Hope and the Lived Experience of Parkinson’s Disease: A Qualitative Meta-synthesis

by

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Abstract

This meta-synthesis study aimed to answer the research question: How is hope reflected in the phenomenological literature on the lived experience of PD? Utilizing Sandelowski and Barroso's (2007) method for meta-synthesis reviews and an analytic strategy informed by thematic synthesis and thematic analysis (Braun & Clarke, 2012; Thomas & Harden, 2008), 31 phenomenological studies were selected and synthesized in answer to the research question. The findings of this review are based on a total sample of 289 individuals with PD (male = 142, female = 146, unknown = 1). The sample sizes of the individual phenomenological studies ranged from one participant to 14 (M=8.5), with ages ranging from 30 - 86. Five categories were constructed based on these 31 studies: (a) Encounters in the Medical Context: Hope and Hopelessness in PD (b) Unfamiliar Being: Hope Wilted, Strengthened, and Transformed; (c) Being Seen: Hope Reflected Through Relationships (d) Enacting Hope (e) (Re)Constructing Hopeful Narratives. These findings were explored for theoretical and clinical implications for medicine and counselling psychology. Lastly, theoretical linkages were made between the findings and avenues of hope and PD research. Findings from this study may be used to offer concrete recommendations for clinicians to enhance their sensitivity and knowledge concerning the lived experience of PD patients.

Preface

This dissertation is an original work by Kenneth Charles Murdoch. This research project was exempt from research ethics approval from the University of Alberta Research Ethics Board. I acknowledge and thank the Parkinson Association of Alberta for funding this project.

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I am sincerely grateful to conduct research in this area of passionate interest. This research has allowed me to grow professionally, academically, and personally. I thank the University of Alberta for granting me this privilege.

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Chapter 1: Introduction

Parkinson’s Disease (PD) is one of the fastest-growing neurological causes of disability in the world (Feigin et al., 2017). The prevalence of PD worldwide is expected to increase exponentially as the population lives longer and global nations industrialize (Dorsey et al., 2018; Dorsey & Bloem, 2018). Current estimates suggest that the number of people with PD worldwide will double from 6.9 million to almost 14 million in 2040 (Dorsey & Bloem, 2018). PD's public health and socioeconomic burden is massive and shows no signs of slowing (Dorsey et al., 2018; Dorsey & Bloem, 2018).

PD is a degenerative neurological disease with no known cure. It is caused by the accumulated death of dopamine-producing neurons in and around the substantia nigra – a substructure of the basal ganglia (Sayyaed et al., 2023). For people with PD (PwP), neurological degeneration manifests in motor symptoms (e.g., bradykinesia, rigidity, tremor, and/or stiffness) and non-motor symptoms (e.g., psychiatric and cognitive problems). The root cause of dopaminergic cell death is not fully understood. Still, researchers point to genetics, environmental contaminants (e.g., neurotoxins, pesticides), age, and neuroinflammation as potential factors involved in the disease (Bloem et al., 2021; Sayyaed et al., 2023).

Although PD is recognized by tremors and movement problems, several non-motor symptoms can severely impact the quality of life of patients (QoL; Marinus et al., 2018). Since PD has no cure, treatments typically focus on symptom management and promoting quality of life (Tarazi et al., 2014). With an accelerating burden of care for PD on the horizon, current guidelines suggest that multidisciplinary clinical care teams should become the norm in PD treatment (Radder et al., 2020). Psychologists will be increasingly called to take part in the treatment of PD – namely, to support the management of mental health complications of PD

(Radder et al., 2020). Indeed, there has been a recent proliferation of psychological therapies to promote well-being and address the various psychiatric symptoms of PD (See Murdoch et al., 2020; Larsen et al., 2023; Lopes et al., 2021).

Alongside a clinical focus on promoting well-being and quality of life, there has been an increase in studies exploring the lived experience of PD (e.g., Bramley & Eatough, 2005; Gibson, 2013; Soundy et al., 2014; Sotgiu & Rusconi, 2013; Whitehead, 2010) and determinants of well-being and quality of life (Simpson et al., 2014; Tu et al., 2017). This research has increased awareness of the immense struggle patients face in adjusting to PD. Until recently, however, positive psychological factors (e.g., hope) have largely been neglected in the clinical and empirical literature on PD (Noordegraaf et al., 2023).

