Self-Management as a means to Achieving Client-Centred Care for the Care Partnership Living with Parkinson’s disease

Danielle M. Hudson
The University of Western Ontario

Supervisor
Connelly, Denise M.
The University of Western Ontario

Graduate Program in Health and Rehabilitation Sciences

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Self-Management as a means to Achieving Client-Centred Care for the Care Partnership Living with Parkinson’s disease

Abstract

Parkinson’s disease (PD) is a chronic condition that manifests through many changing symptoms over time. A person diagnosed with PD is typically supported by a spouse or other family member as their primary care partner, who experiences a host of biopsychosocial challenges associated with their care partner role. The best approach to supporting a care partnership, consisting of the person diagnosed with PD and the primary care partner, through their individualized journey with PD remains to be defined. The aim of this research was to identify clinical insights for providing client-centred care for both members of the PD care partnership. This was achieved through two constructivist theory studies, the first of which sought to elucidate how care partnerships learned to care for themselves while living with PD from their perspective, and the second to learn how clinicians from various health disciplines deliver their care to care partnerships living with PD. Findings from both studies were considered to highlight opportunities for optimizing the delivery of clinical care.

This research program has given rise to four main insights, grounded in the perspectives of both care partnerships and the clinicians who provide their care. First, is the importance of incorporating the care partner into clinical care discussions, both about how to support the person diagnosed with PD, and for their own health. Second, is to consider self-management education as a means of achieving client-centered care by supporting the care partnership to effect the cognitive, emotional and behavioural responses required to manage
the many dimensions of PD. Third, is the importance of supporting the care partnership to assemble a healthcare team of relevant professionals and connecting them with appropriate community resources. Finally, identifying and managing expectations through empathetic, effective communication is paramount to the care partnership’s satisfaction with their clinical care.

Understanding how care partnerships learned to care for themselves while living with PD carries important implications for clinical practice in various disciplines. Healthcare professionals may reflexively contemplate these insights and consider how they may be applied in their clinical settings.

Keywords

Parkinson’s disease, care partner, care partnership, caregiver, self-management, clinical care, client-centred, grounded theory

Author Information
Danielle Hudson, MPT, PhD Candidate
The University of Western Ontario

Supervisor
Dr. Denise Connelly, PT, PhD
The University of Western Ontario
Lay Summary

People living with PD and their care partners must learn to manage their symptoms as they emerge over the course of disease. Self-management refers to these daily activities and skills used to minimize the impact of PD on their well-being. Health professionals help teach these skills for managing symptoms in partnership with the person diagnosed. However, there is no research from the perspective of the people learning the skills or about including the spouse in self-management practices. This research may help us learn about how couples living with PD learn the skills required to manage their symptoms, with the help of healthcare professionals, in clinical settings. It may also highlight the important role of the spousal care partner in managing PD. The perspective of people living with PD will be compared to that of the healthcare professional to help understand any gaps that may exist in needs and expectations related to self-management care in clinical settings. This information is intended to help inform clinical practice related to self-management, meaning how health professionals teach people living with PD how to take care of themselves and skills to manage PD and their symptoms.
Co-Authorship Statement

This dissertation was constructed and written with the support, guidance, and supervision of Dr. Denise Connelly. Dr. Connelly will be a co-author on publications arising out of chapters four and five. Her attention to detail and insightful interpretation were integral in developing thoughtful, coherent renderings of the two studies presented herein. I am exceptionally grateful for her patience, experience, and encouragement throughout this process. In addition, each member of my Thesis Advisory Committee provided important feedback and mentorship throughout the development of this research.
Acknowledgments

I extend my sincerest appreciation and gratitude to my doctoral supervisor, Dr. Denise Connelly, for her steadfast support and encouragement throughout this graduate program. Her unwavering commitment to this research and belief in its meaningful contributions provided the motivation and inspiration I needed to see this project through. I am forever grateful for the opportunity to have worked with Dr. Connelly and to have developed my own research orientation under her gracious direction and through our shared interests and objectives.

I am deeply appreciative for the support and encouragement from members of my advisory committee: Dr. Andrew Johnson, Dr. Marie Savundranayagam, and Dr. Jay Shaw. Early meetings with this group of exceptional scholars helped shape my research questions and methods, and strongly influenced the direction of my doctoral research program. Feedback and conversation with Dr. Shaw helped me to better understand, describe and challenge my own paradigmatic position and its influence on my research contributions. The success of this dissertation would not have been possible without their patient and tactful guidance.

I am wholly indebted to the research participants of both studies who so willingly shared their stories of triumph, defeat and perseverance with respect to living with and caring for those with Parkinson’s disease. Their stories allowed me a glimpse into their realities of living with and caring for those with PD, and their unbridled candour was truly inspiring. I sincerely hope my representation of their stories throughout this dissertation adequately captured their experiences and may contribute in some positive capacity to their ongoing journeys with PD.
I am also thankful to my peers and colleagues of the Master of Physiotherapy and Health and Rehabilitation Sciences graduate programs, who endured the rigorous demands of both programs alongside me. Jess and Laura, without our regular pep talks (and some occasional studying mixed in) I’m sure I would not have survived the MPT program and this dissertation would never be finished – thank you for always cheering me on.

Finally, this dissertation unequivocally would not have been possible without the unflinching love, support and reassurance from my incredible husband. This road we have travelled together to my doctoral degree has been winding, tumultuous and, at times, even felt insurmountable. Thank you for never doubting my ability to succeed and for every word of encouragement, meal cooked, extra chore, and lifestyle consequence you quietly and selflessly accepted to ensure we made it here. Zach, you are the reason this was possible, and this dissertation is dedicated to you.
# Table of Contents

Abstract .......................................................................................................................... i

Lay Summary .................................................................................................................. iii

Co-Authorship Statement .............................................................................................. iv

Acknowledgments .......................................................................................................... v

Table of Contents .......................................................................................................... vii

List of Tables ................................................................................................................... xi

List of Figures ................................................................................................................ xii

List of Appendices ......................................................................................................... xiii

1 Introduction ................................................................................................................ 1

1.1 Background and Significance ................................................................................. 4

1.2 Statement of Thesis Purpose ............................................................................... 8

1.3 Overview of Chapters ............................................................................................ 9

1.4 References .............................................................................................................. 11

2 Literature Review ...................................................................................................... 16

2.1 Search Strategies & Definitions ............................................................................. 17

2.2 Review of the literature about people living with Parkinson’s disease learning to care for themselves ................................................................. 20

2.2.1 Studies focusing on Living with Parkinson’s disease ....................................... 22

2.2.2 Studies Focusing on the Care Partner Experience ........................................... 23

2.2.3 Studies about Self-Management & Parkinson’s disease ................................. 26

2.3 Review of the Literature about Healthcare Providers Caring for People Living with Parkinson’s disease .......................................................... 28

2.3.1 Studies focusing on client-centred care in Parkinson’s disease ..................... 30

2.3.2 Studies about client preferences for involvement in their care ..................... 32
2.3.3 Studies investigating how to improve care delivery for people living with Parkinson’s disease ................................................................. 34

2.4 Discussion and Limitations of Available Literature............................................. 36

2.5 Summary........................................................................................................ 38

2.6 References...................................................................................................... 41

3 Methodology .................................................................................................... 48

3.1 Paradigmatic Position..................................................................................... 49

3.2 Methodology for Studies One & Two ............................................................... 53

3.3 Ethical Approval............................................................................................ 58

3.4 Research Methods .......................................................................................... 59

3.4.1 Participant Sample & Setting: Study One .................................................... 59

3.4.2 Participant Sample & Setting: Study Two ................................................... 61

3.4.3 Data Collection: Studies One & Two ......................................................... 62

3.4.4 Analysis of the Findings: Studies One & Two ............................................ 65

3.5 Methodological Rigour.................................................................................... 68

3.6 Statement of Reflexivity.................................................................................. 71

3.7 Conclusion ...................................................................................................... 76

3.8 References .................................................................................................... 77

4 The Process of Learning Self-Management Skills by Care Partnerships while Living with Parkinson’s disease ........................................................................ 81

4.1 Methodology .................................................................................................. 83

4.2 Methods .......................................................................................................... 84

4.2.1 Participant Sampling................................................................................... 84

4.2.2 Data Collection............................................................................................ 85

4.2.3 Data Analysis............................................................................................... 86

4.3 Findings ......................................................................................................... 88

4.3.1 Participants................................................................................................. 88
<table>
<thead>
<tr>
<th>Section</th>
<th>Title</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>4.3.2</td>
<td>Learning to Live with Parkinson’s Disease</td>
<td>89</td>
</tr>
<tr>
<td>4.3.3</td>
<td>Navigating the System</td>
<td>90</td>
</tr>
<tr>
<td>4.3.4</td>
<td>Bridge into the Parkinson’s World</td>
<td>97</td>
</tr>
<tr>
<td>4.3.5</td>
<td>Inside the Parkinson’s World</td>
<td>98</td>
</tr>
<tr>
<td>4.4</td>
<td>Discussion</td>
<td>117</td>
</tr>
<tr>
<td>4.4.1</td>
<td>Navigating the System throughout the Diagnosis</td>
<td>118</td>
</tr>
<tr>
<td>4.4.2</td>
<td>A Bridge into the Parkinson’s World: Accepting the Diagnosis</td>
<td>121</td>
</tr>
<tr>
<td>4.4.3</td>
<td>Adapting to Life in the Parkinson’s World</td>
<td>122</td>
</tr>
<tr>
<td>4.4.4</td>
<td>Factors that Facilitate or provide Resistance to the Theoretical Process</td>
<td>127</td>
</tr>
<tr>
<td>4.5</td>
<td>Conclusion</td>
<td>128</td>
</tr>
<tr>
<td>4.6</td>
<td>References</td>
<td>130</td>
</tr>
<tr>
<td>5</td>
<td>Healthcare Professionals’ Process of Caring for the Care Partnership living with Parkinson’s disease</td>
<td>143</td>
</tr>
<tr>
<td>5.1</td>
<td>Methodology</td>
<td>144</td>
</tr>
<tr>
<td>5.2</td>
<td>Methods</td>
<td>145</td>
</tr>
<tr>
<td>5.2.1</td>
<td>Participant Sampling</td>
<td>146</td>
</tr>
<tr>
<td>5.2.2</td>
<td>Data Collection</td>
<td>146</td>
</tr>
<tr>
<td>5.2.3</td>
<td>Data Analysis</td>
<td>147</td>
</tr>
<tr>
<td>5.3</td>
<td>Findings</td>
<td>148</td>
</tr>
<tr>
<td>5.3.1</td>
<td>Participants</td>
<td>148</td>
</tr>
<tr>
<td>5.3.2</td>
<td>The Process of Delivering Care to People Living with Parkinson’s disease</td>
<td>149</td>
</tr>
<tr>
<td>5.3.3</td>
<td>The Healthcare Provider’s Scope and Clinical Plan</td>
<td>151</td>
</tr>
<tr>
<td>5.3.4</td>
<td>Boundaries within which the Care Package was Built</td>
<td>153</td>
</tr>
<tr>
<td>5.3.5</td>
<td>Delivering the Care Package through Communication with the Care Partnership</td>
<td>163</td>
</tr>
<tr>
<td>5.3.6</td>
<td>The Care Package as a Bridge between Appointments</td>
<td>165</td>
</tr>
</tbody>
</table>
List of Tables

Table 1. Characteristics of care partnerships living with PD ............................................. 88

Table 2. Characteristics of healthcare providers ........................................................................ 149
List of Figures

Figure 1. The process of care partnerships learning to care for themselves while living with Parkinson's disease
................................................................................................................................. 91

Figure 2. Sustaining the care partnership between clinical visits.............................................. 150
List of Appendices

Appendix A: Ethics Approval Notice for Study One .......................................................... 231
Appendix B: Ethics Approval Notice for Study Two ......................................................... 232
Appendix C: Letter of Information and Consent for Study One ....................................... 233
Appendix D: Letter of Information and Consent for Study Two ....................................... 238
Appendix E: Interview Guide & Script for Study One ..................................................... 244
Appendix F: Interview Guide & Script for Study Two ..................................................... 247
Appendix G: Sample Reflexive Memo .......................................................................... 249
Appendix H: Preliminary Renderings of the Process for Study One ............................... 250
Appendix I: Preliminary Renderings of the Process for Study Two ............................... 252
1 Introduction

Parkinson’s disease (PD) is a progressive neurological condition that results in impaired mobility, communication, cognition and emotional well-being, and therefore impacts many areas of health and participation in daily activities (Wong, Gilmour, & Ramage-Morin, 2014). In Canada, an estimated 55,000 community-dwelling adults and another 12,500 adults in long-term care facilities have been diagnosed with PD (Wong, et al., 2014), making it the second most common neurodegenerative disorder after Alzheimer's disease (Hirtz, et al., 2007). People diagnosed with PD often rely on the partnership of a person close to them, such as a spouse, to manage their variable and progressive loss of independence over the course of their disease. This ‘care partner’ role is critical to the well-being of a person diagnosed with PD, as the care partner often provides a myriad of informal care services in the home setting (Mosley, Moodie, & Dissanayaka, 2017). More specifically, 84% of Canadians diagnosed with PD rely on informal care, at least in part; 64% of whom rely on care provided specifically by a spouse (Wong, et al., 2014). As such, the care partner is an active participant in the PD process who experiences the impact of this chronic disease and has valuable insight into the reality of daily life at home.

The Canadian guidelines on PD recommend “encouragement of self-management by people with Parkinson’s to meet individual needs and preferences” (Grimes, et al., 2012, pp. S5). Self-management involves having the knowledge, skills and confidence to manage daily tasks and live well with a chronic condition, including monitoring disease progress, goal setting, and problem-solving (Lorig & Holman, 2003). Self-management is
a critical element to effective chronic condition management that can contribute to slowed disease progression, reduced complications, and lowered costs (Ory, et al., 2014). It has been reported in multiple studies that self-management interventions specific for people living with PD can provide psychosocial, physical and emotional benefits (Montgomery, et al., 1994; Nelson, Wong & Lai, 2011; Simons, et al., 2006; and Tickle-Degnen, et al., 2010, for example), however, others have shown no significant differences in any measures (Gruber, Goldstein Elman & Huijbrets, 2008; and Lindskov, Westergren & Hagell, 2007, for example). From a reflection of the current literature, it remains unclear which components of self-management interventions are most effective and how to best measure them remain unclear (see Kessler & Liddy, 2017 for an integrative review).

People living with PD may be followed by a number of healthcare providers from different disciplines to support their care. PD management most commonly consists of pharmacological therapy, and may include surgical intervention (i.e., deep brain stimulation) (Grimes, et al., 2012), however, evidence is mounting for other treatment options including physical and exercise therapies, occupational therapy, and speech and language therapy (see Bloem, de Vries & Ebersbach, 2015 for a review). Healthcare providers from any discipline are valuable resources for learning self-management skills and can help impart skills in their clients via education and supportive interventions to increase self-efficacy in managing their PD-related health problems (Adams & Corrigan, 2003). In order to provide client-centred care, healthcare providers must consider the variability in client preferences with respect to care expectations and goals, within the context of their particular support network and manifestation of PD symptoms, and
deliver care in a way that will satisfy and empower clients, yet also meet the regulations of their biomedical profession (Entwistle, et al., 2018). Furthermore, the needs of the care partner must also be valued and addressed, as they may share similar experiences and concerns as the person diagnosed with PD, as well as their own unique set of challenges (Padovani, et al., 2018). Considering this, healthcare professionals caring for people living with PD are tasked with assessing and providing care within a multidimensional, highly complex clinical environment that may also impose its own set of barriers, such as human resource, time, and budgetary constraints.

Given the reality of various care settings, healthcare professionals must carefully consider their clinical plan and which topics they may choose to address within care appointments. As alluded to above, there remains much ambiguity pertaining to self-management education for people living with PD and their care partners, which leaves healthcare professionals with little direction when choosing to include self-management intervention in their clinical care, or when developing self-management programs for people living with PD on a larger-scale. It has been suggested that more studies be undertaken to explore components and strategies of self-management interventions (Kessler & Liddy, 2017). In reviewing available published literature, previous studies employing qualitative methodology to explore the acquisition of self-management skills by people living with PD and their care partners, as well as how healthcare providers may facilitate this process, were not found.

In the context of this dissertation, ‘self-management’ was defined as follows:
Self-management refers to the individual’s ability to manage the symptoms, treatment, physical and psychosocial consequences and life style changes inherent in living with a chronic condition. Efficacious self-management encompasses ability to monitor one’s condition and to effect the cognitive, behavioural and emotional responses necessary to maintain a satisfactory quality of life (Barlow, et al., 2002, pp. 178).

In the first study, I sought to recruit ‘care partnerships’ living with PD, defined as a spousal couple where one person has been diagnosed with PD and the other was the primary care partner. In the second study, healthcare professionals from various disciplines were recruited who cared for at least six people living with PD per year. Initial conversation for all interviews included a review of the operational definition for self-management implemented in these studies.

This dissertation proposes self-management as a means for achieving client-centred care by exploring the process through which care partnerships learn self-management skills while living with PD, and interpreting the process of creating and delivering care by healthcare professionals from various disciplines. In so doing, I hope to offer an interpretive understanding and provide insight into the experiences of care partnerships living with PD and to enhance reflective, meaningful, and careful practice.

1.1 Background and Significance

Despite widely positive subjective reports from participants, self-management interventions for people living with chronic conditions have been demonstrated to improve disease-related symptoms with variable effects. These tepid findings may be attributable to the difficulty of isolating and measuring appropriate outcomes for
multidimensional and complex conditions (Nolte & Osborne, 2014). There is evidence to suggest that self-management interventions are beneficial specifically for people living with PD with respect to perceived benefits by participants, such as improved knowledge and strategies for living with PD, psychosocial support, and quality of life (Montgomery, et al., 1994; Mulligan, et al., 2011; and Tickle-Degnen, et al., 2010), despite a lack of consensus regarding identification and measurement of clinically measurable outcomes (see Kessler & Liddy, 2017 for an integrative review). Although care partners are recognized to play a vital role in providing informal care to their loved one, it is surprising that self-management interventions remain largely designed for the person diagnosed with PD and seem to include the care partner only as a welcomed visitor as opposed to an intentional component of the intervention (Martinez-Martin, et al., 2007). Nonetheless, there remains sufficient evidence to warrant further exploration of the benefit of self-management interventions for care partnerships living with PD – both for the person diagnosed with PD and the care partner. A discussion of how care partnerships have acquired self-management skills through meaningful experiences, from their perspective, may offer valuable insight into the self-management literature and has not been previously presented.

Previous qualitative studies have sought to understand the impact of PD through investigations of the experience of living with the condition from the perspectives of people diagnosed with PD as well as their care partners. In an investigation of how people living with PD define living ‘successfully’, successful living was perceived to have taken place when people were either: 1) able to return to their usual state of health; or 2) considered themselves to be stable within a new or readjusted state of health, such
that symptoms were not perceived to be worsening or there was an established level of comfort and competence with the new state of health (Kang & Ellis-Hill, 2015). Others have described how people living with PD communicate with their care partner about accepting their condition and their daily care needs, revealing that daily interactions with care partners were fundamentally different, requiring them to ‘manage change’ as part of daily life (Roger & Medved, 2010). Previous investigations about living with PD have identified areas of importance to the care partnership that may be amenable to self-management interventions (Hellqvist, et al., 2018; Chenoweth, et al., 2008; and Nelson, Wong & Lai, 2011). Nonetheless, an investigation of the experiences and meanings that constitute the process of learning self-management skills from the perspective of both members of the care partnership has not been previously pursued, and may be helpful in further identifying essential components of self-management education as well as more tangible clinical targets.

Owing to the multisystem and multidimensional effects of PD symptomatology, healthcare professionals from different disciplines can specialize in caring for people living with PD and address specific aspects of the condition, including neurologists, nurses, physiotherapists, occupational therapists, pharmacists, psychologists, nutritionists and others. While pharmacological intervention remains a cornerstone of traditional PD management, national guidelines and new evidence continue to emerge supporting ‘alternative’ therapies to meet clients’ care goals through a client-centred care plan in conjunction with appropriate pharmacology (Grimes, et al., 2012; Bloem, de Vries, & Ebersbach, 2015). Previous research has investigated approaches to clinical care interventions designed to improve clients’ knowledge and skills through education and
strategic communication for various chronic diseases (Coster & Norman, 2009). Although the authors concluded some benefits for clients living with chronic disease, the majority of reviews were deemed to have inadequate evidence, and therefore no particular components could be identified as active ingredients for success (Coster & Norman, 2009). The findings echo the general sentiment in the literature that client education is critical to delivering client-centred care for chronic disease management, however the specific components required for that care to be effective remain to be defined (Coster & Norman, 2009; Davies, et al., 2018; Mudge, et al., 2015). It is therefore reasonable to expect clinicians from various disciplines will endeavour to provide client-centred care through self-management education for the care partnership living with PD, however, specific investigations into such clinical decisions and processes remain to be presented. In order to improve client-centred care for the care partnership living with PD, it is important to understand the process of how clinicians create and communicate self-management education when providing care for this client population.

Together, previous findings suggest a positive role for self-management interventions for people living with PD and, additionally, that healthcare providers from various disciplines may endeavour to deliver client-centred care for the care partnership living with PD through self-management support. Furthermore, literature supports the notion that unique and novel insights may be gained by exploring the perspective of the care partnership with respect to how they have acquired self-management skills, and the perspective of healthcare providers with respect to how they approach self-management support with their clients.
Client-centred care for people living with PD is a best practice guideline that transcends disciplines (Grimes, et al., 2012) and, therefore, it is essential that healthcare professionals reflexively consider how they understand and integrate their clients’ perspectives into their practice. Understanding the meaningful experiences that inform the process of learning self-management skills from the perspective of the care partnership may offer important insights for clinicians and policy makers alike. Furthermore, insights generated from this research may enhance understandings of inherent values and assumptions underlying clinicians’ care decisions, which may encourage healthcare professionals to contemplate their actions while caring for people living with PD in their respective settings.

1.2 Statement of Thesis Purpose

While there is literature separately describing the experiences of people diagnosed with PD and their care partners, as well as a suggested benefit of self-management interventions, there have not been in-depth investigations into the process of the care partnership learning self-management skills while living with PD, nor into the process by which healthcare providers build and deliver their care package for this population. In exploring the experiences of care partnerships learning to live with PD, I strived to develop a theoretical process based in the meanings created by participants that would provide an understanding of how care partnerships had learned to care for themselves; the insights of such a process may inform more empathetic, tactful and meaningful clinical practice related to self-management. Secondly, in turning to healthcare professionals from various disciplines who care for people living with PD, I aimed to describe and
interpret a theoretical process undertaken by clinicians in their effort to include self-management education in their care for clients living with PD.

The two studies integrated in this research are positioned in the regional settings of mid- to large-sized cities across eastern and southwestern Ontario. The objectives of this dissertation were to understand the process by which care partnerships learn self-management skills while living with PD through meaningful experiences, and to enhance understandings of healthcare professionals inherent values and assumptions underlying the composition and delivery of their care for people living with PD. My intention was to highlight tacit but meaningful experiences of a specific population that inform an important learning process of acquiring self-management skills, which may ultimately assist clinicians to more tactfully shape their approach to client-centred care for the care partnership living with PD. Insights generated from this research may motivate healthcare providers and policy makers to reflexively consider their assumptions and decisions pertaining to care for people living with PD.

1.3 Overview of Chapters

This dissertation is presented in an integrated article format, as accepted by the School of Graduate and Postdoctoral Studies at the University of Western Ontario. Chapter Two presents a literature review of relevant research pertaining to the experiences of people living with PD, self-management and delivery of client-centred care by healthcare professionals. Chapter Three presents the methodology guiding this research, including a discussion about my paradigmatic position, the research methods employed in the two studies, and statements on methodological rigour and reflexivity.
Chapter Four presents the manuscript for the first study, a constructivist grounded theory investigation of the process by which care partnerships learn self-management skills while living with PD. Chapter Five presents the manuscript of the second study, also a constructivist grounded theory study that explores the process of caring for people living with PD in various healthcare disciplines. Chapter Six offers a discussion of the key insights from both studies, and presents a number of implications from this research for future application toward empathetic, tactful and meaningful client-centred care for care partnerships living with PD.
1.4 References


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2 Literature Review

Classic grounded theory advocates delaying the literature review “to avoid seeing the world through the lens of extant ideas” (Charmaz, 2006, pp. 6; Glaser & Strauss, 1967). Charmaz’s approach (2006) recognizes that existing literature will be consulted in the early phases of research, but suggests to then delay a formal review until after the analysis stage is complete. In keeping with this logic, existing research was reviewed to complete early research activities prior to commencing any data collection – such as developing my research questions, submitting my prospectus, and completing ethics applications – and I had subsequently “let this material lie fallow” until after the theoretical processes had been developed (Charmaz, 2006, pp. 166). As such, this consultation with the literature throughout my scholarly activities has served to inform my presuppositions and assumptions about living with Parkinson’s disease (PD), and strategies for providing care. As discussed in more detail in the following Methodology chapter, the constructivist epistemological position I embrace suggests that we cannot remove ourselves as the researcher from our presuppositions, rather, we must aim to identify them and recognize how they may influence our interpretations of participants’ responses (Charmaz, 1990).

Herbert Blumer (1969) described the sensitizing concept to explain that researchers have preexisting interests in the subjects of their research and, consequently, have tentative ideas to pursue (Charmaz, 2014). Blumer (1969), and subsequently Charmaz (2006), further underscored the importance of interpretation in meaning-making and theory-generating, which inevitably involves incorporation of my view (i.e.,
assumptions and biases) as the researcher, such that the resulting theory “does not and cannot stand outside of it” (Charmaz, 2006, pp. 130). Rather than presenting insincere claims of bracketing my pre-existing knowledge and reducing its impact on the studies presented herein, I must include and investigate my presuppositions relating to care partnerships living with PD and the healthcare professionals who care for them which inevitably impacted my approach to the research (Charmaz, 1990). As a professional physiotherapist and a graduate student in Health and Rehabilitation Sciences, I acknowledge that I have repeatedly encountered research literature relating to my area of study. I believe a formal review of available literature further enhances my reflexivity and theoretical sensitivity, allowing me to become more aware of how pre-existing knowledge influences my interpretation, which ultimately enriches contextualization and credibility of my research (Charmaz, 2006; Lincoln & Guba, 2003).

2.1 Search Strategies & Definitions

In this literature search, six databases were reviewed: PubMed®, CINAHL®, Medline®, PsycINFO®, Sociological Abstracts® and Scopus®. Both quantitative and qualitative studies were included for consideration in this review. The review was restricted to articles published in English. No date limitations were set and the search was conducted in April 2019. Search terms were combined into four common construct categories. Within these searches, individual terms were combined using the “OR” function prior to being combined with the other three construct categories using the “AND” function. The search strategy for each database included all subject applicable headings and keywords. The first category included the following search terms: Parkinson’s disease, chronic disease, and chronic illness. The second category included
the following search terms: caregiver, spouse, family, and partner. The third search included: self-management and self-care. The final category focused on the process experiences and meanings of people learning how to care for themselves while living with PD, and included the following terms: learn, experience, process, grounded theory, and self-efficacy. This initial search led to 1221 articles. The first category was then specified to Parkinson’s disease only and re-applied across databases, which led to 59 articles. Unrelated studies were initially screened out by title, and then by abstract for less apparent cases. Articles were excluded if they focused specifically on one condition that was not PD. No articles were found specifically investigating the process of care partnerships learning self-management skills while living with PD. After applying exclusion criteria and removing unrelated articles, 9 articles were included in the first review.

A similar process was implemented to find relevant literature pertaining to the process of healthcare professionals providing care to people living with PD. The same search term was applied relating to the construct of ‘Parkinson’s disease’ as described in the former search; however, constructs relating to the process of providing care were also applied. A second category was applied that included the following terms: healthcare professional, clinician, healthcare, provider, care, practice and treatment; and the third category contained the terms: process, theory, grounded theory, and development. A fourth category was added that included ‘patient-centred’ and ‘client-centred’. Filters applied for the second search were for English-language and Human subjects. This search yielded 106 results. Unrelated studies were initially screened out by title, and then further by abstract for less apparent articles. Articles were deemed ‘unrelated’ if they reported no
relation to healthcare providers or provision of care or if they were conceptually describing care models without any data collected. No articles were found specifically investigating the process of healthcare providers providing care to people living with PD. After applying exclusion criteria and removing unrelated articles, 7 articles were included in this review.

For the purposes of this research, a diagnosis of ‘Parkinson’s disease’ was considered to a diagnosis when confirmed by a neurologist. For the purpose of this review, the terms ‘chronic illness’ and ‘chronic disease’ were interchangeable and defined as a condition that is lifelong in duration with a long latency period and protracted clinical course, of multi-factorial aetiology, with no definite cure, gradual changes over time, asynchronous evolution and heterogeneity in population susceptibility, as well as the personal experiences associated with living with the affliction that accompanies chronic disease (Martin, 2007). In this research, the ‘care partnership’ was defined as a spousal couple where one person has been diagnosed with PD and the other is the primary care partner. For the purposes of this review and research, ‘care’ was considered to be an assessment and intervention provided by a healthcare professional in a clinical capacity. ‘Self-management’ was described using the definition by Barlow and colleagues (2002) as:

The individual’s ability to manage the symptoms, treatment, physical and psychosocial consequences and life style changes inherent in living with a chronic condition,” which includes the ability to effect the cognitive, behavioural and emotional responses necessary to maintain a satisfactory quality of life (Barlow, et al., 2002, pp. 178).
2.2 Review of the literature about people living with Parkinson’s disease learning to care for themselves

The objective of the first review was to explore existing research relating to the processes and experiences of people living with PD and learning to care for themselves using self-management skills. No studies were discovered that specifically addressed spousal couples and the process undertaken to learn self-management skills, however, previously published literature has approached aspects relating to my research including: explorations of how people live with PD based on their definitions of living successfully and communication strategies within the care partnership; investigations into the experiences of care partners caring for a loved one diagnosed with PD and how they may be supported; and self-management interventions for people living with PD and their spouses. This overview of research investigating how care partners and people diagnosed with PD live with their condition and self-management considerations provides insights into how both care partners and people diagnosed with PD navigate daily life, redefine their self-identity, and some program interventions designed to support this transition. Furthermore, it highlights important insights which may be learned through explorations of human experiences, behaviours and processes. By sub-categorizing aspects of the process to contextualize the current research, this review also highlights the scarcity of available literature pertaining to first-hand accounts of the processes and subjective experiences involved when care partnerships learn to live with PD.

Approximately 0.2% of Canadian community-dwelling adults (approximately 55,000) are diagnosed with PD, of whom 84% rely at least in part on care partners for daily support in managing their condition (Wong, Gilmour & Ramage-Morin, 2014).
‘Care partners’ are spouses, family members or friends of a person diagnosed with a chronic condition that share the responsibility of providing care, along with healthcare professionals and the person diagnosed. Numerous studies have addressed the impact of being a care partner for a loved one living with PD, including experiencing high levels of depression, anxiety, social isolation, and increased vulnerability to health problems (see Benavides, Alburquerque, & Chana-Cuevas, 2013; and Martinez-Martin, et al., 2007 for reviews). While some programs have been developed to support the needs of care partners for people living with chronic illnesses in general (Savundranayagum & Britnall-Peterson, 2010; Savundranayagam, Montgomery, Kosloski, & Little, 2011, for examples), clinical targets specific to both members of the care partnership living with PD remain to be specified.

Current definitions of self-management refer to the tasks that an individual takes to live well with one or more chronic conditions (Barlow, 2002). In order to do this, the individual must gain the self-efficacy, or confidence, to manage their own medical condition, their roles and their emotions, a nod to the theoretical roots of self-management in the self-regulation and self-efficacy literature by Bandura (1982). Practically speaking, self-management means to empower the person with the necessary skills to cope with their illness (Holman & Lorig, 2004). Considering that 56% of people diagnosed with PD rely solely on care partners for daily support, self-management interventions may be a valuable endeavour to manage concerns related to living with PD, such as self-care, social interactions, and mental health, as well as mitigate out of pocket expenses for formal assistance services (Wong, Gilmour & Ramage-Morin, 2014). In acknowledging the prevalence of PD and the heavily involved role of care partners in
providing care, as well as the potential benefits of effective self-management interventions, it is important to develop an improved understanding of how care partnerships learn to live with PD.

