughs at me with the barometric pressure. I'm like no I know when it's gonna come cause my body feels it. [PF007]*

#### **Other experiential accounts**

**Something that you feel:** *So, this morning I was doing work and I was working on a document, and I could feel myself like not dotting the I's and crossing the T's properly and I thought it's almost time to... my editing skills right now are not good. Like, I'm missing things, it's time to stop working... Like so you can feel it [fogginess, fatigue], like you can really feel it. [PF004]*

*... when you have MS, you have to be like your own like diagnostic, you know, beacon or whatever because no one else is going to see. It's invisible. So much of it you have to feel it [pain], you know. [PF004]*

*You don't have to say why this is pain. You know it's pain because you feel it. [PF005]*

**Fatal:** *It's tough. A lot of them wish they could just take their lives. It's heartbreaking to see that but you can't talk them out of it, and I've seen people trying to talk them out of it, and it's just, you can't talk them out of it, you're not walking in their shoes. Okay, you can express your opinion, you may be against MAiD, you may be against suicide but it's none of your damn business, because you're not living what they're living. [PF002]*

## **COPING STRATEGIES**

### **Main strategies**

**Support:** *I think it helps that I have a great team. I have a great friend support system. [PF007]*

*I had a friend who also has cerebral palsy, but his symptoms exhibit differently. He's like "you put your heart and soul into everything you do. I hope to goodness that on your days off you don't leave your bed unless you have to." [PF009]*

*... it's like you're seeing your child winning a spelling bee or winning a race, or seeing them with their friends and you're getting enjoyment out of it because your part of their lives. Well, our members are... It's our second family, and it's the only family that truly understands it because they live what you live. They've experienced what you're experiencing. [PF002]*

**Rest to renew:** *It's [rest] up there with eating and bathing and like your nighttime sleep, is that one o'clock sleep and five o'clock [rest periods]. [PF004]*

*It's when your body is telling you to rest and shut down and recuperate, and let it regenerate. Whereas before fatigue - but before MS - fatigue was annoying. Whereas now, I know it's telling me that my body needs to regenerate. It's used up all its energy that it's had for the day and needs to get it back. [PF007]*

**Acceptance:** *You just had the crappy draw of the cards and you're dealt with it, and you got to deal with it. [PF002]*

*I have the attitude, you know, that I got thrown this curveball, I'll deal with this curveball. I'll still do my life. [PF007]*

*The quantity rather than quality I think. I think it's just that I have a lot more fatigue.... Everyone has fatigue. Everybody I know has fatigue. I just have more of it, that's all. [PF003]*

*Well I've had pain all my life off and on as everyone does; everyone has pain sometimes. [PF005]*

*I guess it's just, it is part of being normal, everybody experiences pain from time to time. [PF006]*

*To the point where I've had doctors go, "So explain your pain scale." I'm like "what pain scale do you want? Mine or yours?"... If I'm using your regular 1 to 10, mine's*



*like off your chart... Right? Because my one is like non-existent like I don't know what one feels like on the chart... Like my one is I'm a functional human being. I can go up and downstairs. I'm not tripping over my feet, like that's a one, or even like a 3, depending on the day. [PF009]*

**Accommodating:** *Well, it's a warning... you shouldn't really work through pain. You should figure out what's happening, and turn down your activities to try and accommodate it. That's not always easy. [PF006]*

*So, if I do something I really have a mindset to do it and just focus like you know there is an end in sight, and I do it. [PF007]*

*Because I don't take naps during the day on purpose to try to enhance my sleep hygiene. [PF008]*

*A lot of my coping strategies are more like accommodations. So, for example, my niece knows on a bad day that I'm likely not going to chase her around the house or run around a lot, but that there's other ways to play. We can read books, I will do crafts, I'll engage with her in different ways. She's learned that there are certain times of day that I do better than others. I tend to be better in the mornings before noon usually. [PF009]*

*So like yes I would love more people to know or see or not, you know, make assumptions or whatever but like I'm sure I'm guilty of so many of them that I don't even know about, you know. That I don't even know I'm doing it or that it's happening because I make, we all make assumptions, you know. Right, like that's human. [PF004]*

*So, pain is supposed to be a warning system for your body, but it's not in my case... Well, I can't step onto hot pavement or hot sand when bare feet, cause I'll burn my foot and I won't know... the pain will register differently like less, so I don't know necessarily if my foot's burning... Or conversely being frozen. I walk outside to get stuff in the winter in my bare feet, and it drives my wife mad. [PF008]*

**Positivity:** *Just simple things like "this is going to be a good day," you know, "come on, get up, move around, go get your breakfast, make a pot of coffee." Approaching the day with working on doing it with that... I have to tell you it doesn't come naturally some days, you know, you don't feel like that. You get up and you're slow to get around... But usually that's how I work on it. [PF003]*

*I don't regret the fact that I happen to have these things. They shape who you are and often make you a better person. [PF008]*

*So, dealing with it [pain], I either have to compartmentalize it, in essence sending it to a different room in my party house to fuss on their own; and you know, whatever they do in that room is whatever they do in that room, and I just try to, you know compartmentalize it off in that direction. [PF008]*

