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## Navigating Occupation and Identity in Parkinson's Disease: A Qualitative Exploration of Lived Experience

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A thesis submitted in partial fulfillment of the requirements for the degree in Master of Science

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## Abstract

Evidence-based practice requires that health care providers interpret the best research evidence in the context of their clinical experience, while at the same time considering client knowledge and experiences. Although health care providers are becoming increasingly skilled at the evaluation of research evidence, client values and self-identified health issues are often neglected within the evidence-based practice process. Ignoring these key aspects of person-centered practice may lead to interventions that fail to target implications of a client's disease that are important to occupational participation and quality of life. A focus on person-centeredness is particularly important in progressive neurodegenerative disorders such as Parkinson's disease where there are no known curative treatments, and interventions must instead focus on symptom management. The purpose of this research therefore was to deepen the current understanding of the experience of life with Parkinson's disease, and to use these understandings to inform health care practices for this group. Following a review of the lived experience literature, a primary study was conducted wherein six individuals with Parkinson's disease were asked to take photographs and share verbal narrative accounts to illustrate their experience of living with Parkinson's disease. Results highlight the interrelationship between occupation and identity, as many of the participants' stories were interpreted as foregrounding the negotiation of occupation, and how such negotiation shaped their sense of identity. Overall, three major themes were identified: (1) Framing the meaning of Parkinson's disease; (2) Negotiating engagement in occupation; (3) Being ready to accept changes that impact personal or social identity.

These findings were used to make suggestions on how health care providers can enhance the level of person-centeredness in their care.

## Keywords

Parkinson's disease; lived experience; narrative inquiry; photo elicitation; occupation; identity; person-centered care

## Co-Authorship Statement

This thesis was designed through the joint efforts of Sara Lutz, her supervisor Jeffrey D. Holmes, and her advisory committee members – Andrew M. Johnson, Mary E. Jenkins, and Debbie Laliberte-Rudman. Data collection was primarily completed by Sara Lutz, with the assistance of Jeffrey D. Holmes and Debbie Rudman. Data analysis was also primarily completed by Sara Lutz, with supervision and guidance provided by Jeffrey D. Holmes, Debbie Laliberte-Rudman, and Kori A. LaDonna. The following authors also contributed to the creation, review, and edits of the articles presented in Chapters 2 and 3 of this thesis:

**Chapter 2:** Jeffrey D. Holmes, Mike Ravenek, Debbie Laliberte-Rudman, Andrew M. Johnson.

**Chapter 3:** Jeffrey D. Holmes, Debbie Laliberte-Rudman, Andrew M. Johnson, Kori A. LaDonna, Mary E. Jenkins.

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## Abbreviations and Acronyms

ADLs – Activities of Daily Living

HY – Hoehn and Yahr

HCP – Health Care Provider

OS – Occupational Science

OT – Occupational Therapy or Occupational Therapist

PCC – Person-Centered Care

PD – Parkinson’s Disease

PSW – Personal Support Worker

PT – Physiotherapy or Physiotherapist

SLP – Speech Language Pathology or Speech Language Pathologist

QOL – Quality of Life

## Chapter 1

### 1 Introduction and Overview

This thesis was designed to aid in filling an important gap in Parkinson's disease (PD) research and clinical practice. Historically, research on PD has focused on quantifying relationships among various aspects of the disease. A disproportionate amount of research has explored the disease from a quantitative standpoint, thus attention to the *lived experience* of PD has been relatively lacking from the discussion.

Capturing the patient's voice has had longstanding value in the health sciences and in health care (Clandinin, Cave, & Berendonk, 2017; Pierret, 2003). It is a widely accepted notion that, when a patient's care team learns about the underlying meanings and impacts of their illness, their care can be directed to better meet their needs (Schwind, 2014; Schwind, Fredericks, Metersky, & Porzuczek, 2016).

It has been argued that, in order to improve the care of individuals with PD, the *person-centeredness* of health care practices for this group must be enriched (Fargel, Grobe, Oesterle, Hastedt, & Rupp, 2007; Nisenzon et al., 2011; van der Eijk, Faber, Al Shamma, Munneke, & Bloem, 2011). Thus, this study applied qualitative methods in the study of the *lived experiences* of people with PD. By eliciting stories of daily life for this group, this research project sought to unpack a deeper understanding of the meaningful experiences, values, and needs for people with PD and, in effect, inform a greater level of person-centered care (PCC) in health care practices.

The data in this thesis has been analyzed through an *occupational perspective*. Theories are centered around notions of experiencing meaning through daily occupations, and how changes to one's daily occupations threatens and shapes identity. In this introductory chapter, I will provide an overview of PD, the current state of health care for individuals with PD, and key concepts in the occupational science (OS) and occupational therapy (OT) literature.

## 1.1 What is Parkinson's Disease?

Parkinson's disease (PD) is a progressive, neurodegenerative condition (Jankovic, 2008). It is the second most common neurodegenerative disorder in the world, affecting approximately 2% of the global population over the age of 65 years (Alves, Forsaa, Pedersen, Dreetz Gjerstad, & Larsen, 2008). The mean age of onset for PD is 60 years; however, some individuals will begin to experience symptoms at the age of 50 or younger (Schrag, Hovris, Morley, Quinn, & Jahanshahi, 2003). These individuals are classified as having young-onset PD (Schrag et al., 2003). The etiological factors of PD are largely unknown and, as of yet, no cure exists (de Lau & Breteler, 2006). While there is currently no cure for PD, there are a number of well-established pharmacological treatments to manage motor symptoms (Connolly & Lang, 2014).

### 1.1.1 Symptoms and Presentation

Bradykinesia (or akinesia), tremor, rigidity, and postural instability are considered the cardinal clinical features of PD (Jankovic, 2008):

- **Bradykinesia.** Bradykinesia refers to slowness of voluntary movement, and is often labeled as the most characteristic symptom of PD (Jankovic, 2008). Bradykinesia may manifest as difficulties in motor planning, initiating movement, accomplishing a movement, and/or completing movements simultaneously or consecutively. In the earlier stages of the disease, it typically presents as a delay in reaction time and slowed performance in activities of daily living (ADLs). A person with bradykinesia might also experience any of the following challenges: decreased arm swing during gait, reduced blinking, general reduction of spontaneous movements and gesturing, hypomimia (i.e., masked facial expression), micrographia (i.e., smaller handwriting), drooling secondary to swallowing impairments, and difficulties with speech and language, such as reduced volume, pitch range, and difficulty articulating sounds (Jankovic, 2008).
- **Tremor.** For individuals with PD, tremor is observed as an uncontrollable shakiness, which typically occurs at rest (i.e., when the muscles are relaxed) and

disappears with action or during sleep (Jankovic, 2008). Most often, tremor begins in the hand and presents in a “pill-rolling” fashion in which the thumb rubs against the index finger in circular movements as though it were rolling a pill. Although hand tremors are most common, an individual with PD might also experience tremors in the foot, jaw, or face. Tremor will initially manifest unilaterally, and will often affect the individual bilaterally as the disease progresses into advanced stages (Jankovic, 2008).

- **Rigidity.** Rigidity is characterized by an increase in muscle tone during passive movement in the limbs (Jankovic, 2008). In PD, rigidity is often felt as a “cogwheel phenomenon” whereby passive movement elicits a ratchet-like “stop and go” quality (Hou & Lai, 2008). Rigidity can be experienced in joint flexion, extension, and rotations, and might be felt alongside pain (Jankovic, 2008).
- **Postural instability.** Typically, postural instability presents later in the disease process (Hou & Lai, 2008). It is characterized by a loss in postural reflexes, which in turn impacts an individual’s ability to make the positional adjustments necessary for maintaining balance. In effect, postural instability is a frequent cause of falls and subsequent fall-related injuries. Individuals with postural instability may present with forward flexion of the trunk and short shuffling steps during ambulation. Due to involuntary propulsion forward, individuals may also experience festinating gait (i.e., taking smaller, quicker steps; Hou & Lai, 2008).

Outside of the cardinal symptoms of PD, individuals might also experience motor abnormalities from the long-term administration of antiparkinson medication and advanced motor staging (Fahn, 2003). Such abnormalities may include:

- **Freezing of gait.** Freezing of gait (FOG) refers to the sudden inability to move, or “motor block,” that is often experienced by individuals with PD (Giladi et al., 2001; Okuma, 2006). In FOG, individuals become “stuck” to the floor when attempting to lift their foot to step forward, which causes them to feel as though they are “glued to the ground” (Okuma, 2006). This behavior is most common with the initiation of gait, when moving through turns, narrow passages, or



doorways, with increased stress (Giladi et al., 2001), and when reaching a destination (Hou & Lai, 2008). This motor block is transient, typically lasting for 10 seconds or less (Coste et al., 2014).

- **Dystonia and Dyskinesia.** In these cases, the individual with PD experiences prolonged muscle contractions which cause abnormal, involuntary movements and postures (Tolosa & Compta, 2006). In dystonia, muscles tighten and may present as cramping, whereas dyskinesia presents as unwanted movements, such as twisting and jerking. Dystonia and dyskinesia are often painful for the person with PD (Tolosa & Compta, 2006).
- **Wearing Off.** An estimated 10% of PD patients develop symptoms of “wearing-off” after taking antiparkinson medication for one year, and 50% experience this after five years (Schrag & Quinn, 2000). Wearing-off is characterized by a reappearance of PD symptoms before the next scheduled dose of medication. As a result, patients often experience the “on-off” phenomenon of PD in which the overall amount of time spent in “on” state progressively shortens, while the overall amount of time spent in “off” state lengthens (Schrag & Quinn, 2000).

An array of non-motoric symptoms have also been identified as highly common in PD, such as sensory symptoms, autonomic dysfunction, neuropsychiatric disturbances, sleep abnormalities, and cognitive impairment (Wishart & Macphee, 2011). These symptoms may be frequent and highly distressing (Lohle, Storch, & Reichmann, 2009). The literature has suggested that such non-motor symptoms will effect up to 90% of persons with PD (Van Laar & Jain, 2004), as well has revealed that non-motor symptoms have a larger impact on quality of life (QOL) than do motor symptoms (Kuopio, Marttila, Helenius, Toivonen, & Rinne, 2000; Sjobahl Hammarlund, Hagell, & Nilsson, 2012).

Important to recognize is the fact that individuals with PD represent a heterogeneous group and symptom onset, frequency, and severity can vary substantially from person to person (Chaudhuri, Healy, & Schapira, 2006). Consequently, individuals with the disorder will develop unique motor and non-motor symptoms (Chaudhuri et al., 2006), and experience varying degrees of functional impairment and disability (Raggi et al.,

2010). Also important to recognize is that individuals with PD will experience a range of psychosocial consequences as a result of their illness, such as disruptions to employment and family life (Holmes, Lutz, Ravenek, Rudman, & Johnson, 2013). Such consequences are especially prevalent among the young-onset population who are often still working and parenting children at their time of diagnosis (Holmes et al., 2013; Murphy, Tubridy, Kevelighan, & O'Riordan, 2013; Schrag et al., 2003). For many, the symptoms of PD will also have other emotional, interpersonal, and social consequences (Holmes et al., 2013). For example, the experience of physical symptoms might lead to feelings of embarrassment, frustration, anger, anxiety, or depression, and could in turn have implications on one's engagement in social activities (Holmes et al., 2013).

### 1.1.2 Disease Progression

As PD is a progressive condition, individuals with the disease experience increasing degrees of disability with increased time with the disease (Raggi et al., 2010).

Staging of PD is most often determined through use of the Hoehn and Yahr (HY) scale, which designates a rating between one and five to persons with PD (Hoehn & Yahr, 1967). In Stage One, motor symptoms are mild, meaning that they are inconvenient to the individual but not yet disabling. Symptoms at this stage are unilateral. In Stage Two, symptoms become bilateral; however, balance is not yet affected and there still remains minimal disability. In Stage Three, motor symptoms begin to cause mild to moderate disability. This stage is characterized by postural impairment, but the person remains able to mobilize independently. Stage Four is representative of severe motor symptom presentation. Individuals at Stage Four are usually no longer able to live independently, but can still stand and ambulate without assistance. The final stage, Stage Five, represents a person who can no longer stand or walk independently, are confined to a bed or wheelchair unless assisted, and require constant support from caregivers (Hoehn & Yahr, 1967).

The HY Scale has been criticized for its over-simplification of PD (Goetz et al., 2004). Given that the scale focuses on the progression from unilateral to bilateral symptoms, and from no postural instability to postural reflexes being affected, other important aspects of

PD are often ignored. A modified version of the HY Scale (see Table 1) was devised in attempt to add more detail to the assessment process, and is now used by the majority of health care providers (HCPs) working with PD. This scale adds 0.5 increments between stages one and two and stages two and three; however, HCPs continue to report that this rating system does not provide an accurate or comprehensive view of their patients (Goetz et al., 2004).

**Table 1: Comparison of the Original and Modified Hoehn and Yahr Scales**

<b>Hoehn and Yahr Scale</b>	<b>Modified Hoehn and Yahr Scale</b>
1: Unilateral involvement only usually with minimal or no functional disability	1.0: Unilateral involvement only
2: Bilateral or midline involvement without impairment of balance	1.5: Unilateral and axial involvement
	2.0: Bilateral involvement without impairment of balance
	2.5: Mild bilateral disease with recovery on pull test
3: Bilateral disease: mild to moderate disability with impaired postural reflexes; physically independent	3.0: Mild to moderate bilateral disease; some postural instability; physically independent
4: Severely disabling disease; still able to walk or stand unassisted	4.0: Severe disability; still able to walk or stand unassisted
5: Confinement to bed or wheelchair unless aided	5.0: Wheelchair bound or bedridden unless aided

(Goetz et al., 2004)

## 1.2 Health Care Satisfaction and Person-Centered Care in Parkinson's Disease

Individuals with PD often have a number of complex health care needs, which are fluid throughout the course of their illness (van der Eijk et al., 2011; van der Eijk, Nijhuis, Faber, & Bloem, 2013). Presently, treatment approaches for PD are largely focused on pharmacological interventions to alleviate motor disturbances (van der Marck et al., 2013). While the effective management of motor symptoms in PD care is crucial, recent studies suggest that PD patients may have different treatment goals than their HCP; consequently, divergent concerns may impact patient satisfaction and QOL (Dorsey et al., 2010; Fargel et al., 2007; Findley & Baker, 2002).

