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Lived Experience of Having Difficult Conversations Among Care Partners of Individuals with Parkinson's: An Occupational Science Perspective

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

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Abstract

Difficult conversations, which can be challenging co-occupations, play an important role in the lives of care partners of individuals living with Parkinson's disease. In our first study for this integrated-article thesis, we used a critical interpretive synthesis to explore how informal caregiving had been conceptualized in occupation-focused research. We found that an occupational perspective illuminated otherwise overlooked aspects of caregiving. In our second study, we used an occupational science lens to explore how seven care partners of individuals with PD experienced having difficult conversations within the caring role. We conducted two rounds of in-depth semi-structured interviews and used an American Phenomenological Constructivist approach. We learned that not all difficult conversations are equal; difficult conversations may initially increase, then decline over time; and mediating factors impact how difficult conversations will go. Difficult conversations relate to the doing, being, becoming, and belonging of care partners and may contribute to their wellbeing.

Keywords

Parkinson's disease, caregiving, older adults, difficult conversations, occupational science, co-occupation, American phenomenology, constructivism, critical interpretive synthesis

Summary for Lay Audience

Care partners play a major role in the lives of individuals with PD and are arguably just as affected by the disease in terms of how their daily activities are impacted. We conducted two studies as part of this thesis. Our first study looked at how considering unpaid caregiving to be a meaningful occupation could help us to better understand the lives and needs of care partners. In our second study, we spoke with seven care partners about their experiences with having difficult conversations in the hopes that illuminating this one aspect of the caregiving experience would help us better understand the ripple effects of PD.

Our first study focused on how informal caregiving has been thought about within studies that use an occupation-focused approach. We searched five academic journals known for publishing research centred around occupation for articles that focused on informal caregiving for older adults. We found that over time, more researchers have placed their focus on caregivers themselves rather than dividing their attention between caregivers and care recipients. Recent studies give attention to the interconnected nature of caregivers' relationships, the occupation of caregiving, and tasks within the caregiving role. Recognizing these interconnections helps the study of caregiving to have a holistic approach.

In our second study, we learned that difficult conversations can range from monological (one-sided) to dialogical (with both parties contributing) and from non-action oriented (just about communicating) to action oriented (focused on making change). The degree of challenge within a difficult conversation seems to depend on how meaningful the topic is to either party. Our second finding was that difficult conversations seemed to often increase initially and then to decline as changes are accepted or supports introduced. Our third finding was that personal and interpersonal factors impact how difficult conversations will go.

Using an occupational perspective has allowed us to consider the specifics of how care partners carry out difficult conversations and the impact of individual personality characteristics, personal growth, and relationships on their successful engagement in difficult conversations. We have also been able to appreciate how important difficult conversations are to the wellbeing of care partners of individuals with PD. We see engaging in difficult conversations as an important task of care partners of individuals with PD.

Co-Authorship Statement

Chapter 2 of this thesis was co-authored with Dr. Jeffrey Holmes, Dr. Debbie Laliberte-Rudman, and Dr. Andrew Johnson. Ms. Reid designed and carried out the initial search for this study with the support and guidance of Dr. Laliberte-Rudman. Ms. Reid also prepared the initial manuscript, which Dr. Holmes helped edit together with Dr. Laliberte-Rudman and Dr. Johnson. Ms. Reid, Dr. Holmes, Dr. Laliberte-Rudman, and Dr. Johnson engaged in successive rounds of edits and academic dialogue to prepare the version of this manuscript seen in this thesis.

Chapter 3 of this thesis was co-authored with Dr. Andrew Johnson, Dr. Jeffrey Holmes, Brianna Moretti, and Emily Brinovec. Dr. Johnson and Dr. Holmes provided guidance in the design of this study. Ms. Reid worked with Dr. Holmes and Ms. Moretti to coordinate and facilitate the interviews. Ms. Moretti reviewed the initial codes developed by Ms. Reid after the first round of interviews. Ms. Brinovec helped to review the codes and themes developed after the second round of interviews. Dr. Johnson and Dr. Holmes participated in academic dialogue with Ms. Reid and helped to solidify the final set of themes which are presented in this manuscript.

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My second and greatest thanks is to the care partners who participated in this study. It was an honour to learn about the joys you experience and the challenges you face as you navigate PD together with the people you love. I hope that the findings of our study are presented in such a way that they can help others travelling your same path.

Thank you also to Brianna Moretti and Emily Brinovec for your work collaborating on the research for this thesis. Your perspectives and insights were valuable in developing the findings.

Thank you, Dr. Debbie Laliberte-Rudman, for your insights as an occupational scientist that helped me to situate the findings using an occupational lens. I have learned a great deal studying under you and collaborating with you.

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Chapter 1

1 Introduction

Parkinson's disease (PD) presents challenges for the individuals who are diagnosed as well as for the family members and friends who may become informal care partners as the disease progresses. Care partners may need to take on new roles as PD symptoms progress, which can involve occupations such as carrying out difficult conversations. Previous research has focused on other disease contexts to study caregiving tasks as occupations and has studied difficult conversations in other populations. The first study in this thesis seeks to identify the value of using an occupational science perspective for studying informal caregiving and present approaches that can make this perspective optimally effective. Our second study aims to explore difficult conversations as an occupation of care partners of individuals with PD with the hopes of highlighting the meaning and importance of this task in care partners' lives and recognizing the challenges associated with it.

1.1 Background

Parkinson's Disease is an age-related neurodegenerative condition that is typically characterized by four fundamental symptoms: resting tremor; rigidity; impaired voluntary movement; and postural instability (Jankovic, 2008). More recently, cognitive and behavioural symptoms such as dementia and apathy have been recognized in research (e.g., Meireles & Massano, 2012). PD affects nearly 1% of the older adult population (Hirtz et al., 2007), and is a progressive but rarely fatal disease. This means that individuals with PD can live for years with steadily declining function, often relying on family, friends, or neighbours to provide assistance with daily tasks as the disease advances (Wong et al., 2014). The symptoms most troublesome for people in the early stages of PD tend to be slowness, tremor, stiffness, pain, and loss of smell/taste. In later stages of the disease, fluctuating response to medication, mood issues, drooling, sleep problems, and tremor are most frequently reported to be problematic (Politis et al., 2010).

Feelings of psychological wellbeing tend to decrease the longer an individual lives with PD (Nicoletti et al., 2017).

The symptoms of PD and the methods used to manage them often involve taking medications at specific times of the day, which may result in lifestyle changes that can present major challenges for individuals with PD and for their families. It is common for individuals newly diagnosed with PD and their partners to experience shock and anger as they confront their new reality (Roger & Medved, 2010). As PD progresses, function becomes more and more limited and spouses or other family members tend to become informal, or unpaid, caregivers (Hand et al., 2019). The new reality for individuals with PD and these informal caregivers becomes a preoccupation with time and scheduling, cognitive fatigue, loss of independence, tensions between bodily appearance and sense of self, and social withdrawal (Holmes et al., 2013).

Some studies have used the term 'main family support' rather than 'caregiver' as it has been found to align more closely with some caregiving participants' perceptions of their relationships with their loved ones (Roger & Medved, 2010). Within our second study, we found that participants generally seemed to gravitate towards the term 'care partner'. Multiple participants indicated that they were used to being referred to as the 'caregiver' but preferred to think of themselves as 'care partners', saying that the term 'care partner' seemed to emphasize the partnership that existed between themselves and the individuals with PD. We acknowledge that the term 'care partner' is not universally accepted by all who support an individual with PD – in some cases because the relationship is a parent-child relationship rather than a partnership such as a marriage or common-law relationship; however, for the purposes of this study it was necessary to have a universal term that most participants resonated with. As such, the term 'care partner' will be used throughout the rest of this thesis to refer to the person taking on the majority of the caring responsibilities for the individual with PD. 'Care recipient' or 'individual with PD' will be used to refer to the person receiving care, as applicable.

Individuals with PD who have supportive care partners fare much better than those who do not, but the care partners' own needs can be ignored by themselves and others. Care

partners often help care recipients to remain in their homes and community settings for longer than they would otherwise be able to (Zarit et al., 1986). Care partners also keep care recipients from going unheard and unnoticed in the healthcare system and within their social networks (Roger et al., 2018). Despite the importance of supportive care partners for helping individuals with PD to remain active and engaged in the community, care partners' own needs are rarely addressed in clinical settings (Schwartz et al., 2020) and there are few formal programs to support care partners (Hempel et al., 2008).

One factor that may contribute to the lack of recognition of care partner needs may be the care partners' own focus on meeting the needs of care recipients. Care partners are often extremely concerned with helping the individuals they support and may be constantly thinking about their partners' safety (Roland et al., 2010). The 'burden' experienced by these care partners tends to be primarily a mental burden, but it also often results in a decline in the physical health of the care partners (Roland et al., 2011). Care partners of individuals with PD experience declines in their relationship satisfaction, intimacy, and communication (Vatter et al., 2018) and 'little deaths' as their social networks change and social ties are lost due to the demands of the caring role (Roland et al., 2010).

One aspect of providing support to an individual with PD that can be particularly challenging may be conducting difficult conversations, especially since the symptoms of PD can add to the emotional work of these conversations as compared with populations without progressive neurological disease. As PD progresses, the symptom of facial masking, the impaired voluntary movement of the expressive muscles of the face, can impair nonverbal communication of affect (Wootton et al., 2019). Additionally, speech issues such as extreme quietness and slowness of speech are common among individuals with PD (Politis et al., 2010), and these issues can greatly impair mechanical aspects of communication.

Not only do the symptoms of PD result in practical challenges that impair communication, but the changes and challenges the disease brings can result in certain topics becoming difficult to talk about. Care recipients and care partners facing a variety of serious health conditions report wishing for a greater degree of communication with

one another while simultaneously feeling that it is a challenge to discuss the patient's illness (Fried et al., 2005). Many care partners and care recipients avoid talking about important issues, to the detriment of their relationship (Edwards & Forster, 1999) and their individual wellbeing (Fried et al., 2005). The topic of difficult conversations has been studied among couples facing heart failure (Schulz et al., 2017), cancer, (Goldsmith et al., 2016), chronic obstructive pulmonary disorder (Fried et al., 2005), and Alzheimer's disease (Shaunfield, 2015). The second study for this thesis adds to the literature by exploring the experiences that care partners of individuals with PD have had with difficult conversations from an occupational science perspective.

Providing unpaid support to an individual with PD and engaging in difficult conversations as part of the role of care partner can both be viewed as occupations. Within occupational science, the study of human occupations arising from the profession of occupational therapy (Yerxa et al., 1990), informal caregiving has been considered to be an occupation itself while simultaneously being studied as a role that is composed of multiple occupations and as a barrier to care partners' participation in meaningful occupations (Riekkola Carabante et al., 2018). Occupations, the meaningful and purposeful activities people engage in, have been defined as "actions that rearrange and reconstruct the world in which we live" (Frank, 2013, p. 233). The occupation of caregiving, as well as its many related occupations and those occupations that are lost due to caregiving responsibilities, certainly do rearrange and reconstruct the world in which care partners and their care recipients live. A supportive care partner can delay the supported individual's entry into a nursing home (Spillman & Long, 2009) and ensure the individual does not become 'invisible' in the medical system or community (Roger et al., 2018), helping the supported individual to remain active and engaged in community life.

1.2 Overview: Methodology

1.2.1 Constructivism

The paradigm of a qualitative researcher – her set of assumptions about the nature of reality and the production of knowledge – influences the kinds of questions that are asked, the way she analyzes her data, and the conclusions that she draws from her

findings. Paradigms may be understood and described by their ontologies and epistemologies. For example, the ontology of constructivism, or the “theory of existence ... [regarding] the nature of reality and that of human beings” (Lee, 2012, p. 406) is relativist (Guba & Lincoln, 1994). Relativism sees reality as plural and dependent on individual and social factors. Constructivism's epistemology, or “theory of knowledge that explores the relationship between the inquirer and the knowable” (Lee, 2012, p. 407), is subjectivism, which sees findings as co-creations of the researchers and participants (Guba & Lincoln, 1994). The lens of constructivism helps a researcher to embrace the complexity of multiple interpretations on situations and acknowledge her own influence on the creation of understandings.

The research paradigm, or set of beliefs guiding this study, was constructivism. As a relativist and subjectivist, the constructivist researcher assumes an attitude of curiosity and openness to the diverse experiences of participants. She carefully considers how her own interaction with participants impacts the gathering of information and how her existing assumptions affect data analysis. Within this thesis, the assumption of multiple co-constructed realities helped us embrace the diversity of experiences among participants. Constructivism also guided how research-related decisions were made such as how to operationalize bracketing or saturation within the study. Constructivism also impacted how findings were presented, with direct quotes showing the importance of participants' voices in the study.

Constructivism's ontological position of relativism and the epistemological stance of subjectivism led to practical decisions within the second study for this thesis. Relativism was behind the decision to interview only a small number of individuals. Doing so enabled us to share about the contexts in which care partners' experiences occurred. Relativism was also a factor in the decision to use interpretative phenomenological analysis (IPA) as the analytic technique. IPA allowed us to analyze each participant's transcripts individually to support the relativist goal of demonstrating how the realities care partners of individuals with PD experience are not uniform. The subjectivist epistemology was a major factor in the decision to bring emerging findings back to participants in a second round of interviews. We understood knowledge produced

through this study to be a co-creation between researchers and participants; therefore, allowing participants to be part of the refinement of themes fit with the constructivist epistemology of subjectivism. Throughout the process of study design, data collection, data analysis, and writeup, the ontology and epistemology associated with constructivism helped to guide decisions that were made.

1.2.2 American/descriptive phenomenology

Along with the paradigm of constructivism, the methodology of American phenomenology shaped how this qualitative study was carried out. Phenomenology focuses on “understanding the meaning of the phenomenon of interest” (Wright-St. Clair, 2015). This methodology explores how experiences are perceived and understood by people in real-world settings. The aim of phenomenology is to produce “depthful understanding and meaningful insight” (van Manen, 2017, p. 776) within the study of an experience. There is diversity within this methodology – a useful metaphorical image for phenomenology may be a tree branch that has one common origin with several smaller branches coming off it at different points. Phenomenology is rooted in philosophy, and throughout the 20th and 21st centuries, it has divided into four main approaches.

Phenomenology originated within philosophy as a way to explore the essence of human experience, free from contexts of time, space, and culture (Dowling, 2007). In the mid-20th century, this grew into a research methodology used within qualitative studies to explore the meanings of phenomena of interest. Edmund Husserl was one of the most influential people in the early development of phenomenology as a qualitative research methodology. The version of phenomenology he developed came to be known as transcendental phenomenology, and it focused on conducting research in an objective, unbiased way to “arrive at an essential understanding of human consciousness and experience” (Dowling, 2007, p. 132). Over time, three other main branches of phenomenology developed: hermeneutic, existential, and ‘American’ phenomenology. Hermeneutic phenomenology evolved when Husserl’s student, Heidegger, came to reject the notion of an objective, neutral researcher able to study phenomena without contextual or personal factors affecting the findings. Heidegger’s hermeneutic phenomenology approaches research as an interpretive process in which the researcher accepts his or her

influence on the research process (Dowling, 2007). Some of Heidegger's writings, along with those of a later phenomenologist, Merleau-Ponty led to 'existential' phenomenology, which specifically seeks to understand matters of human existence such as life and death. The most recent major development in phenomenology has been 'American' phenomenology, developed through the writings of Amedeo Giorgi and Max van Manen. The aim of this latest branch of phenomenology is not to understand the core essences of phenomena; rather, American phenomenology is about understanding phenomena as they are experienced by people living in the world. This branch of phenomenology can be distinguished from the relatively similar hermeneutic branch of phenomenology because of its assumption that experiences with phenomena occur within an external world that is not merely a construction but exists outside of individuals' interpretations of it.

American phenomenology approaches the study of human experiences in a way that leans more towards human science and less towards philosophy. As Giorgi describes it, the key difference between philosophical phenomenology and scientific phenomenology is that "the philosopher works alone and reflects upon others and the phenomena of the world based upon his own experiences and reflections" (2000, p. 5), whereas with the scientific approach, the researcher "turns toward the world or others as the basis for its interrogations" (p. 5). American phenomenologists must be careful to not "make statements about the 'beingness' of the world or carry over judgments based upon the natural attitude into the phenomenological reduction" (Giorgi, 2000, p. 8). According to Giorgi (2000), the phenomenologist cannot make claims about how things actually are, but she can make claims about how things present themselves to be. The American phenomenologist places a greater emphasis on participants' experiences in the world than on her own interpretations of them. This does not mean that the American phenomenologist does not interpret participants' reports of their experiences; rather, the researcher is encouraged to engage with participants and with other scholars in the analysis process to make sense of the structure of these experiences. Another key distinction within American phenomenology is that the researcher does not seek to understand the essence of an experience. The American phenomenologist asks questions such as "What is this lived experience like?" 'What is it like to experience this

phenomenon or event?’ or, ‘How do we understand or become aware of the primal meaning(s) of this experience?’” (van Manen, 2017, p. 776). These questions and the method of engaging with participants to jointly uncover the meanings of phenomena “uniquely offers: originary understandings and insights into the phenomenality of human experiences” (van Manen, 2017, p. 778-779). Giorgi and van Manen show that American phenomenology is used to provide rich descriptions of how things present themselves to be based on the accounts of participants and through their interactions with the researcher(s).

The use of constructivism and American phenomenology within this study allowed us to illuminate diverse individual experiences so that the uniqueness of these experiences was not lost in generalized findings. This was deemed valuable for research on the experience of care partners of individuals with PD because each pair’s experiences with difficult conversations are influenced by a variety of individual factors including the genders of the care partner and care recipient, stage and symptoms of PD, the values and expectations of both parties, and the established communication patterns between the two. The principles of constructivism and American phenomenology encouraged the use of a small sample size, which was congruent with this study’s aims because of the desire to highlight valuable individual experiences. This combination of paradigm and methodology seemed to be the most effective approach for exposing the unique and varied experiences of a small number of care partners in one geographic region – southwestern Ontario – to show the possibilities and realities that exist for care partners regarding difficult conversations.

1.2.3 Bracketing

A technique to promote rigour within research that has been debated amongst phenomenologists is bracketing. Bracketing has been presented in the literature both as a way for the phenomenological researcher to remove biases (Dowling, 2007) and as a means of engaging in reflexivity (Ponterotto, 2005). Within the world of qualitative research, there has been both enthusiasm for bracketing and pushback against it. A major concern regarding bracketing is that it may inappropriately consider researchers to be capable of what may be seen as impossible: to set aside all pre-understandings,

suppositions, assumptions, and the existing bodies of scientific knowledge to engage in research with absolutely no bias (Wright-St. Clair, 2015). This is one perspective on what it means for a qualitative researcher to bracket, but other definitions for bracketing leave room for the researcher's involvement while still emphasizing a focus on the experiences of participants. The way in which a researcher attempts to – and claims to – bracket must carefully consider the aims, paradigm, and methodology of the research project.

Within American phenomenological research conducted through the lens of constructivism, the researcher cannot claim absolute removal of bias. The paradigm of constructivism explicitly acknowledges the impact of a researcher on the gathering and interpretation of information; therefore, it is impossible for the constructivist American phenomenological researcher to claim full neutrality in her work. Within this type of research, rather than being seen as a bias-removing technique, bracketing may be approached as a means of engaging in reflexivity. Dowling promotes a version of bracketing that “relates to the researcher examining their prejudices in order to allow them to include the views of the respondents” (2007, p. 136). Ashworth agrees that it is acceptable for a researcher to bracket “shared features of experience” (Ashworth, 1999, p. 709) as a means of “facilitating entry to the life-world” (p. 720). In other words, a researcher can use bracketing as a way to fully attend to participant accounts of their experiences. LeVasseur (2003) adds that bracketing should be used for the “questioning of prior knowledge” (p. 417). This approach to bracketing as a reflexive activity contrasts with the view of bracketing as tool for complete removal of bias. Dowling, Ashworth, and LeVasseur's interpretation of bracketing has been used in this study to acknowledge and reflect on the researchers' prior experiences and fully embrace participants' reports.

1.2.4 Member reflection

Member checks or member reflections can be an effective technique for verification and validation of information to ensure rigour in qualitative research (Ravenek & Rudman, 2013; Tracy, 2010). ‘Member checks’ has traditionally been the term used to describe a researcher discussing findings from initial analyses with participants in follow-up interviews. In recent years, the term ‘member reflections’ has been favoured by some scholars who feel “the labels of member checks, validation, and verification suggest a

single true reality” whereas ‘member reflections’ “may be applicable to a wider range of paradigmatic approaches” (Tracy, 2010, p. 844). Dialogue between researchers and participants about the findings while analysis is underway “can be a useful interview strategy for prompting self-reflexivity” (Way et al., 2015, p. 725) and can provide “an opportunity for collaboration and reflexive elaboration” (Tracy, 2010, p. 844). Repeating back to participants what they have said, calling attention to any contradictions or incomplete opinions, and showing acceptance towards participants’ responses can help participants to reflect on their responses and encourage the expression of deeper understandings of their experiences. For these reasons, member reflection was used during the follow-up interviews with care partners in the second study in this thesis.

1.2.5 Sufficiency

Qualitative researchers frequently reference collecting data to a point of saturation. Often, the term saturation means “the point in data collection when no additional issues or insights emerge from data” (Hennink et al., 2017, p. 592). We felt that attempting to use saturation in this way would be discordant with our assumption of limitless unique experiences. Therefore, we collected data until it appeared that there was sufficient information to richly present an in-depth understanding of southwestern Ontarian care partners’ diverse fears, concerns, facilitators of, and experiences with difficult conversations within the caring role. In this way, we acknowledge that the findings presented in our research do not represent the ‘only reality’, but rather a rich and compelling reality that is informed by our discussions with participants.