2.2.1 Studies focusing on Living with Parkinson’s disease

Previous research has described what it means to live ‘successfully’ with PD, from the perspective of people living with PD, and to elucidate what contributed to that success (Kang & Ellis-Hill, 2015). Through thematic analysis of individual interviews, ‘successful living’ was perceived to have taken place when people were either: 1) able to return to their usual state of health; or 2) considered themselves to be stable within a new or readjusted state of health, such that symptoms were not perceived to be worsening or there was an established level of comfort and competence with the new state of health (Kang & Ellis-Hill, 2015). Aspects which were perceived to support positive psychosocial adjustment included a positive mindset, determination, acceptance of new challenges and family support. The authors proposed that the major concerns among people living with PD were maintaining ‘usual life’ as it was before PD and physical ability (Kang & Ellis-Hill, 2015). Clinically relevant implications from this study highlighted the importance of discussing perceived success in living with PD, and to work towards identifying what constitutes ‘usual life’ for the person living with PD. This knowledge may contribute to a realistic, client-centred care plan by considering changes in clients’ routines and health, and by discussing goals and practical options. These findings suggested possible clinical benefits of elucidating client perceptions of their ‘success’ with respect to living with PD, however, did not address the perceptions or factors pertinent to the care partner perspective.
Roger & Medved (2010) employed a grounded theory methodology to interview people diagnosed with PD alongside their primary support family members to explore the perceptions of communication between family supports and individuals living with PD. The authors suggested strategies implemented by people living with PD to address, communicate, and manage real changes associated with PD in partnership with their primary support person, typically a spouse (Roger & Medved, 2010). The authors described how people living with PD communicated with their care partner about accepting their condition and their daily care needs (Roger & Medved, 2010). This study revealed how living with PD fundamentally changed daily interactions with care partners and how they were used to communicating with each other, requiring them to ‘manage change’ as part of daily life. Further complicating the acquisition of care-related communication skills within a care partnership would be the cognitive changes and communication-related symptoms such as the ‘masked’ facial expression, lower voice volume, language comprehension and speech-related motor deficits inherent to living with PD. This study also reiterated the dyadic nature of PD such that care partnerships in the study spoke to the “construction of their daily lives through and with each other” (Roger & Medved, 2010, pp. 7).

2.2.2 Studies Focusing on the Care Partner Experience

A number of prior investigations have focused on the experience of care partners caring for a loved one diagnosed with PD. Padovani and colleagues (2018) sought to understand the experiences of family members caring for a person with PD using thematic analysis. This study revealed three thematic categories related to informal caregivers’ experiences of caring for a loved one with PD, including: 1) feelings of
depression, shame and fear regarding living with and thinking about PD; 2) changes in
daily routines for both the person diagnosed with PD and the care partner, where the
extent of changes were relative to the impact of physical and cognitive symptoms
manifested by the person diagnosed with PD; and 3) care partner strategies for self-care,
including physical activity, health examinations and spiritual care (Padovani, et al.,
2018). This study highlights the individualized experiences of care partners who are also
‘living with PD’ and how they may differ from those of their loved one diagnosed with
PD. These findings suggest some deliberate strategies implemented to maintain the health
of care partners, which may also be clinical targets for healthcare professionals. By
optimizing care specific to care partners, this may result in less physical and mental
symptoms experienced by the care partner, thereby maximizing their ability to continue
to provide informal care for their loved one – a critical component of care for people
living with PD.

Others have queried how spousal care partners of people diagnosed with PD care
for their social life through self-management (Berger, et al., 2019). The researchers
interviewed spousal care partners and employed a grounded theory analysis to describe
the social experiences of care partners and the interrelationship with their ability to care
for their spouse. Findings from this research described how participants sought to strike a
balance of a) their activities with respect to changes in roles and maintaining enjoyable
activities; b) supporting independence and embracing dependence such that the care
partner must tend to the needs of their spouse as well as their own; and c) emotions
related to the burden of being a care partner and compassion for their spouse (Berger et
al., 2019). Clinically relevant implications from this study highlight the importance of
acknowledging and including the care partner in interventions that will support them to meet their social needs, in addition to physical and emotional needs as discussed in previous literature (Hutchison, Doble & Warner, 2011; Won, et al., 2008; and Yesufu-Udechku, et al., 2015, for examples).

Hounsgaard, Pedersen and Wagner (2011) aimed to describe the lived experience of care partners through a phenomenological hermeneutic inquiry with ten women whose spouses had been diagnosed with PD. The researchers described an integral link between the progression of PD manifestation through motor, cognitive, as well as emotional symptoms, and the need for care decisions regarding daily activities and functions (Hounsgaard, et al., 2011). The participants described experiences of learning to live as a partner to a chronically ill patient, including taking responsibility for contacts with healthcare services as well as household chores, and changes in self-management practices for their own well-being, such as exercise and respite activities. The care partners highlighted the challenges associated with cognitive and personality changes with respect to the impact on their marriage, and how this magnified their sense of duty to provide care for their spouses, despite feelings of frustration, exhaustion and powerlessness (Hounsgaard, et al., 2011). Strikingly, this study described a universal finding of exhaustion, helplessness and increasing isolation amongst all participants, owing to the difficulty in managing activities outside of the home and an increasing inability to leave their partner alone (Hounsgaard, et al., 2011). These findings further contribute to the discussion of care partner burden and the need for healthcare professionals to inquire about and support care partners’ self-management efforts in order
to facilitate the care partnership living at home longer and effectively caring for themselves.

Hurt, CLEANTHOUS and Newman (2017) aimed to explore the meaning of illness uncertainty for spousal carers of people diagnosed with PD, where illness uncertainty was defined as “an inability to determine the meaning of illness-related events” (pp. 549). Through thematic analysis, the authors identified several domains of uncertainty including self-management, social functioning and impact, as well as the carer-role (Hurt et al., 2017). These findings described the multi-faceted experiences of care partners as they related to uncertainty in many areas, such as managing symptoms of PD, maintaining control over their prognosis, and continuing to participate in social and occupational activities (Hurt et al., 2017). This was another study describing the vast array of challenges inherent to being a care partner to a spouse living with PD, however, it may also indicate some opportunities for learning in order to optimize and adapt to life with PD.

2.2.3 Studies about Self-Management & Parkinson’s disease

While there is a large body of literature supporting self-management for chronic diseases in general (Coster & Norman, 2009, for example) and in PD (Kessler & Liddy, 2017), the specific components that are effective for people living with PD, and particularly their care partners, remain to be defined. Chenoweth and colleagues (2008) aimed to identify factors associated with improved self-management after an acute medical event. The authors asked 75 participants with PD to complete a questionnaire 1-week and 1-month after an acute medical event that explored topics such as self-rated health status, self-efficacy, and self-management. Interestingly, the authors found self-
efficacy to be the only independent predictor of improved self-management, which was directly mediated through sources of spousal and family support (Chenoweth, et al., 2008). This study emphasized the critical role of family support and informal caregivers as instrumental to optimizing self-management, however, due to the nature of the questionnaire methods, did not elicit rich descriptions from participants about other factors that may have contributed to their perceived level of success with self-management.

Nelson, Wong and Lai (2011) designed and preliminarily evaluated a self-management program specifically for veterans diagnosed with PD based on the Chronic Disease Self-Management Program of Stanford University (Lorig & Holman, 2003) which endeavoured to maximize self-efficacy through education. Despite a lack of significant changes in measures of quality of life, self-efficacy and health status (among others), the authors described important factors related to recruitment and ongoing participation in an educational self-management program, including peer support and guidance from the facilitator (Nelson et al., 2011). Participants’ subjective evaluations of the program were largely positive despite no measurable improvements, perhaps alluding to the difficulty in numerical measurement of changes related to living with PD and further described the social benefit attributable to peer support (Nelson, et al., 2011). While some spousal care partners were invited and did attend the educational program, there was no evaluation of their benefit to participating alongside their spouse diagnosed with PD.

Hellqvist and colleagues (2018) also developed a self-management educational program and endeavoured to identify the experiences most valuable for managing daily
life after participation in the program. The authors employed a focus-group methodology and thematic analysis to describe the experiences and meanings derived from participation in the educational program as: 1) sharing experiences and feeling support; 2) adjustment and acceptance of PD for managing daily life; and 3) promoting life satisfaction (Hellqvist, et al., 2018). The educational program focused on techniques to manage the psychological impact of PD for both the person diagnosed with PD and care partners such that a “common ground” of knowledge could be established and contribute to enhanced mutuality in the spousal relationship (Hellqvist, et al., 2018). This model for self-management education introduces the potential benefit of including both members of the care partnership in interventions designed to enhance their ability to manage daily activities while living with PD through increased social support. Importantly, the authors also encouraged clinicians to foster a care partnership between the person diagnosed with PD and their spousal care partner in order to include both people in shared decision making and to optimize better health and well-being for both individuals (Hellqvist, et al., 2018).

2.3 Review of the Literature about Healthcare Providers Caring for People Living with Parkinson’s disease

The objective of the second review was to explore existing research relating to the processes and experiences of healthcare providers caring for clients living with PD. No studies were discovered that specifically addressed this topic, however, previously published literature has investigated aspects relating to my research including explorations of non-traditional methods for delivery of care and approaches to facilitate client-centred care. This overview of research is provided to contextualize the current
research and highlights not only important insights about providing client-centred care, but points to the complexity of considerations impacting clinicians’ approaches to providing clinical care. This review also demonstrates the paucity of available literature pertaining to first-hand accounts of the processes and subjective experiences involved when clinicians provide self-management support to care partnerships living with PD.

A Cochrane review investigated approaches to clinical care interventions designed to improve clients’ knowledge and skills to manage various chronic diseases (Coster & Norman, 2009). Although the authors concluded that including education and strategic communication in clinical care have definite benefits for clients living with chronic disease, the majority of reviews were deemed to have inadequate evidence, and therefore no particular components could be identified as active ingredients for success (Coster & Norman, 2009). Most studies included investigated interventions for clients living with asthma, epilepsy and diabetes, and the review concluded that assisting clients to become more knowledgeable about their condition, and providing them with basic skills to manage their condition on a day-to-day basis can result in physical and psychological benefits, and perhaps reduce dependence on service use. The findings echo the general sentiment in the literature that client education is critical to delivering client-centred care for chronic disease management, however the specific components required for that care to be effective remain to be defined (Coster & Norman, 2009; Davies, et al., 2018; Mudge, et al., 2015). Furthermore, Canadian guidelines for providing clinical care to people diagnosed with PD include recommendations for client-centred care and inclusion of the care partner for self-management interventions through effective communication with healthcare professionals (Grimes, et al., 2012). Several studies have
suggested the importance of self-management education for people living with PD for improving motor symptoms, depression, quality of life and sources of social support (see Chandler, Robins, & Kinser, 2019; and Kessler & Liddy, 2017 for reviews). As such, it is reasonable to expect clinicians from various disciplines will endeavour to provide client-centred care through self-management education for the care partnership living with PD, and it is important to understand the process of how clinicians create and communicate their care for this client population.

2.3.1 Studies focusing on client-centred care in Parkinson’s disease

A recent review explored emerging approaches to improve the care of clients living with PD by drawing from the literature regarding, amongst other topics, client-centred care, client and care partner perspectives and priorities, gaps in knowledge among clients and care partners and the need for accurate information, individual variability in disease manifestations, new developments in health technologies and personalized medicine, lifestyle and work-related issues, and support groups (Lim, et al., 2017). This review was initiated in response to the ever-growing complexity of caring for people living with PD as a result of better understanding the vast array of motor, non-motor and social symptoms that may be involved for both members of the care partnership. The authors discussed how ‘client-centred’ care must be uniquely defined, nuanced, and individualized for each person living with PD based on their clinical manifestations of PD, their expectations for care and goals, and their desire to be included in care decisions (Lim, et al., 2017). ‘Client-centred’ care also included acknowledging the needs and concerns of the care partner, particularly if falls and cognitive symptoms were present,
both in regular clinic visits and with a healthcare professional separately form the person diagnosed with PD. The authors also emphasized the need for access to accurate and relevant information, delivered in a gradual, timely and strategic method tailored to clients’ needs and expectations, both by community programs as well as clinicians (Lim, et al., 2017). This review highlights the many important considerations for providing care to care partnerships living with PD, however, considering the practical reality of various healthcare settings, these findings also amplify the challenge of adequately addressing client needs. Further investigations into the recommendations proposed in this review are justified.

Entwistle and colleagues (2018) completed an interview study with 26 clinicians to identify tensions and barriers that exist to providing client-centered approaches to self-management support for clients living with PD or diabetes. Clinicians described care experiences they perceived to be successful and less successful, followed by discussions of how they defined successful care compared to their clients’ definitions of success, and finally how they promoted collaborative care with clients. Clinicians’ discussions about client-centred approaches revealed tensions between the many different areas of life affected by PD and their own and each client’s perspectives about the relative significance of these areas. Without careful consideration of client preferences and needs, clinicians’ supportive efforts may indeed disempower clients from participating in their care – perhaps the exact opposite result to their intended delivery of care (Entwistle, et al., 2017). Clinicians described trying to ‘maintain a balance’ between different aspects of their work, a reflection of the many considerations involved with caring for a client with a chronic condition, such as balancing responsiveness to a client’s agenda with
commitment to biomedical-professional goals, for example. The authors suggested a new type of professional judgment when facing “intractable uncertainties” about which symptoms and areas of clients’ lives are most impacted by PD and thereby discern care priorities based on what the client can realistically improve in their life (Entwistle, et al., 2017, pp. 1460). The findings from this study indicate that greater attention and practice of client-centred approaches to care for people living with PD may in fact foster greater recognition and appreciation of the challenges they entail. As such, this study identified a new area for professional development and advocates for increased service development, performance assessment and quality improvement for those who must navigate such tensions and uncertainties in their daily practices.

2.3.2 Studies about client preferences for involvement in their care

In an effort to further support client-centred care implementation, Zizzo and colleagues (2017) investigated how people living with PD wanted to be involved in their care with respect to making healthcare decisions. Through a mixed-methods investigation employing a survey and semi-structured interviews with thematic analysis, the researchers elicited participants’ preferences for involvement in healthcare decision-making, perspectives about client-physician relationship, and preferences for communication of information relevant to decision making. Not surprisingly, findings indicated that preferences for participation in decision-making varied amongst individuals, but also varied within individuals, depending on the decision type, relational and contextual factors (Zizzo, et al., 2017). All participants highly valued communication about relevant information and the therapeutic relationship with their physicians (Zizzo, et al., 2017). This study emphasizes the dynamic nature of decision-making with respect
to healthcare, such that clinicians must regularly evaluate clients’ preferences for participation in order to deliver client-centred care that is respectful of individuals’ wants, needs and values. Contributions from this study inherently suggest that clinicians spend adequate time with clients to assess these preferences, another competing topic in an often already time-pressed healthcare environment.

While learning about client perspectives will certainly help to inform future clinical approaches, others have collected data about clients’ experiences of care for the purpose of improving their current delivery of client-centred care (van der Eijk, et al., 2015). Client experiences were assessed at 20 Parkinson Centres of Excellence in North America using the patient-centeredness questionnaire for PD (PCQ-PD), a validated tool developed in the Netherlands. Results from this study revealed that clients rated the information they received from clinicians and collaboration in their care lowest on their experience ratings (van der Eijk, et al., 2015). This study further adds to the literature that, despite clinicians’ best efforts, clients continue to feel under-informed about critical care issues and experience a lack of collaboration with healthcare professionals (Buetow, et al., 2008; Hayes, 2002; and van der Eijk, et al., 2012). These findings also reflect the complexity of providing the right information to the right person at the right time, necessitating consideration of vast individual differences in information needs, in addition to new information requirements of each stage of disease progression.

Armstrong and colleagues (2019) investigated communication preferences of people diagnosed with PD and their care partners in clinical settings, particularly concerning off-periods of medication effectiveness. The researchers completed semi-structured interviews with people diagnosed with PD, their care partners, as well as
physicians, and used a qualitative descriptive approach to describe experiences, facilitators and barriers to communication in clinical settings. People diagnosed with PD and their care partners identified clinician characteristics such as empathy, respect and taking time to listen as facilitators, whereas severity of cognitive PD symptoms, and perceived lack of appreciation by clinicians of the burden of PD were barriers (Armstrong, et al., 2019). Interestingly, the only factor identified by all participant groups as a facilitator to communication was the presence of a care partner to clarify symptoms and to listen to information from the physician (Armstrong, et al., 2019), which speaks to the critical role of the care partner in clinical settings. Results of this study also demonstrate clients’ preferences to be involved in clinical discussions and thereby advocate for more formal educational materials to facilitate communication about PD, such as off-periods, for example.

2.3.3 Studies investigating how to improve care delivery for people living with Parkinson’s disease

Kessler and colleagues (2019) sought to design a collaborative approach to care in order to integrate client-centred, self-management care with medical models for PD. The researchers implemented a cross-sectional, mixed-methods study using surveys and interviews to gather stakeholder input in order to develop an integrated care program. The authors implemented surveys to elicit the perceptions of people diagnosed with PD and care partners regarding self-management support and activation for managing their health condition, where ‘activation’ was defined as a person’s belief that they have the knowledge, skills, and confidence for managing their own health or that of a loved one (Kessler, et al., 2019). Semi-structured interviews were conducted and analyzed via
content-analysis to gather rich descriptions of participant experiences of managing PD, sources of information and support, and to identify areas for improvement. The authors suggested that participants perceived support for self-management to be inadequate, but were satisfied when they were able to participate in and make decisions collaboratively with their healthcare providers (Kessler, et al., 2019). Findings from this study suggest that levels of activation, perceptions of self-management support and individual experiences of care are critical components to designing improved models of client-centred care for people living with PD. For instance, healthcare providers may learn valuable information by assessing their clients’ levels of activation and subsequently tailor their clinical care approach accordingly in order to meet individualized self-management needs (Kessler, et al., 2019). While participants offered various potential solutions to meeting their outstanding clinical needs, how service delivery may be adapted to address the perceived short-comings of clinical care remains to be defined and evaluated.

To address some of the challenges inherent in many healthcare systems – such as limited healthcare providers, time, and space – with a simultaneous increase in the number of people with multiple chronic conditions, van der Eijk and colleagues (2013) investigated the use of online health communities as a tool to facilitate high-quality and accessible health care. Using a professional network for PD called ‘ParkinsonNet,’ of which participants are both clients and healthcare professionals, the authors developed online health communities designed to connect clinicians to each other and to their clients (van der Eijk, et al., 2013). The findings from this initiative highlighted four domains where online health communities could facilitate and improve the quality of care for
chronic conditions which included: 1) the exchange of medical experience and knowledge; 2) the enhancement of interdisciplinary collaboration across institutions; 3) a platform for supporting self-management through improved communication between clinicians and clients; and 4) to improve client-centred care by engaging clients to take part in their care (van der Eijk, et al., 2013). While the benefits presented by this study merit further investigation, how such an online platform would fit within traditional models of care and funding may present significant challenges to its implementation. Nonetheless, the potential for client-driven access to healthcare professionals and accurate information has been identified by many studies discussed above and represents a worthwhile pursuit to optimize client-centred care for those living with PD and their care partners.

2.4 Discussion and Limitations of Available Literature

The studies presented herein provide insight into existing understandings of the experience of living with PD, current approaches to client-centred care and self-management, and clients’ preferences for their care, as well as recent innovative approaches for healthcare professionals to optimize their delivery of clinical care. Available literature provides support for the potential benefits of understanding client experiences from the perspective of those diagnosed with PD as well as their care partners, discusses the current state of self-management interventions and client-centred care initiatives, and offers insight into client preferences related to their involvement in healthcare decision making.

This review of the literature was presented in a manner which superficially subdivided the aspects of the current research studies, so as to situate the process of
learning self-management skills while living with PD, and the process of caring for the care partnership living with PD, within what is already ‘known’ and presented in the extant literature. However, the categorization of previous studies underscores the limited depth of literature connecting aspects of living with PD, learning self-management skills, and providing clinical care. Recent studies have emphasized the importance of understanding individual experiences and preferences for the general provision of client-centred care (for example, Kang & Ellis-Hill, 2015; Berger, et al., 2019; Lim, et al., 2017; and Entwistle, et al., 2018), however, how the care partnership learns self-management skills from their perspective has not been previously explored. As such, there are no insights from the experiences described by both members of the care partnership that specifically outline the process by which they may learn self-management skills while living with PD.

Available research about practicing clinicians’ perspectives and processes of caring for the care partnership living with PD was largely devoid of discussions surrounding client-centred care and self-management. While emerging research highlights individualized client preferences and the complexity of addressing the multi-faceted domains of PD symptomatology from the perspectives of the care partnership as well as clinicians, the research methodologies employed in the available studies were not conducive to making conjectures about process, and thereby cannot suggest how these factors interplay to influence delivery of care in clinical settings. Available literature on client-centred care for people living with PD has focused on client- and care partner-related factors, with limited understanding of healthcare providers’ inherent processes to address their perceived clinical priorities. To my knowledge, there have not been any
studies undertaken specifically investigating the perspectives and processes of clinicians from various disciplines providing care to care partnerships living with PD.

There remains a distinct void in understandings of the processes involving care partnerships living with PD who must learn self-management skills in order to maintain an acceptable quality of life. The detailed accounts of distress resulting from couples’ experiences of living with PD, coupled with the possibilities participants have recounted for improving their lives with self-management and guidance from healthcare providers, provide a compelling case for the importance of further developing understandings of how clinicians currently support and may improve their delivery of self-management care.

2.5 Summary

In reviewing available published literature, findings pointed to the importance of developing enhanced understandings of the process of learning self-management skills for care partnerships living with PD. Numerous studies underscored the value of understanding the experiences of people diagnosed with PD and the care partner perspective, and have identified some relevant targets for clinical interventions. Some studies have sought to improve self-management interventions for the people living with PD, and there is also growing support for inclusion of care partners in self-management interventions for issues related specifically to caring for their spouse, or in combination with PD support in general. Previous research suggests that self-management education can positively impact perceptions of social support, self-efficacy, physical symptom management, and aspects of mental health. Moreover, there is evidence to suggest that novel insights may be gained by specifically exploring care partnerships’ process of
acquiring self-management skills for the purpose of further identifying clinically relevant targets for support.

There are fewer published studies addressing healthcare providers’ perspectives about caring for care partnerships living with PD. There appears to be a consensus in the literature that self-management support for people living with PD and the inclusion of their care partner in clinical interventions are important components for client-centred care. Emerging research suggests that provision of individualized care to people with PD requires a conscious, nuanced approach in consideration of the multidimensional nature of PD symptomatology as well as clients’ preferences for varying levels of involvement in their care.

While thoughtful approaches to research about living with PD, self-management, and providing care to people living with PD and their care partners are becoming increasingly available, there remains a scarcity of literature with respect to the processes of care partnerships learning self-management skills while living with PD, and of healthcare professionals from various disciplines providing their care. The few studies that address the experiences of people living with PD do not question how their experiences translate into meanings and processes associated with learning self-management skills. Moreover, studies involving clinicians tend to identify barriers to the provision of ideal care, without investigating healthcare professionals’ current processes involved in selecting and delivering their care, such as considerations of the care partnership, their healthcare system, self-management and community resources and how they may be implemented into practice.
The purpose of this dissertation is to develop a thoughtful and meaningful understanding of how care partnerships learn to live with PD through the acquisition of self-management skills, and to interpret the process undertaken by clinicians from various disciplines while assembling and delivering their care packages to provide self-management support. Understanding meaningful experiences that influence the process of learning self-management skills for care partnerships may allow for contextualization and identification of innovative clinical care targets for both the person diagnosed with PD and their care partner. Similarly, exploring clinicians’ processes of caring for people living with PD may assist in understanding current considerations in clinical settings and may encourage healthcare providers to reflexively consider their own clinical practices with respect to self-management and client-centredness.
2.6 References


3 Methodology

The aim of this research was to enhance understandings of how care partnerships learn to live with Parkinson’s disease (PD). The first and second studies addressed the processes of how care partnerships learned to live with PD, and how healthcare professionals from various disciplines provide clinical care to care partnerships living with PD, respectively. Knowledge gained from these studies has important implications for clinical practice and community programs, as it may inform both clinical decisions as well as supportive community or social programming regarding teaching skills to live with PD.

The research presented herein was undertaken from a perspective which values the experiences and interpretations of both care partnerships living with PD – that is, spousal couples where one person has been diagnosed with PD and the other is the primary care partner – and healthcare providers from various health disciplines, with whom understandings of meaning and actions can be co-constructed. The research methodology employed, which will be discussed in detail in this chapter, acknowledges co-creation of knowledge through interpretation and meaning making of participants’ contextualized experiences. Findings generated from these studies are therefore contextually linked to the time and place of this research, to the participants, and to myself as the researcher. The findings are not intended to demonstrate generalizability as truth in a far-reaching, positivist sense; however, insights from this work may carry analytic generalizability in the sense that they raise theoretical and interpretive understandings that may be considered for their relevance in other contexts, as deemed
appropriate by the reader (Charmaz, 2006). In choosing to adopt constructivist grounded theory, I sought coherence between my paradigmatic position, epistemological stance, and the methods used throughout the research process. My paradigmatic position and methodology implemented for both studies are presented below, followed by statements of methodological rigour and reflexivity.

3.1 Paradigmatic Position

“Knowledge is not ‘discovered’ but rather created; it exists only in the time/space framework from which it is generated” (Lincoln & Guba, 2003, pp. 40)

In this section I attempt to articulate and acknowledge the influences behind my adopted paradigmatic position to further elucidate the fundamental ontological, epistemological, and theoretical assumptions underpinning my perspective. I believe people’s experiences of phenomena are unique and that individuals’ experiences, actions, and understandings of the world are always shaped within a context created by society, culture, history and language (Blumer 1969; Guba & Lincoln, 1982). As such, I recognize the existence of multiple, subjective meanings and ‘realities’ unique to each individual’s circumstances and interpretations (Finlay & Ballinger, 2006). Moreover, the epistemological position I adopt espouses that any claims of ‘truth’ arise from individuals’ unique interactions with the world and are situated within their sociocultural and historical context (Charmaz, 2006).

My paradigmatic perspective aligns with constructivism, which underscores the existence of multiple social realities, and the relativist nature of that which can be
‘known’ as reality. I accept that social entities do not ‘really’ exist; that is, “they have ontological status only insofar as some group of persons grants them that status” (Lincoln & Guba, 2003, pp. 39). In other words, knowledge and truth, with respect to social phenomena, are thought to be the result of perspective and creation of the mind – they are not discoverable in the positivist ‘truth-seeking’ sense (Schwandt, 1994). In this regard, I approached this research with the belief that there are multiple ‘realities’, and that each is constructed under specific conditions, which involve various participants and their interactions (Charmaz, 2008). As such, the findings represented here are to be considered as one possible interpretation, based on perspective, which does not preclude the possibility of other interpretations about the meaning, reality, or truth of the topics of study. Constructivism aims to layer in-depth understandings about the world of human actions with theoretical processes; and as such, presents research findings always as confined by our perspective, sociohistorical context, and discursive practices (Lincoln & Guba, 1985; Schwandt, 1998).

I also acknowledge that the basic presupposition of constructivism is transactional subjectivism, meaning that the relationship between the knower (i.e., myself as the researcher) and the knowable, such as the research findings herein, is highly person- and context-specific. The construction of knowledge occurs through a transaction between the knower and the to-be-known, and that transaction is necessarily highly subjective (Lincoln & Guba, 1985, 2003). As such, I state my involvement as an integral part of the research, which is mediated by my own prior experience and knowledge, and other personal factors such as social status, gender, race, nationality, personal and cultural values. Just as participants bring unique contribution to the research, I recognize the
findings generated from these studies are analyzed through and thoroughly interconnected to my interpretations as the ‘knower’ (Charmaz, 2006; Lincoln & Guba, 1985, 2003). Rather than attempting to set aside or bracket my preconceptions about each of the ‘parts’ of my research subjects – older adults, living with Parkinson’s disease, healthcare professionals, and clinical care – and the interactions among them, I acknowledge my positionality and have attempted to identify these influences and implicit meanings such that the findings presented herein are located in relevant circumstances. This means that different researchers in different circumstances with these same data sets would interpret them differently and may produce different results – they are dependent upon the perspective and past experiences of the researcher, as well as their unique interactions with the participants (Charmaz, 2006).

I also acknowledge aspects of symbolic interactionism within my paradigmatic position, as its tenets inform constructivism and provide a framework for deeper consideration of how human behaviour is mediated through our interactions (Blumer, 1969; Charmaz, 2014; Schwandt, 1998). Symbolic interactionism suggests that individuals construct their sense of self, society and reality through interaction with symbols of meaning, including objects and other people (Blumer, 1969). Pragmatism further contributes that people are creative in their actions, and meanings are created through practical actions aimed at solving problems (Charmaz, 2006). As such, there is a general emphasis on the practical function of theory construction and knowledge. Constructivism points to the unique nature of humans as individuals, such that how we make sense and meaning of our experiences is unique and valuable. It acknowledges and values the influences of culture as opposed to constructionism which may criticize it (i.e.,
we are not defined by the “hold” our culture has on us) (Crotty, 2003). As such, I believe that individuals can and do think about their lives and actions freely, albeit influenced by their social situation. I believe people define meaning from their experiences and interactions and conduct themselves in a manner which reflects their interpretations of the meanings as well as their beliefs of other peoples’ expectations. Thus, “human beings act toward things on the basis of the meanings that the things have for them” where ‘things’ refer to everything one might perceive and take note of in their world, including objects and other people (Blumer, 1969, pp. 2). Meaning then arises out of the social interactions one has with other people, and these meanings are then interpreted by the person, depending on their perspective, values, and sociohistorical context (Blumer, 1969).

Symbolic interactionism also emphasizes the role of language in naming the relevant symbols and assigning meaning to interactions with them (Blumer, 1969; Charmaz, 2014). Language therefore underpins the creation and communication of meaning and actions that result from interactions between people (Charmaz, 2006). In turn, symbolic interactionism is derived from pragmatism, which purports that meanings are derived from actions. This establishes a dynamic, reciprocal relationship between actions, meanings, and the influence on future behaviours (Charmaz, 2006). Therefore, I feel this perspective aligns well with my research questions, as I seek to understand the processes associated with learning to live with PD and caring for care partnerships living with PD, based on meanings derived through previous experiences.
3.2 Methodology for Studies One & Two

The first study explored the experiences of care partnerships – that is, spousal couples where one person has been diagnosed with PD and the other is the primary care partner – as they have learned to live with PD. Findings from this study elucidate the processes through which the care partnerships must navigate and may identify areas of need where clinicians could support and optimize their journey of learning to live with PD.

The second study aimed to understand how clinicians make decisions when caring for care partnerships living with PD. Together with the findings from study one, insights into the clinical decision making process for healthcare professionals from various disciplines contributes to understanding any gaps that may exist with respect to recognizing and addressing the clinical needs of care partnerships living with PD.

Both studies employed a constructivist grounded theory methodology, whereby social processes were theorized while remaining grounded in participants’ stories (Charmaz, 2000). Constructivist grounded theory suggests a path through theory and methods to conduct inductive, open-ended research in order to explore and understand human actions. This approach provides researchers the opportunity to construct meaningful understandings of participants’ experiences and theorize processes without claims of an objectivist or external approach to the data (Charmaz, 2003). Rather, constructivism supports “mutual creation of knowledge by the viewer and the viewed” (pp. 250) and, as such, provides a perspective from which understandings of meaning may be interpreted by participants’ stories. Therefore, ‘reality’ is not discovered, but
rather, co-created through an interactive and iterative process between researcher and participants whose interpretations confer meaning upon a situation. In a similar sense, constructivism does not seek to reveal the ‘truth’ as universal, everlasting principles, as the goal may be in the natural sciences, for example (Guba & Lincoln, 1994). Rather, constructivist inquiry recognizes that what may be understood as knowledge and truth is always based upon individuals’ perspectives and interpretations. The findings generated from a constructivist grounded theory study suggest plausible hypotheses which may be useful in explaining and understanding social questions in similar contexts, rather than generalizable ‘truths’ (Charmaz, 2006). In this research, I aim to propose one interpretation of two processes which may reflect individual or shared realities as they are dynamically and continuously constructed related to care partnerships learning to live with PD, and the healthcare professionals who care for them.

If it is accepted that individuals’ understandings and meanings are continuously constructed and interpreted, it is acknowledged that the data gathered through interviews in grounded theory methods must be narrative constructions of experience, which are themselves re-constructed through language and interpretation, rather than pre-reflective experiences (Charmaz, 2003). As described above, the theoretical position from which this research was conducted ascribes to the belief that the meaning in any experience or action is only to be understood in a highly contextualized manner. Our understandings are hence created in a social, cultural, and historical context, and subsequently interpreted through our interactions with objects in the world, and constructed through language (Blumer, 1969; Charmaz, 2014). In keeping with this paradigmatic perspective, the findings presented herein are intended to be understood as representing one possible
interpretation of these processes. Given the deliberate attention to transparency of methodology and methods, the hope is that readers may recognize meanings and insight from thoughtful reflection on the findings that can be considered in other, similar contexts in which they live.

While there are many proponents of grounded theory, the particular form of constructivist grounded theory employed in this research is informed by the theory and methods proposed by Kathy Charmaz (2006). In her own words, “interpretive theory calls for the imaginative understanding of the studied phenomenon. This type of theory assumes emergent, multiple realities; indeterminacy; facts and values as linked; truth as provisional; and social life as processual” (Charmaz, 2006, pp. 126). This position indicates that while the research aim is focused on action in social processes, researchers must acknowledge the relativity of their perspectives and practices and the values and circumstances that inform them, which may be identified through consistent reflexivity exercises (Charmaz, 2008). Research findings therefore emerge through creation of data from shared experiences and relationships with participants (Charmaz, 1990; Charmaz & Mitchell, 1996). Rather than attempting to isolate or bracket the existence of values, beliefs, and presuppositions of the researcher, constructivist grounded theory acknowledges that research is inextricable from values, and instead encourages transparency, reflexivity, and identification of the impact of these value positions on the research findings (Charmaz, 2008).