### 1.2.1 Satisfaction with Health Care and Missed Needs

Patient satisfaction with health care has been a widely researched topic, and many health care organizations have begun to incorporate patient satisfaction questionnaires into their clinical practice (Asadi-Lari, Tamburini, & Gray, 2004; Kravitz, 1998). Patient satisfaction is a significant indicator of QOL; that is, a patient's satisfaction with his or her health care predicts higher subjective QOL scores (Asadi-Lari et al., 2004; Joseph & Nichols, 2007; Lis, Rodeghier, Grutsch, & Gupta, 2009; Wong & Fielding, 2008). Patient satisfaction has also been associated with positive service-related outcomes, including a greater likelihood of treatment compliance, taking an active role in one's own care, and remaining with the same service provider over an extended period of time (Asadi-Lari et al., 2004).

Research suggests that individuals living with PD in Europe and the United States are significantly less satisfied with their treatment than individuals with other chronic conditions (Fargel et al., 2007). Follow-up interview data from this sample found that participants with PD were, in general, most dissatisfied with the number of daily pills they were required to take, that their non-motor symptoms were rarely treated, and that they were seldom provided with tools that would facilitate their independence (Fargel et al., 2007).

In a patient-based needs assessment conducted in Ontario, individuals with PD were asked: “What information is missing from your health care experience or has been missing in the past that would help you live well with PD?” (Kleiner-Fisman, Gryfe, & Naglie, 2013). Study participants identified the following areas as lacking from their health care experience:

- (1) Assistance dealing with the emotional and social aspects of the disease, such as information on coping skills, accepting their diagnosis, dealing with fears of the future, navigating marital challenges, and finding community supports.
- (2) Resources on how to successfully navigate the legal, financial, and bureaucratic implications of PD.
- (3) Strategies for ensuring empowerment and self-advocacy in issues related to such matters as family expectations and health care directions.
- (4) Information on non-motor symptoms and holistic approaches to their treatment.
- (5) Adaptive strategies and lifestyle tips to cope with symptoms.
- (6) Physical approaches to daily challenges and access to community and/or home physical activity programs.
- (7) Comprehensive definitions of PD symptoms and medication side-effects.
- (8) Information on the correct use, common side effects, and diet related interactions with medications.
- (9) Access to scientific information pertaining to the etiology, heritability, and latest developments in PD research.

This study concluded that the absence of such information in the person with PD’s care is a deficit to the delivery of effective person-centered treatment, and subtracts from the person’s level of health care satisfaction (Kleiner-Fisman et al., 2013).

### 1.2.1.1 Person-Centered Care for PD

A popular theoretical model used to facilitate improved patient satisfaction and health outcomes is person-centeredness (also known as patient- and client-centeredness).

Overall, the person-centered care (PCC) model of health care argues that the patient is intrinsic to developing and delivering health care services (Institute of Medicine, 2001). It is often suggested that person-centered values be incorporated within both organizational strategies (e.g., ensuring services are integrated and accessible), as well as within the interpersonal interactions occurring between consumer and provider (e.g., power sharing, conveying positive regard, and maintaining consistent communication; Saha, Beach, & Cooper, 2008). The following aspects of PD care have been identified as important for maintaining person-centeredness:

- (1) Continuity and collaboration of caregivers.
- (2) Patient involvement in decisions and HCP respect for patient preferences.
- (3) Provision of tailored information.
- (4) Knowledge of PD treatment among caregivers.
- (5) Emotional support, empathy, and respect.
- (6) Accessibility of health care.

(van der Eijk et al., 2011)

Focusing primarily on HCP-identified treatment goals runs counter to models of PCC (van der Eijk et al., 2013). This is problematic because the act of actively participating in one's own care is beneficial for patients with PD (Grosset & Grosset, 2005). For example, a survey of 107 individuals with PD revealed that, individuals who perceived themselves as having high levels of involvement in treatment-related decisions, and better communication with their physician, also reported a higher level of intent to comply with their treatment, and were more satisfied with their overall health care. Furthermore, satisfaction and compliance intent scores were also significantly and positively correlated

with QOL scores (Grosset & Grosset, 2005). Thus, the foregoing research would suggest that there is value in promoting person-centered principles within health care services for individuals with PD, and that their effective inclusion may facilitate consumer satisfaction.

### 1.3 The Occupational Perspective

Occupational science (OS) is the knowledge base used to inform the clinical practice of OT (Townsend & Polatajko, 2007). Thus, OS is the study of *occupation*, or, of those activities done to occupy time and bring purpose to a person's life (Hocking & Wright-St. Clair, 2011). Typically, occupations are considered to fall within three major categories: self-care, productivity, and leisure (Hocking & Wright-St. Clair, 2011). It is argued that people engage in occupations based on a variety of motivations, such as their needs, preferences, personal beliefs, and individual skills (Kielhofner, 2008). Conversely, it is also through one's engagement in occupation that they develop their own sense of self-efficacy, construct meaning, and build a sense of identity (Yerxa, 1990).

At the core of OS lies three key ideas (Hocking & Wright-St. Clair, 2011). First, humans are recognized as occupational beings (Hocking & Wright-St. Clair, 2011; Townsend & Polatajko, 2007). In this way, humans are viewed as structuring their daily lives, building relationships, constructing meaning, and adapting to experiences through the use of occupation (Townsend & Polatajko, 2007). Occupation is therefore viewed as an innate human phenomenon and a medium through which people give meaning to life (Townsend & Polatajko, 2007). Second, occupation is recognized as linked to health and wellbeing (Hocking & Wright-St. Clair, 2011). Occupation is understood to impact health, and one's state of health predicts their ability to participate in occupations (Hocking & Wright-St. Clair, 2011). Third, occupation is context-dependent, meaning that various aspects of a person's environment, including the social, cultural, built, and natural environment, will impact which occupations they engage in (Hocking & Wright-St. Clair, 2011).

Central to the current study, there is also a body of OS research that has analyzed the occupational processes that occur during and following the onset of an illness or injury.

Occupational scientists have primarily analyzed the illness experience through two paradigms (Walder & Molineux, 2017). The first is more biomedical in nature as it attends to such concepts as the effectiveness of treatments and how to stimulate improvements in occupational performance (Walder & Molineux, 2017). The other paradigm has been described as more occupation-based in nature, and has been used to explore experiences of change and adjustment to illness (Walder & Molineux, 2017). Some research frames this experience through the concept of *occupational adaptation*, which has been defined as the process of adapting to occupational demands in order to achieve or maintain occupations (Walder & Molineux, 2017).

Other research chooses to analyze these experiences through concepts of *occupational loss* and the reconstruction of *occupational identity* (Walder & Molineux, 2017).

Occupational identity has been defined as "... a composite sense of who one is and wishes to become as an occupational being generated from one's history of occupational participation" (Kielhofner, 2002; p. 119). Thus, one's occupational identity can be considered a result of their occupations over time (Unruh, 2004). A person's sense of identity has been known to give meaning to life and experiences, and the person's identity is often expressed through their chosen occupations (Walder & Molineux, 2017). When a person is faced with an illness such as PD, their ability to engage in those occupations central to their identity may be impacted and, thus, the illness can disrupt that person's sense of self (Walder & Molineux, 2017).

## 1.4 Project Overview

Given the suggested dissatisfaction with treatment by individuals with PD, this study aimed to explore the experiences of PD by those with the condition in order to unravel which aspects of life are meaningful and important to them. To do this, I utilized an innovative blended narrative inquiry and photo elicitation study to explore the experience of negotiating daily life with PD. Six individuals with PD took photographs that were used to elicit stories about daily experiences of living with PD. Participant photographs informed narrative style individual and focus group interviews. Transcripts and photos were inductively coded to generate themes regarding personal and collective perceptions of life with PD. Although each individual participant shared very different stories of life



with PD, similar themes emerged across the data. Results highlight the interrelationship between occupation and identity, as many of the participants' stories were interpreted as foregrounding the negotiation of occupation and how such negotiation shaped their sense of identity.

The key themes provide insights into how participants made decisions regarding a variety of issues, including tensions between wanting to continue with previous roles, but being restricted by PD; thinking about PD in such a way that facilitates coping; and independently implementing ways to manage PD. Results of this study highlight the specific tensions experienced by individuals with PD, and ways individuals self-manage their symptoms. It is suggested that awareness of such issues can help HCPs shift clinical conversations to make patients more active participants in care.

This thesis applied an integrated-article approach resulting in two research articles. The first (Chapter 2) is a literature review designed to improve our understanding of the lived experience of PD from the current literature body. The second article (Chapter 3) presents the methodology and resulting data of the study collection.

After reviewing this thesis, it is hoped that the reader will be left with a clearer understanding of some of the experiential challenges and needs of people with PD, and that the work being completed today can be used to pave the way for more person-centered and effective PD care in the future.

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## Chapter 2

### 2 Literature Review – Enhancing Client-Centeredness in Parkinson’s Disease Care: Attending to the Psychosocial Implications of Lived Experience

A version of this paper can be found at:

Holmes, J. D., Lutz, S., Ravenek, M., Rudman, D. L., & Johnson, A. M. (2013). Enhancing client-centeredness in Parkinson’s disease care: Attending to the psychosocial implications of lived experience. *The Open Journal of Occupational Therapy, 1*(4), Article 7. doi:10.15453/2168-6408.1064

#### 2.1 Introduction

Parkinson’s disease (PD) is a progressive neurodegenerative condition characterized by four cardinal motor symptoms, including tremor, rigidity, akinesia/bradykinesia, and postural instability (Jankovic, 2008). Individuals diagnosed with PD may also experience a number of non-motoric symptoms, including pain, sleeping problems, and cognitive changes (Johnson et al., 2004; Johnson, Pollard, Vernon, Tomes, & Jog, 2005). More recently, it has also been suggested that neuropsychiatric symptoms including depression, anxiety, apathy, and psychosis are common in PD, and affect the majority of individuals at some time during the course of their disease (Aarsland, Marsh, & Schrag, 2009).

Although the physical decline associated with PD has been found to contribute to decreased quality of life (QOL; Schrag, Jahanshahi, & Quinn, 2000), several studies have identified that it is actually the non-motoric symptoms of PD that have the greatest impact on QOL for people living with this disease (Hammarlund, Hagell, & Nilsson, 2012). The literature also suggests that neuropsychiatric symptoms can interact with, and exacerbate, both motoric and non-motoric symptoms of PD, thus further impacting on an individual’s QOL and ability to engage in meaningful occupations (Giladi & Hausdorff, 2006; Hanna & Cronin-Golomb, 2012; Lieberman, 2006). Furthermore, given that PD is a chronic progressive condition, individuals experience a decrement in both physical and cognitive capacities over time, which can result in functional limitations and ultimately



lead to a diminished ability to engage in meaningful occupations as the disease progresses (Jankovic & Kapadia, 2001).

While PD is most commonly managed pharmacologically by dopaminergic therapy, evidence suggests that individuals with PD may also benefit from various rehabilitative strategies to help maintain their level of functioning as the disease progresses over time. Recently, Dixon et al., (2009) published a Cochrane review that examined the literature on the use of occupational therapy (OT) in the treatment of PD. Although this review suggested that clinically meaningful and functional improvements may occur, the varied approaches to treatment and lack of randomized trials illustrated that additional work needs to be done in developing an evidence base that would serve to assist in establishing practice guidelines.

Given that there are no definitive guidelines for the management of PD, health care providers (HCPs) must base their treatment approach on the best evidence available. Although HCPs are becoming increasingly skilled at the evaluation of research evidence, a key aspect of person-centeredness, specifically, the consideration of clients' values and self-identified health issues, can often be a neglected component of the evidence-based practice process. Under such circumstances, interventions may fail to target aspects of a client's disease that are important to the client both in terms of their occupational participation and QOL. Although each person will have a different experience with PD because of their unique life circumstances, studies examining the *lived experience* of PD can serve to heighten awareness and understanding of the ways in which living with a chronic condition influences peoples' occupations, as well as their overall sense of well-being or QOL.

In this paper, we highlight the literature on the psychosocial aspects of the lived experience of individuals with PD, suggesting that it provides insight into the implications of the disease that merit consideration when working with this population. We believe this literature will serve to provide an additional form of evidence that raises awareness of the lived implications of this disease for clients' occupations and QOL that, in turn, may enable HCPs to more fully address client values and self-identified issues

within their practice. Moreover, we believe this knowledge will help ensure that the therapeutic process remains meaningful to the client, which in turn may help to improve adherence and foster a greater sense of empowerment as clients are given the opportunity to become involved with making decisions about their care.

## 2.2 Examining the Lived Experience of PD

We conducted a review of the literature concerned with the lived experience among individuals with PD within PubMed and CINAHL databases using the following key search terms: Parkinson's disease, lived experience, daily life, symptom experience, symptom distress, and illness distress. We selected articles based on their ability to lend support to the notion that lived experience is an important factor that HCPs should consider. Search results revealed that several prominent psychosocial factors are often associated with an individual's lived experience. These factors include unpredictability, preoccupation with time and scheduling, fatigue resulting from cognitive demands, fighting to maintain independence, social and interpersonal consequences, emotional concerns, and body image insecurities.