1.2.6 Interpretative phenomenological analysis

A research project's analytic approach must align with the paradigm, methodology, and aim. The method for analysis that seemed to be best suited for the qualitative study within this thesis was IPA. This analytic method has been primarily developed by Johnathan A. Smith. According to Smith and Eatough, IPA is especially suited for studies in which “there is a need to discern how people perceive and understand significant events in their lives” (2007, p. 35). ‘Significant events’ are described by Smith as those experiences of “existential import to the participant” (2011, p. 9). Given that the goal of this study was

to understand care partners' experiences with difficult conversations, which can be significant events within the existentially important experience of being a care partner, IPA seemed to be a good fit to analyse participants' responses. IPA regards research as an interactive process between researcher and participant, acknowledging the impact of each on one another while aiming to remain as close to participants' perspectives as possible (Clare, 2002). According to Smith, "the primary locus of [IPA's] analytic work has been the hermeneutic researcher interpreting the verbal material provided by the participant" (Smith, 2018, p. 1956). The steps outlined by Smith et al. (1999) for conducting IPA provide a means to interpret participants' accounts of their experiences while remaining centred in these descriptions.

Smith et al. (1999) outline the following steps for conducting an Interpretative Phenomenological Analysis within their chapter 'Doing Interpretative Phenomenological Analysis'. IPA begins with a thorough examination of one transcript. Looking closely at one participant's account at a time is an idiographic approach to analysis. The researcher is encouraged to read and re-read the transcript to become as familiar with it as possible since "each reading is likely to throw up new insights" (p. 220). Through a cyclical process, the researcher identifies relevant 'codes', which are important points, and makes note of these. The researcher pays careful attention to what appears to be important to the participant in determining which points should be coded. These 'codes' come together to form themes, which are then clustered together with other similar themes. In keeping with the cyclical nature of IPA, the researcher is encouraged to drop or change themes if ones that are more relevant become clear. With small numbers of participants (less than 10), it is best for the researcher to analyse each transcript individually, developing themes and clusters of themes for each transcript, before combining themes across accounts. An important point within IPA is that "themes are not selected purely on the basis of their prevalence within the data. Other factors, including the richness of the particular passages which highlight the themes, and how the theme helps illuminate other aspects of the account, are also taken into account" (p. 226). As such, frequency counts within IPA are irrelevant, and themes that relate only to one account can still be considered relevant. The goal of IPA is to see "how different themes come together to help us understand further the participants' experiences" (p. 232), so the researcher must look for "patterns and

relationships within and between the conceptual groups” (p. 232). This can be done using diagrams, memos (notes by the researcher to make sense of the data), or through discussion with other researchers. By following these general steps, a researcher is able to explore such questions as “‘What is the person trying to achieve here?’, ‘Is something leaking out here that wasn't intended?’, ‘Do I have a sense of something going on here that maybe the person him/herself is less aware of?’” (Smith & Eatough, 2007, p. 36). Discussion amongst the research team was used in this study to explore relationships between codes and themes to arrive at the final set of themes which are presented in the second study in this thesis.

1.2.7 Quality Criteria

Criteria for making decisions about inclusion of articles can help to structure and streamline secondary research studies. Within the critical interpretive synthesis (CIS) that was the first study for this thesis, it was necessary to make decisions about inclusion of articles based on their adherence to pre-determined inclusion criteria (which will be discussed in chapter 2) as well as to criteria for quality research, such as Tracy’s ‘big tent’ criteria for excellent qualitative research (Tracy, 2010). Tracy’s 8 criteria (worthy topic, rich rigor, sincerity, credibility, resonance, significant contribution, ethical, and meaningful coherence) are specifically discussed as applying to qualitative research, but many of these criteria may be useful markers of excellence in quantitative or mixed methods studies as well.

All of Tracy’s criteria are helpful for evaluating the quality of qualitative research, but there were a few criteria which were considered to be particularly important in the evaluation of studies for the CIS within this thesis. The main criteria we focused on using within the CIS were credibility, sincerity, and rich rigor. As described by Tracy, studies high in credibility have “thick description, concrete detail, explication of tacit (nontextual) knowledge, and showing rather than telling” (p. 840). In particular, concrete detail, as evidenced by clearly communicated statistics or direct quotes from participants, and explication of tacit knowledge, as evidenced by strong connections between evidence and claims, were elements I looked for in studies. A marker of sincerity that was useful in determining which studies to include in the CIS was “transparency about the methods and

challenges” (Tracy, 2010, p. 840). Each study’s methods and limitations needed to be clearly stated and evident throughout the articles in order to be included in the CIS. I ensured studies that were included in the CIS had rich rigor, described by Tracy as having a “rich complexity of abundance” (p. 841). Studies needed to demonstrate that regardless of the sample size, the data collected was sufficient, abundant, appropriate, and complex. These criteria helped to guide the selection of articles for the first study in this thesis.

Tracy’s eight big tent criteria not only helped to guide the selection of studies for the CIS, but also helped to inform the design of the qualitative study within this thesis. Attention was given to each of the eight criteria, but worthy topic, meaningful coherence, and resonance were a few that were especially influential in decisions about how the study would be conducted and how results would be presented. The topic of this study was deemed to be relevant, significant, and interesting due to the literature gap that was identified and presented in section 1.1. Meaningful coherence was achieved through careful attention to connecting the research paradigm and methodology to the data collection and data analysis methods throughout the study. In order to demonstrate resonance within the writeup of the qualitative study, lengthy direct quotations from participants were included, which created “aesthetic, evocative representation” (Tracy, 2010, p. 840). These criteria helped to strengthen the overall robustness of the study.

1.3 Positionality

My interest in older adult health and wellbeing was sparked during my undergraduate degree in health sciences and community development while volunteering at a retirement home near the university during the week and seeing my grandmother’s health decline on my frequent weekend visits home. Due to the focus of my majors, there was an academic component to my interest in older adult wellbeing, but the personal components from my experiences at the retirement home and my relationship with my grandmother made it meaningful. My grandmother, who lived next door and was a significant part of my life growing up, had diabetes and dementia. As I learned about the technical aspects of health and disease and how to support people at the individual and community level, I also saw the emotional toll that my grandmother’s physical and cognitive challenges took on her as well as on myself and my family, who were responsible for the majority of her care. In

the final months of her life after she had suffered a broken hip, we encountered judgement and lack of understanding by well-meaning friends and extended relatives who weighed in on how we should make care decisions. We also experienced firsthand how a lack of funding and support for individuals with progressive neurological conditions and physical limitations impacts these individuals and their care partners or main family supports. Within the caring role, we engaged in difficult conversations with one another, with my grandmother, with our well-meaning friends and extended family, and with health professionals to decide, defend, and advocate for her best care. There were many points at which we felt we were unheard. I saw other care recipients and care partners in the retirement home I volunteered at whose experiences were also marginalized by those around them and by the healthcare system. These experiences have led me to have empathy for care recipients and care partners and have sparked a desire to highlight their experiences.

I came to this research project as a recent Brescia graduate with the academic experience of a double major in health sciences and community development. During my undergraduate years, I learned to think holistically and consider the contexts of people's health experiences. Western's health sciences program encourages thinking beyond the medical model of health as an absence of disease towards an understanding of health as a multidimensional concept encompassing social, emotional, occupational, physical, intellectual, environmental, and spiritual wellness. Brescia's community development program took similar ideologies to a community level and encouraged critical thinking about allyship. Transitioning into my Master's in Health and Rehabilitation Sciences in the field of Occupational Science was a natural progression from where I had been ideologically in my bachelor's degree. Studying occupational science has helped me to expand my holistic view to consider the dynamic impacts of person, context, and occupation on one another.

Because of my personal experience and my undergraduate and graduate academic training, I believe it is important to approach my work with a recognition of who I am and how my positionality may impact my understanding of the experiences of participants. I acknowledge that the lenses I bring to the studies within this thesis are

informed by the fact that I am a soon-to-be-married, young, neurotypical, able-bodied, middle-class, white, heterosexual, cisgender, Christian, university-educated female. Although I share the experience of caring for an older loved one with cognitive and physical decline, I do not have the specific experience of caring for someone with PD. Nor do I yet have the experience of years communication with someone in the context of marriage as many of the care partners in this study do. I have also not experienced what it is to become an ‘older adult’, and I have not personally experienced disability. I have always been secure financially and have always had my needs met. I have not faced racial or ethnic stereotyping or violence, and I have not been questioned about my sexuality or gender. I belong to a religion that is dominant in the society I live in, but the core tenets of which may not always be supported in mainstream society. With my 6 years of postsecondary education, I am part of the minority of Canadian-born individuals with a bachelor’s degree or higher (Statistics Canada, 2016). In some aspects of my positionality, I have ‘insider’ status with participants, and in many other ways I have ‘outsider’ status. The aspects of myself listed here have resulted in the life experiences I have had to date, which differ in many ways from the experiences of this study’s participants. I acknowledge that someone with different life experiences may have considered asking different questions or may have picked up on different key points from the participants and/or expressed the main points differently than I have in this thesis. It has been my aim throughout to acknowledge my positionality and the role it has played in this research, and to then turn my attention, as fully as I can, to the experiences of this study’s participants to fully attend to the lived realities they have encountered as they have engaged in difficult conversations along their care partnering journeys.

1.4 Reflexivity

Ongoing consideration of the impacts of my positionality was determined to be an essential part of ensuring the quality of the second study for this thesis, as promoted in the literature (Ravenek & Rudman, 2013; Tracy, 2010). Self-reflexivity occurred through a number of written and dialogical reflective exercises. Prior to the development of the study designs, I engaged in a written reflexive activity to consider the aspects of myself that could have the most impact on how I would carry out research. I also journaled over

the course of the first round of interviews, recording some of my initial reactions to participants' accounts of their experiences. In the later stages of data collection, coding, and theme development, I engaged in reflexive discussions within academic dialogue with the co-authors for the second study. These discussions helped me to consider how those with lived experiences distinct from my own saw the data differently and how my positionality came through in the study findings.

1.5 Ethical Considerations

Ethical considerations were central in how both studies within this thesis were conducted. For the CIS, incorporating diverse voices was the primary ethical concern. It was an intentional decision to include the Interinstitutional Brazilian Journal of Occupational Therapy among the journals to be searched within this first study, despite the fact that articles from this journal were not published in English. We wished to ensure that academics from outside of the global north had their voices represented in our study. This required an extra step of translating articles from this journal into English using Google Translate. We considered including articles from this journal to be important for the rigour of our study, and we also considered this to be an ethical decision to promote research from authors whose primary languages were not English and whose work might otherwise be excluded from academic discussions in the global north. Within the qualitative study in this thesis, ensuring participants were aware of their rights as study participants was paramount. The researchers who conducted both rounds of interviews provided written information to participants about their rights, including their rights to withdraw from the study at any time or to skip any questions they did not wish to answer. Participants were reminded of these rights prior to the first round of interviews. The research team also used their own judgement within both rounds of interviews to determine when to avoid asking probing questions based on the verbal and nonverbal cues participants offered to communicate their comfort level throughout the interviews. The final ethical consideration that was made in the writeup of this thesis was the decision to anonymize the participants within the qualitative study. Each participant was assigned a pseudonym. Additionally, the descriptions about participants that are included in the third chapter of this thesis have been left intentionally vague so that participants

could not be easily identified. These descriptions were also shared with participants prior to publication so that they could remove or change any information they determined to be overly identifying.

1.6 Study Aims

Occupational science is a discipline that exists to explore topics related to the activities people engage in which bring meaning to life (Yerxa et al., 1990). Occupational science was originally developed as an academic discipline to support occupational therapy (Kantartzis & Molineux, 2012). Perspectives informed by this discipline have been used extensively to seek out connections between occupation and wellbeing (Yerxa et al., 1990) as well as to draw attention to the meanings associated with occupations (Farias & Laliberte Rudman, 2016). The aim of our first study for this thesis, a critical interpretive synthesis, was to explore how informal caregiving has been conceptualized in occupation-focused research. By engaging in this critical interpretive synthesis, we hoped to identify useful directions that have been taken in previous occupational science studies to inform our work in the second study.

In the planning stages for this thesis, we were aware that difficult conversations could be a challenging aspect of being a care partner to an individual with PD but we had not found any studies exploring this topic within this specific population. Knowing that difficult conversations had been studied in other disease contexts but seeing no previous research studying difficult conversations in the context of PD, we sought to use an occupational science lens to explore how care partners of individuals with PD experience difficult conversations as part of the caring role. Our aim for the qualitative study I n this thesis was to understand the meanings associated with engaging in difficult conversations for a small number of care partners.

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Chapter 2

2 Representing Informal Caregivers of Older Adults in Occupation-Focused Research: A critical interpretive synthesis

Within the current demographic and political context, it is likely there will be an increasing reliance on informal caregivers in the provision of care to older adults in Western nations. Bringing an occupational perspective to research on informal caregiving can generate knowledge regarding how this occupation is shaped in relation to contextual and political elements, as well as its relational nature and implications for the occupations of caregivers and care recipients (Roger et al., 2018). This critical interpretive synthesis explores how informal caregiving has been conceptualized and researched in the occupation-based literature. Five occupation-focused journals were searched for articles on informal caregiving for older adults, resulting in 17 primary research articles which were analysed to identify how this topic has been conceptualized over the past 16 years. One major finding was that there has been an increasing focus on the experiences of caregivers, as opposed to divided focus between caregivers and care recipients. We also identified inclusion of transactional perspectives and co-occupations as two directions that have expanded the scope of the literature in this field. Moreover, this synthesis points to a need to turn greater attention to a diversity of informal caregivers, particularly in relation to gender and gender identity, and raises concerns regarding lack of critical attention to informal caregiving as embedded in social relations of power. Overall, conceptualizing the occupation of caregiving offers opportunities to expand understandings of occupation, and make significant contributions to the study of informal caregiving and inform practices to optimize caregivers' occupational possibilities.

2.1 Introduction

As people age, many eventually experience a rise in either temporary or long-term health conditions that result in a need for assistance with everyday occupations (Jaul & Barron, 2017). Progressive conditions, such as dementia (Orpin et al., 2014) and PD (Hand et al., 2019), often necessitate receipt of assistance, with assistance for various occupations

most often supplied by spouses or children (Hand et al., 2019; Orpin et al., 2014). Within the literature, such family members or others who provide care without receiving financial compensation or formal training are often referred to as ‘informal caregivers’ (Maltby et al., 2020). Support from informal caregivers has been tied to various types of positive outcomes for care recipients, such as enhanced receipt of healthcare services and enabling aging in place (Costa-Font et al., 2009; Fisher, 2016; Mulliner et al., 2020; Roger et al., 2018). As the average age in high income countries increases (Christensen et al., 2009), it has been proposed that there will be increasing reliance on informal caregivers given concerns regarding increased strain on healthcare systems with fiscal environments aimed at limiting public expenditures (Mayhew & Rickayzen, 2012). Within this context, it is important to turn attention to how to best support informal caregivers in optimally enacting this occupation, at both individual and system levels.

Although the support provided by informal caregivers has been shown to have various positive outcomes for care recipients (Spillman & Long, 2009), concerns have also been raised regarding potential negative implications for the health and well-being of such caregivers whose personal needs may be overlooked and unmet (Schwartz et al., 2020). While providing care can be meaningful and satisfying, it can also be extremely challenging. Caregivers may feel a sense of reward and personal growth resulting from the caregiving role while simultaneously experiencing mental exhaustion, physical stress, role conflicts and financial strain (Maltby et al., 2020). Many studies have examined these negative impacts and demonstrated a need for more effective practical supports (Areia et al., 2019; Payne et al., 1999; Roland et al., 2010). Understanding occupation as an essential contributor to health and well-being (Yerxa et al., 1990), there is potential for research viewing informal caregiving as an occupation or exploring its impact on other occupations to optimize the design and delivery of supports for informal caregivers.

An occupation-focused approach to the study of informal caregiving, such as that taken by Riekkola Carabante et al (2018), has the potential to illuminate the multifaceted nature of caregiving as an occupation itself. Drawing upon diverse approaches to conceptualizing and studying informal caregiving as an occupation can serve to advance understanding of how it is experienced and enacted, as well as its situated, relational and

political nature. For example, drawing upon Frank's conceptualization of occupation as "actions that rearrange and reconstruct the world in which we live" (2013, p. 233) could deepen attention to how provision of unpaid care to a family member or close friend reconstructs the world in which caregivers and care recipients live, as well as its implications for the occupational lives of informal caregivers. Attending to informal caregiving as "everyday activities people do as individuals, in families and within communities to occupy time and bring meaning and purpose to life" (International Society for Occupational Science, 2009, para. 1) would facilitate attending to aspects of the occupation done by individuals as well relational aspects, temporal dimensions, and elements of meaning and purpose. Drawing upon critical conceptualizations of occupation that highlight its embeddedness in broader power relations (Farias & Laliberte Rudman, 2016) could inform examination of how occupational injustices are produced and sustained through austerity measures that increasingly download responsibilities onto informal caregivers, particularly female family members, with differential resources, capacities and 'choices' to take up such responsibilities. Considering the significant ways in which the lives of both care recipients and informal caregivers are impacted, the ways that communities and lives are reconstructed as a result, and how caregiving is situated, it is valuable to view informal caregiving as an occupation and explore it using an occupational lens. Thus, integrating an occupational perspective can also serve to direct attention to the experiential, situated, relational and political nature of informal caregiving as an occupation (Farias & Laliberte Rudman, 2016; Njelesani et al., 2014).

The ways in which occupations have been studied within occupational therapy and occupational science have shifted as these disciplines have developed. The primary focus within rehabilitation has traditionally been on those with ill health rather than on their informal caregivers, but this has evolved within the discourse. The biomedical approach, which views health as an absence of disease (Farre & Rapley, 2017), has historically been a strong undercurrent in OT, along with a "Western, Anglophone, and middle-class view of reality" (Kantartzis & Molineux, 2012, p. 39) and a female perspective (Hocking, 2012). The assumptions embedded in these perspectives have played a large role in the kinds of occupation-based research that have been produced. Since the early 2000s, critical approaches (Farias & Laliberte Rudman, 2016), transactional perspectives (Dickie

et al., 2006), and perspectives from outside of the global north (Magalhães et al., 2019) have increasingly informed occupation-based research, ultimately broadening the scope of the field and its understandings of occupation. In particular, these approaches have pointed to the need to shift beyond individualistic and biomedical approaches to understanding and studying occupation, highlighting how attending to occupation as relational, situated and political can generate knowledge that can inform efforts to transform discourses, systems and structures so as to address occupational inequities and injustices (Farias & Laliberte Rudman, 2016). Thus, studying the occupation of caregiving as situated, relational and political has potential to not only highlight its occupational nature, but can serve to inform transformations aimed at working against occupational inequities and injustices that may be experienced by informal caregivers. This critical interpretive synthesis examines changes in how the occupation of informal caregiving of older adults has been and is being conceptualized and researched within the occupation-based literature, highlighting if and how it has embraced the broader turn towards relational, situated, and political conceptualizations of occupation and pointing to future directions for such research.

2.2 Methods

Given the intent to examine how informal caregiving has been conceptualized and researched, a critical interpretive synthesis (CIS) was conducted. This knowledge synthesis approach is useful for combining information from both quantitative and qualitative studies when the goal is to produce a synthesizing argument or overall narrative of how an area has been studied (Kastner et al., 2016). CIS has been used previously to illuminate how particular constructs have been attended to within occupation-based literature (Benjamin-Thomas & Rudman, 2018; Farias & Laliberte Rudman, 2016). The current study used the six steps outlined by Depraetere et al. (2020), which begin with establishing an open research question that can be refined throughout the review. This question is then used to guide a literature search, leading to literature selection that applies inclusion and exclusion criteria, quality appraisal of the selected literature (based on the content of the paper, its likely relevance, and theoretical contribution to the review), data extraction, and finally the formulation of a synthesizing

argument. The question for this study was ‘how have experiences of informal caregiving for older adults been conceptualized and researched within the occupation-based literature?’.

Within a CIS, the intent is to identify relevant material that allows for consideration of how a construct has been addressed, rather than to conduct an exhaustive search to find all available research (Dixon-Woods et al., 2006). As such, we conducted a search to gather a sample of texts that enabled an examination of how informal caregiving has been addressed within occupation-focused literature. This search was ultimately conducted in five journals that include a focus on occupation as a central aspect of their aims and scope; specifically, we searched the Canadian Journal of Occupational Therapy; the Scandinavian Journal of Occupational Therapy; the Journal of Occupational Science; the Interinstitutional Brazilian Journal of Occupational Therapy; and the Occupational Therapy Journal of Research (OTJR: Occupation, Participation, and Health). It was found that a search of these 5 journals resulted in a sample of texts that provided insight into several key approaches to the conceptualization and study of caregiving in the occupation-based literature, which led to a decision to contain the search to five journals. While it is acknowledged that a limitation of this approach is that not all existing occupation-focused journals were searched, the sample of texts was sufficient to address the CIS question and we did not aim to map all relevant literature as would be done in a scoping review study.