In this research, the objective was to explore the actions and processes involved when a care partnership learns to live with PD, as well as the process of providing clinical care by healthcare professionals from various disciplines. As a student researcher
in the PD field for 10 years and as a healthcare professional myself, I recognize that my perspective impacts my theoretical position and research practices in data collection, analysis, and theory proposition. Frequent peer debriefing through discussions with my supervisor helped me to identify and scrutinize the influence of my pre-existing perspectives and assumptions on this research. A statement of reflexivity is provided later in this chapter.

Grounded theory provides a path through data collection and analysis to explore participants’ perspectives of their lived worlds (Charmaz, 2003). Charmaz’s grounded theory methods (2003) suggest strategies for collecting, analyzing and theorizing research findings in order to develop an understanding through theoretical frameworks to explain a social process of interest. A key feature of constructivist grounded theory is an ongoing analytic interpretation, inspired by the explanatory method of hermeneutics, to guide future data collection in the iterative, constant comparative process to enhance and refine the developing theory (Charmaz, 2006; Lincoln & Guba, 2003). A grounded theory begins with initial sampling, and then evolves through theoretical sampling, which enables the researcher to translate findings from description to analysis, explain connections between concepts, and enhance the robustness of the emerging theory.

Theoretical sampling involves starting with data, constructing tentative ideas about the data, and then examining these ideas through further inquiry. This type of reasoning makes grounded theory an abductive method, because it includes reasoning about experiences for making theoretical conjectures and then checking them through further experience (Charmaz, 2006). Consistent with the logic of Charmaz’s (2006) grounded theory, theoretical sampling is emergent, in that the developing ideas shape
next steps in the research process and the questions posed until the goal of ‘theoretical saturation’ is reached. I am uneasy about the term ‘saturation’ as it may be perceived to imply that every experience or interpretation of a category has been fully exhausted for all possible meanings. As described above, my theoretical position assumes emergent and relative realities and acknowledges subjectivity in theorizing; I recognize interpretation is never fully complete or absolute, and therefore I aim for theoretical plausibility rather than absolute or exhaustive accuracy (Charmaz, 2016). For the purpose of these studies, saturation was operationalized as the point at which “gathering fresh data no longer sparks new theoretical insights, nor reveals new properties of these core theoretical categories” (Charmaz, 2006, pp. 113). This position regarding the non-emergence of new categories or theoretical insights has been adopted by others as well (e.g., Birks & Mills, 2015; Olshanky, 2015). In this research, saturation was considered to have been reached when connections between coded categories were identified and theoretical relationships emerged into themes that constructed the descriptive process, such that new interviews were not producing new themes to challenge the proposed theory.

Charmaz’s constructivist grounded theory was chosen to carry out this research as it fits appropriately with my paradigmatic position. Furthermore, it is particularly suitable for studying participants living with chronic illness. Charmaz (1990) has discussed at length the processes involved with living with chronic illnesses and has articulated the importance of participants’ meaning making from their past experiences to influence their future behaviours:

A significant event stands out in memory because it has boundaries, intensity, and emotional force … A significant event freezes and enlarges a moment in time.
Because of inherent or potential meanings of self within the event, people grant obdurate qualities to it. They reify it. To them, the event supersedes past meanings and foretells future selves (Charamz, 1990, pp. 210).

By focusing “on process, patterns, and meaning” of experiences within contexts of daily lives, roles, and relationships (Tweed & Charmaz, 2012, pp. 134), researchers can view problems from participants’ perspective. Therefore, Charmaz’s version of constructivist grounded theory seemingly had the most appropriate fit to access the actions and meanings experiences by participants in order to address the research objectives.

3.3 Ethical Approval

This research was approved by the University of Western Ontario Health Sciences Research Ethics Board (Appendices A and B). All participants were informed that participation was voluntary and anonymous, and they were able to withdraw from the research at any time. Participants were provided with Letters of Information and Consent, which outlined the nature of the research, that interviews would be audio-recorded, and their identities would be removed from data, files, and publications (Appendices C and D). I confirmed participants’ understanding of the letters’ contents and answered any questions that arose. Upon receiving written confirmation of informed consent for the initial interview, and permission to be contacted if follow-up interviews were required, we proceeded with the study protocol. Audio-recorded files of the interviews and digital transcripts were encrypted and stored on a password-protected storage device in a locked office, and observational memos were kept in a locked filing cabinet. Confidentiality was
maintained through de-identification of participants and numeric coding on the transcripts and all associated study materials.

3.4 Research Methods

The research methods utilized for both studies one and two were in keeping with my paradigmatic stance and constructivist grounded theory methodology. The following sections describe in details the methods implemented and how careful consideration was given to each step of the research process to optimize coherence from my paradigmatic position, methodology, and the methods that were ultimately employed.

3.4.1 Participant Sample & Setting: Study One

Spousal couples, where one person has been diagnosed with PD and the other is the primary care partner, were recruited from community programs across Eastern and South-Western Ontario. Purposive sampling was implemented to achieve maximum variation sampling and include participants over the range of PD progression from newly diagnosed to late-stage – provided the person with PD was able to physically participate in the interview (i.e., they had the ability to speak in English) and was cognitively able to recall and reflect on their life with PD. I accessed potential participants through several Parkinson’s Canada support groups, four physiotherapy clinics specializing in neurological conditions, and three community exercise programs for people living with PD. Public notices were affixed in each of these areas, and I made brief in-person announcements at 3 support groups, and one community fitness class.
Sampling was not intended to gain a ‘representative’ sample to statistically mirror the larger population of people living with PD in the province or country; rather, the aim was to seek participants with a rich diversity of experiences and lessons learned about living with PD in order to explore the subject in depth. The intention of recruiting participants from community programs such as support groups, exercise groups, and physiotherapy clinics, was to access community-dwelling spousal couples who were actively participating in activities to manage their condition. Age and sex were not exclusionary. Participants would have been excluded if the spouse was not the primary care partner and if either the spouse or the person diagnosed was not cognitively or physically able to complete the interview. Participants would also have been excluded if they had neurological issues or conditions other than PD. Twelve couples who met the inclusion criteria participated in this study. For additional participant information, see Table 1.

Potential participants contacted me by phone or email and at that time, I confirmed that the person diagnosed with PD had been diagnosed by a neurologist, had no other neurological conditions, and would be able to recall and describe their past experiences of living with PD in English. Informed, written consent was obtained from each participant (Appendix C). After completing eight interviews with dyads together, and four interviews with people diagnosed with PD and their care partners separately, I concluded that no new themes were emerging from the data. The primary factor considered for maximum variation sampling included time since diagnosis. Other sample characteristics are further described in Chapter 4.
3.4.2 Participant Sample & Setting: Study Two

Healthcare professionals who provide care for at least six people diagnosed with PD per year were recruited from healthcare centres in Eastern and Southwestern Ontario. Purposive sampling was used to achieve maximum variation sampling, and to represent the typical healthcare providers described by participants in Study One. Sampling was not intended to gain a ‘representative’ sample to statistically mirror the larger population of all healthcare providers who care for people living with PD; rather, the aim was to seek participants with a rich diversity of expertise and clinical scope related to caring for those living with PD, in order to explore the subject in depth. The intention of recruiting healthcare providers from different professions was to represent the typical healthcare circle of a person living with PD, as described by participants in Study One, who were people diagnosed with PD and their spousal care partners. The typical circle of care consists mainly of a neurologist and a clinic nurse, while some couples’ circles included a rehabilitation professional, and a pharmacist as well. While this is not a comprehensive list of all professionals who may be involved in the care of people living with PD, the sample in this study reflects the most common distribution. Healthcare professionals were sought for inclusion where care was provided for at least six clients living with PD per year. Age and sex were not exclusionary. Participants would have been excluded if they cared for less than six people living with PD per year and/or could not communicate in English. Eight healthcare professionals who met the inclusion criteria participated in this study (Table 1). After completing one interview with each healthcare professional, I concluded that no new themes or categories were emerging from the data. Informed, written consent was obtained for each participant (Appendix D).
3.4.3 Data Collection: Studies One & Two

Participants engaged in audio-recorded, in-depth interviews to explore their experiences of living with or caring for those who live with PD. Participants selected the interview location and time to ensure they would feel relaxed and comfortable, to accommodate busy schedules, and to facilitate in-depth conversation about their experiences of living with or caring for people living with PD. In study one, participants completed interviews either with their spouse or with another care partner or person diagnosed with PD which lasted between 48 and 89 minutes. All participants elected to complete the interviews in their home, other than the care partnerships who interviewed separately, where we met in a private room of a local community building. In study two, participants completed individual interviews which lasted between 23 and 55 minutes. Six participants elected to complete the interviews in their place of employment, the other two chose to complete the interviews at their homes.

Grounded theory involves early analytic work to engage with the emerging data in order to guide theory construction. In keeping with this process, the interview guides and recruitment process for later participants evolved over time to remain consistent with theoretical sampling, and to further explore and develop emerging ideas. The interview guide provided a foundational set of questions and probes that remained instrumental for interview, however, the questions were slightly adjusted within each interview to facilitate engagement and rapport between myself and participants, according to their specific circumstances and experiences. Furthermore, my interview questions developed in theoretical scope and usefulness during the course of the study to reflect my deepening
knowledge in the area, as well as growing skill as an interviewer (Charmaz, 1990). The interview guide and associated list of questions, cues and prompts, ensured interviews explored similar topics to address the research question, that they remained open-ended, directed by participants, and to avoid the use of “awkward, poorly judged questions potentially based on unexamined preconceptions” (Charmaz, 2014, p. 63). The interview guides are provided in Appendices E and F. A more detailed discussion of how I reflexively challenged and engaged my biases, beliefs, and values is provided later in this chapter.

During the interviews in study one, I asked participants to reflect on experiences of living with PD from the time they first began noticing symptoms to the present day. My questions sought to elicit descriptions of key experiences that may have changed the way the dyad takes care of themselves, and thereby provide insight into the process of learning to live with PD. Examples of interview questions are:

- Tell me about a time that taught you something new about PD.
- Tell me how you learned to manage one of the symptoms of PD.
- Tell me about a time that made you realize you could no longer do certain things or that you now have to do them differently because of PD.
- Tell me about a time that a healthcare professional was especially helpful or not helpful in managing your symptoms of PD.
- Tell me about a time you learned a difficult lesson about living with PD. What did you learn from it?
• What is the main piece of advice about caring for yourselves that you would give to people who are newly diagnosed with PD?

These broad questions would be followed by prompts and additional questions to elicit as much detail about the experiences as possible. For example, “Tell me more about that?”, “Tell me what you were thinking”, or “How did you feel when ...?”. All 12 dyads completed one in-depth interview. I decided that no follow-up interviews were indicated as the emergent theory fit well with the data generated by all participants.

After eight interviews with spousal couples, an additional four interviews were conducted with the dyads separated into those who were diagnosed with PD, and care partners. This provided valuable insight and opportunity for theory development related to the perspective of care partners and those diagnosed with PD separately. The intention was to elicit rich descriptions that may not have been accessible in the presence of a participant’s spouse, and to ‘test’ our emergent theory against these isolated perspectives. It has been established that in joint interviews, memories can be shared (Valentine, 1999), and in individual interviews it is possible to probe each partner’s perception of a shared reality (Hertz, 1995). Both perspectives provided valuable contributions to the emerging theory.

In study two, I asked participants to reflect on experiences of providing healthcare to people living with PD, and to consider the involvement of the client’s primary care partner. My questions sought to elicit descriptions of key factors and decisions that determine how a healthcare professional delivers their care to a dyad living with PD, and
thereby provide insight into the process of caring for a care partnership living with PD.

Examples of interview questions are:

- How do you incorporate self-management education in your practice?
- How do you involve the care partner in your treatment sessions?
- What is something that you think could be focused on more in treatment sessions?
- What are the barriers preventing you from addressing important topics?
- If you could give a piece of advice to other healthcare professionals caring for people living with PD and their care partners, what would it be?

These broad questions would be followed by prompts and additional questions to elicit as much detail about the experiences as possible. For example, “Tell me more about that”, “Tell me what you were thinking”, or “How did you feel when ...?”. All eight healthcare professionals completed one in-depth interview. The data generated by all participants fit well within the emergent theory, and therefore, the data did not guide a return to previous participants.

I wrote reflexive notes and memos immediately after each interview to capture my in-the-moment impressions, insights and new questions. The memos were critical to directing future interviews and an important step in the analysis process. A sample memo is available in Appendix G.

3.4.4 Analysis of the Findings: Studies One & Two

I transcribed all audio recorded interviews verbatim to enhance my familiarity and engagement with the data. The constant comparative method was employed by frequently
revisiting the interview transcript throughout data analysis. This facilitated a comparison of “incident to incident, incident to codes, codes to codes, codes to categories, and categories to categories” (Birks & Mills, 2015, pp. 11) and a comparison between descriptions evoked by participants, their experiences and perspectives, as well as points in time and emerging categories (Charmaz, 2000, 2003; Glaser and Strauss, 1967). In order to build the theory up from the data themselves, initial stages of analysis involved line-by-line coding to maintain closeness to the data and to avoid, as much as possible, the intrusion of uncritical assumptions or unidentified biases that may result from studying care partnerships living with PD and healthcare professionals – populations with whom I am familiar, or with which I also identify. Codes were generated based on recurrent themes, actions, and behaviours described in the transcripts, which assisted with the direction of subsequent data collection (Charmaz, 2003).

Constructivist grounded theory involves an abductive reasoning method which entails “reasoning about experience for making theoretical conjectures and then checking them through further experience” (Charmaz, 2006, pp. 103). To achieve this, initial codes were tentatively identified from the data to highlight key insights from early transcripts. After analyzing more data, these codes were consolidated into larger, more abstract categories through focused and theoretical coding. For example, in study one, support’ emerged as an important category and related to initial codes such as ‘isolation’, ‘safety’, ‘healthcare providers’, and ‘family’. Theoretical coding identified a core category ‘overcoming challenges’ which connected the remaining themes from codes to produce a descriptive theory that articulates this process. Whereas in study two, ‘system and time’ emerged as an important category and related to initial codes such as ‘funding’, ‘rushed’,
‘limited time’, and ‘resources’. Theoretical coding and abductive reasoning identified a core category of ‘delivering the care package’ which connected the remaining themes to produce a descriptive, most plausible explanation of the process of caring for care partnerships living with PD (Charmaz, 2006). As is characteristic to abductive inference and theoretical sampling, codes and categories that emerged from earlier transcripts continued to guide recruitment and interview questions until a comprehensive theoretical process had been developed. Examples of earlier renderings of the processes in studies one and two are provided in Appendices H and I, respectively.

Data collection and analysis were concluded when a level of data saturation was felt to be reached. For the purpose of this study, saturation was operationalized as the point at which “gathering fresh data no longer sparks new theoretical insights, nor reveals new properties of these core theoretical categories” (Charmaz, 2006, pp. 113). This position regarding the non-emergence of new categories or theoretical insights has been adopted by others as well (e.g., Birks & Mills, 2015; Olshanky, 2015). This is in contrast to the original description of saturation in classic grounded theory by Glaser and Strauss (1967) which required that the data collection ends only when it can no longer develop a category, provided that the researcher has sought groups that “stretch diversity of data as far as possible”. In this analysis, saturation was considered to have been reached when connections between coded categories were identified and theoretical relationships emerged into themes that constructed the descriptive process, such that new interviews were not producing new themes to challenge the proposed theory. For this reason, additional follow-up interviews with the participants were deemed unnecessary. My theoretical position assumes emergent and relative realities, and I acknowledge
subjectivity in theorizing. Therefore, I do not claim absolute saturation in the traditional sense of exhausting all possible data sources. Instead, I emphasize the emergence of – or lack thereof – new codes and themes, for the purposes of explaining aspects of the theory, and do not claim saturation of the entire phenomenon (Saunders et al., 2018).

3.5 Methodological Rigour

Methodological rigour in constructivist studies, which do not claim ‘objectivity’ or ‘truth’ in their contributions to the literature, can be demonstrated through the classic quality criteria of achieved via credibility and transferability, and to authenticity, achieved via fairness, tactical authenticity, and educative authenticity criteria (Guba & Lincoln, 1989; Guba & Lincoln, 1994; Lincoln & Guba, 2013; Charmaz, 2014).

The selection of these criteria reflects my belief that the interpretations presented herein are only one of a number of possible representations, and that my own values and experiences are implicated in the production of findings. Furthermore, this discussion of rigour contributes to the transparency, consistency, and coherence of the methodological approach beginning from my theoretical perspective through to my research aim and methods.

Credibility contributes to achieving trustworthiness of research findings, in that it aims to “establish a match” between the constructed realities of participants and the interpretations presented by the researcher (Guba & Lincoln, 1989, pp. 237). In an effort to achieve intimate familiarity with the research setting, I endeavoured to elicit numerous in-depth responses and immersed myself in the texts via transcription of all interviews,
reading and re-reading the texts, as well as engaging each interview text with a peer through discussion about findings and tentative analyses (Charmaz, 2006, Guba & Lincoln, 1989). Constant comparison, theoretical sampling, and reflexive memos also assisted to monitor my developing constructions and to ensure credible categories arose from the full range of participant responses (Charmaz, 2006). Systematic comparisons between data observations and categories, and the generation of logical links between a wide range of gathered data and the emerging analysis also contributed to monitoring my developing constructions and ultimately delivering credible findings (Charmaz, 2006).

Transferability is a parallel criterion to the positivist quality of generalization, however the aim of these findings is not to be generalized in the far-reaching sense that some positivist studies may claim. Rather, I invite readers to determine if these findings resonate with their everyday realities within similar circumstances (Charmaz, 2006). To facilitate this judgment of transferability, I have endeavoured to provide rich, careful descriptions of the time, place, and contexts in which these findings were elicited, such that readers can determine whether the proposed theory and interpretations relate to their understandings and experiences in similar settings (Guba & Lincoln, 1989).

Fairness is thought to be a quality of balance, where all stakeholder views, perspectives, claims, concerns, and voices are apparent in the text (Guba & Lincoln, 2005). To achieve this, interview questions were revised and theoretical sampling was used in an attempt to achieve this balanced quality in perspectives. Direct quotes from all participants have also been included in the findings, in an effort to truly co-construct the research and new knowledge as a result of both participant and inquirer contributions. However, I do acknowledge that the power of many research decisions with regard to
methods and dissemination rest with myself, as opposed to having had an “open negotiation of recommendations and of the agenda for subsequent action” (Lincoln & Guba, 1985, pp. 246). To maximize fairness, I actively sought to include all participants’ stories in the research findings such that “all voices in the inquiry effort had a chance to be represented… and to have their stories treated fairly and with balance,” (Guba & Lincoln, 2005, pp. 180).

Tactical authenticity refers to the ability of a given inquiry to prompt action and education in social processes (Guba & Lincoln, 2005). This has been achieved in study one through the translation of research findings into clinically relevant information. This research may contribute to positive additions to clinical teaching methods and empower interested parties to improve how people live with PD. Interpretations from this study contribute to understanding how couples living with PD learn to manage their condition, and may challenge accepted clinical practices, thereby inspiring and leading to future work that may improve how we provide education to those living with PD.

Educative authenticity refers to the “extent to which individuals, including the inquirer, have become more understanding of the experiences and constructions of others” (Lincoln & Guba, 2013, pp. 70). This has been achieved in study two by the exploration and rich descriptions of various healthcare professionals and their approaches to providing care for their clients living with PD. The use of dialectical conversations with participants, peer debriefing, and memos of my introspective statements about my emerging understandings of interview transcripts all contributed to maximizing educative authenticity (Guba & Lincoln 1994; Lincoln & Guba, 2013). These study findings also support Charmaz’s (2006) criterion for usefulness, as the interpretations contribute to
understanding how clinical care decisions are made by frontline professionals in public and private healthcare settings, and may challenge accepted or taken-for-granted clinical processes. These understandings may therefore better inform future work to address barriers and improve the delivery of clinical care for those living with PD.

### 3.6 Statement of Reflexivity

I present my involvement as an integral part of the research process and understand that contributions to the literature from these studies are contextually bound to time, place, participants, myself, and my thesis supervisor (Charmaz, 2008). I intend to acknowledge my positionality and explore the various ways in which my perspective, created from prior knowledge and value positions, impacted my decisions throughout the research process (Charmaz, 1990; 2006; 2008; 2014). I have been a student researcher in the field of PD for 10 years, and both my supervisor and I are physiotherapists and researchers trained in the foundations of both quantitative and qualitative research methodologies.

At the outset of my journey through graduate school, I had no clinical background in physiotherapy. My undergraduate education was in kinesiology and biology which I hoped would lead to a career in health and helping others maintain a healthy lifestyle in some way. I serendipitously began volunteering in a PD exercise class several times a week over the last two years of my undergraduate training, where I became thoroughly intrigued by the pathophysiology and biopsychosocial implications of living with PD. I completed two undergraduate projects investigating the link between visual perception and freezing of gait. I completed a Master’s degree in Neuroscience where I continued
studying kinematic aspects of gait in people living with PD and the feasibility of a virtual reality prototype to deliver physical rehabilitation interventions for clients living with PD. I also had the opportunity to observe many clinical neurology treatment sessions for people living with PD. While conducting these positivist, quantitative studies, I was deeply impacted by participants’ stories of living with PD, which inspired the research questions for my doctoral studies. I would also complete my professional training through the Master of Physical Therapy program while completing the research requirements for the doctorate program in years 3 and 4. Since the completion of my professional training, while remaining enrolled in graduate school and immersed in this research, I have also worked as an occupational health physiotherapist in a public tertiary acute care centre in a large Ontario city. Clients I have worked with in this setting have widely varied demographics, backgrounds, injuries and ailments. Since beginning my professional training and working in a physiotherapy capacity, my understanding relating to the language and assumptions underpinning physiotherapy practice has expanded tremendously. This increased familiarity and now identification as a healthcare professional with its inherent assumptions, expectations, and values, complicates my reflections of the presuppositions I currently have versus what I had at the outset of this research, and how this professional evolution may have influenced my interpretations.

My intentions of discovering the process of care partnerships learning to live with PD was twofold: to highlight the role of the care partner in caring for their spouse diagnosed with PD and the meaning of PD as a ‘couple’s disease’; and, to identify if there exist any unmet areas of clinical need that could serve as clinical targets to facilitate learning self-management skills. In posing an action-oriented “how” question to explore
the experience of care partnerships learning to live with PD, I made an assumption that there would be an inherent, taken-for-granted social process through which care partnerships must navigate. By investigating processes healthcare professionals navigate when providing clinical care, I also anticipated that I might recognize aspects relating to the ways in which I care for clients. I also acknowledge that my perspective is influenced by past experiences having conversations with care partnerships living with PD and of observing medical appointments that did not always seemingly align with clients’ concerns. In fact, many of these conversations inspired the research presented herein.

Importantly, however, while there may be similarities between my previous observations and my approach to care with those experiences of participants, I also expected that there would be critical differences that make the experiences unique for care partnerships and healthcare professionals in this research.

Recognizing these previous experiences and perspectives I had developed, I was cautious to prevent my interpretations from interfering with those of the participants. Just as any interpretations of mine will differ from those of others, my personal biases for the importance of exercise in managing chronic conditions, for example, often varied in direction or magnitude from the stories I encountered. However, the purpose of my research was to investigate the research aims through the lens of participants, as well as through my own interpretations, in a co-constructive manner. My goal was to feature participants’ voices, using my interpretations to link quotations and categories together, but without omitting or censoring the spirit of participants’ responses. This was particularly important when themes arose which did not align with my pre-suppositions, or which led the research in a new direction. This situation arose, for example, in Study
One with participants discussing the weight of their physicians’ advice, as I expected participants to take more initiative in the trajectory of their care; and in Study Two with discussions of self-management and education as an afterthought, rather than a cornerstone, of a clinical care session. It was important for me to remain open to topics highlighted by participants, and to base my interpretations on the data and perspectives presented to me in the research process. Conversations with my supervisor as we discussed our interpretations from the interview texts help to identify assumptions I held but had not previously identified or considered.

Kathy Charmaz highlighted, “what we can and do ask in a setting depends on how our research participants identify and know us” (2014, pg. 23) and “how your research participants identify you influences what they will tell you” (2014, pg. 29). This raises the question as to how I presented myself as the researcher to participants. I wanted participants to be as open as possible in the interviews and feel like we could have a conversation about their experiences. I often shared that I had previous experience in conducting PD research, and, once I completed my professional training, I also shared that I was a physiotherapist. I wondered if that would moderate the influence of responses from other healthcare providers, depending on their presumptions about the physiotherapy profession. It was plausible that identifying my previous experiences of people living with PD and my professional physiotherapy training could, in fact, work to my advantage in gathering rich descriptions of the processes of learning to live with PD and caring for care partnerships living with PD. If participants felt that we shared a certain level of comfort or understanding around PD terminology, disease processes, and care options, perhaps it would allow for additional information sharing. I particularly
found participants in care partnerships to be exceedingly forthcoming about their experiences of living with PD, with several people becoming visibly emotional while sharing their stories.

I also considered my personal and professional values of exercise and how they may influence my expectations of participants’ responses. I believe highly in the benefit of exercise, particularly for people living with neurological conditions such as PD, and I also believe that participation in exercise is a choice to be made. This belief is evident in my professional practice, but required some moderation over the course of this research. For example, I found myself rather surprised when healthcare professionals of other disciplines did not value exercise, and client education about exercise, as a form of care in a similar sense as I do. Or similarly, when care partnerships were not highly motivated to help themselves towards an active lifestyle and higher quality of life, I was surprised that it was not a priority.

My paradigmatic position assumes that all knowledge is interpreted within a specific context and constructed through language, a position that has become more defined through enacting this research, and putting theory into action. My previous research experiences had all been involved with positivist, quantitative studies, and as such, at the outset of designing this research program, I was new to qualitative research. In reading and completing coursework to understand qualitative research and epistemologies, I could piece together a theoretical position which resonated with my beliefs in a way I never appreciated prior to my introduction to qualitative theory. It was not until undertaking the research process, however, that I truly understood the impact of my pre-existing beliefs and values on my view of the world, including the types of
research questions I endeavoured to ask. In discussions with my research supervisor, and being consistently asked to ‘tell me more about’ certain ideas or reflect on the degree to which I was imposing my experiences upon participants’ words, I believe I have become much more aware of the truly relativist nature of this research, and my beliefs about knowledge altogether. Together, my experiences as a student researcher, a graduate student, and a physiotherapist have sculpted my approach to research and to clinical practice. This research highlights for me the meaning of truly ‘client-centred’ care, including the importance of trying to understand clients’ experiences and expectations in order to deliver empathetic, meaningful care.

3.7 Conclusion

This chapter outlined the constructivist grounded theory methodology surrounding my research, and how that aligns with my paradigmatic position, epistemological stance, and the methods implemented throughout this research. I also highlighted considerations of methodological rigour, including coherence, trustworthiness, and authenticity, and how they were implemented in these studies. I reflected upon the indissoluble links between myself as the researcher, the participants, and the findings presented herein. In the following chapters, I present the manuscripts for the first and second studies, followed by an overall discussion of the key insights from both studies and implications for this research with respect to meeting the needs of care partnerships living with PD.
3.8 References


4 The Process of Learning Self-Management Skills by Care Partnerships while Living with Parkinson’s disease

In Canada, the prevalence of Parkinson’s disease (PD) among community-dwelling older adults is 0.2% and 4.5% in long-term care facilities, making it the second most common neurodegenerative disease, only after Alzheimer’s disease (Hirtz, et al., 2007; and Wong, Gilmour & Ramage-Morin, 2014). PD symptomatology is highly variable and management must be catered to each client’s unique manifestation, their care goals, as well as their available support systems (van der Eijk, et al., 2013; Zizzo, et al., 2016). In order to meet these complex and multidimensional needs, the Canadian National guidelines on PD recommend clinicians consider “encouragement of self-management by people with Parkinson’s to meet individual needs and preferences” (Grimes, et al., 2012, pp. S5).

Self-management refers to the ability to manage the symptoms, treatment, physical and psychosocial consequences and life style changes inherent in living with a chronic condition, such that the individual is able to monitor their condition and effect the cognitive, behavioural and emotional responses necessary to maintain a satisfactory quality of life (Barlow, et al., 2002). There is considerable support for chronic disease self-management interventions with respect to slowing disease progression, reducing complications, and lowering healthcare utilizations (Ory, et al., 2014). Specific to people living with PD, some studies have reported that self-management interventions can provide psychosocial, physical and emotional benefits (Montgomery, et al., 1994; Nelson, Wong & Lai, 2011; Tickle-Degnen, et al., 2010; and Simons, et al., 2006),
however, others have shown no significant differences from traditional management in any measures (Gruber, Goldstein Elman & Huijbrets, 2008; and Lindskov, Westergren & Hagell, 2007), a reflection of the current state of the literature which indicates that the most effective components of these interventions and how to best measure them remain unclear (see Kessler & Liddy, 2017 for an integrative review).

The majority of people diagnosed with PD rely on the partnership of a person close to them, such as a spouse, to manage their variable and progressive loss of independence over the course of their disease (Wong, et al., 2014). This ‘care partner’ role is critical to the well-being of a person diagnosed with PD, as the care partner often provides a myriad of informal care services in the home setting (Mosley, Moodie, & Dissanayaka, 2017). As such, the care partner is an active participant in the PD process who experiences the impact of this chronic disease and has valuable insight into the reality of daily life at home. Although care partners are recognized to play a vital role in providing informal care to their loved one, self-management interventions remain largely designed for the person diagnosed with PD and seem to include the care partner only as a welcomed visitor, as opposed to an intentional component of the intervention (Martinez-Martin, et al., 2007). Nonetheless, there remains sufficient evidence to warrant further exploration of the benefit of self-management interventions for people living with PD – both for the person diagnosed with PD and the care partner. A grounded theory investigation of how self-management skills are acquired, from the perspective of people living with PD, may offer valuable insight for the design of self-management interventions and has not been previously presented.
The objective of this study was to explore the process of learning self-management skills while living with PD from the perspective of the ‘care partnership,’ defined as a spousal couple where one person has been diagnosed with PD and the other is the primary care partner. Insights generated from this study may highlight tacit but meaningful experiences that inform the critical learning process of acquiring self-management skills, which may ultimately assist clinicians to more tactfully shape their approach to client-centred care for the care partnership living with PD.

4.1 Methodology

This study implemented a constructivist grounded theory methodology, as described by Charmaz (2006), to explore and describe the process of care partnerships learning self-management skills while living with PD. Constructivism acknowledges “mutual creation of knowledge by the viewer and the viewed” (pp. 250), and thus provides a perspective from which interpretive understandings of meaning and action can be co-constructed and developed into a theoretical process (Charmaz, 2003).

In keeping with the constructivist perspective, I acknowledge that individuals each experience their own ‘realities’, and that each is constructed under specific conditions, which evolve through participants’ interactions (Charmaz, 2008). Knowledge claims based on constructivist grounded theory research, such as those presented herein, do not purport to be ‘true’ or permanent realities (Charmaz, 2000; Guba & Lincoln, 2005). As such, constructivism does not aim to seek truth; however, it maintains a component of realism in that it acknowledges human ‘realities’, which individuals act upon and within; further, it purports that what people take as ‘real’ and ‘true’ are based upon their
individual understandings formed within a particular social context and subsequently guide their actions (Schwandt, 1998; Charmaz, 2000). Understandings and meanings from experiences are interpreted through interactions in the world and constructed through language (van Manen, 1990; Charmaz, 2014). Thus, the data are constructions of participants’ experiences, and the analytical theory presented herein is a construction involving interpretation and representation by the research team (myself and my thesis supervisor), grounded in participants’ words.

4.2 Methods

Constructivist grounded theory was selected as an inductive approach to provide insight into participants’ perspectives and to generate a theory that is co-constructed through, and grounded in, the data created by interviewing participants (Guba & Lincoln, 1994). The result of this process was a substantive theory of human actions and behaviours, presented here to describe the process of learning self-management skills by people diagnosed with PD and their care partners. This study was approved by the Health Sciences Research Ethics Board at Western University, in London, Ontario, Canada (Appendix A).

4.2.1 Participant Sampling

Spousal couples, where one person has been diagnosed with PD and the other was the primary care partner, were recruited from community programs across Eastern and Southwestern Ontario. Purposive sampling was implemented to achieve maximum variation sampling and include participants over the range of PD progression from newly diagnosed to late-stage. Participants included in this study are described in Table 1.
Potential participants were included if the person with PD was diagnosed by a neurologist, and if both members of the care partnership were able to physically participate in the interview, had the ability to speak in English, and were cognitively able to recall and reflect on their experiences of living with PD. Age and sex were not exclusionary. Participants would have been excluded if the spouse was not the primary care partner and if they had neurological issues or conditions other than PD. Informed, written consent was obtained from each participant (Appendix C).

4.2.2 Data Collection

Constructivist grounded theory aims to explore and describe processes of human actions and behaviours, which is completed through rich and descriptive data. To achieve this, I engaged participants in audio-recorded, in-depth interviews – either with their spouse or with another care partner or person diagnosed with PD – which lasted between 48 and 89 minutes. Participants were offered to select the interview location and time to ensure they would feel relaxed and comfortable, and to facilitate in-depth conversation about their experiences of living with PD. All participants elected to complete the interviews in their home, other than the couples who interviewed separately, where we met in a private room of a local community building.