### 2.2.1 Unpredictability

The unpredictable nature of PD symptoms and medication side-effects is a frequently reported issue within the lived experience literature (Haahr, Kirkevold, Hall, & Ostergaard, 2011). This unpredictability affects an individual's ability to commit to social outings, work responsibilities, and other activities of daily living (ADLs) that support the development and continued enactment of meaningful personal and professional occupation. As the disease progresses, and its unpredictability escalates, many individuals begin to report feelings of being imprisoned within their body (Bramley & Eatough, 2005; Haahr et al., 2011; Sunvisson, 2006; Sunvisson & Ekman, 2001). Some individuals with advanced PD report feeling totally at the mercy of their body; these individuals note that they are never able to predict how their body will act or react to daily life events, thus taking away much of their personal control (Haahr et al., 2011). For example, Haahr et al. (2011), share the following account of a participant with PD who described the unpredictable on/off fluctuations of the disease as being awkward:

*It is awkward. And you cannot plan that in 1½ hour you will be doing this and this, because if the medication doesn't work, whether it is too little or too much, then you are not well. Everything falls apart. You get an invitation – yes, I might come...right? (p. 413)*

### 2.2.2 Preoccupation with Time and Scheduling

Many individuals with PD, particularly those in advanced stages of the disease, report a perceived need for rigid scheduling of daily activities. As PD progresses, individuals tend to report an increased level of unpredictability in their symptoms, as well as more severe consequences resulting from not taking medications at their exact scheduled time. In effect, clients report a greater need to abide by a strict schedule when taking their daily medications, and begin to plan activities according to when they expect that their symptoms will be effectively managed (Benharoch & Wiseman, 2004; Bramley & Eatough, 2005; Haahr et al., 2011). For example, Haahr et al. (2011), recount the following quote provided by a participant with PD who reveals her reluctance to go shopping at certain times of the day:

*When we go shopping downtown, locally... I say to my husband, I don't want to go at noon, because it is medication-time, and it takes some time before it works... I will stand there like a statue unable to move anywhere. People are looking strangely, they really are, and I don't like it. Even if people in town know that I am slow ... you really don't feel good... I simply don't want to advertise for the disease. (p. 412)*

### 2.2.3 Fatigue Resulting from Cognitive Demands

Concerns regarding functional capacity are commonly reported in studies that examine the lived experience of individuals with PD (Haahr et al., 2011). As PD progresses, individuals often develop impairment in their ability to act automatically, exerting high levels of concentration and using such strategies as “self-talk” in order to conduct basic movements and actions (Farley & Koshland, 2005). These individuals state that basic functions, such as walking, require purposeful effort (Bramley & Eatough, 2005). Basic movements must also be divided into smaller parts, and calling the body into action

requires significant cognitive effort (Sunvisson & Ekman, 2001). Accordingly, both mental and physical fatigue are frequently reported symptoms of the disease – and are important features of the lived experience which may significantly impact on one's engagement in meaningful occupation (Benharoch & Wiseman, 2004; Bramley & Eatough, 2005; Haahr et al., 2011; Sunvisson, 2006; Sunvisson & Ekman, 2001). For example, an individual who is fatigued is likely to become less active, less inclined to pursue hobbies and interests, and will likely have a greater tendency to become withdrawn.

#### 2.2.4 Fighting to Maintain Independence

Individuals with PD appear to reject help from caregivers as part of their efforts at maintaining independence and maintaining an acceptable self and social identity (Roland, Jenkins, & Johnson, 2010). These subtle rejections are often manifested by individuals in their desire to remain engaged in activities (such as working or driving) for as long as possible after their diagnosis (Benharoch & Wiseman, 2004; Harshaw, 2002). Individuals in more advanced stages of PD may also reject the use of mobility aids, associating these devices with dependency, disability, and weakness (Haahr et al., 2011; Sunvisson, 2006). Thus, although the use of a mobility aid is an important marker of neurological progression in PD, often indicating that an individual's balance has been affected, not everyone with PD experiencing balance impairment will be accepting of this technology. Consequently, these individuals may be hesitant to engage in activities resulting from a heightened risk of fear of falling.

#### 2.2.5 Social and Interpersonal Consequences

Individuals with PD report social withdrawal and impaired social abilities. For some, this results from feelings of embarrassment or apprehension about experiencing physical symptoms (e.g., tremor, falling, shuffling gait, intermittent bouts of sweating) in public (Bramley & Eatough, 2005; Haahr et al., 2011; Sunvisson, 2006; Sunvisson & Ekman, 2001). The experience of facial masking appears to have an especially great affect on social involvement and one's level of comfort when interacting with others. This discomfort develops from the conscious awareness that others may misinterpret a masked

facial expression (Haahr et al., 2011; Harshaw, 2002). For example, as one participant states in Haahr et al. (2011):

*When I go OFF... Then my face 'dies'. My mimic is gone and I am kind of gone too, because I use so much energy standing the pain. The pain attracts my attention so I am not that sociable when I am OFF. (p. 412)*

As the disease advances, social withdrawal, including decreased participation in occupations with others, appears to worsen, with individuals reporting heightened levels of apprehension as symptoms become more unpredictable in nature (Haahr et al., 2011; Sunvisson & Ekman, 2001). Interestingly, some individuals have indicated that it is not concern over public symptoms that causes the greatest distress, but rather the presentation of symptoms in front of close friends and family. Sunvisson and Ekman (2001) reported that some individuals with PD felt more severe embarrassment in front of those closest to them, explaining that they did not wish for these important individuals in their lives to see their limitations or weaknesses. Sunvisson and Ekman (2001) also suggested that social withdrawal appears to result as a consequence of the cognitive and motoric slowing associated with PD. For example, individuals may withdraw or limit engagement in social activities if they perceive it is impossible to make timely or appropriate conversational responses, or to finish a meal within a socially acceptable amount of time.

## 2.2.6 Emotional Concerns

Some commonly reported emotional concerns among individuals with PD include feelings of frustration, anger, and depressed mood. The source of much of this frustration and anger comes from decreased levels of mobility and a perceived lack of control over functional motor actions (Benharoch & Wiseman, 2004). In a personal account, Tichler (2010) described frustration as resulting from feelings of being undeserving of a disabled life. Other individuals report feeling an almost overwhelming sadness associated with their experience of the disease. For example, Harshaw (2002) described PD as a persistent struggle with depression, a finding that is not all that surprising given the high rate of comorbidity among depression and PD (Aarsland et al., 2009).

### 2.2.7 Managing Tensions Between Bodily Appearance and Sense of Self

Individuals with PD are not only affected by the functional capacity of their body, but also by changes in physical appearance. Both men and women with PD report experiencing distress as a result of their changing physical appearance. Many wish for strangers to be able to see more than the mere physical images of their body, and feel that their outward appearance is not representative of their true selves. Haahr et al. (2011) report that individuals with advanced PD often feel as though their body is “alien” to them, and note that this negatively affects their self-esteem and perception of personal identity. Harshaw (2002), in his personal account of living with PD, described himself as being “grotesque” and “freak-like,” and said that he assumed that people no longer wished to be around him due to his appearance. Dominant within much of the current literature on lived experience in PD is the desire of individuals to be able to present themselves as who they “actually are” as opposed to their perception of being seen in a state that has arisen as a result of their disease (Bramley & Eatough, 2005; Haahr et al., 2011; Harshaw, 2002).

## 2.3 Discussion

This summative, descriptive review of key thematic elements within the literature addressing the lived experience of PD brings to light a number of potential barriers to the development of meaningful occupations among individuals with PD. At issue, of course, is how this information may be incorporated into clinical practice.

One way this can be achieved is for OTs to ask their clients probing questions informed by the lived experience literature. For example, OTs may be able to implement a more client-specific approach to fatigue management by using their knowledge of the lived experience of PD to inform their questions and strategies. The typical process for fatigue management involves reviewing a person’s daily routine, prioritizing tasks, restructuring activities according to energy levels, introducing regular rest periods, and teaching good sleep hygiene (Jahanshahi & Marsden, 1998). Such guidelines are, however, focused on the physical aspects of fatigue, which may not be of the utmost importance or relevance

to an individual client. Relating such suggestions to the literature reviewed in the present paper, OTs may benefit from asking their clients questions that reflect cognitive fatigue, such as whether they need to “self-talk” and, if so, how clients perceive the impact on their cognitive functioning.

A second domain of clinical practice that is facilitated by investigating the lived experience relates to research suggesting that individuals with PD engage in poor help-seeking behaviours (Roland et al., 2010), meaning that they tend not to ask for assistance when needed. Individuals who refrain from asking for help risk exacerbating their social isolation and potentially reducing their ability to learn of (and implement) better social, cognitive, and motoric strategies (particularly with regards to the use of support services and assistive devices). Client education and referral for support services may have the effect of encouraging individuals with PD to accept the help they need. Although this may appear to be in conflict with an OTs goal of increasing and maintaining independence, positive help-seeking behaviors may actually serve to increase autonomy and strengthen the capacity to engage in those occupations most meaningful to an individual. For example, by receiving help with particularly fatiguing tasks (e.g., getting dressed), the individual with PD may retain energy to engage in additional activities that may hold more significant meaning (e.g., gardening). Improving the help seeking behaviors of an individual with PD can, however, be particularly challenging when the primary caregiver is a family member or close friend. As previously discussed, Sunvisson and Ekman (2001) suggest that individuals with PD feel more severe embarrassment in front of those closest to them, and do not wish for these important individuals in their lives to see their limitations or weaknesses. Thus, although in typical practice OTs may make the recommendation that individuals with PD accept help from those close to them, the aforementioned literature on lived experience suggests that, in fact, it may be more appropriate to arrange an outside agency to provide assistance. Doing so will help the client retain dignity within the relationship, and will preserve the roles of the client and family member or friend outside the caregiving relationship.

More important, not only can evaluation of the lived experience benefit clients, it may be an asset to reducing caregiver distress. As discussed in Roland et al. (2010), caregivers

often view social outlets as a means of distraction, rather than as a source of support. It is, therefore, important for HCPs to consult caregivers to ensure that they are not in distress, as this may lead to a further deterioration in social relations, both at home and in the community. This can be a challenging conversation for the OT, as the role of caregiver is likely entangled with the role of family member. This may be particularly problematic in the case of spousal caregivers. The family member may feel an obligation to provide care without relying on outside agencies, even to the point where outside assistance is seen as a betrayal of his or her relationship with the client.

The foregoing suggests, therefore, that it is important for HCPs to identify the needs and wishes of both the client and the family caregiver. It is entirely possible that the client does not want to receive care from the family caregiver, and that the family caregiver would prefer to engage the services of an outside agency. It is also possible that neither will be willing to verbalize his or her preferences. The OT must take care to ascertain the true wishes of the client and the caregiver, and work to balance the importance of caregiving needs and family roles.

## 2.4 Conclusion

In this paper, we have discussed the benefits of incorporating research on the lived experience of PD into the evidence-based practice process. A client's lived experience informs his or her values, occupational goals, and expectations for treatment, and this is a critical consideration for the HCP in the implementation of the best possible interventions. As PD remains a chronic and progressive disorder, with highly variable impairment of motor and non-motor function, it is crucial that treatment interventions be individualized, client-centered, and focused on improving day-to-day QOL via enabling occupational participation. The consequence of this focus on client values may lead HCPs to treat PD more holistically and reduce the focus on physical symptoms that may or may not be of primary concern to the client. As presented in this paper, this refocusing on the psychosocial outcomes of PD is entirely in keeping with the current research on patient values in this population.



Moving forward, in order for OTs to fully integrate knowledge on client values and perspectives of living with PD into practice, thereby enhancing client-centered evidence-based practice, there is a need to identify clear linkages between increasing HCP awareness of the lived experience and positive outcomes, such as increased occupational engagement. In doing so, HCPs may increase their knowledge of the spectrum of challenges experienced by their clients, thus allowing them to become more attuned to the specific needs of these clients in their day-to-day lives.

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## Chapter 3

### 3 “I’m Not Mrs. Parkinson’s”: A Visual Narrative Inquiry of the Inter-Related Navigation of Occupation and Identity

A version of this paper can be found at:

Lutz, S. G., Holmes, J. D., Laliberte Rudman, D., Johnson, A. M., LaDonna, K. A., & Jenkins, M. E. (2017). Understanding Parkinson’s through visual narratives: “I’m not Mrs. Parkinson’s”. *British Journal of Occupational Therapy*.  
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#### 3.1 Introduction

While research has begun to highlight the psychosocial challenges of Parkinson’s disease (PD), there remains a lack of attention to the *experience* and daily negotiation of such challenges (Holmes, Lutz, Ravenek, Rudman, & Johnson, 2013). Thus, while we know that individuals with PD face challenges related to issues such as receiving their diagnosis, losing physical capacities, changing their daily occupations, and accepting supports (Benharoch & Wiseman, 2004; Hartley et al., 2014; Holmes et al., 2013; Murdock, Cousins, & Kernohan, 2015), little is known about *how* such issues are navigated or the implications of such navigation (Soundy, Stubbs, & Roskell, 2014). Previous research has highlighted that challenges to occupation resulting from chronic illness have implications on one’s identity and well-being (Bryson-Campbell, Shaw, O’Brien, & Holmes, 2016; Laliberte-Rudman, 2002; Vrkljan & Polgar, 2007). Thus, occupation-focused research addressing the experience of PD can provide insight into how persons with PD negotiate daily life through occupations, and how this negotiation interacts with identity. Within this constructivist narrative study, six individuals were asked to story what living with PD was like for them, using photos and providing a verbal narrative. In this article, we discuss results of a narrative analysis that was guided by an occupational lens, highlighting how the inter-related negotiation of identity and occupation were a key part of the experiences shared.

## 3.2 Literature Review

Parkinson's disease (PD) is a progressive neurodegenerative condition, traditionally conceptualized as a disorder affecting movement and motor control (Jankovic, 2008). Cardinal symptoms include tremor, rigidity, bradykinesia, and postural instability (Jankovic, 2008). At the same time, there has been increasing attention to non-motoric aspects of PD, such as neuropsychiatric, autonomic, sleep, and sensory symptoms (Macphee & Stewart, 2012). Symptoms are heterogeneous, and their presence, severity, and impact on function varies across individuals (Lewis et al., 2005).

Although each person's experience of PD is situated in a particular sociobiographical history, set of personal traits, and life circumstances, research has pointed to particular events and issues that persons with PD often have to negotiate. For example, a body of research has revealed diverse ways persons with PD react to receiving their diagnosis (Reese, 2007). Some individuals report feelings of relief resulting from having a name for their symptoms, while others describe feelings of devastation, confusion, and fear (Phillips, 2006; Reese, 2007). In one study, participants with PD discussed their diagnosis as equivalent to a bomb being dropped on their sense of existence, and described the need to reconstruct their identity following this event (Phillips, 2006).