*Humor is huge in my life. I like to be funny. I like to laugh. I like to, well I don't like to be funny I just seem to make people laugh a lot more... I enjoy making people laugh. So, humor is important. [PF008]*

*I'm not against being positive but it also needs to be real... So, I've been learning to improve my own personal self-talk. Learning how to meditate, which has been very useful. [PF008]*

**Pain management:** *I feel like we also are taught to run away from pain, which we shouldn't. We should learn how to manage it. [PF001]*

*I feel like moving in water... you're like a newborn baby in the embryotic sac and you're free. There's nothing... I feel nothing. [PF001]*

*Knowing that the treatments are imperfect, in terms of targeting pain, and it's often a cocktail of treatments that you need to work on your specific pain environment or your pain landscape. [PF008]*

*Coping strategies is also knowing when to take the medication. [PF009]*

*It's [steroids] difficult and hard on your system and hard on your aura, for me it is. It's in a lot of people it makes you like worse coping skills, and it makes you hyper and like hard to sleep at night. So, there was lots of big decisions to make and that I had to make myself. [PF004]*

**Planning:** *That I have to say, "whoa, whoa, whoa" like I need to build in a time where I'm lying down from 5 to 5:30. Still have time to freshen up and get dressed and ready, and I can't meet you guys until 7 or 6:30 or and then on the back end of that I also can't stay up late. [PF004]*

*Yeah, it's a bit of a tightrope, but that's okay. It's all about having a goal and trying to get to it. [PF008]*

*On the weekends I would cook big batches of pasta or cook up something in the crockpot that I could freeze in portions. So that through the week, when I had no energy, I could just thaw, grab and go. Or I'd have things that I could easily just shove in the oven, and it would heat up, and I didn't have to really think about anything other than, did I press the timer? Is it the right temperature? [PF009]*

**Physical activity:** *I do workout at home with weights and stuff like that; but we're very conscientious of what I used to be able to do before what I can do now. [PF002]*

*So, an excessive amount of physical activity usually triggers that [pain]. [PF008]*

**Other strategies**

**Relaxation:** *For the next day I woke up, and I was in pain... my leg was sore and tight and so today's gonna be more of a relax day. So, I had a foot bath... soak my feet, use heating pads and stuff... basically with the pain I had more of a quiet day and took care of it. Listen to it. Dealt with it. [PF007]*

**Independence:** *That's the person I am. I'm not one of those people like "oh feel sorry for me" type people... I think it kind of makes light that you know what I was given this disease because they knew I could deal with it without whining. [PF007]*

**Feeling lucky:** *And I'm lucky, in that there are people with Parkinson's who have constant pain; whether it's a low level or a high level but it's constant and I can't imagine what it would be like. Every so often I get to bed, and I think well I only had one pain today or I didn't have any pain today, and it's like, well, I'm lucky, because a lot of people don't have that. [PF006]*

#### **PAIN AND FATIGUE ACROSS CONDITIONS**

**Similarities:** *Fatigue is associated to lack of sleep, which is associated with the pain in my body, which ends up being associated with mental fatigue. [PF001]*

*The pain restricts you from moving, so does the fatigue. It restricts your cognitive... It restricts your mobility, your communication levels... they're both very restrictive. It's like having a straight jacket on you but then also with the straight jacket you're being tied to a pole. [PF002]*

*Fatigue is a natural extension of pain. I think. I think when you're in pain all the time fatigue is sort of a given. [PF007]*

**Differences:** *... I think for me the fatigue was more at the beginning, more cumbersome than the pain. [PF008]*

*Pain is something that I can kind of is more tangible in terms of, it's not fatigue. Like it's not exhaustion. It's not general worn out outness. It's more. [PF009]*

**Appendix G: Frequency of References Across All Interviews Sample Calculation for Final Theme ‘Lack of Understanding’**

$$\begin{aligned}
 & 87 \text{ [aggregated references to a lack of understanding]} \\
 & \quad \div 848 \text{ [total references across the three final themes]} \times 100 \\
 & = 10.2\%
 \end{aligned}$$

$$41 \text{ [references to a lack of understanding by others]} \div 87 \times 100 = 47.1\%$$

$$47.1 \times 0.102 =$$

$$4.9\% \text{ [frequency of references coded to a lack of understanding by others]}$$

$$30 \text{ [references to a lack of understanding by clinicians]} \div 87 \times 100 = 34.5\%$$

$$34.5 \times 0.102 =$$

$$3.6\% \text{ [frequency of references coded to a lack of understanding by clinicians]}$$

$$16 \text{ [references to a lack of understanding by the patient themselves]}$$

$$\div 87 \times 100 = 18.4\%$$

$$18.4 \times 0.102 =$$

$$1.9\% \text{ [frequency of references coded to a lack of understanding by the patient themselves]}$$

## Curriculum Vitae

|  |   |
|--|---|
| <b>Name:</b>                                 | Lauren Kane   |
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