A single search term, “caregiv*”, was used in each of the five journals. No parameters were set regarding date of publication so that articles could be explored across time to see how the topic of informal caregiving has been studied and conceptualized within the occupation-based literature over the years. Articles were selected for inclusion if they reported on primary research and focused on the experiences of older adults as defined by the United Nations (60 years of age or older) (UN High Commissioner for Refugees (UNHCR), n.d.) who were informal caregivers. It was anticipated that the experience of paid caregivers, such as personal support workers, would be significantly different than that of family members and friends who have a longstanding close, personal connection to the individual cared for, do not receive financial compensation for their caregiving

duties, and may have little training in, or choice over whether to provide care to the loved one. As a result, articles focused on occupational experiences of formal caregivers were excluded. Additionally, articles referring to informal caregivers of individuals under 60 years of age were excluded to specifically highlight the experiences of people caring for older adults. We also opted to focus exclusively on primary research. Articles that were published in a language other than English were translated using Google Translate so that the primary author could glean the necessary information from them. Articles were assessed for goodness of fit with the research question; those which focused exclusively or nearly exclusively on the experiences of care recipients were excluded due to their lack of focus on the experiences of informal caregivers. After these inclusion/exclusion criteria were applied, a total of 17 primary research articles published between 2005 and 2020 were identified and used for data extraction. The principal author (AR), a graduate student in the field of occupational science, performed the article selection procedure which involved successive screenings of article titles and keywords, abstracts, and full-text documents. Data from each of the final articles (see Table 1 and supplemental material in the appendix) were extracted, and then organized using tables in Microsoft Word. Data were summarized using a conventional content analysis approach wherein main variables were identified (e.g., Year, Country, Participants, Study Design, Study Focus etc.) and descriptive frequencies used to identify trends across time. Trends that surfaced through this analysis were then considered in relation to literature addressing theoretical, methodological and paradigmatic developments in the field of occupational science so as to situate and interpret these trends. The analysis and interpretation of findings were deepened through dialogue with, and feedback from, study co-authors who collectively have expertise in critical occupational science scholarship, with academic and clinical experience in psychology and occupational therapy that focuses on informal caregivers.

Table 1: Summary of Articles Included in Review

	Authors	Title of Article	Journal Title	Year	DOI
1	Vikström S, Borell L, Stigsdotter-Neely A, & Josephsson S	Caregivers' Self-Initiated Support toward Their Partners with Dementia When Performing an	OTJR	2005	https://doi.org/10.1177/153944920502500404

		Everyday Occupation Together at Home			
2	Cruz ED	Elders' and Family Caregivers' Experience of Place at an Assisted Living Center	OTJR	2006	https://doi.org/10.1177/153944920602600303
3	Rudman D L, Hebert D, & Reid D	Living in a restricted occupational world: The occupational experiences of stroke survivors who are wheelchair users and their caregivers	Can. J. Occup. Ther.	2006	https://doi.org/10.2182/cjot.05.0014
4	van Nes F, Runge U, & Jonsson H	One body, three hands and two minds: A case study of the intertwined occupations of an older couple after a stroke	J. Occup. Sci.	2009	https://doi.org/10.1080/14427591.2009.9686662
5	Pickens ND, O'Reilly KR, & Sharp KC	Holding on to Normalcy and Overshadowed Needs: Family Caregiving at End of Life	Can. J. Occup. Ther.	2010	https://doi.org/10.2182/cjot.2010.77.4.5
6	Van Dongen I, Josephsson S, & Ekstam L	Changes in daily occupations and the meaning of work for three women caring for relatives post-stroke	Scand. J. Occup. Ther.	2014	https://doi.org/10.3109/11038128.2014.903995
7	Piersol CV, Herge EA, Copolillo AE, Leiby BE, & Gitlin LN	Psychometric Properties of the Functional Capacity Card Sort for Caregivers of People with Dementia	OTJR	2016	https://doi.org/10.1177/1539449216666063
8	Schaber P, Blair K, Jost E, Schaffer M, & Thurner E	Understanding Family Interaction Patterns in Families with Alzheimer's Disease	OTJR	2016	https://doi.org/10.1177/1539449215610566
9	Atler KE, Barney L, Moravec A, Sample PL, & Fruhauf CA	The Daily Experiences of Pleasure, Productivity, and Restoration Profile: A case study	Can. J. Occup. Ther.	2017	https://doi.org/10.1177/0008417417723119
10	Riekkola Carabante J, Rutberg S, Lilja M, & Isaksson G	Spousal caregivers' experiences of participation in everyday life when living in shifting contexts	Scand. J. Occup. Ther.	2018	https://doi.org/10.1080/11038128.2017.1337810
11	Ribeiro MM, Dias FC, Da Costa CO, & Oliveira SG	Desempenho ocupacional de cuidadores informais em atenção domiciliar / Occupational performance of informal caregivers of patients at home care	Rev. Interinst. Bras. Ter. Ocup.	2018	https://doi.org/10.47222/2526-3544.rbto12750
12	Costa ACMB, Tavares Paulin GS, & Trindade da Cruz KC	Cuidar, Cotidiano e Ocupações: Um olhar da Terapia Ocupacional sobre cuidadores familiares de idosos / Caring, everyday and occupations: a look at occupational therapy about elderly family caregivers	Rev. Interinst. Bras. Ter. Ocup.	2018	https://doi.org/10.47222/2526-3544.rbto12737

13	Evans KL, Millstead J, Richmond JE, Falkmer M, Falkmer T, & Girdler SJ	The impact of within and between role experiences on role balance outcomes for working Sandwich Generation Women	Scand. J. Occup. Ther.	2019	https://doi.org/10.1080/11038128.2018.1449888
14	Womack JL, Lilja M, Dickie V, & Isaksson G	Occupational Therapists' Interactions with Older Adult Caregivers: Negotiating Priorities and Expertise	OTJR	2019	https://doi.org/10.1177/1539449218799445
15	Watford P, Jewell V, & Atler K	Increasing Meaningful Occupation for Women Who Provide Care for Their Spouse: A Pilot Study	OTJR	2019	https://doi.org/10.1177/1539449219829849
16	Alencar Leão da Costa MB, Azevedo MJT, Torgal MCP, & Gomes JCR	Grupos de ajuda mútua com cuidadores informais de pessoas com demência: empowerment do cuidado/Mutual help groups with informal caregivers of people with dementia: empowerment in the care	Rev. Interinst. Bras. Ter. Ocup.	2020	https://doi.org/10.47222/2526-3544.rbto30025
17	Nissmark S, & Malmgren Fänge A	Occupational balance among family members of people in palliative care	Scand. J. Occup. Ther.	2020	https://doi.org/10.1080/11038128.2018.1483421

2.3 Situating the Findings

The first author began analysis by plotting the demographic data from the studies and information about how the studies were conducted to identify general trends. The included articles (identified by superscript numbers referenced in Table 1) covered participants from Sweden^(1, 10, 17), the United States^(2, 5, 7-9, 14), Canada⁽³⁾, the Netherlands⁽⁴⁾, Austria⁽⁶⁾, Brazil^(11, 12), Australia⁽¹³⁾, and Portugal⁽¹⁶⁾. Either sex or gender was reported in all but two of the articles^(2,5), but no study differentiated between sex and gender or explored the experiences of gender nonconforming individuals. Fourteen of the 17 studies had exclusively female or majority female participants^(1, 3, 6-17), with only 1 study reporting exclusively on the experience of a sole male spousal caregiver⁽⁴⁾. Thirteen of the seventeen studies were qualitative^(1-6, 8-10, 12, 14, 16, 17), two were quantitative^(7, 13), and two used mixed methods^(11, 15). Eight of the seventeen studies did not explicitly state the methodology used^(1, 7, 8, 11-13, 15, 17), but of the nine that did, grounded theory was the most commonly employed (used in three articles^(3, 10, 14)), as

well as phenomenology (used in two articles ^(6, 16)), and ethnography (used in two articles ^(2, 5)). In addition, there was one study each that used narrative inquiry ⁽⁴⁾ and case study ⁽⁹⁾. One mixed method study used a survey to gather quantitative information and qualitative information, which were analyzed by using absolute frequency and content analysis, respectively ⁽¹¹⁾. The other mixed method study used a one-group pretest–posttest quasi-experimental design as well as inductive content analysis of reflective journal entries recorded by participants ⁽¹⁵⁾. One quantitative study explored cross-sectional data using a 3-point Likert scale to assess a set of functional capacity card sort tests ⁽⁷⁾, and the other used nonparametric descriptive statistics to explore variables in relation to their median, range and frequency from questionnaires with closed-ended questions ⁽¹³⁾. Nine articles approached caregiving as composed of occupations ^(1, 2, 4, 6-10, 13), meaning that specific caring duties of the informal caregivers were described as their daily occupations; 8 articles presented informal caregiving as preventing occupational engagement by caregivers, showing how caregivers had to give up meaningful occupations to fill the caregiving role ^(3, 6, 10-13, 15, 16), and 4 articles discussed informal caregiving as an occupation itself, not necessarily divided into various discrete caregiving occupations ^(5, 10, 14, 17).

2.4 Findings

Over the span of sixteen years from 2005 to 2020, the occupation-based literature focused on the experiences of informal caregiving has grown. More than half of the articles included in this study were published in the most recent five years ⁽⁷⁻¹⁷⁾, between 2016 and 2020. Among the most recent research, there has been a growing emphasis on solely addressing the experiences of informal caregivers as compared with earlier research that included caregiver experiences within studies that split the focus between caregivers and care recipients (see Table 1). In line with broader calls to attend to occupation as situated and relational, two notable perspectives evident in the literature were transactional perspectives and exploration of co-occupations. A consistent observation across time is that there appears to be substantially more attention given to the experiences of female caregivers than male caregivers. Among the seventeen articles in this study, six included only female caregivers ^(6, 8, 9, 12, 13, 15) whereas only one study had a sole male caregiver ⁽⁴⁾.

Two of the studies did not report the sex or gender of the caregiving participants^(2, 5), and the remaining studies included mostly female caregivers^(1, 3, 4, 7, 10, 11, 14, 16, 17), ranging from 53% to 90% of the study samples. Post-positive^(1, 3, 7-9, 11, 13-15, 17) and constructive-interpretive^(2, 4-6, 10, 12, 16) paradigms were dominant, with critical approaches and attention to occupation as political being largely absent.

2.4.1 Focus on caregivers

There has been a noteworthy shift over time in the attention paid to the informal caregiver. A greater proportion of the articles published within the last five years, as compared with those published between 2005 and 2015, focus primarily on caregivers rather than dividing their focus between caregivers and care recipients (see Figure 1). For example, Cruz's (2006)² study of the experiences of older adults and their family caregivers within an assisted living facility in the United States splits the focus between the experiences of caregivers and care recipients. Even with direct quotes by the caregivers on their experiences of the assisted living facility, their voices are not prominent in the article and a greater emphasis is given to the experiences of the care recipients. Also of note, the broader contexts of the lives and occupations of the informal caregivers outside of the caring role are not included in this study. Studies that have subsequently focused solely on experiences of informal caregivers have rendered more complex understandings of the multidimensionality of caregiving as an occupation. For example, Ribeiro et al. (2018)¹¹ used a mixed methods approach to explore the performance of occupational roles of informal caregivers of family members in home care in Brazil. They examined the occupations of informal caregivers relating to the caregiving role while also demonstrating that caregivers are distinct individuals who have other meaningful occupations beyond that of caregiving, such as shopping, going to the bank, and spending time with family or friends. As another example, Nissmark and Malmgren Fänge (2020)¹⁷ presented the mental and emotional costs for family members of individuals in palliative care, such as changes in roles and occupations, feeling lonely, and being under constant stress. Much of the recent literature has turned the focus towards the experiences of caregivers, as these authors have.

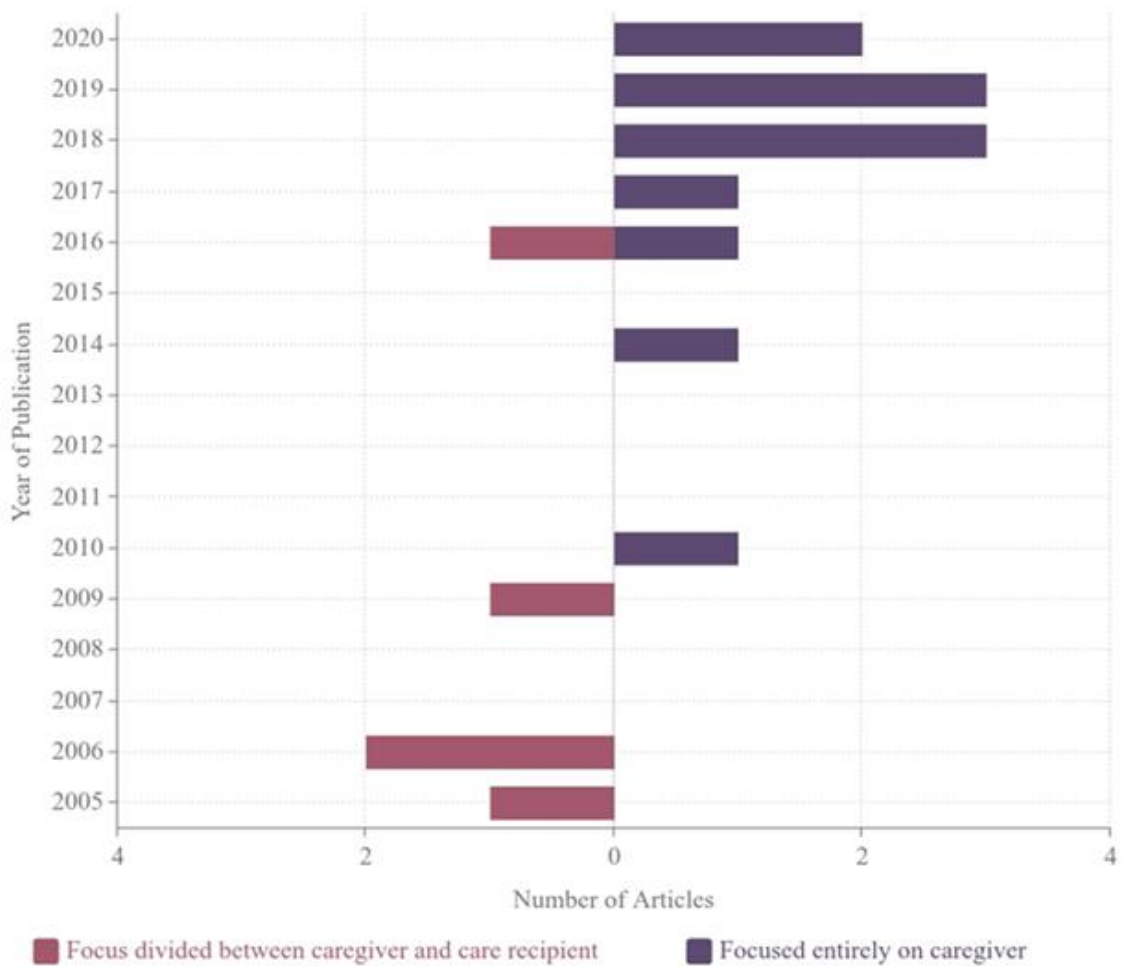


Figure 1: Number of Articles with Focus Divided Between Caregiver and Care Recipient or with Focus Entirely on Caregiver, by Year of Publication

2.4.2 Transactionalism

Studies that have taken up a transactional perspective have generated understandings of this occupation as situated both within various elements of context, such as physical, temporal and cultural aspects, as well as in social contexts and relationships. The transactional view approaches occupations, of individuals and groups, as also embedded in in these contexts, so that “what we would typically see as separate from each other are really part of each other” (Dickie et al., 2006, p. 88); thus, “suggesting an ever-present

and always changing interpenetration of humans and their world” (p. 88). While the majority of the 17 studies did not explicitly state that they were using a transactional perspective, two recent articles^(10,14) provide exemplars of how this perspective enables understanding the occupation of informal caregiving as both situated and relational, generating understandings of complex ways this occupation is dynamically generated through on-going transactions of personal, contextual, and occupational elements encountered in caregiving situations.

Riekkola Carabante et al. (2018)¹⁰ and Womack et al. (2019)¹⁴ make the connection to transactionalism clear by referencing Dickie et al. (2006) in their articles. Within a grounded theory study conducted in Sweden that focused on how elderly spousal caregivers experienced participation in everyday life, Riekkola Carabante et al.'s (2018)¹⁰ application of transactionalism enabled them to situate spousal caregivers' occupational experiences within the context of the spousal relationship and as influenced by opportunities for respite. The following demonstrates the complexity that is illuminated by their transactional stance: “Even though the respite care service gave them time [alone], it also generated other issues like concerns about their partner’s well-being and participation in meaningful activities, which in turn influenced their own participation in everyday life” (p. 462 - 463)¹⁰. The interconnected nature of the caregiver/care recipient relationship within the context of respite are shown as transacting to produce the occupational opportunities experienced by the spousal caregivers. In their grounded theory study, Womack et al. (2019)¹⁴ focus on exploring the perspectives of occupational therapists regarding their interactions with informal caregivers and their understandings of how caregivers experience this occupation. Drawing on transactionalism, they highlight how the expectations and values within occupational therapy influence the way therapists perceive and interact with caregivers. They discuss how external and internal factors impact occupational therapists' interactions with caregivers: “When the complex needs of the care situation come into conflict with or demand broader considerations from [healthcare professionals], the caregiver is positioned in ways that can be managed within the context. For occupational therapists, these negotiations represent a struggle between their adherence to responsibilities in the care setting and a desire to form caregiver alliances” (p. 53)¹⁴. Their findings situate caregiving within broader discourses

in occupational therapy, demonstrating that informal caregiving is a complex, dynamic occupation involving interconnected and interdependent relationships with healthcare professionals.

2.4.3 Co-occupations

Another concept drawn upon to examine the occupation of informal caregiving as relational, that is, as occurring in the relationships between people, is the concept of co-occupations. In particular, the relationship between informal caregivers and care recipients within occupations has been explored in the occupation-based literature with the concept of 'co-occupations'. Pickens and Pizur-Barnekow (2009) explain that "co-occupation occurs when two or more individuals engage in an occupation which becomes transformed by aspects of shared physicality, shared emotionality, and shared intentionality. Co-occupations produce and are embedded in shared meaning" (p. 155). The study of co-occupations, like transactionalism, considers the reciprocal impact of relationships on occupations, and identifies occupations that require at least two people who are dependent on each other for completion of the occupation. Focusing on co-occupations allows the researcher to examine how two or more people are intertwined and dependent on one another within their engagement in an occupation. Two articles^(1,4) were found to discuss co-occupations within this study.

Vikström et al. (2005)¹ implicitly attend to co-occupation in their study of Swedish caregivers and care recipients in describing how informal caregivers offered support to their partners with dementia when jointly performing the everyday occupation of preparing afternoon tea. Although the caregivers played the dominant role in overseeing the preparation of coffee and sweet treats, the roles of both partners are identified as being valuable and interconnected. In a more explicit way, van Nes et al.'s (2009)⁴ narrative inquiry case study of an older couple in the Netherlands shows the role of co-occupations for the couple following a stroke. In this article, the phrase, "one body, three hands and two minds" (p. 194)⁴ is used to describe how the couple function together. The complementary roles each play in personal care, enjoying mealtimes, and doing crafts show the impact of each partner on one another's experience of the shared occupations,

shifting away from conceptualizing caregiving as a one way delivering of care to viewing it as an occupation that is inherently relational.

2.4.4 Paradigmatic positions represented

Within the available literature on informal caregiving in occupational science and occupational therapy, post-positivism and constructivism-interpretivism appear to be the dominant guiding research paradigms. Paradigmatic positioning of the authors was generally not explicit, but close examination of the articles in this study using Ponterotto's (2005) and Guba and Lincoln's (1994) definitions for the post-positivist, interpretivist-constructivist, and critical-ideological paradigms allowed for identification of the authors' paradigms. There was a nearly even split between post-positive^(1, 3, 7-9, 11, 13-15, 17) and constructive-interpretive^(2, 4-6, 10, 12, 16) perspectives among the 17 articles in this study. The 10 articles underpinned by a post-positivist paradigmatic position tended to focus on generating generalizable data addressing how informal caregivers of older adults are impacted occupationally. Within the 7 articles in this study exploring the topic from an interpretivist-constructivist perspective, the roles of the researchers were acknowledged, and the unique experiences of participants were placed within their contexts. No authors integrated a critical-ideological perspective, leading to a lack of attention to understanding the political dimensions, or power relations, shaping the occupation of informal caregiving, or how enactments of informal caregiving can serve to reproduce or resist broader power relations.

2.5 Discussion

The seventeen articles reviewed demonstrate the utility of the occupational perspective for advancing an understanding of informal caregiving for older adults and showed how changes have occurred within this area of study over time. An occupational perspective “can apply at the level of individual doing through to societal doing; considers contextual factors; assumes occupations are connected to health and well-being; attends to the form, function, and meaning of occupations; and can contribute to being, becoming, and belonging” (Njelesani et al., 2014, p. 231). In applying an occupational perspective to the study of informal caregiving, the studies reviewed demonstrate the utility of such a

perspective for addressing the complexity of caregiving as an occupation and exploring the occupational lives of informal caregivers of older adults. The shift towards spotlighting the experiences of informal caregivers in occupation-based literature has generated insights regarding the form, function, and meaning of caregiving and its related occupations. Transactional perspectives and exploration of co-occupations have begun to further turn attention to contextual factors, thereby situating this occupation and also highlighting its relational nature. The existing focus on female perspectives and the use of post-positivist and interpretivist-constructivist paradigms offer insight into the dominant frames used thus far in occupation-based research, pointing to possible areas for further exploration.