A review of literature addressing psychosocial aspects of the lived experience of PD identified seven major issues, including: unpredictability, preoccupation with time and scheduling, fatigue resulting from cognitive demands, fighting to maintain independence, social and interpersonal consequences, emotional concerns, and body image insecurities (Holmes et al., 2013). Although much of this research did not focus on occupation, the ways in which these various issues had implications on the negotiation of occupation often surfaced. For example, Haahr, Kirkevold, Hall, & Ostergaard (2011) share the following account of a participant with PD who reveals her reluctance to go shopping at certain times of the day:

*When we go shopping downtown, locally... I say to my husband, I don't want to go at noon, because it is medication-time, and it takes some time before it works... I will stand there like a statue unable to move anywhere. People are looking*

*strangely, they really are, and I don't like it. Even if people in town know that I am slow ... you really don't feel good... I simply don't want to advertise for the disease (p. 412).*

Haahr et al. (2011), also highlight how the unpredictability of PD can lead to withdrawal from social occupations. This is particularly evident in the more advanced stages of the disease when unpredictability escalates, as individuals with advanced PD report feeling that most of their personal control has been taken away and that they are totally at the mercy of their bodies (Haahr et al., 2011). This is evidenced by the following account of a participant with PD who described the unpredictable on/off fluctuations of the disease as being awkward:

*It is awkward. And you cannot plan that in 1½ hour you will be doing this and this, because if the medication doesn't work, whether it is too little or too much, then you are not well. Everything falls apart. You get an invitation – yes, I might come...right? (Haahr et al., 2011, p. 413).*

Some research has focused more specifically on occupational challenges, including work, self-care, and leisure (Benharoch & Wiseman, 2004; Murdock et al., 2015; Wressle, Engstrand, & Granérus, 2007). Such research has pointed to the psychological consequences associated with occupational loss, such as depression, anxiety, and decreased self-esteem, as well as relationship changes and financial impacts. Moreover, this research suggests that challenges to occupation associated with PD can also present challenges to the maintenance of acceptable personal and social identity.

Taken together, existing research has identified a number of psychosocial challenges a person with PD may face throughout the course of their illness. To build on this discussion, it is important that research more fully engage with the experiences of people living with the condition. To date, research methods have been concentrated in semi-structured interviews with researchers dictating the flow of questions (Eccles, Murray, & Simpson, 2011; Wressle et al., 2007). By shifting research to narrative methodologies, participants have a more active role in sharing their experiences (Bukhave & Huniche, 2016). Moreover, given that narratives provide a means to actively shape and convey

identity as well as to story occupation (Connelly & Clandinin, 1990; Molineux & Richard, 2003), this approach also has the potential to provide insights into how identity and occupation are negotiated within the daily lives of persons with PD. Thus, we conducted a visual narrative inquiry using an open elicitation approach to capture individuals' stories of life with PD.

### 3.3 Methodology and Methods

#### 3.3.1 Research Objectives and Overview of the Study Design

In light of the current state of PD care, which may be dominated by values that are incongruent to those of persons with PD themselves (Findley & Baker, 2002), the overarching goal of the proposed research was to unpack the values and needs of persons with PD. To achieve this, the study aimed to enhance the understanding of life with PD by exploring the daily lived experiences of this group. As discussed by Holmes et al. (2013), attention to the lived experience of PD is an essential first step to improving the person-centered care (PCC) for PD. In order for health care providers (HCPs) to integrate client values into their practice, research on the spectrum of challenges individuals with PD face, from the perspective of those individuals themselves, must be explored (Holmes et al., 2013). After this is achieved, HCPs can begin to better understand, for example, which probing questions to ask their clients so as to become more aware of what values deserve greater therapeutic attention (Holmes et al., 2013). Given that little research has investigated PD to this regard, this study aimed to explore the daily lived experiences of PD with the hopes that it would lead to a discovery of some of those factors of everyday life that are most important and meaningful to people with the condition. To address this objective, and work towards the long-term goal of improving the person-centeredness of PD care practices, the following question guided the research: How do persons with PD make sense of their everyday experiences?

To answer this question, a visual narrative inquiry (Bach, 2008) situated within social constructionism (Crotty, 1998) was conducted. Narrative methodology is based on the assumption that humans are driven to construct an overarching sense of meaning and purpose for themselves through story. When a person acquires a chronic illness, the sense



of self they once knew may be altered leading to biographic disruption and ongoing narrative reconstruction (Roussi & Avidi, 2008). Thus, through personal narratives, the interactions between illness and identity can be further understood (Connelly & Clandinin, 1990; Hyden, 1997). Moreover, narratives provide a means to explore occupation (Molineux & Richard, 2003). Within occupational therapy (OT) and occupational science (OS), narratives can provide key information on the range and type of occupations people participate in, a person's experience of occupational change and transition over time, and how one's perception of themselves and their abilities are enacted and shaped through their occupations (Josephsson, Asaba, Jonsson, & Alsaker, 2009; Wicks & Whiteford, 2003). Gaining this depth of understanding can help HCPs better understand the complexity and contexts of clients' experiences, thus aiding in promoting a more humanistic practice (Larson & Fanchiang, 1996).

Visual narrative inquiry combines stories and visuals to explore experience and the construction of identity, and has been shown to enhance participants' reflections on everyday experiences (Bach, 2008; Clark-Ibanez, 2004; Harper, 2002). In the present study, narratives were elicited through oral accounts and supplemented with photo-elicitation, such that participant photographs were used to elicit stories (Clandinin & Huber, 2010; Harper, 2002; Harrison, 2002). Photos acted as a way to guide stories, and offered a means for continuous reflection and deeper interpretations of experiences (Clandinin & Huber, 2010; Harrison, 2002).

### 3.3.2 Theoretical Framework

As mentioned, this research was situated within a constructivist paradigm (Crotty, 1998), which facilitated a focus on studying how the experiences and occupations of individuals with PD were shaped within their social contexts (rather than solely influenced or determined by their symptoms). This position allowed us to explore the ways in which various contextual aspects (e.g., gender norms, societal attitudes towards disability, age-based life course expectations, perceptions of mobility aids, etc.) were negotiated by the individuals as they carried out daily life with PD. Epistemologically, constructivism argues that knowledge is *transactional*, *dialectical*, and *subjectivist* (Guba & Lincoln, 1994). This indicates that notions regarding knowledge depend on the meaning a person

places on phenomena, as well as the relationships formed between those individuals who are co-constructing the knowledge. Thus, the methods used in the present study were designed to provide a space for people to discuss the meaning of PD in their lives, and acknowledged the need for researcher reflexivity within the context of the interviews. In making methodological decisions, this paradigm assumes that researchers should aim to understand the phenomena of study through the lived experience of the persons who actively live it, and thus facilitates analysis of individual and collective constructions of experience (Guba & Lincoln, 1994). Given its devotion to uncovering socially constructed meaning, values, and experiences (Guba & Lincoln, 1994), the paradigmatic assumptions of constructivism were deemed most appropriate for guiding the research. In addition, the focus on meaning and participant perspectives is well aligned with the underlying principles of PCC (Carpenter & Suto, 2008).

### 3.3.3 Narrative Inquiry Methodology

Narrative inquiry is based on the assumption that it is through *story* that individuals best understand, give, and convey meaning to their lives (Chase, 2005). A narrative approach was selected so as to provide the study participants with a space to explore instances of importance, and the meanings associated with various experiences, in the contexts of daily life. In line with the constructivist underpinnings informing the study, narrative inquiry provides a *hermeneutical* and *dialectical* approach to the processes of data collection and analysis, and conversational discussion between the researcher and researched facilitates the creation of the intersubjective meaning (Chase, 2005).

Narrative inquiry revolves around notions regarding story and storytelling (Chase, 2005). In narrative inquiry, the act of eliciting a story is viewed as a “distinct form of discourse” that involves “retrospective meaning-making” (Chase, 2005, p. 656). This indicates that the methodology is concerned with seeing how people go back, reflect on prior experience, and make meaningful connections while they story important moments from their lives. Within this study, we sought to elicit individuals’ stories of living with PD, particularly focusing on moments and events that convey what it is like to live with PD over time, as well as instances that communicate how PD influences the doing of occupations.

### 3.3.4 Rationale for the Inclusion of Photo Elicitation

One of the major innovations of this study is the addition of photo elicitation as a way to enhance the narrative data collection. Photo elicitation was first used, and formally named as a method of inquiry, by Collier in 1957. Compared with strictly verbal interviews, it was reported that using photos during the interview process helped to improve participants' memory and their depth of responses, and also allowed participants to engage for longer periods of time (Collier, 1957). Photographs thus acted as a "language bridge" allowing participants to more clearly articulate their thoughts and experiences (Collier, 1957). Art therapists argue that the use of colours and symbols can better represent complex emotions or experiences, and that images can help people to understand themselves in ways that words cannot (Malchiodi, 2003). Visual arts have also been described as beneficial when the subject matter at hand is difficult to speak about (Malchiodi, 2003). Photo elicitation is a way to enhance conventional forms of research, providing a different type of information for both the researcher and research participants, that has remained largely underutilized (Clark-Ibanez, 2004; Harper, 2002). In this way, interviews using the photo elicitation method provide the researcher and the research participant with both visual and verbal information, which together elicit deeper levels of experience, meanings, and consciousness than using only verbal information (Clark-Ibanez, 2004; Harper, 2002).

To present knowledge, only two studies to date have used photo-based methods with individuals with PD (Hermanns, Greer, & Cooper, 2015; Roger, Wetzell, & Penner, 2017). Roger et al. (2017) used photovoice, a methodology similar to photo elicitation, in a single case study on the experience of life with PD. The themes of (a) medication and time; (b) household daily living; (c) physical activities; (d) mental activities; and (e) community activities were revealed as important to the participant and his spouse (Roger et al., 2017). In this study, the researchers specifically analyzed those instances when the participant's symptoms were visible and invisible to the public, and discussed the factors that determined whether being visible with PD was comfortable or uncomfortable for that participant (Roger et al., 2017).

In Hermanns et al. (2015), nine participants with PD completed a photovoice study on life with PD, which revealed the following sub-themes: (a) staying active; (b) finding purpose and meaning; (c) finding joy; (d) keeping it private; and (e) staying connected despite a loss, which were all situated within one overarching theme of “staying determined” (Hermanns et al., 2015). This study highlighted that participants with PD can experience happiness despite living with the negative aspects of their disease, and described how all of the participants with PD expressed their experience with the disease through a primarily positive lens (Hermanns et al., 2015).

The aforementioned use of photovoice in PD research suggests that photos may be a touchstone within the interview process. Photos may serve to explicitly acknowledge the context in which participants experience their disease, and thus can be helpful for understanding the manner in which participants construct their experiences. Furthermore, given the symptoms experienced by individuals with PD, some individuals may have limited ability to verbally articulate their experiences. Thus, using a visual methodology would facilitate their ability to more vividly describe their own experiences. By allowing participants to contribute to the topic of lived experience in a non-verbal manner, feelings of intimidation, anxiety, or discomfort may be reduced, which may then open up room for discussion of aspects of the experience not previously captured in research. We believed that, by allowing participants the freedom to create visual representations of their experiences in an environment that was free from the presence of researchers, they were enabled to share more genuine and novel information.

### 3.3.5 Participant recruitment

Individuals with a confirmed diagnosis of idiopathic PD from a neurologist specializing in movement disorders who were able to participate in study methods in English were considered eligible. Individuals were excluded from participation if they experienced cognitive dysfunction, as determined by their attending neurologist, as this was judged likely to impede participation in the photo-taking and interview processes. Following receipt of institutional ethics approval (Appendix A), six participants were recruited through the use of a poster (Appendix B) displayed within a local movement disorder clinic located in a mid-sized Canadian city. Upon study entry, each participant was given

a pseudonym to ensure confidentiality. Table 2 provides a brief demographic overview of each participant.

**Table 2: Participant Profiles at the Time of their Individual Interview**

	Meg	Lawrence	Gail	Clint	Robert	Trevor
Gender	F	M	F	M	M	M
Age	70	70	57	63	70	73
Years with PD	9	5	Not disclosed	7	10	10
Care Partner	N/A	Spouse	Partner	Spouse	Spouse	Spouse

### 3.3.6 Data collection

Prior to data collection, each participant attended a meeting with the first author (SL) to discuss study procedures, receive a digital camera, undergo camera training, and provide informed consent (Appendix C). Following this, participants spent four weeks taking photos to illustrate their experience of living with PD. Specifically, participants were asked to take pictures of what it is like to live with PD, and in doing so to reflect on the people and/or things they consider to be barriers or facilitators to living successfully with PD. Participants could direct a friend or care partner to take photos for them should they be physically incapable at a particular moment, or, if they would like to appear in a photograph. Participants were also allowed to select existing photos from their personal collection. Individuals using photos that included the face of an individual were required to have a signed consent and release form from those individuals. Participants were not given a recommended minimum or maximum number of photos to take.

After photo collection, participants completed an individual narrative interview with the first author, either at the research institution or the participant's home. Partners/spouses were permitted to attend interviews with the participant's consent. During the interviews, which lasted from approximately 50 to 90 minutes, participant discussion surrounding each photo was initiated by asking them to describe the photo, their reasons for taking it,

and what the photo meant to them. To further elicit narratives that placed the photo within the participants' broader experiences of living with PD, probes were used to elicit more in-depth descriptions (e.g., How does the photo connect with living with PD? How has the object in the photo led to changes in occupations over time?).

Following the one-on-one interviews, participants engaged in a focus group session with the other participants in the study. Three participants were included in each focus group. At the end of each individual interview, participants chose two photographs to share with their group, and provided a title to each. During the focus group sessions, individuals shared their experiences surrounding their chosen photos, and the group discussed their shared or differing experiences. Focus group sessions were approximately 120 minutes.

Individual and focus group interviews were audio recorded and transcribed verbatim by a professional transcriptionist.

### 3.3.7 Data analysis

Analysis was conducted by the first author (SL) who, at the time, was a student in OT, with previous research experience in topics surrounding mental health and the psychosocial experience of people with neurodegenerative disorders. Supervision and guidance was provided from authors DR and KL throughout the data analysis processes.

Data coding and synthesis was managed through the use of NVivo 10 software.