During the interviews, I asked participants to reflect on experiences of living with PD from the time they first began noticing symptoms to the present day. The interview guide is provided in Appendix E. A more detailed discussion of how I reflexively challenged and engaged my biases, beliefs, and values during the interview process is provided in Chapter Three: Methodology. My questions sought to elicit descriptions of key experiences that may have changed the way the care partnerships took care of
themselves, and thereby provide insight into the process of learning self-management skills. Examples of interview questions are: “Tell me about a time that made you realize you could no longer do certain things or that you now have to do them differently because of PD,” and “What is the main piece of advice about caring for yourselves that you would give to people who are newly diagnosed with PD?” These broad questions would be followed by prompts and additional questions to elicit as much detail about the experiences as possible. All care partnerships completed one in-depth interview. I decided that no follow-up interviews were indicated as the emergent theory fit well with the data generated by all participants.

After eight interviews with spousal couples, an additional four interviews were conducted with the care partnerships separated into those who were diagnosed with PD, and care partners. This provided valuable insight and opportunity for theory development related to the perspective of care partners and those diagnosed with PD separately. The intention was to elicit rich descriptions that may not have been accessible in the presence of a participant’s spouse, and to ‘test’ our emergent theory against these isolated perspectives. It has been established that in joint interviews, memories can be shared (Valentine, 1999), and in individual interviews it is possible to probe each partner’s perception of a shared reality (Hertz, 1995). Both perspectives provided valuable contributions to the emerging theory.

4.2.3 Data Analysis

I completed verbatim transcription of all audio recorded interviews to enhance my familiarity and engagement with the data. In keeping with the constant comparative data analysis method characteristic of a constructivist grounded theory methodology, the
transcripts were frequently revisited throughout the analysis. This facilitated a comparison between descriptions evoked by participants, their experiences and perspectives, as well as points in time and emerging categories (Charmaz, 2000, 2003; Glaser and Strauss, 1967). Initial stages of analysis involved line-by-line coding to maintain closeness to the data, ensure the analysis remained grounded in the words of the participants and to avoid, as much as possible, the intrusion of uncritical assumptions or unidentified biases that may result from studying a population I am quite familiar with. Codes were generated based on recurrent themes, actions, and behaviours described in the transcripts, which assisted with the direction of subsequent data collection (Charmaz, 2003).

Initial codes were provisional and comparative, to help highlight key insights from early transcripts and to direct further theoretical sampling within data collection through revisions to the interview guide and recruitment strategies (Charmaz, 2014). I subsequently consolidated codes into larger, more abstract categories through focused and theoretical coding. For example, ‘support’ emerged as an important category and related to initial codes such as ‘isolation’, ‘safety’, ‘healthcare providers’, and ‘family’. Theoretical coding identified a core category of ‘problem solving’ which connected the remaining themes from codes to produce a descriptive theory that articulated this process. Data collection and analysis were concluded when a level of data saturation was felt to be reached.

To enhance methodological rigour in this study, careful attention was applied to trustworthiness, achieved via credibility and transferability, and to authenticity, achieved via fairness and tactical authenticity criteria (Guba & Lincoln, 1989; Guba & Lincoln,
1994; Lincoln & Guba, 2013; Charmaz, 2014). Please refer to Chapter 3: Methodology for an in-depth discussion of how theoretical saturation was defined and achieved, as well as further discussion of how methodological rigour was maintained throughout this study.

4.3 Findings

4.3.1 Participants

The sample (n = 22) included eleven married couples where one spouse was diagnosed with PD and the other spouse was the primary care partner. Participants had been living with PD for 4 months to 21 years (mean = 10.6 years), and were all being followed by a neurologist. A description of the participants is provided in Table 1. One interview was completed with each spousal couple. Each interview lasted for between 48 and 89 minutes and were conducted in the couples’ homes, except for two interviews that were conducted in a private room at a local community centre.

Table 1. Characteristics of care partnerships living with PD

<table>
<thead>
<tr>
<th>Part. #</th>
<th>Diagnosed with PD (PD) or Care Partner (CP)</th>
<th>Sex</th>
<th># Years living with PD</th>
<th>Living Environment</th>
<th>Person with PD driving **</th>
<th>Involved with Parkinson's Canada?</th>
<th>Primary PD Information Source***</th>
<th>Healthcare Team for PD***</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>PD</td>
<td>M</td>
<td>0.3</td>
<td>2-story home</td>
<td>Yes</td>
<td>No</td>
<td>Neurologist</td>
<td>Neurologist, physical therapist</td>
</tr>
<tr>
<td>2</td>
<td>CP</td>
<td>F</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Neurologist, family physician</td>
</tr>
<tr>
<td>3</td>
<td>PD</td>
<td>M</td>
<td>18</td>
<td>Addition of multi-family home</td>
<td>No</td>
<td>Yes</td>
<td>Parkinson's Canada, online Neurologist, physical therapist</td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>CP</td>
<td>F</td>
<td></td>
<td>2-story home</td>
<td></td>
<td></td>
<td>Online, neurologist</td>
<td>Neurologist, medical pharmacist</td>
</tr>
<tr>
<td>5</td>
<td>PD</td>
<td>F</td>
<td>18*</td>
<td>2-story home</td>
<td>No</td>
<td>No</td>
<td>Online, neurologist</td>
<td>Neurologist, occupational therapist</td>
</tr>
<tr>
<td>6</td>
<td>CP</td>
<td>M</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Healthcare professionals</td>
</tr>
<tr>
<td>7</td>
<td>PD</td>
<td>M</td>
<td>3</td>
<td>2-story home</td>
<td>Yes</td>
<td>No</td>
<td>Healthcare professionals</td>
<td>Registered nurse</td>
</tr>
<tr>
<td>8</td>
<td>CP</td>
<td>F</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Registered nurse</td>
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<td></td>
</tr>
</tbody>
</table>
| 9 | PD | M | 21* | 2-story home | No | No | Michael J. Foxx website Support group  
physical therapist Neurologist, registered nurse  
Neurologist, family physician, ophthalmologist  
Neurologist |
| 10 | CP | F |   |   |   |   |
| 11 | PD | M | 17 | Accessible bungalow | No | Yes | Neurologist, family physician, ophthalmologist  
Neurologist |
| 12 | CP | F |   |   |   |   |
| 13 | PD | M | 5 | Bungalow with modifications | Yes | No | Peer-reviewed literature, online, books, neurologist  
Online, Parkinson's Canada, research participation Support group  
Neurologist, pharmacist, dietician |
| 14 | CP | F |   |   |   |   |
| 15 | PD | F | 0.75 | 2-story home | Yes | Yes | Neurologist  
Neurologist |
| 16 | CP | M |   |   |   |   |
| 17 | PD | M | 17 | Retirement home | No | Yes | Neurologist |
| 18 | CP | F |   |   |   |   |
| 19 | PD | F | 0.6 | 2-story home | Yes | Yes | Books, online, support group Support group  
Neurologist |
| 20 | CP | M |   |   |   |   |
| 21 | PD | M | 16 | 2-story home | Yes | Yes | Neurologist  
Neurologist, massage therapist |
| 22 | CP | F |   |   |   |   |

*Person diagnosed with PD has had deep brain stimulation surgical procedure  
**All participants diagnosed with PD previously drove  
***As identified by care partnership

### 4.3.2 Learning to Live with Parkinson’s Disease

Participants described the process of learning to live with PD through two overarching processes: *navigating the system* and *problem solving in the Parkinson’s world*. These two processes were joined by a bridge, which was defined differently for various couples, that represents when the couple entered the *Parkinson’s world*. The two theoretical processes, *navigating the system* and *problem solving in the Parkinson’s world* were distinct but separate processes, through which all care partnerships described passing. They are proposed sequentially as all care partnerships described some ‘tipping
point’ where they entered the second process, and there was never a return to the ‘pre-Parkinson’s world’ process. Three themes related to navigating the system were: the primary healthcare provider, building a relationship with the specialist, and receiving the diagnosis. Three themes related to the process of problem solving in the Parkinson’s world were described in terms of resources accessed by participants when faced with PD-related challenges: building support, the couple on their own, and gathering knowledge (Figure 1). Learning to navigate the system was a meaningful experience for participants, as it defined their relationship with their primary medical contact: the PD neurologist. All participants described a tipping point of accepting that they have entered the Parkinson’s world which was often associated with receiving their diagnosis or beginning PD medications, for example. After transitioning into the Parkinson’s world, learning to live with PD was achieved by integrating several resources. Couples would draw on these resources differently depending on their coping style and the problem at hand. Despite the varying contribution of these resources, couples learned new skills every time a solution was identified or a new equilibrium was established in order to move forward. Couples moved through the problem-solving process at different rates, depending on their coping styles, accessibility of the three resources, complicating factors, and past experiences with PD.

4.3.3 Navigating the System

Navigating the system began with noticing symptoms and deciding to seek medical attention from the primary healthcare provider, which was typically the family physician. Couples described various symptoms that prompted them to seek medical evaluation, however, when recounting their decisions to see their family doctors, all
Figure 1. The process of care partnerships learning to care for themselves while living with Parkinson's disease.
participants described symptoms that had been present for a considerable period of time before their first formal assessment.

In addition to the small handwriting, he was shuffling. Which to me is a sign like that (snapped fingers). He was shuffling. Um, he, his – everything had become slow. (Participant 2, care partner)

There was um, a point when I found that my right arm was just kind of lifeless, even when I was walking the other arm made a stride but this one would just sit here. That was the first thing I noticed, but later on I realized I had other symptoms that I hadn’t noticed. (Participant 5, diagnosed with PD)

Well the first thing I noticed was problems with my speech, particularly hypotonia, so that it became increasingly difficult – I give a lot of lectures and stuff – projecting my voice. (Participant 13, diagnosed with PD)

Accounts of the time immediately after referral typically involved long periods of waiting, while the couple questioned if they would be diagnosed with Parkinson’s. This time was often characterized by questions and anxiety.

And it took a year to get into a specialist. Well I shouldn’t say a year. It took 8 months and then they said 2 more months. And I said, “No he’s falling out in the
street and everything – people picking him up” and then the doctor said, “Well, you can’t get in, it’s all booked”. Well it was 2 months that we were supposed to go. And then what? Now 4, 6, 8, now you’re telling me 10. I said “No”. And he said, “Well what are you going to do?” and I said “I’m going to the hospital with [spouse], I’m not going home, ‘cause I don’t know what to do anymore”.

(Participant 8, care partner)

I did have changes on my MRI, but, you can’t get a diagnosis of Parkinson’s out of an MRI. And I actually didn’t meet the criteria for Parkinson’s, and there are other things that can cause those symptoms – Parkinson’s is not the worst. But I was really sensitive to the labelling, I didn’t really want to be labelled as a person with Parkinson’s – particularly when I didn’t meet the criteria. (Participant 13, diagnosed with PD)

I would describe, for me anyways, and I think for you (to spouse), quite tumultuous. A tumultuous time. Difficult time. Cause [spouse], I don’t know, was in some denial to some extent, I don’t know if it was, ah, kind of the semantics, sort of like “I don’t have Parkinson’s” but it was because a definite diagnosis hadn’t been given yet. (Participant 14, care partner)

During the initial visits with the specialist, participants described a range of interactions that indicated a therapeutic relationship was beginning to form. Building a
relationship with the specialist, including their perception of whether their initial expectations were met, seemed to influence the couple’s perception of their level of care.

I was a little disappointed with the healthcare people because, uh nobody ever really came close to telling – I won’t say not telling the truth, they weren’t telling lies – but came close to disclosing you know what this disease entails, where does it lead, and what’s the ultimate, the ultimate, ah, thing that happens? Reading I think, of course discloses that. I was a little disappointed that the doctor and the physiotherapist never really, ah, discussed it. Maybe the physiotherapist really wasn’t the appropriate person to have that sort of discussion with. Anyways I had trouble with the doctor because the doctor really didn’t disclose it very much at all. (Participant 1, diagnosed with PD)

He’s wonderful. If I phone and talk to his research nurse, she comes right back with an answer. He doesn’t drop us off like [other healthcare professional]. No, he listens to her and then “bring her in, bring her in a little early – tell them at the desk that if there’s an opening, to put her in. (Participant 8, care partner)

Couples’ expectations surrounding the confirmation of their diagnosis and their therapeutic relationship appeared to impact their satisfaction with and level of confidence that the physician would adequately address their needs.

Yea, um, the neurologist um, is who he is, um, I’m not at all happy with him and I want to see if we can change. But that may be easier said than done… I don’t like
his manner. As [spouse] said, he didn’t give much information, said you should just bip babip babip, didn’t give a chance for any questions. And I just don’t tolerate that. I don’t like to be talked down to. And he didn’t say among other things, “do you have any questions?”.

Participant 2 (care partner)

Participant 8 (care partner): And the day we saw him the first time, remember? He said, “The first thing I wanna tell ya, is [spouse with PD], you’re not gonna die of Parkinson’s, cause nobody dies of Parkinson’s”. And he said, “You’ll hear everybody saying it, in the papers, you know, that they died from Parkinson’s – no they didn’t”.

Participant 7 (diagnosed with PD): And I didn’t want to break that record (laughs).

Participant 8 (care partner): Put him right at ease, saying all that…. Oh, he jokes with him. And then he pats him on the shoulder and says “You’re a good old guy”. Treats him just like it’s his grandfather.

Once I heard the word at the first appointment, I just went blank til I staggered to my car, got into my car, had a breakdown and tried to drive home without hitting anyone. I think I asked, “What’s going to happen?” and he said “Oh, it’s different for everyone.” Well that doesn’t help me. Tell me something… tell me that for the
first month, I won’t end up in the nursing home, because I thought I was. More information, better education. (Participant 15, diagnosed with PD)

Couples also described individualized preferences for information and what they would have liked at the time the diagnosis was communicated. Participants responses highlighted the range of needs and expectations placed on healthcare professionals.

Do you know Dr. [neurologist]’s book about Parkinson’s? Because to me that is the most wonderful thing. It is such a good thing. When I wonder about something I look it up and there it is. It is so clear and so concise, it is excellent. (Participant 4, care partner)

[The diagnosis] was kind of a non-experience. It was Dr [first neurologist they saw] actually. He had taken an interest in me but I would say it was at arm’s length. He didn’t do a lot of discussion any of the times I saw him. (Participant 5, diagnosed with PD)

Well, I felt that right from the beginning I was in great hands. I had no worries about the neurologist or any quarrel with any ways he managed the diagnosis or the treatment part of it. I had confidence in his judgment. He was open to discussion on various alternatives that were available. (Participant 13, diagnosed with PD)
The doctor doesn’t give you very much information, he just sort of says, “This is what you’ve got, and I’ll talk to you again in 9 months,” something like that, I started to look after myself. Right away I went to the library, took out all the books on Parkinson’s. (Participant 19, diagnosed with PD)

4.3.4 Bridge into the Parkinson’s World

After a series of healthcare provider appointments – learning to navigate the system – and receiving a confirmation of the PD diagnosis, couples described experiences that caused them to enter the Parkinson’s world. This was characterized by an acceptance of living with PD for the rest of their lives and a change in mindset that they would need to find solutions and coping strategies for moving forward.

And the Parkinson world really, is really well-served by people in the field. So I downloaded and copied brochures – actually I think the doctor gave it to us. The neurologist gave us a copy. It’s really a well-done piece of literature I would say. Um, so that really made me say, I said “Oh my god” my heart was like “Oh my god” the thing is, in other words, up until that point we were sort of like wishing things away. Yea because we hadn’t gotten an official diagnosis. Yea so, anyways.. So that was the initial – for me anyways – sort of the initial entry into the Parkinson’s world. (Participant 1, diagnosed with PD)
But I do remember it took quite awhile to get the medication balanced out. You know, one would be a dose increased a bit, or decreased a bit, or eliminated altogether. And it was at one of the sessions where he was writing out the prescription for the drugs I was gonna be on for the next six months, and I realized, I gotta take these damn things for the rest of my life. (Participant 12, diagnosed with PD)

These experiences of entering the Parkinson’s world depict a tipping point that give a sense of no returning to life as it was before PD. Participants recalled experiences that pushed them to accept their new state of living, and to begin the process of learning how they will continue to live with PD for the rest of their lives.

4.3.5 Inside the Parkinson’s World

Once inside the Parkinson’s world, care partnerships relied on various resources in order to maintain or improve their quality of life when faced with a new issue or problem, such as the manifestation of a new symptom, or the realization that the couple could no longer participate in the same activities they once did, for example. Participants provided several examples of successful problem solving, where ‘success’ is defined as the care partnership being able to identify a solution that fit within their daily activities and routines.

For many care partnerships, travelling was a highly valued activity that required some adjustment in order to achieve it. Couples described the importance of planning ahead, choosing different types of travel than they would have previously done, and new considerations that were previously taken for granted.
So we’re talking about maybe going to New York. Ok, well… we used to do a lot of walking. As I said, (spouse) used to walk me into exhaustion. Well, so, we’ll have to plan what we’re going to do much more carefully because, I mean the exercises have made a difference but he’s never going to be able to do what he did 5 years ago. Part of its aging, part of its Parkinson’s. (Participant 2, care partner)

Care partnerships often spoke about burden on the care partner and how they are managing the additional demands of caring for a spouse with a chronic illness.

He does get someone now 1 hour seven days a week and they get him ready for bed and do some massage and do some things that help make him feel better. So that’s helpful too, another little factor if that helps… We also have another group which is called Retire-at-Home, its one you hire… So we’ve kept her for 3 hours per week which is wonderful cause she’s really good with [spouse]. She cleans my house which is wonderful. (Participant 4, care partner)

And we do also have – but we did, we started when both of us were working, you know we have someone who comes and helps – and not particularly because of Parkinson’s, but it’s a part of our life – someone who comes several days a week to clean the house, and do laundry and do things like that to take some of the load off. And even though we’re retired we kept it going. And I suspect it’s just so we can have time for other things and because we can afford it. (Participant 6, care partner)
I guess I just always figured my role was feeding [spouse], getting her to exercise, going to appointments with her, making sure she has fun. And being a delightful person. I figured if I looked it up, that’s what it would say. However I could be wrong, maybe I’m missing something. (Participant 16, care partner)

Care partnerships described how they address planning for the future. Participants had various strategies, however seemed to be deliberate in their mindset and approach to planning for their future.

I try not to because I think that’s open for despair. That kind of thinking, you can’t really – with symptoms of Parkinson’s you can’t really predict which way you’re going to end up. So I think I’m doing better just kind of dealing with one day at a time. (Participant 5, diagnosed with PD)

A common discussion with participants involved strategies for energy conservation. Couples described deliberate planning and scaling back what they were once able to complete in a day. There was a general sense of acceptance of this new level of activity. Participant 19 (diagnosed with PD) explained, “Stamina… Yeah you just have to be realistic with yourself and try not to get frustrated with yourself. Just be aware that, ‘Well this isn’t going to happen today.’” Another participant described her strategy for the study interview:

This is what today is all about – this interview, I’m not going to do anything else. Because by the time we’re finished, I’ll be tired. Before you came, I’m just
anxious to see you and find out who you are and all that. So one important appointment per day is all I like to handle. That’s a significant difference because in previous decades, you know, I’m a multi-tasker – I can handle six major events in the same day, no problem, one handed. So that’s made a big, big difference. There’s also been positive in the sense that – because I’m going to be careful about my energy supply – I’m actually doing better when I go and see medical doctors, or go to get groceries, even. (Participant 6, diagnosed with PD)

Couples described how they have been able to maintain meaningful and enjoyable activities while living with PD. Some described adapting to their changing abilities by seeking new activities, while others implemented strategies to maintain activities previously important to the person diagnosed with PD. Participants appeared to develop a sense of accomplishment through their participation in meaningful activities, despite living with PD.

I think that that decision to step away from the martial arts, because I was having so much trouble – both the performance and the memory – that that turned out to be a very good move on my part. And now I’m going back to Tae Kwon Do on a very light basis, so to speak… I basically have withdrawn from a lot of activities. But on the other hand, I try to exploit those that I can still do. Like, for example, we created this salon so that I could display my art and I use this room to entertain one or two friends at a time who will come over here. Because I don’t travel so well anymore, (Participant 5, diagnosed with PD)
Yeah, I think things are falling off all the time. You start out with one, and you can do it for a while and then that falls off and you gotta do something else. So, its continuous, it’s a process. When you can’t do something, you have to do something else. (Participant 9, diagnosed with PD)

So I started learning Chinese characters. The months of the year, numbers, and seasons, I can’t remember what all there was. But anyway, Chinese characters are combined, you can put 2 or 3 characters together and get a fourth character. But the four characters have to fit on the same space on the piece of paper that each of the individual characters take up. Because Parkinson’s makes my handwriting small and cramped, I can draw those little characters! They were beautiful! (Participant 11, diagnosed with PD)

I’ve been a line dancer for 10 years, and I find its really, really important to keep moving. Everything I read says to keep moving. Move as often as you can, do exercises. You know, the books say do this, do that, and that sort of thing. So I line dance, I’m a good walker still, so I’ll make sure I go out. I don’t get out every day but I get out as often as I can. I do a good hard walk, um what’s the other thing? Oh, the Rock Steady boxing, is a new program, and I went and watched it on Monday. I’ll probably sign up for that, I haven’t yet, but I expect to, because everything I read about this boxing program is really, really good… Gentle Yoga. You do what you can, if you can’t do it, they don’t fuss about that, but I thought
the yoga classes were wonderful. Like, I can’t say enough good things about it.

(Participant 19, diagnosed with PD).

Participants’ stories of finding solutions and learning to live with PD, contributed to developing a model that would explain how this process occurs. Care partnerships living with PD referenced three resources when adjusting to new challenges related to living with PD: support, the couple on their own, and knowledge.

4.3.5.1 Support

Participants described searching for sources of support from family and from healthcare providers throughout their journey of living with PD. Care partnerships expressed gratitude for having adult children nearby and grappling with finding other sources of support if family did not live in accessible areas.

I would say try and find somebody around for the caretaker and the person to help lean on. Because, you know, because our daughter is here it just makes a huge, huge difference and we knew it would. And it’s wonderful, it really is, you know – you feel very much alone if you’re the caretaker and you really need somebody to sort of be around and cheer you up (laughs). And cheer him up. (Participant 4, care partner)

We get asked to babysit quite a lot so that keeps me busy… It tires you out. But its exercise. You have to get down on the floor, you have to get up, and bend over, so just those kinds of physical movements when you’re looking after a little
one, it’s gotta be beneficial, even if it makes you tired. (Participant 19, diagnosed with PD)

Participants emphasized the importance of, and appreciation for, community support. For example, Participant 21 (diagnosed with PD) explained: “some of the neighbours around, once they found out that I had Parkinson’s they were quite shocked. We had an amazing outpouring of support that I had in the community.”

Healthcare professionals, and particularly a PD specialist, were perceived to be the main sources of support for a range of care needs, and not only for treatment options.

[The neurologist] also goes in the ride for Parkinson’s every year, you know, gives you the feeling that he’s on the team. And we’ve also been to several lectures now, various kinds through various groups, and he has spoken sometimes, so we’re impressed with him. (Participant 10, care partner)

Participant 14 (care partner): We have a local physio, that when things crop up for either of us she’s sort of the go-to person in town here.

Participant 13 (diagnosed with PD): We’ve got a good team. The speech pathology, actually, I just had a message from dancing for Parkinson’s, that someone is working in the [city] area. So I’m going to look into that. It’s not like you can fix my voice, but there’s things you can do with your voice, if you practice them, just like the exercise for your balance and so on, that will help.
The pharmacist, in [town]. Yeah, he’s really good ‘cause if I get a new drug to take, he wants to know whether it’s going to coincide or affect any Parkinson’s meds. And he’s always keeping fairly close tabs on me. Anything that’s new. (Participant 21, diagnosed with PD).

Participants described their information needs from healthcare professionals as a source of support as well. Participants had varying expectations and informational needs.

Some people don’t want to know why and what’s going on, and whatever. But the ones who talk about what’s going on give me a little bit more confidence. But I’m curious about knowing those kinds of things, maybe not everyone is. (Participant 6, care partner)

Maybe there could be more information available through the Parkinson’s doctors because they’re your first, they’re the ones you reach first. Maybe they could have some specialized nurses who take the time with you afterwards, and keep in touch with you? Do they have time for that? (Participant 10, care partner)

Dr [neurologist] didn’t say anything about learning all that you can, he just said, “We’ll talk more.” Don’t be afraid to talk to other people… I didn’t know there was a Parkinson’s Society of Ontario. But I found it online. If he had given me a
list of, “Contact these people in your neighbourhood” kind of thing, that would have been one step that I could have done a little bit quicker than I did. (Participant 19, diagnosed with PD).

But what exercise is good for you? That’s another factor. What should you be doing? That’s where somebody – it doesn’t have to be a doctor. It could be a physiotherapist (Participant 23, diagnosed with PD)

Participants were often actively seeking information, however, it seemed that confidence in their ability to find relevant answers or appropriate sources presented the biggest challenge. Conflicting information provided by different healthcare professionals also appeared to add to feelings of confusion and frustration.

Few participants described building a social support network. Participant 17 (diagnosed with PD) referred to the social support – perhaps at the expense of factual information – provided by meeting others living with PD at support groups, “we learned we can inform one another, we can talk to one another, and maybe we’re not giving the correct information, you know, and we pass it on anyway.”

If care partnerships were not able to establish a support network of family and social connections, it was apparent that the couple quickly became isolated. For example, when asked where to go to for help, Participant 10 (care partner) replied, “Hm. Yeah. Well, we’re… we’re it. We’re fairly knowledgeable, we’ve researched it a lot,” and
participant 23 (diagnosed with PD) simply stated, “Nowhere.” Others described the social implications of living with PD and some more noticeable symptoms in particular:

He doesn’t want to go out and cry in front of people. In his words, he says it makes him feel dumb. So, there are a lot of things about Parkinson’s that are even more isolating. And society on the whole doesn’t know about that. (Participant 8, care partner)

We had a sailboat, and I’d get dizzy spells on the sailboat so, you know, I figured a sailboat wasn’t a good thing to have, so we sold it. Now what that did, in a sailboat we’re just the two of us and that’s it. But the yacht club had a thousand members. Suddenly you no longer have a social interface or interaction with that thousand members. They’ve got sailboats, they go sailing. What do we got? (Participant 11, diagnosed with PD)

Yeah, one of the things that’s gonna keep me in the house in the not-too-distant future is eating. I have a hell of a time eating… My hands shake. The closer the food gets to my face, the more it shakes, and so my head is going down, the spoon is coming up, it’s gotta be an awful looking sight. (Participant 9, diagnosed with PD)

Care partnerships seemed to accept their isolation, rather than seek out new connections as their symptoms changed.
4.3.5.2 Couple on their Own

Another resource for adapting to changes and learning how to live with PD was the couple themselves. Participants described finding strategies through their experiences in order to adapt to and overcome challenges. Navigating changes in abilities due to PD often involved a renegotiation of roles between the couple. Transportation in particular was a prominent concern that had to be addressed amongst the couples.

And anyways, all I meant is that losing it meant the burden of transportation fell on my wife. Ordinarily at least I could go a few blocks in a car, if I had to, I could drive myself. But I couldn’t do that without a driver’s license, so it all fell on her. (Participant 1, diagnosed with PD)

I do pretty much everything. I certainly do all the money things, which he did before. Certainly all the wash– he used to help with the dishes but he doesn’t do that because it’s too- well he can’t do it. So I do all the meals and all the cleanup. And I now do all the driving which, was a big change, because he always drove you know, males always do. (Participant 4, care partner)

Now I was always very independent with the car, so I could go anywhere and do anything and be participating or else contributing to my household and so on. Looking back, it was I think the hardest thing I had to deal with – looking back over 20 years. … Like, for example [spouse] and I had a discussion about how
he’s gonna have to drive me around. Well, we – he says he doesn’t mind doing
that cause he likes to drive and he likes to be involved. But I feel like it’s a burden
on him and I have to organize my interests and days around his schedule. Because
I don’t want to make too much demand on him when he already has his own
demands. (Participant 5, diagnosed with PD)

Yeah, go to the cleaners, go do some grocery shopping, any of the number of
things that he would do to keep the load somewhat even in terms of looking after
the house. You know, that’s largely gone. (Participant 2)

Both the care partner and the person diagnosed with PD were living the reality of
the disease. For couples who were recently diagnosed, the care partner may not have
entered the Parkinson’s world yet, such as one care partner who explained:

[My role] really is just trying to be understanding, I think, about her concerns.
There’s not a lot that I can do. I can try and remind her about her pills if she’s
forgetting those, but usually she remembers those. I don’t feel I have a lot I can
offer her at this point in time. Participant 22 (care partner)

For the majority of care partnerships, however, the care partner played an integral role in
managing symptoms of PD in everyday life. Participant 15 (care partner) questioned how
others with a chronic illness manage without a care partner: “but how does one person
[manage] without – cause there are people out there who don’t have that – without a
caring brother or sister or parent or something?”
The care partner’s perspective and insight into their spouse’s changing abilities, combined with a tendency to compensate for the spouse’s lack of insight or denial about their symptoms, may have been acting as a buffer for the person diagnosed with PD. For example, when asked how their symptoms have changed from the time of diagnosis to present, Participant 3 (diagnosed with PD) seemed to be unaware of their symptom progression: “That’s a good question. Not dramatically I think. I have the same problems I had at the outset,” while the care partner responded, “But more. Much weaker, physically. Much weaker. He says sometimes ‘I can’t move, I’m tired, I’m so weak I can’t do anything’. Which he does – which is true.” When asked if they could offer any advice to others newly diagnosed, participants diagnosed with PD responded with, “No, I can’t think of anything” (Participant 3); “You have to accept it and pray for the best” (Participant 7); “Just go with it, I guess. Go where it leads you. Everything clears up on its own, to reach an equilibrium” (Participant 9); and “But I don’t see how you could give people advice. Try to keep smiling” (Participant 11). Participant 21 (diagnosed with PD) acknowledged, “This has all just fallen into place for me. So rather than having to do all the digging myself, everybody seems to look out for me.” In contrast, care partners had very specific advice, based on their experiences of living with PD and adapting to change:

You need to think ahead, um, and not just think “Oh well, someday we’ll move”… And it’s a good thing we did, because [spouse] is quite a bit worse now. I mean just the physical activity involved in moving is horrendous and the longer you wait, the worse it’s gonna be. (Participant 12, care partner)
Well, one piece of advice would be, if you’re first diagnosed, you better do all the travelling and other types of activities very soon, because probably in 5 years you’re not going to be able to do it. (Participant 10, care partner)

It seemed that care partners provided a sheltering effect to improve the quality of life for their spouse, often at their own expense. Couples described an understanding of the burden placed on the spouse who was the care partner.

But I have a caregiver who is so committed that she’s not gonna cart me off somewhere. Although I want to be brought somewhere to relieve her of the strain of having to care for somebody else. So you’re caught in a dilemma. And it’s not a pure selfish dilemma. My concern is why should my great partner (voice breaks) have to suffer as much as she does [while] coping with this? (Participant 3, diagnosed with PD)

The caregiver’s question is absolutely critical… The caregiver has to deal with it. The neurologist doesn’t know that as a patient, and you’re restricted to time, but the other person has 24 hours a day – how do you put up with someone with hallucinations? (Participant 2, diagnosed with PD)

I guess, in any doctor-patient relationship, the patient is always the primary focus. So in some ways it’s not really realistic to think that there’s going to be much time being spent with the caregiver and what their needs are. And I sort of see that
as a gap in the system. It shouldn’t necessarily be up to the neurologist to do that, but there doesn’t really seem to be anyone else to help out with that. So for me, it’s been a lot. (Participant 14, care partner)

Both the care partner and person diagnosed with PD acknowledged the burden of providing care to their spouse, but seemed unaware of resources for support in managing this role.

Additional interviews were conducted with care partners and participants diagnosed with PD separately to determine if any further insight into the care partner perspective would be available in a setting without the spouse present. No new categories emerged, however, previous categories were reinforced:

And like, I don’t know anything about pills, but I know that the schedule said 8, 10, 2, whatever. And, um, it makes he and I rub together because he won’t do it (crying). So that’s the kind of thing I think we need help with. He needs help. I think its him that needs the help. So that I can stay out of it. So, I just think, I can’t handle him anymore. And I’m just about ready to leave, but I can’t do that, cause that’s not the right thing to do. I don’t want to leave. (Participant 18, care partner)

I find that the biggest thing is mental. It’s not – like it is physical for sure – and it’s changed a lot of our lives… But (pause, crying). It’s mental more than anything… I can’t get away from him. We’re together 24/7… He’s a mean
person. So. That needs to be addressed more than anything. The mental side…

I’m going to [his] appointments, but I can’t talk in front of him… It would be nice to be able to talk to somebody, like the nurse or whatever, about your concerns without him in the room. (Participant 22, care partner)

4.3.5.3 Knowledge

Methods of gathering information varied for couples, but all described seeking and building knowledge of PD and how to manage symptoms. Participants considered the benefits and drawbacks of attending support groups.