Between 2005 and 2020, the literature shifted to place increased value on the experiences of caregivers. The division of focus between caregivers and care recipients in articles between 2005 and 2009 may reflect the dominance of a biomedical and individualistic lens within occupational science at that time – leading to a focus on illness as an individual phenomenon, rather than on holistic and collectivist understandings of wellbeing; therefore, a biomedical perspective would place little value on spotlighting the experiences of seemingly healthy informal caregivers for their own sake. The 2010s have seen more inclusive, holistic, and transactional perspectives being represented, as evidenced by the increased focus on the experiences and occupations of informal caregivers. The recent shift within the occupation-based literature towards focusing on the experiences of caregivers themselves rather than exploring caregiving only as it relates to the care recipients can be situated within a broader shift towards studying the occupational experiences of individuals and groups that are often marginalized, silenced, or neglected. For example, amidst calls to diversify understandings of occupation and generate research that addresses occupational injustices (Farias & Laliberte Rudman, 2016), studies addressing transgendered experiences of occupation (Dowers et al., 2019) and occupations of youth in Brazilian favelas (Gonçalves & Malfitano, 2020) are examples of this turn in attention towards individuals, social groups, and occupations which might otherwise be ignored. As suggested by Hocking (2012), this is an important way forward for occupational science, to “engag[e] with more diverse populations in order to broaden our epistemic basis and the ontologies we may seek to represent” (p.

62). Creating space for the voices of caregivers to be heard contributes to not only the broadening of the scope of occupation-based research and practice, but also creates an opportunity to contribute to a gap in the broader interdisciplinary study of informal caregiving.

The incorporation of transactional perspectives and exploration of co-occupations within the articles included in this study, along with an increasing focus on the experiences of caregivers, have expanded the horizons of the occupation-based literature on informal caregiving for older adults. Various historical and foundational influences, such as a deeply embedded biomedical perspective and Eurocentric origins (Kantartzis & Molineux, 2012) have meant that occupation-focused research often historically assumed a dualism, or division, between persons and context, and studied occupation as an individualized and Westernized phenomenon. Drawing upon Dewey, Dickie et al. (2006) write that a transactional perspective asserts that “occupation rarely, if ever, is individual in nature” (p. 83). Aldrich (2008) agreed that transactionalism is about rejecting dualisms, requiring occupation to be conceptualized and studied as always embedded in situations. With this perspective, phenomena – such as occupations, contexts, and persons – “move through one another and transact as co-constituted entities” (Aldrich, 2008, p. 151). Thus, experiences cannot be separated from the conditions that produce them and the relationships that influence them. Within the literature reviewed, the insights to be derived from the application of a transactional perspective to the study of caregiving as an occupation were demonstrated. This points to the important knowledge to be generated through further application of such a perspective.

Along with transactionalism, the study of co-occupations has drawn attention to the dynamic, reciprocal nature of occupations. Co-occupations have been described as activities involving two or more people in an interconnected, mutually responsive way (Pickens & Pizur-Barnekow, 2009). The study of co-occupations advances understanding by illustrating how the occupation of caregiving and secondary occupations within the caregiving role are carried out within the dynamic caregiver/care recipient relationship. Exploring the occupation of informal caregiving and occupations that fall within the caregiving role as co-occupations opens up possibilities for studying these occupations as

they actually occur in a relational way – that is, jointly between caregivers and care recipients. The exploration of co-occupations works together with the holistic perspective of transactionalism to inform conceptualizations of occupations that situate them relationally, historically, and otherwise contextually. Transactionalism and co-occupations allow relationships between the caregiver and the context to be explored. These perspectives illuminate how the various occupational possibilities afforded to caregivers, the occupations within informal caregiving, and the occupation of informal caregiving are situated.

In light of the advances occupation-based research has made towards incorporating diverse perspectives, it is of particular interest that a majority of the participants in the 17 articles included in this study were female. The reason for the emphasis on female caregivers could be because a greater proportion of informal caregivers are female (Hand et al., 2019). Moreover, this emphasis on females may reflect a broader long-standing feminization of informal caregiving, particularly in the context of family relations, in which providing care has been dominantly socially constructed as within the purview, nature and responsibilities of women, at the same time as it has been economically undervalued and been allocated in ways that often amplify financial strain for women who take up this role (Maidment & Beddoe, 2016; Noddings, 2021). Additionally, this emphasis on female informants and perspectives may have arisen due to bias in the recruitment of participants and design of studies. As noted by Hocking (2012), most occupational scientists and therapists are female, and it appears that has also meant that the most studied groups are female (Pierce et al., 2010). This may be because researchers are likely to study others who they most readily identify with, resulting in higher rates of female participation in studies. Moreover, application of a feminized lens within recruitment materials and practices may have also bounded the occupation-focused study of informal caregiving through attracting higher rates of female participants. For example, traditionally female occupations such as meal preparation and cleaning may be more readily seen as caregiving within and outside the occupation-based literature; however, traditionally male occupations such as fixing of household devices and maintenance may not be recognized as caregiving activities. Both types of supportive occupations could be viewed as caregiving, but a feminized lens might eliminate

traditionally male roles from being conceptualized as caregiving occupations. Cisgendered and heteronormative views have also been dominant, as no occupation-based study has yet explored the experiences of gender nonconforming informal caregivers and/or care recipients or those of marginalized sexual orientations. Expanding beyond cisgendered and heteronormative perspectives could allow the field to tap into the lived experiences of gender nonconforming individuals who are too often overlooked (Hash & Mankowski, 2017).

Along with a lack of male or other gendered perspectives within the available literature on informal caregiving in occupational science and occupational therapy, there appears to be an absence of critical perspectives. Such perspectives would have the potential to explore this occupation as “a means of governing and maintaining the social order” (Farias & Laliberte Rudman, 2016, p. 42); “as a site of resistance and political action” (p. 43); and as “a vehicle for [social] transformation” (p. 43). There may be great potential for a critical paradigm to be mobilized to explore and expose power structures and generate knowledge that can inform social transformation; for example, knowledge that can expose the implications of the taken-for-granted assumptions that family caregivers can and will take up increasing responsibilities within a larger context of austerity and health care cutbacks or that attend to how gendered power relations may mean that some caregivers have little ‘choice’ in taking up such responsibilities. While a critical approach may not have yet been taken up in occupation-based research on informal caregivers because other paradigms have been better suited for their study aims, there is also a need to consider what questions are not being asked if a critical perspective is not integrated (Farias & Laliberte Rudman, 2016). Within occupational science and occupational therapy, we have broadly seen a move towards more critical perspectives in research, as in Kiepek et al.'s (2019) study critiquing the silence within occupational science around occupations seen as unhealthy, illegal, or deviant. However, critical perspectives are applicable beyond the study of ‘non-sanctioned occupations’, allowing for space to consider how power relations are embedded and expressed through the occupation of informal caregiving, and how power relations can be resisted and transformed through such an occupation.

2.6 Limitations

Given the critical interpretive synthesis approach used, we acknowledge that this analysis, which focused on a selection of texts drawn from five journals, cannot claim to describe how informal caregiving has been approached in all occupation-focused research. Our findings are also bounded within the specific time frame of 2005 to 2020, and, for those articles published in a language other than English, to our limited understanding of the findings based on the rough translation from Google Translate. A useful next step in understanding knowledge generated about informal caregiving for older adults from an occupational perspective could be the conduct of a scoping review that would include all occupation-focused journals as well as occupation-focused research published within other disciplinary journals.

2.7 Conclusion

While there are opportunities for further growth in occupation-based research on informal caregiving for older adults, the findings of this study demonstrate the contributions that have been generated through applying an occupational perspective in this area, underscoring the diverse occupational lives of caregivers and illustrating the complexity of caregiving as an occupation. The recent shift towards focusing primarily on the experiences of caregivers, along with the use of the transactional perspective and exploration of co-occupations, have expanded contributions and provided insights into fruitful areas for future research on informal caregiving. At the same time, this synthesis points to a need to turn greater attention to a diversity of informal caregivers, particularly through the incorporation of perspectives of caregivers who are male and members of LGBTQ2S+ communities. Moreover, this synthesis raises concerns regarding the lack of critical attention to informal caregiving as embedded in social relations of power. Use of a critical lens could serve to enhance understanding of the complex social and political conditions within which informal caregiving is enacted and negotiated, which may be particularly important in contemporary sociopolitical contexts marked by austerity and downloading of caregiving responsibilities. Overall, conceptualizing the occupation of caregiving as relational, situated, and political offers opportunities to not only expand understandings of occupation, but to make significant and unique contributions to the

study of informal caregiving and inform practices designed to optimize caregivers' occupational possibilities.

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Chapter 3

3 Engaging in Difficult Conversations Within the Role of Care Partner to an Individual with PD

Navigating difficult conversations is an important, yet challenging, co-occupation in the lives of informal care partners of individuals living with PD. In this study, we explore care partners' experiences with difficult conversations, gain insight into different types of conversations that are held and elucidate mediating factors that care partners perceive to influence how successfully difficult conversations are managed. Two rounds of in-depth semi-structured interviews with 7 care partners of individuals with PD were undertaken. Applying an American Phenomenological Constructivist approach, three themes representing experiences of care partners emerged. We learned that a wide range of different types of difficult conversations occur along the care partnering journey, the frequency and intensity of difficult conversations may change over time, and mediating factors influence the success of difficult conversations. Understanding care partner experiences with difficult conversations is a crucial first step to guide the development of resources tailored to improving communication and decreasing burden associated with the co-occupation of care partnering in early disease stages.

3.1 Background

Informal unpaid care partners of individuals with PD commonly report experiencing 'caregiver burden' (Zarit et al., 1986). These informal unpaid care partners are typically spouses, but they may (less frequently) be children, or (much less frequently) be extended relatives or close friends (Hand et al., 2019). Caregiver burden is a particular form of stress resulting from the demands of the caregiving role that primarily manifests as a mental burden rather than physical strain (Roland et al., 2010). Other terms, such as caregiver stress, may be used interchangeably and may resonate more for care partners who feel that the term 'burden' carries a negative connotation (Hamad et al., 2018). Caregiver burden or stress is associated with progressive PD-related impairments (Henry et al., 2020; E. R. Smith et al., 2019), which may include mood disorders, and changes in facial and vocal expression that lead to impaired communication and increased stress on

the care partner/care recipient relationship (Schwartz et al., 2020). With communication compromised, it can become increasingly challenging for care partners to engage in ‘difficult conversations’, defined by some as those conversations that involve asking someone to stop doing something they wish to continue, or to begin doing something they do not wish to do (Soehner & Darling, 2017). Previous research suggests that informal caregivers of people with a variety of chronic and life-threatening conditions often avoid difficult conversations altogether (Ayers et al., 2017; Schulz et al., 2017; Tang, 2019), which can place strain on the care partner/care recipient relationship and can be detrimental to the wellbeing of both parties (Edwards & Forster, 1999; Fried et al., 2005; Tang, 2019).

While the topic of holding difficult conversations has been explored in other contexts, to the best of our knowledge no study has yet investigated the unique experiences of care partners of individuals with PD. PD differs from many other chronic health conditions in that symptoms are highly unpredictable (Haahr et al., 2011; Holmes et al., 2013), and despite being progressive, PD is rarely a cause of death (Fall et al., 2003). Thus, the conversation topics relevant for individuals with PD and their care partners may differ from topics relevant for individuals living with other chronic health conditions. Additionally, the effects of PD on motor systems with the resulting impacts on verbal and nonverbal communication can present communication challenges. The purpose of this study is to explore the lived experiences that informal care partners have with engaging in difficult conversations with individuals living with PD and with others as part of the caring role. We hope to illuminate the facilitators of, barriers to, and most salient topics of difficult conversations within this unique population.

3.2 Methods

3.2.1 Methodology

We used the paradigm of constructivism and the methodology of American phenomenology to frame this qualitative study. Constructivism acknowledges multiple valid realities and prioritizes participants as experts in their own experiences (Ponterotto, 2005). This means that one care partner’s experience with engaging in difficult

conversations would neither be assumed to be generalizable to all others, nor as an outlier to be excluded. Each care partner's experiences are accepted as valid and true for him or her and as useful for understanding the broader picture of what it means to have difficult conversations as a care partner for an individual with PD. Constructivism allowed us to incorporate the distinct perspectives of each participant involved. American phenomenology seeks to explore how experiences are perceived and understood by people in real-world settings, focusing on understanding people's own perceptions of their experiences, or their lived experiences with phenomena (Giorgi, 2012). Along with the paradigm of constructivism, the methodology of American phenomenology allowed us to create space within this study for care partners' voices to be heard.

3.2.2 Positionality

The primary investigator, AR, approached this study from the perspective of a female master's student in her early 20s studying Occupational Science. This background, together with the first author's undergraduate experience in the holistic, people-focused disciplines of health sciences and community development, shaped her decisions within this qualitative study. AR had some prior knowledge about PD from visits as a child with a distant relative who had PD, and from a volunteer placement at a retirement home as a young adult. AR also had an understanding of the experiences of informal caregivers from involvement with a grandmother who relied on the support of nearby family members as she aged with diabetes and dementia. The lens through which AR viewed this study was informed by these aspects of her positionality. The second and third authors (AJ and JH) contributed their guidance to the conduct of this study, which was informed by their decades of experience in PD research as well as their respective experiences as a psychologist and occupational therapist.

3.2.3 Procedure

Care partners of individuals with PD living in Southwestern Ontario who were connected with the organization Parkinson's Society Southwestern Ontario (PSSO) were recruited from a pre-established participant database. We reached out to potential participants via email or telephone (dependant on contact preferences) for participation in individual

semi-structured, in-depth interviews. With the support of JH, the first and fourth authors (AR and BM) conducted an initial online interview with 7 care partners using the videoconferencing platform Zoom. During the initial interview, 7 questions were used to explore participant experiences of providing care to an individual living with PD; one question specifically probed for information related to participants' experiences with holding difficult conversations.

Throughout the process of conducting the first round of interviews, AR and BM individually coded each transcript. Coding of each participant's transcripts occurred on different days so that AR and BM could give attention to each participant's individual experiences and avoid projecting one participant's experiences onto another. These two researchers each developed tentative themes from the first round of interviews. Scholarly dialogue between AR and BM then followed, and the tentative sets of themes were amalgamated. AR and BM then presented the major emerging themes along with some of the prominent observations unique to each participant visually using PowerPoint slides (see appendices 7 – 13) and verbally within a second round of interviews over Zoom. Within this second round of interviews, participants clarified some of our understandings and added to our knowledge of their experiences. AR then repeated the coding process with the second round of interviews, coding each person's transcript separately.

After coding was complete, code names representing similar concepts were adjusted so codes could be easily compared across accounts. As the codes were combined, AR looked for the important ideas that were coming through in the individual transcripts and across the two rounds of interviews. Codes were clustered into categories. EB then reviewed the codes and categories that were developed by AR after reading through all the transcripts. EB provided feedback on codes that should be added or changed and made suggestions about important points from the transcripts that should be added to specific codes. AR used the feedback and suggestions to update the codes and categories, and then shared the findings with JH and AJ, who reviewed the codes and categories that had been developed. AR then met with JH and AJ to discuss the research and come to a final set of themes which encapsulated the major findings from the study.

Throughout the research process, ‘bracketing’ was used as a means of engaging in researcher reflexivity, questioning prior knowledge, and being open to the lived experiences of participants (Ashworth, 1999; Dowling, 2007; LeVasseur, 2003). Data were collected to a point of sufficiency. Although many qualitative researchers have used the term ‘saturation’ to mean “the point in data collection when no additional issues or insights emerge from data” (Hennink et al., 2017, p. 592), our assumption of limitless unique experiences led to ‘saturation’ being operationalized as the point at which there was sufficient information to richly present an in-depth understanding of the diverse experiences care partners of individuals with PD in southwestern Ontario have had with difficult conversations.

3.2.4 Ethical Considerations

Each participant in this study signed a letter of informed consent prior to the initial interview and was informed of their rights as study participants prior to commencing audio recording of the interviews. Participants were reminded to feel comfortable skipping any questions at any point in the interviews and AR and BM used their own judgement within interviews to decide which questions should be probed further and which ones should not. Participants’ names were also anonymized in the analysis and writeup to protect their privacy.

3.3 Participants

All participants were either currently providing unpaid care to an individual with PD or had been doing so within a year and a half of the initial interview. Four out of the 7 care partners were female (Barb, Diane, Tracy, and Linda) and 3 were male (Ben, John, and Dan). Six of the care partners were spouses of the individuals with PD (2 were husbands and 4 were wives), and the remaining one, who did not identify with the term ‘care partner’, was a son of a man with PD. Five care partners were living with the individuals with PD they cared for and the remaining two had done so before the individuals with PD they cared for passed away. In this study, all participants resided in southwestern Ontario, were connected with the PSSO, and had attended at least one conference hosted by the PSSO.

Barb, who was in her late 70s at the time of our interview, was married for more than 3 decades to her husband, who was diagnosed with PD in their retirement years. Barb's husband had passed away less than 2 years prior to the beginning of this study. Barb and her husband worked together in faith-based ministries before retiring. Barb was directly involved in her husband's care from the beginning of his decline to the end; coordinating appointments with healthcare professionals, implementing dietitians' advice, and assisting him with occupations of daily living such as getting out of bed to get seated in a wheelchair became an ordinary part of Barb's relationship with her husband. Barb actively sought out PD-related supports such as therapies and webinars. Barb identified with the term 'care partner' and preferred to use this over the term 'caregiver'. Barb emphasized the importance of prayer and of her relationship with God as a support that she could always depend on for strength and wisdom through the challenges of caregiving. Barb also enjoyed the support of their children and close connections with other family and friends who provided assistance and helped her feel cared for.

Diane was married for more than 4 decades to her husband, who retired early because of his PD symptoms. Diane's husband had passed away less than 2 years prior to the beginning of this study. Diane and her husband spent their careers working in the education sector. Diane retired shortly after her husband did in order to accommodate her increasing caregiving responsibilities. Diane preferred the term 'care partner' over 'caregiver'. Diane was dedicated to caring for her husband and also enlisted the help of their children and accessed paid in-home supports so that she could help her husband while maintaining her own physical and mental well-being. In his final years, Diane's husband lived in a nursing home where she would visit him daily; this eased her caregiver burden and allowed her to feel that her relationship with her husband was once again primarily a spousal relationship. It was important to Diane to stay active and involved in the community, with friends, and with Parkinson's support groups. Diane emphasized the importance of care partners speaking up for their own needs.

Tracy had been married for more than 3 decades to her husband, who developed PD in his 50s. Both Tracy and her husband were employed in the agricultural sector at the time of our interview. Tracy primarily considered her relationship with her husband to be a

spousal, rather than caregiving, relationship due to his mild symptoms and slow progression, but she accepted the term ‘care partner’. Tracy’s husband was very active and independent, but they recognized that changes might come as his PD progressed. Tracy had attempted to access PD-related supports such as a caregiver support group but found that the group did not help her to focus on the positive, which was an important part of her approach to life. Tracy emphasized the importance of gratitude and of considering how one can make the best of any situation. Tracy also talked about how important her friends and church community were for encouraging her and lifting her spirits.

Linda, who was in her mid-60s at the time of our interview, had been married for more than a decade to her husband, who developed PD before reaching retirement age. Linda held various jobs throughout her career, most recently working in long-term care. Her husband stopped working earlier than he had planned due to his PD symptoms; Linda also retired early in order to accommodate her increasing caregiving responsibilities. Linda’s husband’s PD had steadily progressed, and she was primarily responsible for providing the hands-on daily care he needed at the time of our interview. Linda talked about her intentional use of the term ‘care partner’ as a reminder of the partnership aspect of her relationship with her husband, even though she often felt that caregiver was a good fit given how far his care needs had progressed. Linda discussed how her faith in God helped her to stay positive through the challenges of caregiving. Linda emphasized the importance of planning ahead, thinking carefully, and choosing her words wisely to respect her husband and support his dignity within difficult conversations.

Ben, who was in his late 20s, had been living for the last decade with his father, who had early-onset PD. Ben had experience in social work and was employed in the long-term care sector. Ben’s father had retired early due to his PD symptoms but was still able to engage in most activities of daily living with little to no assistance. Ben helped his father by offering knowledge about PD that he had gained from his studies and his experience in long-term care. Ben also helped his father by encouraging him to be as independent as possible. Ben talked about the importance of PD-related exercise programs for helping slow the progression of his father’s PD. Ben did not identify with the term caregiver or

care partner, saying that supporting his father through his journey with PD was just a new part of their father/son relationship. Ben brought up the fact that thinking about the future and about the unpredictability of how his father's PD might progress could be a mental burden. Ben talked about how he avoided sharing information within difficult conversations that could cause unnecessary stress for his father. He emphasized the importance of using discretion in deciding whether and when to have a difficult conversation.

John had been married for nearly 5 decades to his wife, who developed PD around retirement age. Both John and his wife were retired at the time of our interview. John's wife's progression with PD had been fairly steady and they worked together to seek medical treatments that would help them manage symptoms. Both John and his wife had also been navigating other health issues throughout their PD journey. In our interview, one of John's primary focuses was the medical aspect of treatment for his wife. John also spoke about the emotional burden of watching his loved one face the challenges of a progressive illness. John preferred the term 'care partner' rather than 'caregiver' because the word 'partner' underscored the partnership aspect of his relationship with his wife. John emphasized his wife's role in initiating difficult conversations, stating that, as a natural planner, she was often the one to take the lead in noticing or bringing up difficult topics that should be discussed.