Following professional transcription, interview transcripts, photographs, and notes made during interviews were included in the analysis. Data was analyzed in an iterative, inductive process, first attending to the voices *within* narratives, and then addressing voices *across* narratives (Riessman, 2008). The present paper focuses on the across-narrative analysis.

To consider the cross-narrative experience of participants, a thematic narrative analysis was conducted, which focused on the "what" of the stories told and sought to identify commonalities to theorize across cases (Riessman, 2008). Following the steps outlined by Braun and Clarke (2006), analysis was initiated with immersion through repeated and active readings of transcripts. Next, initial codes were generated through line-by-line

coding of the transcripts, as well as analysis of contents within the photographs (Braun & Clarke, 2006). Themes and subthemes were developed out of the list of codes, and interpreted through the lens of narrative theory with specific analytic focus on identity and occupation (Bury, 1982; Roussi & Avidi, 2008).

## 3.4 Findings

Three major themes were identified: (1) Framing the meaning of PD; (2) Negotiating engagement in occupation; and (3) Being ready to accept changes that impact personal or social identity. Overall, our analyses highlight the interrelationship between occupation and identity as many of the participants' stories were interpreted as foregrounding the negotiation of occupation and how such negotiation shaped their sense of identity. In turn, participants' sense of identity often shaped their chosen occupations.

### 3.4.1 Framing the Meaning of PD

In narrating stories about daily life with PD, participants incorporated ways of talking about PD that served as a means to frame their illness. Illnesses were framed in ways that facilitated processes of making sense of their life circumstances, and it appeared that this framing influenced how each person addressed how having PD was integrated into their identity. Participants discussed a continuum of framing that spanned from accepting the disease as part of who they were to striving to maintain a sense of continuity with their pre-PD self. Moreover, participants explained that their ways of framing PD was not static. For example, Gail stated: *"I keep telling myself that it's a make work project."*

#### 3.4.1.1 Acceptance of the Parkinson's Self

Some participants discussed the need to "accept" PD as part of their new reality. These participants described how they incorporate PD as part of their identity so that it does not negatively impact their daily life. Thus, the participants tended to try not to let negative emotions control their everyday experiences. For example, Robert stated:

*Because what can you do about it? You got Parkinson's. Well, you can say well, I hate it, but you got it. It's not that you're going to hate that much then it is gone. It's going to stay with you. I say accept it and you live with it.*

In negotiating his acceptance of PD, Clint made comparisons to other diseases, and considered himself lucky for having PD: *“But, as someone once said to me, – if I’m going to have a chronic illness, Parkinson’s is probably the one I’d choose, rather than cancer, or strokes, or anything like that.”*

In discussing their acceptance of PD, some participants also spoke of the importance of “appreciation.” For these participants, it was important to remember the positive things accomplished in life prior to the onset of PD, and to find ways to maintain that positivity in the present. Lawrence explained that his photos represented both the challenges associated with PD, as well as the positive memories of things he had previously accomplished. For example, as seen in Figure 1, Lawrence took a picture of electrical work he had completed prior to his diagnosis and used this photo to story how he appreciates having maintained the mental capacity to understand how to complete the electrical wiring despite having lost the physical dexterity to actually perform the task. For Lawrence:

*When I’m having a down day or just an off day, I just think about my old electrical days or roofing houses or buying properties. And my mind will go on a trip. And it’s an appreciation. [...] with Parkinson’s, it’s not a lot of fun. And I just think that it’s not all negative.*





**Figure 1: Lawrence’s representation of an occupation he has given up as a consequence of progressing PD.**

#### 3.4.1.2 Maintaining Continuity with the Pre-Parkinson’s Self

For those participants who positioned themselves as striving for continuity with the person they were prior to PD, stories were often paired with statements that indicated that PD was not a large influence within daily life. As Trevor stated: *“I don’t really try to think about it. I don’t try to talk about it. It’s just something that I have.”*

In this form of framing of PD, participants often communicated a desire to remain the same person they were prior to the onset of PD. As Meg noted: *“I’m still [Meg]. I’m not Mrs. Parkinson’s.”*

These forms of framing the disease appeared to run in contrast to those surrounding the idea of acceptance. For the participants providing acceptance narratives, PD was often expressed as a part of who they were. Conversely, for those providing continuity narratives, PD appeared to be distanced from the person’s sense of self.

#### 3.4.1.3 Grey Areas

The participants’ positions within spaces of acceptance of, and distancing from, PD was not concrete. For example, two participants discussed their attendance at PD-related support groups and conferences. Attendance at such events would suggest that these

individuals had accepted PD as part of their identity. However, in sharing a greater depth of response regarding their experiences within these support groups, it became apparent that both of participants remained somewhat distanced from PD. As discussed by Gail:

*It's funny. I was the facilitator of that group for a year. And I loved it. It was so much fun but then after a while – it was still very good but there's a difference in opinion between myself and the rest of the group or a lot of the group because it just, you know – they just didn't want to do what I thought we should do. I wanted to stay away from Parkinson's, because you go to the meeting and you get down, you know you just have so much – can we talk about something else now. [...] You know? You know, something that is not Parkinson's. I suggested that maybe we should go for a walk around the block or something like that. They looked at me like I was absolutely out of my mind and that was just the end of it.*

Meg also described her attendance at a PD conference, explaining:

*I left halfway through it. I thought it was boring. I thought it was sad. I thought I'm uncomfortable. We had [a doctor] give a very learned and explicit talk on something. I don't know what it was. I couldn't understand it. [...] I remember thinking why am I here? I'm not feeling very positive. [...] So I went home. And vowed I wasn't going to another conference because I didn't learn anything. [...] I never hear anyone talk about the foods you eat, or the exercise you do. That area seems to be missing for me. I think well, I turn on Dr. Oz and find out about oil of oregano. You know what I mean. [...] Things that can actually make a difference in everyday life.*

Despite their negative experiences in these PD groups, these participants did state that they found value in the focus group portion of the present study, thus further reinforcing that acceptance is not a black and white concept. As explained by Meg,

*I was just thinking that it's so valuable [...] when you share your stories then I learn a lot about someone else and how courageous you are and you are and you are and I think we're really – we're really brave people when we go through this.*

Gail also shared similar feelings toward the focus group portion of the study. As she explained, she finds benefit in having a support network of people also living with the disease, stating:

*Yeah, and people – it's nice to compare notes so to speak because you're thinking you're the only person that has this or you're very lonely and no one understands you and then you see somebody, as I said before, you see somebody else doing what you do and you think, oh, I wonder what they did to cope with that or whatever. I think that's what keeps you going sometimes is just a matter of thinking, okay, I've got this problem, who can I call?*

### 3.4.2 Negotiating Engagement in Occupation

The drive to maintain engagement in daily occupations, conveyed as meaningful activities, pervaded many of the participants' stories. Participants shared various types of stories on occupational engagement, including stories of engagement in new occupations, stories of maintaining engagement in pre-existing occupations, and stories of occupational loss. Concepts of identity negotiation were found to permeate each story of engagement, thus providing insights into the interrelationship between identity and occupation.

#### 3.4.2.1 Discovering New Occupations

For Gail, the initiation of a new leisure occupation was important for reconstructing her sense of who she was amidst a life transition. As she described, she was experiencing a time where important relationships were changing as a partial consequence of recently having received her diagnosis of PD. At that point, she began to engage in gardening and found that it gave her a sense of mental and physical strength (see Figure 2):

*Oh, when it [the garden] started was like my new life. And it really was because I don't think I went out there and said, "oh I really want to make a garden." I just thought, "I should put some plants in, some colour or something." And it was just – I think it was the thing that kept me going when I was all by myself [...]. And I just thought, "I have to have something my own. And I have to be able to do it*

*myself, by myself, with no other input.” And that’s how it happened. It just happened. And I surprised myself by being so – strong, I suppose, mentally and physically.*



**Figure 2: Gail’s representation of a new occupation that she initiated once being diagnosed with PD.**

### 3.4.2.2 Maintaining Prior Occupations

Participants also storied their negotiation of engagement in occupations that existed prior to the onset of PD. Stories of engagement were frequently positioned within a space of ongoing deliberation regarding whether to continue or to stop engaging in certain aspects of life as PD progressed. Each participant discussed how he or she devised personal methods for engaging in activities in spite of their PD-related symptoms. For example, some participants strategized ways to facilitate their engagement in self-care tasks such as negotiating dressing and personal hygiene, connecting the importance of these tasks to maintaining a sense of independence. For example, Trevor described the process he developed for putting on different items of clothing, which has been crucial for managing his challenges with balance. As seen in Figure 3, Trevor captured a series of five photos that he used to describe the strategy he uses to maintain independence with donning socks:

*That's the stepping stool I use to get my socks on. Then the next one is starting my socks. I have to bend over. I get them about halfway up my foot – then, you get the next picture – I have to get on my toe and get them slid up. Then, the next picture is just emphasizing that I have difficulty getting it around my heel. The shorter the socks, the better off. Then, I got the sock up there in the last picture.*



**Figure 3: (a–e). Trevor uses a step stool to maintain engagement in dressing.**

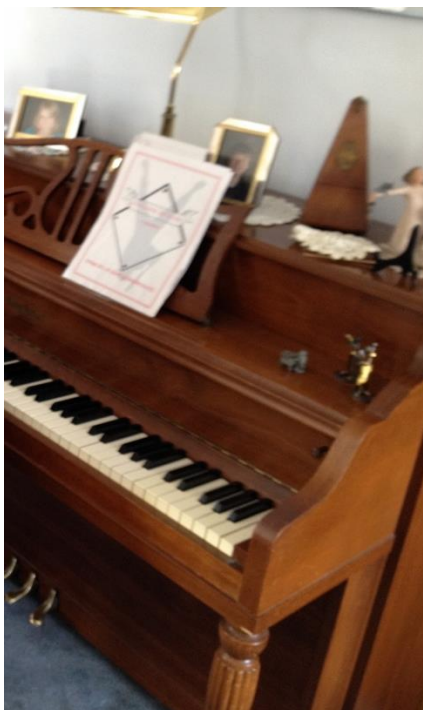
Across participants, stories revealed ways that maintaining engagement in occupations acted as a means to maintain the participants' desired identities. For example, while Trevor found it important to his sense of self as an independent person to adapt his self-care occupations, other participants discussed how their partners help them with difficult tasks around the home, explaining that this was often helpful and not detrimental to their sense of self as an independent person.

As another example, it was important to Meg's identity to be a helper, leader, and teacher. Thus, she maintained involvement in various volunteer, leadership, and teaching roles, such as leading yoga classes and providing reflexology services at a local hospice. By maintaining her engagement in these occupations, Meg appeared to resist negotiating a change in this part of her identity: *"I'm too stubborn, too determined. And I'm – maybe things change so you accept it, but right now I wouldn't like that to happen. I'm not ready for that to happen."*

Participants storied tensions between wanting to continue with previous occupations, and being restricted by their symptoms. When making decisions about whether to maintain or give up engagement in a particular occupation, participants often took into consideration whether the activity in question was meaningful to how they viewed themselves or wanted to be viewed by others. For example, Gail used a photo of her piano to express

that music had been a constant part of her life and a way she defined who she was; thus, she continued to play the piano in spite of the PD-related difficulties (see Figure 4):

*Well, I have a degree in music education. And I've been playing the piano since I was 11. So it's a real big part of my life. And I thought, you know when I move out of this house, "oh I better, I've got to have room for my piano." So it's just – and it's another way of sort of saying, "I still have this," you know, "I can still do this."*



**Figure 4: Gail maintains engagement in music because it is meaningful to her, and important for her to “have that there”.**

Adaptations were discussed as a way to facilitate continuation with occupations key to identity. For many participants, physical activity was an important part of life that was continually impacted by PD. Clint, Trevor, and Robert all took photos while on the golf course to describe how they found ways to continue golfing through adaptations. For example, Robert adapted his routine by playing nine holes instead of 18 and by using a golf cart to travel between holes. As well, Robert also found ways to continue his identity as a worker. For Robert, work was an important part of life and he had founded a welding



business. Although he was no longer able to do the physical labor involved with the job, Robert used a photo taken at his welding shop (see Figure 5) to discuss how he is continuing with his work by going into the workplace and involving himself in the environment, thereby maintaining his identity as part of the shop and as someone able to contribute: *“Go into the shop, talk to the guys and be re-involved in it, certain – to a certain extent. If there’s a problem, they know where I am.”*



**Figure 5: Robert adapts his engagement in work by still going into his shop, talking to the employees, and making himself available to provide help.**

Similarly, Lawrence also described how he continues on with his identity as a “hard worker” despite his current physical limitations. For example, Lawrence described how shoveling snow (see Figure 6) led to a sense of great satisfaction as it allowed him to demonstrate his ability to identify as a hard worker:

*That’s my yard where I spent a lot of time shoveling snow. And the reason I took that picture is because it gives me great satisfaction to get out and do plain, simple, hard work. That’s my farm background or whatever. And so a lot of the time, I don’t even use my snow blower. I shovel this off by hand with a shovel.*

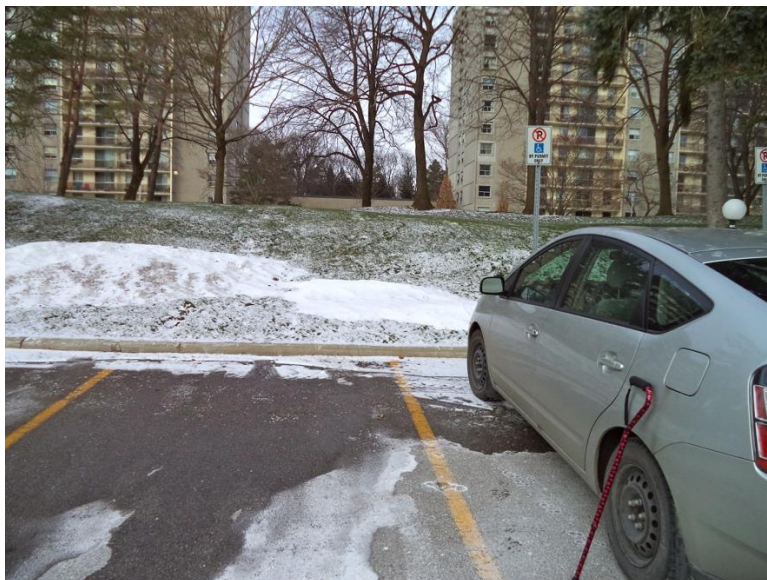


**Figure 6: Occupations such as shoveling snow allow Lawrence to see himself as a hard worker.**

For Meg, community engagement was key to her sense of identity. At times, transportation posed a threat to gaining access to community activities. For example, she narrated difficulty driving in such conditions as winter weather and in the dark, and described instances where she had to return home because she could not find parking near the entrance of her destination. In order to maintain engagement in community activities, Meg implemented the use of mobility devices and accessibility strategies (see Figure 7). As she explained:

