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"It's not that I have Parkinson's, I am Parkinson's": The management and negotiation of identity in older adults with Parkinson's disease

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Abstract

Prior research has identified that older adults with Parkinson's disease experience both personal and social difficulties due to the interactions between environmental factors (e.g. social attitudes about impairments) and their physical and cognitive challenges of their condition. My thesis explored how older adults with Parkinson's disease negotiated their contexts of personal and social identity post-diagnosis. Using a constructivist, narrative approach, I aimed to understand what personal and social factors contributed to how people with Parkinson's disease maintain, negotiate, and adapt their identity within the private sphere of the home and the broader community. For all five participants, three sessions took place, including two in-depth interviews, in order to gain as much insight and detail as possible into each participant's story, ideas, and opinions about negotiating their identity with Parkinson's disease. From this data, four major themes emerged including: *Negotiating identity while managing Parkinson's disease*, *Acceptance as a process*, *Resisting a disabled identity*, and *The centrality of occupations and roles*. From this research, greater understanding and awareness can be raised for the hardships impacting the identities of those with Parkinson's disease, such as stigmatizations and physical and cognitive limitations leading to loss of occupations, to encourage further attention and expansion of community engagement and activities for these individuals.

Keywords

Personal Identity, Social Identity, Parkinson's Disease, Older Adults, Identity Theory, Narrative

Summary for Lay Audience

Parkinson's disease is a neurological condition that impacts the motor and cognitive skills of the person affected. This disease most commonly affects individuals at 60 years of age and older. When an individual is diagnosed with Parkinson's disease, the symptoms can vary between people, and not everyone with Parkinson's disease will show the same symptoms. Because of this, there is minimal public understanding and education on Parkinson's disease and how an individual is affected and presents symptoms. This in turn, can affect how someone with Parkinson's is perceived in both private and public spaces.

The identity of an individual can vary greatly depending on personal and social factors. This study intended to investigate and understand how the personal and social identity of an older adult with Parkinson's disease may be negotiated, adapted, or maintained following diagnosis of their condition. By conducting in-depth interviews with participants, narratives were created to story the experiences of those participants affected by Parkinson's, and understand if and how their identity had been negotiated since their diagnosis. Personal identity was defined as the characteristics, traits, and/or qualities that make someone unique or distinct from another, whereas social identity was thought of as the significance and meaning we tie to the memberships or groups we belong to within society.

From conducting multiple interviews with each participant, narrative accounts were created to capture the stories each individual described about their journey with Parkinson's and their feelings towards their identity. From these narrative interviews, four major themes emerged: *Negotiating identity while managing Parkinson's disease*, *Acceptance as a process*, *Resisting a disabled identity*, and *The centrality of occupations and roles*. From this research, greater understanding, awareness, and acknowledgement of Parkinson's can be raised to understand the hardships and challenges these individuals face with their identity, such as stigmatizations and physical and cognitive limitations leading to loss of activities, tasks, and hobbies, to encourage further attention and expansion of community engagement and activities for these individuals.

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A big, big thank you to all my participants who were not only willing, but excited to be a part of my study. I am inspired by each and every one of them, for their optimism, enthusiasm, and dedication to live their lives to the fullest and not take any day for granted. I cannot thank you enough.

Dedication

This thesis is dedicated to anyone who has ever been affected by Parkinson's disease, no matter how small.

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Chapter One: Introduction

In this chapter, I outline the purpose of my study, including an introduction to my guiding research question. I also provide a summary of the epidemiology of Parkinson's disease, as well as a brief history of the neurological and molecular characteristics of the condition. I then touch on the motor symptoms associated with the disease, as well as a variety of non-motor symptoms that individuals may experience. Some of the most common treatment options are highlighted, followed by a conceptualization of personal and social identity and how these terms were taken up in this study. A summary of how my thesis will be structured then follows.

1.1 Study Purpose

Due to the number of varying motor and non-motor symptoms that can impact a person with Parkinson's disease, research has identified a number of issues associated with the disease that may present challenges to negotiating identity in both social and personal contexts. The nature of Parkinson's disease is such that those affected by the condition can gain a strong sense of solidarity, support, and community from each other, while also feeling misunderstood, alone, and embarrassed due to the different range of symptoms each person can experience (Lawson, Collerton, Taylor, Burn, & Brittain, 2018). Non-motor symptoms of the disease, such as a change in mood, may also affect how older adults cope with Parkinson's disease. As a consequence, those older adults with Parkinson's may feel a shift in how they are perceived by others, and by themselves, as someone who must adapt or negotiate their identity to compensate for what Parkinson's disease has altered in their movements and attitudes (Vann-Ward, Morse, & Charmaz, 2017). To date, no research has specifically focused on how older adults with Parkinson's disease present themselves from a personal and social identity standpoint. This gap will be discussed in further detail in the following literature review chapter.

The focus of this narrative research study was on understanding the challenges to negotiating and adapting both personal and social identities as experienced by older adults diagnosed with Parkinson's disease. By learning firsthand about older adults' stories surrounding their lives with Parkinson's disease, I aimed to advance understandings of the environmental and personal features that can present threats or challenges to their sense of personal and social identity. I wanted to understand how specific factors, whether they be personal, social, or a

combination, vary depending on an older adult's personal experience with Parkinson's disease. By engaging older adults in a process of reflection of their own personal narrative regarding life with Parkinson's disease, I wanted to gain insight into how older adults with Parkinson's disease felt their identity changed since their diagnosis and how they negotiated those changes. As such, the overall aim of my research was to understand how the identity of older adults with Parkinson's disease is managed and negotiated from both a personal and social context. The research question that my study sought to answer was: "How do older adults with Parkinson's disease story their experiences of managing identity within their social and personal contexts?"

A brief background on Parkinson's disease prevalence, clinical symptoms, and treatments are outlined next to give greater context to how this disease can affect an older adult and provide insight as to how this may be connected to associations with their identity in later chapters.

1.2 The Nature and Epidemiology of Parkinson's Disease

Parkinson's disease is a chronic, neurodegenerative condition that causes debilitating challenges for people in their daily lives, which have been shown to have psychosocial consequences, such as depression, anxiety, social withdrawal, uncertainty, and apathy (Maffoni, Giardini, Pierobon, Ferrazzol & Frazzitta, 2017; Pluck & Brown, 2002; Reijnders, Ehrt, Weber, Aarsland, & Leentjens, 2008). While this disorder can be seen in people as young as 40, it tends to manifest itself in older adults over the age of 60 (Lau & Breteler, 2006). Within Canada, the average age of onset of disease symptoms is 64.4 years (Wong, Gilmour, & Ramage-Morin, 2014). Parkinson's disease affects more men (0.3%) than women (0.2%) (Wong, et al., 2014). Approximately 55,000 Canadians, 18 years of age or older, living in private households have been diagnosed with Parkinson's disease, accounting for 0.2% of this population (Wong et al., 2014). Of the Canadian population living in long-term care facilities, such as retirement and nursing homes, 4.9% of residents have Parkinson's disease (Wong et al., 2014). There is a general increase in the prevalence of Parkinson's disease as people reach the age of 65 and older (Wong et al., 2014). However, there is a decrease in prevalence for those aged 80 or older within long-term care institutions, which may be attributed to higher disease severity and mortality within this age group (Wong et al., 2014).

Parkinson's disease is the second most common neurodegenerative disease worldwide for adults older than 65, secondary only to Alzheimer's disease (Schuller, Vaughan, & Wright,

2017). It is biologically defined by a loss of dopaminergic neurons in the substantia nigra region of the brain, leading to a deprivation of the neurotransmitter dopamine (Elbaz, Carcaillon, Kab, & Moisan, 2015). Along with this loss of dopamine, there is a presence of Lewy Bodies, an abnormal aggregate comprised of the protein class α -synuclein that acts as a major biological marker for the disease (Mackenzie, 2001). This loss of dopamine, plus the appearance of Lewy bodies ultimately leads to disruptions in motor control, accounting for the motor symptoms that characterize Parkinson's disease (Elbaz et al., 2015).

1.3 Symptoms and Characterizations of Parkinson's Disease

Parkinson's is diagnosed and most commonly characterized by the motor symptoms of the disease, such as resting tremor, slow movements (akinesia/bradykinesia), rigidity, and balance problems, including postural instability, and freezing of gait (Reijnders et al., 2008). Research has shown that up to 80% of dopaminergic neurons are lost before any of the cardinal symptoms begin to appear (Sveinbjornsdottir, 2016). The manifestation of symptoms in older adults with Parkinson's disease is heterogeneous, and each person affected may show different types and severity of clinical symptoms (Sveinbjornsdottir, 2016). Highlighting these symptoms gives the reader greater understanding as to how the disease may manifest, and how such symptoms can impede on daily living, thus negotiating identity. Some of these clinical symptoms include:

1.3.1 Resting tremor

According to the Tremor Task Force of the International Parkinson and Movement Disorder Society, a tremor is defined as "an involuntary, rhythmic, oscillatory movement of a body part" (Bhatia et al., 2018, p. 75). Tremors are the most commonly attributable symptom of Parkinson's disease (Jankovic, 2008), and tend to affect limbs asymmetrically (Williams-Gray & Worth, 2016). The most common type of tremor is pill-rolling, where the thumb and index finger come into contact in a circular motion (Sveinbjornsdottir, 2016). These tremors tend to affect the hands most commonly, but may also involve lips, chin, jaw, and legs (Jankovic, 2008). These tremors typically arise during actions or sleep (Jankovic, 2008).

1.3.2 Bradykinesia

Bradykinesia, otherwise known as slowed movement and decreased amplitude of speed, is the most common clinical symptom of Parkinson's disease (Jankovic, 2008). Initially, this symptom decreases the speed of performance of daily tasks, specifically those involving fine motor control of the hands (Jankovic, 2008). This feature also affects executive functioning by slowing down not only the motor functions, but also cognitively planning, initiating, and executing such tasks (Jankovic, 2008). Eventually bradykinesia may lead to hypomimia, otherwise known as a lack of expression in facial muscles (Sveinbjornsdottir, 2016).

1.3.3 Rigidity

Rigidity is known as the resistance of a range of passive movement of a limb, including flexion, extension, or rotation about a joint (Jankovic, 2008). This symptom is typically associated with pain, and a common area of complaint is within the shoulder joint, which can be mistaken by professionals as arthritis (Jankovic, 2008). Body posture may stoop over time, as the postural muscles are also affected by this muscle stiffness (Sveinbjornsdottir, 2016).

1.3.4 Postural instability

Postural instability is due to the loss of postural reflexes that tends to manifest later in the progression of the disease (Jankovic, 2008). As the body posture stoops due to muscle stiffness, this causes balance problems, as the reflexes that allow a person to stay upright are lost over time (Jankovic, 2008). This postural instability leads to an increase in the number of falls that those with Parkinson's disease face, especially in older adults (Sveinbjornsdottir, 2016).

1.3.5 Freezing of gait

Freezing of gait, a type of akinesia, or loss of movement, is a brief, reoccurring absence in forward movement of the feet (Heremans, Nieuwboer, & Vercruyse, 2013). Even though the person has the intention of walking forward, they are unable to progress (Heremans et al., 2013). This lack of movement is a common cause of falls in those with Parkinson's disease (Jankovic, 2008). This symptom tends to manifest later in the disease progression, typically several years after symptom onset (Sveinbjornsdottir, 2016).

It is important to acknowledge that the severity and appearance of motor symptoms of Parkinson's disease can vary significantly between people. While motor symptoms are the

cardinal characteristic of Parkinson's disease, there are also varying non-motor symptoms that affect those with the condition. These symptoms range from mental health issues including depression, anxiety, and social phobias; cognitive difficulties including comorbidities with dementia and obsessive-compulsive disorder (OCD); sleep disturbances; visual impairments; as well as bladder and sexual dysfunction (Abell, Baird, & Chalmers, 2016; Ahn, Lee, Chu, & Sohn, 2017; Jankovic, 2008; Smeltere, Kuznetsov, & Erts, 2017; Turner, Liddle, & Pachana, 2017; Weil et al., 2016). These non-motor symptoms are imperative to emphasize as the variety and multitude of symptoms can greatly impact an individual with Parkinson's in both personal and social aspects of their life, including daily activities, hobbies, and social engagements. How they are impacted and how that can affect aspects of identity will be discussed in detail in following chapters.

1.3.6 Cognitive impairments and neurological comorbidities

There are a number of neurological disorders that often occur in conjunction with the progression of Parkinson's disease, with the most common being dementia. Dementia commonly occurs later in the disease progression, with an increasing likelihood of development as people age, occurring in as many as 50% of patients within 10 years of being diagnosed (Williams-Gray & Worth, 2016). The loss or dysfunction of executive functions such as planning, initiating, and executing daily tasks are common comorbid symptoms of Parkinson's disease and dementia (Sveinbjornsdottir, 2016). This Parkinson's disease-related dementia is also associated with hallucinations, states of psychosis, apathy, depression, and anxiety (Jankovic, 2008; Sveinbjornsdottir, 2016).

1.3.7 Mood changes

Mood changes and disturbances account for the most common psychiatric issue in relation to Parkinson's disease (Williams-Gray & Worth, 2016). Depression, anxiety, and apathy are among the most common mood disruptions associated with Parkinson's. Depression and/or anxiety affect around one-third of patients with Parkinson's and tends to emerge near the onset or early stages of the disease (Williams-Gray & Worth, 2016). Another symptom to account for is apathy, defined by Pluck & Brown (2001) as:

A constellation of behavioural, emotional, and motivational features including a reduced interest and participation in normal purposeful behaviour, lack of initiative with problems

in initiation or sustaining an activity to completion, lack of concern or indifference, and a flattening of affect. (p. 636)

This symptom is commonly a pre-motor symptom, meaning that onset of this feature can occur before Parkinson's disease is even diagnosed (Sveinbjornsdottir, 2016).

1.3.8 Sleep disturbances

Researchers have discovered that the neuropathology of Parkinson's disease affects neurotransmitters that are integral to the regulation of the sleep cycle (Sveinbjornsdottir, 2016). Because of this, there are multiple sleep disorders commonly associated with Parkinson's disease, including rapid eye movement (REM) sleep behaviour disorder, insomnia, and excessive daytime sleepiness (Jankovic, 2008). REM sleep behaviour disorder is now considered a pre-Parkinsonian state, because of its common prevalence prior to diagnosis (Jankovic, 2008). This disorder is characterized by an intense dream state, which causes the person to act out their dream, and can involve talking, yelling, kicking, thrashing, jumping, and other vigorous and potentially violent actions that can injure the person and/or anyone else sleeping in close proximity (Jankovic, 2008). Insomnia, in particular fractionated sleep, is the most common sleep disturbance associated with Parkinson's disease (Sveinbjornsdottir, 2016). Those with Parkinson's disease tend to have shallower and lighter sleeps than those without and are more likely to wake up frequently during the night (Sveinbjornsdottir, 2016). This disturbance, plus potential side-effects of any Parkinson's disease medications, may lead to an increase in daytime sleepiness, as well (Sveinbjornsdottir, 2016).

1.3.9 Autonomic abnormalities

There are a multitude of autonomic functions that commonly weaken or decline during the progression of Parkinson's. A common function included in this category is orthostatic hypotension (a decrease in blood pressure when changing from a sitting to a standing state) resulting in sudden dizziness (Sveinbjornsdottir, 2016). Gastrointestinal (GI) problems are also extremely common, as the GI tract muscles begin to slow down over progression of the disease, leading to gastric retention and constipation with the latter being the most common, present in 70-80% of people with Parkinson's (Sveinbjornsdottir, 2016). Urinary issues are also common, including bladder irritability, and urinary dysfunction including increased frequency, urgency, and incontinence (Sveinbjornsdottir, 2016).

1.3.10 Sensory dysfunction

At least 80% of people with Parkinson's report a loss or reduction of olfactory sensation, or a sense of smell. This commonly appears as a pre-motor symptom of the disease (Sveinbjornsdottir, 2016). There is also a number of visual disturbances that patients may have in association to their Parkinson's disease. Some symptoms associated with visual difficulties include a change in colour perception, contrast, and increased light sensitivity (Weil et al., 2016). There is also an increased difficulty at completing visual tasks, such as mental rotation or orientation of objects (Weil et al., 2016).

While non-motor symptoms are not the key marker of Parkinson's disease recognition and diagnosis, these heterogeneous non-motor symptoms are just as important as diagnostic characteristics in understanding the progression and prognosis of those with Parkinson's disease. These non-motor symptoms are especially important in connection to the identity negotiations of older adults with Parkinson's disease. Non-motor symptoms can significantly impact activities, relationships, and personal qualities that the individual associates or attributes to facets of their personal and/or social identity.

1.4 Parkinson's Disease Treatment Options

Although there is currently no cure for Parkinson's disease, there are a number of treatment options offered to help reduce, alleviate, and/or manage the symptoms of the disease. While there are a variety of medication options available, levodopa remains the gold standard in treating the disease (Djamshidian & Poewe, 2016). While effective, this drug is associated with many adverse side effects, including nausea, vomiting, confusion, sleepiness, and light-headedness (Vasta et al., 2017). The dosages of levodopa will likely increase over time, as some symptoms can become progressively resistant to treatment (Okun, 2012).

If medications cannot control symptoms of the disease, screening for deep-brain stimulation (DBS) is another option (Okun, 2012). DBS is a surgical intervention in which one or more electrodes are placed, or implanted, within the specific brain regions that are associated with the motor changes attributable to Parkinson's disease (Okun, 2012). When these electrodes are activated, it causes episodic impulses that send stimuli to those areas surrounding the implants, to regulate patterns of neural signals that ultimately reduce the motor symptoms of Parkinson's disease (Okun, 2012). This treatment is also accompanied by side effects, including

cognitive impairment, memory retrieval difficulties, speech deficits, and motor and sensory disruptions (Okun, 2012). The side effects of these treatments may further present challenges to negotiating social relations and activities that the individual ties to their identity.

In addition to medication and surgeries, rehabilitation offers an accommodation to Parkinson's disease symptoms, as it is proven to optimize functional ability and reduce secondary complications of the disease (Abbruzzese, Marchese, Avanzino, & Pelosin, 2015). Exercises are proven to show positive effects on the motor and non-motor symptoms of those with Parkinson's disease (Abbruzzese et al., 2015). However, the type of rehabilitation and exercise therapy program varies, largely depending on the type of symptoms each person presents with (Abbruzzese et al., 2015). Thus, rehabilitation is another treatment option that can be positive or negative depending on the individual and is also important to consider how this type of treatment can impact the negotiation of identity.

1.5 Personal versus Social Identity

Identity is a complex concept that can be understood and interpreted differently (Deschamps & Devos, 1998). Throughout my thesis, I examined two aspects of identity: personal identity and social identity. I will define both personal and social identity according to its definitions by Deschamps and Devos (1998), as their outlined definitions align well with my own personal understandings of identity. These definitions are the ones that I will use throughout my thesis in connection to my participants. In a study by Soundy, Stubbs, and Roskell (2014), the researchers set out to understand the significance of social identity based on lived experience of those with Parkinson's disease. Social identity was defined as an individual's understanding of belonging to a social group and having personal connection and attachment to their membership within it (Soundy et al., 2014). They concluded that social identity was a significant factor in contributing to both the establishment and significant impact of overall well-being of the individuals with Parkinson's (Soundy et al., 2014).

Deschamps and Devos (1998) agree that identity is both constructed personally - in that identity is very much situated within the person themselves - and socially - such that relationships and social interactions also contribute to the self. Personal identity can be thought of as the more personal or specific features, characteristics, or qualities that make us unique and different from each other (Deschamps & Devos, 1998). Personal identity is difficult to explicitly

define, but in essence it is what separates you from others, and makes you different (Deschamps & Devos, 1998).

Social identity is characterized by how an individual integrates his or herself into groups, memberships, and/or categories based on social relations (Deschamps & Devos, 1998). Social identity refers to both the feeling of belongingness to a social group, but also the distinctions between groups we do not belong to, as well (Deschamps & Devos, 1998). Those people who have similar social groups or backgrounds can find commonplace in their social identities and connect with each other (Deschamps & Devos, 1998). In regard to social and personal identity, Burke & Stets (2009) state that these two facets of identity are inextricably linked. How we define ourselves is impacted by the roles and meanings that we place on our contributions and engagements within society (Burke & Stets, 2009). Our personal identity is influenced by the interactions that we have within society and is a fluid state that can be changed and negotiated based on life events and experiences (Burke & Stets, 2009). Therefore, personal and social identity will be associated with each other for all aspects of this research and further analysis, because they are impacted by each other.

1.6 Situating the Researcher: What Led me to Study this Topic?

Before beginning my Master's degree, I was studying medical and biological sciences in my undergraduate degree. From this degree, I was able to learn about a variety of topics pertaining to both medical and biological disciplines, such as anatomy, physiology, microbiology, and genetics. One topic that always piqued my interest was neuroscience. I was fascinated with understanding how one key area of our body had so much control, and more importantly, how if one thing went wrong with our brains, a variety of detrimental impacts would occur throughout the rest of our body. Parkinson's disease was always a condition that intrigued me the most, not only because of how much is yet to be uncovered about it, but also because of how every single person affected is impacted differently by symptoms and prognosis; no two people are alike.

Throughout my life, I have known a few people who have been affected by Parkinson's disease, and knew how tough it has been for those coping from a physical standpoint. It wasn't until my thesis supervisor, Dr. Colleen McGrath, mentioned a study she was doing on older adults with age-related vision loss (ARVL) and how they negotiate identity that made me wonder

how older adults with Parkinson's are also impacted by changes to their identity. I was left wondering how older adults with Parkinson's disease cope with the aftermath of their diagnosis, the constellation of symptoms, and uncertainty of its presentation, from a social and personal standpoint, especially in terms of how they identify themselves?

1.7 Organization of the Thesis

My thesis is organized into six chapters. The first chapter is the introduction, which establishes the rationale for my study. Within the introduction there is also information pertaining to the biological aspects of Parkinson's disease, including a brief understanding of pathology, a summary of the most common motor and non-motor symptoms, as well as the most common treatment options. The introductory chapter also aims to establish how social and personal identity are tied to Parkinson's disease, in order to justify my research focus and question. In this chapter, I also situate myself within the research by discussing what personal motivations led me to study this particular topic.

The second chapter uses relevant qualitative and quantitative literature to compose a comprehensive literature review. This chapter outlines the current literature pertaining to my research question, in which I aim to unpack the influence of aging, disability, and most specifically Parkinson's on experiences of identity, as well as highlight any gaps. I also touch on those studies that influenced my decision to research this topic.

In the third chapter, the methodology and research methods used in this study are detailed including a discussion of how paradigm, ontology, and epistemology guided my work. I discuss the narrative methodology as well as the narrative interviewing method used, called the Biographic Narrative Interpretive Method (BNIM). This chapter also underlines my guiding theoretical approach, Identity Theory (Burke & Stets, 2009), which was used to frame my thesis around the personal and social identity of an individual with Parkinson's disease.

In chapters four and five, I present the results of my thesis. Chapter four specifically details each participant's narrative, including reflexive notes that I wrote detailing my reflections regarding each participant. Chapter five shares the results of the study, including the key themes and subthemes that emerged.

Chapter six provides a discussion and conclusion of the thesis, by framing the research findings in the broader context relating back to existing literature, sharing the strengths and

limitations of the study, and reflecting on how the study findings may shape future research, societal contributions, and practice.

1.8 Conclusion

This chapter outlines important background information relevant to Parkinson's disease, including the clinical and epidemiological data that is necessary to understand how those with Parkinson's disease are affected. By mentioning the prevalence of the disease, we can understand how increasingly prominent Parkinson's is becoming, especially among older adults. The clinical symptoms and manifestations of the disease were underlined, as well as the varying non-motor symptoms that are associated. A few of the most common treatment options were presented, to give greater understanding to how difficult this disease is to live with, and the side effects that can come from treatment. The study purpose and reasoning behind my research focus was stated, as well as an overall outline of the organization of my thesis.

Chapter Two: Literature Review

In this section of my thesis, I will discuss prior research focused on how older adults identify themselves as they age, whether that be with or without the presence of disease or disability. I will also present an overview of current and past literature regarding the underlying factors that contribute to challenges older adults with Parkinson's disease face, to better understand how, after being diagnosed, identities might shift or change. I will delve into different areas of research relating to Parkinson's disease that has helped to shape the context of my research, including non-motor symptoms, daily living challenges, stigma and shame, community engagement, and identity.

2.1 Negotiating Identity with Aging

Identity negotiation is an ongoing process that continues as people age and has been shown to involve an integration of the past with the present. In a narrative analysis conducted by McLean (2008), comparisons were made between the narrative identity of youth as compared to older adults. The research supported the idea that identity is generally developed during the young adult life stage, however this identity is revised over time as new experiences contribute to formation of the self (McLean, 2008). A study conducted by Moore, Metcalf, & Schow (2006), showed that older adults ranging from 66 to 92 years of age partially connected their current sense of self with the meaningful experiences they had over their lifetime. For example, one participant in the study stated: "Human beings must create meanings that allow them to integrate and make sense of how they function in their worlds" (Moore et al., 2006, p. 293). Conclusions of this study suggested that continuing to live a rich and personally fulfilling life, despite any hardships or struggles, contributed to a sense of meaning in the older adults' lives that was connected to identity (Moore et al., 2006). As mentioned in McLean's (2008) study on comparisons between young adult and older adult identity, she supports the notion that identity "is viewed as the construction of a sense of personal continuity between one's past and present through the creation of a life story" (p. 253). Thus, identity changes due to life experiences that occur over the lifespan of the individual. In comparison to adolescents, McLean (2008) reports that older adults have a more stable outlook on their identity. This is due to the increase in self-explanations of actions they contribute to the identity they currently have, rather than attributing this experience to a change in their identity (McLean, 2008). Older adults tend to find a reason as

to why they acted in a certain way because of their identity, rather than changing their identity to understand the action. In other words, “older adults were predicted to narrate the self in terms of self-explanatory connections in order to preserve a sense of self-continuity, which may be particularly important in late life” (McLean, 2008, p. 255).

As well as associating with a younger age identity to feel a greater sense of satisfaction in older age, older adults also use personal memories of their past to help achieve a sense of identity (Singer, Rexhaj, & Baddeley, 2007). Older adults and young adults were given a questionnaire in which they had to write down five self-defining memories, and comparisons between the subsets were made from specificity of memory, affect (negative versus positive), integrative meaning (significance), and content (themes within the memories) (Singer et al., 2007). Compared to young adults, the older adults ranked their memories with higher importance, leading researchers to discuss the possibility that as we age, we are better able to distinguish defining and pivotal moments in our lives that help us to establish our sense of identity (Singer et al., 2007).

2.2 How the Presence of Chronic Illness Impacts Identity

From Erikson’s (1968) seminal work on lifespan psychosocial development, identity is characterized based on the individual’s understanding of what pertinent features and assets are attributed to the self, as well as how this understanding of the self is then cast into actions and habits. This identity can be influenced and altered by various life events, including disability or chronic illness (Oris, et al., 2018). Individuals with chronic illness will cope or manage the burdens of their disease better than others, and the differences between individuals in terms of their management of illness is theorized to be due to illness identity (Oris et al., 2018). Illness identity, as defined by Charmaz (1995), is the level or intensity at which an illness is assimilated into one’s current identity.

Charmaz (2000) believes there is a distinction between what is considered illness and disease. Illness is defined as a person’s experiences with disease, whereas disease is diagnosed by doctors in the form of a bodily disorder (Charmaz, 2000). Charmaz (2000) states that “some people do not experience illness when they have a disease” (p. 278), in which people might not associate themselves and their experiences with the actual diagnosis. Chronic illnesses may be continuous or episodic; they include bodily, emotional, and social sensations personal to each individual (Charmaz, 2000). Chronic illnesses, such as Parkinson’s disease, are associated with

more social and interpersonal problems than an acute illness, due to the longer duration of the experience that a chronic disease can have (Charmaz, 2000). The self is considered in understanding illness because “experiencing serious illness challenges prior meanings, ways of living that have been taken for granted, and ways of knowing self... The self has become vulnerable, and thus problematic” (Charmaz, 2000, p. 278). Becoming ill puts three major problems into perspective. When an individual is ill, they must: a) make sense of their symptoms, such as by defining their illness; b) reconstruct order by creating new tasks to accommodate for their illness, such as medication management and healthcare regimens, and; c) maintain a sense of control over their life (Charmaz, 2000). One way that people try to maintain the self is by normalizing their symptoms, which they will do for as long as possible (Charmaz, 2000).

In those older adults that are chronically ill, dealing with disease such as diabetes, heart failure, and cancer, Charmaz (1983) supports the notion that these individuals not only experience the physical manifestations of their disease, such as pain and distress, but they also can experience a loss of self as they attempt to manage their chronic illness. Due to the detriments of these certain conditions, “a fundamental form of suffering is the loss of self in chronically ill persons who observe their former self-images crumbling away without the simultaneous development of equally valued new ones” (Charmaz, 1983, p. 168). Many chronic illnesses are associated with less control over life and lack of independence, which results in not only a loss of self-esteem, but also a diminished sense of self (Charmaz, 1983). The degree to which an individual assimilates illness into their identity can have an effect on their psychological wellbeing (Oris et al., 2018). Someone who is more accepting of their condition will experience more adaptive psychological wellbeing than someone who denies or rejects it (Oris et al., 2018). As well, the more symptoms of an illness that someone has, the more negative or disabling their illness identity may become, leading to an increase in psychological impairments such as anxiety and depression (Garlovsky, Overton, & Simpson, 2016).

Illness beliefs are another important factor that can contribute to one’s understanding of their overall identity, most significantly with their psychological wellbeing (Simpson, Lekwuwa, & Crawford, 2013). Illness beliefs are the representations that individuals have about a certain illness, including but not limited to the causes of illness, consequences of illness, ability to control their illness, and identity (Simpson et al., 2013). Research from Simpson et al. (2013)

found that in individuals with Parkinson's disease, their beliefs about the cause of the illness, and the level of understanding the individual had about Parkinson's were the two most important factors linked to the psychological outcome of the individual. Participants' psychological functions were measured by their levels of depression, anxiety, stress, positive affect, and emotional wellbeing (Simpson et al., 2013). Higher belief in a psychosocial cause of the disease, such as work, stress, or family drama was correlated with anxiety, whereas a less coherent understanding of the disease was correlated with decreased emotional wellbeing (Simpson et al., 2013). They determined these two pre-onset factors of anxiety and emotional wellbeing could be related to the post-onset reaction to their diagnosis (Simpson et al., 2013).

Charmaz (1991) believes that people experience and cope with illness in one of three ways: illness as an interruption, an intrusion, or an immersion. Interruption of illness means looking for a recovery or cure, and is attributed to an illness that one would falsely consider acute instead of chronic, often leading to denial (Charmaz, 1991). An intrusion of illness is one that "demands continued attention, allotted time, and forced accommodation. People learn to expect symptoms and treatments, and to plan around them. These people struggle... to minimize the intrusion of illness upon their lives" (Charmaz, 1991, p. 42-43). This understanding of illness is one that affects daily habits, activities, and tasks, threatening control over the self and introducing uncertainty (Charmaz, 1991). In this way, individuals struggle with control over their self, due to the notion that controlling their illness also dictates the control they have over time, which can be unpredictable with an illness. People would rather try to keep illness in the background of their lives to maximize their self-worth (Charmaz, 1991). Lastly, individuals can also become immersed in illness, which causes the priorities in their lives to shift, and issues regarding their condition to become more prominent (Charmaz, 1991). The severity and progression of illness causes individual's lives to become tailored towards their condition. (Charmaz, 1991). This feeling of immersion into one's illness creates new challenges in physical and psychological forms, something that people may have never experienced before. As Charmaz (1991) states:

Immersion in illness means experiencing the vulnerability of one's body: facing dependency. Certainly, physical dependency, if not also social and economic, can result from illness. However, many ill people just glance at their dependency and turn away. They

cannot accept it, even when foisted upon them. For them, dependency remains a greater specter than death. (p. 80)

Charmaz (2002) also looks at chronic illness from the perspective of the disruption of habits, in which illness shifts and destroys understandings and routines of the self that are taken for granted. An illness causes individuals to have to make modifications and alterations to tasks that have been routine and innate for a long time (Charmaz, 2002). She defines habits as “the modes of thinking, feeling, and acting that people invoke without reflection” (p. 31S). Charmaz (2002) further states that the fundamentals and core of identity are grounded in the habits that people form over time and are connected to emotional attachments they hold to those habits and to themselves. These habits are not something people consciously even think of, until illness poses a threat or challenge to their completion (Charmaz, 2002). The chronic illness an individual has can create changes, big or small, to their daily tasks and habits, but the most detrimental impact comes when the ill person faces challenges with familiar, everyday tasks in the home (Charmaz, 2002). This change takes time for the person to come to terms with. Charmaz (2002) attests that:

By trying to manage ordinary life, people call into question and re-examine habitualized notions of self. The changes wrought by illness and revamped through treatment shift a person's ways of being in the world and therefore may directly affect his or her sense of self. (p. 32S)

Things that were once innate and ingrained from habitual activity may become an accomplishment or a loss (Charmaz, 2002). Individuals with chronic illness oftentimes find that the daily tasks they once easily accomplished, or took for granted, are seemingly much more difficult to complete (Charmaz, 2002). When these tasks and activities are changed due to a chronic illness, it may not only affect the activity they once easily completed, but also alter the ways that they think or feel about themselves in the process (Charmaz, 2002). Chronic illness can impact social and personal identity, as Charmaz (2000) believes that stigma can create issues in the ways that an individual understands themselves and the situation. Charmaz (2000) states that the self and our social identity are intermixed through daily tasks and activities, and changes to those social and active endeavours creates tension in the social identity they had prior to their chronic illness.