Dan, who was in his early 70s at the time of our interview, had been married for more than 4 decades to his wife, who developed PD around retirement age. Dan's wife's PD progression had been fairly slow at the time of our interview, and she was able to engage in most or all activities of daily living with little to no accommodation. Dan's wife was retired, and Dan was semi-retired at the time of our interview. Dan noted that his wife's tendency to seek knowledge and to take an active and directive role in her own care may have been related to her experience in her career within the education sector. He also noted that her active approach to managing her own PD likely made his role as a care partner easier than it could have been otherwise. Dan's wife was very involved in PD-related activities and supports such as exercise programs and support groups. Dan and his wife had made lifestyle adjustments together since her PD diagnosis to ensure they could

both live well together. Dan talked about how his wife's positive outlook helped him to stay positive. Dan preferred the term 'care partner' over 'caregiver', and he felt that his relationship with his wife did not yet involve much caregiving. Dan emphasized the importance of the supportive spousal relationship that he had with his wife and talked about how it helped in all aspects of their decision-making and in their difficult conversations. He talked about how it was important to him to consider her needs first and foremost. Dan anticipated that there could be difficult conversations in the future such as discussing the need for one or the other to move into a long-term care home or make other major life changes. He preferred to think about most of the 'difficult' conversations he had with his wife as important or life-changing conversations.

3.4 Data Analysis

Smith's (1999) interpretative phenomenological analysis was used to search for patterns within and across accounts. This analytic method is participant-centred and hermeneutic, acknowledging participants' natural reflectiveness concerning their experiences, and considering the contexts in which the experiences and reflection occur. The qualitative analysis software NViVo was used by AR and BM as a tool to transcribe the audio recorded interviews, and to organize and share the codes that were developed from these transcripts through the iterative process of data collection, analysis, and interpretation. Throughout the initial round of interviews, codes were developed independently by AR and BM, who independently aggregated the codes into tentative themes. AR and BM discussed these tentative themes prior to the second round of interviews. The repeat interviews allowed for member reflection (Tracy, 2010) to ensure that participant voices were represented with clarity and authenticity. Following round two of interviews, AR revised the codes and themes. EB then reviewed the updated codes and themes after analyzing the transcripts to ensure the codes and themes captured the main points participants were trying to communicate. AR then met with JH and AJ, who brought their prior research experience and clinical knowledge into the discussion to develop the final set of themes which are presented in this paper.

3.5 Findings

Each person's experience with difficult conversations is unique and dependant on a range of factors. Care partners in our study had difficult conversations with the individuals with PD they cared for as well as with adult children, other family members, and healthcare professionals. Major topics of discussion and the way these conversations played out seemed to change throughout the care partnering experience. We noticed individual differences in what care partners classified as difficult conversations and in the ways they approached such conversations. The three overarching themes we identified were that not all difficult conversations are equal; difficult conversations may initially increase, then decline over time; and mediating factors impact how difficult conversations will go.

3.5.1 Not all difficult conversations are equal

A wide range of different types of difficult conversations exist for care partners of individuals with PD. Based on our discussions, we believe there are three primary dimensions to consider which impact the nature and experience of difficult conversations. Difficult conversations seem to range on continuums from monological (one-sided) to dialogical (both parties contributing), from non-action-oriented (not expected to lead to change) to action-oriented (a hoped-for tangible outcome exists), and from high emotional valence (very meaningful to either or both parties) to low emotional valence (less meaningful/less challenging). The first two dimensions primarily influence how difficult conversations are carried out, while the third dimension – emotional valence – primarily impacts how difficult conversations are perceived. A difficult conversation can sit anywhere on the continuum from monological to dialogical, from non-action-oriented to action-oriented, and from high emotional valence to low emotional valence. Through our discussions with care partners, we have developed four terms to describe monologic non-action-oriented (difficult disclosures), monologic action-oriented (frank conversations), dialogic non-action-oriented (emotional/relational conversations), and dialogic action-oriented conversations (important conversations), though in reality, difficult conversations may not sit neatly within any one of the quadrants.

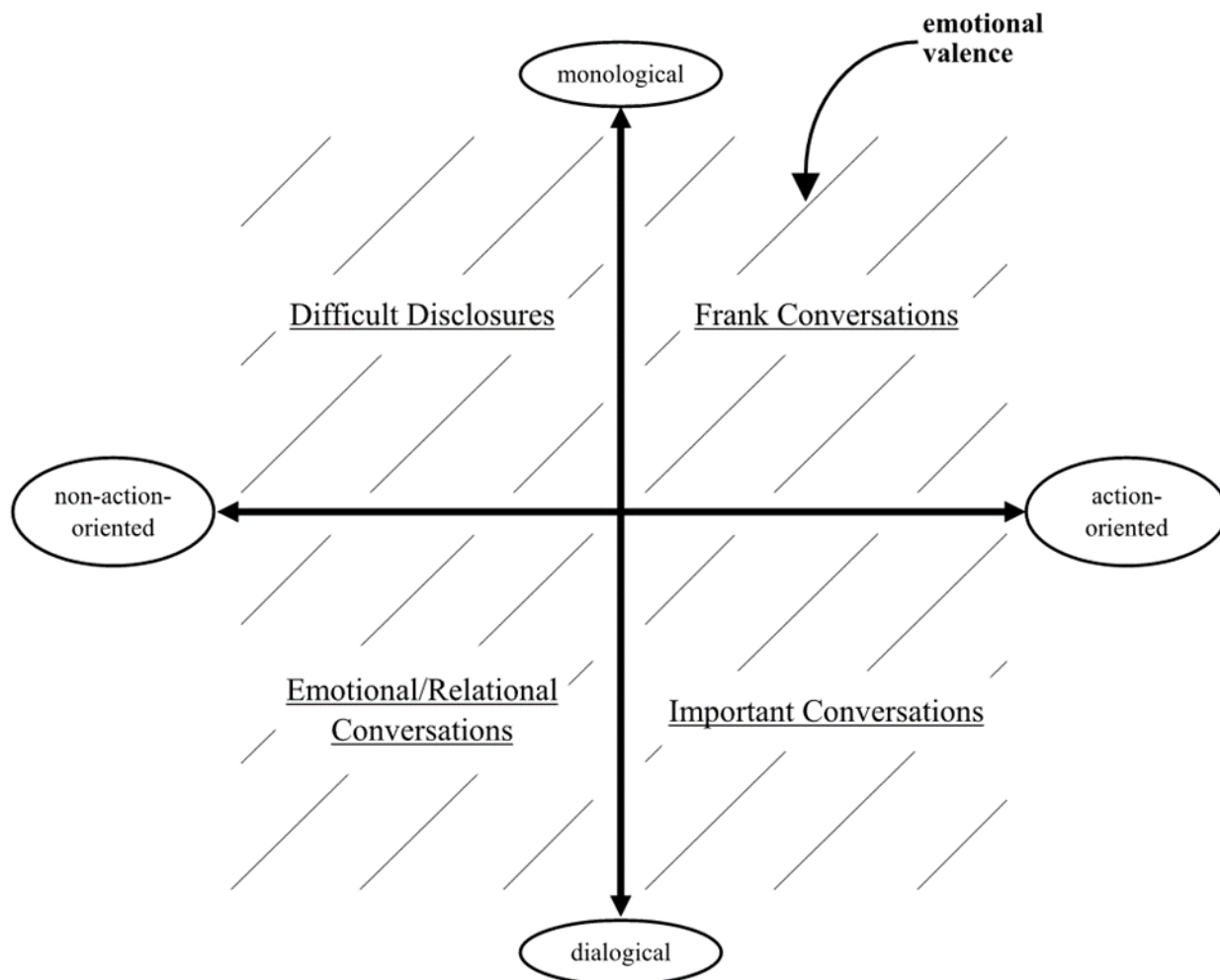


Figure 2: Dimensions of Difficult Conversations

‘Difficult disclosures’ describe monologic non-action-oriented conversations – one-sided discussions where the goal is for one party to deliver information to another. The most obvious example of a difficult disclosure within the care partnering role could be disclosing the PD diagnosis to family members and friends – multiple care partners recalled this being a difficult task in the early days of their PD journey. Difficult disclosures may also include conversations about progression of the disease. As John told us: “it’s often difficult to [communicate with our children] what we go through here on a day-to-day basis. They only see us maybe once a month or something because they’re both in other cities ... We’ve tried to get into more detail on that with them, but it’s hard

to convey when you only see them every few weeks or something” (CG06). Telling his children about his wife’s decline with PD was a one-way conversation that was difficult because of the sensitive nature of the topic and the barrier of distance which made it hard for their children to fully understand. Ben showed us that these kinds of difficult disclosures also occurred between the care partner and individual with PD: “sometimes trying to figure out what [my father] could deal with could be hard to disclose ... the only thing that I could really see having to [disclose to him] is I guess when he starts slipping mentally” (CG05). While many examples of difficult disclosures may occur along the PD journey, the common element among them is that these conversations involve one person delivering information that is to be received by another, with the only expected outcome being increased communication and understanding.

‘Frank conversations’ is the term we are using to describe monologic, action-oriented conversations, where there is a practical outcome or change that is expected and the conversation is directed primarily or exclusively by one person. Little to no input is required of the individual receiving the information, and he or she is expected to mobilize towards the change envisioned by the individual directing the conversation. In Dan’s opinion, “I think [a frank conversation] would be the most difficult ... if it comes to this point that it's getting to be too much for me to handle so we have to find some other solution, whether it be a support worker, whether it means you go into a nursing home or whatever the solution might be” (CG07). Many examples of frank conversations within the caring role positioned the care partners as advocates – either for themselves or for the individuals with PD. Diane protected her personal time to engage in meaningful occupations: “as I used to say to my husband, it's my retirement, too, and I'm not sick. So I'm not going to live with you because I'm not sick ... I am going to see my friends. I am going to go out for lunch” (CG02). Linda had a frank conversation with her husband when she told him he needed to wear incontinence briefs, saying: “I just can't deal with this laundry load ... I just put my foot down on that one and said, ‘you know, like while you're on this medication, this is happening’” (CG04). At times, a frank conversation could involve the care partner advocating for the individual with PD. While her husband was staying in a nursing home, Diane “went to the woman in charge many times. I had many complaints ... they would wake them up in the morning to give them those pills and

they wouldn't stay long enough to see that he swallowed them ... I said, that has to be like first day in nurse training. You do not leave the room until you've seen that the person has swallowed the pills" (CG02). It was also important to have frank conversations with family members at times; Diane spoke with her daughters and grandchildren: "I had to say to them, your dad isn't the conversationalist anymore, but he wants to know what you're doing. So just come and keep talking and he'll respond as he can" (CG02). The care partners in our study generally regarded 'frank' conversations as the most difficult type of conversation they could have as part of the caregiving role. While challenging, these conversations held great potential for ensuring the needs of the care partners and individuals with PD were met.

'Emotional/relational conversations', characterized as being dialogical and non-action-oriented, were recalled by care partners in our study as involving feelings about the care partner/care recipient relationship and thoughts about parent/child relationships. Ben felt that "meaningful conversations may not happen much if you're not very emotional people" (CG05). Barb considered when she had had meaningful conversations and recalled discussions with her husband involving "things about our children ... how is this child going to deal with [your PD diagnosis] when she's so far away" (CG01). Barb also mentioned "how each of us are feeling in regard to our relationship with the Lord at the time" (CG01) as an emotional/relational conversation. These kinds of conversations involved each party sharing their thoughts and opinions, but there was not usually any kind of end goal of change or action. The desired outcome of emotional/relational conversations was to increase understanding between the two individuals. By enhancing understanding, emotional/relational conversations seemed to contribute to overall effective communication, potentially making other types of difficult conversations easier.

'Important conversations', dialogical action-oriented conversations, have both parties actively involved and working together to discuss an issue and decide on a solution. The care partners in our study emphasized the mutuality of important conversations; most often, these seemed to involve the care partner and individual with PD making decisions together. Barb's examples of important conversations she had with her husband included "things like having a will in place and planning for the future of the person that's left

behind” (CG01). Care partners also gave examples of talking about downsizing or determining the most effective treatment options together with the individual with PD. Dan saw great value in having important conversations with the individual with PD: “I find that the more you can converse, the more you can solve the problems together, the less headaches you have down the road” (CG07). Care partners did not enter important conversations with a set agenda in mind; instead, they worked through the conversations to arrive at decisions through a collaborative process, which made important conversations productive and far less daunting than frank conversations.

Emotional valence is a factor which influences the degree of challenge in any category of difficult conversation. Based on our understandings from speaking with participants, we consider emotional valence to be the degree of meaningfulness of a topic for either party involved – that is, the extent to which either party cares deeply about the topic or the potential outcome(s) of the conversation. Low emotional valence means that neither party has a strong vested interest in the outcome or topic of conversation and are unlikely to feel greatly upset as a result. High emotional valence means that the topic is of substantial significance to either or both parties and the conversation thus carries a weightiness. High emotional valence can be a barrier for care partners to initiate difficult conversations or it can make successfully carrying out difficult conversations more challenging. We understand that care partners and individuals with PD each experience their own mental and emotional challenges as they learn to navigate the disease together. Diane told us about her grief: “the depression that I had was more over the loss of my husband ... I missed that partner that I used to have. He wasn't the same person” (CG02). John also opened up about the emotional challenges of being a care partner to an individual with PD, saying “the illness itself, psychologically, it's something tough to deal with because there's no solution to it. It continues to advance” (CG06). These emotional impacts of care partnering impacted how care partners felt about entering difficult conversations related to PD. We have observed that regardless of where a conversation might fall on the scale from monologic to dialogic, or from non-action-oriented to action-oriented, emotional valence can determine how challenging it is for the initiating party to broach a difficult topic or for both parties to carry out a difficult discussion.

3.5.2 Difficult conversations may initially increase, then decline over time

There may be situations in which difficult conversations increase in frequency or level of difficulty as PD progresses, as well as cases where difficult conversations become fewer or easier to conduct over time. While a multitude of individual-level factors influence the frequency and intensity of difficult conversations, our discussions with care partners suggested that in the initial stages of PD progression, difficult conversations may become more frequent and/or more challenging, but in the later stages of the disease, difficult conversations can become fewer or more easily navigated. New challenges introduced by the disease in the early stages can precipitate an increased intensity of difficult conversations, but symptoms, experiences, or supports in the later stages of the disease can ease the challenge of difficult conversations.

In the early stages of PD, the many new symptoms which can arise may bring frustration and challenges for individuals with PD and care partners. These symptoms, or side effects from medications required for treating PD, may necessitate life changes that can be difficult to accept or adapt to. Because of this, PD may result in new difficult topics of conversation arising. Within our discussions with care partners, we learned that the progression and effects of PD, care of the individual with PD, the care partner's time and energy, and changes to the care partner's and individual with PD's shared social life are topics that may surface entirely or mostly due to PD. Barb gave an example of a difficult conversation she had to have with her husband directly because of PD: "trying to encourage him to eat and to drink. And so, he would 'I just don't want to. I don't feel like it.'" (CG01). Diane also had difficult care-related conversations with her husband because "He couldn't dress himself and he didn't want a [paid] caregiver coming in" (CG02). At the time of our discussion, Linda could see this stage on the horizon for her and her husband, so "one of the things lately it's been, 'Well, if you don't do this exercise ... I'm not going to be able to care for you because it's going to be too much physically'" (CG04). These discussion topics were directly a result of the symptoms of PD.

While PD may introduce new difficult topics, it can also add a layer of additional challenge to pre-existing difficult topics of conversation; difficult conversations on the

PD journey occur within an existing context of ordinary life challenges. Care partners told us about how PD, with its impacts on each individual, on the relationships between individuals, and on the occupations in which each is free to engage, added complexity to challenging conversation topics that could have existed regardless. John said, “there's always difficult topics between regular married couples whether it's physical exercise, sexual topics, those are sort of normal for any couple I think ... [Parkinson's] just accelerates or adds on to any previous [difficult conversations] we've already had as a couple” (CG06). Tracey also wanted to emphasize how difficult conversations that happened were not solely because of PD: “I would say even apart from having Parkinson's, right? As we age or as we change in our lives, we're constantly having to regroup” (CG03). Dan also reminded us that “it starts with the person's underlying health situation ... if you have ... any other underlying medical thing, the Parkinson's will add on to that. And then as the Parkinson's progresses, more things will be added on” (CG07). The existing context of everyday life challenges and pre-existing difficult topics of conversation impact how difficult conversations will occur; PD adds a layer of complexity that may influence ordinary difficult topics of conversation including lifestyle changes, intimate relations between the care partner and individual with PD, and finances.

Symptoms of PD and effects of medications can make even the act of engaging in a difficult conversation challenging. Care partners in our study talked about how symptoms and side effects seemed to hamper the individuals with PD's engagement in difficult conversations over time. In some cases, cognitive and physical effects made it challenging for individuals with PD to comprehend and formulate responses within conversations. Linda had heard that “with Parkinson's, they are taking it all in but it's slow to process, and pulling it out can be very difficult because it's the processing” (CG04). The lengthy processing time meant that Linda sometimes needed to make important decisions by herself, preventing important conversations from happening between her and her husband. Ben also noted that “if it's at a point where the meds are starting to influence their thinking a little bit or their thinking is sort of slowing down, it can make it a lot harder to try to discuss the more complex parts of things” (CG05). The symptom of quietness also caused difficulty for care partners and individuals with PD

and led to discussions between care partners and individuals with PD becoming more monological over time. This could be emotionally challenging, and some care partners felt isolated, particularly when topics of discussion would arise which impacted both the care partner and the individual with PD equally and dialogical conversations were warranted.

While the effects of PD seemed to increase the number of difficult conversations care partners needed to have and made some existing difficult topics more challenging to discuss, in some circumstances, it became easier for care partners to engage in difficult conversations over time. Diane told us her husband's "personality wasn't always [laid back], but when he got sick, he became very placid ... it would have been a nightmare if he argued with everything you wanted to do or say" (CG02). Because of her husband's increasingly placid personality over his PD progression, difficult conversations were unlikely to become major conflicts in the later stages of PD. For example, Diane had a frank conversation with her husband about having him move into a nursing home when his care needs were beyond what she could handle at home and she reported that "his only comment was, 'I don't want to go, but I know I have to.' ... and he never once complained" (CG2). Some care partners conceptualized the newfound openness to change as apathy, which was discussed as being a symptom of PD. It appeared that as the disease progressed, it was possible for the individual with PD to either accept the changes that needed to occur or become more open to the care partner's ideas and opinions.

As PD progresses into the middle and later stages, the care partner and individual with PD may discover supports and resources which meet both parties' needs and allow both to engage in meaningful occupations. Additional supports may explain why difficult conversations might decline in number or degree of challenge in the later stages of PD. We observed a difference in the recollection of difficult conversations by care partners in our study who had little support compared to those who had a strong support system consisting of friends, paid staff, or adult children who were eager to help. Barb had a great deal of support; she said, "I don't think I had to [have difficult conversations with my children about providing support] because my kids lovingly just offered 'what can we do?'" (CG01). Barb also recalled having few very difficult conversations with her

husband. On the other hand, care partners who had significant gaps between supports provided and help needed in the middle and later stages of the disease encountered more situations requiring difficult conversations. As PD progressed, it seemed to be the case that both parties became aware of their needs and limitations and obtained supports which resulted in a decline in difficult conversations.

It appears that as PD progresses and new limitations arise, there may be a need for more difficult conversations to occur, and these may be particularly challenging in the early to middle stages of the disease. With further progression, it is possible for shifts in attitude or personality or increased support to ease the challenge or decrease the frequency of difficult conversations. Based on our observations, it appears that the difficult conversations in which care partners must engage can become more frequent and perhaps more challenging as PD progresses but may decline again as care recipients accept changes as necessary and/or supports are implemented to enable participation in meaningful occupations.

3.5.3 Mediating factors impact how difficult conversations will go

A large and varied mix of mediating factors can impact how well difficult conversations will go. From our discussions with the care partners in our study, we noticed how a strong relationship between the care partner and individual with PD, individual skills or personality traits, the care partner's faith, and the care partner's efforts at planning and preparing could help difficult conversations to go well. When each of these factors was optimized, difficult conversations appeared to be relatively easy.

Strong relationships between the care partners in our study and the individuals with PD were apparent and seemed to help difficult conversations to happen smoothly. Care partners talked about how reassuring it was to feel comfortable with the individual with PD and know that no topic was off-limits. Tracey said, "If [you] have a good relationship, if you feel like someone's got your back, you can deal with a lot of things a lot easier" (CG03). Linda emphasized that "when you add in the spouse relationship, it's a different partnership ... it's based on a different type of love" (CG04) and so difficult conversations could be easier between two loving spouses who had a history of

prioritizing one another. John added that “marriage by definition is a partnership” (CG06), which seemed to make difficult conversations more collaborative than combative. The supportive, trusting relationship between spouses seemed to make it easier to have difficult conversations. Dan demonstrated this supportive relationship between he and his wife, saying that “no matter what happens, how each person goes into the beginning of the conversation, the outcome has to be a mutually agreed upon result. If there is no mutual understanding or same outlook as to what’s going to happen, then it’s going to continue and linger because it’s never going to get solved” (CG07). Ben also showed us how a close father/son relationship can provide a context for open communication, saying: “With him, he’s been there forever ... I’ve gone out of my way to never really keep anything from him” (CG05). The longstanding relationship in each of these cases seemed to have allowed care partners to feel comfortable with having difficult conversations with the individuals with PD.