*So basically that picture says I have freedom. A cane gives me balance and I'm not so afraid of falling. The sign I think is another one. It's disabled parking. That's really a real freedom.*





**Figure 7: Meg’s accessible parking permit has been key for allowing her to access meaningful community supports.**

### 3.4.2.3 Navigating Occupational Loss

Participants also discussed moments when they decided that they could no longer continue an activity. Decisions to stop were often described alongside feelings of frustrations and mourning, especially when an aspect of identity was threatened. For example, Meg’s valued occupations often required a high level of physical abilities, and this sense of movement was key to her identity. Many of her photographs centered around the valued physical activities, and the struggles of losing some of those activities as a result of her PD. As she described:

*Well, I think all of mine [photographs] is based on movements since that’s been an important part of my life. I think it started when I was adopted. I started running to see what I could find. That’s been the hardest is stopping doing what I love to do.*

Clint also described how physical changes associated with PD have impacted his identity. For example, his past area of employment involved frequent writing and he expressed a sense of pride in his penmanship. His ability to write was impacted by PD, which caused a threat to his identity (see Figure 8):

*My handwriting, my penmanship was the big deal, and I've always been very sharp. I guess I could say proud of my penmanship, and to suffer that deterioration was – because I frankly had difficulty writing an entire sentence at the time. And I recall saying to [my neurologist] that if you can get my handwriting back that's the one I choose to be fixed.*



**Figure 8: Clint's challenges with writing were difficult for him to conceptualize with his sense of self.**

Lawrence described the struggle he experienced hiring someone to do electrical work he would usually do himself:

*The size of the project has a bearing on whether I will attempt to do it. And it's a fight or a struggle within me because part of me wants to be able to do these things forever, and the other part of me says maybe you shouldn't do it.*

Lawrence, however, negotiated ways to keep electrical work as part of his identity by recognizing the value of mentally remembering how to do the work: *“And so just the understanding. It gives you self worth. It makes you feel good about what you've accomplished, what you're capable of thinking about.”*

As another example, some participants in the study found that PD was beginning to place limits on their social identity. For example, Lawrence described himself as being a very active and social person prior to the onset of PD symptoms. In discussing his recent engagement in social occupations, Lawrence described:

*There's times I don't want to mix in crowds. I had a chance to go to [a] hockey game a while ago, and I just didn't want to fight the crowd. [...] At the top of that list is going to the washroom. When I go to the arena, and the boys go to the boys' room, and the girls go to the girls' room, anyway, we line up, and you can imagine. We go through the process of doing our business. I can't. I'm afraid to go there because I don't do my clothes up as well as I – as quick as I'd like to. [...] So I find myself avoiding things like that just because of the washroom.*

In deciding when to cease engagement in a valued occupation, participants also discussed tensions with receiving unwanted opinions from other people. For many of the participants in this study, it was important for this decision to be made independently. As explained by Lawrence:

*When people tell me I shouldn't do stuff, I sometimes don't like it because I think I'm still smart enough to figure that out for myself. But they don't know that. [...] Just my appearance when people sit across the table from me, they sometimes don't give me credit for being with it.*

### 3.4.3 Being Ready to Accept Changes That Impact Personal or Social Identity

Participants discussed having to negotiate several types of changes, all of which appeared to be negotiated in relation to the idea of maintaining personal and social identity. The extent to which a participant was ready to accept changes arising out their illness, given their potential implications for how they saw themselves and were seen by others, appeared to influence how they navigated such tensions. Overall, the concept of readiness emerged as a fluid and context-dependent concept in relation to changes associated with accepting help, physical changes, and taking up the identity of being person with PD.

### 3.4.3.1 Readiness to Accept and Receive Help

Accepting and receiving help from others was an issue that participants frequently narrated through a discussion of readiness. Participants often described their readiness to accept help as variable and dependent on the context. For example, Meg used a picture of herself walking with the support of a family member (see Figure 9) to explain that receiving help from a close, trusted person was both comfortable and necessary for her to manage PD. For Meg, having an arm from a trusted family member facilitated going for a walk along her favorite trail, which she expressed was a meaningful activity for her to continue. Accepting help from strangers or in public spaces, however, was often a difficult and uneasy task for Meg, which appeared to threaten her identity as a helper to others: *“It’s that little old lady thing. I’m the one that should be taking care of somebody. You know, I worked with seniors all my life. [...] it’s hard to do it the other way around.”*

Thus, for Meg, the degree of readiness to accept help was connected to both who was providing the help and in what context, as these features influenced whether the acceptance threatened Meg’s sense of herself as a person who helps rather than a person who is dependent on others.



**Figure 9: Meg is comfortable accepting help from trusted friends and family members, which allows her to maintain engagement in meaningful occupations.**

### 3.4.3.2 Readiness to Accept Physical Changes

Participants also discussed issues of readiness with regards to tensions associated with accepting physical changes, particularly when such changes threatened how they saw themselves and how others saw them in relation to age. Both Meg and Gail discussed the difficulties of using a mobility device given that they perceived themselves as too young for a device: *“I’m not even 60 yet. I’m not going in a wheelchair.”* (Gail)

Meg indicated that her ego partly explained her resistance towards mobility device use, but that she needed to weigh this against being at a point in her illness where she needed such equipment for her own safety. Meg also described the challenge of accepting her limitations, comparing herself to a same age or older peer: *“I have friends who are in the mid-80s and they can walk faster than I can. That’s makes me mad sometimes.”*

### 3.4.3.3 Readiness to Identify as a Person with Parkinson’s

A last type of change discussed in relation to readiness was that of being ready to identify oneself, and be identified by others, as *a person with PD*. Lawrence discussed his readiness to talk about his condition, as well as his readiness for people to see him as a person with PD. For Lawrence, engaging with close friends and family was a comfortable situation, and he felt he could talk openly with these individuals about his challenges with PD. Lawrence, however, felt uncomfortable engaging with or seeing individuals who were not a part of his close circle of friends and family. For example, Lawrence used a picture of his computer to explain that he prefers to communicate with people who he has not seen in a while via email rather than face to face as he is fearful for them to see him as a person with PD:

*People I haven’t seen for a while, and I meet them, and they knew me the way I was before. And I’m afraid to meet them [...] I don’t want them to see me different than I used to be.*

Some participants also provided narratives regarding their feelings towards socializing with other individuals with PD, and reflected on their readiness to engage and identify with them. For example, Gail used narratives surrounding her participation in support

groups to discuss how she feels more comfortable in settings with individuals with regular-onset PD, as opposed to early-onset. As a person with early-onset PD herself, Gail discussed her discomfort after attending a conference for individuals with early-onset PD:

*That had quite an effect on me, that early onset. Like up to now I've just had [...] support group members as being older people, and you think, "Okay, that's acceptable" [...] I don't know why I felt more comfortable with the older age group, but this – this conference I looked around and I thought, all these people are my age and all of the sudden I got really, really scared.*

### 3.5 Discussion

A key way that the participants storied their experience of life with PD was as an ongoing navigation of occupation and identity, situated with how they framed the meaning of having PD. Participants' narratives contained many occupational engagement stories, highlighting the centrality of occupation in daily life. Participants centered their narratives around their occupations, reflecting on occupations initiated, maintained, adapted, and lost throughout their journey with PD. As participants conveyed occupational engagement stories, the link between occupation and identity became apparent; as occupations were negotiated, one's sense of identity was also impacted. For example, Meg viewed herself as a helper and caretaker to others. Receiving help, and not being able to provide help to others, was difficult for her to conceptualize as it ran counter to her personal identity. Identity also played a key role in determining which occupations the participants chose to maintain. If a particular occupation was strongly linked to a participant's sense of self or if its loss could threaten a desired social identity, they storied how they worked to keep that occupation in their life, even if at a lesser or different extent. For example, although Robert could no longer work directly in his welding business, he visited the shop and stayed involved in social and consulting roles.

The finding that occupation and identity are interrelated and mutually shaping complements other research within OS and OT, which uses the term occupational identity to describe the relationship between a person's perceived sense of self and their

occupational history, current repertoire, and expected future (Kielhofner, 2004; Laliberte-Rudman, 2002; Unruh, 2004). Qualitative investigations addressing occupational identity have shown that the ability, or inability, to engage in occupation molds how a person perceives and is perceived by others (Klinger, 2005; Vrkljan & Polgar, 2007). Further, research has uncovered that individuals aim to engage in occupations that contribute to a sense of identity that is both acceptable and fulfilling to them (Laliberte-Rudman, 2002).

Studies on identity following a life transition, including chronic illness onset, have pointed to the potential for occupational disruption or a temporary state of restricted participation in desired occupations (Vrkljan & Polgar, 2007). Occupational disruption can threaten occupational identity and lead to a period of identity reconstruction, where a person may adapt their occupational engagement to redefine their sense of identity (Vrkljan & Polgar, 2007). In an investigation of occupational adaptation following traumatic brain injury, Klinger (2005) concluded that brain injury survivors negotiated a new sense of self in order to adapt their occupations and initiate a new way of engaging in activities (Klinger, 2005). In the present study, participants with PD often positioned themselves as striving for continuity in key aspects of identity, where they wished to be viewed by themselves and others as the same person they were prior to PD. As articulated by Meg, who stated *“I’m not Mrs. Parkinson’s,”* these participants storied a need for their identity not to be based on having PD, but rather on the occupations that they engage in, or engaged in prior to the onset of PD. In many cases, maintenance of occupations allowed for the maintenance of their identity. This finding is similar to that of Habermann (1999), who found it was important for participants to manage their PD by maintaining continuity, or *“[carry] on as usual.”* In addition, this study shows that participants were able to creatively adapt occupations in ways that also supported key aspects of identity, such that continuity does not always necessitate doing occupations in the same ways as before. These findings support a recent phenomenological investigation conducted by Smith and Shaw (2017), wherein people living with PD and their care partners described the importance of coming to terms with PD and adapting their routine to overcome the barriers PD presents: *“Well you just take it as it comes and you change your routine, as you need to...”* (p. 18).

The present study, however, is not without limitations. An important limitation is that participants were at similar stages of disease progression (years living with PD ranged from 5–10 years); as such, this study does not encompass experiences of those newly diagnosed or those in later stages of the disease process. This study was also limited in that it only captured the experiences of one participant who had young-onset status (that is, received diagnosis before 50 years of age). Given that younger individuals are more likely to be employed for pay and to have young dependents, the occupational disruptions they experience are likely to differ from those of older adults living with PD. As a constructivist narrative study which employed an occupational and narrative lens in the analysis phase, the objective was not to obtain generalizable results via the use of a representative sample; rather, this study provides insights into the inter-connections between occupation and identity that are part of the daily negotiation of PD. Further research with more diverse participants is required to achieve more complex understandings.

### 3.6 Conclusion

This study contributes to the occupation-based literature by supporting findings that occupation and identity are interrelated, and adds an occupational lens to the body of work addressing lived experiences of PD. In this study, participants told stories of engagement in occupations that were critically linked to the negotiation of their identity. Occupational therapists (OTs) working with clients with PD should be aware of the threats that occupational disruption can cause to identity. When therapists approach subjects such as changing, altering, or giving up occupations, it is recommended that they are empathetic toward the threats that such occupational changes can have on one's identity, and strive for collaboration in their relationship with the client and to supporting maintenance of occupations defined as central to identity by clients. Importantly, help-seeking and help-accepting behaviors appear to be woven within a person's occupational identity, and may be related to an individual's willingness to accept the changes that are frequently associated with PD (for example rigidity, postural instability, bradykinesia, etc.). This underscores the importance of supporting individuals with PD as they navigate maintaining independence while balancing safety concerns. This may also suggest that



there is value in speaking with caregivers and family members about the importance of being sensitive to the specific needs of the individual with PD – and the critical role that valued aspects of identity, such as independence, may play in how daily life, including occupation, is negotiated by persons with PD.

### 3.6.1 Key messages

- Individuals with Parkinson's navigate living with their diagnosis by forming a strong interrelationship between occupational engagement and their identity.
- OTs should strive to support maintenance of occupations that their clients define as central to their identity.

### 3.6.2 What the study has added

This study is the first to use visual narratives to examine the interrelationship of occupation and identity among individuals with PD. In this study, participants told stories of engagement in occupations that were critically linked to the negotiation of their identity such that disruptions to occupational attainment served to threaten their sense of identity.

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## Chapter 4

### 4 Discussion

The navigation of life with a progressive illness is a complex area of study. To understand a patient's illness experience, all aspects of the person must be understood, including the physical body, environmental influences, relationships, self-image, and the consequences the illness has on the person's capacity for engagement (Pierret, 2003). When considering the person with Parkinson's disease (PD), it is well known that a variety of physical (Jankovic, 2008) and psychosocial (Holmes, Lutz, Ravenek, Rudman, & Johnson, 2013) changes will be experienced as the illness progresses. What has been relatively lacking, however, is a discussion of *how* such changes are experienced. This is a key deficit in the PD literature as attention to meaning behind daily life experiences has been supported as improving health care quality (Mohammadi et al., 2015) and informing person-centered care (PCC) practices (LaDonna & Venance, 2015).