2.3 How Disability Impacts Identity

As older adults age, the presence of disability and disease are factors that may influence their sense of identity. While disability is not an inevitable consequence of aging, older adults are more likely to develop a chronic illness or physical disability as they age (Kelley-Moore, Schumacher, Kahana, & Kahana, 2006). In older adults aging with a disability, research shows that these individuals often struggle to identify themselves as ‘disabled’ (Kelley-Moore et al., 2006). For example, many older adults with a disability do not consider themselves ‘disabled’ but rather attribute their impairments to normative aging processes (Kelley-Moore et al., 2006).

Disability is an umbrella term used to describe limits and impairments to activities, occupations, and life events (World Health Organization, n.d.). Chronic disease, which is the long-term duration of a disease, can encompass different types of disabilities (World Health Organization, n.d.). While the presence of a disability may have easily observable limitations, such as mobility challenges or vision loss, the label of being ‘disabled’ is often associated with the stigma of outward signs of supposed poor health (Kelley-Moore et al., 2006). These experiences of stigmatization may diminish the self-perception that older adults have of their own capacity to fulfill social and physical roles (Kelley-Moore et al., 2006). Identifying as an older adult with a disability commonly leads to perceptions from others including lack of independence, and consistent state of poor health, which these individuals do not want to be associated with (Kelley-Moore et al., 2006). Disability then becomes a supposed ‘spoiled identity’ because “it is not consistent with the images of wellness and vitality associated with good health and successful aging” (Kelley-Moore et al., 2006, p. 9).

Personal and social identity can be compromised when disability arises that causes cognitive impairment, such as in the case of individuals recovering from a stroke (Clarke & Black, 2005). While medical advancements have increased the likelihood of surviving a stroke, the recovery and aftermath of a stroke have shown to pose a threat to quality of life, such as in the case with Parkinson’s disease, as will be touched on in the following subsection. Due to the cognitive and physical limitations that individuals must cope with after a stroke, adjustments must be made in order to feel their sense of self is maintained. Such adjustments include returning to salient roles and activities, as well as making modifications to more challenging activities, such as leisure or intellectual pursuits. Mental and social hinderances can also affect how likely an individual is to return to their activities: “Factors such as fear of criticism, loss of

social roles, and a lack of self-confidence are cited as demoralizing consequences” (Clarke & Black, 2005, p. 319-320). Specifically, the loss of physical functioning leads some individuals to struggle with the identity that they had prior to the stroke, due to their limitations in mobility (Clarke & Black, 2005).

As well, impairments in cognitive and intellectual pursuits make it frustrating and difficult for individuals who relied on those aspects of their life prior to the stroke as a large contributor to their sense of identity (Clarke & Black, 2005). In order to minimize the physical and cognitive impairments of their condition, qualitative interviews of people who had previously experienced a stroke showed that adaptations and adjustments were made to their daily life in an effort to compensate (Clarke & Black, 2005). Modifications to previous tasks and roles helped those individuals achieve an adapted sense of self that enhanced their quality of life and former identity (Clarke & Black, 2005). From this study, comparisons can be made to those managing Parkinson’s disease, because as individuals post-stroke have to deal with the changes to their physical and cognitive abilities, so do those with Parkinson’s as their mobility and cognitive limitations change over time. While the conditions are different in nature, they both require individuals to make adaptations, accommodations, and modifications to daily tasks from the aftermath of their conditions. Connections can be drawn to understand the changes to sense of identity due to cognitive and physical limitations of each condition.

2.4 The Impact of Parkinson’s Disease on Daily Life.

Past Parkinson’s disease research has centered heavily around neurological, pharmacological, and genomic areas, since a cure has yet to be found. While there is significant research being done from a biomedical standpoint, there has also been a more recent emergence of research focused on the challenges that people living with Parkinson’s disease face. This area of research is becoming more prevalent because as more people live with Parkinson’s, there is a greater awareness for how many aspects of daily living are threatened by the disease (Vann-Ward et al., 2017).

One of the biggest challenges faced by those living with Parkinson’s disease is the decline in perceived health-related quality of life. Sabari et al. (2015) found that “improving health quality of life (HQoL) is an important outcome of a successful intervention for people with degenerative conditions such as Parkinson’s disease” (p. 1411). Health-related quality of

life in those with a disability is characterized by multiple components including disease pathology, functional impairments, environment, personal factors, and participation and activity limitations (Sabari et al., 2015). It is important that those with Parkinson's disease continue to engage in meaningful daily activities and routines to the best of their ability, even if they must accommodate due to their symptoms (Sabari et al., 2015). Lawson et al. (2018) support the notion that quality of life must be maintained through successful coping and adjustment strategies to stressors that people with a chronic disease, such as Parkinson's, may face. When people with a chronic illness do not have successful coping and adjustment strategies, this causes potential psychological distress such as fear, anger, and depression, as a result of handling stressful situations and challenges in an ineffective way (Lawson et al., 2018). This can lead to Parkinson's affecting emotional wellbeing as well as social relationships (Lawson et al., 2018).

However, there is significant evidence that health-related quality of life is improved in individuals with Parkinson's disease through community engagement programs (Sabari et al., 2015). For example, it has been found that patients who participated in activities such as singing, or dancing increased their overall quality of life. These activities also decreased disease symptoms including abnormal moods such as apathy and depression, increased cognitive function such as memory and concentration, and improved their postural instabilities (Abell et al., 2016; Butt, 2017; Gibson & Robichaud, 2017). Research by Ahlskog (2009) found that there may be a neuroprotective effect on individuals with Parkinson's disease who participate in intense, voluntary exercise. This shows that by engaging in community exercise programs offered to older adults with Parkinson's, it not only improves mental state, but can also improve motor symptoms of the disease (Ahlskog, 2009). This is indirectly associated with how an older adult defines their identity with Parkinson's disease, because of the improvements that these programs can have on mental state and overall health-related quality of life (Ahlskog, 2009).

2.5 Social Challenges, Changes, and Stigmatization Experienced with Parkinson's Disease

Many individuals with Parkinson's disease express that along with the physical symptoms of the disease come negative impacts on their social engagement and participation. At times, the psychosocial challenges can be more detrimental and difficult to deal with than the physical symptoms themselves (Sunvisson & Ekman, 2001). The way that an individual with a chronic illness, such as Parkinson's, deals with the impact of their illness has to do with the

interactions between their social world, relationships, and lifestyle (Hedman et al., 2015; Sunvisson & Ekman, 2001). A sense of being “enslaved by illness” can often be caused by the unpredictability of the disease and lack of control individuals feel with the symptoms and progression, making it hard to manage personal and social lives (Sunvisson & Ekman, 2001, p. 44). It also causes instability and insecurity within social situations, in which the individual with Parkinson’s disease might not know exactly what types of symptoms will arise during a social event (Sunvisson & Ekman, 2001). Increased anxiety over social situations and the unpredictability of their illness also makes it harder for those with Parkinson’s to want to engage in interactions and activities, leading to limitations on social lives and identity associated with it (Sunvisson & Ekman, 2001).

Stigma can be defined as a complicated, personal experience that ultimately affects personal and social identity due to the manifestations of a certain condition and/or social environment (Burgener & Berger, 2008). The degree and severity of stigma depends on many factors, including but not limited to: if the individual is responsible for their disease state, the severity of symptoms and their impact on physical state and appearance, and how their disease impacts others (Burgener & Berger, 2008). The stigma associated with Parkinson’s disease revolves around how others may respond to mental impairments and physical limitations in motor movements, including slow and unbalanced gait (Burgener & Berger, 2008). Not every individual with Parkinson’s disease exhibits the same symptoms, but that individual with Parkinson’s gets labeled with those stigmatizing labels even if they are not true to the person (Bergener & Berger, 2008). This leads to mechanisms of the stigmatizations including social isolation, social rejection, and internalized shame, causing a decrease in self-esteem and mood, which can cause negotiations to the identity of the individual (Bergener & Berger, 2008; Maffoni et al., 2017; Vann-Ward et al., 2017). Research shows that individuals with Parkinson’s disease tend to withdraw or decrease participation in social activities due to their self-awareness of their disease symptoms, as well as the negative perceptions they might receive from outsiders (Bergener & Berger, 2008). Bergener & Berger (2008) tested measures of perceived stigma on individuals with Parkinson’s disease, and recorded their descriptions of personal experiences regarding stigmatization from others with respect to their disease. Some of the responses about stigmatization included, “People don’t talk to me like they used to”, and “I feel less competent than I did before my impairment” (Burgener & Berger, 2008, p. 48).

Maffoni et al. (2017) concluded, from their literature review, that four types of stigmatization exist for those with Parkinson's disease including: a) stigma from symptoms, b) stigma linked to relational and communication problems, c) social stigma from others' perceptions, and d) caregivers' stigma. Stigma arising from symptoms was due to the physical manifestations of the disease, including motor issues such as tremors, instability and difficulty walking, that provokes shame and thus leads to isolation (Maffoni et al., 2017). Furthermore, this stigma is also associated with the progressive deterioration of motor function, leading to further perceptions of loss of autonomy and lack of confidence self-image (Maffoni et al., 2017). In relation to communication impairments, stigma arises from difficulty conversing and exercising appropriate conversational cues, with many people labelling their speech as 'drunkenly' or 'slow' (Maffoni et al., 2017). Stigma may also be linked to how the individual with Parkinson's disease believes that others view them in their state (Maffoni et al., 2017). Lastly, as much as stigma can be directed at the individual with Parkinson's, the caregiver may also experience stigmatizations of shame and pity that they now have to tend to this individual (Maffoni et al., 2017). All of these factors can impact personal and social identity as the individual copes with their own feelings and others' perceptions of the manifestations of their disease.

Stigmatization related to chronic illness contributes to how an individual is able to cope with and adjust to their condition (Helgeson & Zajdel, 2017). Parkinson's disease patients are subject to stigmatization on a daily basis, and is linked to feelings such as shame, embarrassment, and disgrace (Maffoni et al., 2017). These individuals feel that there is both stigma surrounding their physical appearance, as well as surrounding their functional ability (Maffoni et al., 2017). This stigma might stem from how conscious the individual is of their changes to movements and presentation (Maffoni et al., 2017). Stigma can be internalized and present challenge to personal identity, and it can be experienced in social relations and present challenges to social identity. Due to this stigma, older adults with Parkinson's might reduce their number of activities and social engagements (Maffoni et al., 2017), which may have been linked to their identity, and thus cause a threat to aspects of it.

2.6 Preserving a Sense of Self with Parkinson's Disease

Uncertainty can develop in individuals who have a disease where many underlying factors are undefined, such as unclear disease state, complexity of treatments, inconsistent

results, and unpredictability of prognosis (Ahn et al., 2017). Uncertainty can impact the ability of an individual to cope with hardships and overcome difficulties (Hurt, Cleanthous, & Newman, 2017). Uncertainty is highly prevalent in older adults with Parkinson's disease because of the ambiguity of treatments, prognosis, and symptom development (Ahn et al., 2017). Uncertainty in old age and illness gives older adults a reason to be more flexible in their identities that could even be "strategic and positional" (Rozario & Derienzis, 2009, p. 540). This is important to my study because uncertainty is a growing concern in older adults with Parkinson's due to the nature and treatment of the disease and can be an influence in the development and maintenance of the self. In fact, their uncertainty may impact how their identity is negotiated based on coping strategies to manage the unpredictability of symptoms and disease progression.

Furthermore, there is growing research to support that older adults with Parkinson's disease face detriments to coping with their ever-evolving symptoms. As such, "Parkinson's disease subtly and deceptively changes how people function, interact, and subsequently view themselves" (Vann-Ward et al., 2017, p. 964). Nijhof (1995) identified shame that people with Parkinson's disease feel within a community context due to the limitations of their disability. The nature of Parkinson's disease causes those with the disease to feel they are engaging in behaviours that challenge social etiquette or lacks social competence, which is out of their control (Martin, 2016; Nijhof, 1995). As a consequence, it can lead those with the disease to remain isolated or within their homes to reduce the amount of shame and embarrassment they feel in a public setting (Maffoni et al., 2017; Martin, 2016; Nijhof, 1995). The deterioration and decline in physical appearance and movement causes the individual to feel shame in how they are able to present themselves, further enabling these individuals to retreat into isolation (Martin, 2016; Maffoni et al., 2017).

There is relatively little information known about how people manage Parkinson's on a daily basis or how this contributes to their sense of self (Vann-Ward et al., 2017). In a recent study by Vann-Ward et al. (2017), researchers looked at how individuals with Parkinson's disease, ranging from 40 – 95-years-old, progress over time with their diseases and how those people keep their identity intact. This research used both quantitative (diagnostic tools for disease symptoms and severity) and qualitative (in-depth interviews and observations to understand details about personal and social factors contributing to identity) methods to collect data. From this study, a five-stage theory was created for how those with Parkinson's disease

preserve their sense of self from a social and personal perspective (Vann-Ward et al., 2017). The five stages generated were: (a) making sense of their disease symptoms; (b) defining turning points; (c) experiencing identity dilemmas, such as trying to hold onto their former identity, and coming to terms with how to adapt accordingly with physical and mental limitations; (d) reconnecting the self by forming new identities that encapsulate who they are now after going through physical and mental changes associated with Parkinson's disease, and; (e) envisioning a future (Vann-Ward et al., 2017). From the researchers' perspective, turning points are defined as events of value and significance, such as being diagnosed, memorable challenges faced, or beginning to use new medicines and treatment options (Vann-Ward et al., 2017). Researchers reported that adults with Parkinson's became watchful of themselves, because they anticipated situations of adversity with their condition. Vann-Ward et al. (2017) found that "embarrassing, humiliating, and demoralizing situations occurred routinely" (p. 972) and so "they became attentive to subtle nuances of expression, sidelong glances, and even well-meaning efforts of friends" (p. 972). From this study, two strategies to preserving the self were established including: a) interacting and; b) taking action. Interacting encompasses how an individual forms, establishes, and views relationships, as well as relating to others. Interactions and relationships with others are how people maintain, evolve, and transform their sense of self (Vann-Ward et al., 2017). Individuals continuously want to be able to relate to others, and "strive for normalcy" in order to maintain those connections (Vann-Ward et al., 2017, p. 977). The other strategy, taking action, refers to the notion that the self is the foundation for decision-making and putting thoughts into action (Vann-Ward et al., 2017).

Older adults with Parkinson's disease continue to struggle with their identity not only because of their own battles with the disease, but because of how their condition makes them appear to other people and affects the relationships they have with others. This struggle with one's sense of identity can be understood further if we continue to research the challenges that older adults with Parkinson's disease experience in both personal and social contexts.

2.7 Gaps in the Literature

Previous research has largely focused on the non-motor symptoms of Parkinson's disease and their connection to social engagement, isolation, and personal attributes. While this research has been helpful, there is a lack of understanding regarding the connection between older adults

with Parkinson's disease and how their identity is shaped in relation to their condition. There are few studies that focus on the identity of a person with a chronic illness, specifically Parkinson's disease, as this topic has been studied more so with a focus on other conditions, such as patients with cancer (Cheung & Delfabbro, 2016; Soanes & Gibson, 2018). As studies focus on how chronic illness is tied to a sense of self, there is greater attention drawn to how daily habits and tasks are negotiated due to limitations in mobility and cognition. No published qualitative study, to date, has specifically focused on solely older adults with Parkinson's disease and how that diagnosis impacts both social and personal identity. Further, Parkinson's disease is well-known as a condition in which no two individuals experiencing symptoms are alike. As such, a narrative study is necessary as it will show how nuanced identity is for older adults with Parkinson's disease. This type of study will allow for an analysis of individual stories and how the experiences of older adults with Parkinson's before and more importantly, after diagnosis, are tied to the personal and social identity they have assumed.

2.8 Conclusion

The existing literature related to Parkinson's disease in older adults and the negotiation of their identity post-diagnosis has been reviewed. Multiple variables have been considered in relation to the scope of this study. First, literature surrounding how our identity can shift or be impacted as we age was outlined. As well, how chronic illness impacts identity was also presented, including how people might define themselves as having an illness identity, or the various ways they come to terms with their disease. Furthermore, disability and its relation to identity was also highlighted, as disability can also be related to Parkinson's disease. The impact that Parkinson's disease can have on daily life and tasks was then touched upon, to emphasize the difficulties this may cause to experiences of quality of life, as well as to how they identify themselves. Finally, literature was addressed that pertained to preservation of a sense of self in relation to Parkinson's disease. This literature was used to support what literature is currently missing from the field, and how my research can help address some of those identified gaps

Chapter Three: Methodology and Methods

In this chapter, I provide an overview of the paradigmatic position I assumed and address the ontological and epistemological bodies of knowledge that were used to conduct this narrative study using a constructivist approach. I then address my choice of narrative analysis as my methodological approach, as well as the biographic narrative interpretive method that I drew upon to build my interview sessions. I provide details of my participant sample, recruitment strategies, as well as the modifications I made to my method to frame my study appropriately in regard to my research question. Finally, I draw upon the quality criteria and ethical guidelines that I considered when using a constructivist, narrative approach to conduct this study.

3.1 Paradigm

This study was guided by a constructivist paradigmatic position. Constructivism has been delineated as a paradigm in which the researcher and the participant co-construct data (Lincoln & Guba, 2003). Constructivists believe that learning (and research) is an active process, in which people create, or construct, their own representations of reality (Lincoln & Guba, 2003). Constructivists welcome methodologies which are hermeneutical and dialectical in theory, meaning that findings emerge through interactions that are open to multiple interpretations (Lincoln & Guba, 1994). Further, a qualitative study design was chosen in contrast to quantitative, as this type of approach is useful for uncovering emic views, which are generally grounded in studies that are subjective in their perspective, which my study intends to do with a constructivist view of identity (Lincoln & Guba, 1994). An emic view is one in which the approach of the study is derived from internal elements, meaning that the interpretations of the study encompass internal factors such as perceptions and categorizations from the participants.

Within the scope of my study, internal factors such as personal and social identity will be integrated into the understanding and analysis of results. My study fits within the frame of a constructivist lens because my study investigated how identity is constructed in diverse ways between individuals, by allowing each person to share their personal experiences with Parkinson's disease. Through a narrative storytelling of their illness experience, what the participants decided to share was completely subjective to their experiences. What they chose to share with me, as well as how they chose to say it, was dependent on their own mental representations of their narrative storytelling and was also influenced in part by my presence and

how they wanted to portray themselves to me. The data was co-constructed based on the marriage of the participant's choice of words and actions in storytelling their experience, and my presence - including what I said, how I said it, and my body language. How I chose to put their story into a narrative recount was also co-constructed, and subjective, as my interpretation of their story was influenced by their tone of voice, choice of words, and body language, as well as who I am as the researcher. Together, we created an authentic narrative that recounted the individual's experience with Parkinson's disease and what that meant for their identity in a personal and social context, which fits within the constructivist lens of knowledge generation as a collaboration.

3.2 Ontology

Ontology asks the question "What is the form of nature and reality and, therefore, what is there that can be known about it"? (Guba & Lincoln, 1994, p. 108). Ontology focuses on the nature of being and existence, or social reality. Ontologically, constructivism is characterized by relativism, meaning that "realities are apprehend-able in the form of multiple, intangible mental constructions, socially and experientially based, local and specific in nature, and dependent for their form and content on the individual persons or groups holding the constructions" (Lincoln & Guba, 1994, p. 110-111). Constructivists tend to adopt an antifoundational approach towards ontology, which "denotes a refusal to adopt any permanent, unvarying (or foundational) standards by which truth can be universally known" (Lincoln & Guba, 2003, p. 273). Therefore, constructivism does not accept objective truths about reality, but rather suggests that realities are a fluid, individualistic concept that can be altered and reconstructed through individual experiences in interactions with others within context (Lincoln & Guba, 1994). Narrative inquiry fits this ontological positioning, because this methodology states that stories, or narratives, help us to understand the ways that individuals define and construct their own realities (Smith & Sparkes, 2008). Specifically, my research study aligned with a constructivist ontology as it looked at individual experiences of forming an identity with Parkinson's disease that are subjective to each participant and understood that these identities are subject to change or evolution due to personal experiences, events, and encounters through their daily lives.

3.3 Epistemology

Epistemology poses the question “What is the relationship between the knower and what can be known?” (Lincoln & Guba, 1994, p. 108). Epistemology focuses on how we can come to obtain knowledge. Epistemologically, constructivism is classified as transactional and subjective. Constructivists believe “inquirers take their primary field of interest to be precisely that subjective and intersubjective social knowledge and the active construction and cocreation of such knowledge by human agents that is produced by human knowledge” (Lincoln & Guba, 2003, p. 271). Thus, in a constructivist study, there is an interactive relationship between the researcher and participant, so that knowledge is collaboratively created as the study is conducted (Lincoln & Guba, 1994). The researcher plays an interactive role in research findings and is aware and acknowledges their influence on the participants’ actions and emotions. Therefore, knowledge is created as an interplay between the researcher and the participants of the research (Lincoln & Guba, 1994).

Narrative inquiry uses stories as a form of verbal and social action, which can be used to form a deeper understanding of someone’s past experience and their version of reality (Smith & Sparkes, 2008). Smith and Sparkes (2008) support this by stating that “epistemologically narratives are both a way of telling about our lives and means of knowing” (p. 18). This study fits the epistemology of constructivism, due to the collaborative nature of the data collection. In a narrative study, the researcher acknowledges the influence they play in constituting the data that is then analyzed (Reissman, 2008). The interviewer understands that they are an active participant, along with the interviewee, in constructing the narrative and meaning behind it. Various verbal and non-verbal actions, including specific wording of questions, emotional attentiveness, and timing of responses, can elicit different responses from the participant, and adds to the co-construction of the data (Reissman, 2008).

3.4 Methodology

The methodology of a study is used to question, “How can the inquirer go about finding what he or she believes can be known?” (Lincoln & Guba, 1994, p. 108). Not every methodology is appropriate for every study question. For my research study, I chose the narrative methodology approach to be most fitting to answer my research question. Defined by Leiblich, Tuval-Maschiach, & Zilber, (1998), narrative research “refers to any study that uses or analyzes

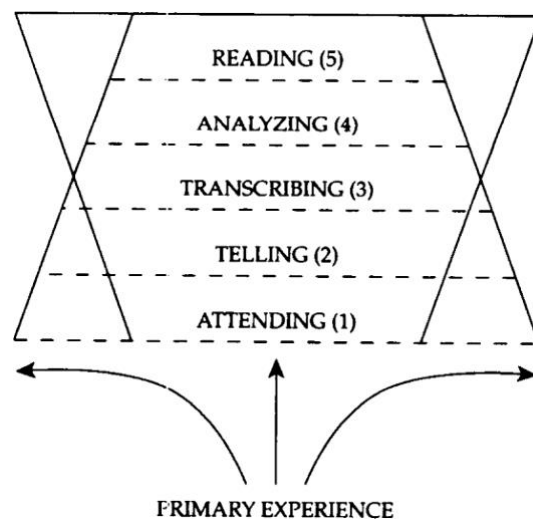
narrative materials” (p. 2), and that “data can be collected as a story (a life story provided in an interview or a literary work)” (p. 2), which aligns well with my study on Parkinson’s disease and identity. While there is no simple definition of what constitutes the narrative inquiry methodology, Reissman (2008) states that “a speaker connects events into a sequence that is consequential for later action and for the meanings that the speaker wants listeners to take away from the story” (p. 3). From there, “events perceived by the speaker as important are selected, organized, connected, and evaluated as meaningful for a particular audience” (Reissman, 2008, p. 3). Narrative inquiry focuses on how people form stories out of their lives, either in a biographical sense, or as a natural means of communication (Smith & Sparkes, 2008). Narrative inquiry was a suitable methodology to use for my research focus on identity because narratives “provide a structure for our sense of selfhood and identity” (Smith & Sparkes, 2008, p. 18). Narratives are also suitable because of the “insights [they] can give into the active, self-shaping qualities of human thought and the power of stories to create and refashion selves into their multiple guises and different contexts” (Smith & Sparkes, 2008, p.18). In other words, a narrative study is the most suitable methodology for my study because it offers a way for people to reiterate the stories and events that unfolded to make them who they are; each person will have unique events and experiences that shape and influence how they form their identity over time and context.

According to Reissman (1993), there are five levels of representation in a narrative research study (see Figure 1): attending, telling, transcribing, analyzing, and reading. The first stage, attending, is for the narrator themselves, to be present in the moment, and make note of specific features in the moment of consciousness: “reflecting, remembering, recollecting them into observations” (p. 9). Telling of the experience, the second stage, is where the narrator recounts their events, and in the scope of this study, they recounted those life experiences to myself, the interviewer. The narrator recounts the events, usually in sequence (although events may be placed out of sequence depending on how the story is recounted), with whatever details they want to include or choose to omit, to make it their own personal representation of their story (Reissman, 1993). However, “meaning also shifts in ways because it is constructed at this second level of representation in a process of interaction” (Reissman, 1993, p. 11). It is important that the interviewer knows that their presence and interactions will influence the way that the story is

recounted, and in part how the narrator wants to portray themselves in their narrative (Reissman, 1993).

Next, transcription of the events will occur. In this study, this occurred through audio recordings followed by verbatim textual transcriptions. Audio recording is not always the choice in research, but “whatever form of taping used, they would ultimately have to represent it in some kind of text, a ‘fixation’ of action into written speech” (Reissman, 1993, p. 11). This means that whatever form of transcription is used, a textual document is required regardless. The analysis of the experience is used to define and emphasize crucial moments from each narrative, and to uncover similarities and connections between the multiple transcripts (Reissman, 1993). The end goal for the analyst should be to create a metastory about the event(s) that unfolded to signify, represent, and reshape what the narrator recounted (Reissman, 1993). At the final level of representation, reading the narrative occurs as the story is encountered by a reader. Reading the text can come in forms of edits, circulated by the interviewer to colleagues and supervisors, perhaps to the narrator to ensure the narrative is a correct representation, or to an outsider in the final version of the story (Reissman, 1993). Reissman (1993) states that “every text is plurivocal, open to several readings, and to several constructions” (p. 14). Collaboration is bound to happen between the reader and the author because the reader is an “agent of the text” (Reissman, 1993, p. 14), and thus each reader will have a different interpretation of the story.

Figure 1: Levels of Representation in the Research Process



3.4.1 Illness in the narrative methodology

As my study focused on narratives of older adults diagnosed with Parkinson's disease, how a narrative is told from an individual with an illness is an important factor to consider. When someone becomes ill, diagnosed with a chronic illness, or develops a disability, the individual often begins to "think differently and construct new perceptions of [their] relationship to the world" (Frank, 1995, p. 1); the story that they once had and envisioned for their future has shifted. The story is not just about their illness, their story is coming from the body housing the illness itself (Frank, 1995). Frank (1995) states that "the body sets in motion the need for new stories when its disease disrupts the old stories" (p. 2). Frank (1995) supports the notion that in regard to postmodern illness, individuals experience and recognize their illness when they understand that the illness is more than the medical diagnosis itself. As defined by Morris (2000), postmodern illness constitutes illness as a holistic experience – it is biological in nature, but also attributes mental, emotional, and even cultural events to the overall meaning of how we understand an illness. Postmodern illness underlines the storytelling as a whole experience between the body with the disease and the self (Frank, 1995). Individuals with Parkinson's disease would be classified by Frank (1995) as part of the remission society. For these people, wellness and sickness are always at battle with each other, as living with a disease or illness is something that shifts in and out of consciousness depending on the changing state of their condition (Frank, 1995). A narrative about illness is "the attempt, instigated by the body's disease, to give a voice to an experience that medicine cannot describe" (Frank, 1995, p. 18). One key component that Frank (1995) contributes to the illness narrative is the problem of control. Frank states that "people define themselves in terms of their body's varying capacity for control" (p. 30). The problem comes along when control becomes a conscious effort, as disease is a loss of predictability in functioning. The feeling of illness comes when control is lost or surrendered (Frank, 1995).

Stories come into the foreground for 'ill people' because they "have to repair the damage that illness has done to the ill person's sense of where [they are] in life, and where [they] may be going" (Frank, 1995, p. 53). These types of stories are told in different conditions, whatever state the illness has taken on the person: fatigued, in pain, uncertainty, hope, as well as fear that will turn the person into a "narrative wreck", a phrase displaying equal wit and empathy" (Frank, 1995, p. 54). Becoming a narrative wreck can be salvaged by the telling of self-stories, in which

the self is being formed as the story is told (Frank, 1995, p. 54). These factors are important to consider in how a narrative from an ill person may differ from someone in a “healthy” state of mind and body. Understanding how a participant defines their illness plays an important part in how they identify themselves, and whether or not they find that illness is associated with their identity at all. This will be discussed further in the findings chapter of my thesis, as codes are examined and can be related to illness narrative theories.

3.4.2 Reflexivity in narrative studies

Reflexivity, or “the process of reflecting critically on the self as researcher”, is a key component of the narrative methodology and constructivist paradigm (Lincoln & Guba, 2003, p. 283). Reflexivity is key in constructivist, narrative studies because it allows the researcher to comment on how their presence has been an influence in the construction of the data, by reflecting throughout the research study and process. Reflexivity allows the researcher to “come to terms not only with our choice of research problem and with those with whom we engage in the research process, but with ourselves and with the multiple identities that represent the fluid self in the research setting” (Lincoln & Guba, 2003, p. 283).

Reflexivity was practiced throughout the duration of my study, by writing a few small paragraphs before and after each session that detailed my expectations and reactions to each session. By writing reflexive notes, I was able to look back and reflect on my assumptions, thoughts, and feelings towards my study and my data, and how it changed over time, during the data collection, analysis, and write up. The reflexive notes were integral as they were also integrated into each of the narratives I wrote for my participants. The more reflexive notes I did, the greater benefit I found in them, and began to not only find them a sense of therapeutic release, but also a conscious choice to be able to document my thoughts as a constructivist researcher. This was not only interesting to me, but also very valuable to be able to see my growth over time and how I evolved since the beginning of my thesis, as a student, as a researcher, and as a person.

Another form of reflexivity that was practiced was through meetings held with my supervisor, as well as my advisory committee members. These meetings were conducted once every few months in order to discuss my data as I progressed through the stages of my study. This was key to reflexivity as my committee was able to give insight, advice, and comment on

the different ways to “see” my data. This allowed me to reflect on the multiple ways the data could be represented through different viewpoints and further emphasized my constructivist lens as I understood the multivocality that my data holds.

3.5 Theoretical Framework

Identity theory is a framework that can help to explain how people with Parkinson’s disease identify themselves based on their personal characteristics as well as their interactions in society, relating to their social identity. Identity theory, as defined by Burke and Stets (2009), “seeks to explain the specific meanings that individuals have for the multiple identities they claim; and how their identities tie them in to society at large” (p. 3). Burke and Stets (2009) claim that depending on our surroundings – including both people and the environmental setting – we assume specific identities that have important meaning associated with them. They define an identity as “the set of meanings that define who one is when one is an occupant of a particular role in society, a member of a particular group, or claims particular characteristics that identify him or her as a unique person” (Burke & Stets, 2009, p. 3). Different meanings are applied when an individual assumes different roles, such as a student, a parent, a member of a political party, or a person with a disability (Burke & Stets, 2009). When applying identity theory, it is important to acknowledge that the individual and society are inextricably linked in the concept of identity; our identities exist because of social structure and the context we are associating it with (Burke & Stets, 2009). Therefore, identity theory emphasizes the relationship between an individual and society, and how they mutually influence each other to form specific identities (Burke & Stets, 2009). Identity theory stems partly from symbolic interactionism, which focuses on defining the self in terms of how each person interacts with others (Burke & Stets, 2009). In terms of identity theory and symbolic interactionism, the self is constructed through various interactions and experiences, and can be altered, sustained, or evolve as an individual goes through different life events, meets new people, and has new experiences (Vann-Ward et al., 2017).

Identity theory was vital to framing my research theoretically, due to its focus on social structures and identification in society. With respect to Parkinson’s disease, researchers propose that the condition “changes how people function, interact, and subsequently view themselves. Yet they actively strive to maintain established roles and identity” (Vann-Ward et al., 2017, p.