And they’re very caring. They don’t judge – if they do, they hide it if they are. They’re good listeners. I’m very impressed with how they deal with all the uncertainties that victims feel… We find it terribly important to fill in the details. (Participant 3, diagnosed with PD)

To tell you the truth, I just didn’t want to see how other people are affected. I wanted to deal with this face to face, my own self… I just haven’t had the urge to go and find out about what might happen to me, how this thing might develop for me. I don’t want to see other people, it’s too confusing, I just want to deal with this on my own as much as I can. (Participant 5, diagnosed with PD)
[Spouse] has decided he doesn’t want to be in a group of people who are unwell, he wants to be in the general society. But, I thought, it might be good for us to get back in there, for me anyway. Because it’s important for caregivers. (Participant 10, care partner)

Now, I was very, very, afraid to go to a support group… And I didn’t want to see my future. Cause I cope with this thing by living in the day. In the here and now. One week at a time, one day at a time. And I didn’t want to see people who were at the end stage or whatever. But we went to the one with the open house, and that was good. (Participant 15, diagnosed with PD)

Care partnerships had varying expectations of support groups and described their benefits or drawbacks depending on their experiences and general approach to living with PD. Participant 23 believed it was the best source of information: “What are the stages of Parkinson’s and what can you do to help yourself… And that’s the only way you learn is from somebody else.”

Participants also relied on their own experiences to learn how to live with PD, as many emphasized that the journey through PD is highly individualized. Participant 3 (diagnosed with PD) described the difficulty of finding generalizations for living with PD, “you’re testing it out and some things work and some things don’t work… Some things work for the particular circumstances of a particular case.” Similarly, participant 12 (care partner) explained that, “other people’s symptoms may not be what [spouse] has.” By learning through their experiences, participants acknowledged how they need to
do their usual activities differently now, and with more conscious effort, as a result of living with PD:

Sometimes you feel really energetic and limbs aren’t as stiff. And then there are other times when you really just (sigh) you just can’t get to where you’re going very quickly. So… anyways, that’s what I’ve discovered anyways, that some days are better than others. (Participant 3, diagnosed with PD)

The most important thing is don’t get in a hurry, cause I can’t hurry. Walking across the floor will take me 5 minutes, sometimes. That’s terrible. And I was always quick. When I did something, I did it fast and got it over with. It goes on for days now, sometimes. (Participant 7, diagnosed with PD)

Because, I mean, to get coffee, if you have to walk to get the coffee, you have to be able to walk, think about the shaking, and move through the people, and I don’t know, there’s a lot of skill that you forget that’s required just to go get a cup of coffee when it’s across the room. (Participant 12, care partner)

Couples also conducted their own research either proactively or as issues arose. Care partnerships described their sources when conducting PD research: “Well generally I do good medical places like The Mayo clinic, where you know it’s something probably good” (Participant 4, care partner); “Michael J. Fox and his website… He’s got a list of all the research that’s going on” (Participant 9, diagnosed with PD); “I’ve been reading
books by people who have Parkinson's to get the life experience part of it. And then I look on the web on various problems as they arise” (Participant 13, diagnosed with PD); and “The Parkinson’s Society Canada, they have a lot of webinars online, so I listen to a lot of those and found those helpful” (Participant 14, care partner). Other participants described still wanting the final word to come from a physician, and therefore felt more reluctant to seek information themselves:

Most of the information we get is from the PD meetings, you know, or from talking to friends. And that’s not the right way to do it. Or you can get it on the internet. On the internet’s not a good idea, because, possibly, it’s not right. Like, I always figure that if I want the truth, or a real answer, you have to get it from the doctor. (Participant 18, care partner)

Some participants expressed a sense of responsibility and duty to learn about PD and how to manage different symptoms. For example, Participant 1 (diagnosed with PD) stated, “I guess these diseases in a sense are managed by the patient and the family, you have to take a lot of initiative basically.” Similarly, Participant 9 (diagnosed with PD) advised others to “research it yourself to stay up on top of what’s happening. So, you know what to do.”

The participants in this study relied on varying combinations of support, the couple themselves, and knowledge in order to find solutions and learn to live with PD as a partnership. Learning to live with PD was accomplished through overcoming challenges and adjusting to changes associated with PD symptoms.
4.4 Discussion

The main findings of this study of care partnerships – that is, spousal couples where one person is diagnosed with PD, and the other is the primary care partner – suggest that navigating the system prior to and throughout diagnosis, and moving into and adapting to life in the Parkinson’s world are two processes by which they learn to live with PD. Findings from this study are contextualized within a particular time and place, participants’ realities, and my own interpretations (Charmaz, 2008). Although not ‘generalizable’ to all people living with PD, several implications may be interpreted from this study for anyone who may be interested in learning how care partnerships learn to live with PD – people living with PD themselves, healthcare professionals, policy makers or community associations, for example. Insights generated from this study enhance understandings of inherent values, assumptions and meanings underlying the behaviours and actions of care partnerships living with PD. Knowledge gained from these findings may motivate stakeholders to reflexively evaluate their own practices that may influence and affect the process of how care partnerships learn self-management skills to live with PD for improved overall wellbeing.

Understanding how people living with PD manage their condition has been highlighted in previous studies from various perspectives such as, coping (Thordardottir, et al., 2014; Navarta-Sanchez et al., 2017), quality of life (Kang & Ellis-Hill, 2015; Van Uem, et al., 2016), occupational participation (Sperens, Hamburg, & Hariz, 2018) and self-management (Kessler & Liddy, 2017), to name a few examples. Care partnerships living with PD have valuable insight into how they have learned to live with PD that
would contribute to efforts of providing client-centred care (Phillips et al., 2015).

Nevertheless, there are no widely accepted guidelines for the processes involved in
learning to live with PD, particularly from the care partnership dual-perspective. This
ambiguity in the meanings and experiences of people learning to live with PD lends itself
to uncertainty when making decisions that will impact the development and delivery of
clinical care models. Elucidating the processes by which care partnerships learn to live
with their condition may not only impact the direct provision of clinical care, but may
also add to larger, socially accepted understandings of PD, self-management, and client-
centred care, which are disseminated in healthcare-related discourses.

4.4.1 Navigating the System throughout the Diagnosis

All participants described a number of meaningful interactions throughout the
initial experiences surrounding their diagnosis of PD. Navigating the system involved
seeking attention from their primary healthcare provider for an initial assessment, most
often their family physician, being referred to and working to establish a relationship with
a specialist, such as a neurologist, and finally, receiving the diagnosis of PD. Each of
these stages were separated by periods of waiting, that were characterized by uncertainty
and searching for answers. In the overall process of living with PD, the initial experiences
associated with learning to navigate the healthcare system as it related to PD, was the first
process through which all participants described as highly meaningful in their journey of
adapting to living with PD. Participants perceived supportive and less helpful interactions
with various healthcare professionals which largely impacted their confidence in the level
of care they received, as well as their initial attempts to navigate the system effectively.
Importantly, the end of this initial ‘diagnosis’ phase marked the beginning of a notable phase of transition into the ‘Parkinson’s world’ via a bridge. The bridge served as a representation for meaningful experiences that resulted in acceptance of living with PD, although the specific events varied amongst the care partnerships, such as receiving a confirmed diagnosis, or beginning to take PD medications, for example.

The reasons for initially seeking medical attention varied across participants, and, upon reflection, participants recalled that their symptoms had been present for a length of time before their formal assessment. This has similarly been described in others’ research findings, indicating that people living with PD develop symptoms an average of 6.6 years prior to diagnosis, and that only one third of early symptoms involve musculoskeletal symptoms (Farnikova, Krobot, Kanovsky, 2012). In contrast, others have shown that 21% of people with PD present to their primary healthcare provider with non-motor symptoms, including pain, urinary dysfunction, anxiety or depression (O’Sullivan, et al., 2008). This variability in presenting symptoms may contribute to extended periods of waiting and searching for answers as primary healthcare providers attempt to determine the cause of their clients’ symptoms.

Several periods of waiting were described by participants, namely between the initial visit with their primary care physician and the time for referral to a specialist, most commonly a movement disorders neurologist. Some described another period of waiting between their initial assessment and receiving confirmation of their diagnosis. Also contributing to the common description of uncertainty and waiting surrounding the diagnosis of PD is the lack of diagnostic procedures. Diagnosing a client with PD is largely based on clinical presentation and there are a number of neurologic conditions
that mimic the disease, making it difficult to diagnose in its early stages, particularly by non-PD specialists (Gazewood, Richards & Clebak, 2013). National patterns of initial diagnosis and treatment in PD have been described which confirm the variability in initial assessment and diagnostic approaches, based on a number of highly variable clinical and clinician-specific factors (Lage, Tarrants, & Castelli-Haley, 2010). Breen and colleagues (2013) explained their findings related to delayed diagnosis in PD and attributed male sex and presenting motor phenotype with delayed primary care provider presentation. Additionally, patients presenting with gait disturbance experienced the longest delay, whilst those presenting with tremor had the shortest (Breen, et al., 2013). Presenting with non-motor symptoms has also been shown to delay diagnosis (O’Sullivan, et al., 2008). Plouvier and colleagues (2015) discussed that although the journey to diagnosis is full of questioning and waiting, people living with PD are ultimately satisfied with their pathway to diagnosis, however there are improvements to be made with respect to recognizing symptoms during the prodromal stage.

Throughout this period of waiting and uncertainty prior to diagnosis, many participants described either confidence or disappointment in their interactions with healthcare providers. Previous research has discussed the influence of the ‘patient-physician’ relationship in healthcare settings for older adults and has highlighted the importance of effective, sensitive, and empathetic communication as an essential part of their care (Williams, Haskard & DiMatteo, 2007). Furthermore, accurate patient expectations have been identified as a key factor in optimizing treatment success for complex health conditions (Wiering, et al., 2018). Although the period of time before receiving a confirmed diagnosis of PD is perhaps expected to be tumultuous, full of angst
and questioning, it seems that some interpretations of clinician attributes or behaviours contributed to participants’ perception of trust in their care. It is acknowledged that having conversations with clients to define and moderate expectations will take valuable time from clinical appointments, however, findings from this study, as well as the work of others, suggest that these conversations may contribute to greater client satisfaction and even improve health outcomes (Benedetti, et al., 2003; Grosset & Grosset, 2005; van der Eijk, et al., 2013; Shimbo et al., 2004).

Through participants’ descriptions of the process to PD diagnosis, it became apparent that some learning was required about the roles of various healthcare providers which, at this stage, included their primary care physician and specialists to whom they were referred. They also learned about periods of waiting as an integral part of the process for diagnosis.

4.4.2 A Bridge into the Parkinson’s World: Accepting the Diagnosis

After receiving their diagnosis, participants described feelings and events that likened to stages of grief in coming to acceptance of their condition, which effected a change of their identity to someone living with PD – described in this study as crossing the bridge ‘into the Parkinson’s world’. Most commonly, the bridge ‘into the Parkinson’s world’ was associated with beginning to take medications, a change in meaningful activity they were no longer able to complete, or in which they could no longer participate in the same way. A sense of losing control, as a result of taking medications or a change in meaningful activities, for example, has been associated with the process of
acceptance of a new or changing identity in previous work (Eccles, Murray, & Simpson, 2010). Others have described in-depth the process of accepting a new identity after being diagnosed with PD, stating, “The emotional force of the diagnosis vibrated, instantly changing their identity and the fundamental aspects of how participants knew themselves” (Vann-Ward, Morse & Charmaz, 2017, pp. 969). How participants accepted a new identity during these initial turning points was not explored in this sample, however there was a clear demarcation of being different in the sense that participants were not the same as they were prior to their diagnosis. Acceptance of PD in the sense of being at peace with their new identity was a process that continued long into the ‘Parkinson’s world’ as the definition of self continued to adapt over time (Eccles, Murray & Simpson, 2010; Lutz, et al., 2018; Smith & Shaw, 2017; Vann-Ward, Morse & Charmaz, 2017).

4.4.3 Adapting to Life in the Parkinson’s World

Living in the ‘Parkinson’s world’ marked a new state of being once participants had accepted a change in their identity, as a result of receiving the diagnosis of PD. Once in the Parkinson’s World, there was a recurring problem solving process as new challenges arose due to the progressive nature, emergence of new symptoms, and ever changing physical abilities. There were three main resources that care partnerships accessed when faced with new challenges: support from healthcare professionals, family, and social contacts; the couple themselves; and their knowledge obtained through past experiences.
4.4.3.1 Support

Care partnerships described several sources of support including information and treatment interventions from healthcare providers. Healthcare professionals specifically named by care partnerships were neurologists, family physicians, physiotherapists, massage therapists and pharmacists. One care partner also mentioned speaking with a social worker. Building an interdisciplinary team of healthcare professionals has been described as an essential ingredient for successful management of care partnerships living with PD, both in hospital (Giladi et al., 2014) and homecare settings (Ben-Pazi, et al., 2018; Fleisher, et al., 2018). However, this type of multidisciplinary healthcare is not widely available in publicly funded healthcare systems (Post et al., 2011). Some care partnerships sought care from professionals other than their physicians to complement the management of their condition, typically through word-of-mouth referrals from their social circles, or, less commonly, through medical referral. The lack of continuity from physicians to private services may be a reflection of barriers to access these services, including lack of public funding, as well as patient-specific factors such as transportation (Chataway, et al., 2012). Nevertheless, it seems people living with PD rely heavily on their healthcare providers for support in managing their condition. A potential consequence of relying solely on healthcare providers is limited accessibility, and therefore may result in a perception of distant and inconsistent support.

Family and social contacts were another source of support, however, not uniformly across the sample, as opposed to support received from healthcare providers. Social support is identified in this process as any unpaid, non-medical family or community organizations who may be able to engage the care partnership in regular visits
or activities. Social supports have been identified as playing a central role in mitigating anxiety and depression in people living with PD, and it has been suggested that the informal support network of the care partnership be frequently re-evaluated (Saeedian, et al., 2014). The connection between social support and well-being is not surprising, as associations have been made between social support, stress associated with health status, and cognitive function in older adults (Sherman et al., 2016; Liao & Scholes, 2017). The benefit of social support has also been identified for care partners, and is acknowledged as a social determinant of health in older adults as well (Chappell & Funk, 2011). This finding is supported by the existing literature that support for the care partnership from informal social networks as well as from formal healthcare providers is critical for learning to live with PD.

4.4.3.2 The Couple Themselves

Care partnerships described their strategies for addressing new challenges often from within their own abilities as a partnership. The dynamics of the care partnership were moderated by the renegotiation of roles, given the changing abilities of the person with PD, as well as the care partner’s perspective of ‘care burden’. The renegotiation of roles within a spousal couple where one person has a chronic illness is not unique to PD (Bull & McShane, 2002; Liu et al., 2017; Whitehead, et al., 2018). However, the periodic emergence of symptoms and progressive nature of PD require iterative negotiations of roles and redefinition of self amongst spousal couples in order to complete their daily activities and participate in meaningful occupations (Barken, 2014; Erlingsson, Magnusson & Hanson, 2012). The prominent negotiations in this sample revolved around
transportation, travel and daily activities, such as cooking, cleaning, home maintenance, and financial responsibilities.

The care partner perspective is an important factor influencing the care partnership’s general approach to living with PD. Caregiver burden is described in the literature as clinically salient and multifaceted for care partners caring for a spouse diagnosed with PD (Martin, 2015; Martinez-Martin, et al., 2007; Roland, Johnson & Jenkins, 2011). Care partner burden and health outcomes are moderated by a number of factors, including depression and presence of psychiatric symptoms (Schrag et al., 2006), functional ability to complete activities of daily living (Santos-García & Fuente-Fernández, 2015), presence of falls (Schrag, et al., 2006) and mutuality of the marital relationship (Tanji et al., 2008). Others have identified the severity of non-motor signs, patients' and caregivers’ mood, and motor disease severity as the main determinants of caregiver burden (Videaud, et al., 2018). The care partner’s health, caregiving ‘typology’ (Davis, et al., 2014), the types of PD symptoms present, and marital dynamics all contributed to the couple being able to problem solve and address challenges on their own. Considering the numerous factors that have been identified, the variability of PD symptoms and dynamics within a care partnership, addressing care burden is challenging for any one healthcare provider within their clinical appointments. However, the existing literature and findings from this study suggest that support for a partnership approach to managing living with PD is warranted.

4.4.3.3 Knowledge

The final theme identified was the care partnership’s health-related knowledge they had curated throughout the process of living with PD, both from their own personal
experiences of living with PD, and from researching information either online or obtained from stories of others living with PD. Most participants had done some online research related to how PD affects people, however, described their uncertainty about knowing which online sources were trustworthy. Despite this, efforts are being made to understand the utility and to increase delivery of information and support via online platforms for people living with PD (Attard & Coulson, 2012; van der Eijk, 2013). A qualitative study using nominal group technique identified three areas of information as most important for learning to live with PD: Coping with emotions, changing relationships, and social implications of PD (Kleiner-Fisman, Gryfe & Naglie, 2013). Creating accurate, reputable online resources seems to be a promising approach for care partnerships accessing online resources, as the more frequently a person uses the internet as a source of health information, the more likely they are to change their health behavior (Ayers & Kronenfeld, 2007).

Stories of others living with PD were also translated into knowledge for some care partnerships. The processes whereby people's experiences become, or fail to become, valued as sources of health-related knowledge has been described from the perspective of identity work involved in turning other people's experiences into 'experiential knowledge' that can be shared between patients (Mazanderani, Locock & Powell, 2012). Stories of living with PD seemed to be most often shared at support groups. Participation in support groups has been associated with better quality of life and fewer symptoms of depression, anxiety and social phobia (Artigas, et al., 2015). Peer-led support groups for care partners can provide a “safe restful haven” and decrease strain for care partners (Abendroth, Greenblum, & Gray, 2014, pp. 53). There are varying factors to determine whether a care
partnership will access and find support groups helpful, including their level of fear and anxiety related to death (Lieberman, 2007), past experiences related to unwanted interactions and reactions (Pallant & Himmel, 2019), perceived credibility of shared information (Dorsey, et al., 2010), availability, accessibility, and whether social engagement and a sense of belonging or connectedness is generated through interaction with the group (Dare, et al., 2017). Personal factors, as opposed to medical condition or mental health status, has a greater impact on whether care partnerships will access and continue to participate in peer support groups (Sautier, et al., 2014).

4.4.4 Factors that Facilitate or provide Resistance to the Theoretical Process

While speaking with care partnerships throughout this study, it became apparent that some couples were more accustomed to and had strategies in place to address new challenges in a way that suited their disease management styles – both of which were independent of the number of years since being diagnosed.

Factors that facilitated the process included participation in support groups, regular access to information, and an understanding of healthcare provider roles from whom they could seek guidance for solving or overcoming relevant challenges. Charlton & Barrow (2002) identified core differences in members and non-members of PD support groups, indicating that, for group members, the disease and its likely consequences were accepted and incorporated into everyday life and support groups were identified as a positive resource. This may contribute to the proactive problem solving characteristics of care partnerships as they navigated through the episodic nature of the effects of PD. The
ability to manage disruptions caused by PD, accepting limitations and maintaining continuity with pre-illness lives have similarly been identified as important attributes to maintaining quality of life while living with PD (Whitney, 2004).

Resistance was identified in couples if they were unable to identify solutions to current challenges, or were unable to identify possible sources of support for addressing PD concerns. Factors that increased resistance to this process were social isolation, denial or resistance to accept their condition, and decreased confidence in the care received from their healthcare professionals. Vann-Ward, Morse & Charmaz (2017) described a process through which people living with PD achieve a preservation of self while accepting their new life with PD. If the person diagnosed with PD is unable to overcome identity dilemmas and reconnect with a new definition of self, they may be unable to transition into acceptance or envision a future (Vann-Ward, Morse, & Charmaz, 2017). Resistance factors may contribute to a less effective coping style or management strategy for care partnerships living with PD. These may be viable clinical targets to optimize self-management interventions and empower care partnerships to be more active in their care.

4.5 Conclusion

This study presented the process of care partnerships acquiring self-management skills while living with PD. This research first described the challenging process of the care partnership learning to navigate the system – fraught with uncertainty, questioning, and searching for answers – before accepting their diagnosis and entering the Parkinson’s world. The process of acquiring self-management skills was described in terms of key resources for problem solving, including sources of support, the couple themselves, and
knowledge gained through research and experience. These resources may be important considerations for clinicians seeking to facilitate self-management education and skills for the care partnership living with PD. Insights from this study may encourage clinicians and community organizations to consider their clients’ understandings of living with PD and how they may influence their approach to addressing and designing self-management education for the care partnership living with PD.
4.6 References


5 Healthcare Professionals’ Process of Caring for the Care Partnership living with Parkinson’s disease

Parkinson’s disease (PD) is a condition with a complex and diverse phenotype where people become progressively incapacitated, not only due to the well-known motor symptoms of bradykinesia, rigidity, tremor, gait impairment and postural instability, but also because of a vast array of non-motor symptoms. Owing to the multisystem and multidimensional effects of PD symptomatology, healthcare professionals from different disciplines can specialize in caring for people living with PD and address specific aspects of the condition. While pharmacological intervention remains a cornerstone of traditional PD management, national guidelines and new evidence continue to emerge supporting ‘alternative’ therapies to meet clients’ care goals through a client-centred care plan in conjunction with appropriate pharmacology (Grimes, et al., 2012; Bloem, de Vries, & Ebersbach, 2015).

Previous research has investigated approaches to clinical care interventions designed to improve clients’ knowledge and skills through self-management education and strategic communication for various chronic diseases (Coster & Norman, 2009). The findings echo the general sentiment in the literature that client education is critical to delivering client-centred care for chronic disease management, however the specific components required for that care to be effective remain to be defined (Coster & Norman, 2009; Davies, et al., 2018; Mudge, et al., 2015). As the prevalence of PD and other long-term conditions, continues to rise and pressure on public healthcare budgets increases, there is growing interest and advocacy for self-management support to improve the health
and sustainability of health services (WHO, 2013; and Farmanova, et al., 2016). It is therefore reasonable to expect clinicians from various disciplines will endeavour to provide client-centred care through self-management education for the care partnership living with PD, however, specific investigations into such clinical decisions and processes remain to be presented. In order to improve client-centred care for the care partnership living with PD, it is important to understand the process of how clinicians create and communicate their care package for this client population.

The purpose of this study was to describe and interpret a theoretical process undertaken by clinicians in their effort to include self-management education in their care for clients living with PD. Insights generated from this research may enhance understandings of inherent values and assumptions underlying clinicians’ care decisions, which may encourage healthcare professionals to contemplate their actions while caring for people living with PD in their respective settings.

5.1 Methodology

This study followed a constructivist grounded theory approach, as described by Charmaz (2006), to investigate and understand the process of healthcare professionals caring for care partnerships living with PD. Constructivism acknowledges “mutual creation of knowledge by the viewer and the viewed” (pp. 250) and, as such, provides a perspective from which understandings of meaning may be interpreted through participants’ stories. (Charmaz, 2003). This approach provides researchers the opportunity to construct meaningful understandings of participants’ experiences and theorize processes without claims of an objectivist or external approach to the data.
(Charmaz, 2003; 2006). Therefore, ‘reality’ is not discovered, but rather, co-created through an interactive and iterative process between researcher and participants whose interpretations confer meaning upon a situation.

Constructivist inquiry recognizes that what may be understood as knowledge and truth is always based upon individuals’ perspectives and interpretations. The findings generated from this constructivist grounded theory study suggest plausible hypotheses which may be useful in explaining and understanding social questions related to caring for people living with PD in similar contexts, rather than generalizable ‘truths’ (Charmaz, 2006). Understandings and meanings from experiences are interpreted through interactions in the world and constructed through language (van Manen, 1990; Charmaz, 2014). Thus, the data in this study are constructions of participants’ experiences, and the analytical theory presented herein is a construction involving interpretation and representation by the research team (myself and my thesis supervisor), grounded in participants’ words.

5.2 Methods

Consistent with the relativist and subjectivist underpinnings of ‘constructivism’, this study remained open to multiple perspectives, where meaning was co-constructed between the researcher and participants through in-depth interviews (Guba & Lincoln, 1994). The result of this process was a substantive theory, grounded in the data, to describe how healthcare professionals deliver care to a person diagnosed with PD and their primary care partner. This study was approved by the Health Sciences Research Ethics Board at Western University, in London, Ontario, Canada (Appendix B).
5.2.1 Participant Sampling

Healthcare professionals who provide care for at least six people diagnosed with PD per year were recruited from healthcare centres in Eastern and Southwestern Ontario. Purposive sampling via recruitment emails was used to achieve maximum variation sampling, and to represent the typical healthcare providers described by participants in Study One. From the data in Study One, the typical circle of care consisted mainly of a neurologist and a clinic nurse, while some couples’ circles included a rehabilitation professional, and/or a pharmacist. Eight healthcare professionals who met the inclusion criteria participated in this study. Informed, written consent was obtained for each participant (Appendix D).

5.2.2 Data Collection

Constructivist grounded theory requires rich and descriptive data to explore and describe the process of human actions and behaviours, such as those related to caring for people living with PD. To achieve this, I engaged participants in audio-recorded, in-depth interviews which lasted between 23 and 55 minutes. Participants were offered to select the interview location and time to ensure they would feel relaxed and comfortable, to accommodate their busy schedules, and to facilitate in-depth conversation about their experiences of caring for people living with PD. Six participants elected to complete the interviews in their place of employment, the other two chose to complete the interviews at their homes.

During the interview, I asked participants to reflect on experiences of providing healthcare to people living with PD, particularly with respect to self-management, and to
consider the involvement of the client’s primary care partner. The interview guide is provided in Appendix F. A more detailed discussion of how I reflexively challenged and engaged my biases, beliefs, and values is provided in Chapter Three: Methodology. My questions sought to elicit descriptions of key factors and decisions that determine how a healthcare professional delivers their care to a care partnership living with PD, and thereby provide insight into the process of caring for them. Examples of interview questions are: “How do you incorporate self-management education in your practice?” and “How do you involve the care partner in your clinical care sessions?”

These broad questions would be followed by prompts and additional questions to elicit as much detail about the experiences as possible. All eight healthcare professionals completed one in-depth interview. The data generated by all participants fit well within the emergent theory, and therefore, the data did not guide a return to previous participants to further explore codes or categories.

5.2.3 Data Analysis

Constructivist grounded theory involves an abductive reasoning method which entails “reasoning about experience for making theoretical conjectures and then checking them through further experience” (Charmaz, 2006, pp. 103). To achieve this, I transcribed all audio recorded interviews verbatim to enhance my familiarity and engagement with the data. The constant comparative method was employed by frequently revisiting the interview transcripts throughout data analysis. Initial codes were tentatively identified from the data to highlight key insights from early transcripts. After analyzing more data, these codes were consolidated into larger, more abstract categories through focused and theoretical coding. Theoretical coding and abductive reasoning identified a core category
of ‘delivering the care package’, which connected the remaining themes to produce a descriptive, most plausible explanation of the process of caring for people living with PD (Charmaz, 2006). Data collection and analysis were concluded when no new themes emerged from participant interviews, indicating a level of data saturation was reached.

To enhance methodological rigour in this study, careful attention was applied to trustworthiness, achieved via credibility and transferability, and to authenticity, achieved via fairness and educative authenticity criteria (Guba & Lincoln, 1989; Guba & Lincoln, 1994; Lincoln & Guba, 2013; Charmaz, 2014). Please refer to Chapter 3: Methodology for an in-depth discussion of how theoretical saturation was defined and achieved, as well as further discussion of how methodological rigour was maintained throughout this study.

5.3 Findings

5.3.1 Participants

Study participants included eight healthcare professionals from various professions, from both the private and public healthcare systems. Participants were included if they had provided care to at least six community-dwelling clients living with PD per year, to ensure adequate familiarity with the condition and particular considerations for the type of care provided by their profession. Participants in this study identified as a neurologist (n = 3), a registered nurse (n = 2), a physical therapist (n = 1), an occupational therapist (n = 1), and a pharmacist (n = 1). Further description of the participants is provided in Table 1. One interview was completed with each healthcare professional and lasted
between 23 and 55 minutes. The interview was conducted either in the participant’s place of employment, or in their home.

Table 1. Characteristics of healthcare providers
(n = 8; all care for >6 people living with Parkinson's disease per year)

<table>
<thead>
<tr>
<th>Part. #</th>
<th>Clinical title</th>
<th>Client population</th>
<th>Clinical Setting</th>
<th>Time spent with clients in an appointment</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Registered Nurse</td>
<td>Clients living with advanced PD who may be eligible for duodopa infusion clinic</td>
<td>Hospital specialty clinic</td>
<td>30 - 120 minutes</td>
</tr>
<tr>
<td>2</td>
<td>Neurologist</td>
<td>Movement disorders clinic</td>
<td>Hospital Clinic</td>
<td>20 minutes every 3-6 months</td>
</tr>
<tr>
<td>3</td>
<td>Neurologist</td>
<td>Movement disorders clinic</td>
<td>Hospital Clinic</td>
<td>20 minutes every 9-10 months</td>
</tr>
<tr>
<td>4</td>
<td>Registered Nurse</td>
<td>Movement disorders clinic</td>
<td>Hospital Clinic</td>
<td>90 minutes every 3 months</td>
</tr>
<tr>
<td>5</td>
<td>Neurologist</td>
<td>Movement disorders clinic</td>
<td>Hospital Clinic</td>
<td>20 minutes every 6-8 months</td>
</tr>
<tr>
<td>6</td>
<td>Physical Therapist</td>
<td>Clients with Neurological impairments</td>
<td>Homecare and community clinic</td>
<td>60 minutes</td>
</tr>
<tr>
<td>7</td>
<td>Pharmacist</td>
<td>Varied</td>
<td>Pharmacy</td>
<td>5-30 minutes</td>
</tr>
<tr>
<td>8</td>
<td>Occupational Therapist</td>
<td>Varied</td>
<td>Homecare (public funding)</td>
<td>60 minutes, 2-3 visits</td>
</tr>
</tbody>
</table>

5.3.2 The Process of Delivering Care to People Living with Parkinson’s disease

Participants described the overall process of delivering care to people living with PD and their care partners as ‘sustaining the care partnership between clinical visits’, such that the clinical visit resulted in the delivery of a care package via strategic communication. During the clinical visit, the healthcare provider was at the centre and operated within two rings, which represented two common factors forming the base of
their care package delivery: *scope* and their *clinical plan*. Healthcare professionals operated within their clinical scope to address concerns of their clients. Through experience, the participants described their approach to practice in terms of a general *clinical plan* through which they were sure to address all relevant topics in a systematic manner.

Figure 2. Sustaining the care partnership between clinical visits.
way. This process occurred within the bounds of four main factors, all of which had varying influence on the care package, depending on the type of healthcare professional: limitations of the system/time, the nature of caring for people living with a progressive disease, the care partnership, and community resources. The level of influence of each factor depended on the healthcare setting, and the individualized healthcare provider’s approach for caring for care partnerships living with PD. Once the healthcare provider had gathered enough information from their clinical assessment and adequately considered the constraining factors, the care package was delivered through an intentional effort to coach and educate clients via effective communication about how to care for themselves until their next clinical appointment (Figure 1). Combined with strategic communication, the care package served as a bridge between clinical visits, by empowering the care partnership to care for themselves at home.

5.3.3 The Healthcare Provider’s Scope and Clinical Plan

The healthcare provider operated within their clinical scope, that is, what they believed to be the purpose of their assessment and care plan, based on their professional training. Participants described having a defined sense of purpose and overall understanding about how their care fit within their client’s care plan or healthcare circle.

As the physician, and really the only one that can prescribe the medications, um, probably having more time to go through the side effects, you know, we try to discuss side effects, you try to work out and really get a good sense to try to understand what they’re taking and when they’re taking it… because I’m the only
one who can fiddle with the medications, I need to make sure that they’re spending enough time doing that. (Participant 3)

Based on their interpretation of their clinical scope, participants all described a preconceived plan for how they would conduct their assessment and care intervention. This clinical plan formed the base of the care package to be delivered, but was flexible depending on the clients’ needs and the findings of their assessment.

I always ask about the response to levodopa, the peak effect, the duration of effect, if they’re experiencing wearing off symptoms, if they’re experiencing side effects like dyskinesia, um, and then if people don’t have the non-motor system questionnaire completed, I then divide my questioning by month. Because there’s so many questions, from January to June, I ask certain questions, and from July to December, I ask other questions. I see my patients at least every 6 months, if not, every 3 months, some patients. So I know I’m going to address every, you know, non-motor symptom within the year if I do it this way. If I kind of stick to this pattern. Every visit I ask about falls, um, that’s another thing that’s absolutely every visit and I ask about exercise. (Participant 2)

Well, I’ve always got a template in my own head of the kinds of things that I know, that my patients with Parkinson’s are likely to be struggling with. And also, bear in mind, I know the stage they’re at, often. Or I can pretty quickly figure it out when I’m with them. So, you know, I’ll always ask them about some things, like in and out of bed, rolling in bed, dressing, in and out of a chair – huge one,
right? On and off the toilet, in and out of a car. So I’ll go through a little checklist with them. (Participant 6)

Participants described how they entered a clinical session with a loose plan, but were able to modify it based on the individual and their needs. Healthcare professionals described a number of other factors that also determined what their care package would consist of.

5.3.4 Boundaries within which the Care Package was Built

Healthcare professionals must work within boundaries set by a number of governing factors. These factors were described by participants as either limiting their care or greatly influencing it. Four main boundaries were interpreted from the participants’ responses.