The objective of the present research was to explore the lived experience of PD. Six individuals with PD took photographs of their daily life experiences. These photographs informed individual and group narrative style interviews, which revealed the participants' challenges, sources of meaning, and methods of navigating occupational restrictions and choices, as well as highlighted the interrelated nature between occupation and identity. As discussed in Chapter 3, the study participants narrated the ways in which PD was incorporated, or not incorporated, into their perceived identity. As well, participants told stories of occupations initiated, maintained, adapted, and lost throughout their journey with PD. Thus, identity and occupation were revealed as central to daily life. As participants conveyed their stories of occupational engagement, the interrelated link between occupation and identity became apparent. As occupations were negotiated, one's sense of identity was also impacted. As well, the participants' sense of identity greatly influenced their occupational choices. Overall, three major themes were identified: (1) Framing the meaning of PD; (2) Negotiating engagement in occupation; and (3) Being ready to accept changes that impact personal or social identity.

In exploring narratives on life with PD, the present research sought to achieve a deeper sense of the values and needs of people living with the condition. In turn, this research aimed to use this enriched understanding to enhance health care quality by making recommendations for health care providers (HCPs) on how to maximize PCC with their patients.

In this chapter, the experience of PD for the participants in the study (i.e., as a negotiation of occupation and identity) will be further discussed. In doing so, recommendations for HCPs, suggestions for future research, and reflections on the study methodology will also be made.

## 4.1 Occupation, Identity, and the Person with PD

The research findings were consistent with previous research that has recognized the interrelated nature of occupation and identity. This research supports the theory that individuals will choose to engage in occupations that are consistent with their sense of self and, in turn, will have their identity conveyed and shaped through their chosen occupations (Klinger, 2005; Laliberte-Rudman, 2002; Vrkljan & Polgar, 2007).

### 4.1.1 Occupation as a Means to Express and Shape Identity

The occupational science (OS) literature has described numerous instances where occupation has been used by humans as a means to express their personal perception of identity (Christiansen, 1999; Laliberte-Rudman, 2002; Laliberte-Rudman, Cook, & Polatajko, 1997). Identity has been theorized as a result of the occupations people engage in. Specifically, it is argued that, over time, as people engage in occupations and make occupational choices, their identity is constructed and shaped (Christiansen, 1999). One's occupational history creates an identity that serves as a complex picture of who that person is and wishes to be (Kielhofner, 2002). The literature also argues that, when a person is not able to engage in meaningful occupations, their identity inevitably changes (Braveman, Kielhofner, Albrecht, & Helfrich, 2006).

In the present study, participants also related their sense of self to their occupations. For the participants, occupations acted as a “mirror” for the person's values and sources of



meaning (Carlson, Park, Kuo, & Clark, 2012). Many of participants' disclosures of identity were made through stories of occupations engaged in prior to the onset of PD. For example, participants frequently spoke of their past areas of employment, and linked those occupations to their descriptions of the type of person they are in the present.

Some participants found ways to participate in occupations that were similar to their past areas of employment. As discussed in Chapter 3, Robert continued to visit his welding company and involve himself in the work through socialization and consulting. Meg also described numerous activities where she was a caregiver, tour guide, and teacher prior to her diagnosis of PD. Those activities were then used to position herself in the present as a person who needed to continue helping, teaching, and leading others. She used these aspects of her identity to explain why she continues to engage in volunteer work, such as leading yoga classes.

Other participants described being unable to continue engaging in those work-related occupations that would normally express their sense of self. For example, Lawrence discussed and photographed numerous jobs he previously held, all of which involved physical labor that he was no longer able to participate in. Regardless of being able to presently engage in those occupations, it appeared as though the mere act of storying past occupations served to communicate his perceptions identity. Furthermore, these same aspects of his identity appeared in narrations surrounding other, present occupations. For example, Lawrence discussed how he was skilled at "working hard" in his past areas of work. Later in the interview, Lawrence went on to describe some of his current occupations, such as shoveling snow, and utilized the same descriptions of himself as a hard worker.

New occupations were also shown to shape a person's identity. This was seen most prominently in Gail's description of gardening. For Gail, gardening was a new occupation that she initiated following her diagnosis of PD. By engaging in this occupation, she discovered a sense of strength, which grew to become an important aspect of her identity.

### 4.1.2 Identity as a Mediator for Choosing Occupations

Previous research has identified that individuals with an illness will adapt their occupations in order to maintain or redefine their sense of identity (Klinger, 2005; Vrkljan & Polgar, 2007). Unique to the literature is the finding discussed in Chapter 3, that this study's participants negotiated the decision to maintain, adapt, or let go of an occupation based on the weight that occupation held in their identity. For example, some participants discussed how their partners help them with difficult tasks around the home, explaining that that this was often helpful and not detrimental to their sense of self. However, Lawrence prided himself on his independence completing jobs around the home and, therefore, continued managing select activities.

Occupation has been described in the literature as a *servant*, which indicates that occupations serve a larger purpose for individuals who engage in them (Carlson et al., 2012). For the participants of this study, it can be argued that much of the occupations maintained served as a means to preserve the participants' desired identity.

### 4.1.3 Occupational Disruption as a Threat to Identity

Research has shown that, with the onset of an illness, individuals will often experience dramatic changes in their physical abilities which, in effect, may threaten their conception of self (Roussi & Avidi, 2008; Vrkljan & Polgar, 2007). Previous research has described the diagnosis of PD as equivalent to a bomb being dropped on a person's sense of existence, and has explained that participants feel compelled to reconstruct a new sense of identity for themselves following this diagnosis (Phillips, 2006). Other research has described individuals with PD as striving for a sense of continuity with their old sense of self (Hermanns et al., 2015).

The present study revealed these negotiations of identity to relate more specifically to the threats PD posed to occupational engagement. The participants in this study described the need to accept their PD identity once it began to impact their engagement in meaningful occupations. Until these occupations were greatly impacted, participants often described "not needing to go there." This research is similar to other research that has suggested that, when occupation is limited due to a change in one's personal or social abilities,

limits to their identity might also occur (Laliberte-Rudman, 2002). In this study, when PD affected a participant's occupational abilities, limits to their sense of self was also present. For example, Clint expressed a sense of pride in his penmanship and when his ability to write was impacted by PD, it caused a threat to his identity. Similarly, Lawrence described being a very active and social person prior to the onset of PD symptoms, however as the disease progressed he found that PD was beginning to place limits on his social identity.

## 4.2 Relating the Results to Patient-Centered Care: Recommendations for Clinical Practice

The research participants in this study have brought to light some fundamental starting points for enhancing the PCC approach. Participants discussed their preferences, needs, and values, which are defined as key in determining how to direct PCC (Institute of Medicine, 2001). Thus, the participants' individualized experiences, and the commonalities identified between them, can help to inform practice. Below are some recommendations for HCPs which have been derived from the study's findings and researcher reflections on conducting this research.

### 4.2.1 Obtain a Narrative-Style Initial Interview

Humans have an innate need to find meaning in their lives (Chase, 2005). When a person acquires a chronic illness like PD, this sense of meaning may be altered (Bury, 1982). To reveal the effects of illness on a person's perceived identity, narrative interviews have often been used (Josephsson et al., 2009; Wicks & Whiteford, 2003).

For a HCP to appropriately initiate a person-centered approach to their care, it is important for them to first explore their patients' preferences, needs, and values (Institute of Medicine, 2001; van der Eijk, Nijhuis, Faber, & Bloem, 2013). Narrative has been supported as an optimal way to explore such aspects of the patient (Schwind et al., 2016; Stanley-Hermanns & Engebretson, 2010). Research suggests that sharing stories of illness can lead to beneficial health outcomes (Kleinman, 1988; Pennebaker, 2000; Stanley-Hermanns & Engebretson, 2010; Sullivan, Weinert, & Cudney, 2003). For example, some research has suggested that sharing personal accounts can facilitate more

accurate diagnoses by HCPs (Sullivan et al., 2003). Other research has found that the act of verbalizing experiences can improve physical and mental health, particularly with regards to chronic pain. In this research, storytelling has been identified as therapeutic, acting to reduce one's short-term perception of pain, and suggesting that "feeling heard" directly influences pain perception (Pennebaker, 2000; Sofaer et al., 2005). It has also been argued that the inclusion of patient stories in health care acts to evoke greater interest and engagement from its listeners and improves a listeners understanding of the topic being communicated (Dahlstrom & Ho, 2012). The narrative-style interview was also revealed as a beneficial tool in the present study, as was observed by the researchers involved and verbalized by the study participants.

Since humans often make sense of their life through story, narrative can be used to reveal a patient's true identity (McAdams, 2008). Furthermore, narratives have frequently been recommended as an important resource for helping a HCP determine what clinical decisions to make with their patient (Baldwin, 2015). While it can be tempting for a HCP to tend toward direct questioning with their patients, especially in time-constrained settings, questions such as "what is important to you" might not always lead to effective findings. When patients are asked explicit questions regarding their identity, or when they are asked to rationalize their life decisions, it often leads patients to respond with answers they view as socially acceptable (Goffman, 1959). Thus, the person tends to remain somewhat distant from their true experiences and sense of self (Goffman, 1959). Instead, by hearing patients' stories, a HCP can make inferences on what the key preferences, needs, and values of that person are, and then ask that patient to confirm these inferences. Thus, it is recommended that HCPs take a narrative approach when working with their patients and use patients' stories to inform their clinical decision-making.

In conducting narrative interviews, it is important to ask narrative-inducing questions, which are open-ended and ask the patient to discuss the "what" rather than the "why" of their daily life (Gunaratnam, 2009). Depending on the type of HCP and the goal of the health care interaction, the questions used to elicit narrative may vary greatly. For some HCPs, questions such as "What does a typical day look like for you?" or "What is PD like for you?" might be useful in initiating open conversation. Once a patient initiates

their narrative, it is recommended that the HCP allow that patient to do the majority of the talking so they can provide an uninterrupted narrative of their experience. When the HCP begins to feel a sense of the important experiences of that patient, probing follow-up questions can be used to further gauge the meaningful aspects of the patient's life. Some follow-up questions that might be applicable and useful to the HCP include:

- What was that like for you?
- What does that mean to you?
- What effect does that problem have on your ability to complete daily tasks?
- What factors are important for you to weigh when making decisions like that?
- Does that have an impact on your relationships?
- How would you prefer things to be?
- What steps would you like us to take to make this better?

These initial narrative accounts can then be used to help the HCP structure their care plan and encourage a collaborative approach in determining which assessments, treatments, and referrals are most appropriate to the patient.

#### 4.2.2 Access the Multidisciplinary Team

Parkinson's disease (PD) is widely accepted as a multisystem condition, which affects people in numerous spheres of life (Giladi, Manor, Hilel, & Gurevich, 2014). Given the complexity of PD, there is great value in offering a multidisciplinary approach to managing the disease. It has been recommended that a patient with PD's care team should include the following HCPs: a neurologist and a nurse, a psychologist and psychiatrist, a speech and language pathologist (SLP), a physiotherapist (PT), an occupational therapist (OT), and a dietitian (Giladi et al., 2014).

Participants in the present study discussed their personal strategies for managing their condition, many of which could have been assisted by a HCP. For example, Meg often

located her own gait aids, and could have benefited from assessment and recommendation from a HCP trained in assessing and prescribing mobility devices, such as a PT. Trevor devised strategies for putting on his socks, which might have been simplified from an OT who is specialized in analyzing, adapting, or remediating occupational challenges. Meg also discussed the importance of natural remedies in the management of her PD, and discussed using shows such as Dr. Oz to inform her of natural health care approaches. From these narratives, it can be recommended that HCPs attempt to learn about the range of challenges their patient is experiencing, and make referrals to other HCPs as appropriate. As PD is ever-changing in its symptom presentation, it is key to re-refer to HCPs as needed throughout the course of the illness. It is also recommended that HCPs learn about their patients' perspectives on health and wellness, and not rule out natural approaches to symptom management if it is meaningful to their patient.

When considering referrals for OT or personal support workers (PSW), it is also important to highlight that the participants of this study found their readiness to accept help, and negotiations of what occupations to maintain, adapt, and cease, were heavily dependent on their context, values, and sense of identity. For some participants, help was welcomed from trusted family members and not from individuals outside of this trusted circle of social support. Deciding what supports to implement must be a collaborative discussion with the patient to discover what their values are, whether an occupation is most meaningfully experienced independently or with help, and who is the preferred helper. From this, referrals can be made that are within the patient's comfort level and that keep the patient at the center of clinical decision-making.

#### 4.2.3 Facilitate Connections to Community Resources

The participants in this study often discussed the community activities important to their sense of self, and storied the activities helpful to them in managing their PD. For example, community exercise and sport programs were often a central aspect of many participants' daily routine, and some participants also discussed seeking out PD support groups and conferences in their community.

For Meg, transportation to gain access to community supports was occasionally a barrier to her participation. As Meg did not have a care partner to support her transportation needs, she often drove herself to her various community activities. She narrated difficulty driving in such conditions as winter weather and in the dark, and described instances where she had to return home because she could not find parking near the entrance of her destination. Social connectedness and community involvement was central to Meg's sense of identity, thus making transportation a very meaningful aspect of her life.

Based on these narratives, it is recommended that HCPs gain a sense of what community means to their patients, be knowledgeable of the community supports available in their region, and ensure that their patients have appropriate methods of accessing those supports, such as through accessible parking permits, volunteer drivers, or para-transit services.

#### 4.2.4 Initiate a Range of Group-Based Interventions

Diagnosis-specific outpatient groups designed by HCPs have numerous benefits for patients. For example, a group focused on coping skills and identity preservation with individuals with mild dementia found lower depressive symptoms, less discomfort with advanced care plans, improved function, and increased self-reported coping strategies from participants following participation in the group (Hilgeman et al., 2014).

Many of the participants in the present study told stories of their experiences in PD-related conferences and support groups. It was evident from the participant narratives that educational and social events for PD was something that they actively sought out.

However, after participation in such groups, participants often viewed them negatively. As discussed in Chapter 3, participants often did not want PD to be the center of their lives, and often found such groups to focus too heavily on the negative aspects of PD, or to not offer enough useful information to help improve their management of the disease. It might be useful for HCPs to begin to initiate PD groups for patients to attend, and structure those groups around the meaningful aspects of life with PD identified in research on the subject. Groups centered around such topics as adapting meaningful occupations or physical activity might be more meaningful and valuable to patients.