964). Identity theory supports the notion that we identify ourselves based on social structures. Using identity theory, social structure can be viewed as a multi-faceted system (Burke & Stets, 2009). From a small-scale perspective, individuals interact with others in their daily life, whether they be with someone they know, or a stranger (Burke & Stets, 2009). On a medium scale, these patterns of behaviour can be applied to interactions between larger groups of people (Burke & Stets, 2009). For example, behavioural patterns of a nurse and a patient can be compared to other patients to understand how creation of behavioural patterns emerge within the patient rooms, or ward. On an even larger scale, the interactions between different large groups, for example between two different wards or hospitals, can be looked at to see behaviour patterns as a whole (Burke & Stets, 2009). Burke and Stets (2009) acknowledge this as an abstract idea, but it is important to understand how each level of social structure can influence an individual's interactions.

For my research, I focused on small-scale social structures, such as by asking a participant to recount their interactions with people in their daily lives, including friends and family, as well as acquaintances and strangers within the broader community setting. Medium-scale social structures also briefly came up, as participants drew comparisons between themselves and others with Parkinson's disease and the interactions they might have, as well as individuals with different chronic diseases, which will be discussed in greater detail in my findings chapter. While I acknowledge that other scales can come up in personal stories of negotiating identity with Parkinson's disease, I chose to focus on small-scale social structures as this relates, most specifically, to my research question, although some medium-scale social structures emerged from the findings, as well.

3.6 Study Context

3.6.1 Setting

My research study was conducted within the region of Southwestern Ontario, specifically focusing on residents in the city of London, Ontario and surrounding towns such as Arva, St. Thomas, and Ingersoll. In a 2011 brain disorders prevalence report, Southwestern Ontario had a Parkinson's disease prevalence of 4.5 per 1,000 persons (Government of Canada, 2012). This ranked within the top three Ontario regions with the highest prevalence of individuals with Parkinson's disease, behind Erie St. Clair, and Central Ontario (Ng et al., 2015). As of the 2016

Census Report, older adults aged 65 and older represented 16.6% of the overall population in London, Ontario (Statistics Canada, 2016). This subpopulation has increased 14.7% from 16.6% in 2016 (Statistics Canada., 2016). Within the London and Middlesex area, there are many support groups and organizations dedicated to educating and supporting those with Parkinson's, such as the Parkinson's Society of Southwestern Ontario, Parkinson's Carepartner Coffee Club, and Parkwood Institute affiliated with St. Joseph's Hospital that has specialized geriatric services offering exercise groups tailored for those with Parkinson's disease.

3.6.2 Participants

This study recruited exclusively older adults (aged 60 years and older) that had been diagnosed with Parkinson's disease as an older adult and not during an earlier stage of life. This study was limited to participants who were 60 years and older because my research was focused on understanding how identity is negotiated for Parkinson's disease in an older adult population. Using the age of 60 to define older adults was used because Parkinson's disease research has shown that the majority of onset and diagnosis of the disease occurs after the age of 60 (Farlow, Pankratz, Wojcieszek, & Foroud, 2004).

Older adults with Parkinson's disease were purposefully sampled because of their rich lived experience. Prior to my recruitment attempts, I was informed that it can be difficult to recruit participants with Parkinson's disease within London and therefore I planned multiple recruitment strategies to maximize the likelihood of reaching my desired number of participants. I made a list of all potential places and strategies for recruitment to maximize my efforts (see Appendix A). My goal of recruitment was to connect with sites, societies, or groups associated with Parkinson's disease in London, Ontario. I also wanted to target older adults through programs not specifically affiliated with any Parkinson's societies, to allow for a more diverse group of participants. Subsequently, I was able to recruit through the Victorian Order of Nurses, the Society for Learning in Retirement, as well as through Rock Steady Boxing. Conveniently, I was affiliated with London Rock Steady Boxing, which is a boxing program for people with Parkinson's disease, as a volunteer during the time of recruitment.

A gatekeeper was identified at each site to help with recruitment. At all organizations, these gatekeepers were organization managers. They were contacted to inquire about their willingness to allow recruitment to occur at their site. These conversations all occurred over

email, by attaching my email script (see Appendix B) and a recruitment flyer (see Appendix C). Managers were asked to pass along the flyer to their members. I also gave the option to come to their organization and speak about the study in person. All organizations chose to pass out my flyer electronically to participants via their membership email list. On the flyer, interested participants were given my Western University email address and office phone number in order to contact me directly to hear more about the study. Whether participants contacted me by email or telephone, the corresponding script (see Appendix B and D) was used to describe the study.

Since narrative inquiries typically collect in-depth understandings from a smaller sample, I aimed to recruit 3-5 participants for my narrative study. I recruited three men and two women, for my study maximum of five participants. I tried to ensure that I had a proportionate representation of men and women, as there are higher rates of Parkinson’s disease among men. I also tried to attain a diverse representation of marital status – three participants were married, while two were single (divorced) (see Table 1). After successful screening of the first two participants based on the inclusion criteria, the following participants were additionally screened for marital status, to ensure there was a diverse range.

Table 1: Participant Demographic Information

Participant	Age	Sex	Years Since Diagnosis of PD	Marital Status
P1	74	Female	3 years	Married
P2	80	Male	4 years	Married
P3	84	Male	7 years	Married
P4	71	Male	14 years	Divorced, Single
P5	77	Female	2 ½ years	Divorced, Single

To participate in the study, participants needed to meet the following inclusion criteria:

- ❖ Be 60 years of age or older;
- ❖ Have received a diagnosis of Parkinson’s disease;
- ❖ Feel that Parkinson’s disease has affected their functional ability, and;
- ❖ Be able to communicate effectively in English.

Participants were not chosen based on a specific duration of time since diagnosis but rather on how their disease had affected their functional ability. This was a part of my inclusion criteria – participants were asked if their disease had affected their functional ability in their daily life. If the answer was yes, prospective participants could continue with the screening process. Participants were excluded from this study if they experienced any cognitive challenges that would limit their ability to consent to participate. There were no cognitive tests used to ascertain their ability to participate, but rather cognitive status was determined by their ability to understand the scope and requirements of participation in the study. If I felt a participant was unable to understand the purpose of the study, they were not enrolled. This did not happen with any participants in my study, with all willing individuals able to participate. As well, older adults who had been diagnosed with Parkinson’s earlier in life, before the age of 60 (for example, those with young-onset Parkinson’s disease), were also excluded from this study.

You may note that one participant in my study, P4, was diagnosed at the age of 57-years-old. This should have technically excluded this participant from my study. However, at the time of screening, the gentleman was confused about the year he was diagnosed and fit all eligible criteria. It was not until later that he clarified he had been diagnosed earlier in life and was already enrolled in the study. This will be touched upon in my discussion chapter as a limitation of my study. Those diagnosed earlier in life may have a different outlook on their disease than those diagnosed in later life, as the variations in ages and life stages can create differences in uncertainties of the future and disease outcomes (Ravenek, Rudman, Jenkins, & Spaulding, 2017).

3.7 Methods

3.7.1 Data collection

I conducted three separate sessions with each participant, in order to gain as much insight and detail as possible into each participant’s story about how they adapted, managed, or negotiated their identity as an older adult aging with Parkinson’s disease (see Table 2). The format of my data collection was modeled after the biographic-narrative interpretive method (BNIM) by Wengraf (2001), which is often used to study life histories and stories, such as those living with a chronic disease (Corbally & O’Neill, 2014). In using the BNIM, a three-part session process is conducted, in which the first interview is comprised of two sub-sessions (Ross &

Moore, 2016). The first interview begins with the researcher asking an over-arching question that prompts the participant to give an uninterrupted, open narrative, otherwise known as the Single Question for Inducing Narrative (SQUIN). This was followed up with a second sub-session that is lightly structured by the researcher to ask further questions about the participant’s narrative, as well as push for more detail, in the form of Particular Incident Narratives (PINs; Ross & Moore, 2016). The second session takes the form of a semi-structured interview, in which the researcher asks more specific questions regarding what was revealed in the previous interview (Ross & Moore, 2016). Unlike with the BNIM, which requires only two interview sessions, I included a third session which served as a chance to go over the narratives written about each participant. This session was also used as a debrief and review of the past sessions for each participant. Each session took between 1-3 hours, depending on how much information the participant was willing to share, as well as his or her level of functioning (e.g. three hours was not possible for some participants due to fatigue or loss of concentration) (Wengraf, Chamberlayne, & Bornat, 2002).

Table 2: Overview of Method Format

Session	Sub-Session	Content	Method	Objectives
1	1	Gathering the story	Biographic Narrative Interpretive Method (BNIM)	<ul style="list-style-type: none"> ❖ Introducing myself to participant ❖ Addressing letter of information ❖ Answer any questions from the participant ❖ Obtaining consent ❖ Explaining BNIM, asking SQUIN and documenting any key words
	2	Probing questions regarding the story		<ul style="list-style-type: none"> ❖ Probing further details from SQUIN using PINs
2		Completing the story – asking any follow-up questions since analyzing the transcript; Learning about identity	Narrative Follow-Up; Semi- Structured	<ul style="list-style-type: none"> ❖ Introducing general identity questions identical for each participant

			Interview	<ul style="list-style-type: none"> ❖ Asking identity questions tailored to each participant based on details from their first session ❖ Asking specific questions about narrative from first transcript (clarifications, elaborations) ❖ Focused more on identity piece of study rather than Parkinson’s disease background and how that came to be
3		Discussion of the narrative presented to participant	Collaboration of participant and researcher to ensure appropriate representation	<ul style="list-style-type: none"> ❖ Participant and researcher sit down and discuss narrative; any edits, factual discrepancies, misquotes ❖ Validating the written narrative and all details

3.7.1.1 Session one:

Sub-session one: Single question for inducing narrative (SQUIN)

All informants were given the option to choose the environment for the first interview, with all choosing to do the first narrative interview in their homes. Prior to beginning the interview, I reviewed the letter of information (see Appendix E) with the participant and had all consent forms signed. Each participant was given the opportunity to ask any questions they had or voice any concerns about the study process. I also asked them to complete a demographic questionnaire (see Appendix F). During this first interview, I posed my SQUIN as: “Could you please tell me the story of your journey with Parkinson’s disease?”. This question was broad enough that it could be interpreted as each participant liked. By asking only one question, the goal was to allow the participants to give an open narrative of their story of living with

Parkinson's disease (see Appendix G for interview guide). This sub-session was uninterrupted, and instead I remained engaged in active listening for the duration of their storytelling. However, I used non-verbal and non-directive verbal prompts (e.g. nodding my head, 'mhmm', 'yes') in order to allow each participant to tell their story until they decided, on their own terms, that they were done.

Sub-session two: Particular incident narratives (PINs)

Following the SQUIN, in which the participant shared their story of living with Parkinson's disease, I used this sub-session to delve deeper into details that the participant might contribute to their narrative that they did not provide enough information on. In the original structure of BNIM, "no question can be asked which is not a story-eliciting one; no question can be raised about a topic not raised by the interviewee in the initial narration" (Wengraf, 2001, p. 120). Each participant was informed prior to the start of session one about the goals of each sub-session (i.e. – sub-session one will allow the participant to tell their story, and sub-session two will be focused around probing further into their narrative). In order to prompt the participant, I used key phrases or cues, otherwise known as Particular Incident Narratives, that were aimed to help the participant move closer to their own narrative and the memories associated with it (Ross & Moore, 2014). PINs are key phrases or cues that encourage the participant to move closer to their memory of things they mentioned in their narrative, without being too intrusive (Wengraf, 2001). For example, a researcher would make note of reoccurring words or phrases that the participant says during the interview. From this, I would probe further on these key phrases, such as by saying, "You mentioned (insert key phrase) ... Can you remember anything else important from this time?" (Wengraf, 2001). The participants were probed to further discuss certain details of the narrative they provided depending on how their story unfolded using the SQUIN. This allowed me to then ask questions about how the participant felt about themselves, in terms of specific events or moments they mentioned in their narratives. Examples of things that were touched upon were how participants felt when they received their diagnosis, or how they felt when in the presence of unfamiliar people in public. The focus of this interview was to understand how the participant came to tell their own story about living with Parkinson's disease. This interview was audio-recorded and transcribed verbatim. Additionally, reflexivity was practiced, by use of reflexive notes whenever I felt necessary, usually before or after an interview session.

3.7.1.2 Session two: Semi-structured interview

All of the second interview sessions also took place in the participant's homes. This interview was lightly structured to delve deeper into certain areas of interest to my research such as: identity prior to and after diagnosis, specific challenges faced, and experiences of disability, from both a personal and social identity standpoint. Each participant was first asked a set of general questions about identity, followed by specific questions that emerged from their first session. Participants were asked to describe any particular instances where they felt their identity was threatened, shifted, or where they struggled to maintain identity on a personal or social level. These questions were aimed at understanding if there were any negotiations to identity post-diagnosis, as well as in personal versus social spheres (see Appendix H for interview guide). Thus, for the purpose of my interview, the original structure of session two by Wengraf (2001) was altered to fit each participant and their narrative from session one, in that questions could be asked that were not inspired by the initial narration. This second interview allowed for a deeper questioning into the identity portion of each participant and how that is connected to their narrative, as well as to clarify any questions that emerged after the first session. This session was used to help both the participant and researcher explore the topic of identity, clarify any information mentioned in the previous sessions, add any missing information, or ask questions.

This second session also helped to fill in any gaps identified during the previous session, to allow the participant to reflect and elaborate on their story, and to dig deeper into identity, especially if the participant did not talk about it a lot during the first session. Thus, the data gathered from this session emerged partly based on the data gathered from the previous session, and thus was tailored to each participant. As with the first session, this session was audio-recorded, and transcribed verbatim.

This session was modified for two participants, in order to accommodate for their stage of disease. For example, for one participant who had difficulties with effectively forming sentences, the questions were emailed prior to the session in order to allow him to better prepare by giving him extra time to think about his answers. Another participant, who struggled with focus and fatigue, was given the questions one at a time, printed in large text on a single sheet of paper, to keep him on track as best as possible. This participant was also given the option to have the second session split up into two separate dates, to allow him enough time to answer the questions without physical and mental overexertion. This participant chose to break the interview

up into two separate interviews due to fatigue. While the second part of this interview was scheduled, it was never completed as the participant fell ill, and in the interest of time and wishes of the participant, we decided to continue onto the narrative session without the second portion of the interview, as most questions had been answered in the first anyways. Unfortunately, before the final session, the participant became even more ill and was admitted to the hospital. This particular participant's narrative is still included in chapter five, and more information can be found there.

3.7.1.3 Session three: Debrief and review

The final session of this study acted as a review of the narrative for both myself - the researcher - and the participant. By the time the third session was scheduled, three participants continued to use their home as the study location, whereas two participants had fallen ill and required their hospital or rehabilitation institution to be the meeting location. In preparation for this session, I prepared a narrative account of each participant's story (see Chapter 4). The goal of this session was to share their narrative account with each participant and to seek both feedback as well as clarification on the plausibility of my account (see Appendix I for interview guide). This gave the participant an opportunity to voice what they believed was or was not a plausible representation of their story. They were able to discuss what aspects were right or wrong, and also gave me the chance to reflect on how justly I analyzed the participant's story. This third session was included to ensure that each participant was comfortable with how their story was portrayed, and for me to understand if her depiction of the participant's story was plausible. This also allowed for me to ensure that all factual evidence was correct, as there were some discrepancies between retelling of the stories during the previous sessions and what the narrator believed to be true when reading it back. This was seen most often when recounting specific years and durations of time, which were sometimes difficult for people to recall on the spot.

I shared each participant's story with them using a typed copy of the narrative. This session was not recorded if they were only noting on the accuracy of the narrative and did not have much input to add. Instead, documentation of changes was made physically on the narrative papers. If the participant began to add information or details that had not been mentioned in previous transcripts or the narrative, the recorder would be used to document any novel information. This did not occur for any participants, so none of the third sessions required an

audio recording. Prior to this third session, the participants were either mailed or emailed a copy of my interpretation of their narrative. This was done to ensure each participant was given time to read through the narrative and think critically and clearly about the accuracy, plausibility, and their personal comfort level with the narrative itself prior to the third, and final, visit.

3.7.2 Transcription of the data

The way the transcription is completed is also an interpretive experience, and the decision about how to transcribe the narrative will lead to different interpretations and ideological positionings (Reissman, 1993). The amount of details included within the transcription can impact how the person is interpreted. For example, throughout the transcription of my sessions, I included common filler words, such as “um” and “uh”, as well as pauses and repetition or stuttering of words. Other people transcribing the data may omit those words and write the sentence without those details. During the third session, my participants said they became aware of how many times they stumbled over their words once they had read back their narratives and the quotes embedded. While they were not too fond that they said such filler words, I noted that it was what made their voices authentic and true to how they spoke.

3.8 Data Analysis

Data analysis of qualitative research generally involve the identification of key concepts, themes, or patterns found within the data (Coffey & Atkinson, 1996). For the scope of my study, I chose to use coding as the key tool of data analysis. The purpose of coding is to segment data as a way to organize into simpler categories, which can then be expanded and analyzed to add extra layers of interpretation and pose new questions (Coffey & Atkinson, 1996). For narrative analysis, it is important to consider that “language conveys meaning, and that *how* a story is told is as important as what is said” (Smith & Sparkes, 2008, p. 20). As such, I took the approach of a story analyst, specifically taking on a holistic-content approach, in which the interview (or narrative) is interpreted by using the complete life story told by the individual. I adapted my narrative analysis using text from Lieblich *et al.* (1998), and Coffey and Atkinson (1996), which both offered guidance and insight into line-by-line and holistic-content coding. By using the life story of the participant, sections of the text are taken and interpreted in context to other parts of the narrative (Lieblich *et al.*, 1998). First, the transcripts were hand-coded using line-by-line analysis, in order to outline the key words and quotes, along with an analysis list, that would be

useful when creating the narrative write-ups. Following the writing of the narratives, the transcripts were then uploaded into NVivo, a data analysis software, to go through another round of line-by-line coding, but instead creating codes to categorize. Once codes were created, themes were constructed first by myself, and then followed with a collaborative analysis session with my supervisor in which we created broader overarching themes to collapse the codes into.

3.8.1 Data analysis round one: General coding

In my first round of data analysis, each transcript, which was transcribed by myself (the researcher), was then coded line-by-line, individually after each session. Coding, at a general level, is typically the first step towards organizing data categorically (Coffey & Atkinson, 1996). The first session for each participant was co-coded by my supervisor, and then discussed to ensure consistency in terms of codes, but also to open up discussions for ideas or codes that one person saw that the other did not. This was especially apparent when coding my first session transcripts with each participant but became less frequent once I became more comfortable with the coding process. Check-ins with my supervisor were made continuously to ensure I was on the right track in terms of codes used. The first two session transcripts for each participant were used for coding, as these would be used to create the narrative presented in the third session.

I tracked coding by circling, underlining, and marking where significant words and quotes were. The transcripts were read over multiple times until a pattern emerged, and I noted that the significance of the data would depend what kinds of details or context came out of each individual's story (Lieblich et al., 1998). Therefore, I recognized that the codes found in one transcript may not be the exact same as the next participant's, as each may have different important events that added to their narratives. Reading over transcripts multiple times was particularly important, as each re-read helped me to gain more insight into the participant's experiences in their narrative retelling (Lieblich et al., 1998). Each time the data was read over, a few more codes were added. While I completed my coding by hand, I also sent a copy of the transcript to my supervisor for her to hand-code. I then compiled the two coded transcripts into one list and marked where we had similarities and differences between our coding.

From these transcripts, all coded data was compiled into a separate list organized by session and participant to make further analysis easier, as well as to aid in marking important events when writing the narratives. The difference in codes identified by my supervisor and

myself were categorized by using different colour fonts. Coloured markers can be used to distinguish various themes in the story (Lieblich et al., 1998). It is also important to note the general impression, as well as unusual aspects of the story, such as contradictions (Lieblich et al., 1998). In my case, contradictions in the form of fractures to identity, that were coded by using line-by-line analysis, as well, to pinpoint areas where I found contradictions between what the individual was saying and the underlying meaning. These fractures of identity will be discussed in further detail in my findings chapter.

These codes and prominent quotes were then used as a guide to construct the written narratives that were written, and subsequently presented, to each participant. When writing a narrative, I first looked at all the words I had circled and underlined most that related to each other, to determine what the most common concepts mentioned were. I could use these words as a guide to understand both the sequence of events that occurred, as well as where the richest amount of information could be pulled from. I started with this framework as a basis to understand how to piece together the sequential information and structure the identity piece into it. I then looked at the quotes I had highlighted to determine what kind of anecdotal evidence I had to support the events and recount. The demographic questionnaires were used in the writing of the narratives, as well, as data from this was used to frame the background of the participant in the introduction of each narrative.

3.8.2 Data analysis round two: Layering of codes

Following the completion of data collection and presentation of narratives to participants, NVivo 12 was used to further code the transcript into subcategories of codes. Once all narrative sessions had been completed, analysis was also done across and between the transcripts, in order to address the broader research aim. Organizing data into subcategories can allow for overlapping of more general codes, which can then be used to start making connections across and between transcripts (Coffey & Atkinson, 1996). The first two sessions for all participants were uploaded and compiled into one document in NVivo to easily understand the strength and depth of mentioned themes across and between participants.

Using NVivo, I once again completed line-by-line coding and highlighted key words and phrases which I then assigned to a code, a sub-code, or a combination of the two. I went through this process for each transcript. When I came across data which I thought would add to my study,

I either added it to an existing code, made a new one, or a combination of the two, depending on what the significance and topic of the data was. As with the first round of coding, I also reread the transcripts multiple times. Rereading each line can allow for significant patterns in the data to emerge (Lieblich et al., 1998). This kind of coding adds different levels of analysis and complexity to be explored, and to understand where codes can be connected to each other to create broader themes (Coffey & Atkinson, 1996). This list of codes, which included the frequency at which each code was mentioned across and between transcripts, was then co-analyzed by my supervisor.

3.8.3 Data analysis round three: Interpreting the codes

In interpreting the codes created, it is important to display the codes in a way that will be easy to read and optimize the levels of analysis (Coffey & Atkinson, 1996). As mentioned, a list of codes and sub-codes was created, which noted the frequency that each code was mentioned within and between transcripts. Moving to interpretation of the codes means being open to exploring the variation and degree to how those codes can be understood and organized into themes (Coffey & Atkinson, 1996). After the general impression is documented, as done through constructing the written narrative, the researcher must “decide on special foci of content or themes that you want to follow in the story as it evolves from beginning to end” (Lieblich et al., 1998, p. 63), meaning that the researcher should begin to form an understanding of themes that can be connected within and between data sets. Some specific foci are identified depending on their repetitiveness in the data, or number of details provided about it (Lieblich et al., 1998). Once the data is displayed in codes, the categories or themes can emerge and be split into subcategories or subthemes, that are linked together (Dey, 1993).

I, as the researcher, looked at the strength and depth of my codes and sub-codes to help when collapsing them into broader themes and sub-themes. I also looked at how the stories evolved based on the question I posed to participants, and how my themes would intertwine or work alongside the sequence of their stories. For example, as their narratives go in sequence from prior to diagnosis of Parkinson’s to where they are currently in their disease progression and identity, I also paid attention to how my themes would make sense in terms of identity and the process of negotiation that occurred over the course of their disease. Where the codes are placed within the categories can be moved around, to make certain pathways and connections

between the data (Atkinson & Coffey, 1996). It is important to note the conclusions identified from each theme, as well as pay attention to the first and last time each theme appears (Lieblich et al., 1998). It is also important to note the context for each theme and the transitions between themes (Lieblich et al., 1998). I considered all these factors outlined by Lieblich et al. (1998) and Coffey and Atkinson (1996) when creating my codes and when organizing them into theme groups.

Upon analysis of the list, my supervisor and I met to co-construct overarching themes. Throughout the data analysis process, I engaged in ongoing meetings and conversations with my supervisor as a way of participating in collective reflexivity. As noted by Lieblich et al. (1998), “discussion of the case with other independent readers can be highly productive” (p. 63), but notes that as this work is interpretive, and as such inter-rater reliability should not be expected. This is important to note, as I aimed to produce my own rendering of each individual’s story while still acknowledging that each research collaborator, including my supervisor and the members of my advisory committee, will create their own, separate interpretation of the narrative itself that might add to the overall analyses of each story. My supervisor and I both had separate lists of how we had interpreted the data, which was then used to collectively, and collaboratively, discuss and map out how our interpretations could be merged to create a thematic overview of the data analysis. After collaborating with my supervisor, I then made an analysis theme document to be sent to my advisory committee in order for them to provide feedback, in an effort to further the multiplicity of analytical lens being used.

3.9 Data Management

All data including audio recordings, transcriptions, and reflexive notes were stored in a locked filing cabinet in a locked office in Elborn College at Western University. All electronic data was stored using a project-site on OWL that could only be accessed by members of the research team. Participants were identified according to codes (e.g. P1, P2, etc.) to uphold confidentiality. The names of people and places were removed from any quotes included in this thesis to ensure confidentiality of the participants.

3.10 Quality Criteria

To ensure that my research study was of sufficient quality, I followed the guidelines outlined by Tracy's (2010) eight big-tent qualitative quality criteria. These criteria are particularly valuable as they are universal across all paradigmatic approaches (Tracy, 2010).

3.10.1 Worthy topic

Tracy (2010) defines worthy topic as research that is “relevant, timely, significant, interesting, or evocative” (p. 840). My research, which is framed around the identity of older adults with Parkinson's disease, is a worthy area of interest because, as mentioned in the literature review, people with Parkinson's disease often isolate themselves and reduce their hobbies and activities, due to numerous reasons, such as social attitudes, including shame and stigma associated with Parkinson's and inaccessibility in public spaces, which can impact an individual's social identity (Burgener & Berger, 2008; Maffoni et al., 2017). Creating narrative accounts of how older adults with Parkinson's feel about their identity and how it has been negotiated since being diagnosed opens up a dialogue for those individuals, people personally connected to those individuals, as well as the general public to allow for positive changes to be encouraged that accommodate those with Parkinson's. These positive changes may be in the form of personal acceptance of how their identity has changed since being diagnosed with Parkinson's, or, more broadly, community awareness and understanding of those with Parkinson's disease, and how to better accommodate for their needs.

3.10.2 Rich rigor

Research that is rich in rigor has an abundance of “theoretical constructs, data sources, contexts, and samples” (Tracy, 2010, p. 841). As well, “rigor is also judged by the care and practice of data collection and analysis procedures” (Tracy, 2010, p. 841). There were multiple strategies I used to ensure rich rigor was present in my study, including the use of multiple interviews with the same participant and peer debriefing. Conducting multiple interviews allows for greater, more in-depth information to emerge than would occur in a single interview (Tracy, 2010). As well, peer debriefing with my supervisor allowed me to address any issues or errors that may have occurred throughout the data collection and analysis process. This enabled me to have a dialogue to allow for other ways of seeing the data than would have been accomplished had I not engaged in any kind of peer debrief.

3.10.3 Sincerity

To be sincere means “the research is marked by honesty and transparency about the researcher’s biases, goals, and foibles as well as about how these played a role in the methods, joys, and mistakes of the researcher” (Tracy, 2010, p. 841). One way that sincerity was practiced throughout this research study was through the use of reflexive notes. By being reflexive, I was able to document all aspects of my research process, including the accomplishments, errors, and emotions involved. Reflexivity allowed me to be more conscientious of my role as researcher and the influence I had on my participants. It also enabled me to be as transparent and honest as possible throughout the duration of the research (Finlay, 2002). I was also able to look back on my reflexive notes over time, to look at my growth as a researcher, and reflect on my journey as I went through every process and stage of my study.

3.10.4 Credibility

Credibility is defined as “the trustworthiness, verisimilitude, and plausibility of the research findings” (Tracy, 2010, p. 842). Credibility was employed in this study through thick description and member reflections. Thick description was practiced within the context of my study as this involves “extensive accounts, portrayals, and depictions of interactions and communicative processes as they occur in the field” (Tracy & Hinrichs, 2017, p. 6). Through conducting multiple sessions with each participant, in which I, the researcher, got to interact with the participant for a few hours, I was able to gather detailed information both in terms of what they said, and observe their state of being, natural tendencies, and emotional depictions. This allowed me to recount each participant’s narrative in a way that contained multiple details on their stories, as well as try to capture the tone they were conveying. Through my reflections after the sessions, I was able to note details that made each interaction special or memorable. The audio, observational notes, and reflexivity added to my overall research and narratives, as thick description should be used to give rich and in-depth depictions of data recounts by gathering as much data and details as possible (Tracy & Hinrichs, 2017). As well, member reflections were completed, by giving each participant the option to access their interview transcripts, as well as their narrative to look over prior to the final copy, to verify that all findings had been interpreted and documented to the participant’s satisfaction, and further encourage dialogue and collaboration. This step greatly emphasized the participant’s collaboration and input into the

findings, as they were able to comment on the accuracy of their narrative and how it was recounted.

3.10.5 Resonance

Resonance is known as the “ability to meaningfully reverberate and affect an audience” (Tracy, 2010, p. 844). Resonance can be employed through a study’s ability to be transferable, meaning that a study has “potential to be valuable across a variety of contexts or situations” (Tracy, 2010, p. 845). While a constructivist narrative study does not intend to be generalizable due to the subjective and interpretive meanings associated with each personal story, the stories may resonate with individuals that can relate to certain aspects of a participant’s narrative account of their lives with Parkinson’s disease. This study is transferable because even though this narrative study specifically focused on the identities of people living with Parkinson’s disease, the findings can be related to people living with different disabilities, as well. Many other disabilities cause people to feel isolated or singled out within a social context because of their physical or mental differences, as noted by several studies including those with chronic obstructive pulmonary disease (COPD) and cerebral palsy (Balandin, Berg, & Waller, 2005; Keele-Card, Foxall, & Barron, 1993; Paul, Ayis, & Ebrahim, 2006) to name a few.

3.10.6 Significant contribution

Research that makes a significant contribution “points out the ways in which the research will ‘contribute to our understanding of social life... and generate a sense of insight and deepened understanding’” (Tracy, 2010, p. 846). Within this criterion, this study employed both theoretical and heuristic significance. This study built on the theoretical foundation of identity theory and aimed to elaborate on how – in a personal and social context – identity can be defined post-diagnosis of a chronic disease, specifically Parkinson’s. Research is understood as being heuristically significant when the research creates curiosity in the readers and moves them to uncover new discoveries (Tracy, 2010). In terms of heuristic significance, this research aimed to move “people to further explore, research, or act on the research in the future” (p. 846) because it highlighted key issues that people with disability, specifically Parkinson’s, face in terms of their own social identity (Tracy, 2010).

3.10.7 Ethical considerations

Ethical considerations of qualitative research encompass four practices: procedural ethics, situational ethics, relational ethics, and exiting ethics. Procedural ethics, “refer to ethical actions dictated as universally necessary by larger organizations, institutions, or governing bodies” (Tracy, 2010, p. 847). Procedural ethics was practiced through the use of consent forms, which offered participants the choice to voluntarily participate in the study, the option to refrain or withdraw from the study at any point, assure privacy and confidentiality of each participant, as well as state the risks and benefits associated with participation in the study (see Appendix J for Ethics Approval).

Situational ethics refers to ethical considerations that occur due to the specific circumstances during the study (Tracy, 2010). One way to practice situational ethics is to ensure participants protection from harm, a key concern for ethics involved in a narrative study. Narrative studies can often put people in vulnerable positions, because of the details and emotions involved in a personal story (Smythe & Murray, 2000). Prior to obtaining consent, participants were assured that their identities would be protected and that they would collaborate with the researcher, using member reflections, to collectively agree that what has been interpreted is to the participant’s satisfaction.

Relational ethics pertain to “an ethical self-consciousness in which researchers are mindful of their character, actions, and consequences on others” (Tracy, 2010, p. 847). This type of ethics concerns a mutual respect between the researcher and participant. This type of ethics was upheld by allowing the participants to have an active role and voice in defining the boundaries and rules of the research. Prior to beginning any data collection, all consent forms and information pertaining to the study (i.e. the letter of information) were read through with the participant and they were given the opportunity to voice their opinion if anything needed to be modified or omitted. This could have been in terms of modifications of particular interview sessions, such as breaking lengthy or in-depth interview sessions into two, or the types of questions asked during a session, such as rewording, or omitting certain questions.

Exiting ethics is concerned with “how researchers leave the scene and share their results” (Tracy, 2010, p. 847). Typically, in a narrative study, “there is no need for debriefing” (Smythe & Murray, 2000, p. 323) because the intention to learn about a participant’s story is made apparent from the beginning. However, a form of debriefing can occur in which the researcher

shares the results of their analysis throughout the study, known as member reflections (Smythe & Murray, 2000). This type of collaborative analysis, which occurred in this study, gave the participant a sense of reassurance and control regarding how their stories were conveyed. At the end of the study, I shared a copy of each participant's personal narrative with them, that they were able to read and keep as a reminder and token of appreciation for the meaningful contribution that they provided to this study.

3.11 Conclusion

This chapter outlined the ontology and epistemology of the constructivist paradigmatic lens that I adopted for this study. As well, this chapter detailed the methodology and methods chosen for this study. A narrative methodology, with a constructivist paradigmatic lens, was used to research how older adults with Parkinson's disease negotiate their identity post-diagnosis. This study was conducted by using the BNIM narrative interviewing framework outlined by Wengraf (2001), with adjustments made to fit the overall goal of the study. The recruitment strategies, participant demographic information, and the process for how data collection and analysis were executed was also detailed. Finally, quality criteria and ethical considerations were outlined, to ensure that each stage of research was completed carefully, effectively, and respectfully.