5.3.4.1 Working with the Healthcare System & Time

Participants referred to characteristics of the healthcare system, such as time constraints imposed by the number of clients on their caseload. Time seemed to be particularly significant for participants working within the public healthcare system, as there was less control over the amount of time available to spend with each client.

So, we try to address [self-management], but again, the time is short, and often, at the end of the visits, I feel like I haven’t covered it enough. And so it’s definitely a balance between, um, spending enough time with each patient, and actually seeing enough people so that you’re helping enough people… It’s my own personal, I don’t know, guilt, about not being able to see people enough. And so if my follow-up appointments are 10 or 11 months apart, that is atrocious for
reasonable care for people. But that's a fact of how busy the clinics are.

(Participant 3)

Another participant described the challenges of working with a limited healthcare team:

So you know, we don’t have physiotherapy, we don’t have social work, we don’t have a dietician, we don’t have. And so, I think going forward… if we don’t have it, why don’t we? And I think sometimes, it’s the resources here. (Participant 1)

Participants highlighted other perceived short-comings of the system within which they worked:

[Patients] come with their lists, you know, and they’ve been pulling it together for 6 months. And they want those questions answered. And I find a lot of clinics have a nurse. And a nurse makes it a much easier thing to make it through that sort of thing, because a nurse can answer a lot of those things for you. But I don’t have a nurse. Because there’s no funding, no hospital funding to give her the time to do so. Because of that, I do feel it puts patients at such – not having a nurse, not having someone to just call to discuss things. You know, they call me, but it’s really hard to find time to call people back. (Participant 2)

I mean the whole system, is so poor for people with Parkinson’s. There’s so little available in terms of government-funded programs. My patients come in here and say, “I think I’d really benefit from some physiotherapy, you know, for my falls, just to get me exercising.” And you know, the CCAC or LHIN, offers someone
who comes to your house maybe two times, you know, to do some exercises and then kind of leaves you to do them. And then that’s all there is. (Participant 2)

We clearly need to do a better job. These people [living with Parkinson’s], I think there’s so many things that we could help them with, to make their quality of life better, that we don’t. And so it’s a bit of a frustration, in terms of, um, I think we have a lot to offer, but we don’t have a way of maximizing that. (Participant 3)

Participants in the private sector seemed to have fewer issues with the amount of time they could spend with clients, as this was determined by their clients themselves, however, access to their services by those who might benefit in the general population seemed to be of greater concern.

I think, because there’s this perception, firstly that if you can’t offer it publicly funded to everybody, that maybe it’s not right to offer it to anyone. I think people in the public system feel bad saying, “Look, this physio might help, but if you don’t have insurance, I don’t know how you’re going to access it.” That’s a hard conversation, right? I mean, I find that to be a hard conversation in private. That it’s not OHIP covered. (Participant 6)

Healthcare system factors such as resources for funding and appointment time for clients were major mitigating factors on the care package delivered by healthcare professionals.
5.3.4.2 Parkinson’s disease is a Progressive Condition

Participants also considered the implications of caring for people living with a progressive disease, including, for example, the episodic and progressive nature of certain symptoms, effectiveness of medication, multidimensional impact of the disease, and various care options. Several participants discussed the unique considerations of caring for clients with a progressive, debilitating health condition they will have for the rest of their lives.

More than most illnesses, Parkinson’s is a moving target. A person evolves over time, and so, just because someone’s doing well for a while, just because something works for a while, it may not anymore. So I think you always have to maintain an open mind about symptoms, and that adjustments are likely to be required overtime. You can never become complacent with Parkinson’s disease. (Participant 2)

I think it’s really important for us to realize that for any chronic disease, and with Parkinson’s disease of course being one, that patients and their caregivers need multiple touch points of caring. And both a more interdisciplinary approach. Certainly a physio on the team, and also that they’re going to need to come in and out of therapy. Like, they’ll come in for a while, they’ll be doing really well, they’ll self-manage for a while, and then as they progress, and hopefully they don’t, but should they progress, then they’re probably going to need another
optimization again, talk about self-management, look at what’s happening.

(Participant 6)

Another participant (Participant 5) explained that, as opposed to providing care to someone with a non-chronic health condition, “Usually we say if you have a patient with Parkinson’s, likely, you’re gonna stay with me until I retire.” This highlighted another of the contextual factors that influence care dynamics in clinical appointments.

5.3.4.3 Considering the Care Partnership

The care partnership living with PD is defined as two individuals where one person has been diagnosed with PD and the other is the primary care partner. Healthcare providers described considerations of caring for their clients living with PD and the unique dynamics introduced to the clinical atmosphere by the care partner involvement.

Participants described the importance of connecting with their clients on a personal level, to try and build a strong therapeutic relationship.

You might spend four hours with them, and spend 5 minutes on Parkinson’s, but you’re gonna find out everything else about their lives. But, it makes a huge impact, and the thing is, they feel valued, and they will tell you the smallest things. (Participant 1)

So this is one thing we need to work more. This is one thing that I was working on a lot in the clinic, “Does your wife know that you’re having these symptoms? About the pain? What does she say?” “Oh I don’t tell her.” Like, sometimes, they
don’t want to share, or tell, because they’re afraid that it will be too much for the care partner. And I don’t call them caregivers, I call them care partners.

(Participant 4)

I mean I would suggest only one thing – or advice, or whatever – is to spend some time, to understand someone and their beliefs and requirements, and their abilities, and take the bigger picture into consideration. (Participant 7)

Participants acknowledged the integral role care partners have in delivering their care to their clients diagnosed with PD.

Healthcare providers also described the importance of including the care partner in their clinical care interventions.

Oh my gosh, [care partners] play a huge part of the discussion… There’s often an impairment on the person, and I rely entirely on the care partner to give me an accurate representation of the day. But always, I mean, you know, we talk about the health of the care partner, and you know, the importance of respite, and yeah, we talk. I always encourage them to come into the room, and they’re always a major component of the conversation. (Participant 2)

I think that, you know, this is a progressive disease, so the care partner is – if they’re not involved at the start, they’re eventually going to be involved so they
need to understand what’s going on. So they’re definitely a key part of the whole managing the disease. Especially as the disease progresses, I think you get more accurate information from the care partner than the person themselves. So it definitely helps their care when you do have better information. (Participant 3)

So, um, teaching caregivers, for example, how to safely fold up a walker, put it into the car, or how to safely use the brakes, so that they can remind the client to use the brakes, if the client has any cognitive impairments, or cognitive issues related to their Parkinson’s, or otherwise… And, I always review the recommendations that I’ve made with the client and the caregiver, just in case the client forgets, then the caregiver at least knows what we’ve talked about, so, yeah. (Participant 8)

In addition to providing care for their client diagnosed with PD, healthcare providers explained how they may address concerns specific to the care partner:

Sometimes it’s having a separate conversation with their caregivers. So it’s one of those things, like, in the hallway, I’ll have a confidential, sort of, “Ok, hey, how are you feeling? How do you think he’s doing? Or she’s doing?” So it’s having those little things. And sometimes it’s having a conversation, you know, here in clinic. It’s like, “Ok, Mr Smith, I don’t mean to be rude, or whatever, but can I have a conversation with your wife to see how she’s doing?” Because sometimes you don’t see that as a patient. And I don’t mean to be offensive or whatever. And
that’s the conversation I always have. It’s always good to have that perspective. (Participant 1)

As the disease advances more and more, I focus more and more on the care partner. So when people are advanced, often the questions are, “What kind of support do you have?” … And so, as the disease progresses, I certainly have some visits where the patient is sitting there, doing nothing, and the whole appointment is really the care partner. (Participant 3)

Well, when a person is a care partner, she needs a support group, or she needs someone to talk to, she needs to know that she’s not alone, or they need to have like friends or people, they need to have friends or family, they need to talk also. They don’t complain. (Participant 4)

Participants emphasized the care partnership as a dyad to be clinically managed together during their clinical care sessions.

We ask for the care partner and the patient to be present, to kind of embark on this journey, and, um, and so, although we talk a lot about patients, I mean, also implicitly I have in my mind, it’s a dyad. So the care partner also. Because, again, preparing the care partner with knowledge about the disease also, I think, will reduce… undesirable outcomes such as caregiver burnout, and all those things. (Participant 5)
Whenever I meet a caregiver dyad, I always ask the caregiver, “How are you doing, and what do you do for yourself? How do you look after yourself?” And the answers vary… I always try to connect them always with the Parkinson’s Association because there’s a caregiver group. I try to connect both of them, both the patient and the caregiver, because I find often the Parkinson’s Society is as helpful to the care partner as they are to anybody else. (Participant 6)

Care partners provided important information during clinical appointments. One participant (Participant 8) acknowledged that, “A lot of the times, I found that it’s the caregiver who answers most of the questions that I ask.” These discussions with participants emphasized the role of the care partner and the challenges associated with caring for a care partnership living with PD.

5.3.4.4 Connecting the Care Partnership to Community Resources

Several participants described an awareness about community resources and making an effort to connect their clients with local supports. Some participants were very likely to recommend local programs.

I find that people who participate in support groups often have a much better understanding of the nuances of medications, the symptoms, and that sort of thing, than people who just don’t bother with that stuff. (Participant 2)
Reviewing, um, resources, see if there is a support group. Another thing I forgot to mention is funding. And associations. There’s funding opportunities sometimes through these associations. And separately, there’s funding for mobility devices like walkers and wheelchairs. (Participant 8)

In general, there was a recognized benefit to connecting clients with community resources. They were also considered as a way for clients to manage their condition between medical appointments.

[We’re] trying to get people connected to different resources. So we have a list of the physiotherapists in town that we know, or the clinics that we know, subspecialize in seeing people with Parkinson’s. We refer a lot of patients to the geriatric team, a lot of patients to CCAC, we have the falls prevention programs that run, we send a lot of patients to the local Parkinson’s Society for speech, for their support groups. (Participant 3)

In their role as a clinic nurse, one participant described the intentional effort to connect their clients with local resources:

They [would give] me three of their concerns, and together, we were finding solutions. Like, if it was falls, they were falling a lot, we would look at enrolling them in a fall clinic prevention, in an exercise program, finding maybe an adaptive device for them that might be good, like a walker, a cane. And refer them to resources in [city]. (Participant 4)
Healthcare providers valued community resources as a source of support for their clients living with PD. Although it formed a valuable component of the care package, not all participants felt they knew enough information about local resources to adequately share them with their clients.

5.3.5 Delivering the Care Package through Communication with the Care Partnership

Participants described in detail the factors involved in building the care package, however, delivering the care package was also an important consideration. Participants described their approach to translating the care package according to their clients’ needs. For example, Participant 4 explained, “I give them a lot of, not too much, but proper information. You cannot overload them.” Others described their approach to educating patients:

And I think it’s such a personalized thing. It just depends on the patient, and how they respond to my questioning, their overall expectations for the visit, and I think my desire not to inundate them with too much information, that I overwhelm them. (Participant 2)

The notion of empowering patients and trying to give knowledge to patients in the sense that I’m here to help you, and I think that’s an important framework to approach it, as opposed to something more paternalistic. Like, “Ok you have this issue, I’m going to give you a solution, and not much more.” So kind of anticipate
our future problems and how to deal with them. So kind of have that framework. You know, putting the patient in the centre, not only of the healthcare, but actually of how we manage – or how they manage their disease, right? And, um, and that’s perhaps the biggest concept I have in my mind. But I also know it’s difficult to implement. (Participant 5)

So one of the first things I do after I’ve done their assessment, is to explain to patients what’s happening to them. You know, just talking to them about small amplitude of movement and how the initiation is less. And I draw them a picture too to explain it to them. Cause, I feel that if they understand what’s happening to them, then it’s easier for them to manage it. (Participant 6)

Healthcare professionals also described traits or types of clients that would cause them to adjust their education or coaching methods:

I think time and time again, it’s that overwhelming sense of they just don’t, they don’t absorb it. We only absorb, what, about 20% of what’s said to us. That’s what I’ve been taught through my nursing career. So it’s that constant reiteration… So communicate, educate and advocate. That will always be my thing as a nurse. (Participant 1)

I think one of the biggest ones is cognitive function. If my patient is fairly cognitively intact, and they have not lost that initiation piece, I can stimulate
them, or get them to believe in what I’m saying so they’ll do it, or be motivated by what I’m saying, then things are relatively good. (Participant 6)

Another participant described their conversation with a client using a teach-back strategy to determine if they understood their care plan:

[I asked], “Do you have a care plan?” And they would say, “No.” And I said, “Yes we have a care plan, you gave me your concerns, and these are your goals.” They need something written. I did create a care plan, it only says, concerns, goals and what was obtained. So now they have it, and they review it. It reminds them, cause sometimes, cognitively, they have issues also. (Participant 4)

Participants recognized the value of communicating adequate information to their clients, in verbal and written formats, and accepted that this was part of their role as a healthcare provider.

5.3.6 The Care Package as a Bridge between Appointments

Participants carefully analyzed and decided upon specific topics to address with their clients in their clinical appointments. The contents of the care package were intentionally selected as part of the bigger care delivery plan, across multiple visits. The goal was described as empowering the clients to sustain themselves and manage their condition until the next follow-up clinical appointment. For example, when speaking about teaching clients how to manage their medication if their duodopa pump stopped working, Participant 1 explained:
So sometimes with patients it’s kind of confusing for them to know what to do. But no, within half an hour, if things aren’t working and the tube, you know – what if it alarms? It’s 9-o’clock at night, or if it’s midnight and they’re still on the pump… It’s like, “Ok it’s alarming and I can’t fix it, there’s no one available, it’s not possible.” It’s like, “Ok, you know to go back on your pills.” Within 30 to 45 minutes, that’s the plan.

Others described intentional strategies to sustain their clients between visits:

How do we help fill that gap [between visits]? And so that’s a big part of it. And we’re certainly at an advantage because we have nurses who spend a lot of time on the phone dealing with things on the phone. And so there’s that communication tool to help fill the gaps over the time. (Participant 3)

There’s a hiatus of 6-months or 8-months [between appointments] where the patients come back, and we kind of see what has happened… We are hoping that we can bridge this time and support patients. But also knowing that our resources are limited, I think the self-management support part of it, and helping patients to feel more empowered about their disease and living with their disease, it’s important. (Participant 5)

Whether the intent to sustain clients between visits was rooted more in the reality of the public system and limited access to clinical visits, or whether the care goal was to work towards independence, all participants had a shared goal of empowering care partnerships
to live on their own with PD. Thinking about and implementing strategies to act as a bridge between clinical appointments was a common goal shared by all participants.

5.4 Discussion

The findings of this constructivist grounded theory suggest that building the care package is a process by which healthcare professionals from different disciplines provide clinical care to care partnerships living with PD. Findings from this study are contextualized within a particular time and place, participants’ realities, and the interpretations of myself and my doctoral supervisor (Charmaz, 2008). Although not ‘generalizable’ to all healthcare professionals, several implications may be interpreted from this study for anyone who may be interested in how clinical decisions are made surrounding the clinical care of care partnerships living with PD – other healthcare professionals, community leaders who develop programs for people living with PD, people living with PD themselves, and healthcare policy makers, for example. Insights generated from this study enhance understandings of inherent values, assumptions, and meanings underlying behaviours and actions of healthcare professionals caring for people living with PD. Knowledge gained from these findings may motivate stakeholders to reflexively evaluate their own practices with respect to providing care to people living with PD in various capacities.

Several models of care for people living with PD have been investigated in an effort to identify the ideal approach. Nurse-led approaches, where a registered nurse acts as the interface between the person living with PD and the care team, has been shown in one study to improve depression symptoms, but not other clinical quality measures in a
privatized healthcare system (Connor, et al., 2019). In a second study, a nurse-led clinic has been shown to improve self-management education needs of clients living with PD, however the increased workload was not sustainable, with the amount of funding available (Jones, et al., 2016). The ParkinsonNet network has been developed in the Netherlands in an attempt to optimize interdisciplinary community care including allied healthcare professionals, however, remains to be fully evaluated (Keus, et al., 2012). A number of studies have also demonstrated the benefit of non-pharmacological interventions (see Bloem, de Vries, & Edersbach, 2015 for review). Others have suggested to move PD care into clients’ homes to remove barriers to access (Ray Dorsey, et al., 2016). In general, the literature advocates for a transition from a paternalistic, ‘medical model’ of PD towards a more client-centred model where clients living with PD play a more active role in their care (Giroux & Farris, 2008; Holmes, et al, 2013; Lim, et al., 2017, for example). An effective multidisciplinary, client-centred model of care for people living with PD and their care partners remains to be identified that will be sustainable in a publicly-funded healthcare system (van der Marck, et al., 2013). In order to transition to a client-centred model of care, there must be an emphasis on understanding client-values and self-identified health-issues (Holmes, et al., 2013), self-management (Barlow, et al., 2002), and involving the care partner in the PD care plan. The process of building a care package proposed in this study reflects current clinical interactions of interdisciplinary healthcare professionals with care partnerships living with PD, which may contribute to understanding services provided to them.
5.4.1 Building the Care Package

Participants described how they built their care package within the confines of a number of factors. A commonly identified factor was the healthcare system, which was closely linked to available resources and time with clients. Professionals working in the public healthcare system, such as nurses, physicians, and health disciplines in publicly funded programs, felt pressure to see patients in as little time as possible. The pressure to ‘do more with less’ has been described as a system-wide change related to optimizing care for people living with chronic disease (Nolte & McKee, 2008). The authors acknowledged that “changes in staffing and human resources are critical elements of successful chronic care” (Nolte & McKee, 2008, pp. 143), however the most cost-effective method of delivery remains to be determined. Nevertheless, it is acknowledged that time available to spend with clients and their care partners was identified by healthcare professionals, particularly in public healthcare settings, as a significant challenge to delivering optimal support for self-management. Similar challenges and pressures have been presented by others and remains an area in many countries for optimization in providing health care (Kodner, 1993; Pruitt and Epping-Jordan, 2005). A care coordinator or manager has been suggested to optimize the face-to-face time with less accessible professionals, such as a movement disorders neurologist, by increasing education opportunities for clients, maximizing self-management interventions, referring to multidisciplinary healthcare providers, and improving efficiency of the time spent with the neurologist (Connor, et al., 2019; Jones, et al., 2016; Kessler, et al., 2019; Nolte & McKee, 2008; ). Further inquiry into this model may be a promising approach to improving care delivery to care partnerships living with PD.
Another consideration related to building the care package for care partnerships was the nature of PD as an episodic, chronic, progressive condition. Providing care for clients with chronic conditions vary from those with acute conditions, such that “in the chronic care model, the health professionals and patient are partners in care. In addition, patients learn to manage their day-to-day lives to accommodate living with one or more chronic conditions” (Lorig, 1996). Corbin and Strauss (1988) have suggested that living with a chronic disease involves three types of work to maintain an acceptable quality of life: (a) the work necessitated by the disease, such as visits with health professionals, taking medications, and maintaining a therapeutic exercise regime; (b) the work of maintaining everyday life, such as employment, chores, and family responsibilities; and (c) the work of dealing with an altered view of the future. The current biomedical model for care partnerships living with PD addresses the first type of work, however there remains a gap in supporting clients in the last two, despite the growing body of literature that outlines the benefit of the health disciplines to help clients maintain both physical function and occupational roles (Bloem, de Vries & Edersbach, 2015; Holmes, et al., 2013; Nonnekes & Nieuwboer, 2018; Radder, et al., 2017).

Chronic illness often changes one’s life plan, which can result in many emotional responses, such as frustration, anger, and depression. Barlow’s (2002) definition of self-management includes managing emotional responses in order to maintain a satisfactory quality of life. Some emerging work has been done in converging psychology approaches such as cognitive behavioural therapy into other disciplines as a form of self-management support for those experiencing illness distress (Hudson & Moss-Morris, 2019). This could provide valuable clinical tools for clinicians not typically trained in mental health
support, as it is outside their scope of practice, yet are often caring for clients who experience some component of a mental health concern associated with living with a chronic condition. Caring for clients with chronic conditions, such as PD, adds a number of levels of complexity for healthcare professionals, particularly as the literature continues to advocate for care interventions that are client-centred and address more than the physical symptomatology in order to optimize quality of life for the person diagnosed as well as their care partner.

The third factor considered by healthcare professionals in building the care package was the care partnership, including how to involve the care partner in their clinical practice. When caring for a client with a chronic condition, informal care partners are often considered an integral component of delivering healthcare interventions while the couple is at home, without the assistance of healthcare professionals (Kent, et al., 2016; Lafortune, et al., 2015; Yghemonos, 2016). Care partners of people living with chronic illness typically attend clinical appointments and clinicians must consider the information needs of care partners in order to facilitate appropriate care to their loved one (Washington, et al., 2010; Yuen, et al., 2018). The burden associated with being an informal caregiver, or a care partner, to someone living with PD is well documented (see Grun, et al., 2016; Martinez-Martin, 2007; and Mosley, Moodie, & Dissanayaka, 2017 for reviews). However, education and self-management needs of care partners require more specific definition and continue to be an unmet need (Bae, Kim & Cheon, 2017; Berger, et al., 2019). Ongoing education and training for healthcare professionals about how to best support care partners of people living with PD within their scope of clinical practice is an important topic for further inquiry (Davies et al., 2018).
Healthcare professionals also acknowledged the importance of providing client-centred care and grappled with how to operationalize this construct within their own clinical practice. Client-centred care has been identified as a clinical priority for optimizing care of people living with PD (van der Eijk, et al., 2013; Kessler, et al., 2019). Identifying meaningful activities, occupational roles, most troubling symptoms, and barriers to accessing community support programs from the care partnership’s perspective have been suggested as strategies for developing a client-centred care plan (Bloem & Munneke, 2014; Kessler, et al., 2019; Lutz, et al., 2018). PD is accepted as a highly individualized condition, and similarly, client-centred care must also be defined individually for each client, depending on their desire to be actively involved in their care, for example (Phillips, et al., 2015). There remains no consensus on the best definition of truly client-centred care, and how this could be operationalized in terms of discipline-specific practice, which contributes to the challenge of clinicians’ best efforts to deliver client-centred care.

The final factor in this theoretical model considered by healthcare professionals when building the care package was community resources, and decisions associated with selecting the most appropriate supports for particular clients, and how to connect clients with community supports. Linking clients with community supports has been suggested as a strategy to mitigate social isolation and declining mental and physical health in people living with chronic conditions (Mossabir, et al., 2015). However, clinicians’ perceptions of their role in linking clients from healthcare settings to social supports in their community varies, both in the findings of this study, as well as in the literature (Mudge, Kayes, & MacPherson, 2015). Additionally, healthcare providers have
highlighted that they lack a comprehensive knowledge of local and national community and voluntary services, which contributes to the hesitancy of referring clients to community resources (Brandling & House, 2007). Developing up-to-date repositories of local social supports would be a beneficial endeavour for clinicians, and may be further utilized in care-facilitator models of care (Kessler, et al., 2019). Strategies to mitigate financial and transportation barriers may also promote increased participation in community support programs (South, et al., 2008). Linking clients with chronic illness from healthcare settings to community supports is being widely advocated, as it has been shown to increase self-esteem and confidence; improve mental well-being and positive mood; and reduce anxiety, depression and negative mood (Chatterjee, et al., 2017).

Despite previous findings, further investigations into how to best support clinicians in making social referrals are required, in addition to proposed models of referral, as current evidence fails to provide sufficient detail to judge either success or cost-effectiveness (Bickerdike, et al., 2017).

5.4.2 Delivering the Care Package

Once clinicians had gathered sufficient information and considered the relevant factors, a communication strategy was carefully and intentionally selected to deliver the care package through coaching and education. Communication has been consistently highlighted as a core component of client-centred care, both to facilitate sharing information, to empower clients in their care, and to convey compassion and empathy (see Constand, et al., 2014 for a scoping review). Specific to clients with PD, dissatisfaction with communication in clinical settings has been associated with noncompliance, which in turn, has been significantly associated with decreased quality of
life (Grosset & Grosset, 2005). The communication changes inherent to PD contribute to the challenge of effective communication in clinical settings (Miller, 2017), and often create opportunities for increased care partner involvement; for the person diagnosed with PD, this must be tactfully balanced with the risk for further loss in confidence when speaking, feelings of inadequacy, frustration, and/or being negatively judged (Miller, et al., 2008). Communication strategies are therefore tridimensional such that they are mediated by factors at the level of the patient, care partner and clinician (Armstrong, et al., 2019). This challenge is confirmed by findings that only 36% of care partnerships living with PD reported satisfaction that their clinician “listens to each patient and takes the patient’s concerns seriously” (Hatano, et al., 2009). Clearly there is an unmet need to support clinicians in meeting the complicated communication needs of care partnerships living with PD; some supports may include development of improved educational tools and further research to identify optimal strategies for communication in clinical settings.

5.4.3 The Care Package as a Bridge between Clinical Appointments

Clinicians acknowledged the difficulty in fully supporting the care partnership within the limited time allotted for their respective care interventions. Recognizing the finite nature of available clinical time to spend with clients, participants described creative strategies that were considered and implemented to sustain their care package intervention until the following clinical visit. This involved prioritizing clinical concerns that the clinician believed would have the most impact in supporting the care partnership between clinical visits, such that they would be able to manage their symptoms and treatment, as well as the physical, social and psychosocial sequelae associated with PD
on their own – in other words, effective self-management (Barlow, et al., 2002).

Literature discussing clinicians’ perspective and rationale for the implementation of self-management principles in clinical care for chronic conditions is limited (Phillips, et al., 2014; Lake & Staiger, 2009; and Rogers, et al., 2005) and no studies investigating this topic specific to PD has were found. Previous work has highlighted barriers such as the difficulty identifying the ‘subtypes’ of clients and which interventions would be most effective for them, and also suggested that some clients did not have the capacity to self-manage (Phillips, et al., 2014). These findings resonate with the individuality of PD and the challenge associated with delivering client-centred care that will be effective for each care partnership.

According to the participants in this study, the care partner played a significant role in extending the care package outside the clinical setting, a notion that has been echoed in previous work, as discussed above (Yghemonos, 2016). Clients’ available support, such as that provided by a care partner, has also been identified as a key element influencing how clinicians may implement self-management principles for chronic conditions (Lake & Staiger, 2009). Clinicians in this study highlighted the value in supporting clients such that they could sustain their quality of life to an acceptable level until the next clinical visit. Yet, there exists a significant gap in supporting healthcare professionals from various disciplines to implement strategies that will effectively meet this clinical goal. Future work investigating clinicians’ rationale, identifiable barriers, and training opportunities for implementing self-management principles as a means to achieve client-centred care for care partnerships living with PD is warranted.
5.5 Conclusion

This study presented the process by which healthcare professionals from various disciplines create and communicate their care package to promote self-management. This research highlights the factors considered by clinicians when caring for a care partnership within the context of a multidimensional, highly complex clinical environment, including systemic characteristics, PD progression, the care partnership and community resources. With aging populations and increasing prevalence of chronic conditions, healthcare providers will be confronted with considering how to approach self-management and client-centred care, and as such, how they will impact the health and quality of life of those older adults living with PD. Insights generated from this study suggest a process, which healthcare professionals’ experiential knowledge has led them to implement when caring for care partnerships living with PD. Insights may encourage other clinicians to reflect on how clients can be collaborative partners, in order to support client-centred care for care partnerships living with PD.
5.6 References


6 Discussion

The overall aim of the two studies described herein was to enhance understanding and provide insight into the process of living with, and caring for those living with, Parkinson’s disease (PD). The first study was positioned to encourage reflective awareness of the inherent processes involved with learning to live with PD for care partnerships, defined as spousal couples where one person has been diagnosed with PD and the other is the primary care partner. The second study aimed to explore the process in which healthcare professionals from various disciplines engaged when creating and delivering their care to people living with PD. By undertaking these two studies, I hoped to contribute to reflective clinical practice in caring for care partnerships living with PD by highlighting considerations of the processes by which care partnerships learned to live with PD, and by providing insight to and illuminating practices of healthcare professionals from various disciplines who care for people living with PD.

Care partnerships living in the community of mid- and large- cities across Southwestern and Eastern Ontario participated in the first study. Healthcare professionals from various disciplines and healthcare settings, who provided care for at least 6 people living with PD per year, participated in the second study. While the findings from these two integrated studies are not intended to be generalizable across all contexts in a similar sense that positivistic, quantitative research may be interpreted and applied, they offer interesting insight into taken-for-granted processes that characterize caring for care partnerships living with PD. The purpose of this discussion chapter is to review the findings and key insights arising from the two integrated studies, and to discuss implications for practice and future research.
6.1 Summary of Study Findings

In the first study, care partnership participants described the ‘process of learning to live with Parkinson’s disease’ in a series of two sequential processes: navigating the system and problem solving in the Parkinson’s world. These two processes were joined by a bridge, which was defined differently for each care partnership, that represents when the couple entered the Parkinson’s world. The two theoretical processes are proposed sequentially because all care partnerships described some ‘tipping point’ where they entered the second process, and there was never a return to the ‘pre-Parkinson’s world’ process. Learning to navigate the system was a meaningful experience for participants, as it defined their relationships with clinicians who would play important roles in learning to manage PD. All participants described a tipping point where they entered the Parkinson’s world through the acceptance of life with PD, which was often associated with receiving their diagnosis or beginning PD medications. After transitioning into the Parkinson’s world, learning to live with PD was achieved by integrating several resources, including support, the couple on their own, and knowledge. Care partnerships would draw on these resources differently, depending on their coping style, and gained new skills every time a solution was identified or a new equilibrium was established in order to move forward. Couples moved through the problem-solving process at different levels of efficiency, depending on their coping styles, accessibility of the three resources, complicating factors, and past experiences with PD.

In the second study, participants who were healthcare professionals from various disciplines and provide care to people living with PD, described the ‘process of
sustaining the care partnership between clinical visits’ through a circular series of phases: building the care package, and delivery via coaching and education, with the goal of bridging the gap to the next clinical visit. The phases occurred within the context of the particular clinical setting in which the participants provided care. Participants described operating within their perceived scope and clinical plan, as well as within the context of four main factors that were considered when building the care package, including the system, the implications of caring for people living with a progressive disease, caring for a care partnership, and connecting with community resources. Participants discussed their strategies for delivering their care package though communication, depending on the specific circumstances of each person, which highlighted the importance of effective, empathetic communication in the clinical setting. Healthcare providers aimed to provide their clients with client-centred care and facilitate independence in managing their condition until their next clinical visit over various time intervals, depending on the discipline.

### 6.2 Key Insights

The key insights reflect the integrated findings of the two studies, and will lead to a discussion of the implications for clinical practice for caring for people living with PD, as well as directions for future research. The first key insight is the importance of involving the care partner in clinical care discussions; care partnerships described the impact of caring for a spouse living with PD, and clinicians highlighted the important roles the care partner holds in extending care beyond the clinical setting. The second insight is to consider self-management education as a means of achieving client-centered care; care
partnerships described learning how to manage the symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent in living with PD, and clinicians described the potential role of self-management intervention in promoting and sustaining independence between clinical visits. The third key insight is the importance of connecting the care partnership to supports, which may involve providing guidance to assemble a healthcare team of relevant professionals and/or connecting them with appropriate community resources; care partnerships described the benefits of community involvement and seeking care from different healthcare professionals, and clinicians acknowledged the importance of community care. Finally, identifying and managing expectations through empathetic, effective communication is the fourth key insight reflecting the theoretical processes arising from both studies; care partnerships described effective communication and addressing their concerns as paramount to their clinical care, while healthcare providers considered the importance of tactfully delivering relevant information, based on client-specific factors.

6.2.1 Involving the Care Partner in Clinical Care

Both care partnerships and healthcare providers discussed the impact of PD on the care partner, as well as the importance of involving the care partner in clinical care conversations. Care partnerships participating in the first study recounted experiences of being a care partner and how this role may impact their well-being; for instance, some couples described changing expectations for retirement, travel, or negotiating household roles, while others were more deeply affected by the inability to leave their spouse for any period of time. When care partnerships were able to define strategies for managing the care partner role, such as care partner support groups or accessing respite care, the
care partnership was better able to identify and implement solutions to challenges as they presented. Healthcare provider participants highlighted their implicit understanding of the impact of the care partner role, particularly in the later stages of the disease, as the person diagnosed with PD became more functionally dependent or developed cognitive symptoms. Clinicians also spoke to the benefit of the care partner’s involvement in clinical appointments, both for gathering relevant information pertaining to daily life at home, and for extending their care beyond the clinical setting, giving reminders about medications or assisting with transferring on and off the toilet, for example. As such, healthcare providers often spoke about involving both the person diagnosed with PD and their care partner in their clinical care sessions.