Researchers and clinicians are beginning to acknowledge the pivotal role of patient hope in successfully treating PD (McDaniels et al., 2023; Noordegraaf et al., 2023; Subramanian et al., 2024). Hope is a psychological factor strongly associated with mental and physical health across the lifespan (Gallagher & Lopez, 2018). To be sure, a diagnosis of PD can threaten hope. While the search for a cure continues, patients and their families are faced with the immense task of reconnecting with hope in the context of a diagnosis that fundamentally changes their relationship to life. To those with PD, hope may seem ephemeral, yet it is an essential resource in reconnecting with a life that no longer looks familiar. A better understanding of the lived experience of hope for those diagnosed with PD would be beneficial for clinicians and researchers. The following dissertation outlines a qualitative meta-synthesis study focused on the journey of those diagnosed with PD and how hope is reflected through this experience.

Statement of the Problem

With concerning estimates of PD incidence on the horizon, it is timely to take stock of the rich and diverse literature on the lived experience of PD. Two major problems in the literature stand out upon critical examination. First, there is an abundance of individual qualitative studies on the lived experience of PD (e.g., Bramley & Eatough, 2005; Gibson, 2013; Soundy et al., 2014; Sotgiu & Rusconi, 2013; Whitehead, 2010). This literature provides a rich knowledge landscape to clinicians; however, the litany of diverse interpretations offers minimal consensus or guidelines for practice. Clinicians require synthesized evidence to build the concrete clinical guidance needed to address the increasing interdisciplinary demand of PD. Second, the PD literature is replete with qualitative investigations on the difficulties and struggles associated with PD while neglecting the stories of hope woven through participant narratives. To address the problems with the PD literature, a qualitative meta-synthesis was used to investigate the lived experience of hope in the context of current published PD research.

The past 20 years have seen an increase in attempts to better understand the lived experience of PwP (e.g., Bramley & Eatough, 2005; Phillips, 2006; Peek, 2017). These studies have focused on various facets of living with PD, including the experience of diagnosis (Phillips, 2006; Peek, 2017), difficulties with symptoms (Hartley et al., 2014; Redmond & Suddick, 2012; Whitehead, 2010), being a person with PD (PWP) (Van Der Bruggen & Widdershoven, 2004), and navigating a career with PD (Lutz et al., 2018). Each of these studies provides rich information about the lived experience of PD. Still, the heterogeneity of the research literature (e.g., heterogeneity in methodology, sample, and context) makes it difficult to provide concrete guidance to practitioners. This same heterogeneity between studies may make it more difficult for practitioners to traverse the gap between knowing and doing.

A comprehensive qualitative knowledge landscape in PD is an excellent starting place for finding contextualized understandings of patient experiences but is less ideal for translating knowledge into concrete guidance for clinical practice. A strength of qualitative research is that it deepens our understanding of lived experience through vivid and rich descriptions of phenomena. This same strength also means individual qualitative studies can be so unique and contextual that they are rarely generalizable. Indeed, it has been argued that generalizability is not the aim of most qualitative studies (Tracy, 2010). Compared to quantitative literature, some researchers have argued that qualitative research tends to be less influential on policy and clinical practice guidelines - especially in healthcare fields (Zimmer, 2006). In PD research, conclusions from qualitative studies are tentative, context-bound, and specific to the sample, but this takes away from their impact on practice. Synthesis of the literature is required to bridge the gap between research and practice.

The current qualitative PD research focuses mainly on PD symptoms or areas of difficulty and disability. Although existing studies provide much-needed phenomenological information about living with PD, stories of hope for PwP are overlooked. Much like the broader historical landscape of psychology with its focus on pathology and illness, the current landscape of qualitative PD research has emphasized the various problems of PD while de-emphasizing stories of hope. A problem-focused understanding of an issue is still beneficial; in fact, many current psychological therapies proposed for treating non-motor symptoms of PD are problem-focused (Lopes et al., 2021). Recently, however, researchers are beginning to investigate hope-focused interventions for PwP (Larsen et al., 2023; Murdoch et al., 2020).

A research-informed understanding of hope grounded in qualitative literature is foundational to clinical innovation in hope-focused interventions. To develop hope-focused tools to work with PwP, new questions must be asked of previous research. For example, we know much about what it is like to live with PD, but what does hope look like from the perspective of PwP? Ronna Jevne stated that hope is a “yes” to life but stories of how PwP have gone on to engage with life are certainly not central in the literature. I believe that stories of hope, triumph and meaning-making in the face of PD are implicit within the narratives of previous studies, but they are commonly overshadowed by stories of strife and struggle.