Chapter Four: Presenting the Stories

In this chapter, I present the narrative for each of the participants in my study (identified as P1 – P5). The narratives presented represent a recounting of the stories told during their sessions and are constructed and re-written using my interpretations of their storytelling. Before sharing each narrative, I will first provide a brief reflexive recount of my thoughts and feelings after the first interview took place, as well as how I decided to construct each individual's vocalizations into written text. The goal of this is to allow the reader to understand those factors that I took into consideration when writing each narrative, including events that unfolded, body language, and emotions of the participant, as well as the researcher, as this data was co-constructed between myself (the researcher) and the storyteller.

4.1 My Reflections: P1

As noted by the pseudonym, P1 was my first participant. I remember feeling so excited when she agreed to be a part of my study, as I was nervous that I would have trouble finding people who would: a) fit the demographic characteristics necessary to participate in my study, and; b) be willing to share their story with me, a stranger. Once I got to her apartment, I realized that the excitement was still there, but my nerves were even stronger. Even though I had experience conducting interviews with participants before, this felt like a bigger weight on my shoulders because this was for my own research study. I began to wonder if the participant would find my questions too intrusive, if I would be presenting myself in the way that I should and listening intently enough to their answers to produce good follow-up questions.

Once I finished my first session with the participant, I felt accomplished. I felt like I had acquired a lot of information about their experiences with Parkinson's, which was my overall goal. I felt like I had more growing to do in terms of follow-up questions, but I knew I had tried my best for my first attempt. Looking back, I now know that I lucked out with my first participant. She was extremely cooperative, and willing to share lots of information about her life without me having to probe her too much.

When it came to write my first narrative, I was not exactly sure where to begin; although I had reviewed methodological texts addressing the process of constructing a narrative, I had never written a narrative before. It was in this moment, when I was ready to write my account of the narrative, that it became apparent to me just how I would influence the final narrative

account. The interpretations that I had made in relation to the participant, how my presence influenced their words, and now, how the words I chose to use would dictate how their narrative came across. After consulting with my supervisor and advisory committee, they offered me feedback on my first draft, which was extremely valuable as it helped me to develop a good format that would both present the narrative using the participant's experiences (by means of including rich quotes), as well as my interpretation through my choice of words.

4.2 P1's Story:

P1 was a 74-year-old married woman who had been diagnosed with Parkinson's 3 years prior. P1's path to obtaining a diagnosis was complex, as it took multiple doctors' trips, and she struggled to maintain her motivation and involvement in valued activities including church and Toastmasters while searching for the cause of her symptoms. The symptoms of Parkinson's, specifically the changes in her voice, as well as how others perceived her because of the changes, influenced P1's involvement in valued activities, as well as what she and her husband did in retirement. They engaged in less spontaneous activities and tended to stick to events that were closer to home and not too intense in physical activity. At that point, P1 continued with hobbies that were important to her, as well as making time for friends and family. She refused to let Parkinson's rule her life and did her best to live her life to its full potential.

In May of 2014, P1 noticed a change in her health, in that she wasn't feeling entirely herself and was withdrawn from others. She wasn't sure what the cause of it was but thought it might have something to do with the stress associated with helping her brother-in-law move into a new apartment: "I started to feel not well, and part of it was stress because we had to move my brother-in-law into his apartment, and he was having challenges, so that was how it started out." Following that, she started noticing that she had muscle soreness on her left side, including her knee and shoulder. When she went to the doctor about this, they found nothing wrong, and so she started doing physiotherapy to help it, however the amount of health issues she was facing began piling up, with the muscle soreness and feelings of withdrawal. After going to the doctor again with a long list of complaints, he diagnosed her with depression, and gave her anti-depressants for it: "I knew that depression was very much a physical as much of a mental thing, and so I went along with that."

During the time when she was yet to be diagnosed with Parkinson's, P1 began noticing that her enjoyment for things she once loved had changed: "I was finding I was not enjoying things that I used to do, but I kept doing them". And while she continued to keep up with her activities and hobbies, including Toastmasters and being an active member of her church, she was lacking passion and enthusiasm for them, and withdrawing from others when they tried to engage in conversations: "I was okay, but I just felt sometimes like I didn't really want to talk to people". She attributed some of those feelings of detachment to her speech volume and tone: "Not that I didn't want to talk to them, but I found it hard to make myself understood... my voice is starting to, I'm starting to lose my voice. I used to have a really piping voice, I don't have that anymore." Even though P1 noticed something was off, she never asked anyone if there was concerns with her health: "I never asked [my husband], I never asked anybody. No one said to me 'Are you feeling okay?', they just all carried on, so everything was okay".

It became clearer that P1 was not feeling like herself when she attended her mother's 100th birthday party and was not engaging in social situations as she normally did: "And, uh, and that was when it was noticeable, I guess, to my sister and brother-in-law, especially, that I just wasn't myself. I was usually the middle of the action, and I – I wasn't." Later in 2015, her sisters did some research on P1's change in behaviour, gave her some books about Parkinson's disease, and believed that she had all the symptoms associated with it: "And so finally, uh, my sisters... gave me some books that they had, they had gathered up, uh, on Parkinson's. And one of them had a list of all the, you know, the sort of the symptoms, or the things that you – and I fit it, every one of them". Around that same time period, a friend of P1's who worked for a neurologist, recommended that she see a movement disorder specialist. P1 went back to her family doctor again, to ask for a referral for a neurologist. Her doctor started to suspect that P1 might have Parkinson's disease, because while she lacked tremors, she had bradykinesia. By October 2015 when P1 had her neurology appointment, she was diagnosed with Parkinson's disease. She was given medication that worked at first, but began to wear off, so her dosage has been steadily increasing. Despite her diagnosis, P1 never let the diagnosis weigh heavily on her shoulders, and instead decided to accept it for what it was: "I try not to, um, you know, use my Parkinson's, shall we say, as a crutch, but on the other hand I make sure that people know that I have it and that accounts for why I may be different or whatever."

In December 2016, P1 experienced a big fall, when she was bumped by a door opening at an X-ray clinic and cracked her pelvis. After this, she was in rehabilitation for seven weeks, and spent one week in the hospital. This fall, as well as her Parkinson's disease symptoms, made her a lot more cautious in all situations, such as taking a slower pace when walking, and holding onto her husband for stability and support when walking: "I don't want to fall again, and because I do have a bit of, like, I mean, my balance is a little bit off with the Parkinson's – not a lot, like because I don't have those tremors – but when I stand up, for instance, when I get up from sitting, I have to kind of wait and get my bearings before I start moving. And I'm always very cautious that I don't trip or slip."

As well as her slow movements, P1 also had other symptoms that affected her daily life. She noticed that her voice was losing its projection, her rate of talking was slowing down, and sometimes she mumbled her words. She believed that her feelings of slight withdrawal from conversations with people had something to do with the change in her vocal speed and clarity: "But in a group of people, like I can't make myself heard. Or I... I speak – like yesterday in church I was doing the announcements, and I find that I - I speak much more quickly than I used to, and I run out of air... I kind of mumble sometimes, I know I do. And I get going really fast if I'm reading something and then I run out of air and then I run out of voice, and I just have to learn to pace myself." As well, she sometimes felt that while her mind was not completely coherent, she was competent and had a good mental capacity: "I find that I'm, I'm not as, like – my, my words don't come as easily as they used to. Uh, I, uh – but I, I don't feel that I have any kind of, uh, mental issues yet from it, and you know, they talk about the dementia and stuff that goes along with Parkinson's, I don't think about that yet."

Because of the many varying symptoms that Parkinson's disease can cause, P1 and her husband started limiting cumbersome activities, such as trips and cruises: "Yeah, we can't, we don't... we're not quite as spontaneous as we used to be, shall we say." While these things were important to them, they had to adjust their lives to accommodate for their wellbeing, such as reducing the number of spontaneous outings and instead doing things closer to home that limited strenuous movements, such as going to the beach at Grand Bend, or to see a play, not only because of P1's own conditions, but also because of her husband's health issues including neuropathy: "We went on a cruise, which we didn't enjoy because, well [my husband] is also having some health issues. So, we're kind of thinking we don't travel like we used to." Instead,

they enjoyed doing things together closer to home, such as spending time with close friends and family: “And family visits and things like that. I like to, you know, try to keep in touch with all the family.”

In spite of her diagnosis, P1 felt fortunate to have the life she did. Her self-identification included many roles: she is a sister, a daughter, a wife, a church member, and since being diagnosed, was someone who identified as having Parkinson’s disease. However, she did not let this identity make her feel any different, but rather added it to the list of her already large roles in society and her life: “...now I have Parkinson’s and that’s just one more thing that I’ve added to who I am... I don’t, I don’t see myself as any different at this point. I mean, I’m different because I’m slower and I... sometimes have to struggle for words and things like that, but I don’t see myself any different really except for that sort of stuff – an added thing to my repertoire.” She was not afraid to talk about it or to let people know of her condition, because she preferred for people to understand and accept her condition rather than wonder about it: “I want them to know that, that if I’m... slow or if I’m unsteady or if I’m ignoring, or whatever I’m doing, I want them to know that it’s not because of them, it’s because of me.” She believed that people were more sympathetic and patient when they were educated on her condition: “I’d like to, you know, if I know someone that has, is suffering some kind of health challenge, maybe I’ll get a little bit more... I mean, I might not be as accepting or as tolerant of them as if I knew if they had something wrong, then I would be more tolerant. So, I’m looking for that same consideration from other people.”

One of P1’s goals for the future was to become more involved with a support group, to help understand the disease more, and for both her and her husband to gain more awareness and connections with similar people: “That’s one thing I really feel we need to do, both [my husband] and I, because I think [my husband] needs to hear from other people that have - that live with someone with Parkinson’s, you know, some of the other challenges they have, the, uh, you know. And how they maybe change things to be better.” While it took some time for her to get to that point, P1 was a resilient, independent, and good-spirited person who appreciated the life she has and where she was in life.

4.3 My Reflections: P2

Meeting P2 and his wife, I instantly felt like I had known them for years. They welcomed me into their home graciously, and I could tell that there was a lot they wanted to share by the way they greeted me. Something that struck me as heartwarming from this participant was how supportive his wife was throughout his progression with Parkinson's. As his ability to communicate was becoming more difficult, she accompanied him through every session, helping to facilitate conversation when necessary, and encouraging him to participate in the interview wherever he could. While she assisted in speaking for him the majority of the time, their bond was so close that it was as if she knew exactly what he was trying to say even when he couldn't. He would nod in agreement with her every time she spoke for him.

During the first session with this participant, his wife gave me a poem she had written about P2's journey with Parkinson's, which spoke about the losses he has endured because of his condition, while also highlighting the personal attributes of his that remained intact (Appendix K). This poem moved me, and it was in that moment I realized just how applicable my study was to this couple, and how I hoped my study would be beneficial to them.

By the time I was ready to schedule my third session with P2, my visit was not to their home, but to a hospital room, instead. Unfortunately, the progression of P2's disease had become more severe. His wife said that it was unlikely he would be returning home and she was looking into nursing homes for him. This final session was very bittersweet to me; I was happy I was able to put P2's story into words, as I got the impression he and his wife enjoyed having the narrative account to share with friends and family, but saddened at the reality of where the final session was taking place. This really put the uncertainty and severity of Parkinson's disease into perspective for me.

4.4 P2's Story:

P2 was an 80-year-old married man who was diagnosed with Parkinson's disease four years prior. He had a slow progression of disease symptoms but found that they were becoming progressively worse over the course of his condition. His wife acted as his partner, caretaker, and facilitator, as P2 was having increasing difficulty translating his thoughts into words. As an avid golfer, talented orchestral musician, skilled bowler, and public speaker, P2 had to make modifications and sacrifices to his favourite activities in order to keep up with the progression of

his symptoms. Despite this, P2, along with his extremely supportive wife, remained steadfast, resilient, and as prepared for the future as they could be for what Parkinson's may bring in the years to come.

In P2's case, he had a multitude of symptoms that led to the diagnosis of Parkinson's disease, however, it took some time for that conclusion to be drawn. In 2014, P2 began having a change in vocal tone and volume: "Before it was, uh... uh... more of a radio voice, uh... because then it would penetrate. And when the, uh... voice changed, uh... it would get softer." As well as this symptom, he began losing his sense of smell. P2 and his wife went to an ear, nose, throat (ENT) specialist, who was not able to recognize that these symptoms were attributable to Parkinson's disease, as noted by his wife: "But we were – after finding out that it's one of the symptoms of Parkinson's – we were annoyed, because an ear, nose, and throat specialist should be aware of the fact that one of the early signs of Parkinson's is losing your sense of smell and a change in voice". Another key symptom that P2 expressed was a change in posture and facial expression. He began walking slower, dragging his feet, slouching while walking, and had drooping facial muscles, which caused people to begin to notice a visible difference in P2, as his wife has noted: "[P2]'s family doctor plays golf at Sunningdale where [P2] plays. And he said I noticed your posture, and several people noticed and asked, "Are you okay?". Another friend mentioned the fact that [P2] looked very sad all the time now, but that's because of the facial change. And I said "No, he's not sad", "But there's something wrong with him"".

All of these symptoms and interest from others caused P2 and his wife to become a little warier of what was happening with him and his physical changes. Once P2 consulted his family doctor about his symptoms, he was referred to a highly esteemed neurologist who ultimately diagnosed him with Parkinson's disease: "When the doctor and nurse both said, uh... "You've got Parkinson's", and they were sure when they said it". After his diagnosis, P2 began having difficulty not only with vocal changes, but also in conveying and expressing what he was thinking: "I have trouble... uh... processing a whole thought if I'm telling a tall tale. It stops, and I know it's there, and I just... can't, uh...". He knew that the thought was there, but would either lose that train of thought, or not be able to communicate it effectively. His wife was a huge help in facilitating conversations so that P2 could continue to communicate with others and was present to help facilitate for the duration of this study.

Before P2 experienced any symptoms, he had many hobbies and interests that had since been accommodated in order to complete them with motor and cognitive difficulties. From eight-years-old, he began playing saxophone and had remained one of his accomplishments over his lifetime, but since had to give up playing in a concert band: “And it’s a bit of a struggle, because, uh... music – you’re reading the music, and, uh... you... you have to go very quickly, um... So, I have to decipher, you know, but uh... that’s, that’s not working. I can, I can still play, but it’s – it’s, uh...”. P2 had to keep up both physically with playing the instrument, but also being able to follow the music correctly, such as being able to keep up with the notes and pacing, as described by his wife: “But, the processing – how to interpret the notes, the signs, then all the fingering – and so, your movements are slower now. So, you know, the thinking is slower, the fingering is slower”. He was able to keep up with this activity for so long by practicing, as well as asking for help from other players when necessary, as noted by his wife: “But you were saying it was getting more and more difficult to play and follow the music and keep up and organize all the sheets. [P2] needed, needed help. And [his friend at practice] helped you at the rehearsals, one of the other saxophone players, so he needed help with that.”

Another hobby that P2 enjoyed, and had a talent for, was bowling, as he used to be one of the top bowlers in the city: “Um... way back when they, they uh... put the uh... bowling scores in the paper – in the sports page... and I, uh... and another fellow, had uh... the, uh... we had the... um... best score in the city. And uh... but that was a long time ago”. While P2 was still bowling, the range in movements had become more difficult to make and although he did not have any modifications for this activity, he had noticed his average had decreased since having Parkinson’s. He was still trying to remain as active a bowler as he could, not only for the athleticism, but for the social aspect and comradery, as mentioned by his wife: “There’s the social aspect of being on the team and being with a group.” This social connectedness and inclusion was something that P2 enjoyed about bowling and kept him in good spirits. As well as bowling, another sport he was very invested in is golf. Despite the physical difficulty and focus that comes with golfing, P2 still took the time to play. He made accommodations for the increasing number of challenges that come with playing, including driving the golf cart. His wife helped to put these plans into action: “Actually I asked someone from the golf club, if he would be playing golf the next day, could he drive the cart so that [P2] could play, because [P2] isn’t

driving the cart, either. And he has been kind enough through the summer to book times and play with [P2] once a week”.

Throughout his lifetime, P2 was the president and CEO of many companies which required him to do a lot of public speaking. Until last year, P2 was the Convenor of the Senior Men’s Championship Tournament at his golf club, but had to give it up due to the cognitive issues he has been facing in terms of translating thoughts into words, as well as impairments in many other skills required for this position, as noted by his wife: “He’s lost his executive function, as far as organizing, planning, looking after details, running meetings, taking care of introducing people, giving the main speech. He was President of the golf club, um... organized, planned, ran the tournaments, greeted people, gave the speeches, gave out the prizes, I mean he was in charge”. While P2 may have given up that position, he still maintained his composure and patience in the face of his cognitive frustrations. He tried to bring out his sense of humour and comedic timing if he had issues with communicating: “Yeah, if I, if I stumble over a couple of words, I would say, you know, “We can take, uh... a break””. This is an example of humour because P2 acknowledged that he often paused a lot mid-sentence and made light of that fact. While he was facing annoyances and frustrations in terms of modifications to his favourite hobbies and duties, he was still able to complete most of them by asking others around him for help, making modifications to motor movements, and keeping an upbeat and optimistic attitude.

Since being diagnosed with Parkinson’s, P2 felt that his identity had not changed at all. His personality and characteristics remained the same, despite the physical and mental challenges that have come with his condition, as mentioned by his wife: “Now, [P2]’s personality is just the same. He’s cheerful, kind, friendly, positive, good sense of humour, nothing has changed about the [P2] we all know.” The biggest difficulty that P2 faced, that was most threatening to his personality, was his decrease in memory retrieval. This was a huge source of frustration for P2: “It’s negative. Because it’s not going away. And uh... um... I, I have trouble uh, controlling my retrieval of, uh... uh... the, I put it in the memory bank, and what I once wanted, I can’t find it.” Since being diagnosed, P2 had to make some changes to roles and activities that he could complete, as explained by his wife: “He could make his own decisions, he could go where he wanted, he could drive the car, he could look after the yard, he could go shopping on his own, he could – well, except for the laundry, never did that, no, or the cooking – but very capable, very bright, sociable, lots of energy. And so now, life has totally

changed, totally. From going to being totally independent to being dependent”. While P2 and his wife encountered some changes in their roles within their household, he did not believe that this has affected his identity at all and was rather accepting of it as a part of life: “Yeah, at uh... you have to... just by necessity, take on a new role”. Instead of being frustrated, he expressed his gratefulness and was very appreciative of all that his wife did for him: “[P2] always says how much he appreciates everything I’m doing. So, that’s pretty nice!”

Despite the interesting and sometimes frustrating road that P2 had been down from his journey with Parkinson’s disease, he remained the same person he has always been. P2 and his wife continued to make modifications and negotiations to help him keep his activities and life as stable as always. One of the biggest challenges for P2 was his hesitation to ask people for drives, since having his license taken away, as mentioned by his wife: “But you were reluctant to ask anyone other than me for a ride, you don’t, because you don’t, you don’t want to be dependent. “Oh, I don’t want to bother them”, or...” However, he and his wife were beginning to accept this more often in order to keep his daily habits and life as stable as ever, as she noted: “I’ve been asking people for help, because I can’t be driving [P2] everywhere, because I have some things I have to do.” As well, P2 and his wife educated themselves as much as possible on the illness and future steps to take, to ensure they were as prepared as possible for anything that may come their way, even though they acknowledged that some of it was out of their control: “I felt that we were going to learn everything there is, we’re gonna be in control. We are not in control, at all. Parkinson’s has controlled us, in every single part of our life. Um, we have to plan, we have to, it, it just affects everything.” They also wanted to be educated to not only inform themselves, but to help inform others who may not understand what P2 or others in the same situation are going through: “I’m not sure whether this is correct or not, but because we didn’t know anything about Parkinson’s, and then we started learning everything there was about it, conferences and classes and support groups, and everything. We also feel that we’re helping other people, making them aware of Parkinson’s, because in this, in [P2]’s case, no one would know, because as we talked earlier about the tremors, that’s the only thing people know about Parkinson’s. So, we feel that it’s important to educate other people and let them know.”

Together, P2 and his wife were accepting the disease, with help from family and friends, including his two sons and grandchildren. His wife used writing as an outlet to express her thoughts and frustrations and wrote a poem about P2 called *Parkinson’s is a Losing Battle*,

which expressed what P2 sacrificed, but also all the wonderful qualities he still had. P2 remained his ever-optimistic, patient, and understanding self, and tried his best to live his life to its fullest potential given his circumstances: “But we agreed on, uh... there was, there was nothing you could do about it. You do the best you can. And uh...try and, try and work around it”. P2 kept his identity intact and wished that one day, Parkinson’s would have a cure and was hopeful that day was in his near future.¹

¹Since the writing and editing of this narrative, P2’s quality of life progressively declined. Within a few weeks of seeing P2, he was hospitalized for a partial bowel obstruction, and development of symptoms of dementia. Both of these could be attributed to Parkinson’s disease and the non-motor symptoms associated. He began needing assistance with every facet of his life – eating, walking, washing, getting out of bed – as well as lost almost all ability to speak, and needed someone to facilitate in order to communicate with others. His wife and family continued to be his support system and wanted to note that regardless of his state, according to his nurses, he was their favourite patient on his floor and continued to show his personality had not changed by being his ever patient, kind, appreciative, and polite self.

4.5 My Reflections: P3

Conducting P3's interviews was one of the more challenging encounters I had with a participant. This was not because he was uncooperative or unpleasant at all, but because he was a man who loved to talk – particularly not about the questions at hand. I had trouble trying to keep him on track, and probe with appropriate questions when his mind wandered. He liked to talk about his favourite hobbies and past-times and was very detailed in his descriptions. However, he was very self-aware of the fact that he did this, which assured me a little when I would want to bring the focus back to the study. After leaving the first session, I was a little discouraged from the data I had collected, as I knew most of it did not relate to my research question. I worried that I would not be able to analyze a lot of the data in relation to my study, and decided I needed to find a new approach to the second session with this participant if I was going to keep the focus on my study.

I consulted with my advisory committee prior to attending the second session. From the guidance of my committee members, I gave visual cues to this participant during the second session, to remind him of the question I had asked, if he started to divert from the subject at hand. The visual cues consisted of large-print questions, that were given to the participant one at a time. This helped tremendously in keeping the participant more focused on the study questions. I emerged from the second session feeling a little more reassured, however quite uncertain as to how his narrative would be written. After writing the narrative, I was unable to share my recount with the participant, as he fell ill due to non-motor symptoms of his disease. Unfortunately, this participant was never able to complete his third session, and never got a chance to review his narrative. The narrative has been preserved as the first draft, as his wife allowed for his data and narrative to remain a part of the study despite his involuntary withdrawal.

4.6 P3's Story:

P3 was an 84-year-old married man who was diagnosed with Parkinson's disease eight years prior. P3's journey with Parkinson's disease had been slow-progressing but he had noticed that his symptoms were worsening in severity as he aged. The symptoms that he experienced, including balance issues and tremors, rendered him unable to engage in his favourite hobbies: sailing, flying model airplanes, and playing piano. Despite his inability to continue actively participating in these hobbies, his interest in these subjects was strong as ever. His active mind

allowed him to continue teaching and educating others on these subjects, including when he gave speeches at the Society for Learning in Retirement (SLR), a club that P3 was an active member of. While P3 did have frustrations and anger towards his condition, he did his best to maintain a realistic attitude on life, show an authentic zest for his favourite interests, and keep his family, including his daughters and wife, close to him.

While P3 could not remember the entire backstory to how he became diagnosed, due to a decline in his memory, he could remember a few critical details. In 2011, P3 and his wife went on a cruise down the Ottawa River from Kingston to Quebec City. One night, they were dancing near another couple, one of whom happened to be a doctor. After seeing P3 dancing and observing his movements, the doctor asked P3's wife whether he had ever been tested for Parkinson's disease: "She said to [my wife], has your husband ever been tested for Parkinson's disease?". And she said, "No", and so, that started us pursuing it." At the time, neither of them had thought about Parkinson's disease at all, and so this marked the beginning of them investigating the issue. Once they went to their family doctor, P3 presented most symptoms akin to Parkinson's, and was diagnosed: "I guess when he put it all together, I had, symptoms, all the symptoms I had, the symptoms that I had were um... all pointing towards, or the majority of them did."

P3's wife acted as his caretaker, helping him with his medications, taking him to appointments, and supporting him whenever he experienced a fall: "When I uh, when I fall down and can't get up, I'm glad she's there. Well actually, she doesn't do anything but phone the lifeline to the hospital, because as she keeps reminding me, I weigh two hundred and, over two hundred and ten pounds, and she's not that strong." She did her best to help him, but with the role came hardships: "[My wife] has been very good at trying to help me, uh, all those years, losing patience at the moment. I guess being a caretaker." For example, P3 noticed that his wife might have held him back from things he enjoyed doing due to being overly cautious: "I would've thought that, in my condition and so on, I could've been more independent and uh... I think that with [my wife]'s help I could've been more independent. For example, when she came back, she went out just before you were here, and um... or came back just before you came back, and I had gone into the front room where we have my piano. Well, I've got pianos, I've got one piano upstairs, and [my wife] has a piano upstairs, and I have two electric pianos. I can do a lot with those, but other instruments I don't play very well but I've got them, and I really thought

that I would be, I thought it would be a holiday, and it's not a holiday because I'm not allowed to go downstairs. I might fall down the stairs. Now, I spent \$3,000 on a chairlift, but that isn't good enough, I'm not supposed to go on that." While they both had moments of frustration and losing patience, he really appreciated the help: "When I uh, when I fall down and can't get up, I'm glad she's there.", and acknowledged that being a caretaker could not be an easy role to take on at his stage of illness: "I think I should be at the stage where I should at least be going in...

occasionally into a respite program. [My wife] should be going into it." He knew that he might not be "a good patient" sometimes, and that his wife might have overprotected him, but that she did it because she wanted to ensure he was always safe: "She's afraid that I'll fall over, or fall downstairs and crack my head open, or something, and she would have to deal with it... or more importantly wouldn't want me to have this problem, wouldn't want me to hurt myself." P3 and his wife both liked to be educated on the disease and attended a number of conferences on the matter, including one, most recently, in Waterloo. They enjoyed going to conferences because they did not believe they know everything about the disease and "want to learn a little bit more".

P3 considered himself fortunate to have had a slow progression of Parkinson's compared to others: "I seem to be, um... steadily deteriorating, but not, um – to any – some people, they're dead in two years, I guess. Not – well, not really, but um, they um, certainly some people suffer from it at a quicker rate than I seem to." He also acknowledged the fact that every person who has Parkinson's disease will show and have varying symptoms: "You could put ten Parkinson's patients in a row and they'd all be different". He noticed that while the progression of the disease had been slow overall, that he showed greater severity of symptoms as he aged, one of which was losing his ability to use his hands for fine motor skills - including writing - which he considered very important: "My biggest problem currently, is, um... I've lost the ability to write, both handwritten and even typewriting." Another problem he was dealing with was motor and balance issues: "The trouble is I'm getting to that point I think where now I can't really hold my balance as well as I used to, and that's an important thing, I found." Because of his balance challenges, P3 had to spend a lot of his time sitting down, and this took away from his ability to continue pursuing and practicing his favourite hobbies. He firmly stated that he had three major hobbies: sailing, flying model airplanes, and playing piano. These hobbies were difficult for him to continue doing because most required open spaces, and a steady gait: "I'm certainly a lot less confident than I used to be. Um... I think that's because I find that, there seem to me to be many,

three major hobbies, and uh, I'm being prevented by doing... all of those rely on open spaces – not all of them – but sailing, obviously. Flying radio-controlled model airplanes also outside, and then um, music is the inside". While P3 believed he would still be able to play the piano in his current state, he regretted not keeping up with it because of how much his motor and cognitive skills declined by not practicing "I had to quit playing. I didn't have to quit playing, I stupidly quit playing", and was discouraged and irritated by his decline in ability to engage in his favourite hobbies: "Frustrated. I used to be able to play piano pretty well. Now I can't, it's my fault I should have kept up playing but uh, no, I'm uh... If it was ten years ago, I knew what I knew now, I would uh, be different. There's nothing at the moment that I'm really good at."

As well as gait issues, P3 faced some difficulties in three other areas: cognition, memory, and speech volume and tone. He realized that sometimes he lost track of his thoughts or could not remember certain things that he wanted to say. At the Society for Learning in Retirement (SLR), P3 would sometimes give a talk about sailing, model airplanes, or music, and to aid in his memory problem, he would tell people before he began his talk that he may lose his train of thought: "I'll say that I'm, I'm gonna give this a shot, but if I stop in the middle of a sentence it's because I've forgotten what I'm talking about." However, he found ways to cope with his issue, including using humour as a coping mechanism: "Of course, I have, I make a point of having a, at least a, not necessarily, completely forget or written in front of me. Although I tend to, if I do that, I sort of tend to ignore it and tend to ad-lib, but I'm not, I'm a lot more cautious about ad-libbing now. Um... if I get stuck, if I want to get stuck, where [my wife] or maybe the person in charge of the thing, um... just get me two or three words and I'm okay again. But uh, actually I usually end up making a joke of it." In terms of his speech, he was finding that it was getting more difficult for him to speak in a loud volume and tone: "When I sometimes want to, I can't, you know? Someone says, well just a minute, but now, it suddenly doesn't come out. So yeah, I can't explain that". He knew that his voice was declining and was aware that it was one of the symptoms associated with having Parkinson's disease: "Yeah, but that's all, no, I, I haven't gotten to the point, but I do know that Parkinson's patients have different things that are wrong with them, and one of them is speech. And I'm saying, I won't be surprised if I get to the point where I can't speak, or hear, either."

P3 felt that his identity had not changed since being diagnosed with Parkinson's. When asked if he had ever experienced a shift or change in his identity, his response was: "I really

can't... the answer to that is no, I can't". Instead, he acknowledged the frustrations and anger that came along with having Parkinson's and was not in denial about his stage of illness; he knew he could get frustrated but also understood and admitted that about himself: "I tend to get angrier quicker." He was not embarrassed to tell people he had the disease, because he felt that people may not have understood his situation entirely until they knew what he was dealing with: "Some people, some friends, some association, seem somehow ashamed that they have Parkinson's, or any other illness for that matter. But um... uh, yeah, I, I uh, I think, my problem, they uh, I can't be blamed, I, um... I can't blame, they don't know the problem, then um, they shouldn't be criticized because they don't know enough about it." He also found that people in general were very helpful, and that it was society and structural barriers that made it more difficult than the people themselves: "I don't feel as though somebody in a wheelchair is as listened to as much as somebody, I mean there are exceptional cases where people... have uh, um... been listened to. But I, I, people listen but I'm not sure they understand. You know, I mean you talk about amazing how many, uh... obstacles, physical obstacles there are when you go out. I mean, just getting up and down a curb is not that easy, and you don't want to tip the person out, and uh, even some government buildings aren't very uh, accommodating."

P3's balance had been declining steadily over the past two years and was beginning to cause him to face challenges in certain social situations. For example, he had begun to realize that the deterioration of his balance was affecting how he could complete certain actions: "Two or three years ago, I could stand up no problem, now I can't, I've lost some sense of balance, yeah that's it. So, what do you do when you line up for queues? What do you do... um... just to get in somewhere? What do you do when you're in a line for a buffet, you know? Or even at family get-togethers, um... usually the host of this thing, usually my daughters, uh... a Sunday dinner or something. And we've got a big family, so there might be twenty people there, um, or more, um... You know, what we usually do is have [my wife] go up and be the person in line." He was beginning to realize that his physical instability had caused changes to the way he could interact with others in social situations: "I'm getting to that point I think where now I can't really hold my balance as well as I used to, and that's an important thing, I found. Yeah, and if you're in a group of – see, now I'm retired now, luckily – but, say I'm um... if you're in a group of people, what if this was at somebody's funeral, and um, I could stand up for a short time but not

for a very long time. Everybody at a funeral stands up and talks. So, you're down here, I mean, I'm here and everybody else is up here.”

P3 considered himself lucky to live the life he had, and fortunate that his pace of decline had been gradual “It has been – touch wood – slow, nice and slow”. Despite his condition, he chose to see the positive aspects of his life, including that he did not have a more complicated illness, in comparison to other people: “I’ve been very lucky, I think, in not having any strange disease. My father died of cancer in 1944, but I’ve been lucky, I’ve been healthy.” He framed himself as being realistic in his circumstances but was hopeful that things would change in the future for others: “I suppose I’m accepting my situation, because I can’t see any realistic alternative. Nobody’s going to give me a medicine to make me better, or if they are, that’s great, you know. That’s why you give, donate, to the, to the research, isn’t it? Maybe it just depends on one’s mood at the moment, yeah. Maybe I was really annoyed a week ago because I was hoping to do so and so, and I couldn’t, and I got frustrated, and I was angry. Was angry at the disease, or I was angry at a person, um... But I think ultimately, I know I’m going to get worse,” P3’s attitude towards life and his current state may not have always been optimistic, but his realistic outlook allowed him to be accepting of his situation and to deal with the challenges that came with it.²

²After the second interview session with P3, I was unable to show the participant the narrative that had been written. The session was scheduled and rescheduled a few times, however due to the unfortunate circumstances of his condition, P3 became hospitalized with delirious episodes and was unlikely to return home. His wife relayed to me that if he were able to make it out of the hospital, she would be looking into long-term assisted care homes due to his progression of disease symptoms and delirium. His wife has allowed me to use all of the information gathered during the first two sessions. However, this narrative has not been reviewed by the participant himself, and edits were stopped once I knew he would no longer be able to participate in this study. This narrative is therefore a rough draft and it must be noted that the participant was not able to voice his opinion on the plausibility and accuracy of his narrative.