Understanding the processes of learning to live with PD and providing care to people living with PD involved an appreciation for the care partnership’s beliefs and behaviours related to care partner burden, strain, and role in extending clinical care, and a consideration of the impact of this role on the care partnership’s process of learning to live with PD. For the care partnerships in the first study, couples described varying levels of burden and strain, as well as varying levels of defined strategies to mitigate and manage the impact of the care partner role. Similarly, the care partnerships described varying levels of participation in clinical care settings, and in extending clinical care interventions, depending on their perceived role. All care partnerships described some level of role negotiation as the symptoms of the person diagnosed with PD continued to progress, such that the care partner gradually took on more responsibilities and the person diagnosed scaled back their activity from what they were once able to do. The care partnership’s ability to negotiate roles, identify and mitigate strain caused by the care
partner role, and have a perceived sense of involvement in clinical care interventions seemed to facilitate the process of solving problems in the Parkinson’s world. The healthcare providers in the second study seemed to appreciate the need to address the strain that can be imposed by the care partner role, particularly in later stages of PD. The clinicians also emphasized the benefit of eliciting information from the care partners to better understand how PD is affecting the care partnership in various aspects of daily life, and to direct considerations of the care partnership as a dyad when building their care package.

The significance of involving the care partner in the clinical management of PD is becoming increasingly conceptualized in the literature for various health disciplines (for example, A’Campo, et al., 2010; Beaudet & Ducharme, 2013; Oguh, et al., 2013; Sturkenboom, Nijhuis-van der Sanden & Graff, 2016; Viwattanakulvanid, et al, 2014). I see the benefit of including the care partner in clinical interventions as two-pronged: 1) the care partner supports the care of the person diagnosed with PD, both by enhancing information available about the care partnership’s daily life and to optimize clinical interventions outside of the clinical setting; and 2) promote balance and well-being for the care partner and their role in supporting the person diagnosed with PD, by monitoring their emotional, physical and mental health, and by connecting with appropriate care interventions or supports, as appropriate. From this perspective, client-centred approaches – despite clinicians’ best efforts to achieve effective communication, partnership, and health promotion – that do not fully incorporate the care partner’s perspective and health remain insufficient for optimizing care delivery for PD (Constand, et al., 2014). Rather, a
clinical approach that fully integrates both members of the care partnership will optimize care delivery and independence of the care partnership (Yghemonos, 2016).

A number of qualitative and quantitative studies have explored the impact of being a care partner to a spouse living with PD (Mosley, Moodie & Dissanayaka, 2017; Torny, et al., 2018). Currently, the Canadian best practice guidelines for PD suggest that “caregivers and family members should have the opportunity to be involved in the discussion and decisions about the person’s care and treatment” (Grimes, et al., pp. S5) and have a reliable source of information about clinical and social matters of concern (NICE, 2017); however, there remains limited evidence that this advice is implemented within clinical practice. Moreover, this study may be the first to suggest truly integrating both members of the care partnership in clinical appointments to optimize care through a client-centred practice approach. Despite wide acceptance of the impact of being a spousal care partner, including burden and strain, and that the needs of the care partner must be addressed, previous research has noted that clinicians may feel underprepared to address the broader contextual factors that contribute to the impact of being a care partner (Mosley, Moodie & Dissanayaka, 2017). Furthermore, care partnership relational dynamics, management styles, and limited resources may be considered as further obstacles to overcome for successful management of the care partnership in clinical settings (Torny, et al., 2018).

In a recent critical review of caregiver burden in Parkinson’s disease, it was suggested that clinicians should aim to identify and reduce burden by directly targeting caregivers or by addressing PD symptoms associated with burden, including education and psychotherapy for the person with PD and their care partner (Mosley, Moodie, &
Dissanayaka, 2017). However, clinical practice guidelines for how clinicians from different disciplines may operationalize these recommendations within their clinical scope remain to be developed and systematically tested for efficacy. Nonetheless, identifying and responding to burden experienced by care partners is important for clinicians because informal caregivers make major personal and societal contributions to the support of people with PD.

Previous studies have highlighted the impact and also the clinical value of care partners for people living with PD, yet how to best support the care partnership as a dyad in clinical settings remains to be defined. The findings of this dissertation fit well within the literature, echoing the physical and emotional toll care partners accept while caring for their spouse with PD. The findings further suggest some opportunities throughout the process of providing care to people living with PD where healthcare providers seek to involve the care partner in clinical discussions and decisions. Healthcare providers underscored the benefits of including the care partner in clinical discussions as well as interventions, such as gaining further insight into the care partnership’s daily lives or to assist in implementing rehabilitation interventions, for example. Healthcare providers also acknowledged the valuable contributions of the care partner’s perspective when building and delivering their care package. The findings of this research highlight the importance of encouraging both members of the care partnership to participate in clinical settings, both to optimize delivery of care to the person diagnosed with PD, and also to identify and implement interventions to support the care partner directly.
6.2.2 Self-Management as Client-Centred Care

In the first study, care partnerships described the process of problem solving in the PD world by accessing three resources: support, the couple themselves, and knowledge. If the care partnership could efficiently navigate and access these resources, they were more likely to find solutions to problems associated with living with PD. Healthcare professionals described their conscious efforts to provide client-centred care and partner with clients in directing their care plan, as considerations for the care partnership and their disease progression greatly contributed to the assembly of the care package. These findings from both studies related to problem solving and efforts to provide client-centred care suggest that self-management interventions in clinical settings may be a key ingredient for clinicians to deliver client-centred care.

Three main components of self-management for people living with PD are education, goal setting, and guided problem solving (Kessler & Liddy, 2017). Participants described a process of learning to live with PD that fits well within these components, such that care partnerships used problem solving opportunities to learn how to live with PD; this process required accessing knowledge (education), support (guided problem-solving) and their own resources to achieve their goal of living with PD (goal setting). Healthcare providers were not always familiar with the term “self-management” and how it might apply to their practice, however, all participants considered the care partnership in an effort to provide client-centred care. Considering the care partnership was an important moderator in determining the contents of healthcare providers’ care package, as participants frequently described the individualized nature of PD, preferences of the care
partnership and the implications for the delivery of care. Meeting the care partnership’s self-management needs for supported problem solving via client-centred care could set the stage for creating mutually agreed upon goals and care plans, which would lead to positive outcomes for both the clinician and the care partnership.

Self-management is a critical element of effective chronic condition management, contributing to slowed disease progression, reduced complications, and lowered costs (Ory, et al., 2014). Self-management is defined as:

…the individual’s ability to manage symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent in living with a chronic condition. Efficacious self-management encompasses ability to monitor one’s condition and to effect the cognitive, behavioural and emotional responses necessary to maintain a satisfactory quality of life. Thus, a dynamic and continuous process of self-regulation is established. (Barlow, et al., 2002)

Maintaining a clinical focus on self-management in clinical setting for care partnerships living with PD has been highlighted in a recent review, and emphasized specific self-management skills such as goal setting and problem solving (Kessler & Liddy, 2017). At the conclusion of their integrative review, the authors suggested that self-management interventions should include the key components of education, goal setting, and guided problem solving (Kessler & Liddy, 2017). While self-management interventions have gained acceptance as important care priorities for people living with chronic illnesses, the specific components that are most effective, as well as how self-management support programs can be implemented in Canadian healthcare settings, remain to be defined.
Nonetheless, self-management is a promising tool to assist in bridging the gap between clients’ needs and the capacity of healthcare providers to meet those needs through a client-centred approach.

The meaning of client-centred care is “contested and obscure” (Tanenbaum, 2015). Particularly, with respect to people living with PD, delivery of collaborative, client-centred care is especially challenging given the complex, individualized and debilitating nature of the disease, including cognitive, emotional, and physical symptoms (Lees, Hardy & Revesz, 2009). This may contribute to why client-centredness remains far from being implemented in everyday clinical practice in Western countries (Davis, Schoen & Stremikis, 2010), despite evidence it improves treatment adherence, quality of life, and physical health among chronically ill clients and improves job satisfaction among healthcare professionals (Bauman, Fardy & Harris, 2003; Michie, Miles & Weinman, 2003). Client-centredness requires more than a respectful attitude towards clients or an individualized style of clinical interviewing; rather, clients must be engaged as active participants in their own care (van der Eijk, et al, 2013). The authors suggested shared-decision making as a method to access client-centred care for people living with PD in client-physician settings, however, specific recommendations for other health disciplines remain to be identified.

Self-management interventions implemented by healthcare professionals can incorporate several aspects of client-centred care. Considering the three key components of self-management are education, goal-setting, and guided problem solving, there is potential to address several of the seven types of client-centred interventions identified by Poitras and colleagues (2018): 1) Supporting decision process and evidence-based
practice; 2) Providing patient-centered approaches; 3) Supporting patient self-management; 4) Providing case/care management; 5) Enhancing interdisciplinary team approach; 6) Developing training for healthcare providers; and 7) Integrating information technology. For example, goal setting through a self-management clinical focus would lend to creating an individualized care plan, structured to reflect the client needs, specific conditions, personal challenges, and goals. Similarly, educational resources developed as part of a self-management intervention would be amenable to client-centred care principles as well.

Both care partnerships and health care professionals emphasized the importance of self-management and client-centred care. The findings of this dissertation provide insight into how these constructs are connected and may be achieved in clinical practice. Involving both the person diagnosed with PD and their care partner in self-management interventions may empower the care partnership to actively participate in their care, which could ultimately have the power to improve their self-efficacy and quality of life.

6.2.3 Connecting with Community Resources

Among the care partnerships in the first study, participants spoke about learning roles of some other healthcare providers than their family physician or PD neurologist. Care partnerships described benefitting from care provided by physiotherapists, massage therapists, pharmacists, nurses, and social workers. Participants also mentioned the benefit of community programs, such as Parkinson’s Canada support groups and educational events, as well as Reiki, dance, boxing, and Tai Chi programs, and expressed a need for more direction about these programs from their clinicians. Healthcare
providers in the second study expressed varying levels of enthusiasm for community programs, but did consider resources in the community as an important factor in building their care plan, in the sense that accessing community resources may help sustain clients between clinical visits. Referring or connecting clients with community resources was largely dependent on client-specific factors such as their management style, area of residence, access to transportation, financial ability, and interest in a particular type of support. Healthcare providers also described a desire to be more aware of available programs in order to facilitate appropriate referral and connect their clients to resources that may be useful.

Community care provided by physiotherapists, occupational therapists, and speech and language pathologists have been suggested as complementary non-pharmacologic therapies in PD management in the Canadian Guidelines on Parkinson’s Disease (Grimes et al., 2012). Although the benefit of a multidisciplinary approach, including rehabilitation therapies, has been demonstrated (see randomized controlled trials by Ferrazolli, et al., 2018; van der Marck et al., 2013), access to these therapies continues to be a challenge. Barriers include cost to the clients, transportation, accessibility, and individual client preferences that vary from clinical best practice guidelines (Bloem & Munneke, 2014; Post et al., 2011; van der Eijk, et al., 2013). The variation in client preferences contributes to the challenge of delivering multidisciplinary care and is in keeping with findings from the first study: that some – but not all – care partnerships were highly interested in learning about and sought non-pharmacologic care options, while others were more apt to follow only the treatment provided by their neurologist and not venture to other professionals.
A recent review sought to understand the effectiveness of ‘linking schemes’ from healthcare providers to community resources, in an effort to improve the well-being of people with long-term conditions (Mossabir, et al., 2015). ‘Social prescribing’ is defined as “enabling primary care services to refer patients with social, emotional or practical needs to a range of non-clinical services” (Brandling & House, 2007, pp. 3). The authors proposed ‘social prescribing’ as a method of addressing the gap of formal health care services to address clients psychosocial well-being, and emphasize the vital role of healthcare professionals in connecting their clients to community services. Mental health and social isolation were the most common reasons for referral to the community programs, and studies reported improvement to participants’ psychological and social well-being, as well as decreased use of health services, indicating health, social and cost-effectiveness outcomes (Mossabir, et al., 2015). Of note was that almost all interventions were facilitator-led, whereby the facilitator worked to identify and link participants to appropriate community-based resources, highlighting the potential role of clinical facilitators, as has been suggested by others (Kessler, et al., 2019). Moreover, community organizations may be an appropriate setting for health support to overcome barriers associated with access, transportation, finance, and health literacy (Lamb, et al., 2012; Wagner, et al., 2001). Empirical evidence of the impact of social prescribing remains limited, however the potential to broaden the availability of services to care partnerships living with PD and other chronic conditions warrants further inquiry into its role in client-centred care.

Each of the studies previously discussed adds substantiation for the importance of expanding the circle of care for care partnerships living with PD to include community
supports, both clinically and non-clinically oriented. However, no research was found specifically exploring the implications of integrating primary health care with community clinical care as well as social resources for care partnerships living with PD. Care partnerships living with PD have a number of inter- and intra-personal factors which could impact their ability to successfully seek or follow recommendations to participate in community programs. For instance, care partners may feel overwhelmed with their role and may not be willing to take on another appointment or commitment, which could impede upon prioritization of their own health, such as the results seen in a multidisciplinary intervention where coordination was not optimized (Wade, et al., 2003). Moreover, care partnerships living with PD are typically older adults and, as such, pre-PD factors such as lifestyle and relational dynamics may influence their willingness to not only become more involved in their care plan, but to access services outside of a traditional paternalistic medical model (Blickem, et al., 2013). Despite individual factors, insights from this research highlight the importance of care partnerships developing problem solving skills to overcome challenges; for instance, maintaining meaningful activities, which may be facilitated through rehabilitation interventions and through social connections. For example, learning a new skill such as Tai Chi, and maintaining or making new social connections with neighbours or a support group will contribute to the care partnership’s support resource, which in turn will facilitate their problem solving ability. Moreover, encouraging healthcare professionals – and instating the relevant resources – to connect care partnerships to clinical and social community referrals may facilitate client-centred conversations about self-management needs and the importance of building both healthcare and social support networks.
6.2.4 Client Expectations and Effective Communication

Care partnerships living with PD described their previous experiences relating to their initial appointments with healthcare providers prior to and shortly after receiving their diagnosis. These initial appointments – typically separated by lengthy waiting periods – formed the initial process of learning to navigate the system. Care partnerships described their impressions of physicians, their experiences throughout various referrals, and vividly recounted the conversations where they received their diagnosis. Care partnerships in the first study described feeling satisfied or disappointed with their experiences in these appointments; for instance, receiving sufficient or inadequate information compared to what they were expecting, or discussing topics or referrals they had been wondering about. In cases where the care partnerships’ expectations were not met, suggestions were often made for what would have been preferred, such as reassurance they were not going to be quickly institutionalized, providing a booklet of information, a list of local resources, connecting with peer support groups, or referring to other services. The varying accounts indicates the equally variable expectations of each care partnership, which contributes to clinicians’ challenge of providing care in a manner that will suit each client they see. Healthcare providers in the second study reiterated this challenge, highlighting the struggle of addressing the issues within their clinical scope and loosely following their clinical plan, while assessing their client’s desire for information and their willingness to co-create a management plan. In an attempt to resolve this in a time-efficient manner, healthcare providers drew on their clinical experience and knowledge of PD to identify and target issues that have typically shown to have the highest impact for clients in the past. This strategy was particularly salient for
clinicians in public healthcare settings with defined time constraints. When considering the value of spending precious clinical time to discuss expectations and their intentions for the appointment, all public healthcare providers expressed they could use that time more efficiently by addressing other topics. However, considering the described process of navigating the system, taking the time to understand clients’ expectations and to effectively and empathetically communicate how they may align – or not align – with the healthcare provider’s clinical scope and capacity, may be informative for clinicians to focus their assessment, care package, and ongoing support of care partnerships living with PD in a client-centred manner.

The findings of this research suggested that developing shared expectations through effective communication may be especially important in care partnerships living with PD, particularly in the initial stages when they are learning to navigate the system. However, healthcare professionals caring for care partnerships with PD ought to have an interest in developing shared expectations and care goals with their clients at any stage, as the clinician-client relationship has been associated with increased self-reported client satisfaction and treatment adherence, even in the absence of apparent changes in motor scores or activities of daily living (Grosset & Grosset, 2005; Nisenzon, et al., 2011). It has been well-established that people living with PD are a heterogeneous group, particularly when it comes to expectations and desires for their clinical care (Nisenzon, 2011). Clinicians are tasked with building trusting relationships with their clients in order to elicit their care expectations regarding the multiple domains impacted by PD, and subsequently open a dialogue to create shared understandings and goals for client education and care strategies.
For the care partnerships in the first study, participants described building relationships with their healthcare providers that influenced their satisfaction with their care. Empathetic communication may be an effective method for eliciting and managing client expectations, as well as fostering strong therapeutic relationships throughout the course of PD, in order to strengthen the care partnership’s support resource from healthcare providers. While individual client preferences may vary, people living with PD largely prefer a shared-decision making approach to their care (Zizzo, et al., 2017). Ineffective communication and insufficient delivery of information from the client’s perspective may result in clients feeling under-informed about critical care issues, and experience a lack of collaboration between healthcare professionals (van der Eijk, et al., 2015). Furthermore, the way in which healthcare professionals communicate, disclose, frame, and contextualize information to clients may modulate symptoms in PD, either alone or with other care options (Annoni & Miller, 2016). Evidently, effective communication with clients is paramount to a number of factors that determine health outcomes.

The client-clinician relationship plays a central role in providing care to people living with PD. As a result, clinicians must acknowledge that clients are complex, social beings, with interdependencies and interconnections that can influence decision-making, (Ells, Hunt, & Chambers-Evans, 2011), and as such, communication is key to developing clinical relationships (Zizzo, et al., 2017). Healthcare professionals in the second study emphasized the challenge in catering the delivery of their care package via communication, according to individualized factors of their clients living with PD. The existing literature described above suggests that clinicians assess client preferences on an
on-going basis in order to establish shared expectations and deliver client-centred care. Considering that communication is central to both eliciting client expectations and establishing therapeutic relationships, resources to support clinicians in initiating conversations that will empower clients in relation to their wants, needs and values are in need of further investigation.

6.3 Implications of Key Insights for Practical Care

6.3.1 Implications for Parkinson’s disease Practice

Participants living with PD, both those diagnosed as well as their care partners, described strategies for solving problems throughout their journey with PD. Others have eloquently described this process from a constructivist stance as ‘preserving self’ (Vann-Ward, Morse & Charmaz, 2017), whereas in this dissertation, it has been oriented to a more clinically practical concept of self-management. Healthcare professionals in the second study emphasized their consideration of the system in which they provide care, PD as a progressive disease, the care partnership as a dyad and community resources when building a care package to sustain the care partnerships between visits. The processes that have emerged from this dissertation emphasize the importance of implementing a co-created approach to delivering client-centred care by engaging the care partnership in empathetic discussions about care partner well-being, self-management, community resources, and expectations. These findings encourage healthcare providers to reflexively engage with their taken-for-granted assumptions that may inform their clinical care decisions from within the social contexts within which they
practice, in order to collaboratively develop care plans for care partnerships living with PD.

Traditional assessment and care for people living with PD under the biomedical paradigm are typically delivered in a didactic manner where the healthcare professional imparts their expertise on the person diagnosed with PD. In an attempt to deliver client-centred care, findings from this dissertation aim to inspire clinicians to go beyond a respectful demeanour towards the client, and to reflexively engage both members of the care partnership to understand their experiences of learning to live with PD. Healthcare providers in the second study described systemic challenges and unique considerations inherent to caring for people living with PD as a progressive, chronic condition, but also emphasized their efforts to consider the care partnership as a dyad, connect them with relevant community resources, and to tailor their communication according to individualized factors. This type of approach to caring for people living with PD is in keeping with constructivist underpinnings of the research constituting this dissertation; that is, a co-creation of care that is situated within the social contexts pertaining to the care partnership with whom they are interacting. Empathetic communication with both the care partner and the person diagnosed with PD is critical to accessing the meanings and experiences created by care partnerships learning to live with PD, and is the cornerstone around which a client-centred care package may be built and delivered. By reframing caring for people living with PD within a constructivist framework, healthcare providers may be able to better utilize the evidence base outside the traditional biomedical literature and implement it via social interaction knowledge translation initiatives (McWilliam, et al., 2008).
As discussed above, self-management interventions are amenable to principles of client-centred care and are a viable method to promoting independence to sustain care partnerships living with PD between clinical appointments. Effective self-management interventions for care partnerships living with PD remain to be fully defined, however, insights from the first study may encourage clinicians to review available evidence, particularly with respect to building care partnerships’ support networks, opportunities for supporting the care partner and the renegotiation of roles within the care partnership, and access to reliable sources of knowledge. These three areas were described by care partnerships as the primary resources utilized in the process of solving problems related to living with PD, and fit within the core components of self-management interventions of education, goal setting, and guided problem solving (Kessler & Liddy, 2017). As such, clinicians are encouraged to reflexively consider their socially situated ideas of client-centred care and how they may incorporate principles of self-management intervention through empathetic communication with their clients living with PD as well as their care partners.

In order to create opportunities to engage in these types of co-creative discussions with both members of a care partnership, healthcare providers may indeed require increased time resources in their respective clinical settings. This is discussed from a systems policy perspective below, however there may be opportunity at the clinician level to create space for these conversations in existing organizational frameworks. In current PD practice, with demanding clinic schedules, high patient volumes and various compensation models depending on the health discipline, as well as the emphasis on time efficiency balanced with the provision of quality healthcare, interactions between
healthcare professionals and clients may be cut short to encourage more patient throughput and, as a result, evidence-based recommendations for practice may be compromised (Dobkin, et al., 2013; Lageman, Mickens & Cash, 2015). ‘Taking the time to listen’ has been identified as a major facilitator to communication with clients living with PD (Armstrong, et al., 2019); as such, this change to allow more time warrants further investigation to prioritize its implementation, despite clinician- and system-level barriers. However, it is important to consider the influence and indispensability of creating a quality, foundational clinician-client relationship for healthcare, grounded in care partnerships’ concerns, preferences, and goals based on their previous experiences of living with PD. Building a collaborative, client-centred care package for care partnerships living with PD may require more sensitivity and time than what is currently reflected in clinic schedules – lending a closer reflection to care practices and durations for the provision of care for people living with PD and other populations with chronic conditions. While there may be some opportunity for individual clinicians to initiate allocating more time in their practices, I do not intend to soften the challenges within existing, larger funding and service systems which may restrict others from implementing such changes. If allocating more time to interactions with care partnerships living with PD negatively impacts individual clinicians’ financial income, it is doubtful that this recommendation be initiated on a large scale. In contrast, if the benefit of increasing time is reflected in improved outcomes and understood as imperative for client-centred care, it may be a change that healthcare associations, policy makers and other regulatory bodies can advocate for. It is my hope that the findings from this research will stimulate conversations among clinicians and policy makers about the importance of considering
care partnerships’ experiences of learning to live with PD as they relate to self-management in client-centred care.

6.3.2 Implications for Parkinson’s disease Best Practices

Best practice models for caring for people living with PD, such as the Canadian Guidelines on Parkinson’s Disease (CGPD) place pharmacological interventions at the centre of clinical management for care of people living with PD, yet, also clearly discuss the importance of communication, consideration of care partner needs and rehabilitation therapies, such as physical, occupational and speech and language therapies (Grimes, et al., 2012). Key insights from this dissertation provide additional evidence to emphasize the importance of care partner involvement, self-management support, connecting with community resources, and empathetic communication to deliver client-centred care. Experiences described by care partnerships living with PD suggest that, despite the recommendations from the CGPD, there is much room for improvement to clinically operationalize many of the best practice guidelines in all health disciplines.

The CGPD encourage healthcare professionals to address motor and non-motor symptoms through a series of recommendations, the first eight of which are centred around communication practices (Grimes, et al., 2012). While it is encouraging that the importance of communicating with people living with PD is centralized in the guidelines, how this may be operationalized from a co-created perspective with respect to inclusion of the care partner, self-management support for the care partnership, connecting with local resources, and managing expectations, remains to be defined. As such, best practice models such as the CGPD may not optimally contribute to the efforts of healthcare providers to enact a more collaborative, tactful and client-centred approach to caring for
people living with PD. For instance, the CGPD mentions self-management as “an issue to consider when communicating with people with Parkinson’s and their caregivers” (Grimes, et al., 2012, pp. S5), however does not define self-management or delineate how to navigate those conversations. Findings from this dissertation propose a theoretical process by which care partnerships learn to live with PD and problem solve challenges using three types of resources. Insights from this process may inform discussions about relevant evidence surrounding self-management approaches, in order to assist guideline developers to make recommendations for implementing client-centred self-management goals in their clinical practice.

Healthcare providers in this dissertation described their consideration for the care partnership as a dyad to be clinically managed as a unit, as well as a consideration of community care options and support programs to assist in building their care package. Furthermore, care partnerships described the impact of PD on both members of the care partnership, and the importance of building support networks with both social and healthcare contacts. In the context of co-creating a care package, healthcare professionals would further encourage care partnerships to identify their main concerns for care targets in order to collaboratively establish care goals. Such approaches to care for people living with PD are inspired by a constructivist approach to caring, based on collaboration and co-creation of client-centred care plans, which precludes a didactic, biomedical approach to care for people living with PD. As such, best practice documents such as the CGPD may not suffice in the level of guidance sought by healthcare providers attempting in earnest to deliver client-centred care, and may need to be revised to consider a more reflexive understanding of the elements of co-creation for enacting care plans for care
partnerships living with PD. In order to accomplish this goal, developers of best practice guidelines may need to look beyond the ‘level of evidence’ and consider the social and organizational contexts that shape their decisions regarding the particular types of evidence that are considered as valuable contributions to best practices for caring for people with PD, particularly with respect to involvement of the care partner, self-management interventions, connecting with community resources, and managing expectations. In so doing, they may seek to integrate evidence that reflects the meaningful experiences of both the care partnerships learning to live with PD and healthcare providers, with the conventional biomedical body of literature that composes best practice guidelines.

6.3.3 Implications for Knowledge Translation for the Care of People living with Parkinson’s disease

While a great deal of research exists regarding effective ways to deliver client-centred care for people living with PD both in community and primary care settings (for example, Jankovic & Poewe, 2012; Kruger, et al., 2016; Lim, et al., 2017; Radder, et al., 2017; van der Eijk, 2013), when and how this body of research is applied remains open to critical debate. With the exception of one known group from the Netherlands, (Bloem, et al., 2017), conventional discussion in academic literature about the evidence base for PD practice by healthcare providers takes a distinctly didactic tone, focusing primarily on how to improve care for people living with PD – as well as their care partners – as opposed to critically questioning when, why, and how to apply such research with care partnerships living with PD in the community.
Findings from this dissertation suggest that critical reflection regarding the implications of involving the care partners in all aspects of caring for people living with PD, self-management as a method for implementing client-centred care, connecting care partnerships with community resources, and the importance of effective clinical communication, may contribute to more empathetic and tactful approaches to caring for people living with PD. As such, approaches to knowledge translation that encourage critical reflection on the primarily biomedical body of evidence for caring for people living with PD, and further reflection on qualitative research findings as well as the above-stated key insights of this dissertation, may more aptly contribute to promoting more informed and client-centred approaches to primary and community-based care for care partnerships living with PD.

An interesting observation in reviewing the literature in which to situate the findings of this dissertation revealed that the key insights of these studies fit well within already documented best practice guidelines, with some opportunities for expansion from a constructivist perspective, as described above. It would seem the body of evidence-based literature has been advocating for client-centred care for people living with PD, yet there exists a delay in uptake into clinical practice, a common finding in chronic disease management for older adults (Ahmed, et al., 2015; Tricco, et al., 2018). For this reason, knowledge translation initiatives are required that take a social interaction approach, emphasizing attention to the social contexts that mediate healthcare providers’ as well as policy makers’ interpretations of research evidence, as it relates to client-centred care for people living with PD and their care partners (McWilliam, et al., 2008). Social interaction knowledge translation (McWilliam, et al., 2008) is an approach that considers
constructivist co-creation of knowledge to be central to the knowledge translation process, understanding that research evidence will always be situated within the experiential knowledge and social and organizational contexts in which healthcare providers practice. As such, people from diverse disciplines and with diverse roles and statuses come together to co-create knowledge, blending research evidence with their experiential knowledge to develop mutual understandings, amplify knowledge, solve problems, test ideas, validate strategies, and adapt the knowledge to their own culture, context, and situation (McWilliam, et al., 2008).

Drawing on tenets of social interaction knowledge translation, healthcare providers in both primary and community-based settings may be encouraged to engage in critical reflection regarding the ways in which the social contexts of health care inform their approaches to caring for care partnerships living with PD. This may involve reflexive discussion and self-reflection exploring the social, political, and economic assumptions that are integrated into their taken-for-granted meanings of living with PD, care partnerships, and self-management. In so doing, clinicians may develop a broader understanding of the nature of research evidence, conscientiously integrating quantitative biomedical research evidence and qualitative evidence exploring the experiences of people diagnosed with PD as well as their care partners into their experientially learned practice knowledge. A social interactionist approach to knowledge translation aligns with the findings presented in this dissertation and may be integral to fostering healthcare providers’ and policy makers’ understanding of client-centred care in relation to caring for care partnerships living with PD.
6.3.4 Implications for Healthcare Systems Policy

The findings of this dissertation present unique challenges for health care policymakers. The first major challenge is that an authentic constructivist ethics of care, that is, a model that advocates for the co-creation of care plans, cannot be directly legislated, monitored, or enforced (Charmaz, 1990). While knowledge translation initiatives have been developed to foster health service providers’ critical reflection and practical learning necessary to encourage approaches to health care that build upon principles of client-centred care (Prowd, et al., 2018), policy cannot dictate a more constructionist orientation – in the sense of analyzing how clients’ and our own taken-for-granted interactions may influence perceptions of chronic illness – toward primary and community-based health services. However, by funding research projects and health care delivery programs integrating such knowledge translation initiatives, policy makers may be able to encourage health care professionals to engage in the critical reflection necessary to foster truly client-centered approaches to self-management for people living with PD.

The second major challenge for policymakers is that a client-centred, self-management approach to care for people living with PD requires service providers to spend time and build relationships with care partnerships through empathetic communication in order to foster a trusting, effective therapeutic relationship. Other options warranting consideration may include providing human resources to act as clinical care facilitators, or additional funding for access to community care providers, including a range of health disciplines. Considering the limitations in resources that tend
to characterize contemporary health care delivery systems, providing practitioners with
the opportunity to spend additional time with clients, or additional human or financial
resources to fund multidisciplinary approaches, may not seem plausible. However, such
investments may be necessary in order to encourage a broader impact on meaningful,
effective client-centered approaches to care for people living with PD over longer periods
(Grimes, et al., 2012; Poitras, et al., 2017; Post, et al., 2011). As resource limitations are
such a pervasive issue in the context of contemporary health care, ethical, practical, and
political debate is warranted regarding the allocation of scarce resources toward various
approaches to care for people living with PD. While further inquiry into the impact of a
client-centred, self-management approach to caring for people living with PD is
necessary before any specific policy changes may be recommended, this dissertation
research may help to inform the debate regarding the ethical and practical dimensions of
the allocation of both human resources for care and research resources for the critical
study of self-management for care partnerships living PD.

6.4 Future Research

This research expands the existing body of evidence for providing client-centred care
for people living with PD, by emphasizing the importance of the care partnership
perspective, and suggesting self-management as a method of implementing a
constructivist co-creation approach to care. Several potential research questions arise out
of the findings of this dissertation research.
While the importance of including the care partner is discussed throughout this dissertation, intra- and interpersonal factors of the care partnership and how this may influence clinical care interventions is warranted. Care partnership factors such as effective communication, mutual respect, and shared goals were identified as facilitators to problem solving that underpins the process of learning to live with PD, however it is unclear whether these are skills developed as a result of living with PD, or more attributable to pre-PD relational attributes. Describing a typology of care partnerships living with PD and clinical methods for identifying and facilitating different types of care partnerships to facilitate their journey with PD via self-management interventions would be a valuable pursuit for healthcare professionals in a variety of disciplines.

The practical impact of a self-management approach to client-centred care for care partnerships living with PD in both primary and community-based care settings merits longitudinal inquiry. Such longitudinal investigation would not only explore health outcomes, but would focus qualitatively on the experiences of the care partnerships and discipline-specific healthcare professionals involved in the self-management initiative. In so doing, further investigation might explore the ways in which the initiative was meaningful for care partnerships living with PD related to their ability to live with PD. It may also aim to understand healthcare providers in various disciplines related to their confidence in providing truly client-centred care, and seek to understand issues with its practical implementation in particular health care contexts. Longitudinal study may substantiate the need for a co-creative, social interaction approach to care for care partnerships living with PD to augment conventional biomedical approaches, providing
necessary support to advocacy efforts for health policy that recognizes the legitimacy of such an approach to care for those living with PD.

A surprising finding in reviewing the literature of best practices in PD was the inclusion of several care principles suggested in this dissertation, surrounding both communication practices and care partner involvement. However, the findings indicated that these guidelines are far from being widely implemented. Further research might therefore also focus on a social interaction approach to knowledge translation to understand the ways in which health care providers from various disciplines may learn to understand and enact client-centred recommendations to caring for care partnerships living with PD. Considering the critical reflection and dialogue that characterizes such an approach to caring for those living with PD, research investigating strategies for educating service providers about this approach and clinician-level barriers is likely warranted. Furthermore, the organizational- and system-level barriers to implementing co-creative, client-centred care may also be identified.