Purpose of the Study

The purpose of this study is to better understand hope from the perspectives of those living with PD. This study utilized Qualitative Meta-synthesis (QMS) to aggregate, evaluate and synthesize published phenomenological studies on the lived experience of PD. Although there are many valuable phenomenological studies documenting the lived experience of PD, this research needs to be synthesized to optimize its impact on practice.

Research Question

This QMS study attempted to answer the following question: How is hope reflected in existing phenomenological literature on PD?

Definition of Key Terms

This document has employed several terms, as clarified below. Since my study bridges the gap between counselling psychology and neurology, some key terms require definition.

People with Parkinson’s Disease (PWP)

This study is cross-disciplinary; thus, I use the terms client and patient interchangeably throughout this manuscript. The term patient is most often used in healthcare settings, while the term client is typical in psychology. However, for this study, they refer to the same individuals: people with Parkinson’s Disease (PwP).

Hope

As will be seen in the next chapter, hope has been defined in many ways. For a comprehensive definition, I turned to the nursing literature in which Stephenson (1991) defines hope as “a process of anticipation that involves the interaction of acting, feeling and relating, and is directed toward a future fulfillment that is personally meaningful” (p. 1459). For a more accessible definition, counselling psychology researcher Ronna Jevne defined hope as “the ability to envision a future in which we wish to participate” (Jevne, 1994, p. 8).

Healthcare Professional

A healthcare professional can include medical doctors, nurses, occupational therapists, rehabilitation specialists, client care aides, social workers, counsellors, and therapists. For the purposes of this research, a healthcare professional is any professional who plays a role in the medical care of PwP.

Neurologist

Neurologists are medical doctors specializing in neurological disorders. Neurologists who work with PD are sometimes specialized in the field of movement disorders. Neurologists are often the experts who work with patients to manage and monitor the symptoms of PD.

Psychologist

A psychologist is a mental health professional specializing in assessing, treating, and preventing mental disorders, as well as promoting positive development, wellness, resilience, and strengths. Within the profession of psychology, some sub-specializations further differentiate the roles and scope of practice for each professional. This study takes place in the context of a counselling psychology training environment. In Canada, counselling psychologists use psychological knowledge to facilitate and promote growth and mental wellness for individuals and groups (Bedi et al., 2011). The term "psychologist" is provincially regulated and legally protected in Canada. Psychologists have specific training to earn licensure from provincial regulatory bodies in Canada.

Qualitative Meta-synthesis (QMS)

A QMS study aims to formally integrate qualitative findings from existing qualitative research studies, including phenomenological, ethnographic, grounded theory, and thematic analyses (Sandelowski & Barrosso, 2007). Within the tradition of QMS, there is a diversity of approaches, each with unique assumptions and methodological approaches. Common to these approaches is the aim to synthesize the research and create something more than the sum of each study (Sandelowski & Barroso, 2007).

Background of the Researcher

Just as with individual qualitative studies, articulating the researcher's background and history is essential for promoting reflexivity in the analytic process. It also gives the reader an opportunity to understand how the researchers' preconceptions and foreknowledge inform the study. Below, I articulate how I came to ask my research question about hope in PD.

In June 2016, I joined a clinical research team investigating the effects of a hope and strengths intervention for PD patients. I knew nothing of PD, but I soon learned about the significant impact of this disease on patients. Being a part of this study was an immense but meaningful task. In the context of this project, I met and spoke with many individuals who faced the challenge of PD in different ways. I was profoundly impacted by the despair of those recently diagnosed and their inspiring struggle to reconnect with hope. The relationships I built and the stories I heard made me interested in the role of hope in their lives.

While working with PwP, I also pursued a fervent passion for qualitative research methods, particularly phenomenology. A phenomenologist at heart, I have always sought to examine life carefully and pay attention to the lived quality of experience. I sought specialized coursework in qualitative, hermeneutic, and phenomenological methods to deepen my understanding of qualitative research. Taking these courses and appreciating the value of qualitative research led me to ask questions about the connection between qualitative research and practice. I knew the purpose of qualitative research differed from quantitative research. Still, I was perplexed by the commonplace practice of overlooking qualitative research in clinical decision-making and policy development. Qualitative research connects clinicians more deeply and sensitively to the lived experience of others. When it comes to clinical decision-making in counselling psychology, qualitative research can be extremely valuable. Through conducting this qualitative meta-synthesis study, I aimed to help sensitize practitioners and community members alike to pay attention to the insights of phenomenological research.