4.7 My Reflections: P4

My time spent with P4 was both exciting and interesting. When I first knocked on the participant's door, he answered it with a bloody hand. While preparing his lunch, he had sliced his hand with a knife due to his tremors. I entered his home and proceeded to say that we should postpone the interview, as his hand needed to be tended to. He insisted he was fine and wanted to continue with the interview that day, even though he was cut deep and was bleeding quite a lot. He said he had called his brother to come take a look at the wound. I walked him through the consent forms, and then rescheduled his interview to a new day. This was an eye-opening experience for me, as this put Parkinson's disease in a whole new perspective for me; I saw first-hand how the motor symptoms can impact daily tasks, such as cooking.

The rescheduled first session gave me an opportunity to prepare a bit more, as I was able to get a first impression of his character and attitude from my first meeting with him. I got the impression that he was a quieter man, who did not want to elaborate too much on details. I realized that I would need to probe more than with other participants, in order for him to express his thoughts and opinions to a degree of depth that was needed for my data collection. Despite the unfortunate and stressful circumstances around our initial meeting, it allowed me to gain a greater appreciation for the resilience and positivity of P4's character.

4.8 P4's Story:

P4 was a 72-year-old, single man who was diagnosed with Parkinson's disease approximately fourteen years prior. As a retired mail carrier and avid gardener, he liked to be active and had a love for the outdoors. He maintained an optimistic outlook on life despite his diagnosis, often living by the philosophy that you should "do the best you can".

Prior to his diagnosis, P4 was not aware that anything was off with his health. It wasn't until his sister-in-law witnessed him driving a car and became concerned that something was amiss, as he was not driving in a straight line: "My sister-in-law said to me one day, one evening, 'Your driving's getting really bad. You're wandering down the road, and the kids had gotten a little worried about it. So maybe you should go in to get yourself checked out, see what's going on.'" This caused P4 to consult his family doctor, to make sure that he was in good health: "I went to see my doctor, and uh, he gave me some, a few tests." Following that, he was referred to a neurologist who confirmed that he had Parkinson's disease: "And, uh, he lined up an

appointment at the neurologist and the neurologist gave me some tests and verified that I did have it. So... that's about the start of it." When P4 was first diagnosed, he was optimistic about the outcome, because his symptoms were subtle: "At first, of course, you know I was having a good day and I felt really good about it, you couldn't really tell". Despite his optimistic outlook, he was still very surprised to receive his diagnosis, because he did not notice anything was wrong with himself: "Everything seemed normal to me. And, uh... I was surprised when she said I was wandering down the road". P4 was also aware that the symptoms would progress and was concerned about how debilitating it would become over time: "Well, the neurologist explained that, how it was, how it was gonna develop type of thing, and what it'd be like. I was concerned about getting to a point where I can't, can't move, but no she said, "You'll always be able to move, you'll always be able to walk, but uh, you're moving in slow motion when it's bad."

Looking back on his diagnosis, P4 recognized that he may have been experiencing some symptoms before consulting his doctor, however he did not think it was anything too serious. He recounted a time he went skating with his niece when his balance was off, prior to being diagnosed: "I've got a niece that's 22 right now. And for a couple years, when she was about 10 or 12 or so, I was taking her down to the... skating rink in Victoria Park. And I had an old pair of skates, and she seemed to enjoy it and I enjoyed it. And uh, I wasn't a great skater, but I could go around the ice. I thought, I should try getting a new pair of skates, maybe I'll do a little better... I found that my balance wasn't – I wasn't skating as well as I had the year before. So, surely after I was, I guess I was told I had Parkinson's and realized why I wasn't skating so well." At the time, P4 attributed any symptoms to getting older: "I just thought I was getting older. I put it down to my balance being off. I didn't attribute it to anything specific". He also attributed his lack of awareness of his own disease because of the slow progression of symptoms: "Yeah, it's tricky. You don't realize until it creeps up on you. It comes on slow, so it's not like something drastic happens overnight."

P4's main symptoms consisted of balance issues, fatigue, and feelings of disorientation. He continued to make modifications to his activities to help him with the symptoms of his disease: "And uh, I get sort of wonky feeling in the head, or feel kind of dizzy. I switched from having a shower to a bath, because sometimes I've gone in the shower and uh, I'm not sure whether I can keep standing up, so I just sit in the bath now. I think it's safer. I have a bit of a problem with my back". Along with his fatigue and extreme tiredness, P4 also experienced the

freezing of his gait, which he considered a nuisance: “It’s a good thing that I’m getting it, that I’m getting extra sleep, but it’s, you kind of work your day around napping several times, you know, it’s a pain in the neck. Uh... when I’m not feeling good sometimes I, I feel uh... well I have something called freezing. And when it comes on, it feels like you’re in slow motion, type of thing. So, you know, if it’s a day when I’m tired and I’ve got to nap quite a bit, and I’ve got cases of freezing going on, I’d say that’s a bad day. Anything to do with a bad day would be regarding, related to my health.”

To help him with his balance, P4 used a walker: “Uh... actually when I go out for a walk, I go on a walker. You know the walkers? And uh, I can walk further in a walker, with a walker than just by walking. Normally I don’t use a walker if I’m going, my brother’s going to the store or something like that, I’ll go get some groceries, but I won’t bother taking the cane or the walker, I’ll just use a buggy at the supermarket. Lean on it and push it along, it keeps you up fairly straight.” This helped him continue to do the daily tasks and activities he had always done. He also used a cane when it was slippery outside: “You can put spikes on the bottom of the cane, and it digs into the uh, ice. So, I’ll be using it again in a few more months, to go through the winter.”

However, one thing P4 was no longer able to do was drive: “So, I haven’t – that was, eight, nine years ago, I haven’t driven since”. He considered driving to be what he misses most since being diagnosed, because he attributed driving to a sense of independence: “No, I haven’t lost my independence. Uh... well, as far as driving, obviously I have.” He also considered that being a driver was a part of his identity, and that role had since shifted: “You know, you consider yourself to have a certain identity when you’re driving and getting around. I think if I took the bus a lot, I’d feel I was uh... how should I put this? I think I’d feel older than I, than I do.” Once P4 stopped driving, he began to walk everywhere. While he had nothing against transit services, he preferred to walk than take the bus because he felt he could keep a greater sense of independence that way: “It’s an excellent service, and uh, I’ll use it again but, when you’re, when you’re getting on the bus as a passenger, and when you’re going to parking lot to get your car, it’s two different things, totally different. I think that’s the thing I miss the most, driving a car.”

Aside from driving a car, P4 also felt that his identity had shifted in his professional role, as he was retired: “I should say I was a union, I was a union steward for twenty-three years, and

uh, I got to know a lot of people in the post office. I was kind of used to being in a situation and taking charge of it, type of thing. I don't have that role anymore. I'm just another retired, older retiree, you know." He also wasn't able to walk as much as he used to when he was a mail carrier: "I don't go out for a walk, which didn't affect me when I retired because I was used to walking five or six miles when I was working." P4 had come to terms with his disease in the years since being diagnosed and accepted it for what it is: "Yeah, you just have to accept it. When you look, when you look around at the people around you, people in the stores and walking down the street they're in much worse health than myself. So, no sense getting upset, just do the best you can." He considered his health to be better in comparison to other conditions and diseases that people face: "I think uh, being blind would be pretty rough, having two legs amputated, having a serious problem with your back, being paralyzed." He believed that you should do the best you can in life at the moment and not take it for granted: "Well, I've accepted it now. Things aren't likely – I'm just going to get older and it'll get worse. So, there's no sense worrying about it." He had the mentality that everyone should make the best of the life you have, because we are all going to grow old eventually, and we can't help that: "I think, when you look at it, really, it's like growing old. You have to accept it, and uh, you can't do anything about it but try to keep healthy."

P4 did not mind telling people about his condition, however he preferred not to mention it to someone if he disliked them: "If it was somebody I disliked I wouldn't want to tell him I got Parkinson's but uh...". He tended not to tell strangers about his condition, however he would if necessary: "If I said it to a stranger, they might think I was feeling sorry for myself. But I don't think it hurts to discuss uh, things like Parkinson's with people, because uh... they said, quite often, people say, "Do you got Parkinson's?", and I say, "Yeah", and they say, "Well, you don't shake". I say, "Well, for some reason, I never, you know, my hands never, uh, shook", which is good, really." He found that people were generally very helpful and warm towards him: "No, I'm a little more compassionate of some people, I guess. Not that I wasn't when I was younger. But probably even more so now. And uh, I find people hold the door for me, if I'm walking with a cane or a walker. A lot of people are very compassionate, you know, when they see an elderly person"

P4 remained determined not to let the disease get him down, and not feel sorry for his situation: "No, I've got a certain amount of empathy for myself, but uh... it doesn't uh... I don't

really feel sorry for myself, you know. Whatever you're dealt you have to make the best of." His views on life changed over time, as he has grown older: "I mean, all I can say is that, when I was younger, I used to— doesn't sound, doesn't make any sense at all – but, I believed that I'd never grow old." Whereas he used to think he would remain in the same condition forever, he now accepted and realized that growing old is a normal process of life: "Well, I think you just come in for a certain amount of time, and uh, you gotta make the best of it, whatever, you know." He understood the importance of doing things that you enjoy and remaining as healthy as you can: "I do try and get out for a walk, usually a couple miles, I didn't go out this morning. But, uh, it's important to get some fresh air and exercise." His outlook on his current and future state remained positive because he realized that growing old is a part of life: "So, you have good days and you have bad days, and I tend to be tired quite a bit. So, I just try and take each day as it comes."

4.9 My Reflection: P5

My connection with P5 began prior to the first session. As a previous volunteer member for Rock Steady Boxing for Parkinson's disease, I had first met her there when she was a member of the boxing team. P5 expressed her interest and willingness to be a part of my study, which I was excited for, but also had slight hesitations about. I wondered how our past connection would influence her participation in the study – if this would be a benefit or disadvantage. In one way, I thought perhaps our history would be of benefit, as the participant would already feel more comfortable sharing details with someone she knew. On the other hand, I felt as though it might be a disadvantage in that she would not share as much details or thoughts with me to preserve the image I had of her at boxing - if it was different from the person she thought her story might project her to be.

I felt that throughout our sessions, P5 really took the opportunity to delve deep into her emotions and feelings towards Parkinson's disease, and reflect on the circumstances and story that made her who she is. I was able to learn a lot more about this participant through this study, way more than I did at Rock Steady, and I was very thankful that she wanted to contribute to this research. I found it satisfying that she also found benefit by participating and took something away from this study: a deeper understanding of who she is because of her journey with Parkinson's disease.

4.10 P5's Story:

P5 was a 77-year old, single woman who was diagnosed with Parkinson's disease two-and-a-half years prior. She had a gradual progression of disease symptoms that intensified in severity over time. As a retired priest, a loving mom, and grandmother, she did not let Parkinson's define her, and was currently still trying to come to terms with what role Parkinson's disease played in her life. She tried to keep an optimistic outlook, along with having moments of sadness and pity for herself but she accepted this as how she coped with the disease, and what it was like to live with Parkinson's.

P5's journey with Parkinson's disease began when she started experiencing tremors in 2016, which she attributed to what she considered a heavy amount of drinking: "I thought I had a problem with alcohol, it runs in my family, and so I was going to [Alcoholics Anonymous] AA because of the tremors. And, uh, and I discovered that I do have, um, some warning signals about the amount that I was drinking." Around the same time P5 joined AA, she also signed up for a gym membership, which included personal training sessions. When she began her gym membership, her trainer noticed that the left side of her body was much weaker than her right: "The first machine that we went on, he asked me if I had had a stroke, because my left side was so much weaker than my right side, within ten minutes. And um, and I said, "No, I didn't, never did", and uh, eventually as we went on, he encouraged me quite often to see, to talk to my doctor about it, and of course I didn't." The weakness of her left side never concerned her until one day after her training session, when she felt more shaky than before: "One day after a really hard work-out, I went to an AA meeting, and I went to pick up the coffee pot with my left hand, and I was just shaking so hard the pot almost fell on the floor, and uh, somebody had to come over and help me take it, take it out of my hand, and uh, so, then I went to see my doctor." Once she went to her doctor, she was referred to a neurologist who diagnosed her with Parkinson's: "She referred me to a neurologist, and uh, the neurologist went through all of the... stuff, um, and of course in retrospect I can see the red flags from way back, from several years back, in fact. And um, so, um, she put me on levodopa and that helped the tremors".

Upon being diagnosed with Parkinson's, P5 chose to accept this new condition and find healthy ways to cope with it: "So, I embraced it, and it was like, "Okay, so this is life", and uh, what can you do? You know, I have it, I have it, that's it, that's all". However, a year after being diagnosed, P5's daughter, who lives in Greece, came to Toronto for a visit. While P5 really

wanted to go, her son and daughter advised her not to go because she was not doing well enough to keep up with all the activities they were going to do: “It was a big, driving to Toronto and going to the museums and the aquarium and my son was really worried about me, didn’t... wasn’t encouraging me to go. He said, “You can come, mom, but really, I think it would be too much”. And my young daughter absolutely refused to have me join them, um, because... um, um, well she was really afraid that I wouldn’t manage at all. And then the whole trip would be focused on taking care of me instead of taking the twins to see what they wanted to see. So, I stayed home.” Missing out on this trip really put P5’s condition into perspective for her, and while she tried to be accepting, she began feeling really sad about what her condition was preventing her from doing: “But so, at that time, at that point, I got really depressed. Um, I started – and I was very accepting about, even with the boxing, I was really accepting of the fact that I was forever catching up with my body. Like, I was forever, I was forever adjusting to what my body could not do instead of um, well it was hard to move forward.”

P5 attributed part of her extremely emotional expression around the time of the trip to side-effects of her medication: “I had just changed medications for something, and as soon as I went off it, my emotions weren’t quite so at the surface”. However, she also believed that these emotional outbursts had to do with her struggle to cope with her condition: “I’m thinking that often I just identify the stage I’m going through, but I don’t really sit still and express it, feel it. Yeah, I can identify what’s in my head, but it’s not in my, it’s not connected to my feelings. Yeah, so um, so I’m trying to do that more often.” Since being diagnosed, trying to process how she felt about her condition and how it was progressing was what she was working on most. Along with her changing emotions, P5 had also experienced a multitude of physical symptoms that affected her daily life.

Two areas of mobility that P5 struggled with most are her facial muscles, specifically when speaking, and her fine motor skills: “My jaw that gets tight, so I can’t talk, it’s my hands don’t work properly, I can’t do buttons and, to put on a coat. And I always say I know exactly what it feels like to be a three-year-old... Getting your one arm, your arm, into your sleeve of a coat, it’s just like, I’m just like watching my kids when they were little. And now it’s the same with um, doing up shoelaces, you know, you just... your fine motor skills just aren’t quite in control anymore.” She found ways to complete these tasks by herself by planning and modifying the ways she used to complete these actions: “The small buttons, so I leave them buttoned up,

and I take them on and off like a t-shirt, my blouses. Um, I have a hard time slicing stuff, cleaning vegetables, paring vegetables. So now I've bought turnips, and um, well not carrots, but turnips and sweet potatoes and squash. So, I buy them pre-done, pre-peeled and sliced, and I buy frozen onions that are already chopped, and frozen, and mushrooms, and either I buy them frozen or buy fresh and put them in the freezer. And use them". In terms of communicating, P5 struggled with physically moving her jaw enough to articulate, and also mentally when forming a sentence: "I have difficulty talking, and sometimes I have a hard time putting a sentence together to say what I really mean, and sometimes I say things that I don't think I mean but it comes out just all wrong. And uh, I have no subtlety. But, if I stop and think long enough of what I'm going to say I can do it subtly, but if I just blurt it out it's not, doesn't get out the way I want it to". P5's issues with fine motor skills hindered her ability to complete tasks we would normally take for granted such as preparing food, buttoning up a shirt, and typing: "I can't type anymore because my fingers just don't do the routine. And um, so but I can do one finger at a time, but part of my hand sometimes moves, and I'm, I'm um, typing in letters that I don't intend".

P5's fatigue started to limit how often she could complete daily tasks, as well: "But now I'm having a hard time even just preparing a meal, because by the time I get the meal ready I'm not hungry anymore. And I can't clean up, like I'm too tired to clean up after, so – well I can but I'm just so tired." A past symptom that she experienced was sleep problems that disrupted her from having a well-rested night but had since cleared up, fortunately: "I had terrible sleep problems, just wicked sleep problems. Um, yeah, I forgot about that, actually and it's only been a few months I haven't had them. Yeah, um, I, I... well, I would go to bed anywhere between midnight, ten o'clock in the evening into midnight, and or one o'clock and I would lay awake until five or six in the morning, and then I'd finally fall asleep and sleep until noon or two in the afternoon. And I had no trouble sleeping once I got to sleep, but terrible time falling asleep. But once I was asleep, I would just sleep for hours and hours, and in fact, every couple, every couple, couple times a year I would go to bed and sleep sometimes for 48 hours. Yeah, and or I would be awake for 48 hours or longer, and then I would, you know, sleep for long, long periods of time for the next week or so." These sleep problems could be a reason why P5 had been experiencing such severe migraines, which are also another symptom of Parkinson's disease: "Parkinson's is just one very minutia part of proper brain problems, brain disease, it's just a terrible little dot in the whole spectrum of brain disease. And it affects every other part of the brain, and so my, the

migraines that I have, um, affects the Parkinson's because it's all part of the brain. And so, when one little part of the brain goes off kilter, it just jilts everything else. I did not know that. I kept yelling at my doctor, you know, I have this migraine and the Parkinson's medication doesn't work, and my family doctor finally said, "It's part of the brain, and one thing affects the other." However, she noted that her migraines may have been a side-effect of the medication that her doctor put her on for depression: "We changed the anti-depressants that I was on, and I think that has triggered more migraines, and that's why I've been having so many in the last year. And uh, this new neurologist gave me another anti-depressant, and it's got three levels to it, and it's probably replacing what was lost when I switched the anti-depressants last year because it just slows right down, it's just amazing, the change. So... I've been coping with a lot of things, and it's not all Parkinson's, but it's all related to Parkinson's."

From her varying symptoms, P5 struggled with understanding what her identity was with Parkinson's, but knew what kind of outlook she wanted to have in the future: "I've been, I've read about 'don't let Parkinson's identify you', and um, I haven't given it much thought. But I think I allow two things to identify me. I identify as an ordained priest, and uh, I also identify with, like I, it's not that I have Parkinson's, I am Parkinson's". In the future, she aimed to correct the current mentality that she had about Parkinson's, in that she did not want to feel she had succumbed to the disease: "That means I would be walking around with a big sign on my shirt. If I am Parkinson's, I'm a victim of Parkinson's, like I play more of a victim, I'm more, I feel more helpless". She thought about the roles that she took on in her life, both in the past and the present roles that defined her: "I think of myself with my family, and I'm mum... and now I'm grandma. So, so I still have that part of me. And a little part of me, well it depends, if it's my daughter-in-law's family, and with my cousins, I'm still part priest, like they still know me as being a clergy. I'm finding that I have fewer and fewer roles to play." While she thought of herself in the role of being a mom, a grandmother, and a priest, she did her best to separate Parkinson's from her identity, but still accepted that it was a part of her life: "That's just it – accepting it. Um, being comfortable with who I am and what my limitations are now. Because I used to think of limitations as being something to overcome. And there's some with Parkinson's that you don't overcome, you just live with it. I try hard to, you know, to, to not let my identity be, um, ruled by the Parkinson's"

When P5 was outside, she did not mind telling people that she had Parkinson's, because sometimes she needed assistance with tasks: "If I'm in the grocery store, I'll turn and ask somebody to give me a hand with something. You know, when I'm unpacking my groceries or if somebody offers to help, I'll say, "Oh, of course", you know. And I'll ask the cashier that normally doesn't bag groceries to please bag my groceries, because I take too long and I'm awkward, you know. I really need help with this, and they'll do it. And when I ask the grocer, the cashier, my goodness some people just come out of the woodwork just to give me a hand, yeah." While she may not have always felt comfortable being outside because of her physical changes and how people treated her, she still did her best to maintain her stature and self-respect: "Now what I experience, and I'm always surprised, but when I'm talking to people, and I suppose the way I move now, they tend to treat me as if I'm cognitively impaired. And so, they feel they have to shout or have to repeat anything or explain like talk like to a child when they're talking to me, yeah. I feel awkward outside. I'm not confident, at all, no. Less and less. But, until somebody treats me like I'm an idiot, and then I get... But I stand a little straighter and walk a little, less shuffle, and dig deep for my dignity". However, P5 began to realize that while she did not mind telling people she had Parkinson's, she did not like the feelings that she associated with having it herself and what it had affected in her daily life: "I filled in a questionnaire about something a couple months back, and it said, um... something about you're reluctant to meet with people that knew you when you weren't, did not have Parkinson's. And I was, I would, I would have answered no all the time to that, oh no, and I'm not embarrassed by Parkinson's, and I tell people I have Parkinson's whether they're interested or not. I just throw it out there. And, and um... but when I thought about it, um, I don't go to church, I don't go to the gathering for HR clergy... and I'm gonna cry. And so... the feelings I have around Parkinson's, I cannot describe them. I don't have the words for them, because I would say no, no, no, no, no, no. But, obviously I'm not comfortable, and I think it, I don't know what to call it, don't know whether to call it shame or... maybe I'm just feeling sorry for myself, pity".

P5 continued to reflect on her life and how she defined herself based on her current state, as it was always changing with Parkinson's disease and the severity of symptoms: "Okay, so I'm happy with where I am, I can do this much. And I know it's hard to do that, so, okay that's where I am. But then two days later, or a week later, I'm in a totally different place, and then I have to get, I have to get acclimatized to that, as well. So, now what I'm doing, is I'm trying to embrace

the fact that it's just getting worse and worse and perhaps it will continue to get worse. So, I have to be not happy with where I am, but happy with what's happening, yeah. Because it may get much worse. So, I have to, that's what I'm wrapping my head around, yeah. And I'm not ignoring it...I'm not denying it, but I'm somewhat ignoring it." She celebrated accomplishments, no matter how small, and always reminded herself how fortunate she was to have lived a full life: "I have so much more than most people have. Even where I am today." P5 was thankful to be surrounded by family, friends, medical support, and resources to aid her through the next stages of her progression with Parkinson's, and preparing for what was to come: "I think of the opportunities I had and options that I had, and things that are available to me to help me through the stages that I'll be going through, the next part of the journey. That's what I've been getting ready, that's what I've been thinking the last little while, is this is the next part of my journey, another part of the journey, so, how do I want to travel? And um, what will I take with me? Yeah, and what will I leave behind? Oh, I've never articulated that, but that's what I've been thinking." She wondered what the future would bring: "This is another stage of the journey that you're on. What are you gonna take with you, what are you gonna leave behind? And... what can you do? Things, is there anything you can do, anything about it? Or you can't do anything about it, are you gonna let it go? I've got Parkinson's, but here's what I can do, and that's all I can do. Eat well, exercise, keep, get sleep, you know. Good lifestyle, a healthy lifestyle, and carry on."

4.11 My Conclusions

Upon finishing the final session with each participant, and sharing their narratives with them, it dawned on me that this project was much bigger than myself. While my goal was always to capture the stories of older adults with Parkinson's disease post-diagnosis, I did not really understand how important it was for participant's to be able to share their stories and have someone listen. As I thanked each participant for allowing me to enter their homes and be willing to participate in my study, I noticed that each participant was even more grateful to have been a part of it. Many of them said this study not only allowed them to share their story but reflect and maybe even understand themselves more than they had before. It was a sort of catharsis, a therapeutic release of tension and frustration, of the highs and lows of being diagnosed with a chronic illness. Many of them had never even thought about how their identity

may have changed since their diagnosis. This gave me solace for all the times I worried that my research would not be deemed significant. It made me feel inspired to do their stories justice.

After reading through the transcripts of the sessions that unfolded, my advisory committee members and I discussed the identity component of this study. I found it interesting that when I asked each participant questions about their identity, for the most part, they did not really have much to say about it. Most stated that they felt they were the same person they had always been, or that Parkinson's disease did not contribute to who they were. What was interesting was that while many participants said things to deny changes to identity, oftentimes a participant would say something to contradict that statement – what I would like to call ‘fractures to identity’. I wondered how both the participant and the image they were trying to portray to me might affect these kinds of fractures, or how my presence influenced their answers to questions centered around identity. Was the person trying to portray an unchanged image of the self because they wanted to appear that Parkinson's had not affected their lives? Was it because I was an able-bodied, young woman, who had no obvious chronic illnesses? Or was it truly that they believed their identities had not changed since their diagnosis, despite the contradictions in their sessions? This will be discussed in further detail in the next chapter, with specific examples to support the fractures uncovered. As well, the coding and thematic analysis that emerged from the data will be discussed in detail in the next chapter.

Chapter Five: Results of Thematic Analysis

In this chapter, the four overarching themes, with corresponding subthemes, that emerged from the thematic analysis of the narrative data are presented. These overarching themes include: *Negotiating identity while managing Parkinson's disease; Acceptance as a process; Resisting a disabled identity*, and; *The centrality of occupations and roles*. I have integrated some academic literature throughout to relate to the themes generated, which will be more thoroughly covered in the discussion, as well as included quotes from my narrative sessions. In order to protect the anonymity of the participants, participant numbers (P1, P2, etc.) have been used. The purpose of this analysis is to help gain a greater understanding of how older adults with Parkinson's disease make sense of their identity post-diagnosis.

Participants discussed several topics related to their identity post-diagnosis, in both personal and social contexts, that contribute to the understanding of chronic illness and identity. In the case of my study, it seemed that participants mostly did not want to accept their illness as a part of their identity, but rather it was something that impeded the identity that they had before the diagnosis. Rather than integrating it into their identities, they thought of it more like a roadblock towards the identity they strived to have as an able-bodied individual. They managed with their illness the best they could, through education and knowledge, support systems, and asking for help. They thought of acceptance as a multi-stage process, ending with a type of reluctant or hesitant acceptance of their state, once they came to terms that Parkinson's disease was a part of their lives. They used tools and strategies to resist a disabled or illness identity such as humour and expressing their desires to not want to be seen as a burden or pitied by others and society. They strived to maintain their occupations and roles, despite being limited due to the physical and psychological symptoms of their disease, particularly those central to maintain an acceptable personal and social identity.

5.1 Theme 1: Negotiating Identity While Managing Parkinson's Disease

The management of Parkinson's disease was discussed, in great detail, by each participant. Certain sub-themes that relate to managing Parkinson's disease have to do with how they were diagnosed, if and how the individual is able to ask for help, how the participants are able to manage the symptoms of Parkinson's, and what kinds of supports they use to help manage their condition. All of these sub-themes could be tied to the participant's sense of

identity and how they see themselves post-diagnosis, as each participant used management strategies and adaptations to try and maintain the same sense of identity that they had pre-illness. Management of the disease may allow individuals to try and keep their routines, roles, and occupations the same as they have always been. Roles and occupations contribute to the personal and social identity that one might have defined for themselves personally and within society, which will be touched upon in greater detail in themes to come.

5.1.1 Asking others for help

A common theme that came up between participants was the willingness to ask people for help. Participants noted that they were generally okay with asking for help from strangers, rather than friends and family, because they found that the general public typically enjoy helping out. For example, P3 mentioned that:

I mean first of all, I find very uh... general public very helpful. A door, they open it for you. I didn't expect otherwise, but it's gratifying to know that people do seem to care - most of them, anyway.

P5 also expressed how pleased she was with strangers offering her assistance:

If I'm in the grocery store, I'll turn and ask somebody to give me a hand with something. You know, when I'm unpacking my groceries or if somebody offers to help, I'll say, "oh, of course", you know. And I'll ask the cashier that normally doesn't bag groceries to please bag my groceries, because I take too long and I'm awkward, you know. I really need help with this and they'll do it. And when I ask the grocer, the cashier, my goodness some people just come out of the woodwork just to give me a hand, yeah.

However, when it came to asking family and friends for help, it seemed to take the participants more time and adjustment to come to terms with asking for help. Participants noted that asking for help meant giving up a bit of their independence and beginning to rely on others rather than themselves. The participants may have wanted to resist being viewed as disabled and instead worked hard to maintain an identity that they were able-bodied and independent. Asking strangers for help versus friends and families contributed to the individual's sense of personal identity, because they preferred asking people who their identity was anonymous to, rather than people who knew them prior to their diagnosis. By asking strangers for help, rather than friends and family, the participant could try and maintain the personal identity that their friends knew

before being diagnosed with Parkinson's. Asking a stranger for help was less threatening to their identity because that person would not be able to notice any changes between their appearance and identity pre- and post-diagnosis. P2's wife (and facilitator of the narrative interview process) discussed how difficult it was for P2 to ask for help from friends:

But, when it came – because [he] couldn't drive – then he was dependent, and you needed help getting to all your activities. But you were reluctant to ask anyone other than me for a ride, you don't, because you don't, you don't want to be dependent. "Oh, I don't want to bother them", or...

She also expressed how it required her to ask for some assistance from people to help. As an example, she described how members at the golf club were not voluntarily willing to lend a hand without prompting:

Um, actually I asked someone from the golf club, if he would be playing golf the next day, could he drive the cart so that [he] could play, because [he] isn't driving the cart, either. And he has been kind enough through the summer to book times and play with [him] once a week. But, without asking anyone else, no one else has offered. And that's, that's a big change.

5.1.2 Attempting to exhibit a sense of control

One of the key aspects of Parkinson's disease is the variation in symptoms, severity, and progression. This makes controlling the condition very difficult, as noted by several participants. Controlling their situation with Parkinson's disease was one way that participants could try and hold onto the identity that they had prior to diagnosis. In trying to manage their symptoms, treatment options, and progression, participants may have been attempting to keep their routines and daily habits in check without feeling that their disease was changing anything, and thus potentially changing their identity associated with those occupations. In the beginning stages following diagnosis, participants stated that they felt they were in control of the situation, and that they would do everything they could to continue to stay on track with the disease progression, as well as understanding the various symptoms and treatment approaches. P2's wife talked about how much time they invested in educating themselves, "...because we didn't know anything about Parkinson's, and then we started learning everything there was about it, conferences and classes and support groups, and everything."

However, as disease symptoms vary both in terms of progression and severity, it is difficult to predict the journey that Parkinson's disease will take for each individual. As participants' disease progressed, they found that the unpredictability of their condition made them uneasy and uncertain of what the future would hold. The only way they could continue to manage their prognosis was by planning for the future. In planning for the future, perhaps participants felt that they could still exhibit some sense of control over their situation, and not let the condition overcome their daily roles and occupations. The concern became on how the disease would impact their future roles and occupations rather than the present, trying to keep their lives as stable as possible under the limitations of their condition. All participants expressed anxiety or worry about their future. P1 mentioned, "*But I'm, um, concerned because I, I uh, you know, I wonder what's gonna happen down the road*". P2's wife discussed all the plans they had put into place to plan for the unpredictability of the disease progression:

And that, you know, what we're trying to do is, we're trying to be proactive in making sure that we have things in place. Um, you know, we, our – [his] brother has a key to the house, they have a code to get in... they're aware of the problem. We've, you know, told friends and family, so if we had an emergency, we hope that, you know, everything's in place. We posted on the fridge all of [his], um, information about all his doctors, medications, who to call, and we put the sticker on the front door, if paramedics come they know where to look. So, we're trying, aren't we?

Similarly, P5 had also began to think about the next stages in her disease:

That's what I've been getting ready, that's what I've been thinking the last little while, is this is the next part of my journey, another part of the journey, so, how do I want to travel? And um, what will I take with me? Yeah, and what will I leave behind? Oh, I've never articulated that, but that's what I've been thinking.

If participants were able to attain a sense of control, this was often tenuous. For example, a situation, such as experiencing a fall, often caused a participant to lose the sense of control they had worked so hard to obtain. P2's wife, for example, discussed how much attention and assistance is required for P2 to be able to walk:

That has to be the one thing that you just can't go anywhere on your own anymore. In fact, you don't even go for a walk anymore because it's a worry that, after you had that

fall, now you're not as steady, so, you know, we have to really be careful, wherever we walk.