6.5 Limitations

The two studies discussed throughout this dissertation were completed within particular social and cultural contexts at a particular time within mid- to large-sized cities across Southwestern and Eastern Ontario and, therefore, must be understood within the confines of these contextual factors. The findings of each study are considered as co-constructions created between the researchers and participants and, as such, the findings are not meant to be overly generalized or simply translated to all people and care partners living with PD or all healthcare professionals in other contexts. In the first study,
participants included twenty-two participants living with PD – eleven people diagnosed with PD and their care partners – who lived in the community, were physically able to participate in the interview, and had no other neurological conditions. Participants were recruited from Parkinson’s Canada support groups, physiotherapy clinics, and community exercise programs, which may have contributed to a sample overrepresented with people who seek community support, relative to the greater population of people living with PD. The second study involved eight healthcare professionals of different disciplines primarily caring for people living with PD in ambulatory care settings. The sample was meant to be representative of the healthcare professionals described by care partnerships in the first study, which consisted mainly of neurologists and nurses, as well as some community care health professionals, such as rehabilitation therapists and pharmacists. Insights arising from this research are therefore not discipline-specific, and are informed by experiences of healthcare professionals from several disciplines. The findings may inform aspects of clinical practice in ambulatory, outpatient settings, but do not wholly represent the experiences of all people living with PD – as they are particularly unrepresentative of those living with advanced disease or pronounced cognitive symptoms – or all healthcare professionals who may care for people living with PD in Ontario.

For the sake of reference, in this research I employed the term ‘care partnerships’ to refer to spousal couples where one person has been diagnosed with PD and the other is the primary care partner. Moreover, the commonest term for the person who provides informal care to a person diagnosed with PD is a ‘caregiver’; however, I chose to implement a language of inclusivity to highlight the equal – or at the very least,
substantive – impact and role in managing PD that both members of the care partnership have. By implementing this ‘partnership’ language, I hope to further emphasize the clinical management of both members of the care partnership in clinical settings; nonetheless, I do recognize this is not the conventional terminology in the PD literature. Terminology aside, an important consideration of this cohort is that people living with PD are a highly heterogeneous group when taking into account physical, functional, psychological, and social characteristics (van der Eijk, et al., 2013). For instance, although the majority of care partnerships consist of spousal couples (Caap-Ahlgren & Dehlin, 2002), it is recognized that care partners can also be adult children, siblings, or other family members. The heterogeneity of people living with PD will ultimately result in variable perceptions of ability, healthcare options, care models, and goals of care. Thus, an essential component when caring for care partnerships living with PD will always require care plans tailored to the person and their care partner, rather than assimilating all ‘care partnerships’ into one category.

I also recognize my application of a constructivist paradigm to this research may be perceived as a limitation. I would advocate that through the implementation of constructivist research, I have become much more cognizant of my views on the relative nature of ‘knowledge’ and ‘truth’ and have consequently developed a deep appreciation for how important it is in the healthcare profession to remain open-minded to the perspectives and experiences of other people, particularly our clients. Throughout these two studies, I endeavoured to remain open to topics highlighted by participants, and to base my interpretations on the data and perspectives presented to me in the research process. However, in so doing, I also recognize the findings are ‘co-constructions’ from
my own social context and, thus, never truly represent the full extent of the meaning of the experiences, values, beliefs, and behaviours as lived and understood by the participants. Through iterative analysis and evocative writing (as described in Chapter 3), I have attempted to demonstrate trustworthiness and authenticity and, ultimately, I hope to achieve resonance with both research participants and readers alike.

6.6 Conclusion

This research sought to explore the processes of care partnerships learning to live with PD and of healthcare professionals providing care to people living with PD. In the first study, care partnerships described the processes of navigating the system and problem solving in the Parkinson’s world in order to learn to live with PD. Once inside the Parkinson’s world, Participants described accessing three resources each time a new problem presented, related to living with PD: support from healthcare professionals and social contacts such as family and friends, the couple on their own as they renegotiated roles and considered the impact on the care partner, and knowledge gained through their own experiences or research from various sources. Healthcare professionals’ process of ‘sustaining the care partnership between clinical visits’ was comprised of: building the care package, which considered four key factors of: the system, PD as a progressive disease, the care partnership, and community resources; delivering the care package via communication and education; and bridging the care partnership until the next clinical visit. The process was embedded in clinicians’ social contexts, including their intent to deliver client-centred care and facilitate independence between clinical appointments.
Key insights from the findings of this research included: the importance of involving the care partner in clinical care discussions including the impact of caring for a spouse living with PD and supporting the important roles the care partner holds in extending care beyond the clinical setting; considering self-management education as a means of achieving client-centered care by supporting the care partnership in the management of symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent in living with PD in order to promote and sustain independence between clinical visits; connecting the care partnerships to supports, which may involve providing guidance to assemble a healthcare team of relevant professionals and/or connecting them with appropriate community resources; and finally, identifying and managing expectations through empathetic, effective communication as a key ingredient to clinical care in order to tactfully deliver relevant information, based on client-specific factors.

These key insights build upon the evidence base of client-centred care for people living with PD, and suggest specific elements to discuss with care partnerships using effective communication in order to co-create a client-centred care plan. A discussion of the implications of these insights related to PD clinical practice, best practice guidelines, knowledge translation, and healthcare systems policy was presented, with the intent of stimulating and informing future discussion and research on these topics, as opposed to calling for immediate implementation of organization- or system-level change.

The findings of this research provide important information for healthcare providers who care for people living with PD and their care partners. Insights gained may challenge clinicians’ inherent, taken-for-granted assumptions about the challenges of living with PD, and may inspire more reflexive, co-creative approaches to clinical practice. I hope to
mobilize the findings of this research in ways that will reach care partnerships living with PD, such as disseminating findings in an accessible format via Parkinson’s Canada, in order to inform and support care partnerships living with PD to maximize their ‘resources’ for problem solving PD-related issues. With these insights, I hope to inspire a more sensitive, empathetic approach to co-creating client-centred care plans in order to support both the care partnerships living with PD, as well as the clinicians working tirelessly to provide their care.
6.7 References


Appendices

Appendix A: Ethics Approval Notice for Study One

Western University Health Science Research Ethics Board
HSREB Annual Continuing Ethics Approval Notice

Date: October 31, 2016
Principal Investigator: Dr. Denise Connolly
Department & Institution: Health Sciences/Physical Therapy, Western University

Review Type: Delegated
HSREB File Number: 106873
Study Title: Learning self-management skills in Parkinson disease: The couple’s perspective.

HSREB Renewal Due Date & HSREB Expiry Date:
Renewal Due: 2017/11/30
Expiry Date: 2017/12/10

The Western University Health Science Research Ethics Board (HSREB) has reviewed the Continuing Ethics Review (CER) Form and is re-issuing approval for the above noted study.

The Western University HSREB operates in compliance with the Tri-Council Policy Statement Ethical Conduct for Research Involving Humans (TCPS2), the International Conference on Harmonization of Technical Requirements for Registration of Pharmaceuticals for Human Use Guideline for Good Clinical Practice (ICH E6 R1), the Ontario Freedom of Information and Protection of Privacy Act (FIPPA, 1990), the Ontario Personal Health Information Protection Act (PHIPA, 2004), Part 4 of the Natural Health Product Regulations, Health Canada Medical Device Regulations and Part C, Division 5, of the Food and Drug Regulations of Health Canada.

Members of the HSREB who are named as Investigators in research studies do not participate in discussions related to, nor vote on such studies when they are presented to the REB.

The HSREB is registered with the U.S. Department of Health & Human Services under the IRB registration number IRB 00000940.

Ethics Officer, on behalf of Dr. Joseph Gilbert, HSREB Chair

Ethics Officer: Enka Basiie, Katryn Harris, Nicole Kamile, Grace Kelly, Vikki Turr, Karen Gopal
Appendix B: Ethics Approval Notice for Study Two

Western Research

Date: 12 March 2018
To: Dr. Denise Connolly
Project ID: 111008

Study Title: Parkinson disease care partnerships: Bridging perspectives in clinical self-management interventions
Application Type: HSREB Initial Application
Review Type: Delegated
Meeting Date / Full Board Reporting Date: 03/Apr/2018
Date Approval Issued: 12/Mar/2018
REB Approval Expiry Date: 12/Mar/2019

Dear Dr. Denise Connolly,

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

Documents Approved:

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<td>Recruitment Pack-v2</td>
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Documents Acknowledged:

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No deviations from, or changes to, the protocol or WREM application should be initiated without prior written approval of an appropriate amendment from Western HSREB, except when necessary to avert an imminent and/or irreversible harm(s) to study participants or when the change(s) involve(s) only administrative or logistical aspects of the trial.

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

The Western University HSREB operates in compliance with, and is constituted in accordance with, the requirements of the TriCouncil Policy Statement: Ethical Conduct for Research Involving Humans (TCPS 2), the International Conference on Harmonization Good Clinical Practice Consolidated Guideline (ICH GCP), Part C, Division 1 of the Food and Drug Regulations, Part 6 of the Natural Health Products Regulations, Part 3 of the Medical Devices Regulations and the provisions of the Ontario Personal Health Information Protection Act (PHIPA 2004) and its applicable regulations. The HSREB is registered with the U.S. Department of Health & Human Services under the IRB registration number IRB 00000940.

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

Sincerely,
Patricia Sargent, Ethics Officer (ext: 85990) on behalf of Dr. Marcelo Kremenchutsky, HSREB Vice Chair

Note: This correspondence includes an electronic signature (validation and approval via an online system that is compliant with all regulations).
Appendix C: Letter of Information and Consent for Study One

Letter of Information and Consent

Study title: Living with Parkinson disease: How spousal couples learn self-management skills.

Principal Investigator:
Dr. Denise Connelly, PhD, School of Physical Therapy, Western University.

Co-Investigator:
Danielle Hudson, MSc, PhD student, Graduate program in Health and Rehabilitation Sciences, Western University

Sponsor Information:
The funding source for this study is a grant from the School of Graduate and Post-doctoral Studies awarded to Dr. Denise Connelly as a supervisor of a PhD student.

Conflict of Interest:
There are no conflicts of interest to report related to this study.

Introduction:
You are being invited to voluntarily participate in a research study designed to learn about how spousal couples, where one person has been diagnosed with Parkinson disease (PD), learn self-management skills. Self-management refers to the skills used on a day-to-day basis to reduce the impact of PD in everyday life. You are being asked to participate in this study because either you or your spouse have been diagnosed with PD by your physician and you meet other criteria to be in the study such as: no history of brain injury or diseases other than PD, and you have the ability to communicate in English about your experiences of living with PD.

Background/Purpose:
We know that people living with PD and their care partners learn to manage their symptoms as they emerge over the course of disease. Self-management refers to these daily activities and skills used to minimize the impact of PD on their well-being. Health professionals help teach these skills for managing symptoms in partnership with the person diagnosed. However, there is no research from the perspective of the people learning the skills or about including the spouse in self-management practices. This study may help us learn about how couples living with PD learn the skills required to manage their symptoms. It may also highlight the important role of the spousal care partner in managing PD. This information
could help inform clinical practice related to self-management, meaning how health professionals teach couples living with PD how to take care of themselves and skills to manage PD and their symptoms.

The primary purpose of this study is to learn how couples living with PD learn to manage their symptoms through experience and in collaboration with health care professionals. The secondary purpose is to determine the role played by the spousal care partner in learning these skills. We know that PD is a “couple’s disease” but clinical practices are geared toward the person diagnosed only and do not advise how to include the care partner in the approach to management.

The usual treatment for PD is pharmacological treatment to maintain dopamine levels in the brain. By participating in this study, there will be no alteration to your standard of care or treatment regimen.

**Procedures of the research project:**
Up to 20 couples (i.e., 40 people) will participate in this study and it will take approximately one year to complete. It is expected that you will be in the study for the duration of your interview and possibly for a second follow-up interview.

You will be asked to participate in an interview with your spouse at a location of your choice. During the interview:
- You will be asked a series of questions about your experiences of living with PD and how you have learned to live with your symptoms.
- The interview will last between 60 and 90 minutes.
- The entire interview will be audio recorded and the researcher may take notes.

Due to the nature of this interview study, the study data is created from the interview transcript and therefore it is mandatory to have the interview audio recorded. If you or your spouse does not wish to be audio recorded then you will not be enrolled in the study and the interview will not take place.

Only one interview is required, however as the study continues the researcher may contact you to ask for a follow-up interview. It is your choice to participate in a second interview and you may decline the invitation for any reason.

**Voluntary Participation**
Your participation in this study is voluntary. You may decide not to be in this study, or to be in the study now and then change your mind later. You may leave the study at any time without affecting your standard of care. We will give you new information that is learned during the study that might affect your decision to stay in the study. You may refuse to answer any question you do not want to answer, or not answer an interview question by saying “pass”. You may end the interview at anytime if you do not wish to complete it.

**Confidentiality:**
Data obtained in the study will not be labeled with any of your personal information (name, initials, date of birth, etc.) and will not be able to be linked back to your health information in any way. We will use a special numbering system to identify the information collected in the study. We will keep a master list that has your assigned number, your name and contact information. However, this list will be stored on an encrypted flash drive, separate from any study data. Recorded interview data will be stored on a separate flash drive with no identifiable information. Your signed consent, which will have your name on it, will not be stored with the data collected from the study and will not be connected to the data collected. Consent forms will be stored in a secure location in the research office of Dr. Connelly.

Any use of your data for publication in scientific journals or presentation at professional conferences, will not contain any of your personal information that could be linked back to you or to your health information. Due to the nature of the research, some quotes from your interview may be used in publications, however no identifying information will be associated with your quotes. In order to preserve your confidentiality, during the study only the investigators in the study, namely Dr. Denise Connelly and Danielle Bell Boucher will have access to your research information. Representatives of The University of Western Ontario Health Sciences Research Ethics Board may contact you or require access to your study-related records to monitor the conduct of the research.

Withdrawal from the Study
The researcher may decide to withdraw you from the study prior to or during the interview if the researcher feels continued participation would impair your wellbeing. For example if the interview seems to be too strenuous or detrimental to your health the interview will be terminated and you will be withdrawn from the study.

If you decide to withdraw from the study, you have the right to request the information collected about you and your interview responses be removed from the study. Let the researcher know. If you do not tell the researcher you would like to be withdrawn, your interview responses will be included in the study analyses and will contribute to the study’s findings.

Benefits, Risks, and Inconveniences:
A direct benefit could be increased awareness of how you have learned to manage your disease. This could promote confidence related to your ability to take care of yourself. However, the larger impact is to the patient population being studied. Although many studies exist that have tried to design self-management models, none of these studies involve the perspective of people living with PD and most do not consider the role of the spousal care partner in this process. This research will increase awareness of the role of the spousal care partner in the self-management process and could inform clinical practice related to teaching self-management skills.

You will not benefit directly from participation in this study.

There are no risks of physical harm to you with this study. However, some people may experience increased anxiety and nervousness with being interviewed. Furthermore
recounting difficult experiences related to living with PD may be emotionally difficult including feelings of sadness or grief. We have minimized these possible concerns for you by completing the interview in a comfortable environment of your choice, providing breaks as requested, and positioning the recording equipment in a way that it interferes as little as possible.

Participation in this study will NOT change in any way the treatment of your Parkinson’s disease or your medical care.

**Alternatives to Participation:**
An alternative to the procedures described above is not to participate in the study and continue on just as you do now.

**Costs:**
There are no costs to you by participating in this study, only the time required to complete the interview.

**Rights as a Participant:**
You do not waive any rights by signing this consent form.

**Who to contact with Questions:**
For more information about this research study please contact Denise Connelly at [519-661-2111 x82238]. 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 [email: ethics@uwo.ca]. Should you have any questions about this study or the activities in which you will participate, please do not hesitate to contact us. This letter is for you to keep.
Consent Form

STUDY TITLE: Living with Parkinson disease: How spousal couples learn self-management skills.

Principal Investigator:
Dr. Denise Connelly, PhD, School of Physical Therapy, Western University, Room 1588, Elborn College, 519 661-2111 x82238

Co-Investigator:
Danielle Bell Boucher, MSc, PhD student, Graduate program in Health and Rehabilitation Sciences, Western University

CONSENT
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.

Signature of Participant                Printed Name                Date
________________________________________________________________________________________
Signature of Participant                Printed Name                Date
________________________________________________________________________________________
Signature of Person Obtaining Consent  Printed Name                Date
Appendix D: Letter of Information and Consent for Study Two

Letter of Information and Consent

Study title: Parkinson disease care partnerships: Bridging perspectives in clinical self-management interventions

Principal Investigator:
Dr. Denise Connelly, PhD, School of Physical Therapy, Western University, Room 1588, Elborn College, 519 661-2111 x82238

Co-Investigator:
Danielle Hudson, MSc, PhD student, Graduate program in Health and Rehabilitation Sciences, Western University

Sponsor Information:
There is no funding or sponsor information to disclose.

Conflict of Interest:
There are no conflicts of interest to report related to this study.

Introduction:
You are being invited to voluntarily participate in a research study designed to learn how self-management skills are taught in clinical settings and how healthcare professionals can meet the needs of care partnerships living with Parkinson’s disease (PD). Self-management refers to the skills used on a day-to-day basis to reduce the impact of PD in everyday life. You are being asked to participate in this study because you fit into one of the following groups:

1. You have been diagnosed with PD by a physician, and you have no other neurological conditions;
2. You are, or have been, the primary care partner for someone diagnosed with PD; or
3. You are a healthcare professional who provides care to those living with PD.

You also meet other criteria to be in the study, including the ability to communicate in English about your experiences of living with PD (groups 1 & 2), or of treating people who are living with PD (group 3).

Background/Purpose:
We know that people living with PD and their care partners learn to manage their symptoms as they emerge over the course of disease. Self-management refers to these daily activities and skills used to minimize the impact of PD on their well-being. Health professionals help teach these skills for managing symptoms in partnership with the person diagnosed. However, there is no research from the perspective of the people
learning the skills or about including the spouse in self-management practices. This study may help us learn about how couples living with PD learn the skills required to manage their symptoms, with the help of healthcare professionals, in clinical settings. It may also highlight the important role of the spousal care partner in managing PD. The perspective of people living with PD will be compared to that of the healthcare professional to help understand any gaps that may exist in needs and expectations related to self-management care in clinical settings. This information could help inform clinical practice related to self-management, meaning how health professionals teach couples living with PD how to take care of themselves and skills to manage PD and their symptoms.

The primary purpose of this study is to obtain the perspectives of people living with PD, care partners, and clinical professionals about how to best promote self-management skill acquisition in clinical settings. This will provide valuable insight for meeting the clinical needs of care partnerships living with PD in their acquisition of self-management skills.

The usual treatment for PD is pharmacological treatment to maintain dopamine levels in the brain. By participating in this study, there will be no alteration to your standard of care or treatment regimen.

**Procedures of the research project:**
Up to 36 people will participate in this study, 12 people diagnosed with PD, 12 care partners, and 12 healthcare professionals. The study will take approximately 6 months to complete. It is expected that you will be in the study for the duration of the focus group or interview and possibly for a second follow-up interview.

You will be asked to participate in a focus group or interview at a local community centre in the City of Ottawa. The exact location will be provided to you via email. During the focus group or interview:

- You will be asked a series of questions about your experiences of living with PD, or treating those living with PD, related to learning self-management skills.
- The focus group or interview will last between 30 and 60 minutes.
- The entire focus group or interview will be audio and video recorded and the researcher may take notes.

Due to the nature of this study, the study data is created from the focus group and interview transcripts and therefore it is mandatory to have the focus group or interview audio recorded. A video recording is necessary for focus groups to be able to identify the speaker when transcribing. The video recording will only be used for identifying who is speaking, for the purpose of transcribing the focus group. If you do not wish to be audio or video recorded then you will not be enrolled in the study and will not participate in the focus group.

Participation in only one focus group or interview is required, however as the study continues, the researcher may contact you to ask for a follow-up interview. It is your choice to participate in a second interview and you may decline the invitation for any reason.
**Voluntary Participation**

Your participation in this study is voluntary. You may decide not to be in this study, or to be in the study now and then change your mind later. You may leave the study at any time without affecting your standard of care. We will give you new information that is learned during the study that might affect your decision to stay in the study. You may refuse to answer any question you do not want to answer, or not answer a focus group question by saying “pass”. You may leave the focus group at any time if you do not wish to complete it.

**Confidentiality:**

Data obtained in the study will not be labeled with any of your personal information (name, initials, date of birth, etc.) and will not be able to be linked back to your health information in any way. We will use a special numbering system to identify the information collected in the study. We will keep a master list that has your assigned number, your name and contact information. However, this list will be stored on an encrypted flash drive, separate from any study data. Recorded interview data will be stored on a separate flash drive with no identifiable information. Data will be stored for 7 years after the conclusion of the study, as per Western University’s research policy.

Your signed consent, which will have your name on it, will not be stored with the data collected from the study and will not be connected to the data collected. Consent forms will be stored in a secure location in the research office of Dr. Connelly.

Any use of your data for publication in scientific journals or presentation at professional conferences, will not contain any of your personal information that could be linked back to you or to your health information. Due to the nature of the research, some quotes from your focus group or interview responses may be used in publications, however no identifying information will be associated with your quotes. In order to preserve your confidentiality, during the study only the investigators in the study, namely Dr. Denise Connelly and Danielle Hudson will have access to your research information. Although the researchers will strictly follow the steps outlined here to maintain your privacy, all research studies carry an inherent risk for a privacy breach. If this occurs, you will be contacted to explain what information was compromised. Representatives of The University of Western Ontario Health Sciences Research Ethics Board may contact you or require access to your study-related records to monitor the conduct of the research.

**Withdrawal from the Study**

The researcher may decide to withdraw you from the study prior to or during the focus group if the researcher feels continued participation would impair your wellbeing. For example, if the focus group seems to be too strenuous or detrimental to your health, the focus group will be terminated and you will be withdrawn from the study.

You may choose to withdraw from the study at any point. Given the nature of focus groups, if you choose to withdraw after completing part or all of a focus group session, it will not be possible to isolate your contribution to the session without discarding the
entire focus group session. Therefore, your responses cannot be withdrawn once provided. However, you may choose to not have your responses quoted in the manuscript without limitation.

**Benefits, Risks, and Inconveniences:**
A direct benefit could be increased awareness of how you have learned to manage your disease. This could promote confidence related to your ability to take care of yourself. However, the larger impact is to the patient population being studied. Although many studies exist that have tried to design self-management models, none of these studies involve the perspective of people living with PD and most do not consider the role of care partners in this process. This study uniquely compares responses from those living with PD, care partners, and healthcare professionals to better understand the gap between patient needs and clinicians’ approach to clinical self-management education. This research may inform clinical practice related to teaching self-management skills.

You will not benefit directly from participation in this study.

There are no risks of physical harm to you with this study. However, some people may experience increased anxiety and nervousness with speaking in front of others in a focus group or while participating in an interview. Furthermore, recounting difficult experiences related to living with PD may be emotionally difficult including feelings of sadness or grief. We have minimized these possible concerns for you by completing the interview in a comfortable environment, providing breaks as requested, and positioning the recording equipment in a way that it interferes as little as possible.

Participation in this study will NOT change in any way the treatment of your Parkinson’s disease or your medical care.

Participation in this study may result in out-of-pocket expenses that will not be covered or reimbursed (for example: gas, mileage, alternate transportation and your time).

**Alternatives to Participation:**
An alternative to the procedures described above is not to participate in the study and continue on just as you do now.

**Costs:**
There are no costs to you by participating in this study, only the time required to complete the interview.

**Rights as a Participant:**
You do not waive any rights by signing this consent form.

**Who to contact with Questions:**
For more information about this research study please contact Denise Connelly at [519-661-2111 x82238]. 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 [519-661-3036], email: [ethics@uwo.ca]. Should you have any questions about this study or the
activities in which you will participate, please do not hesitate to contact us. This letter is for you to keep.
### Consent Form

**STUDY TITLE:** Parkinson disease care partnerships: Bridging perspectives in clinical self-management interventions

**Principal Investigator:**
Dr. Denise Connelly, PhD, School of Physical Therapy, Western University, Room 1588, Elborn College, 519-661-2111

**Co-Investigator:**
Danielle Hudson, MSc, PhD student, Graduate program in Health and Rehabilitation Sciences, Western University

**CONSENT**
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.

<table>
<thead>
<tr>
<th>Signature of Participant</th>
<th>Printed Name</th>
<th>Date</th>
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<table>
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<tr>
<th>Signature of Person Obtaining Consent</th>
<th>Printed Name</th>
<th>Date</th>
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Appendix E: Interview Guide & Script for Study One

Interview Guide & Script

Thank you for agreeing to participate in this study about living with Parkinson disease. Our goal is to learn about how you have learned to care for yourselves over the course of your disease. All questions asked are directed to both of you and you are both invited to share your points of view and experiences.

Provide information letter and obtain signature.

Do you have any questions about what I have just explained or about anything in the information letter?

Answer any remaining questions and then begin interview. Numbered questions are examples of main questions and lettered questions below are examples of probes. Depending on time constraints, all questions may not be asked.

1. When do you remember noticing your first symptoms?
   a. What did you think about the.... (shaking, small handwriting, etc)? Were you worried?
   b. How did your first symptoms affect your everyday functioning? Was your work affected? Were there activities you could no longer do?
   c. What changes did you make to manage or disguise your symptoms?

2. Tell me about a time that a healthcare professional was especially helpful or not helpful in managing your symptoms of PD.
   a. How did the healthcare professional make you feel before/during/after the appointment?
   b. What particular things did the healthcare professional do to make the appointment especially helpful/unhelpful?
   c. How did your disease management strategy change after that appointment?
   d. If you could change something about that appointment to make it better, what would it be and why?
   e. If you could suggest/say something to the healthcare professional now, what would it be?
3. Tell me about a time that made you realize you could no longer do certain things or that you now have to do them differently because of PD.
   a. What type of emotions do you feel thinking about these changes?
   b. How did you manage the changes together?
   c. What were you thinking when your symptoms stopped you from doing ......?
   d. What were your roles in managing this change?

4. Tell me about a time you learned a difficult lesson about living with PD. What did you learn from it?
   a. Looking back, what is the most important lesson you have learned about caring for yourselves with PD?
   b. Would you have done anything differently?
   c. What made this experience/circumstance/situation more difficult than any other day with PD?

5. Tell me about a time that taught you something new about PD.
   a. How did you learn to manage a new symptom of PD?
   b. What would you tell other people living with PD who are learning to manage this particular symptom/issue?
   c. How did this lesson change the way you care for yourselves now?
   d. How did this lesson change the way you approach new challenges in PD?

6. What is the main piece of advice about caring for yourselves that you would give to people who are newly diagnosed with PD?
   a. What information do you wish you had as you took on the challenges of PD?
   b. If you could give a piece of advice to healthcare professionals treating people living with PD and their care partners, what would it be?

7. Is there anything else you would like to add about your experiences of living with PD or about how you care for yourselves since PD?

Thank you very much for answering my questions and offering your stories about living with PD. I’ll be analyzing this information as well as the interviews provided by other participants. With this type of study, early analyses may highlight the need to ask new questions and gather more information. If needed, could I contact you for another
interview? You can always change your mind and choose to not participate in a second interview at a later time.

The results will contribute to my doctoral dissertation and will also be submitted for publication in a scholarly journal. I’ll be happy to send you a copy of the published manuscript, if you are interested.

Thank you for your time today.
Appendix F: Interview Guide & Script for Study Two

Interview Guide & Script – Healthcare Professionals

Thank you for agreeing to participate in this study about how Parkinson’s disease self-management skills can be facilitated in clinical settings. The goal is to hear about how you incorporate self-management principles into your daily practice, and to hear how you think this can be improved. You will be invited to share your opinion and experiences related to each question.

Provide information letter and obtain signature.

Do you have any questions about what I have just explained or about anything in the information letter?

Answer any remaining questions and then begin interview. Numbered questions are examples of main questions and lettered questions below are examples of probes. Depending on time constraints, all questions may not be asked.

1. Self-management and self-management skills are everyday actions an individual completes to take care of themselves while living with a particular condition. For example, setting a timer to remember to take medication. How do you incorporate self-management education in your practice?
   a. Do you think it is important?
   b. What topics do you believe are most important?
   c. How do you teach or facilitate the acquisition of self-management skills?

2. How could clinicians improve the delivery of self-management education?
   a. What resources would be most helpful?
   b. Do you experience significant challenges or barriers to including self-management principles in your treatment sessions?
3. Do you involve the care partner? If so, how do you include them?
   a. If you do not, why not?

4. Is there something that you think should be focused on more in treatment sessions?
   a. Are the important topics covered?

5. If you could give a piece of advice to other healthcare professionals caring for people living with PD and their care partners, what would it be?

6. Is there anything else you would like to add about your experiences of caring for people living with PD, related to self-management education?

Thank you very much for answering my questions and offering your stories about caring for those living with PD. I’ll be analyzing this information as well as the interviews and focus groups with other participants. With this type of study, early analyses may highlight the need to ask new questions and gather more information. If needed, could I contact you for a follow-up interview? You can always change your mind and choose to not participate in a second interview or focus group at a later time.

The results will contribute to my doctoral dissertation and will also be submitted for publication in a scholarly journal. I’ll be happy to send you a copy of the published manuscript, if you are interested.

Thank you for your time today.
Appendix G: Sample Reflexive Memo

I completed an interview with a couple living with PD today.

Both the care partner and the person diagnosed with PD were retired from prominent academic and government positions. The person with PD had a very inquisitive and what I would call ‘intellectual’ view of PD. He has read much of the literature surrounding treatment options and what may cause PD, and has come to the conclusion that “there is so much we don’t know”. His perception is that treating PD is a game of trial and error.

Both members of the care partnership were actively seeking information, even after living with the disease for nearly 20 years. They sought information from the internet, Parkinson’s Canada, as well as others who are living with PD. This strikes me as being resourceful, and as though the couple is doing everything they can to manage their condition. I find myself thinking that if I were to be diagnosed with a chronic illness, I would be thinking of all that I could do to manage it.

I observed strong communication skills between the care partner and the person diagnosed with PD. I suspect that this has been present and developed throughout their marriage, as opposed to a management strategy adopted just for living with PD. The way they spoke to each other was very kind and respectful, and they each of them were deeply concerned for the well-being of the other. Even though some cognitive changes were evident from the responses provided by the person diagnosed with PD, his spouse would simply rephrase the question or ask him to clarify what he meant. This ensured he was able to participate in the interview and provided him the opportunity to convey his thoughts.

The person diagnosed with PD was deeply concerned about living a burden to his wife. At one point, he became very emotional speaking about the work required of his wife to provide him care. He mentioned living in a nursing home so he would not have the burden of caring for him. This spouse adamantly replied that she would rather have him at home with her, fearing living alone, and does not feel burdened, as she actively has measures in place for appropriate needs. While I felt deeply saddened by the husband’s comment about living in a nursing home, I was also touched by their desire to work together and implement strategies so they may continue living in their home, together.

Both participants expressed fear of being lonely, and described PD as a ‘lonely disease’. I interpreted this as isolation from friends and family, due to symptoms of PD. Again, this couple seemed to be successful in avoiding loneliness by seeking social opportunities and all the information they could. This couple seemed to be coping well with PD, perhaps a reflection of the many years of ‘practice’ and peer support. I wonder how much their personal factors such as education, level of income, marital dynamics have influenced their ability to live well with PD?

Commented [A1]: I seemed to feel a sense of approval about this management style. I wonder if this is from my personal belief in ownership of one’s health status. I find myself thinking that even if diagnosed with a chronic illness, there is so much we can do to optimize quality of life, such as seeking information and management strategies.

Commented [A2]: I have no way of evaluating what “strong communication skills” are. I suppose it was my interpretation of the way they spoke to each other and listened to the other’s responses. The care partner was not trying to compensate or correct her spouse, but wanted him to have the opportunity to contribute. I wonder how important relationship dynamics are in forming a management strategy? This may also be a question stemming from my belief that this is a couple’s disease and, as such, there is no separation of the couple from the disease process itself.

Commented [A3]: I find myself wondering how one could not feel like a burden when your spouse has taken the role of influential care provider. I can remember my own emotions and feeling threatened at the idea of one day happening in my own marriage. Perhaps that’s why I feel a sense of awe at the care partner’s ability to remain so steadfast in her role, while caring for her own health through people and social activities.

Is the care partner role consciously accepted? Or something that indirectly creeps in over time?
Appendix H: Preliminary Renderings of the Process for Study One
Appendix H (cont’d): Preliminary Renderings of the Process for Study One
Appendix I: Preliminary Renderings of the Process for Study Two
Curriculum Vitae

Name: Danielle Hudson

Post-secondary Education and Degrees:

The University of Western Ontario
London, Ontario, Canada
2013 – Present. PhD Health & Rehabilitation Sciences, Physical Therapy field

The University of Western Ontario
London, Ontario, Canada
2015-2017 Master of Physical Therapy

The University of Western Ontario
London, Ontario, Canada
2011-2013 MSc. Neuroscience

Wilfrid Laurier University
Waterloo, Ontario, Canada

Honours and Awards:

Province of Ontario Graduate Scholarship
2011-2012, 2017-2018

London Health Research Day Poster Competition Winner
2013

Faculty of Science Student’s Association Research Award
2011-2012

Canadian Interuniversity Sports Academic All-Canadian
2007-2009

Related Work Experience

Teaching Assistant
The University of Western Ontario
2012 - 2015

Publications:

Papers

Book Chapters

Dissertations
1. Investigating Immersive Augmented Reality as a Rehabilitation Tool for Parkinson disease. University of Western Ontario.

Presentations