Individual skills or personality traits (on the part of the care partner or the individual with PD) may act as mediating factors for successful difficult conversations. Barb’s husband was skilled in having difficult conversations of an emotional nature, perhaps from his experience in his career in faith-based ministries: “he was caring, visiting people who were ill or grieving, and he just learned so much of how to come alongside them and get them to talk about their feelings and hear their feelings ... and so I think for him, specifically, because of his background, he was more able to have those kind of touchy feely conversations” (CG01). Barb’s husband’s skill and experience seemed to make it easier for them to have difficult conversations as a couple throughout the PD journey. Diane showed us how experience in the workplace and personality could combine to make it easier to have difficult conversations. She told us, “I think I learned a lot of [how to have difficult conversations] through my [work] background (CG02)”, but she also added, “not every caregiver is an independent personality either. I am ... I think it’s part of your personality or it isn’t” (CG02). While success in difficult conversations may be related to inherent personality characteristics, practice can also help. Barb recalled that: “I probably changed over time. And my approach [to difficult conversations] probably changed over time ... I mean, we’re talking a lot of years, so I wasn’t nearly as good at it in the beginning as I was at the end” (CG02). Whether through life experiences of the

individual with PD or care partner or through inherent personality characteristics, individual-level factors have the power to make difficult conversations easier.

One important point that we noticed in the conduct of our study was that PD symptoms have the potential to negatively impact communication abilities regardless of how successful people had been with having difficult conversations prior to diagnosis. Linda had learned that “with Parkinson’s, they are taking it all in, but it’s slow to process, and pulling it out can be very difficult because it’s the processing ... two weeks later, suddenly he says something and it’s like, did it take that long to process?” (CG04). She told us: “every once in a while I do find, like I make a decision about something and then it’s like a week, two weeks later he’ll suddenly say, well you just decided that on your own ... like I just didn’t realize you could even be interested, you know, and it kind of brings me up short ... maybe another aspect to difficult conversations is ... remembering to include them in decision making processes” (CG04). Because of her husband’s slowness to process information, Linda recognized that she was more likely to make decisions by herself rather than discussing important decisions with her husband. This could sometimes result in difficult conversations after decisions had been made. Tracey also noticed that PD impaired her husband’s communication with her. She said: “[my husband] doesn’t pay attention too much to looking at me when he talks. So yes, then I have to be really conscious of, hey, if I need to hear from him or I need to converse with him, I better make sure that I follow him and sit close to him so I can hear what he’s saying” (CG03). Care partners had to consider the abilities of the individuals with PD when engaging in difficult conversations with them.

Another factor that seemed to increase care partners’ self-efficacy when it came to difficult conversations was faith. Linda had told us that “often people come into a journey like this, and they seek out a faith support because you need that to know that even when there’s not family around, there’s not friends around ... you don’t want to be alone. And if everything happens based on your own strength, well that can deplete” (CG04). Barb, Tracey, Linda, and Dan all mentioned how important their faiths were to them in approaching difficult conversations. Whether speaking about the church, their Christian religion, prayer, or a personal relationship between themselves and God, they talked

about how their faith made it easier for them to face the emotional challenges of care partnering to an individual with PD. It appeared that their faith gave them a source of peace, which offered them clear thinking and a positive mindset when approaching difficult conversations. When asked about her biggest piece of advice for successfully having difficult conversations, Barb said “Well, for myself and my husband, because we have this strong relationship with the Lord, our go-to situation or tips or tricks is prayer ... so many times a day I would just call out to the Lord or ‘please help me to know what to do or give me the right words to say’” (CG01). She found that when it came to difficult conversations, it was helpful to “just withdraw for a bit and think it through, pray it through and come back” (CG01). Linda also found her faith reassuring, “knowing that I’m not on my own, like I have a heavenly father that watches over me. And ... another part of my journey is probably going to be being on my own ... but I’m not alone because I don’t believe that I’m alone” (CG04). This knowledge helped her to face the most challenging aspects of the PD journey and to engage in those important yet difficult discussions with her husband or with others as needed. Tracey and Dan especially appreciated the shared nature of their faiths; each focused on the fact that they shared their faith with their spouse with PD, and this allowed them to join together with their spouses in looking to something greater than themselves when PD-related challenges made difficult conversations necessary. Tracey said: “I’m going to call it church, but, so, faith – everything that’s connected to that – is fantastic as well. And that’s something we can do together. We have a small Bible study group, I’ll call it a small group of about eight people that we get together. ... we see each other weekly and it’s, you know, different ages and we’re just connecting about all different things” (CG03). Dan felt that “if you have [a faith-based system] as an underlying part of your everyday life and then you develop your relationships all the way through that, ... I think that will make any of these difficult, meaningful, frank conversations easier, especially if the person that is your care partner or your caregiver has got a similar background” (CG07). Faith as a mediating factor seemed to help care partners feel more emotionally prepared to engage in difficult conversations as the need arose.

A mediating factor which care partners have a great deal of control over is their own efforts in planning and preparing for difficult conversations. The way care partners

prepared for difficult conversations seemed to impact how well these conversations were reported to have gone. As Tracey reminded us, “it’s not just about touching on difficult things, but how do you handle that difficult conversation” (CG03). Having difficult conversations as far in advance as possible, choosing a good time and place for the conversations, and considering the other party’s perspective were three strategies care partners used to prepare.

Having difficult conversations as early as possible was one way care partners talked about trying to ensure both they and the individuals with PD were prepared for challenges and in agreement. When speaking about the importance of having difficult conversations as far in advance as possible, Linda said, “I think a lot of it, it's having the discussion well ahead ... I know from listening to other care partners that they're afraid, and I would encourage them to do it well ahead” (CG04). Linda was extremely diligent in thinking ahead and planning for difficult conversations. One example she spoke about was the messiness of mealtimes with her husband. She told us: “That’s one of the things I’m pondering right now. How am I going to have that conversation? ... You know, who ever expects that at sixty-seven they’re going to wear a bib? Or do I wear one, too ... so it’s one that I’m having to come up with the ideal solution” (CG04). Metaphorically putting themselves in the other party’s shoes was an important way care partners prepared for difficult conversations. Linda tried to “think of it from his perspective too, like, ‘but I'm totally dependent on you’” (CG04). Having difficult conversations about potential issues long before they became serious problems requiring quick decisions or drastic changes seemed to make the discussions far easier for both parties.

Being sensitive to the other party’s needs was an important part of considering the timing of a difficult conversation. Dan felt that “the more you can converse, the more you can solve the problems together, the less headaches you have down the road ... It might not happen for two years, four years and might never happen. Who knows? But at least you've laid the groundwork and you've had some discussions” (CG07). Dan described how it could be beneficial to have “a lead up to [a difficult conversation], say maybe on a Monday ‘I’d like to talk to you on Wednesday night if you’re free about this, that or the other thing’, rather than saying you’re going to talk tonight on finances or we’re going to

talk tonight on doctor's appointments or we're going to talk on treatment or something. So give the person time to think about whatever it is you might be wanting to talk about rather than just jumping in and sort of catching somebody, either party unaware of what this major decision might be or whatever" (CG07). Tracey told us about the significance of being "sensitive ... and just being aware, you know, this is maybe not the time right now ... just to give each other a little space and say, hey, maybe this is not a good day" (CG03). Making the timing of a difficult conversation a mutual decision could allow both to be "in a proper frame of mind ... open to suggestions, you've had time to think about it. You've got your oxygen going and your brain cells going and everything" (CG07), as Dan said. Choosing a time when both parties felt ready was stressed as an important part in preparing for difficult conversations.

In addition to timing a difficult conversation well, choosing a good location helped to ensure conversations went smoothly. Dan suggested "I think one of the first tips is to find a quiet room, shut off the TV, shut off whatever. Find some place where you both feel comfortable and discuss it" (CG07). Together with careful selection of the timing of a difficult conversation, a carefully chosen location could help both parties to feel at ease when engaging in difficult conversations. The considerate planning of the care partners in our study seemed to ensure that topics were broached at a time and in a way that supported the dignity of the individuals with PD and cultivated a positive, supportive atmosphere for difficult conversations to take place.

3.6 Discussion

Difficult disclosures, frank conversations, emotional/relational conversations, and important conversations evolve over time in response to PD-related changes and as care partners intentionally or unintentionally draw on mediating factors to promote positive difficult conversations. Within difficult conversations, care partners in our study worked together with the individuals they cared for or others to enhance understanding and lead to positive outcomes. When considering care partners' engagement in difficult conversations as a necessary occupation within the care partnering role, we can see aspects of doing, being, becoming, and belonging – a concept developed by Wilcock (2006) and frequently used in occupational science.

Doing is active engagement in an occupation that is personally meaningful (Hitch, 2017; Hitch et al., 2014; Martin et al., 2020). Care partners in our study demonstrated the ‘doing’ aspect of occupational engagement in preparing for and carrying out difficult conversations, which could be personally meaningful when it allowed them to enhance communication with others and solve issues. Hitch, Pépin, and Stagnitti suggest that the “skills and abilities needed for doing accumulate across time” (2014, p. 241); we have seen this in the increased confidence some care partners seemed to have with engaging in difficult conversations in the later stages of their care partnering journeys. Hitch (2017) and Martin, Hocking, and Sandham (2020) point to how the ‘doing’ of occupations becomes adapted to the circumstances in which people find themselves. Care partners had longstanding relationships with the individuals with PD and many prior experiences with having difficult conversations; these prior skills and experiences were brought into the context of PD where care partners adapted their handling of difficult conversations to suit the circumstances.

Through engaging in the occupation of carrying out difficult conversations, care partners’ **being**, or sense of self, changed. Being is how we understand ourselves through our engagement in occupations. Hitch, Pépin, and Stagnitti say that being “encompasses the meanings [people] invest in life, and their unique physical, mental, and social capacities and abilities” (2014, p. 241). Care partners developed and demonstrated their sense of being through their engagement in difficult conversations; it appears that whether care partners felt confident and capable within difficult conversations or hesitant reflected and further developed their identities. A similar concept is used in the social sciences to explain how we understand who we are; Charles Horton Cooley’s idea of the looking glass self (1902) explains that we understand who we are through our interactions with others. Within occupational science, we might extend the concept of the looking glass self by considering how being is tied to occupation. Martin, Hocking, and Sandham (2020) also suggest that being is tied to spirituality. In listening to how care partners described the importance of their faith for successfully navigating difficult conversations, we observed how their sense of being as spiritual individuals was linked to their identities as care partners and to the occupation of carrying out difficult conversations.

Becoming refers to the continual development and change of the individual that influences occupational engagement. Hitch says, “The momentum for becoming is provided by goals and aspirations, which may arise from either choice or necessity, individually or collectively. Momentum for growth, development, and change is also sustained through the revisiting and revision of goals, and is stimulated by the opportunity to engage with new or novel situations and challenges” (2017). In our study, we saw how the new challenges of care partnering to an individual with PD influenced how care partners engaged in difficult conversations, which was a necessary occupation. In some cases, difficult conversations appeared to get easier over time, which may have been a result of individual growth in this area. As the seven individuals in our study grew into their roles as care partners and became familiar with their own needs and the needs of the individuals with PD, it appears that handling difficult conversations in an empathetic, tactful way may have become easier.

Belonging is the connection to others that provides the context within which occupations occur. Martin, Hocking, and Sandham note that “Belonging contributes to a person’s own identity within a group of other people. As relationships are formed, shared identity and sense of purpose can be developed, as individuals establish a sense of who they are through interactions with others” (2020, p. 2). We noticed how powerful the existing relationships were for care partners to feel confident entering into challenging discussions. Care partners also demonstrated great tenderness and care for the individuals with PD in their approaches to difficult conversations, showing a potential connection between supportive relationships and positive difficult conversations. When care partners discussed working together with the individuals with PD within important conversations to arrive at mutually beneficial solutions, they seemed to be building those relationships and their sense of belonging.

3.7 Conclusion

A care partner of an individual with PD has new challenges to face as the disease brings about symptoms that can make it more challenging to have difficult conversations and may necessitate addressing new difficult topics. With these new challenges may come new resources as the care partner continues to build on the relationship with the

individual with PD. We can see how doing, being, becoming, and belonging set the stage for successful difficult conversations in the context of PD and evolve over time as the care partner grows into his/her role. The difficult conversations a care partner has may be carried out in a monological or dialogical way and may be conducted with an end goal of change or simply to increase communication. The way both parties feel about the subject matter can have a significant impact on how challenging the difficult conversation is perceived to be. PD impacts each of these aspects of difficult conversations as its symptoms place demands on the care partner and individual with PD and changes both parties over time.

By understanding how care partners of individuals with PD navigate difficult conversations, we gain insight into the potential challenges produced by the disease that create ripple effects for others involved in the lives of individuals with PD. We can see the compassion, determination, and resilience of care partners in the ways they tenderly approach challenging conversations. This helps us to understand what this disease means for the loved ones of people with PD and what new changes and challenges each may face over time.

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Chapter 4

4 Discussion

Our study has opened a window into the lives of care partners of individuals with PD by exploring one specific challenging aspect of the care partnering experience – that is, engaging in difficult conversations. With our occupational lens (Yerxa et al., 1990), we have been able to view engaging in difficult conversations as an occupation that is important for the wellbeing of care partners and individuals with PD. We recognize that another valid perspective would be to view care partnering as an occupation and engaging in difficult conversations as one small task within that larger occupation. Highlighting engaging in difficult conversations itself as an occupation has helped us to recognize the significance of this task for care partners and others in their lives. Our lens has allowed us to observe how PD and occupation interact as care partners prepare for and engage in difficult conversations, demonstrate and develop their sense of self, grow as individuals, and operate within and further develop the meaningful relationships in their lives. We see relevance in connecting our findings to the occupational science concept of ‘doing, being, becoming, and belonging’ (Hitch, 2017; Hitch et al., 2014; Martin et al., 2020), so our findings will be further discussed in relation to these four aspects of occupation.

4.1 Doing

“Doing has been described as the way people engage in personally meaningful occupations” (Martin et al., 2020, p. 2). We see connections between what our discussions with care partners have allowed us to observe about the ‘doing’ of engaging in difficult conversations and what other researchers have found. Our participants talked about the importance of intentionality in preparing for difficult conversations and the significance of active listening; these same points have been promoted in research on successfully conducting difficult conversations. How difficult conversations operate has been researched within a variety of contexts, including in healthcare provider/patient relationships, employee/employee relationships, and employee/manager relationships.

While there are marked differences between these contexts and the context of the care partner/individual with PD relationship, there are also important similarities.

Across the literature, there is a great deal of emphasis on the importance of the initiator of a difficult conversation making preparations in advance. We view this as part of the occupation of engaging in difficult conversations. After summarizing and assessing established strategies for conducting difficult conversations, Polito (2013) provides six takeaways for managers to successfully conduct difficult conversations in the workplace; four of Polito's six takeaways describe ways a manager can prepare themselves for conversations in advance through self-reflection and role-play. The importance of the initiator of a difficult conversation engaging in personal preparation is corroborated elsewhere; the SPIKES protocol for delivering bad news, which was developed and written about by Baile, Buckman, Lenzi, Glober, Beale, and Kudelka (2000) for use in a healthcare context, begins with "Mental rehearsal [as] a useful way for preparing for stressful tasks" (p. 305). Mental rehearsal and advance preparation were evident in our discussions with care partners as they considered difficult topics they needed to discuss. Linda was struggling with the messiness of mealtimes as her husband's PD advanced and she told us: "That's one of the things I'm pondering right now. How am I going to have that conversation? ... You know, who ever expects that at sixty-seven they're going to wear a bib? Or do I wear one, too ... so it's one that I'm having to come up with the ideal solution" (CG04). Linda was deeply pondering ways she could support her husband's dignity at mealtimes in advance of initiating a conversation. Other care partners talked about challenges they foresaw as the disease progressed and how they were preparing in advance to initiate difficult conversations about these potential challenges.

We cannot know whether careful consideration in advance of a discussion by care partners would have changed the outcomes of their difficult conversations, but we suggest that it may lower the emotional valence of discussions. By taking time to carefully consider the important issues that must be discussed, care partners may find that they have time to reflect on and process any emotions which could negatively impact the difficult conversations. This time could offer care partners the opportunity to consider the individual with PD's perspective, allowing them to employ active listening strategies

such as paraphrasing, asking open questions, and reflecting feelings; these strategies signal emotional awareness and can enhance communication between two individuals (Bodie et al., 2015). This might then lead to conversations becoming more dialogical than monological, which could be particularly helpful given that care partners in our study almost universally agreed that ‘frank conversations’ (monological action-oriented discussions) were the most difficult type of conversation they could have within the caring role. If personal reflection, consideration of the other party’s perspective, and mental rehearsal could lead to conversations being more dialogical than monological, this could make it easier for care partners to help maintain the partnership aspect of the relationship. As Dan pointed out, “no matter what happens, how each person goes into the beginning of the conversation, the outcome has to be a mutually agreed upon result. If there is no mutual understanding or same outlook as to what’s going to happen, then it’s going to continue and linger because it’s never going to get solved” (CG07). Considering that this mutually beneficial result was a goal of care partners in our study, we suggest that, in agreement with prior research, it can help for care partners to prepare themselves emotionally and mentally for difficult conversations by first engaging in mental rehearsal.

Another way care partners prepared for difficult conversations in advance was by mentioning the need to discuss a topic in advance of actually initiating a conversation so that both parties could mentally prepare for the discussion. Girgis and Sanson-Fisher (1998) talk about how helpful it can be to touch on the possibility of a difficult conversation well in advance so the receiving party is not taken off guard when the time arises for the discussion to be had. This was supported by our findings. Dan suggested that it could be helpful to have “a lead up to [a difficult conversation], say maybe on a Monday ‘I’d like to talk to you on Wednesday night if you’re free about this, that or the other thing’, rather than saying you’re going to talk tonight on finances or we’re going to talk tonight on doctor’s appointments or we’re going to talk on treatment or something. So give the person time to think about whatever it is you might be wanting to talk about rather than just jumping in and sort of catching somebody, either party unaware of what this major decision might be or whatever” (CG07). Tracey, Linda, and Dan each talked about how important they felt it was to bring up difficult topics in advance to prepare the other person (in most cases, the individual with PD) for a difficult conversation. This

appears to be promoted as a useful approach to difficult conversations more broadly, as evidenced by the supporting academic literature, and it may be especially important within the context of PD. Linda spoke about how PD seemed to make it harder for her husband to process information: “every once in a while I do find, like I make a decision about something and then it’s like a week, two weeks later he’ll suddenly say, well you just decided that on your own ... like I just didn’t realize you could even be interested, you know, and it kind of brings me up short ... maybe another aspect to difficult conversations is ... remembering to include them in decision making processes” (CG04). While remembering to include the individual with PD in important decisions could be beneficial, it could also be challenging to put into practice. Linda had learned at a Parkinson’s conference that “with Parkinson’s, they are taking it all in, but it’s slow to process, and pulling it out can be very difficult because it’s the processing ... two weeks later, suddenly he says something and it’s like, did it take that long to process?” (CG04). One of the non-motor symptoms of PD is dementia, which may impact up to 75% of those who live with PD longer than 10 years, impairing both concept formation and phonetic fluency over time (Meireles & Massano, 2012). Given that PD may cause symptoms that result in delays in information processing, it may be especially helpful for care partners of individuals with PD to mention the possibility of a difficult conversation well in advance to allow the individual with PD time to consider the matter so they can have maximum input in the conversation.

Once a difficult conversation has begun, it needs to be conducted with empathy and tenderness. Active listening is an important way that the initiator of a difficult conversation can demonstrate this empathy and tender caring. Tracey reminded us, “it’s not just about touching on difficult things, but how do you handle that difficult conversation” (CG03). In their protocol for physicians delivering bad news, Baile, Buckman, Lenzi, Gloger, Beale, and Kudelka (2000) promote intentional use of empathetic statements, exploratory questions, and validating responses within difficult conversations. Active listening and empathy by participants in our study were evident, especially in their conversations with the individuals with PD. Tracey said: “[my husband] doesn’t pay attention too much to looking at me when he talks. So yes, then I have to be really conscious of, hey, if I need to hear from him or I need to converse with

him, I better make sure that I follow him and sit close to him so I can hear what he's saying" (CG03). Making a conscious effort to listen as closely as possible to her husband with PD within difficult conversations demonstrated how much she valued his ideas and input and helped her to promote a safe and positive atmosphere for their discussions to take place. Dan also emphasized the importance of being fully and actively involved in the conversation, saying: "you should both be in a proper frame of mind ... open to suggestions, you've had time to think about it. You've got your oxygen going and your brain cells going and everything" (CG07). Being fully engaged was considered to be essential for successfully conducting difficult conversations. Truly listening, processing, and responding to the other party's thoughts and feelings "reduces the [other party's] isolation, expresses solidarity, and validates the [other party's] feelings or thoughts as normal and to be expected" (Baile et al., 2000, p. 307). Perhaps in part due to the strong relationships that existed between care partners in our study and the people they interacted with as part of their caregiving roles, empathy in difficult conversations seemed to come relatively easily. Many of the difficult conversations that needed to occur were between the care partner and individual with PD. Linda explained that "it's different as well I think between having a conversation with a care partner who is your spouse as opposed to being a care partner for someone else, like a mom or a dad or an aunt or an uncle, like there's different types of care partners. So when you add in the spouse relationship and that, it's a different partnership, and it's based on a different type of love than the love you have for a parent, right?" (CG04). The partnership aspect of the relationship was also discussed by other care spousal care partners as a factor that seemed to make it easier to hear, understand, and tenderly care for the other person's needs and points of view. This facilitated successful 'doing' of this occupation.