Falls were often discussed as a precipitating event that decreased the individual's sense of control over their daily life. By falling, the individual perhaps came to realize that their condition was not something that they could realistically control forever, and thus would have to make some negotiations to their identity that they associated with being completely able-bodied. As a result, these individuals expressed the need to exhibit the utmost safety and caution in their mobility. One strategy to ensure personal safety was the use of a mobility aid, such as a walker or cane. P4 commented on his use of a walker, and how he felt that people may pity him when they see him use it in public: "*Well, with a, with a walker, you know. Some people walking with a walker, you can't help but see them and feel sorry for them, or a cane, you know*". There is a contradiction between the use of a walker for safety, but also projecting the image of a disabled or illness identity. P1 noted that she has taken falls prevention courses in order to try and control her ability to walk independently without falling for as long as possible:

And it's so easily done, I mean, that's why I take falls – this VON course, falls prevention and things like that. Because even... but, I'm just, um... and you know, I don't know that if I, if I hadn't been diagnosed with Parkinson's whether I would've fallen that day or whether I would've been able to catch myself or what I don't know. It was, uh, one of those things where I was just so caught unaware.

5.1.3 Social supports as a way to manage

The participants credited their social support networks as one of the main factors supporting their management of Parkinson's disease. This support was in the form of formal caregivers, such as PSW's, as well as friends and family. Social supports seem to contribute to the social identity that an individual upholds. Relationships and memberships within society and between individuals adds to the identity that an individual establishes for themselves from a social standpoint. In leaning on people for support, social identity may be encouraged, while also allowing the individual to feel they are less hindered by the limitations of their condition to better manage it and complete occupations and roles that were easier prior to diagnosis. Many participants expressed that their spouses were pillars for support in their state and appreciated having them to assist and support them through their daily lives. P2's wife discussed that she and

her husband work together (although she is the primary caregiver), to try and make their lives as manageable as possible, *“The situation is that we’re working together, and if we do all the right things, that’ll... that will be, uh... making smoother situations here in the condo and going out”*.

Support systems offered a way for participants to feel they were receiving the help they needed, while also maintaining a sense of independence. The participants felt that these support systems were different than asking acquaintances and strangers for help, as their family, friends, or formal caregivers knew the scope of their illness. Whereas earlier in this chapter I commented on how participants expressed that they did not mind asking strangers for help, this was in the context of simple tasks that maintained their anonymity, such as bagging groceries, or helping to do up their coat. When it came to close support systems in regard to friends and family, participants expressed that these close support networks were who they went to for assistance and guidance, as they were better able to understand what they were going through and offer better support. They were hopefully then better educated and empathetic to the individual’s needs, and understanding that their identity was not necessarily tied to their illness. They felt that this was less of a burden than asking someone who does not understand the illness or the individual’s needs. P5 expressed that her idea of an ideal support group would be a companion for an activity or hobby:

But I think for me a good support group would be somebody I could go to the movies with, just go out for a coffee, um, go to a concert, maybe a trip to Toronto to the theatre, or Stratford. I don’t know if I could do that, but I would like to try.

5.2 Theme 2: Acceptance as a Process

The second theme of acceptance being a process refers to how the participants began to come, or came, to terms with their condition, and how their identity was a factor in this journey towards acceptance. Before delving into this theme, I would like to note that there were several instances throughout the data collection where fractures to the identity of the self was observed and will first be introduced within the ‘feeling fortunate’ subtheme. For example, when going through the transcripts, it was apparent that many participants demonstrated contradictions between the self-image they reported to portray, and how they described their self-image during the interviews. It was these situations that I refer to as ‘fractures’. The words chosen by the participants to represent their perceived identity struggled or vacillated between asserting a

consistency of identity and facing challenges to maintain consistency. All participants stated that their identity had not changed since their diagnosis and that they were the same person they had always been. At the same time, however, the transcripts conveyed the many challenges that participants experienced and the ways in which aspects of their identity had changed as a result of their diagnosis, thereby demonstrating a fracture in the narrative.

5.2.1 Feeling fortunate and comparisons to others

A common statement among participants was that they felt very fortunate for the life that they had lived up to the point of diagnosis. Even though they were having to manage the various symptoms of Parkinson's disease and the uncertainties that go along with that, they felt fortunate particularly as compared to others that they perceived as "worse off". I believe this coping mechanism may have been a way for the participants to refrain from associating their disease with an illness identity, by saying that Parkinson's is not that "bad" of a disease to have. Comparisons to others could be considered a coping strategy as they are able to look at their stage and realize that their symptoms could be worse (Murdock, Cousins, & Kernohan, 2015). P2 expressed, *"I've been very lucky, I think, in not having any strange disease"*. They held comparisons between themselves and individuals without Parkinson's disease, in which this case they felt fortunate to be in the state they were in given someone else in a "worse off" health state. For P4, he described types of disabilities that he would consider worse than Parkinson's: *"I think uh, being blind would be pretty rough, having two legs amputated, having a serious problem with your back, being paralyzed"*. This comparison to others may be a way of coping with their illness, in order to make themselves feel better about their own chronic illness. Feeling fortunate can be looked at as a coping strategy for managing illness and helps individuals to feel as though their identity is still intact (Murdock et al., 2015).

As P2 mentioned, *"My identity changed from uh... um... uh, it's, it hasn't changed that much, that uh... um... personality, uh... uh... Things that uh, um... are, are short-term"*. He began talking about how his identity had changed but then articulated that it has not changed too much, a good example of a 'fracture' of the self. Similarly, P1 also discussed that her identity is different within her home versus her community, but again did not attribute it to Parkinson's:

I think I'm the same, I think I'm the same. I mean I don't think, I guess, probably, I'm, I guess I'm no different, like I may be different at home than I am out in public, but I'm not, that's not because of Parkinson's.

A commonality among the study participants was that they all noted that Parkinson's is not a uniform disease. They constantly reminded me and themselves that no two people with the diagnosis will show the same symptoms. P3 described the variation in individuals with both Parkinson's disease and other health states:

You do notice, over a period of time, how people change – most of them. Now, the guy I sit next to all the time, and we've become good friends, doesn't have a disease, he lost his leg in a car accident. So, he doesn't change, in fact, he gets better, because he does more. He was two years old when this happened... Other people might never change, or, it's funny you see somebody who's diagnosed, and you read their obituary and, a few years. Somebody else, um... there seems to be no change. It depends what disease they have.

This comparison to others with the disease is a constant reminder of the uncertainty that comes with having Parkinson's, and in comparing to others in future stages of progression, it offers knowledge on the stages of decline (Vann-Ward et al., 2017).

In my study, I noticed that comparisons to others with Parkinson's relates to a more negative and anxious frame of mind, whereas a comparison to others with different health conditions besides Parkinson's seemed to give participants peace of mind. Participants deemed other chronic health conditions and disabilities as worse than their own, such as cancer, an amputated limb, or paralysis. They considered themselves lucky to “only” have Parkinson's disease in contrast to other health issues they could have been dealing with. This may be attributed to the personal identity that the individual would like to associate with having Parkinson's disease, in trying to continuously assure themselves that their state is not that bad, and that their situation could be much worse if dealing with a different health concern. I believe this could have been another way for the participants to continue to try and preserve their personal identity as much as possible and refrain from letting their disease become too integrated into their identity.

5.2.2 Frustrations with the body

Frustrations with the body was a common occurrence among participants. Constant feelings of irritation with their lack of mobility or the progression of disease symptoms amounted to participants having to either adapt or withdraw from daily habits and activities. I found that participants in my study wanted to hold onto the identities that they had associated with their physical capabilities, such as driving, or being members of teams and clubs. There is a component of identity associated with being able-bodied, and connection to the occupations that individuals wish to maintain.

There was variation in participants and how they chose to deal with their frustrations with the body and occupations they could no longer complete. P1 noted that her and her husband began making changes to their activities and hobbies that they once used to do. Instead of traveling great distances, they took trips to closer destinations. However, other participants separated who they were from what their body could no longer do. For example, P3 mentioned his love for playing piano, and his disappointment that he could not play anymore. While he was upset he had lost this occupation, he did not believe his identity had changed since his diagnosis. P3 described his frustrations as a fluid state, which changes regularly, because of the daily changes that occur with Parkinson's: *"Maybe I was really annoyed a week ago because I was hoping to do so and so, and I couldn't, and I got frustrated, and I was angry. Was angry at the disease, or I was angry at a person"*. This could be seen as a fracture in identity, as his frustrations associated with losing an occupation is apparent, yet he denied that his identity had changed since his diagnosis.

As well, P4 aired some of her frustrations in saying, *"So, I can't do this, or I'm not managing very well, because I'm not adjusting to what my body can't do, and I could never get, quite keep up with it"*. She also went into greater detail about specific areas of her body that she has the hardest time with: *"The most frustrating part is, I have a hard time correcting my legs, my mobility to go, but it's actually my upper body. And it's my jaw that gets tight, so I can't talk, it's my hands don't work properly, I can't do buttons and, to put on a coat"*.

Vann-Ward et al. (2017) conducted a constructivist, grounded theory study which explored and theorized both social and personal processes used by individuals with Parkinson's disease. From in-depth interviews, observations, and photos, the researchers were able to theorize a five-stage theory for which individuals with Parkinson's are best able to preserve their

sense of self (Vann-Ward et al., 2017). From their findings, they concluded that their five stage theory encompassed: a) making sense of symptoms, b) defining turning points, c) experiencing identity dilemmas, d) reconnecting with the self, and e) envisioning their future (Vann-Ward et al., 2017). In regards to frustrations with the body, within stage three of experiencing identity dilemmas, “being unable to respond or function predictably led to frustration, confusion, and questions about one’s capabilities” (p. 971). This may have caused a discrepancy between the identity that the individual wanted to uphold before their diagnosis, and the identity that they had since experiencing bodily limitations.

5.2.3 Progressing through the stages of grief

The experiences of grief among those affected by Parkinson’s disease may not follow the typical grieving stages, as this is more of a grieving of the self, rather than another person. Tichler (2009) states that, “physical impairment is an object loss comparable to the loss of a loved one” (p. 194). This self-object loss, proposed by Tichler (2009), as a man with Parkinson’s disease himself, stems from the emotional and physical adjustments that an individual goes through with having a chronic illness. With Parkinson’s disease, “the functioning of the brain inhibited in Parkinson’s can be seen as an object loss, and has a part object, intrapsychic dimension” (Tichler, 2009, p. 195). Research by Lawson et al. (2018) found that:

Through living with PD and cognitive impairment, their previous self-image and social identity were no longer congruent with their current physical and mental state; PD participants suggested that periodic deteriorations caused a crisis which disrupted their emotional equilibrium. Such crises have been proposed to trigger a grief-like mourning period, where individuals grieve for the person they were and their past life before the disease (p. 8)

In analyzing the transcripts, several emotions emerged that were related to the traditional stages of grief. Whereas the five stages of grief are denial, anger, bargaining, depression, and acceptance (Pastan, 2017), not all stages of grief were present among the study participants. The two prominent stages were denial, and (reluctant) acceptance.

5.2.3.1 Denial

In talking about their diagnosis, I noted that, in relation to the unawareness participants had of their disease, they seemed to have trouble coming to terms with their illness. A few even

noted that they were in denial at the time of diagnosis and were hesitant to even go to the doctors about it. This denial, I feel, was a way of preserving their pre-diagnosis identity for as long as possible. By denying that anything was wrong, they may resist an illness identity of Parkinson's disease. Especially in the earlier stages, when symptoms were not as prominent and/or debilitating, individuals could deny that anything was wrong by suppressing any bit of illness identity. P5 reflected on her feelings when she was first made aware that something might be wrong with her:

I don't know if I was in denial or just ignorant. My trainer kept asking if I had had a stroke, and um... he kept, "almost identical to stroke diagnosis, you better talk to your doctor". And it was like, "yeah, yeah I will, I will". But I knew I didn't have a stroke, well I was pretty sure I didn't, maybe. And, and but I just, yeah, I guess I was in denial, I didn't want anything to be wrong. I never did think about why it took me so long, yeah.

Whether the denial occurs before diagnosis, after diagnosis, or throughout both stages, participants in my study appeared to suppress the reality that their wellbeing had been negatively impacted and hold onto the identity that they had prior to their health deterioration. As P2's wife mentioned: *"I think, I think everyone has a feeling like, hey, I'm absolutely fine, I don't need anybody's help. As soon as you admit, then you're less than, if you're less than perfect? Nobody's perfect"*. Denial is a common trait amongst those coming to terms with a big change in their life. It takes time and adjustment to accept and understand the loss of something, such as self-object loss, as mentioned by Tichler (2009). In the process, the individual will deny the fact that anything is amiss (Tichler, 2009). This is connected to the identity of the individual with Parkinson's disease, as admitting that something has changed for the person is admitting that their illness is a part of them (Tichler, 2009). In the case of Levin (2011), a doctor diagnosed with Parkinson's disease, he reflects on his experience with Parkinson's stating, "My greatest fear is becoming bed-ridden and totally dependent. I know this might happen, but I live each day in a state of 'informed denial'. And it works" (p. 334). Effort is made to appear as "normal" as possible, in order to maintain the sense of self the individual had prior to their diagnosis (Telford, Kralik, & Koch, 2006).

5.2.3.1 Reluctant acceptance

I refer to this as reluctant acceptance, rather than outright acceptance, because all participants responded to their feelings of acceptance towards the disease as hesitant and lacking

confidence. It felt more that participants were forced to accept their condition due to the fact that it would not improve. P4 discussed his feelings towards his condition:

Yeah, you just have to accept it. When you look, when you look around at the people around you, people in the stores and walking down the street they're in much worse health than myself. So, no sense getting upset, just do the best you can.

P3 also expressed his feelings of acceptance, “*I suppose I'm accepting my situation, because I can't see any realistic alternative*”. P5 described her acceptance as a process, as well:

Well, that's just it – accepting it. Um, being comfortable with who I am and what my limitations are now. Because I used to think of limitations as being something to overcome. And there's some with Parkinson's that you don't overcome, you just live with it.

In using words such as “I suppose”, “live with it”, and “do the best you can”, the participants expressed their reluctance to fully come to terms and accept Parkinson's disease as a factor in their lives. These kinds of word choices gave me the impression that they were very hesitant and not quite willing to allow Parkinson's to be integrated fully into their identities.

5.2.4 Relying on a sense of humour

Another commonality among study participants was their reliance on humour as a means of dealing with the challenges of their diagnosis. They stated that despite the challenges they experienced as a result of Parkinson's disease, their humour remained intact. P1 mentioned that she still maintained her sense of humour, “*I guess the good news is that I still have a good sense of humour. Yeah, so I can laugh at myself and my situation*”. P2 and his wife gave an example of how he would use humour to lighten up his situation:

Wife: You don't worry about not finishing a sentence. [He] usually says something funny.

P2: Yeah, if I, if I stumble over a couple of words, I would say, you know, “We can take, uh... a break” and...”

As well, P3 discussed that he used humour as a tool to make light of his condition: “*But uh, actually I usually end up making a joke of it*”.

I think the use of humour can be looked at in one of two ways. First, humour may be understood as a defence mechanism, in order to make light of the situation rather than focusing on the negatives of the disease. Secondly, humour may be thought of as a quality that the

individual attributes to their identity that has not changed despite the progression of the disease. For example, I know that I would categorize humour as a facet of my identity, as it is the way I react to life events and situations. There are times when I would also use humour as a strategy to lighten up a situation, but I think using humour as a defense mechanism, rather than another such as displacement or projection, speaks to an individual's identity and how humour is integrated in their reactions to difficult life situations.

5.3 Theme 3: Resisting a Disabled and/or Illness Identity

Resisting a disabled and/or illness identity means taking actions to disassociate one's identity with a disability or illness. This relates to the process of acceptance, the theme described above, as it takes both emotional adjustment as well as time to come to terms with a life-altering event, such as a diagnosis of a chronic disease. An individual may try and resist the association of disability or illness with their identity by clarifying and disclosing the details of their chronic illness and/or by expressing their desires to not feel like a burden to others or as a victim of their disease.

5.3.1 Self-disclosure as a strategy to manage identity

The study participants described how they did not mind telling people that they had Parkinson's disease. This self-disclosure, in both private and public spaces, seemed linked to their attempt to control how they were perceived by others. In controlling how they are perceived by others, individuals may try and maintain the identity that they had prior to their diagnosis. Most participants stated that observers noted that they did not look like a "typical" Parkinsonian patient, in that they were not displaying the characteristic tremors people generally associate with the disease. P1 described her encounters with individuals that said, "*Some people are quite surprised, they look at me and they say 'Well, you don't look like, you know, you don't have tremors'.*". P4 also mentioned that people did not associate his appearance with Parkinson's:

But I don't think it hurts to discuss uh, things like Parkinson's with people, because uh... they said, quite often, people say, "do you got Parkinson's?", and I say, "yeah", and they say, "well, you don't shake.

This self-disclosure was important to the older adults with Parkinson's disease because it not only might have allowed them to, at least partially control, how others perceived them, but it

also could have provided an opportunity to educate individuals who might not understand why they are moving or acting in the manner they were. In educating those around them, it gives participants the opportunity to disclose why they appear or act in a certain way, and justify their characteristics, rather than have people make assumptions. They can exert a sense of control over their identity in a social context by limiting how they might be wrongly perceived. For example, P2 made a point of disclosing to individuals why his train of thought may wander:

But there is a point when I'm, many, many, most people know that I have a problem. And I usually, at the beginning, as you can see pretty well that people already know, I'll say that I'm, I'm gonna give this a shot, but if I stop in the middle of a sentence it's because I've forgotten what I'm talking about. And, uh... I know some people might think that's, that's too much, and some people might think that's a good idea, a good idea.

P1 explained how her reasoning behind disclosure was to allow individuals to understand her behaviours and appearance:

Because I want them to know that, that if I'm... slow or if I'm unsteady or if I'm ignoring, or whatever I'm doing, I want them to know that it's not because of them, it's because of me. I don't want people to think that I'm ignoring them or, or uh, or bored or whatever because, it's because I have Parkinson's that I feel like I'm different now.

Similarly, P2's wife also described that P2 disclosed his illness as a way for individuals to learn more about the disease and understand his behaviours:

We also feel that we're helping other people, making them aware of Parkinson's, because in this, in [his] case, no one would know, because as we talked earlier about the tremors, that's the only thing people know about Parkinson's. So, we feel that it's important to educate other people and let them know.

While some participants noted that they were okay with disclosing to immediate friends and family in order to educate them more on the disease, and were also okay with asking strangers for help, not everyone felt that telling strangers outright that they had Parkinson's disease was necessary. This difference in self-disclosure from friends to strangers might be because strangers do not necessarily know the identity, or every part of the identity of an individual that they have just met and might make false assumptions or see that individual as their illness, rather than for other characteristics of their identity. A friend or family member knows the individual on a personal level and would not necessarily judge them on a first

impression based on their diagnosis. As explained by P3, *“I didn’t tell people, and I think that’s fairly common”*, and P4, *“If I said it to a stranger, they might think I was feeling sorry for myself”*. There is a comfort and trust level associated with disclosing to people that the individual knows on a more personal level and educate them as to why the person is acting in such ways.

5.3.2 Managing the perceptions of others

In asking participants about their identities, many stated that remaining independent and self-reliant was extremely important to them. Tied along with that, they did not want anyone to perceive them as dependent, a burden, or a nuisance. They expressed that they did not want any pity from others, or to feel like a victim. It was also imperative to the participants that people perceived them as capable, and that their identity was not compromised by the disease.

5.3.2.1 Independence

One commonality between participants was their desires to stay, as well as be perceived, as independent. In fact, many participants expressed their disdain for being dependent on others. In this study, independence emerged as a central aspect of identity that participants strived to maintain. As individuals with the condition start to experience more deterioration of physical and cognitive abilities, their reliance on others increases, and their ability to make their own decisions and act independently decline (Hedman et al., 2015). This takes away from the personal identity the individual had that related to their ability to independently complete tasks, and not rely on others.

P3 reflected on his condition and decline in independence by saying, *“One is that I would’ve thought that, in my condition and so on, I could’ve been more independent and uh... I think that with [my wife]’s help I could’ve been more independent”*. P2’s wife also commented on how much P2’s dependence on her had increased, *“And so now, life has totally changed, totally. From going to being totally independent to being dependent in everything”*. P1 also talked about the importance of independence in her life in order to keep enjoying activities she likes to do:

But it’s important to me to, uh, to keep... and not because I’m trying to be a... a, advocate for people with Parkinson’s, I just think it’s important for me to keep doing things... excuse me, that I like to do.

In able-bodied individuals, independence is not something that is frequently threatened (Hedman et al., 2015). With Parkinson's disease, however, mobility and cognitive decline causes individuals to rely on others for assistance with tasks that once were easy (Vann-Ward et al., 2017). The increase in falls further affects the confidence of the individual, thereby threatening their sense of identity (Gardiner, Pendlebury, & Jackson, 2017). The identity of the individual is still that they are able-bodied, and do not fall, and thus being at risk of this threatens their independence (Gardiner et al., 2017). P2's wife described how her husband has needed much more support and reliance since falling:

That has to be the one thing that you just can't go anywhere on your own anymore. In fact, you don't even go for a walk anymore because it's a worry that, after you had that fall, now you're not as steady, so, you know, we have to really be careful, wherever we walk.

Activities and tasks the individual was once able to complete on their own are now relied on to be completed with the assistance of another.

5.3.2.2 Not a burden/nuisance

Participants in this study did not want to feel like they were a burden or nuisance to others. Perhaps most significantly, they did not want to be a burden to their spouse, as they felt the physical difficulties of their disease often frustrated their partner. They also did not want strangers to worry when observing their mobility in public spaces. These feelings of being perceived as a burden seemed to threaten their confidence in both completing desired tasks, as well as how often they went out in public, thus threatening their social identities, as both occupations and roles within the community diminished. Within the scope of my study, individuals expressed feeling like a burden to loved ones and acquaintances – people that the individual knew on a more personal level. Feeling burdensome or like a nuisance often came from completing former activities that now took the participant far longer to complete, such as getting ready to leave the house, or taking public transportation. While their family did not make outright comments about the individual, it was their own feelings towards themselves and how people perceived them that made them feel like a burden. P1 commented on her husband's frustrations and annoyances when she takes too long to get ready as a result of her condition:

Well, usually we go to go somewhere, and I've got to go one more time to the bathroom. Or I take forever to get out of the car. Or I'm fiddling with my jacket or something, and I

can just hear him huffing behind me, like he's – I know, he gets frustrated because I take longer to do things.

As well, P5 reflected on how observers interact with her and perceive her, and how it affects her confidence:

I take the bus. Well, there is, the bus I was always taking, from Kipps Lane, the drivers all look very, have a concerned look on their face when I get on the bus. And I think it's because they knew me from, you know, when I moved in four years ago, and I'm moving differently now, but it's almost like they're worried about me. And it's like, oh my God, do I look that bad? That people have to worry about me when they see me out on my own?

5.3.2.3 Not an object of pity or victimization

Similar to not wanting to be perceived as a burden, individuals did not want to feel pitied or victimized. Oftentimes the participants would pity themselves for the state of their physical limitations and what they had to give up or abandon because of it, however they did not want others to feel that way for them. The participants in my study expressed that how people treated them made them feel as if they were being pitied for their physical and mental capabilities. As mentioned by P5, people talking to her will treat her as if she has a cognitive impairment, even though her cognition is perfectly intact. This perceived pity appeared to affect the confidence of the individuals, as they become more aware of the physical symptoms of their disease that people make unjust judgments about. As confidence declines, the individuals may not feel as comfortable going into public spaces and altering the social identity that the participant once had when talking to strangers or the general public. They may become more self-aware of how their mobility and cognitive limitations affect how they are perceived by others. In addition to feeling pitied by others, participants talked about how despite needing them, mobility aids could also often act as a marker of frailty and therefore threatened the individuals' feelings of confidence and competence in public spaces, diminishing the identities that they had as competent and contributable members of society. For example, P5 noted that regardless of her ability to be a competent and autonomous person, individuals treated her as if she had a cognitive impairment, due to her slow movements and speech:

So, now what I experience, and I'm always surprised, but when I'm talking to people, and I suppose the way I move now, they tend to treat me as if I'm cognitively impaired. And

so, they feel they have to shout or have to repeat anything or explain like talk like to a child when they're talking to me, yeah.

P3 also noted that individuals often find shame in those with Parkinson's, and even that those with the disease often pity themselves: *"Some people, some friends, some association, seem somehow ashamed that they have Parkinson's, or any other illness for that matter"*.

In addition to not wanting to feel pitied, participants also did not want to feel like a victim. Within my study, one participant expressed that they were at the stage where they felt they were a victim of Parkinson's disease, but wanted to work towards not feeling like one. In taking on a victim identity, the participants often felt helpless, whereby their decisions and actions were hindered significantly by the limitations of their condition. While I think feeling like a victim varies from person to person and is affected by how they cope with illness, I also think it is easier to assume a victim role when you are presented with a challenging situation. With Parkinson's disease, I think it is easy to put yourself into a victim mindset, because as in my participants' cases, you are constantly dealing with new challenges, unexpected changes, and constant uncertainty. This could make anyone feel as if they are not in control.

P5 reflected on her feelings of the limitations of her condition. She expressed that if she succumbs to her disease, and lets it define her, she feels that she is a victim of it, rather than her controlling it:

If I am Parkinson's, I'm a victim of Parkinson's, like I play more of a victim, I'm more, I feel more helpless... It's something I dealt with for so, but now maybe I just feel it more acutely, or because I... you know what's happening is I like to feel sorry for myself. I, I get in that victim role and... and that's pretty pathetic and I can't do anything.

5.4 Theme 4: The Centrality of Occupations and Roles

Occupation is an umbrella term used to group all of the activities we involve ourselves in, as well as the meaning and significance attached to those events (Murdock et al., 2015). Roles are defined as the sets of expectations attached to positions within certain networks of relationships (Stryker & Burke, 2000). Occupations and roles are key in how an individual understands and shapes their identity (Hammarlund, Westergren, Astrom, Edberg, & Hagell, 2018). In the context of Parkinson's disease, occupations and roles may have to be adjusted to compensate for the progression of disease symptoms. Participants in this study mentioned many

of the hobbies, activities, and daily tasks they had to alter, adapt, or sacrifice as a result of their illness and the significant impact that had on their sense of identity.

5.4.1 The challenges and loss of occupations

Participants in this study frequently mentioned the hobbies, daily tasks, and activities that they once had completed with ease, but now could no longer do without requiring assistance or had abandoned because of the difficulty and complexity of completing it with Parkinson's disease. The symptoms of Parkinson's disease impedes everyday functioning, thereby impacting the capability of individuals to continue with their daily routines, activities, and occupations (Hammarlund et al., 2018; Liddle, Phillips, Gustafsson, & Silburn, 2018; Murdock et al., 2015; Oris et al., 2018; Turner et al., 2017; Vann-Ward et al., 2017). Many of the occupations that individuals engage in are a reflection of their personal interests, and thus comprise some aspects of their identity (Murdock et al., 2015). Day-to-day tasks often change as the demands of Parkinson's disease become more significant, such as managing medications, limitations in physical functioning, energy loss, and cognitive impairment (Hammarlund et al., 2018). This leads to certain occupations being abandoned or adapted into a new occupation that is easier to manage and/or less time-consuming (Hammarlund et al., 2018), as described by P4 and his hygiene practices:

I switched from having a shower to a bath, because sometimes I've gone in the shower and uh, I'm not sure whether I can keep standing up, so I just sit in the bath now. I think it's safer. I have a bit of a problem with my back.

Some occupations individuals reported having difficulty with since the diagnosis of Parkinson's included traveling, socializing with friends, and hobbies such as playing instruments or sports. For example, P1 is no longer able to travel, like she used to, due to her mobility issues:

We just don't, aren't able to do some of the things we like to do, or not as much. We don't travel very much, the last time we were on a cruise... I had my walker with me but, you know, I found it really difficult to, uh, to enjoy the things that were going on around me.

P3 has found that his three most important and enjoyed hobbies had to be retired because he no longer has the fine motor skills and mobility to engage in them:

I find that, there seem to me to be many, three major hobbies, and uh, I'm being prevented by doing... all of those rely on open spaces – not all of them – but sailing,

obviously. Flying radio-controlled model airplanes also outside, and then um, music is the inside.

As well, P4 is no longer able to go ice skating, an activity he used to enjoy with his family: “*I bought a new pair of, a really nice pair of skates, and uh, ended up, I gave them to my brother to sell, because it was obvious, I wasn’t going to be able to take my niece skating anymore, unless standing on the sidelines*”. P5 reflected on the fact that she no longer engaged in the activities that she derived the most passion and joy from, and when reflecting upon it, realized that it deeply upset her:

I filled in a questionnaire about something a couple months back, and it said, um... something about your reluctant to meet with people that knew you when you weren’t, did not have Parkinson’s. And I was, I would, I would have answered no all the time to that, oh no, and I’m not embarrassed by Parkinson’s, and I tell people I have Parkinson’s whether they’re interested or not. I just throw it out there. And, and um... but when I thought about it, um, I don’t go to church, I don’t go to the gathering for HR clergy... and I’m gonna cry.

Four of the five participants in this study had lost their driver’s license. The one participant who still could drive chose not to because she preferred her husband driving. Participants expressed that of all their occupations, driving was the most significant occupational loss in their daily lives that threatened the participant’s independence. In the case of P4, he mentioned, “*You know, you consider yourself to have a certain identity when you’re driving and getting around... I haven’t lost my independence. Uh... well, as far as driving, obviously I have.*” Despite saying that his identity had not changed, he mentioned that driving was a part of his identity, and that he lost that aspect of his life. This example of a fracture of identity shows that the participant had to work hard to maintain important aspects of identity, such as the desire to be perceived as able-bodied, while managing some of the challenges associated with Parkinson’s. The ability to drive had previously allowed the participants to travel independently and complete tasks that would otherwise be extremely difficult. Having to rely on another person to drive, threatened the individual’s sense of identity, as being a driver was a component of their identity that they had for so long.

When P2’s license was revoked, he found it very frustrating stating: “*It, it’s really an inconvenience. And you have to do everything differently.*” P4 also expressed his unhappiness

with not being able to drive a car: *“I think that’s the thing I miss the most, driving a car”*. P2 also stated that driving was something he associated with pride: *“Something that everybody’s proud of, you know, how good a drive I am, and “look at my car”*”.

Associated with independence, autonomy, and quality of life, driving is the foundation of mobility and accessibility for community living (Holmes et al., 2019). The ability to drive is a factor that adds to identity, such as being perceived as a competent human being (Holmes et al., 2019). It is important to note that while driving is the foundation of older adults in many contexts, there are also situations where this may not be the case, such as seniors who are located within urban settings. While driving, and its importance varies from person to person (e.g. in people that rarely drive or never had a license, driving would likely not contribute to their identity at all), in the scope of my study, driving played a large role in almost all participant’s lives. In the case of the individual that still had her license, but chose not to drive frequently, driving did not seem to be a big component of her identity. Perhaps this was because she never drove a lot in the first place, or because she still had that aspect of her identity as her license had not technically been revoked. Cars not only represented a tool to travel, but they also allowed participants to engage in social events, complete daily activities, listen to music and stories, and share conversations with family and friends, as P4 describes: *“You’re, when you’re getting on the bus as a passenger, and when you’re going to parking lot to get your car, it’s two different things, totally different. I think that’s the thing I miss the most, driving a car”*. Specifically, for older people, such as those in my study, driving was extremely important for their health, as doctor’s appointments and check-ups often require travel in older age (Stepney, Kirkpatrick, Locock, Prinjha, & Ryan, 2018).

Common cognitive impairments such as memory deficits, loss of executive functioning, and trouble focusing were common amongst participants. These types of impairments may limit the extent to which individuals can perform occupations and tasks, as executive functions are key to completing a multitude of actions. This could lead to negotiations of identity, intertwined with social engagements, occupations, and roles that the individual associates with themselves and activities of daily living. Identity begins to shift or change as occupations and roles are lost or adapted, leading to changes in social identity throughout the community or memberships in society. It may also lead to negotiations of personal identity, as what makes the individual unique may begin to shift with changes in their appearance and confidence. The negotiations might even

be something that causes the individual to have confusion as to how they identify themselves anymore. As an example, P5 stated that, at the moment, she was unsure of what her identity even was:

Well, I'm not sure how I feel about it, in general. Right now, I almost feel like I don't have one. Although I try hard to, you know, to, to not let my identity be, um, ruled by the Parkinson's.

Participants in this study voiced the varying symptoms they had which impacted how they either adapted occupations, maintained occupations, or abandoned, depending on severity and type of symptoms. As P1 stated, *"I can't stand around and have a chat or talk to people without feeling like I'm losing my concentration"*. As well, P2 expressed that he has been experiencing memory impairments: *"And uh... um... I, I have trouble uh, controlling my retrieval of, uh... uh... the, I put it in the memory bank, and what I once wanted, I can't find it"*. P3 was aware that his mind wandered, and tried to use prompts and reminders to get back on track:

Well I'll give it the beginning, if my mind goes blank, if I just stop whether that's a mid-sentence or the end of a paragraph, I, I go ahead and can't remember what I was talking about... Um... if I get stuck, if I want to get stuck, where [my wife] or maybe the person in charge of the thing, um... just get me two or three words and I'm okay again.