### 4.3 Study Limitations and Recommendations for Future Research

As discussed in Chapter 3, this study was limited by the fact that participants were at similar stages of disease progression, and that young-onset individuals were not proportionately represented. Individuals with PD represent a heterogeneous group, and patients at differing stages of the disease will inevitably be situated in differing stages of occupational engagement and perceptions of identity. Thus, it would be beneficial for similar research to explore the lived experiences of patients in different stages of PD progression.

The participants in this study also completed their photo-taking during the winter months, which may have impacted the findings. Weather conditions during the winter may have impacted the participants' levels of occupational engagement, or prevented them from photographing meaningful occupations that they would typically engage in during summer months. Thus, it is also recommended that future research conduct similar studies in all seasons so as not to skew results.

This study was also limited in the fact that member checking was not conducted as a way to improve the trustworthiness of the results. The decision not to engage participants in member checking was made as the narratives were co-constructed through dialogue with the interviewer. Thus, the narrative data do not provide an unmediated picture of the participants' realities or voices, but are dynamic accounts told in a particular context. To try and mitigate this limitation and improve the trustworthiness of the study, two separate researchers were involved in checking interview codes, and two other researchers coded segments of the transcripts for comparison to my own codes. Future research might consider incorporating elements such as member checking to increase the trustworthiness of the results.

### 4.4 Conclusion

In conclusion, this research has contributed to the body of research on PCC in PD by providing an expanded understanding of the lived experience of the condition. In this study, participants storied their life with PD as an ongoing negotiation of occupation and



identity, which was fluid and context-dependent. Within this negotiation, the participants' key challenges, values, and sources of meaning were revealed. These findings have important implications for the future of health care for PD. Presently, research indicates that health care for individuals with PD has not been aligned with patient goals. By eliciting stories regarding the meaningful experiences, values, and needs of this group, this research unpacked a deeper understanding of life with PD and, in effect, was able to use results to make recommendations for HCPs in their delivery of PCC.

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# Appendices

## Appendix A: Ethics Approval for the Visual Narrative Inquiry Study



Research Ethics

Use of Human Participants - Initial Ethics Approval Notice

Principal Investigator: Dr. Jeffrey Holmes  
 File Number: 103356  
 Review Level: Delegated  
 Protocol Title: Snapshots of the experience of living with Parkinson's disease  
 Department & Institution: Health Sciences/Occupational Therapy,  
 Sponsor:  
 Ethics Approval Date: October 11, 2013 Expiry Date: October 31, 2015  
 Documents Reviewed & Approved & Documents Received for Information:

Document Name	Comments	Version Date
Western University Protocol		2012/12/18
Response to Board Recommendations	Response to REB Comments	2013/09/05
Other	List of Resources	2013/09/05
Instruments	Data Collection Form	2013/09/05
Response to Board Recommendations	Response to board recommendations	2013/09/25
Response to Board Recommendations	Response to Board Recommendations	2013/10/08
Recruitment Items	Revised Recruitment Poster	2013/10/08
Revised Letter of Information & Consent	Revised LOI	2013/10/08

This is to notify you that The University of Western Ontario Research Ethics Board for Health Sciences Research Involving Human Subjects (HSREB) which is organized and operates according to the Tri-Council Policy Statement: Ethical Conduct of Research Involving Humans and the Health Canada/ICH Good Clinical Practice Practices: Consolidated Guidelines; and the applicable laws and regulations of Ontario has reviewed and granted approval to the above referenced revision(s) or amendment(s) on the approval date noted above. The membership of this REB also complies with the membership requirements for REB's as defined in Division 5 of the Food and Drug Regulations.

The ethics approval for this study shall remain valid until the expiry date noted above assuming timely and acceptable responses to the HSREB's periodic requests for surveillance and monitoring information. If you require an updated approval notice prior to that time you must request it using the University of Western Ontario Updated Approval Request Form.

Members of the HSREB who are named as investigators in research studies, or declare a conflict of interest, do not participate in discussion related to, nor vote on, such studies when they are presented to the HSREB.

The Chair of the HSREB is Dr. Joseph Gilbert. The HSREB is registered with the U.S. Department of Health & Human Services B 00000940.

Ethics Officer to Contact for Further Information

This is an official document. Please retain the original in your files.

## Appendix B: Recruitment Poster



### RESEARCH OPPORTUNITY

Volunteers are needed for a study using digital photography to examine the daily experiences of living with Parkinson's disease

#### This study will involve you:

- Attending an information session
- Taking photographs with a digital camera
- Participating in a one-on-one interview and a group discussion



#### To participate you:

- Must have a clinical diagnosis of Parkinson's disease
- Be able to operate a simple digital camera

*Sessions will take place in Elborn College at Western University **Free Parking is available***

For more information, please contact:

**Dr. Jeffrey Holmes - Principal Investigator or  
Sara Lutz - Student Investigator  
At The University of Western Ontario**



Phone: [REDACTED]  
Email: [REDACTED]



## Appendix C: Letter of Information and Consent Form

Version August 10, 2015

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### Snapshots of the experience of living with Parkinson's disease

**PRINCIPAL INVESTIGATOR:**

Dr. Jeff Holmes, MSc(OT), PhD [REDACTED]

**CO-INVESTIGATORS:**

Dr. Andrew M. Johnson, PhD  
 Dr. Debbie Rudman, MSc(OT), PhD  
 Dr. Mary Jenkins, MD, FRCPC  
 Dr. Kori A. LaDonna, PhD  
 Emily Field [REDACTED]

**STUDENT INVESTIGATOR:**

Ms. Sara Lutz, BSc [REDACTED]

You are invited to participate in a study that will use visual images (photographs) to explore the experiences of individuals living with Parkinson's disease. In this study we will ask you to take photographs that represent things that affect your day-to-day experience with Parkinson's disease. We are interested in both "good" and "bad" things within your everyday life—and we are interested in hearing about your interpretation of how these people, places, and things affect your experience with Parkinson's disease.

Although you may certainly use your own camera, we will provide you with one for use within this study, and we will show you how to use it. At the end of the study, we will review your photos with you individually, and with a group of other individuals living with Parkinson's disease, and we will attempt to identify common themes within all of the photos taken by participants in this research.

We plan to speak with a total of 40 individuals with Parkinson's disease. In order to be eligible for participation, you must be fluent in English, you must be capable of taking photographs with a simple digital camera, and you must be capable of discussing the photographs that you take in both an individual and group situation.

We will ask you to participate in three study visits: (1) to receive an orientation to the cameras that will be used in this study, and to review this letter of information and provide written consent to participate; (2) to speak with the investigators about the photos that you have taken, and to discuss your thought process in choosing to take these photos; and (3) to speak with a small group of other individuals that have participated in this study, and discuss the issues raised within this study. Visits 1 and 2 may take place at Elborn College or at a location that is convenient for you; Visit 3 will take place at Elborn College.

In between the first and second visit, we will ask you to take photos that are relevant to your experience of living with Parkinson's disease. For example, as a "good" or "positive" thing, you may take a picture of your car because it allows you to remain independent. Alternatively, as a "bad" or "negative" thing, you may take a picture of a steep set of stairs that you find difficult to

\_\_\_\_\_  
 Initials

climb. We would like to audio record both the individual interview (during visit #2) and the interactions during discussion group (visit #3). Visit #1 is expected to take approximately 30 to 45 minutes, and visits #2 and #3 are expected to take 60 to 90 minutes. We will also ask you to keep a diary during your study participation. We will ask you to record your ideas about study participation, what you took pictures of and why, and any other information you want to share about your experiences living with Parkinson's disease. You may keep a written diary, or you may verbally record your diary. [REDACTED] email that only Dr. Holmes and the study team will access. You may call [REDACTED] to record your diary entries. The diary portion of the study is optional.

You may invite a family member or friend (a "caregiver") to assist you with taking pictures and/or to join you during your individual interview. This is optional, but if a family member or friend chooses to participate, we will ask him/her to provide written consent.

Although you will not experience any direct benefits from participating in this research, it is our hope that this study will help us understand the aspects of the disease that are most challenging to you, so that we can develop treatments that address the specific needs of individuals with Parkinson's disease. We also hope to identify coping mechanisms that are used by individuals with Parkinson's disease, and share these with other individuals with the disease that may benefit from these strategies.

You are going to be asked to take pictures of "bad" or "negative" aspects of living with Parkinson's disease; as a result, there is some risk in this study that you may become upset or sad. If you begin to feel upset or sad you are encouraged to contact your physician to discuss these emotions. In addition, at the beginning of this study you will be provided with a list of resources that you may contact to speak to someone about how you are feeling.

You may also experience some discomfort in this study, as you will be asked to discuss your photos in a small group setting with other individuals with Parkinson's disease. As a result, other study participants will be aware of your participation in this study. To minimize this discomfort, groups will be small in size ranging from 5-10 individuals per group, and issues regarding confidentiality will be discussed with all participants at the start and end of the focus group session.

Your participation in this research project is voluntary. You may refuse to participate, refuse to answer any questions, and you may withdraw your participation at any time with no effect on your future participation in university-sponsored activities, on your academic status (if applicable), or your future medical care. If you withdraw your participation in the study before the conclusion of data collection, your data will be destroyed. In order to assure complete confidentiality, no identifying information will be attached to the data collected in this study. The only record of your name that will be retained will be on the attached consent form, and this information will be stored in a locked file cabinet, within a locked room, that is (in turn) inside the Interdisciplinary Movement Disorders Laboratory (which remains locked at all times). If the results of this study are published, your name will not be used, and no information that discloses your identity will be released or published without your explicit consent to the disclosure. Electronic data collected during the course of this study will be kept indefinitely.

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As a token of our appreciation for the time you spend completing this study, we will provide you with a \$25 gift certificate for each study visit you complete. We will provide you with a parking voucher for any visits you attend at Elborn College. If you take public transit, we will reimburse you the value of a round-trip bus ticket.

If you have any questions about this research project, please contact the principal investigator, Dr. Jeffrey Holmes at (510) 661-2111, ext. 28867, or by email [REDACTED]. If you have any questions about your rights as a research participant, or the conduct of this study, you may contact the Office of Research Ethics, [REDACTED], or Dr. David Hill, Scientific Director, Lawson Health Research Institute [REDACTED]. You are not waiving any legal rights by signing the attached consent form. This letter is yours to keep.

            
Initials

**Snapshots of the experience of living with Parkinson's disease**

Please sign this form to indicate that you agree with the following statement:

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

Participant (Printed Name): \_\_\_\_\_

Participant (Signature): \_\_\_\_\_

Person Obtaining Informed Consent (Printed Name): \_\_\_\_\_

Person Obtaining Informed Consent (Signature): \_\_\_\_\_

Date: \_\_\_\_\_

I consent to having my name added to a list of potential participants in future research. I understand that I may withdraw this consent at any time, by contacting the principal investigator (Dr. Holmes). *Note: this consent has no impact on your ability to participate in the present research.*

Participant (Printed Name): \_\_\_\_\_

Participant (Signature): \_\_\_\_\_

<b>I give permission to use my photographs for:</b>	<b>YES</b>	<b>NO</b>
Educational purposes		
Research purposes		
Posters/publications/presentations		

\_\_\_\_\_  
Initials

**Snapshots of the experience of living with Parkinson's disease**

Please sign this form to indicate that you agree with the following statement:

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

Caregiver (Printed Name): \_\_\_\_\_

Caregiver (Signature): \_\_\_\_\_

Person Obtaining Informed Consent (Printed Name): \_\_\_\_\_

Person Obtaining Informed Consent (Signature): \_\_\_\_\_

Date: \_\_\_\_\_

\_\_\_\_\_  
Initials

## Curriculum Vitae

**Name:** Sara G. Lutz

**Post-secondary Education and Degrees:** St. Francis Xavier University  
Antigonish, Nova Scotia, Canada  
2008-2012, B.A. Honours Psychology

The University of Western Ontario  
London, Ontario, Canada  
2014-2016, MSc. Occupational Therapy

The University of Western Ontario  
London, Ontario, Canada  
2016-2017, MSc. Rehabilitation Sciences

**Honours and Awards:** Canadian Occupational Therapy Foundation (COTF) Scholarship  
2013

Ontario Society of Occupational Therapists (OSOT) Graduating Student Award  
2016

**Related Work Experience** Teaching Assistant  
The University of Western Ontario  
2012-2014, 2016

Occupational Therapist  
Woodstock General Hospital  
2016-Present

### Publications:

1. Lutz, S. G., Holmes, J. D., Laliberte Rudman, D., Johnson, A. M., LaDonna, K. A., & Jenkins, M. E. (2017). Understanding Parkinson's through visual narratives: "I'm not Mrs. Parkinson's". *British Journal of Occupational Therapy*. doi:10.1177/0308022617734789
2. Lutz, S., Holmes, J. D., Jenkins, M. J., Ready, E., & Johnson, A. J. (2016). Clinical presentation of anxiety in Parkinson's disease: A scoping review. *OTJR: Occupation, Participation and Health*, 36(3), 134-147. doi:10.1177/153944921666174

3. Kogutek, D. L., Holmes, J. D., Grahn, J. A., Lutz, S. G., & Ready, E. (2016). Active music therapy and physical improvements from rehabilitation for neurological conditions. *Advances in Mind-Body Medicine*, 30(4).
4. Holmes, J. D., Brigham, L. K., Jenkins, M. E., Ready, E. A., Lutz, S. G., Johnson, A. M., & Grahn, J. A. (2015). The effects of manipulating spatial location of visual cue placement on gait among individuals with Parkinson's disease: A pilot study. *Physical and Occupational Therapy in Geriatrics*, 33, 263-278. doi:10.3109/02703181.2015.1045109
5. Holmes, J. D., Lutz, S., Ravenek, M., Rudman, D. L., & Johnson, A. M. (2013). Enhancing client-centeredness in Parkinson's disease care: Attending to the psychosocial implications of lived experience. *The Open Journal of Occupational Therapy*, 1(4), Article 7. doi:10.15453/2168-6408.1064
6. Lutz, S. G. (2013). Barriers to the diagnosis of affective disorders in Parkinson's disease. *Health Science Inquiry*, 4(1), 76-77.