4.2 Being

Being "encompasses the meanings [people] invest in life, and their unique physical, mental, and social capacities and abilities" (Hitch et al., 2014, p. 241). The concept of being relates to engagement in difficult conversations within the care partnering role because each individual's pre-existing sense of self influences how they interact within difficult conversations. Throughout the care partnering experience, a care partner's sense

of being may also grow and develop as new situations are encountered. Being has been described as a “psychological/philosophical/spiritual dimension” (Hitch et al., 2014, p. 236); a space for contemplation about who an individual is and how they wish to express themselves occupationally. Being includes the abilities that are innate or developed over time and unique to each individual (Hitch, 2017; Hitch et al., 2014). Within the literature on difficult conversations, gender is discussed as an innate characteristic that impacts how individuals engage in difficult conversations. We have also seen innate personality characteristics presented as an explanatory variable for the success of difficult conversations with a presentation of caregiver ‘types’, which may relate to how care partners of individuals with PD approach this occupation.

Emotional intelligence has been presented in the literature as one specific individual-level factor that impacts how couples experience conflict resolution. Zeidner and Kloda (2013) found that when individuals had high emotional intelligence, they were successful with conflict resolution because they were able to empathize with their partners and understand where they were coming from. Care partners in our study demonstrated emotional intelligence by recognizing when to initiate or avoid a difficult conversation. Diane talked about times when she felt highly emotional about a care partnering task and how helpful it was for her to “just withdraw for a bit and think it through, pray it through and come back” (CG01); temporarily backing away from a difficult situation when she was feeling very emotional helped her to bring her best, calm self to a difficult conversation. For the care partners in our study, having the intrapersonal emotional intelligence to know what they needed for entering difficult conversations with a peaceful attitude seemed to be just as important as understanding the feelings of others. Tracey spoke about the importance of using her interpersonal emotional intelligence in difficult conversations with her husband: “I think just being sensitive again and just being aware, you know, this is maybe not the time right now ... just to give each other a little space and say, hey, maybe this is not a good day” (CG03). Recognizing when someone else was not ready to engage in a difficult conversation helped to ensure topics were broached at an appropriate time.

Gender may play a role in individuals' comfort with engaging in difficult conversations and may impact the types of difficult conversations that are initiated. In multiple studies, wives have been found to be more likely than husbands to directly engage in conflict-driven conversations, such as requesting changes in the other spouse (Heavey et al., 1993; Mackey & O'Brien, 1999). Reasons for this have been suggested in other research, including that "women might be expected and/or want to invest more in their relationships than men because they have been socialized to do so through prescribed gender roles" (Afifi et al., 2016, p. 668). Although there were too few participants in our study to make conclusive connections between gender and willingness to engage in difficult conversations, we observed that the males we spoke with tended to voice their hesitancy to engage in difficult conversations while our female participants tended to make it clear they were willing to initiate difficult conversations. Our first four interviews were with women who were caring for or had cared for their husbands with PD. Diane, Barb, Tracey, and Linda spoke about how comfortable they were with initiating difficult conversations. This contrasted with our final three interviews with male care partners. The two male spousal care partners, John and Dan, told us their wives were more likely to be the ones to bring up difficult topics, which eased their burden when it came to difficult conversations. Interestingly, in the example in which both the care partner and individual with PD were male, the participant (Ben) talked about how both he and his father were somewhat reluctant to enter into emotional or difficult conversations. Personal reasons were provided for this, but it may be that gender plays a role in the willingness of males and females to engage in difficult conversations.

Not only did we observe a difference in the willingness of male and female participants to engage in difficult conversations, but we also noticed a difference in the types of difficult conversations that were discussed by male and female participants. We were careful in our interviews to avoid, to the best of our abilities, offering leading examples of types of difficult conversations so participants would share whatever came to mind when they thought about difficult conversations. Without our prompting, the women in our study talked a great deal about emotional-relational discussions, while our male participants more often mentioned conversations focused on disease progression or care and treatment-related decisions. Based on our observations within our limited sample of 7

care partners, there appeared to be a greater focus by women on emotional aspects of living and progressing with PD while men seemed to focus more on direct symptoms of PD. As Zarit, Todd, and Zarit (1986) found in their longitudinal study of husbands and wives as care partners to spouses with dementia, “husbands were often observed to adopt an instrumental approach to daily problems, while wives had difficulty maintaining the emotional distance necessary to consider alternative strategies for managing problems” (p. 265). Our experience in talking with our limited sample seems to concur with this finding.

As we explore associations between gender and willingness to engage in difficult conversations and types of difficult conversations that are initiated, we notice a potential connection to research on personality traits. Expressive and instrumental personality traits (Spence & Helmreich, 1980), developed from Bem’s ‘sex-role inventory’ (1974) offer a way to consider the impact of gender in a multidimensional way. Individuals can rank high or low for expressive (or feminine) traits and also rank high or low for instrumental (or masculine) traits, regardless of sex or gender. Seeing gender as a complex rather than dichotomous factor in care partners’ sense of being may help us to understand why some dive into difficult conversations while others avoid them, and why some seem to gravitate towards emotional conversations while others stick to discussions about PD treatments. One notable exception to the hesitancy of males to engage in difficult conversations of an emotional nature was Diane’s husband. Diane shared with us that through her husband’s training for his career in faith-based ministries and his experience with supporting people through life’s challenges, he became very skilled at having difficult emotional conversations. She told us that he easily brought up emotionally difficult topics and that it was easy for her to have emotional conversations with her husband as a result of his strength in this area. Although it appeared that women were often more likely to feel comfortable with initiating difficult conversations that might venture into emotional territory, Diane’s husband is an example of how instrumentality and expressiveness may exist in any individual regardless of sex or gender and can be fostered through training and experience. We understand gender as a component of ‘being’ that is a combination of inherent characteristics of individuals as well as characteristics that are developed over time, guided by social norms and interactions with others.

We cannot conclude based on our discussions with seven care partners that male-identifying individuals are less likely to initiate emotionally difficult conversations or that female-identifying individuals are more likely to do so. Our small sample size is our first reason for hesitating to draw such conclusions. We are also disinclined to make such a statement because we understand gender to be a fluid concept. Scholars in the field of occupational science have presented the idea that “gender is socially constructed and depends on people’s occupational performance” (Schneider et al., 2019, p.220). The fluidity of Bem’s (1974) expressive (feminine) characteristics and instrumental (masculine) characteristics seems to agree. The occupational possibilities afforded to an individual, those occupations which are voluntarily chosen, and how the individual expresses themselves in their performance of occupations all play a role in producing gender. Therefore, we must take this into consideration when exploring gender differences in engagement in difficult conversations.

Another aspect of being that has been studied in relation to difficult conversations within the care partnering experience is the four caregiver ‘types’ written about by Goldsmith, Wittenberg, Platt, Iannarino, and Reno (2016). Their work with patients and care partners in an oncology clinic found that “Manager caregivers lead patients by utilizing extensive medical knowledge, whereas Carrier caregivers were led by patients and described tireless acts to maintain the family and avoid difficult conversations. Partner caregivers facilitated family involvement and open communication on a variety of topics, while Lone caregivers focused solely on biomedical matters and a hope for cure” (p. 463). The ‘caregiver types’ seem to depend on personality and comfort level of the care partners, which then translates into the types of difficult conversations they might choose to engage in. Although this was not an aspect we specifically looked for our in care partners, and thus not something we specifically probed for within our interviews, we can draw connections between some of the descriptions care partners shared about their experiences with difficult conversations and what has been found about manager, carrier, partner, and lone caregivers. Diane and Ben seemed to have ‘manager caregiver’ characteristics because of how they used medical knowledge in difficult conversations. Barb, Tracey, Linda, and Dan seemed to be ‘partner caregivers’ because of their comfort with engaging in difficult conversations on a wide range of subjects. John appeared to

have ‘lone caregiver’ tendencies because of his focus on treatments in difficult conversations. Exploring a connection between ‘being’ as seen through care partner ‘types’ could be a fruitful area for future research on the experience of care partners of individuals with PD.

4.3 Becoming

“The momentum for becoming is provided by goals and aspirations, which may arise from either choice or necessity, individually or collectively” (Hitch, 2017, p. 497). Care partners of individuals with PD grow through their experiences in the caring role, which contributes to their success in difficult conversations. Personal growth is one of a handful of potential positive aspects that can be a common part of the caregiving experience (Maltby et al., 2020). Many of the difficult conversations care partners in our study talked about were ones between themselves and the individuals with PD; among our participants, this was usually a spousal relationship, which reflects broader patterns of relationships for individuals with PD (Wong et al., 2014). There are many factors that can contribute to growth in intimate relationships, including length of time together as a couple and life stage (Mackey & O’Brien, 1999). The growth that occurs in the context of PD is unique because of disease progression. As a result of changes that occur over time, there can be shifts in the power balance between the care partner and individual with PD, and the care partner may experience an increasing feeling of isolation (Hounsgaard et al., 2011). This context is important for understanding how care partners experience becoming over the course of disease progression, which sets the stage for difficult conversations.

Change that occurs in the care partner/individual with PD relationship as both learn to navigate the challenges of the disease plays a role in their successful communication. Hounsgaard, Pedersen, and Wagner (2011) spoke with female care partners of spouses with PD and found that they had to learn new ways of living together as a couple as the disease progressed and impacted more areas of their lives. In their qualitative study, Roger and Medved (2010) found that “it is critical to understand the extent to which the [Parkinson’s] disease experience became a ‘partner’ in [a couple’s] ongoing daily communications in a way it had not been previously. The disease became part of their

identity as a couple” (p. 5). Parkinson’s disease becomes a factor in how individuals with PD and care partners relate and communicate with one another. Roger and Medved go on to say that “communication between patient and caregiver also becomes like a finely tuned machine that outsiders cannot always understand or have access to” (p. 6). Shared understandings arise as couples with PD share new experiences and as they learn to become a supportive and cooperative unit within their daily interactions and difficult conversations. In our study, Barb reflected back on her experiences with having successful difficult conversations and concluded that “I probably changed over time. And my approach [to difficult conversations] probably changed over time” (CG02). She felt that she had become more skilled at having difficult conversations over the course of her care partnering journey because “we’re talking a lot of years, so I wasn’t nearly as good at it in the beginning as I was at the end” (CG02). As care partners in our study learned what the individuals with PD needed and what they themselves needed as care partners, their communication seemed to get easier. PD changes and progresses over time, which leads to personal growth and change for care partners. The way that difficult conversations occur along the care partnering journey reflect the growth and change of care partners.

4.4 Belonging

“Belonging contributes to a person’s own identity within a group of other people. As relationships are formed, shared identity and sense of purpose can be developed, as individuals establish a sense of who they are through interactions with others” (Martin et al., 2020, p. 2). Belonging is an important component of spirituality. In occupational science literature, spirituality seems to have been more often presented as related to the ‘being’ aspect of occupations (Hitch et al., 2014), yet we find descriptions within other disciplines that emphasize the belonging aspect. Saroglou (2011) identifies belonging as one of the four major dimensions of religions cross-culturally. Malone and Dadswell describe how older adults experience belonging as an important aspect of religion, spirituality and/or belief that supports positive aging. In their qualitative study, they found that “[the sense of community and belonging associated with religion, spirituality and/or belief] was discussed in terms of being part of a religious community and

participating together in religious practices and traditions, such as going to church and praying together” (2018, p. 9). In our study, we were able to see how the belonging aspect of care partners’ faiths relates to the occupation of having difficult conversations. Belonging manifested as care partners feeling a connection to God as well as feeling a sense of connection to other people through religious activities.

Each of the care partners in our study who mentioned their faith as an important factor in how they approached difficult conversations talked about how their faith connected them to something larger than themselves. According to Saroglou, faith, religion, or spirituality “includes self-transcendent experiences that bond the individual with what it perceives to be the transcendent ‘reality’” (2011, p. 1326). For Diane, prayer was what made her feel connected to God. She referenced her “strong relationship with the Lord” (CG01) multiple times and how she would often “call out to the Lord or ‘please help me to know what to do or give me the right words to say’” (CG01). Diane’s feeling of connection to God seemed to be the foremost thing that helped her to have difficult conversations along her care partnering journey. Linda also shared with us about her sense of connection to God: “I have a heavenly father that watches over me. And ... another part of my journey is probably going to be being on my own ... but I’m not alone because I don’t believe that I’m alone” (CG04). For Linda, this belief that she was not alone enabled her to face the challenging aspects of the care partnering experience, including difficult conversations, with peace and confidence. Linda had spoken with other care partners and found that, “often people come into a journey like this, and they seek out a faith support because you need that to know that even when there’s not family around, there’s not friends around ... you don’t want to be alone. And if everything happens based on your own strength, well that can deplete” (CG04). Feeling connected to something larger seemed to give a sense of assurance and renewed strength. Feeling a sense of belonging to God helped to offer some of our participants a sense of peace as they faced challenges that required difficult conversations.

The interpersonal aspect of care partners’ faith was also important for providing a sense of belonging. Malone and Dadswell noted that “religion, spirituality and/or belief also served as a canvas for social activity which can lead to companionship, for example

sharing a meal together” (2018, p. 9). Connection and companionship with other people have powerful positive effects. Tracey talked about how much she appreciated the relational aspect of her faith: “I’m going to call it church, but, so, faith – everything that’s connected to that – is fantastic as well. And that’s something we can do together. We have a small Bible study group, I’ll call it a small group of about eight people that we get together. . . . we see each other weekly and it’s, you know, different ages and we’re just connecting about all different things” (CG03). The support and connection Tracy got from her Bible study group helped her to maintain a positive outlook and approach her difficult conversations with optimism. Dan appreciated that his faith was something he shared with his wife: “if you have [a faith-based system] as an underlying part of your everyday life and then you develop your relationships all the way through that, . . . I think that will make any of these difficult, meaningful, frank conversations easier, especially if the person that is your care partner or your caregiver has got a similar background” (CG07). The shared nature of Dan’s faith gave he and his wife common ground for relating to one another well in difficult conversations. This connection that these two care partners felt to other people, whether to the individuals with PD or to members of a church community, seemed to help them to feel safe, supported, and more able to have difficult conversations.

The belonging that care partners in our study felt in their relationships with the individuals with PD, aside from faith, also seemed to have a positive impact on their ability to have successful difficult conversations. Each of the care partners spoke about how close their relationships with the individuals with PD were; in fact, one had known the individual with PD for 50 years. The longstanding relationships that existed between the care partners and individuals with PD appeared to play a role in the cooperative mindset care partners had as they approached difficult conversations. Reports of mutual decision-making have been found to increase over time in people’s marriages (Mackey & O’Brien, 1999). We saw evidence of mutual decision-making in our discussions with care partners, which seemed to help in making difficult conversations successful. John reminded us that “marriage by definition is a partnership” (CG06), and we noticed many examples of how a partnership attitude helped in difficult conversations. Dan reported that there were few conversations he would classify as difficult because of the

cooperative approach he and his wife took to difficult conversations. He said: “but as to difficult conversations with, say, your spouse or your partner, I don’t think we had difficult conversations, we’ve had conversations, which is to decide what we’re going to do. I wouldn’t say they’re difficult as of yet” (CG07). Whether it was a spousal relationship or parent-child relationship, mutual decision-making was important. Ben said, “we got to be able to count on each other or this doesn’t work. You know, the only way we manage to be self-sufficient is if we work together” (CG05). Ben had an attitude of cooperation in difficult conversations with his father, which seemed to help make them easier. Based on our study findings, it appears that a cooperative mindset can move a difficult conversation from being monological to being dialogical. Monological difficult conversations seem to be more challenging or unpleasant than dialogical ones – particularly when those conversations are action-oriented. A sense of belonging within the relationship between care partners and individuals with PD seems to benefit both when it comes to mutual decision-making in difficult conversations.

The “shared identity and sense of purpose” (Martin et al., 2020, p. 2) aspect of belonging can be appreciated by considering difficult conversations as co-occupations. Whether monological or dialogical, difficult conversations can be seen as co-occupations when they involve at least two people “in a mutually responsive, interconnected manner that requires aspects of shared physicality, shared emotionality, and shared intentionality” (Pickens & Pizur-Barnekow, 2009, p. 151). Importantly, difficult conversations “produce and are embedded in shared meaning” (Pickens & Pizur-Barnekow, 2009, p. 155). Shared meaning provides the context for, and emerges through, difficult conversations between care partners and the people they interact with along the care partnering journey. Dan told us: “I think how the people interact, how they connect is very [important] and as you say, the values and the existing relationship dynamics are very, very important to have the discussions and ... find a middle ground ... Discussions you have have to be beneficial for both parties” (CG07). When dialogue occurs or information is delivered, shared understandings develop as both parties work towards a common understanding. Shared understandings that emerge through difficult conversations may contribute to the sense of belonging care partners and individuals with PD feel. Roger and Medved (2010) explore how couples manage identity together in the context of PD and discuss how one couple

“had developed such a personalized way of communicating, that when one nurse turned to [the partner with PD] and demanded he say thank you to his wife, they told the nurse that they said thank-you once a day, something she was not aware of. In this way, communication between patient and caregiver also becomes like a finely tuned machine that outsiders cannot always understand or have access to. Autonomy had disappeared and instead, the relationship had become one intertwining identity” (p. 6). Because of the close relationships that often exist between individuals with PD and care partners, communication can become a co-occupation that involves both parties employing shared emotionality and shared intentionality as they draw on shared, personalized meaning to communicate with one another in a way no one else can. The co-occupation of difficult conversations can occur in a healthy way because of the sense of belonging that exists in the relationship between care partners and individuals with PD.

4.5 Limitations

There are several limitations associated with the studies for this thesis. The guiding discipline for a thesis, which in this case was occupational science, creates boundaries for what may be observed. Additionally, the expectations of the author and co-authors play a role in how research is conducted and how findings are interpreted. Finally, when two studies are conducted concurrently – as the first and second studies in this thesis were – insights from one may not be available in time to benefit the other.

As presented in the second chapter for this thesis, an occupational science lens allows for certain aspects of people’s meaningful activities to be highlighted; at the same time, an occupational science perspective cannot capture everything. Due to the focus of my degree, I chose to focus on the utility of an occupational science lens for studying care partnering and this was the approach I took to the qualitative study within this thesis. I recognize that many other disciplines would provide useful contributions to the study of care partnering and could offer insights not captured by the lens I chose.

Constructivists do not deny the impact of a researcher on her findings. While efforts are made to focus on the experiences of participants, it is acknowledged that the researcher’s prior experience will play a role in how findings are interpreted and presented. I do not

see this as a limitation that can be removed through more rigorous research methods. I understand that every part of this study bears the influence of the author and co-authors, from the decision to focus on care partners of individuals with PD to the development of research questions and the choice of methodology to the identification of themes and the writeup. Any other researcher leading the studies for this thesis would have brought a different perspective. I acknowledge that the outcomes of these studies are influenced by my own unique perspective and the perspectives of those I collaborated with.

It is wise to use knowledge gained from prior studies to inform the design of future ones, yet when two studies are conducted concurrently, it is not always possible to apply findings from one to the other. Within the first study presented in this thesis, I discovered a need for occupational science studies to be explicit in discussing the distinct impacts of sex and gender on research findings. The two studies composing the body of this thesis were conducted concurrently, which meant that interviews for the first study were already underway when the importance of discussing both sex and gender were fully recognized. After identifying this gap in the occupation-focused literature, I considered asking participants about their sex and gender. Having carefully considered the potential benefits and disadvantages of this, I determined that since I had already conducted an initial round of interviews, questioning participants about their sexual and gender identity could risk harming the rapport we had already begun to build. As a result, the findings in the second study discussed in chapter 3 and in this discussion chapter report the assumed gender of participants. Had I completed the critical interpretive synthesis prior to conducting interviews, I would have used a short survey asking about the sex and gender with participants prior to the initial round of interviews.

4.6 Implications for Future Research, Practice, and Policy

The findings from the studies in this thesis bear implications that may point out helpful directions for future research in this field. The results of the first study suggest that it may be helpful to conduct research on informal caregiving from a critical perspective and to include male caregivers, gender nonconforming caregivers, and care partners or care recipients who identify as LGBTQ2S+ in future studies. Future studies could be

intentional in gathering this information about caregivers prior to conducting interviews or gathering information. The qualitative study within this thesis has made a potential connection between the experiences care partners of individuals with PD have had with difficult conversations and caregiver ‘types’ that have been discussed in other research. Future research could explore this possible connection in a more intentional way. Additionally, the three dimensions of difficult conversations presented in the results of this second study could be studied further and expanded upon since this is a novel way of studying difficult conversations.

By exploring the topic of difficult conversations in this thesis, we were able to demonstrate the kinds of challenges care partners face and how they navigate those challenges together with the individuals with PD, with friends and family, and with the healthcare system. The most significant takeaway from this research that may benefit clinical practice is the understanding that care partners’ lives are deeply impacted by the effects of PD. In clinical settings, understanding how difficult conversations operate within the lives of care partners of individuals with PD could lead to offers of connection to programs and resources for the care partners upon diagnosis of the individual with PD and an openness to discussing the wellbeing of care partners for their own sake.

In the realm of policy, this research can add to previous work that has been done showing the burden care partners experience and the need for practical supports for care partners. The nature of the qualitative study that is part of this thesis may help policymakers to feel a connection to care partners of individuals with PD and better understand their needs for support. Among our participants, we observed a marked difference between the difficult conversation experiences of those care partners who had the means to access supports such as in-home care and those who were providing care in the middle to later stages of PD with little or no support. Better access to paid in-home supports would appear to improve the lives of care partners of individuals with PD.