Motor issues such as freezing of gait and balance instability were also common, as was the case with P4 who stated: *"At the beginning, the only thing that was noticeable was that I seemed to be, catch my feet on, and trip on things, and uh... I had good balance, and seemed to, my balance seemed to be getting worse"*. Surprisingly, tremors were not something that participants commented much on as being a debilitating symptom. Fine motor skills were also troublesome and caused individuals to experience significant challenges with their writing and communication skills, as well as to complete routine tasks such as buttoning up a coat or tying shoes. Fatigue and low energy were also very common symptoms that impeded a participant's ability to engage in occupations, such as with P1:

Feeling very tired, and weak, and not a lot of energy, and not a lot of strength, and, and sometimes I was discovering that when I walked, I was sort of meandering instead of going in a straight line.

5.4.1.1 Isolation and decreased social engagement with occupational losses

As a consequence of occupational losses, participants stated that they felt lonelier and more isolated than ever before. In a lot of the cases, individuals felt that they wanted to be social and participate in conversations and activities with others, but it was their disease that prevented them from doing so. As participants gave up occupations they once did, they lost the social connections and sense of engagement that was associated with their occupational involvement and identity associated with those occupations. Symptoms of Parkinson's disease threaten the pre-illness identity of the individual, as they lose occupations they were once able to do (Martin, 2015). This 'loss of self' is in part due to the limitations of their disease that impact their ability to engage in activities and tasks, thereby decreasing the amount of social engagement the individual once got from community mobility and involvement (Maffoni et al., 2017; Martin, 2015). The disease can be so variable day to day or hour to hour, that it is difficult for people to plan out their day. For example, an individual may wake up and feel "off", thus impacting the original plans or outing that they had for the day. This has a significant impact on social connections as people are often unable to commit to outings ahead of time as they need to wait and see how they are on a given day, and thereby making plans becomes troublesome.

P4 recounted a time when she first noticed her social engagement was becoming more limited, in particular with her family:

My youngest daughter who lives in Greece came over to visit with her two children – twins – and they were five. And I, by that time I was not... managing well enough to join them in Toronto. It was a big, driving to Toronto and going to the museums and the aquarium and my son was really worried about me, didn't... wasn't encouraging me to go. He said, "you can come, mom, but really, I think it would be too much" ... So, I stayed home.

P4 also expressed that she would really like to continue engaging in activities and events, but she does not want to attend alone, and so she refrains from going at all:

Like, I want to go to concerts and stuff, but I don't want to, I can't, I don't, I don't want to think about going alone, so I don't go. Where before, I went everywhere by myself. But I'm feeling more lonely now.

P1 found that she began withdrawing from social engagements and interactions because she could not find the energy to carry on a conversation: *"There was a time when I just didn't even*

want to be bothered. I didn't want to be, I didn't want to isolate myself, but I couldn't be bothered, you know, standing around and chit-chatting with people."

Not being able to meet up socially with others, an inability to drive, and social embarrassment from their physical appearance are key reasons why individuals feel socially isolated with Parkinson's disease (Hammarlund et al., 2018). The presence of particular physical symptoms also impacted social engagement. For example, voice and speech issues, including difficulty moving their jaw, pitch, volume, and tone problems, increased or decreased speed of speech, and stuttering all presented challenges. As expressed by P2:

"This is the changed voice. Uh... before it was, uh... uh... more of a radio voice, uh... because then it would penetrate. And when the, uh... voice changed, uh... it would get softer. It was doing that yesterday, and maybe a bit the day before".

Furthermore, P1 articulated that she saw herself as different because of her change in speech but doesn't really attribute that to her identity:

But I don't, I don't see myself as any different at this point. I mean, I'm different because I'm slower and I... sometimes have to struggle for words and things like that, but I don't see myself any different really except for that sort of stuff.

While participants acknowledged that changes in motor skills, such as impacts to linguistics and communication, made it more difficult to converse and engage with others, they tried not to let it impact their identity. While it is a side-effect of their ability to communicate with others, they chose to overlook those issues and try and continue on with everyday life and commitments. In the case of P1, she often would remind herself that her voice had changed and she may need to focus on her speed, pitch, and pronunciation in order to get her point across, rather than completely withdraw from socialization, as social activities were an important aspect of her social identity. Whereas for P2, he remained patient and refrained from getting frustrated when he could not get his point across and had his wife help facilitate communication instead. Having that support system allowed him to continue with his most significant activities that were associated with his identity.

5.4.2 Losing, shifting or maintaining roles

In addition to occupational losses, participants commented on how roles were either lost due to the progression of their disease or shifted onto another person in an effort to compensate.

In the case of spouses or caretakers, it was common for them to take on a lot of the roles within the household that the individual with Parkinson's disease once did. Most of the participants were not bothered by this shift in roles. Rather, they were thankful that they had someone to assist them in completing tasks and did not take it for granted. While they were not bothered by the change in roles, the shift still causes some changes to the roles associated with identity. Some roles, however, were too important for the participants to relinquish. They talked about how those roles, which were a vital part of their beliefs and core to their sense of identity would stay with them, even through the progression of Parkinson's. For example, P2's wife acknowledged some of the roles and occupations that P2 could no longer do:

He could do anything. He could make his own decisions, he could go where he wanted, he could drive the car, he could look after the yard, he could go shopping on his own, he could – well, except for the laundry, never did that, no, or the cooking – but very capable, very bright, sociable, lots of energy.

Furthermore, P5 commented on some of the roles that remained a part of her, regardless of Parkinson's disease, such as her religious beliefs:

I am a priest, and I can't change that. I mean, it's me, it's part of me, it's who I am. Even before I was ordained, I was a priest, you know, except for doing the sacraments. Um, I, you know, I've always been, for as long as I can remember, this person. So, it's different than 'being Parkinson's'

Caregivers and spouses of individuals with Parkinson's often have to take on more roles than previously when caring for them. Not only do they need to take on more roles, but often, there is "a reversal in roles they previously had with Parkinson's disease participants" (Lawson, et al., 2018, p. 5). This was seen in my data through P2 and his wife, who commented that she was now taking on household roles that her husband previously did prior to Parkinson's disease, such as cleaning and repairs. This can also affect negotiations to identity that the individual tied to family roles, such as their role within the household as a spouse or as a parent, for example.

5.5 Conclusion

The themes presented in this chapter, have all helped to further understandings of how identity is negotiated, maintained, or shifts for older adults after being diagnosed with Parkinson's disease. Initially when participants were diagnosed with Parkinson's disease, they

were trying to not only understand the diagnosis, but also symptoms, treatment options, disease progression, and future timelines. They did everything in their control to understand the disease, as well as manage the characteristics and manifestations of the disease, in order to maintain the identity they had pre-diagnosis. From my data, it became clear that participants viewed acceptance as a process and that it takes time to understand your identity as you age and go through various life stages. Acceptance might include such stages of grief as denial and reluctance to admit and believe that they have a chronic illness. Acceptance may also take the form of disclosure of their condition in an effort to educate friends and family on any physical or cognitive changes that have occurred. Individuals may have used coping strategies such as humour, feeling fortunate, and comparing the self to others in order to further their feelings of reluctant acceptance and negotiations to identity. By using humour to lighten situations and comparing their condition to others that they might deem in a 'worse' state, the participants were giving themselves, and others who know them, validation that their identity has not been impacted by their illness.

Furthermore, as they were reluctant to accept their diagnosis, they resisted an illness identity in order to hold onto their pre-diagnosis identity, including holding onto their independence, and avoiding being seen as a victim, as a burden to others, or being pitied. Even though participants might have resisted a disabled identity, fractures to their identity and self were noticed as data was analyzed. While denying any changes to their personal identity, participants would sometimes say something that contradicted their justification of unchanged identity. This might have been because they did not want to admit or accept that their illness had, in fact, changed facets of their identity and thus resisted a disabled or illness identity. This was mostly seen through an individual's description of their occupations and roles that had changed since diagnosis. Participants lost, or at times adapted, many occupations as a way to compensate for the physical, emotional, and cognitive symptoms of their disease. These occupations were often meaningful and tied to their sense of identity and the roles they held within family and/or social circles. These occupational challenges, changes, and sacrifices allowed people to reflect on their lives with Parkinson's disease, and start to come to terms with what aspects of their identity remained regardless of the disease, and which were negotiated as a result.

Chapter Six: Reflection and Conclusion

In my closing chapter, I will reflect on the results of my study including providing a reflection on my thoughts and opinions of the data as well as how the data has affected me. I then discuss the findings in greater detail than mentioned in the previous data findings chapter, by specifically highlighting comparisons between my findings and existing supporting literature, as well as similarities and differences with existing literature. I present the challenges and limitations that arose before, during, and after the study was conducted. After the challenges are addressed, I then discuss the strengths of the research, as well as how this study can contribute and impact future directions in research, policy, and clinical practice. Finally, I conclude my thesis with a summary of my research and overall thoughts.

6.1 My Reflections

Looking back on the results as well as the research process, I became increasingly satisfied that I decided to use the narrative approach in my study. Through narrative, I was able to capture in-depth stories and perspectives regarding the lives of my participants that turned out to be a productive means to understand their personal journey with Parkinson's. I think using narrative was a great way to form connections with my participants that allowed them to feel comfortable with me and share parts of their lives and their stories that they may not have in a different setting or study context. Considering the participant's expressions of gratitude and willingness to participate fully in the process, I also feel that the participants genuinely enjoyed the narrative process.

Writing the narratives themselves was difficult for me in the beginning. It was a new and interesting process learning how to properly encapsulate the significance and meaning that each individual tied to their stories. I did not want to wrongly portray anyone, leave any important information out, or not do their stories justice. I put a lot of pressure on myself to make sure that I kept their stories as accurate and authentic as possible. I had to piece together the chronology of each story, as aspects of each individual's story was spread out between two sessions, with parts of each scattered throughout. Making sure I got the sequences of events proved more difficult than I thought, and I was thankful that I was able to run this by each participant in the third session. I was even more grateful that each participant was so understanding if something was wrong and needed to be fixed. This study was as much new territory for me as it was for them.

I really enjoyed that I was able to connect with each individual over multiple sessions. In meeting each participant, I was lucky enough to learn their unique stories, and piece together how their identity came to be following their diagnosis of Parkinson's. It felt nice knowing that my time with them would be spread out over a few months, and I would get to learn new things about them each time I visited. I found that each person had different family dynamics, personal struggles, and symptoms of Parkinson's. Each had varying factors that contributed to their identity and I was able to catch glimpses of those factors with each visit.

Within this study, unfortunately two participants fell quite ill, both being hospitalized. One participant I was able to visit in the hospital to complete their final session, whereas the other had to withdraw prior to completion of the third session. In seeing the one participant in the hospital, it was eye-opening to see the changes in their presentation in such a short period of time. This really put Parkinson's disease in an even more serious and scary perspective, one in which you could see how quickly and significantly the disease can progress.

6.2 Discussion

My research on older adults with Parkinson's disease and the negotiation of their identity post-diagnosis had many analytic themes emerge that will contribute to the growing study findings surrounding narrative research and chronic illness. There has been limited research, thus far, that focuses specifically on older adult populations with Parkinson's disease, and investigates how their diagnosis and life after diagnosis has impacted the evolution and negotiation of their former identity. One study that was particularly relevant to my own research findings was by Vann-Ward et al. (2017), which will be referenced throughout my discussion based on its connection to my own data analysis findings. By conducting in-depth interviews, observations, and including photos and videos of participants, Vann-Ward et al. (2017) theorized a five-stage process to preserving self with Parkinson's disease through both social and personal processes. Their five-stage theory is as follows: a) making sense of symptoms, b) defining turning points, c) experiencing identity dilemmas, d) reconnecting the self, and e) envisioning a future (Vann-Ward et al., 2017). I found that Vann-Ward et al.'s (2017) work was very relevant to the findings of my study. Of the four themes I presented in my previous narrative results chapter: *Negotiating identity while managing Parkinson's disease; Acceptance as a process; Resisting a disabled identity, and; The centrality of occupations and roles*, various subthemes were also addressed,

and all are interconnected in some ways. I intend to delve deeper into these themes and how they connect to identity throughout this discussion section.

Before delving into the discussion pertaining to themes analyzed, I would like to focus on the fractures to identity that were observed in data collection and emerged further through data analysis. These observed fractures may be due to several different reasons. For example, as a constructivist, I am aware that my presence as the researcher may have contributed to these fractures, and the identity that the participant's described. As an able-bodied, young woman, it is also possible that the participants did not want to show any degree of illness identity, in order to maintain that they were also able-bodied in an effort to relate more to myself. Some key challenges may have contributed to their identity negotiation post-diagnosis such as loss of roles, decreased social engagement, and particular symptoms of Parkinson's disease. I believe fractures may have contributed to their narratives as they worked to maintain particular key values tied to desired continuity of identity and resist a disabled identity.

In the participant's management of Parkinson's disease, all used various strategies and techniques to help manage the disease, their situation, and various outcomes in order to refrain from having to compromise their sense of their identity in relation to their illness. In attempting to manage their illness, individuals resorted to asking for help from others such as strangers, or utilizing their support system which included personal support workers (PSWs), formal caregivers, friends, and family. This control can be linked to exercising an individual's autonomy, competence, and independence, as well as ensuring they have a say over their decisions and maintaining independence, which may be extremely difficult when faced with a chronic illness that impedes speech or coherency. I found that autonomy and independence were central in negotiating personal and social identity within the context of my study. All participants expressed their frustrations that they had to rely on others to complete tasks that were previously manageable by themselves and had decreased confidence in themselves and their physical state because of their dependence on others. A decrease in confidence can affect how the individual views their identity, in that they might begin to doubt their own capabilities and qualities that they attribute to themselves that are now being compromised because of their dependencies. As well, depending on someone else can impact how able a participant is to go and complete the occupations they were once able to do without support, and can take a toll on the social identity that they once associated with specific roles related to those occupations. As mentioned from

identity theory outlined by Burke & Stets (2009), people tie specific meanings to the roles they play in their personal and social lives. Social interaction is intertwined within the social identities that people associate with themselves. A change in interactions, such as now asking for assistance or relying on another, can shift the identity that the individual tied to specific social roles (Burke & Stets, 2009).

Autonomy in chronic illness, such as in Parkinson's disease, is derived in part from experiences and life events. Autonomy is linked to independence in that they both relate to making decisions for the self (Hedman et al., 2015). While autonomy is defined by control in decision-making, and the right to free human agency without intervention or interruption, independence is foundational in autonomy, but it specifically implies a lack of dependency on another (Hedman et al., 2015). In a study by Hedman et al. (2015), they found that in older adults with a chronic illness, the meaning of autonomy was made more apparent when certain life events emerged that evoked an emotional response. Such examples would be the emotional adjustment tied to activities that the individual used to be able to do, but now needs help with, or can no longer do (Hedman et al., 2015). This was apparent in my study through certain challenges like traveling or accessing transportation to get somewhere, in which the participant may need to ask someone to give them a ride. This presents difficulties for the participants because this is often a task that could formerly be done independently, and the reliance on someone takes a small part of their independence and autonomous decision-making away. For example, P2 began needing to ask friends for transportation to his support group, or for someone to drive his golf cart when at the club. This was something he was reluctant to do because it was something he used to be able to do independently, and having to ask someone meant that he had to rely on someone else in order to continue doing something he loved. This takes away from the personal identity that individual has in terms of their confidence and independence, but also his social identity in the feelings and membership he associated with golfing and being a part of the golf club.

Participants within my study also had interesting views on disclosing their diagnosis to others. While most had no problem letting acquaintances and people close to them know about their condition, they did not necessarily enjoy telling strangers. Strangers I would distinguish as an individual the participant has never met before – such as a person standing in line, a store clerk, or a taxi driver. Whereas, acquaintances are people the individual has had multiple

conversations and contact with, but are not necessarily a close friend, such as neighbours or activity members. There are a few reasons as to why this might be. Vann-Ward et al. (2017) noted that in their study, “participants quickly realized the limited knowledge of other people regarding Parkinson disease” (p. 971). In their study, educating others was a way of preserving how others perceived them, by letting acquainted and friends know that the manner in which they presented themselves was because of their disease. Participants in my study expressed that they wanted to educate others in order to give them a greater understanding and empathy for what the older adult with Parkinson’s was going through. This could also be a way to help preserve the identity of the individual prior to diagnosis, by disclosing and distinguishing to people who knew them formerly as to why there is a change in behaviour. However, Vann-Ward et al. (2017) noted that participants also may not want to disclose to others because “keeping secrets and keeping private was a tactic used to reduce potentially hurtful situations” (p. 971). This is another way for the individual to try and preserve the identity that they had prior to diagnosis, by keeping their diagnosis to themselves. One participant in my study, for example, noted that he felt that telling strangers may evoke pity. This pity would be hurtful to both his personal and social identity as he wanted to feel able-bodied and that his disease was not something to be pitied by those around him. Indeed, the stigma associated with chronic illness can also lead to a harder time with adjustment to their condition in relation to identity (Charmaz & Rosenfeld, 2010). Stigma makes it more difficult to adjust to one’s condition and identity associated with their illness because of the negative perceptions that the individual feels based on Parkinson’s disease and his appearance. An individual may not want to accept or hold onto an identity when they feel it is associated with embarrassment, disability, and limitations, such as those stigmas associated with Parkinson’s disease.

Similar to my study, Vann-Ward et al. (2017) also found that individuals with Parkinson’s disease were ashamed and embarrassed by their decline in cognitive and physical abilities. For example, one participant in Vann-Ward et al.’s (2017) study was embarrassed that she was beginning to forget the names of her grandchildren. In my study, one participant was embarrassed that his physical impairment prevented him from standing up at a funeral, thus leading him confined to his wheelchair. The embarrassment and shame that he associated with himself then translated into him believing that observers were pitying him. In a study by van der Cingel (2011), she highlighted the difference between compassion and pity: “Both concepts are

used to refer to an emotion that indicates a feeling of being sorry, of understanding someone else's predicament" (p. 682). Pity has a negative connotation attached to feeling sorry for someone, whereas compassion does not (van der Cingel, 2011). Participants do not want to feel their condition is cause for people to feel sorry for them, because this confirms that their illness is, in fact, debilitating. This pity confirms that there is a noticeable change or shift in their movements, appearance, cognition, or conversations that imposes on their ability to ignore their condition, or to at least not have their condition be central to how they identify themselves, and how they are identified by others.

In relation to pity, "feeling sorry victimizes a patient and evokes powerlessness" (van der Cingel, 2011, p. 682). Participants, in my study, expressed that they did not want to be victimized by Parkinson's as this relegates them to a position of helplessness, thus threatening their independence and autonomy. The acknowledgement of not wanting to be a victim is a step towards separating the burdens of the illness itself from the identity of the individual prior to diagnosis. The participant can recognize that the condition does not define them, rather they are challenged and antagonized by it, but it does not define who they are or their identity. In trying to preserve the self, the role of a victim is a step towards reformulating their identity with disability and/or illness (Morse & O'Brien, 1995). I believe my data fits this model as participants currently recognized that they felt they were in a victim role, but wanted to remove themselves from that feeling eventually. They wanted to instead move past feeling victimized by their disease, and instead accept Parkinson's as a part of their life, rather than specifically tied to their identity. Recognizing the self as a patient is an intermediate stage, whereas the end goal is for the self to be reformulated as a disabled person (Morse & O'Brien, 1995). Instead of being a victim, "preserving self in this stage is recognizing and confronting the ramifications of the injury to the self, and the regrouping, choosing to move on, and learning to get back into the world" (Morse & O'Brien, 1995, p. 895). I believe that P5 showed that she wanted to have this type of mentality. While she expressed that she does feel a bit like a victim of Parkinson's disease, she also shared that you have to accept your situation for what it is and be aware that Parkinson's, while frustrating, is not something that she should let rule her identity.

For some individuals, controlling how they perceive themselves and/or are perceived by others is also achieved by preparing for a future with Parkinson's disease. For some participants, it included the physical stages of putting plans into order and increasing cautiousness, whereas

for others it was more emotional, preparing for the state of mind necessary to cope with the changes and challenges of Parkinson's. This preparation for the future is linked to each older adult's identity and how it will change over time, as this is always a concern when an individual has a chronic illness. The permanence or long-term duration of the illness causes those with a condition to worry and plan for a future with disease burden. This presence of chronic illness can alter the sense of self as an illness identity emerges (Charmaz & Rosenfeld, 2010). The illness identity, as touched upon in chapter two, focuses on how illness becomes integrated into the individual's identity, as they must consider physical, emotional, and cognitive aspects of the illness that will affect their daily life (Helgeson & Zajdel, 2017). Illness controllability is associated with a high psychological and physical adjustment to the disease, which allows the individual to alleviate some of their illness identity (Helgeson & Zajdel, 2017).

In relation to exhibiting control, humour can be interconnected throughout many themes in this study. Humour can be looked at during the process of acceptance. It can also be used to resist a disabled and/or illness identity, as it is often used as a defence mechanism or form of denial. In a study by Roger, Wetzel, Hutchinson, Packer, & Versnel (2014), the researchers found that in individuals with a neurological condition, humour was used as a tool to uphold a positive sense of self. Participants stated that this was a way to bring people together (Roger et al., 2014). While humour can certainly be used as a defence mechanism, to show off a brave face that their illness is not affecting them, it may also be a way for individuals with Parkinson's disease to connect with others and show that their illness does not define them; they are still able to find humour and optimism in their situation. One participant in my study defined his personality as a big piece of his identity, which he stated did not change as a result of his diagnosis. A big component of his personality was humour, which he used as a tool to not take his situation too seriously or dwell on the negatives. I believe humour can be an aspect of identity, and was a part of the participant's identity that they had prior to diagnosis, because they did not want Parkinson's to define who they are.

In relation to the control theme and using support systems, participants in my study had different kinds of support systems in place that helped them with managing their disease. For the three participants that had spouses, all spouses took on a supportive role, and was the participant's caretaker in two of the cases. For those two participants who were not married, their support systems were other family members, such as siblings, or PSWs. P5, who lived alone,

expressed frequently that she was quite isolated from social interaction, as she found it difficult to go out and do things by herself with her mobility limitations. Support systems offer help, not only with management of the disease within the household, but can also offer support in helping the individual to maintain their occupations within society, supporting their desire to keep the identity they had prior to the disease as intact as possible. Research by Vassilev et al. (2016) states that in an ageing population, care provided by a friend-dominated social network results in increased confidence in self-care and better physical and mental health for the care recipient. This is related to identity, as positive health behaviours are associated with less of an illness identity and overall perspective the individual with a chronic illness will have towards their condition (Helgeson & Zajdel, 2017). Both emotional and informational support can be found through caregivers and support workers, which correlate to increased overall management and self-care (Helgeson & Zajdel, 2017). There is a positive correlation between social support and adjustment to chronic disease, and studies show that this support is related to increased self-esteem and promoting identity (Cohen, 1998; Helgeson & Zajdel, 2017).

One of the biggest threats to independence and identity within my study was the cessation of driving. The inability to drive not only impacted identity on the level of perceived individual competency and autonomy, but a lack of transportation also affected the social lives and participation of the study participants (Hammarlund et al., 2018; Hedman et al., 2015). As expressed by my participants, the ability to meet with others and access daily activities that required travel was made more difficult without use of a license. Being able to drive was maintained for as long as possible until participants needed to weigh the benefits of driving, with the risk of road safety. One participant in my study decided to stop driving before his license was revoked, because he noticed that his reaction time was beginning to decline. As Stepney et al. (2018) states, “when ill-health threatens the ability to drive, the emotionally charged nature of giving up driving and relinquishing autonomy (and becoming a passenger in someone else’s car) can be difficult” (p. 1187).

Due to the multitude of motor and non-motor symptoms that can accompany Parkinson’s disease, various physical, cognitive, and psychological impacts may affect how the individual goes about their daily occupations. For example, participants in my study voiced how their symptoms impacted how they adapted, maintained, or abandoned occupations depending on symptom type as well as severity. While there were some similarities across symptoms,

especially with speech and voice difficulties, cognitive impairments, and depression, there was also a lot of variation in how it affected their daily lives. This is partly due to the identity of the individual, and how they chose to deal with the symptoms and occupations that were important to them. For example, participants may compensate to maintain or adapt hobbies that are extremely important to them. For example, one participant was able to keep up his hobby of playing the saxophone by getting assistance from his other band members, rather than quitting it completely, whereas another individual abandoned his love of playing piano because of his symptoms. How an individual decides to continue a hobby can be dependent not only on their identity, but disease severity and the importance of the hobby, as well as presence of supportive others.

Having to adapt or abandon occupations may cause changes or negotiations to identity as the individual ties some characteristics and qualities to activities and involvement in events (Hammarlund et al., 2018). The individual is not able to complete and engage in tasks that were once simple, or to the extent that they could before. Sometimes, as in the case with one of my participants, individuals within the community may even treat them as if they are cognitively impaired because of their symptoms. This makes the individual even more aware of the limitations of their disease, and decreases their self-confidence to perform tasks and duties they once completed with ease (Maffoni et al., 2017). As Maffoni et al. (2017) states, “Parkinson’s disease is linked to a diffused and stigmatizing belief of being a disease characterized by a cognitive impairment transforming patient into an insane” (p. 5). Communication becomes increasingly difficult if the individual has memory retrieval issues, or trouble forming coherent sentences, leading to isolation, and decreased self-confidence (Hammarlund et al., 2017).

As people often form part of their sense of identity through occupation, losing those occupations will invariably alter the identity of the individual as a result (Martin, 2016). These physical and cognitive changes that affect occupation, can take a significant toll on self-esteem, and confidence, which impacts how they are perceived by others (Hammarlund et al., 2018; Martin, 2016). This in turn, impacts their identity, as their dignity and self-confidence is diminished (Hammarlund et al., 2018). In a study by Hammarlund et al. (2018), with individuals with Parkinson’s, the researchers noted, “although they felt that deep inside they were still the same person, they were also aware that they were physically changing... Now they had to give

up doing things or taking responsibilities...” (p.3). This feeling was described by my participants, as well, who also maintained they were the same person they had always been.

With the physical changes of the disease, also comes emotional adjustment to the diagnosis. Since the most prominent symptoms of the disease are motor-related, it takes a toll on the mindset of the individual to acclimatize themselves and come to terms with the changes in their mobility and cognition. Vann-Ward et al. (2017) found a similar theme in their study with persons diagnosed with Parkinson’s disease. What I termed ‘reluctant acceptance’, Vann-Ward et al. (2017) termed ‘reformulated identity. This reformulated identity of individuals was one that was accommodating for their disease symptoms (Van-Ward et al., 2017). They had to let go of past identities to come to terms with their disease state, and also learn to separate themselves and their identity from the illness itself (Vann-Ward et al., 2017). I believe perhaps reluctant acceptance might be a step on the way to a more reformulated identity, in which participants were more accepting of the challenges associated with Parkinson’s, and how their identity is not defined by it.

According to Hammarlund et al. (2018), in order to achieve psychological wellbeing, three basic needs are necessary: competence, relatedness, and autonomy. If one of these needs is threatened, there may be a shift in behaviours that causes the individual to compensate for those threats (Hammarlund et al., 2018). For example, threats to relatedness, or the feeling of belongingness, may cause an individual to act sad or lonely (Hammarlund et al., 2018). Thus, psychological changes are generally related to the physical changes that the individual is going through during the progression of Parkinson’s disease (Hammarlund et al., 2018). Anxiety becomes prominent as worries about the future and disease stage overwhelms the individual as their physical state declines (Hammarlund et al., 2018). I had many participants express anxiety and worry over what the future would hold for them in terms of their disease progression. As the symptoms inhibit the individual from engaging in previous activities and events, depression is also heavily associated with withdrawal due to social isolation and loss or adaptations of enjoyed activities (Hammarlund et al., 2018). These mental changes affect their self-esteem and how others perceive them (Hammarlund et al., 2018), leading to shifts in identity.

The change in physical appearance since before illness also may lead to shame and embarrassment of the self that causes individuals to choose to isolate themselves from people who knew them as able-bodied (Maffoni et al., 2017). For those individuals with Parkinson’s

disease that encounter speech problems, including the physical ability to pronounce words, as well as the cognitive ability to formulate comprehensive sentences, these symptoms can also lead to involuntary isolation, as individuals may have difficulty conversing with them (Maffoni et al., 2017). This social rejection leads to internalized shame, which may impact the identity of the individual as they lose confidence and self-esteem conversing with others (Burgener & Berger, 2008). Within the context of my study, participants expressed that they were not as confident in themselves since being diagnosed as their physical abilities were limited. This was apparent from P5's wishes to continue with social engagements but finding it difficult because of her limitations in both mobility and communication impairments. She mentioned that she was ashamed of her disease, because it had caused her to withdraw from some of her favourite occupations, such as going to church.

As discussed with the loss of occupations and roles tied to identity, the roles within the family dynamic may also shift, as someone who becomes diagnosed with Parkinson's disease may feel less significant than they did previously (Lawson et al., 2018). This decreases self-confidence and threatens identity within household roles, often feeling dissatisfied with their new status within the family (Lawson et al., 2018; Liddle et al., 2018). As stated by participants in my study, their roles within their family changed, due to the tasks they were no longer able to complete effectively or independently. As Lawson et al. (2018), states, "challenges to identity and perceived role were important issues, where participants described feeling less confident or insignificant, and PD patients reversed roles with their carer" (p. 8). Roles continually shift and fluctuate as changes and progressions are made in disease and symptom severity (Liddle et al., 2018). Their roles within social groups may change, as they decrease engagement and participation in social events and gatherings (Maffoni et al., 2017). The severity of the disease can also cause one to re-evaluate their more important roles, and prioritize those that are most significant to their lives and identity as a result (Vann-Ward et al., 2017). In regard to my own study, participants noted that they chose to focus on roles that they valued more and tied meaning to. For example, while P1 initially withdrew from her involvement with her church, upon re-evaluating she realized that this was something she wanted to continue her involvement with and found ways to participate that accommodated for her illness. As well, upon struggling with his ability to play in his orchestral band, P2 began asking another band member to assist

him when he needed troubles, rather than giving up his hobby entirely, as this occupation was significant in how he identified himself.

Similarly to my results, Vann-Ward et al. (2017) found that one of their participant's greatest fears was becoming a burden on family and friends. The limitations of their disease altered their physical capabilities and ability to engage in desired activities which then required support from caregivers for continued engagement. (Vann-Ward et al., 2017). Specifically, their study indicated that in participants whose spouse or family member was a caregiver, the participants expressed that they would feel burdensome if caregiving took over their life (Vann-Ward et al., 2017). There is a burden associated with changes in roles within the family and management of the older adult with Parkinson's disease (Maffoni et al., 2017; Whetten-Goldstein, Sloan, Kulas, Cutson, & Schenkman, 1997).

Within the context of my narrative study on older adults with Parkinson's disease and the negotiations to their identity post-diagnosis, individuals recounted important life events and emotions that related to how they defined themselves in terms of their chronic illness. From their narratives, I was able to formulate and analyze themes that helped to understand the transitions and stages involved with identity related to the diagnosis of Parkinson's disease. It can be understood from my study, that individuals had to come to terms with their disease, which was often a fairly lengthy process. Through support systems, understanding the scope and progression of the disease, and asking for assistance, the participants were able to better manage their symptoms. They also underwent acceptance as a process that takes time and varying levels of emotion, including comparisons to others in both positive and negative ways, going through the stages of grief, and using pre-existing qualities of their personality, such as humour, to lessen the intensity of the illness. Through occupational and role losses, the participants also underwent stages of acceptance and transitions to accept new roles and changes to daily life and hobbies.

From identity theory delineated by Burke and Stets (2009), individuals tie certain significance and meaning to the multiple identities they hold. As defined by Burke and Stets (2009) identity is "the set of meanings that define who one is when one is an occupant of a particular role in society, a member of a particular group, or claims particular characteristics that identify him or her as a unique person" (p. 3). However, identity can be separated into both social and personal identity. Social identity would describe those roles or memberships to a group in society that an individual ties meaning to, whereas personal identity is associated with

the qualities that make someone an individual (Burke & Stets, 2009). Society, and our place within it, is an extremely important to aspect of our identity and how we define ourselves and relate to others (Burke & Stets, 2009). There are influences from society as to how we view ourselves, which is an extremely important facet to each individual's identity. Thus, from my study I learned that identity negotiation is due to a multitude of both social and personal factors that depend on both the individual's mindset, as well as how they define their roles in society. Those roles can be influenced by our physical and cognitive state. In the case of those with Parkinson's disease, as their physical and mental symptoms of the disease impact their ability to engage in occupations within society, it takes a toll on their social identity, and can impact how they view themselves from a personal identity standpoint, as well. The self can be molded and negotiated based on interactions between members of society and the individual. I noticed that participants in my study wanted to resist any association between Parkinson's disease and their identity. They expressed that their identity had not changed since diagnosis, despite showing 'fractures' to their identity that suggested otherwise. They did their best to control their situation and the future progression of the disease, in order to maintain the same occupations and roles within society and in their personal lives to keep hold of the identity that they had pre-diagnosis.