4.7 Conclusion

The occupational science perspective we have brought into this study on the experiences care partners of individuals with PD have had with engaging in difficult conversations

has allowed us to look at difficult conversations as an important part of the care partnering experience. We have been able to explore techniques care partners may use that have been supported by other research on difficult conversations while situating the ‘doing’ of this occupation within the following contexts: care partners’ unique personalities, the changes that occur due to the progression of PD, and the relationships between care partners and the people they have difficult conversations with. Presenting our findings in relation to ‘doing, being, becoming, and belonging’ has aligned with our goal of illuminating the diverse experiences of the seven care partners in our study, which is in accordance with our lenses of constructivism and American phenomenology.

While our study has made a useful step towards understanding the unique challenges and experiences of care partners of individuals with PD with having difficult conversations, additional research could expand on these findings in useful ways. Future studies could further explore a potential connection that may exist between caregiver ‘type’ and likelihood of initiating difficult conversations or comfort level with various difficult topics. More explicit attention to the distinction between sex and gender and exploration of the roles of each could benefit future studies. It may be useful to include larger sample sizes in future studies and incorporate quantitative elements because this could potentially make findings applicable to a wider range of care partners. Involving a greater number of participants in future studies might also allow for a deeper exploration of the role of gender differences in how difficult conversations are carried out by care partners of individuals with PD. We hope that the lived experiences we were able to highlight in this thesis can inform future studies by adding to the foundation of knowledge about this population and their experiences with having difficult conversations.

Our qualitative study has opened a window into the lives of care partners of individuals with PD by seeking to understand how care partners navigate difficult conversations. We have observed thoughtfulness and tender caring in how care partners approach difficult conversations with the individuals with PD. We have noticed how care partners use difficult conversations to advocate for their own needs and the needs of the individuals with PD. This occurs within an existing context that consists of personality and relationship dynamics which evolve over time as care partners and individuals with PD

experience changes and learn to navigate challenges together. We see engaging in difficult conversations as a dynamic co-occupation that helps to promote wellness for care partners and individuals with PD.

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Appendices

Included as appendices are the letters of ethics approval, recruitment, and information/consent as well as the guiding questions used to guide the first round of interviews and the individualized PowerPoint slides that were created for each of the seven care partners to guide our member checking in the second round of interviews.

Appendix 1: Ethics Approval Document 1



Date: 19 March 2019

To: Dr. Jeffrey Holmes

Project ID: 112490

Study Title: Psychosocial Support Needs Experienced by Caregivers of Individuals with Parkinson's Disease

Application Type: HSREB Initial Application

Review Type: Delegate

Full Board Reporting Date: 9April2019

Date Approval Issued: 19/Mar/2019 13:19

REB Approval Expiry Date: 19/Mar/2020

Dear Dr. Jeffrey Holmes

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:

Document Name	Document Type	Document Date	Document Version
02.19.2019.V1_Caregiver Ethics Protocol Research Plan	Protocol	19/Feb/2019	1
Caregiver Focus Group LOI & Consent March 18 2019 V3	Written Consent/Assent	18/Mar/2019	3
Caregiver Individual Interview LOI & Consent March 15 2019 V1	Written Consent/Assent	15/Mar/2019	1
Caregiver Online Survey LOI & Consent March 15 2019 V2	Written Consent/Assent	15/Mar/2019	2
Caregiver Stakeholder LOI & Consent March 18 2019 V3	Written Consent/Assent	18/Mar/2019	3
Caregiver Survey Part 1 of 5 LOI Eligibility & Draw:Future Research	Online Survey	15/Mar/2019	2
Caregiver Survey Part 2 of 5 Demographic & Burden Surveys	Online Survey	15/Mar/2019	2
Caregiver Survey Part 3 of 5 End of Survey Message	Online Survey	15/Mar/2019	2
Caregiver Survey Part 4 of 5 Failure to Provide Consent End of Survey Message	Online Survey	15/Mar/2019	2
Caregiver Survey Part 5 of 5 Failure to Meet All Eligibility Criteria End of Survey Message	Online Survey	15/Mar/2019	2
Recruitment Advertisement Caregiver Focus Group February 19 2019 V1	Recruitment Materials	19/Feb/2019	1
Recruitment Advertisement Caregiver Online Survey February 19 2019 V1	Recruitment Materials	19/Feb/2019	1
Recruitment Advertisement Stakeholder March 18 2019 V1	Recruitment Materials	18/Mar/2019	1
Recruitment Email Caregiver Focus Group February 19, 2019 V1	Email Script	19/Feb/2019	1
Recruitment Email Caregiver Online Survey February 19 2019 V1	Email Script	19/Feb/2019	1
Recruitment Stakeholder Telephone Script March 18 2019 V3	Telephone Script	18/Mar/2019	3
Semi-Structured Interview Guide Caregiver Focus Group March 15 2019 V2	Focus Group(s) Guide	15/Mar/2019	2

Semi-Structured Interview Guide Caregiver Individual Interview March 15 2019 V1	Interview Guide	15/Mar/2019	1
Semi-Structured Interview Guide Stakeholder Environmental Scan March 15 2019 V2	Interview Guide	15/Mar/2019	2

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

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

The Western University HSREB operates in compliance with, and is constituted in accordance with, the requirements of the TriCouncil Policy Statement: Ethical Conduct for Research Involving Humans (TCPS 2); the International Conference on Harmonisation Good Clinical Practice Consolidated Guideline (ICH GCP); Part C, Division 5 of the Food and Drug Regulations; Part 4 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,

Nicola Geoghegan-Morphet, Ethics Officer on behalf of Dr. Joseph Gilbert, HSREB Chair

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

Appendix 2: Ethics Approval Document 2



Date: 19 November 2020

To: Dr. Jeffrey Holmes

Project ID: 112490

Study Title: Psychosocial Support Needs Experienced by Caregivers of Individuals with Parkinson's Disease

Application Type: HSREB Amendment Form

Review Type: Delegated

Full Board Reporting Date: 01/Dec/2020

Date Approval Issued: 19/Nov/2020 18:20

REB Approval Expiry Date: 19/Mar/2021

Dear Dr. Jeffrey Holmes ,

The Western University Health Sciences Research Ethics Board (HSREB) has reviewed and approved the WREM application form for the amendment, as of the date noted above.

Documents Approved:

Document Name	Document Type	Document Date	Document Version
19.11.2020.V3 Amended Caregiver Ethics Protocol Research Plan	Protocol	19/Nov/2020	3
19.11.2020.V3 Caregiver Individual Interview LOI & Consent	Consent Form	19/Nov/2020	3

Documents Acknowledged:

Document Name	Document Type	Document Date	Document Version
19.11.2020.V3 Track Changes Amended Caregiver Ethics Protocol Research Plan	Summary of Changes	19/Nov/2020	3
19.11.2020.V1 Holmes NVivo TRAC letter	Sponsor Correspondence	19/Nov/2020	1

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 Harmonisation Good Clinical Practice Consolidated Guideline (ICH GCP); Part C, Division 5 of the Food and Drug Regulations; Part 4 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 0000940.

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

Sincerely,

Ms. Nicola Geoghegan-Morphet , Ethics Officer on behalf of Dr. Joseph Gilbert, HSREB Chair

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

Appendix 3: Ethics Approval Document 3



Date: 3 March 2022

To: Dr. Jeffrey Holmes

Project ID: 112490

Study Title: Psychosocial Support Needs Experienced by Caregivers of Individuals with Parkinson's Disease

Application Type: Continuing Ethics Review (CER) Form

Review Type: Delegated

Date Approval Issued: 03/Mar/2022

REB Approval Expiry Date: 19/Mar/2023

Dear Dr. Jeffrey Holmes,

The Western University Research Ethics Board has reviewed the application. This study, including all currently approved documents, has been re-approved until the expiry date noted above.

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

Western University REB operates in compliance with, and is constituted in accordance with, the requirements of the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS 2); the International Conference on Harmonisation Good Clinical Practice Consolidated Guideline (ICH GCP); Part C, Division 5 of the Food and Drug Regulations; Part 4 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 REB 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,

The Office of Human Research Ethics

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

Appendix 4: Email Script for Participant Recruitment

Good **Morning/Afternoon/Evening**

My Name is **(INSERT NAME)** and I am a Masters student at Western University. My supervisor Dr. Jeffrey Holmes spoke at the Living Well Conference hosted by the Parkinson Society Southwestern Ontario. I am sending this email on his behalf as a follow up to the care partner workshop that you participated in on **(INSERT DATE)** 2019. We are currently looking to speak with people individually about their unique experiences of being a care partner and would like to know if you would be interested in sharing your own experience? Overall we are interested in learning about the challenges you have faced, and/or continue to face, and what resources/supports you would like to see made available.

If you agree to participate we will set up a time to speak either over the phone or virtually using zoom (which ever you prefer) at a time that is convenient for you.

If you have any questions, or would like to schedule a time to chat please contact me at your convenience via email **INSERT EMAIL**

Appendix 5: Letter of Information and Consent

Version 3 November 19, 2020

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Letter of Information and Consent Caregiver Individual Interview

Letter of Information

Project Title

Psychosocial Support Needs Experienced by Caregivers of Individuals with Parkinson's Disease

Principal Investigator

Dr. Jeff Holmes, MSc(OT), PhD

Co-Investigators

Dr. Liliana Alvarez, PhD

Dr. Andrew M. Johnson, PhD

Dr. Marie Savundranayagam, PhD

Student Investigators

Ms. Lisa Moszczynski

Ms. Abigail Reid

Ms. Brianna Moretti

Invitation to Participate

You are invited to participate in a study to explore the experiences of providing care to an individual living with Parkinson's disease. In this study we will ask you to share with us your day-to-day experience of caring for someone with Parkinson's disease. We are interested in both "good" and "bad" things within your everyday life—and we are interested in hearing about the supports that you access, and/or you would like to access to help you manage the role of being a care-partner.

You are being invited to share your caregiving experiences in a one-on-one interview based on your prior participation in a caregiving focus group conducted by our research team in partnership with Parkinson Society of Southwestern Ontario. Specifically, you are being invited to participate in a one-on-one interview based on your demographics and on responses provided during the focus group. For example, the research team is looking to speak with both men and women caregivers who have experienced success and/or challenges with accessing caregiver supports. The individual interview will allow the research team to gain a deeper understanding (from 15-30 individuals) of the common themes identified during the group sessions. The individual interview will be scheduled for a date/time that is convenient for you, and based on your preference may take place either in person, over the telephone or by means of videoconferencing (e.g. Western Corporate zoom). **The one-on-one interview will be audio/video recorded.** If you do not wish to have the interview recorded with video please let a member of the research team know and you will be presented with the following two options:
 OPTION 1 - conduct the interview with the video setting in zoom disabled/turned off, and
 OPTION 2 - conduct the interview over the telephone.

If you agree to participate, you will be asked to take part in a one-on-one interview lasting approximately 60-90 minutes to share your experiences, knowledge, perceptions, and attitudes around being a care-partner for someone with Parkinson's disease. Specifically, you will be asked to discuss your day-to-day experiences of providing care, and to describe supports that you are currently accessing, and/or would like to access to help you manage the role of being a care-partner, including any factors that would enhance accessibility to these supports. To allow you sufficient time to share your experiences, and to provide the research team an opportunity to seek further clarification, if needed, you will be invited to participate in up to two follow up interviews to be scheduled at your convenience. You may decline to participate in the follow up interviews without negative consequences.

In order to be eligible for participation, you must be fluent in English, and currently be providing care for someone living with Parkinson's disease in Southwestern Ontario.

What are the benefits of participating in this study?

Although you may not experience direct benefits from participating in this research, it is our hope that this study will help us understand the aspects of caregiving that are most challenging to you, so that we can develop supports (e.g., Parkinson's specific care-partner manual) and/or make existing supports that address the specific needs of care-partners of individuals with Parkinson's disease more readily available.

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

Participants in this study are at a low risk to experience harm resulting from this study. You are however going to be asked to speak about "bad" or "negative" aspects of caring for someone living with Parkinson's disease; as a result, there is some risk in this study that you may become upset or sad. If you begin to feel upset or sad you are encouraged to contact your physician to discuss these emotions. In addition, we have provided at the end of this letter of information a list of resources that you may contact to speak to someone about how you are feeling.

Despite our best efforts at securing your data (through de-identification, encryption using complex passwords, and physically locking up the data), it is possible that a security breach may occur. We plan to use artificial intelligence technology to transcribe all of the audio recordings collected within this study, and as a consequence of this method of transcription, any personal identifiers (e.g you accidentally use the care recipients real name instead of a pseudonym) will be temporarily uploaded to NVivo (for transcription processing). Once transcription is received all data will be deleted from the NVivo sever and will instead be stored on Westerns system with any personal identifiers removed. In the unlikely event that a security breach occurs, we will notify you directly of the nature and extent of the breach.

Can participants choose to leave the study?

Your participation in this study is voluntary. You are free to refuse to participate, or to withdraw from the study at any time without giving a reason and without negative consequences. If you choose to withdraw from this study, the information that was collected prior to you leaving will be discarded. No new information will be collected without your permission.

How will participants' information be kept confidential?

In order to assure complete confidentiality, no identifying information will be attached to the data collected in this study. The only record of your name that will be retained will be on the attached consent form and on a master list that links your identity to a de-identified code (e.g., Participant 001), and this information will be stored in a locked file cabinet, housed within a locked room located within Elborn College at the University of Western Ontario. If you choose to withdraw from this study, the information that was collected prior to you leaving will be discarded. No new information will be collected without your permission. In addition, all responses will remain accessible only to the investigators of this study. Unidentifiable data may be shared for purposes of secondary data analysis or during the dissemination of this research (e.g., journal publication). Electronic data will be stored in a password protected computer and server network according to the privacy and confidentiality policies of Western University.

We plan to transcribe all of the audio recordings gathered in this study using artificial intelligence technology. If you would prefer not to have your audio recording transcribed in this fashion, we will employ a professional transcriptionist for your recording. After these transcripts have been verified against the audio recordings, the audio recordings will be deleted from within the software used for this purpose (if applicable), and any directly or indirectly identifiable information will be removed from the transcripts during the verification process.

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. Data will be retained for 7 years after which it will be destroyed in accordance with the policies set forth by Western University.

Are participants compensated to be in this study?

As a token of our appreciation for the time you spend completing this study, we will provide you with a \$25 gift certificate to Tim Horton's.

What are the rights of participants?

Your participation in this study is voluntary. You may decide not to be in this study. Even if you consent to participate you have the right to not answer individual questions or to withdraw from the study at any time. If you choose not to participate or to leave the study at any time, this will have no negative consequence to you. You do not waive any legal right by consenting to this study.

Whom do participants contact for questions?

If you have any questions about this research project, please contact the principal investigator, Dr. Jeffrey Holmes at _____, or by email at _____.

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: _____.

This letter is yours to keep for future reference.

List of Resources

If at any time during the course of this study you begin to feel worried, sad, scared, or overwhelmed please contact one of the following resources:

1) Canadian Mental Health Association

534 Queens Avenue London Ontario Canada N6B 5Y6

Phone Toll Free: 1 (855) 668-0624

<http://www.cmhamiddlesex.ca>

2) Parkinson Society Southwestern Ontario

4500 Blakie Road, Unit 117 London, ON N6L 1G5

Phone: (519) 652-9437; Toll Free: 1-888-851-7376 Fax: (519) 652-9267

Email: info@parkinsonsociety.ca www.parkinsonsociety.ca

3) London and District Distress Centre & Senior's HelpLine

Distress Line 519-667-6711; Crisis Response Line 519-433-2023

Senior's HelpLine 519-667-6600 www.londondistresscentre.com

This letter is yours to keep for future reference.

Caregiver Individual Interview Consent Form**Project Title**

Psychosocial Support Needs Experienced by Caregivers of Individuals with Parkinson's Disease

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

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

Participant (Printed Name): _____

Participant (Signature): _____

Person Obtaining Informed Consent (Printed Name): _____

Person Obtaining Informed Consent (Signature): _____

Date: _____

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

Participant (Printed Name): _____

Participant (Signature): _____

Preferred Method of Contact (telephone or email): _____

I agree to having my audio file transcribed through the use of NVivo artificial intelligence.

Participant (Printed Name): _____

Participant (Signature): _____

Appendix 6: Guiding Questions for Round 1 Interviews

Round 1 Interview Questions	
1	How has your life changed since taking on the responsibility of being a caregiver to an individual with Parkinson's disease? (e.g., home, work, social)
2	What information/resources/supports have you successfully accessed to help you care for someone with Parkinson's disease (e.g., print, online, conferences, workshops)?
3	What information/resources/supports have you successfully accessed to help you care for your own health and well-being as a caregiver (e.g., print, online, conferences, workshops)?
4	What information/resources/supports have you successfully accessed that are specific to managing caregiver burden (e.g., print, online, conferences, workshops)?
5	What information/resources/supports would you like to receive/access to help you manage your experience as a caregiver, but that you have either been unable to access, or you experienced difficulty accessing?
6	Describe the underlying reason(s) why the information/resources/supports were unavailable and/or difficult to access (e.g., cost, lack of programming in region, resource not developed etc.)?
7	We wanted to know about your experiences along your caregiving journey with having difficult conversations. Have there been things throughout _____'s Parkinson's disease journey that you wanted to talk about with him/her but felt restrained from bringing up, or perhaps conversations that just weren't as easy as you hoped they would be?

Appendix 7: Round 2 Interview Prompts for Barb (CG01)

What is a difficult conversation?

Depends on ...

- values
- expectations
- existing relationship dynamics
- stage of PD

**Few topics were
difficult to discuss**



**Strong, loving
relationship made
conversations easier?**

difficult conversations

vs

meaningful conversations

vs

important conversations

vs

difficult disclosures

vs

frank conversations

the relationship, the care partner,
the individual with PD

affect the difficult conversation

TIPS & TRICKS??

Appendix 8: Round 2 Interview Prompts for Diane (CG02)

What is a difficult conversation?

Depends on ...

- values
- expectations
- existing relationship dynamics
- stage of PD

difficult conversations

vs

meaningful conversations

vs

important conversations

vs

difficult disclosures

vs

frank conversations

the relationship, the care partner,
the individual with PD
affect the difficult conversation

ADVOCACY
(for self & others)

**wasn't always comfortable
with difficult conversations**



work background
gave helpful skills



husband had an
easygoing personality



time & practice



**became comfortable with
difficult conversations**

TIPS & TRICKS??

Appendix 9: Round 2 Interview Prompts for Tracey (CG03)

What is a difficult conversation?

Depends on ...

- values
- expectations
- existing relationship dynamics
- stage of PD

**PD making
communication
challenging**

PD symptoms & effects



difficult conversations
surrounding lifestyle changes

difficult conversations

vs

meaningful conversations

vs

important conversations

vs

difficult disclosures

vs

frank conversations

the relationship, the care partner,
the individual with PD
affect the difficult conversation

difficult conversations can
be easy to approach



experience with having
open communication

**being supportive
& sensitive**

TIPS & TRICKS??

Appendix 10: Round 2 Interview Prompts for Linda (CG04)

What is a difficult conversation?

Depends on ...

- values
- expectations
- existing relationship dynamics
- stage of PD

difficult conversations

vs

meaningful conversations

vs

important conversations

vs

difficult disclosures

vs

frank conversations

thinking/
planning ahead

focusing on
the positives

the relationship, the care partner,
the individual with PD
affect the difficult conversation

TIPS & TRICKS??

Appendix 11: Round 2 Interview Prompts for Ben (CG05)

What is a difficult conversation?

Depends on ...

- values
- expectations
- existing relationship dynamics
- stage of PD



difficult conversations
 vs
meaningful conversations
 vs
important conversations
 vs
difficult disclosures
 vs
frank conversations

the relationship, the care partner,
the individual with PD
affect the difficult conversation

symptoms, prognosis, the future
are difficult topics



training about not
bringing things home

**close bond/
openness**

TIPS & TRICKS??

Appendix 12: Round 2 Interview Prompts for John (CG06)

What is a difficult conversation?

Depends on ...

- values
- expectations
- existing relationship dynamics
- stage of PD

difficult conversations

vs

meaningful conversations

vs

important conversations

vs

difficult disclosures

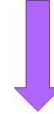
vs

frank conversations

the relationship, the care partner,
the individual with PD
affect the difficult conversation

males vs females ...
comfort with having
difficult conversations

PD adds complexity
to existing difficult
topics & adds some
new difficult topics



new topics related
to treatments &
physical issues

TIPS & TRICKS??

Appendix 13: Round 2 Interview Prompts for Dan (CG07)

What is a difficult conversation?

Depends on ...

- values
- expectations
- existing relationship dynamics
- stage of PD

supportive, loving partnership



conversations that aren't difficult?

difficult conversations will be about lifestyle changes resulting from PD effects

difficult conversations

vs

meaningful conversations

vs

important conversations

vs

difficult disclosures

vs

frank conversations

meaningful conversations about planning & preparing as a team (e.g. end-of-life & treatments)

the relationship, the care partner, the individual with PD affect the difficult conversation

may be initiated by the individual with PD

PD adds complexity

TIPS & TRICKS??

Curriculum Vitae

Name: Helen Abigail Reid

Post-secondary Education and Degrees: The University of Western Ontario
London, Ontario, Canada
2016-2020 B.A.

Honours and Awards: First Place, Brescia's Take the Lead Speaking Competition
2016

Dean's Honour List
2016-2017, 2017-2018, 2018-2019, 2019-2020

Pocock Continuing Scholarship
2017

Parkinson's Society Southwestern Ontario Graduate Student Scholarship
2021-2022

Related Work Experience Teaching Assistant
The University of Western Ontario
2021-2022

Publications:
Reid, A. (2021) Overlooked in Healthcare: Supporting Family Caregivers from Diverse Backgrounds. rehabINK. Available from <https://rehabinkmag.com>