Identity negotiation was clear through their management of identity to try and maintain the identity that they had prior to the disease and not let their condition impact their personal and social identity. I believe that the difficulties faced with coming to terms with their condition is part of the process of acceptance. Individuals may have shown reluctant acceptance to their condition because they did not want to their identities to change as a result of having Parkinson's disease. By resisting a disabled and/or illness identity, these individuals could also try and maintain the identity they had post-diagnosis, and expressed their wishes to not be viewed as 'less than' in society (such as through pity, being burdensome, or victimization). The challenges associated with occupations and roles and the meanings that people can tie to them and their social and personal identity could be a way that individuals begin to negotiate their identities when they have to abandon or accommodate for previously simple activities and tasks. These themes and subthemes allowed me to understand just how Parkinson's affected these individuals' personal and social identities, as they went through stages of acceptance and denial, because of changes to their physical and emotional wellbeing, relationships with loved ones and strangers, and limitations to daily roles and activities.

6.3 Challenges and Limitations of my Study

One issue that arose during the data collection process of this study, was the inability for some participants to verbalize what they wanted to say. In some cases of Parkinson's disease, people are able to form a thought in their head, but due to the motor challenges associated with the disease, they are unable to formulate the proper words and communicate effectively. This created a problem as data collection occurred in the form of verbal interviews that were audio recorded. In the event that the participant had difficulty maintaining a conversation due to speech issues, their spouse and/or caretaker was present to help convey their responses. In those situations where a participant had difficulty with their speech and/or syntax, the contributions of the spouse were both meaningful and necessary for the study to proceed. This did make it, however, more difficult to understand the first-hand perspective of the individual with Parkinson's, as their thoughts and expressions had to be translated through their facilitator. As a constructivist, I acknowledge that how the caretaker expresses themselves may be different than how the older adult with Parkinson's disease might choose to convey their experiences, including tone of voice, facial expressions, and body language.

In future studies, I would like to consider studying both older adults with Parkinson's and their caretakers, to understand the dynamic between the individuals, and how that relationship might influence the identity of the individual with Parkinson's. I think it is also important that in future studies, the caretakers' responses, who were not specifically facilitators, are included as part of data collection so that their answers could be analyzed and used in the dissemination of research.

Another challenge of this study was that cognitive challenges faced by the participants emerged over the course of data collection. As this study took, on average, 4 months to complete data collection with each participant, cognitive challenges that may not have been present at the beginning of the study emerged or became more apparent as the study went on. In the case of one participant, their delirium progressed to the point where they had to be hospitalized and could not finish data collection. One strategy that may have helped in this situation would have been different methods of data collection that could have been done with someone facing expressive and cognitive challenges to accommodate for their speech and communication issues. For example, participant observation may have been a useful way to learn about some of the experiences and challenges that older adults with Parkinson's face. A more structured interview

format for the second session could have also assisted those individuals who had cognitive difficulties, or more clear, formidable questions to answer in easier terms or less abstract concepts that were simpler for individuals to describe.

Cognitive challenges also posed as an issue in the recruitment process, as well. As briefly mentioned in chapter three, one participant had difficulty identifying how old he was when he was diagnosed. Upon screening, the participant expressed he had been diagnosed when he was older than 60-years-old. However, during the data collection process, the participant changed his answer to a diagnosis at 57-years-old, that made his diagnosis younger than allowed by the inclusion criteria to participate. This was troublesome as this participant had already consented to participate and data collection had begun. A more thorough screening process, particularly when age of diagnosis is important for inclusion, would be extremely beneficial, such as by asking a few more questions that offer more detail as to date of diagnosis. As participants with Parkinson's often have memory recollection issues, this extra screening questions would likely aid in the screening process.

One thing that I did not know before starting my study was that I could have benefitted from practicing interviewing much more prior to my first session. Although I had learned all about narratives, and read up on different methods and approaches to form my data collection sessions, I realized that I lacked practice. The method I chose required me to ask the participant to tell their story and allow them to speak without any interruptions. As I conducted my first session, I became increasingly aware that I was interrupting their stories with small sentences that may have contributed to the individual's narration (more than what is recommended by Wengraf's (2001) BNIM). This may have distracted participants or changed the course of what they wanted to say, as I sometimes found it difficult to mask my emotions and keep a neutral state while in the role of interviewer, for example, by commenting on activities the participant described I would say things such as "Oh, I like to travel, too!". It's hard to say what would have changed if I had sat there and not interjected as intended but I do think that my small interruptions could have altered the course of their narration, and may have resulted in perhaps more or less details in the sequence of their story.

Relating to this, and as mentioned earlier in my thesis, my role as the interviewer and how I presented myself could have also limited the information that a participant chose to share with me. As an able-bodied, young, educated woman, interviewing older adults with a chronic

illness, it is possible that individuals wanted to present themselves in relation to me, such as able-bodied, and therefore omitted or refrained from sharing personal details with me related to their narratives. While I would like to believe this is not the case, as a constructivist, I realize and acknowledge that my own identity could be a limitation to how these individuals chose to frame their narratives.

6.4 Strengths of my Study

Narrative research, in itself, was a strength of my research study. This is because, as presented in my third chapter, narrative methodology is a great approach to understanding the depth and perspectives of individuals and their lived experiences (Lieblich et al., 1998; Reissman, 2008). While the results and analysis of data are indeterminate, as each narrative can have varying interpretations, appreciations, and understandings, there were several comparisons and similarities between the study findings that contributed to the overall complexity and fluidity associated with understanding how Parkinson's disease can affect negotiations of identity in older adults.

Due to the long duration of my data collection, and several sessions with each participant, I was able to gather rich and detailed data. Multiple interactions with each older adult allowed me to build a relationship over time, and with each session, further depth and details about the individual were discovered. Furthermore, I was able to gather rich and broad data, as I was fortunate enough to recruit a diverse group of participants to my study.

Furthermore, as each individual with Parkinson's disease varies in disease progression, severity, and symptoms, I was able to develop a greater appreciation and understanding for just how differently this disease impacts each person. Through their narratives, I was able to understand the similarities and differences that each person had with their own illness. Some individuals were in the earlier stages of progression, whereas others had been dealing with it for a longer time or had greater severity and more debilitating issues. This gave great perspective into the variation between individuals.

As well, participants were given the opportunity to choose where the study would be conducted, and all of them chose their home. Being welcomed into each person's home offered a different perspective on the disease itself, as I was able to catch a better glimpse at the personal lives of each individual. The impact of the disease could be understood in greater detail by

seeing an individual's home, and what kinds of devices, resources, or lifestyles the individual had.

Another strength that I found after conducting several sessions with each participant, was that the individuals began to express their sincere gratitude and appreciation for being asked to participate in my study. Not only did they want this research to make meaningful contributions to future studies and findings related to Parkinson's, but participating was a meaningful contribution to their own lives as well. For example, as the nature of narrative research is to allow the narrator to choose how their story is told, participants told me that by giving them the opportunity to talk about their journey with Parkinson's disease, they were able to voice things they had never talked about before. They learned things about themselves they did not know and expressed that this process became cathartic for them. I was extremely humbled and honoured that participation in this research not only benefitted myself, but the participants found that they benefitted as well.

6.5 Implications for Research and Practice

In this section, I present the implications of my study findings on future research, social contributions, and clinical practice including physicians, nurses, and rehabilitation services, such as occupational therapists and physiotherapists.

6.5.1 Research contributions

The results of my study will make meaningful contributions to enhancing the understanding of older adults with Parkinson's disease and their experiences with identity post-diagnosis. As mentioned previously, there are limited studies that focus on the older adult demographic with Parkinson's disease, and in particular studies within this demographic that focus on issues of identity. As a result, I believe there are many positive research contributions that this work will make.

First, as mentioned earlier in this chapter, the connection between caregivers and the older adults with Parkinson's disease should be investigated. For example, it would be interesting to look at how the identity of an individual with Parkinson's disease may be impacted by the presence of their caregiver – understanding if having a caregiver, and what their relation to their caregiver is, has impacted the identity they have negotiated post-diagnosis. As well, investigating the identity of the caregiver themselves and how they have also made potential

negotiations to their identity would be very interesting and give insights into the dynamics between caregivers and older adults with Parkinson's disease.

I believe comparison studies between Parkinson's disease identity post-diagnosis and a variety of demographic factors should be completed in the future. As Parkinson's disease can have an earlier onset, it would be interesting to compare and contrast how identity is negotiated as a factor of age of diagnosis. This would give insights into how identity is tied to both age and having a chronic illness. Furthermore, comparisons could also be drawn between older adults with Parkinson's disease, and those with another chronic illness, such as chronic obstructive pulmonary disease (COPD) or diabetes. Comparisons between illnesses would give greater understanding into how the type of disease and both physical and emotional manifestations differing between chronic illnesses impact the identity of the individual post-diagnosis.

On another level of comparison, looking at different geographic locations could also offer appreciation for how individuals living in certain areas (whether it be another region of Ontario, another province, or another country) can impact how the individual copes with their illness, thereby potentially impacting the negotiations made to their identity as a factor of healthcare, society, and personal values.

Furthermore, comparisons between males and females, the varying lengths of diagnosis, marital status, and caretaker dependencies would be very interesting data to look at. I was unable to draw any types of comparisons between these factors in my own research, as it did not fit with my intended research question. It would be beneficial for future research to compare and contrast the differences between each individual, and take into account how they were similar or different in regard to personal and/or social identities despite differences in gender, family dynamics, and duration of disease.

6.5.2 Societal contributions

As this study looked at older adults and their identity post-diagnosis of Parkinson's disease, there can be connections drawn to society and the impact that they have on those with this disease and negotiations to their identity within a social context. For example, I believe that this study can help to raise awareness of the needs of older adults with Parkinson's disease, how negotiations to their identity are made as a factor of society, and the stigma associated with their disease. As mentioned in my study, participants frequently felt judged and stigmatized by

strangers who they communicated with, due to the limited knowledge and awareness that individuals unaffected by the disease have. This study could help to increase awareness in a societal context, in order to educate more people on the challenges of daily living and differences in symptoms associated with the disease and identity negotiations. Increasing education and awareness for the disease would, in turn, decrease the bias and stigma associated with Parkinson's.

This study could also help to increase opportunities for meaningful activities, hobbies, and involvement within the community that are available to older adults with Parkinson's disease. While there are some support groups and community programs available to those with Parkinson's within the London area, the amount and variety of programming could be expanded, including more programs tailored specifically for older adults with Parkinson's and enhancing community participation, such as through social activities. For example, programs including activities such as dancing and singing classes have been shown to reduce the severity of symptoms while also encouraging social participation (Abell et al., 2016; Butt, 2007; Gibson & Robichaud, 2017).

Further, I had many participants express their desire to share their written narratives with friends, family members, and physicians. By sharing their narrative accounts, this study could be used to increase awareness within the social circles of the individuals. While I understand the narratives are not generalizable to everyone affected by Parkinson's disease, there are connections between each individual narrative that might resonate with an older adult who is experiencing Parkinson's firsthand or members of the community who desire to know more about what a person with Parkinson's experiences. This information could be shared by the participants with their social circles, including any Parkinson's-related support and social groups. Sharing this with organizations such as the Parkinson's Society of Southwestern Ontario would also be a great way to emphasize the impacts on identity following diagnosis of the disease.

6.5.3 Practice contributions

From a clinical standpoint, a number of participants expressed their frustration and disappointment with a few clinicians involved in their diagnosis, and the journey with Parkinson's disease that followed. Some healthcare professionals the participants dealt with either diagnosed them incorrectly, did not appropriately handle the side effects or non-motor

symptoms of the disease, or did not provide adequate support and care. As such, healthcare professionals such as physicians, nurses, physical therapists, and occupational therapists may benefit from my study findings by gaining insight into some of the important needs and wishes that their patients with Parkinson's disease have, and more specifically, how the disease impacts their sense of identity.

Greater support for patients with Parkinson's disease from healthcare professionals could be achieved by offering more resources such as support groups, conferences, and educational information when first diagnosing the disease, providing supportive coping strategies, or practicing empathetic and attentive care for each patient and listening to their needs. From this study, I learned that regardless of the individual's symptoms, all of the participants required support, in one way or another, in order to better cope with the challenges of the disease. Identity is tied to how the participants learned to cope with their illness, therefore, how clinicians handle the diagnosis of Parkinson's can affect how these older adults decide to continue living their lives with the disease, and what resources and tools they use to do so most successfully.

6.6 Conclusion

This research on older adults with Parkinson's disease and their personal and social identity post-diagnosis will contribute to future research uncovering the importance of psychosocial factors involved with disease progression. The ongoing discussion of research within this field, and the significance of the person experiencing chronic illness, will continue to grow and expand until hopefully stigmas, biases, and judgments will begin to dissipate into the background of the illness.

Being able to conduct this research study is something I will always be grateful for. I learned so much as a student, as a researcher, and as a person. I grew in ways that I never thought I could both professionally and academically. In working with the older adults with Parkinson's, I learned how to become a better, more active listener, and immerse myself in research. I gained wonderful relationships and knowledge from each participant, and meaningful interactions that I will always remember and attribute to this study. In learning about their identities, I feel as though I have been able to not only understand the complexities of identity more, but also understand my own identity, and the multitude of factors that an individual attributes to it.

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Appendix A

Places for Participant Recruitment

Seniors' Programs and Centres:

1. London Boys and Girls Club Senior Program
2. The Victorian Order of Nurses (VON)
3. The Society for Learning and Retirement (SLR)
4. The Kiwanis Seniors' Community Centre

Parkinson's Support Groups, Programs, and Organizations:

1. London Parkinson Connection Support Group
2. London's Parkinson's Care Partner Coffee Club
3. London Rock Steady Boxing
4. Parkinson's Society of Southwestern Ontario

Appendix B

Email Script

Research Title: The management and adaptation of identity in older adults aging with Parkinson's Disease (PD)

This email script will only be used by the research assistant, Elena Sheldrake, when a participant emails to inquire about participating in the research study. They will have heard about the study through the Parkinson's Society of Southwestern Ontario (PSSO), a support group, a senior's day program, recruitment flyer or newspaper advertisement.

Hello,

My name is [REDACTED]. I am a Masters student in the Health and Rehabilitation Science (Health & Aging) program at Western University. Thank you for your interest in the research study that I am conducting, under the supervision of [REDACTED].

In order to participate in this study, you must be 60 years of age or older, have a diagnosis of Parkinson's disease, and be able to communicate in English. As well, you must believe that your condition has caused changes to your functional ability and/or identity. This study will examine how older adults with Parkinson's disease manage and negotiate the personal and social aspects of their identity, since being diagnosed. The study will involve three sessions that will each be 1-3 hours long, depending on how much you want to share. Each session will occur in your home or another preferred location, at a time of your choosing. The first meeting will involve a narrative interview, in which the researcher will ask you to share your personal story and journey with Parkinson's disease. This will be followed-up with some questions regarding how the diagnosis has impacted how you identify yourself. The second session will be a semi-structured interview. This session will allow both you and the researcher to clarify any information that was missed in the first interview or add or remove any information from the previous session. Prior to the final meeting, the researcher will share their analysis of your personal narrative. At the final meeting, which is a debrief and review, you will be given the opportunity to discuss any issues regarding the researcher's interpretation of your narrative, as well as to voice any questions about the study and reflect on the experience.

A letter of information about this study has been attached to this email. If you are willing to participate in this study, or have more questions, please contact the researcher at the contact information provided below.

Appendix C

Recruitment Flyer

PARTICIPANTS NEEDED FOR A RESEARCH STUDY

WHO: Older adults who are 60 years or older with Parkinson's disease.

WHAT: We are looking for volunteers to participate in a study to examine how older adults with Parkinson's disease manage and negotiate the personal and social aspects of their identity.

WHEN: You will be asked to participate in three sessions (ranging from one to three hours each) over a period of 3 months. The three sessions will take place at a date and time that is suitable for you.

WHERE: The sessions will take place in your home or another location of your choosing.

If you are interested in participating in this study or would like more information, please contact:

Appendix D

Telephone Script

Research Title: The management and adaptation of identity in older adults aging with Parkinson's Disease (PD)

This telephone script will only be used by the research assistant, Elena Sheldrake, when a participant calls the number provided. *They will have heard about the study through the Parkinson's Society of Southwestern Ontario (PSSO), a support group, a senior's day program, recruitment flyer or newspaper advertisement.*

Hello, this is [REDACTED], the research assistant associated with the study regarding the negotiation of identity in older adults with Parkinson's Disease. How may I help you?

**If participant expresses interest in participating in the study*

Thank you for your interest in this study. Before we move on to discussing details regarding the study, I would like to ask you a few questions to confirm your eligibility to participate. You can answer with a yes/no response.

1. Are you 60 years of age or older?
2. Have you been diagnosed with Parkinson's disease?
3. Do you believe that your condition has caused changes in your functional ability and/or identity?
4. Are you comfortable participating in sessions in English?

**If participant answers yes to all questions, the researcher will continue with sharing details regarding the study*

**If not, the researcher will say: I am sorry, you do not meet the eligibility criteria to participate in this study, thank you for your time. Good-bye.*

Under the supervision of [REDACTED], this study is being conducted by myself, [REDACTED], a graduate student in Health and Rehabilitation Sciences at Western University. This study will examine how older adults with Parkinson's disease manage and negotiate personal and social aspects of their identity since being diagnosed. The study will involve three sessions that will each be 1-3 hours long, depending on how much you want to share. Each session will occur in your home or another location, at a time of your choosing. The first meeting will involve a narrative interview, in which the researcher will ask you to share your personal story with Parkinson's disease. This will be followed-up with some questions regarding how that diagnosis has impacted how you identify yourself. The second session will be a semi-structured interview. This session will allow both you and the researcher to clarify any information that was missed in the first interview or add or remove any information from the previous session. Prior to the final meeting, the researcher will share their analysis of your personal narrative. At the final meeting, which is a debrief and review, you will be given the opportunity to discuss any issues regarding

the researcher's interpretation of your narrative, as well as to voice any questions about the study and reflect on the experience. Would you be interested in hearing more about this study?

If no, thank you for your time, good-bye.

If yes,

I am now going to read to you the letter of information over the phone [**letter of information will be read clearly to the participant over the phone and participants will receive a copy via e/mail for their reference**]

Do you have any questions?

[**Any questions they may have will be answered at this time**]

Do you agree to participate in this study?

**If no, thank you for your time and good-bye.*

**If yes, will continue with the study*

Appendix E

Letter of Information

Project Title: The management and adaptation of identity in older adults aging with Parkinson's disease

1. Invitation to Participate

You are being invited to participate in a study about how older adults with Parkinson's disease manage and negotiate their identity.

To participate in this study, you need to: 1) be 60 years of age or older; 2) have received a diagnosis of Parkinson's disease; 3) feel that you have experienced changes to your functional ability and/or identity since diagnosis and; 4) be able to communicate in English.

It is important for you to understand what participation in this study will involve. Please take the time to read the following information carefully and if there is anything that is not clear or if you would like more information, please contact the researcher using the details provided below. Thank you for reading this letter.

2. Why is this study being done?

While there is significant research being done on Parkinson's disease from a biomedical standpoint, there has also been a more recent emergence of research focused on the challenges that people living with Parkinson's disease face. This area of research is becoming more prevalent because as more people live with Parkinson's, there is a greater awareness for how many aspects of daily living the disease threatens. This study is being done to delve deeper into the understanding of negotiation of identity for older adults with Parkinson's disease. Negotiation of identity is understood as how people form and change their identity over time.

People can have multiple identities, based on the roles they associate themselves with. I am interested in looking at how the identity of older adults may change or evolve since being diagnosed with Parkinson's disease, and the personal story that is connected to that. From this study, I hope that people will gain more awareness and insight into how this disease impacts everyone differently, and how identity is changed because of it.

3. How long will you be in this study?

If you choose to take part in this study, you will be asked to participate in three sessions over a period of approximately 4 months. Each session will take approximately one to three hours, depending on how much information you are willing to share, as well as your level of functioning (e.g. 3 hours may not be possible for some participants due to fatigue or loss of concentration). Each participant will have the option to break up any of the sessions into shorter sessions if they would like. This may be particularly helpful to those participants who experience

fatigue. This can be discussed with the interviewer when scheduling any of the sessions. Each of these sessions will be arranged at a date, time, and location that is convenient for you.

4. What are the study procedures?

During the first session, you will participate in a narrative-style interview. During this session, the researcher will ask you an over-arching question that prompts you to give an uninterrupted, open narrative. This first sub-session will be followed up with a second sub-session that is lightly structured by the researcher. This session will be audio-recorded.

During the second session, the researcher will ask further questions about your narrative, as well as particular questions about personal and social identity. Furthermore, the researcher will give you the opportunity to clarify and elaborate on information that you shared with the researcher during the first session. This session will be audio recorded.

In the final meeting, you will participate in a debrief and review of your personal narrative. Prior to this session, the researcher will mail, or hand deliver their interpretation of your narrative to you for review. At the third session, you will be given the opportunity to give your opinion of the researcher's account of your narrative, and the plausibility of it. All sessions will take place on a date, time, and location that is convenient for you. This session will be audio recorded.

If your spouse or caregiver would like to take part in any of the sessions for facilitation purposes, they are more than welcome to, however their contribution to the study is solely to facilitate in the discussion between yourself and the interviewer, not to add in extra information from themselves.

5. What are the risks and harms of participating in this study?

There are no known risks associated with taking part in this research. Occasionally some people experience discomfort when they talk about health issues. You are free to choose what you will

and will not discuss. This research does require you to commit time. All sessions will be scheduled based on participants' convenience, and you can request to stop a session if you experience any discomfort or fatigue, and continue the session at another scheduled date and time. Participants who do not wish to be recorded can notify the researcher and they may still participate in this study.

6. What are the benefits of participating in this study?

You may not directly benefit from participating in this study, however, your views may help influence the services, programs, and policies that are put in place for older adults with Parkinson's disease.

7. Can participants choose to leave this study?

Participation in this study is voluntary. You may refuse to participate, refuse to answer any questions, or withdraw from the study at any time with no effect on your future. Information collected prior to withdrawal will be kept, unless you ask to have it removed from the study. If

you wish to have your information removed, please let the researcher know. We may give you new information that is learned during the study that might affect your decision to stay in the study. You do not waive any legal right by signing this consent form.

8. How will participants' information be kept confidential?

Representatives of the University of Western Ontario Non- Medical Research Ethics Board may require access to your study-related records for monitory purposes. All three sessions will be audio-recorded. In addition, the researcher may take notes during any of the three sessions. All identifying information will be removed from these notes. What you say will be typed out by a typist. The only people who will listen to the recording will be members of the research team. The only people who will read the meeting and interview transcripts will be the research team.

To protect your identity, only an identification number will be used to identify recordings, notes, transcripts, and interviews. You are free to request that parts of the recording be erased, either during or after the sessions. A list linking your study number with your name will be kept by the researcher in a secure place, separate from your study file. The consent form, notes and recordings will be locked in a secure place at the University of Western Ontario, and all information transferred into typed format and digital files will be password protected and stored on an OWL project site. All information will be erased after 7 years.

While we do our best to protect your information there is no guarantee that we will be able to do so. If data is collected during the project, which may be required to report by law, we have a duty to report. For example, although the researcher does not anticipate a duty to report, given

the nature of this study, if a participant expresses any desire to hurt themselves or others, this will be reported to the necessary health care provider.

9. Whom do participants contact for questions?

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

This letter is yours to keep for future reference

Written Consent

Project Title: The management and adaptation of identity in older adults aging with Parkinson's disease

I confirm that I have read the Letter of Information and have had all questions answered to my satisfaction:

YES NO

I agree to participate in this research:

YES NO

I agree to be audio-recorded in this research:

YES NO

I consent to the use of unidentified quotes obtained during the study in the dissemination of this research:

YES NO

Print Name of Participant

Signature

Date (DD/MM/YYYY)

My signature means that I have explained the study to the participant named above. I have answered all questions.

Print Name of Person Obtaining Consent

Signature

Date (DD/MM/YYYY)

Appendix F

Demographic Questionnaire

Research Project Title: The management and adaptation of identity in older adults aging with Parkinson's disease (PD)

The research team will ask each participant the following questions verbally and will record their answers on the following demographic questionnaire.

1. How old are you?

2. How long ago were you diagnosed with Parkinson's disease?
 - a. 0 – 2 years
 - b. 3 – 5 years
 - c. 6 – 10 years
 - d. More than 10 years
3. How would you describe the onset of your condition?
 - a. Sudden
 - b. Gradual
4. Would you say that Parkinson's disease has affected your functional ability and/or how you identify yourself?
 - a. Yes
 - b. No
5. How would you describe your current living situation?
 - a. Your own house/condominium/apartment
 - b. A rental home/condominium/apartment
 - c. An apartment/condominium in a retirement or adult lifestyle community
 - d. An apartment/room/flat/house owned by a family member
 - e. Boarding with a friend in a house or apartment
 - f. Other: _____
6. How would you describe your current financial living situation?
 - a. Excellent
 - b. Good
 - c. Fair
 - d. Poor
7. What is the highest level of formal education that you have engaged in or completed?

- a. Less than grade/elementary school completed
 - b. Grade school completed
 - c. Some high school
 - d. High school completed
 - e. Some college/university
 - f. College/university degree completed
8. What is your current partnership or marital status?
- a. Married/Common law
 - b. Living with partner
 - c. Divorced/Separated
 - d. Widowed
 - e. Single

Appendix G

Session One Interview Guide

Interview Guide: Sub-Session One (SQUIN)

During the first sub-session of session one, participants will be asked a Single Question for Inducing Narrative (SQUIN). This session will be audio-recorded. This sub-session will focus on learning each participant's individual narrative of their journey with Parkinson's disease. Using a SQUIN, the researcher will ask only one question that prompts the participant to share their story of living with a chronic disease. Specific examples of a SQUIN that may be used with participants for this study include:

1. Can you please tell me the story of your journey with Parkinson's disease?
2. Can you please tell me the story of your personal experience with Parkinson's disease?

The researcher will not engage in collaborative dialogue with the participant during this sub-session, but rather engage in active listening, to allow the participant to share their narrative uninterrupted.

Interview Guide: Sub-Session Two (PINs)

During the second sub-session of session one, participants will be asked questions that relate to the narrative that was shared during the first sub-session. This sub-session will be audio-recorded. The researcher may ask questions that involve key phrases or cues that will help the participant get closer to their own personal experiences and memories, otherwise known as Particular Incident Narratives (PINs). Examples of questions that may be asked are:

1. You mentioned (key phrase) ... Can you remember anything else important from this time?
2. Can you talk a little bit more about (key phrase)?
3. What happened in the moments after (key phrase)?

The questions asked will be individualized to each participant's own narrative, and thus these questions are only a guide of the structure of the interview.

Appendix H

Session Two Interview Guide

In this second session, the participant will be asked questions that will help to clarify or add to the information shared during the first session (sub-sessions one and two). This session will be audio-recorded. This session will be tailored to each participant, as the questions asked will be dependent on the data that emerges during the first session.

Questions asked will be to either add on to the story that emerged during the first session that requires further elaboration, to clarify information that may have been unclear, or to ask new questions that were thought of either after the interview had ended, or after the transcripts had been reviewed and analyzed by the researcher.

Examples of questions that may be asked are:

1. Can you tell me how you feel about your identity, in general?
2. Can you tell me about your experience with having a sense of identity when in the private realm of your home?
3. Can you tell me about your experience with having a sense of identity when in the public realm of a community setting?
4. Can you share with me any times when you felt change in your identity between the public and private settings of your life?
5. Thinking about the person you are now and your narrative, how would you identify yourself? Is it different from the identity that you had prior to your diagnosis with Parkinson's disease?
6. Can you think of any times or examples in which you faced challenges in terms of your disease? Did they take place in the community or in the home?
7. Can you tell me about a time when you felt your identity was threatened, shifted, or struggled to maintain?

Appendix I

Session Three Interview Guide

In this third session, the participant will be asked to comment on the plausibility of the researcher's account of their personal narrative. In advance of the session, the participant will be given a copy of the researcher's account of their narrative, which will include an analysis of the themes found. Questions asked during this session will be to help the researcher understand if their interpretation of the participant's story is plausible as well as to clarify if anything needs to be changed to the story.

Examples of questions that may be asked are:

1. What do you think of your narrative?
2. Is this narrative a plausible representation of your story of your negotiation of identity with Parkinson's disease?
3. Is there anything you think should be changed?
4. Is there anything you think is missing?
5. Are there any themes you disagree with?

Appendix J

Ethics Approval



Date: 1 August 2018
To: ██████████
Project ID: 111982
Study Title: The Management and Adaptation of Identity in Older Adults Aging with Parkinson's Disease
Application Type: NMREB Initial Application
Review Type: Full Board
Meeting Date: 06/Jul/2018
Date Approval Issued: 01/Aug/2018
REB Approval Expiry Date: 01/Aug/2019

Dear ██████████

The Western University Non-Medical Research Ethics Board (NMREB) has reviewed and approved the WREM application form for the above mentioned study, as of the date noted above. NMREB approval for this study remains valid until the expiry date noted above, conditional to timely submission and acceptance of NMREB Continuing Ethics Review.

This research study is to be conducted by the investigator noted above. All other required institutional approvals must also be obtained prior to the conduct of the study.

Documents Approved:

Document Name	Document Type	Document Date	Document Version
Appendix A - Session One Interview Guide Version 2	Interview Guide	28/Jul/2018	2
Appendix B - Session Two Interview Guide Version 2	Interview Guide	28/Jul/2018	2
Appendix C - Session Three Interview Guide Version 2	Interview Guide	28/Jul/2018	2
Appendix D - Recruitment Flyer Version 2	Recruitment Materials	28/Jul/2018	2
Appendix E - Email Script Version 2	Recruitment Materials	28/Jul/2018	2
Appendix F - Telephone Script	Recruitment Materials	28/Jul/2018	2
Appendix G - Newspaper Advertisement Tracked	Recruitment Materials	28/Jul/2018	2
Appendix H - Verbal Recruitment Script Version 2	Oral Script	28/Jul/2018	2
Appendix I - Places for Participant Recruitment Version 2	Recruitment Materials	28/Jul/2018	2
Appendix J - Letter of Information Version 2	Verbal Consent/Assent	28/Jul/2018	2
Appendix J - Letter of Information Version 2	Written Consent/Assent	28/Jul/2018	2
Appendix K - Demographic Questionnaire Version 2	Other Data Collection Instruments	28/Jul/2018	2

Appendix K

Poem by P2's Wife

PARKINSON'S IS A LOSING BATTLE

No one likes to lose.....ever!
No one wants to lose....whether
It's a wallet, a set of keys, glasses, a friend....anything
But with Parkinson's...it's a losing battle
And there are so many ways to lose.

For [REDACTED] – these are the things he is losing...
His sense of smell is gone
His beautiful handwriting is gone
His wonderful public speaking talent is gone
His excellent driving ability is gone
His terrific golfing skills are gone
His exceptional bowling skills are gone
His computer and organization skills are gone
His perfect spelling ability is gone
His quick math skills are gone
His energetic walking ability is gone
And ...
His saxophone playing skills are going
His bridge playing skills are going
His conversation skills are going
His memory is going
His energy is going
His attention is going
His fine motor skills are going
His thought processing is going
His balance is going

BUT.... There are so many things that he has not lost!
His sense of humour
His love of reading
His interest in history and politics
His love of sports
His friendly personality
His love of family
His kindness
His consideration of others
His thoughtfulness
His loving and affectionate nature
His positive attitude
His amazing wonderful self!

by [REDACTED] 2018

Curriculum Vitae

Name: Elena Sheldrake

Post-Secondary Education and Degrees: Bachelor of Sciences, Double Major Biological and Medical Sciences
The University of Western Ontario
London, Ontario, Canada
2013-2017

Master of Science, Health & Aging
The University of Western Ontario
London, Ontario, Canada
2017-2019

Related Work Experience: Graduate Teaching Assistant
The University of Western Ontario
London, Ontario, Canada
2017-2019

Graduate Research Assistant
The University of Western Ontario
London, Ontario, Canada
2017 – 2019

Undergraduate Research Assistant
The University of Western Ontario
London, Ontario, Canada
2016 – 2017

Volunteer Experience: VP Media Relations
Health & Rehabilitation Sciences Graduate Student Society
The University of Western Ontario
London, Ontario, Canada
2018-2019

Rock Steady Boxing London
London, Ontario, Canada

2017-2019

Western Student Research Conference Planning
Committee

The University of Western Ontario
London, Ontario, Canada
2017

SOGS Peer Support Committee
The University of Western Ontario
London, Ontario, Canada
2017-2018

Conferences:

Qualitative Methods Conference
Oral Presentation
Banff, Alberta, Canada
May 2018

London Health Research Conference
Poster Presentation
London, Ontario, Canada
May 2018

**Certifications/
Awards:**

Nominated for the Graduate Teaching Assistant Award
The University of Western Ontario
London, Ontario, Canada
June 2018

Tri-Council Policy Statement
The University of Western Ontario
London, Ontario, Canada
October 2017

Good Clinical Practice Certification
All Modules
2018