To date, no meta-synthesis has explored the existing qualitative evidence on PD from a theoretical framework within positive psychology. Further, no previous meta-synthesis has looked specifically at phenomenological studies on PD. My research experience and the depth of my theoretical understandings of hope and positive psychology provided me with a unique perspective in this meta-synthesis literature. Being steeped in the theoretical literature on hope as well as participating in numerous studies focused on hope prepared me as a researcher to sensitively interpret and synthesize data with a hope-focused lens.

Relevance to Counselling Psychology

Counselling psychologists are increasingly tasked with working across disciplines and providing care and consultation in diverse contexts, including healthcare, industrial settings, universities and beyond (Bedi et al., 2011). The discipline of counselling psychology focuses on individuals' unique strengths and aims to promote mental wellness, personal growth, and optimal functioning (Bedi et al., 2011). Indeed, the study of hope has been identified as one of the many critical contributions of Canadian counselling psychologists to a comprehensive understanding of wellness at the individual and collective level (Sinacore et al., 2011).

The profession of counselling psychology in Canada demands sensitivity to the lived experience, cultural context, and unique attributes of an increasingly diverse client population (Cohen et al., 2022). The holistic nature of practice as a counselling psychologist demands a correspondingly diverse and inclusive research literature. The in-depth examination of hope has the potential to benefit counselling psychologists and a wide variety of other professionals who support PwP.

As the population of PwP continues to grow and teams working with those with PD are becoming more diverse and multidisciplinary, an increasing number of psychologists and other helping professionals may find themselves supporting PwP (van der Marck & Bloem, 2014). As a counselling psychologist, helping PwP cope with the psychiatric complications of PD (e.g., depression and anxiety) while promoting well-being and hope may be key foci. To better support PwP, counselling psychologists may benefit from a comprehensive overview of the phenomenological literature on hope in PD. This can offer counselling psychologists increased sensitivity and ethical awareness for their work with PwP. It can also provide practice-focused understandings of hope from the perspective of patients.

Overview of Dissertation

This dissertation has five chapters. In chapter one, I outline the problem, purpose and key terms in my study, along with my background as a researcher. In Chapter two I review the literature on PD and hope and contextualize the current QMS study. In chapter three, the historical background of QMS is explored, along with the rationale for its use. Next, Sandelowski and Barroso's (2007) method for QMS is introduced and articulated as it applies to the current study. The results of the QMS are introduced in chapter four with a focus on building findings applicable to counselling psychologists and other health professionals. The fifth and final chapter discusses the results in the context of hope literature and healthcare practice.

Chapter Summary

This study explored the lived experiences of individuals with PD. My experience, understanding and prior training have prepared me to conduct an in-depth QMS study examining the lived experience of hope in PD. Synthesizing research from phenomenological studies on PD can foster practice recommendations and in-depth experiential insights for healthcare professionals working with PD. Psychologists working with individuals with PD may also be more prepared when helping individuals in their journey with PD. In the next chapter, a literature review focused on PD and hope is provided. This review situates my study in the context of current PD research and counselling psychology.

Chapter 2: Literature Review

The following chapter summarizes the literature on Parkinson’s Disease (PD) and Hope. It is divided into three sections. The first section provides an overview of PD, including its etiology, symptoms, and treatment. The second section describes the lived experience of PD, critiquing current literature and highlighting gaps in our understanding. The final section reviews the literature on hope and its role in medicine and psychotherapy.

Overview of PD

The last 40 years have produced an immense knowledge base on PD etiology, diagnosis, and treatment. These areas will be explored in the section below to provide information relevant to this study. This literature may be informative to counselling psychologists and other healthcare professionals supporting PwP.

Causes and Risk Factors of PD

PD is caused by the progressive, accumulated loss of dopamine-producing neurons in the substantia nigra. There is little conclusive research on the cause of this cell death (Bloem et al., 2021; Hawley, 2014). Research has shown that environmental and genetic factors may increase risk (Bloem et al., 2021; Hawley, 2014; Sayyaed et al., 2023). For example, Delamarre and Meissner (2017) found that coffee, black tea, cigarette smoking, anti-hypertensive drugs (i.e., calcium channel blockers), and ibuprofen can decrease the risk for PD. Exposure to pesticides and affective disorders like depression and anxiety seem to increase risk.

Several genetic markers have also been shown to have a cumulative effect on the risk of developing PD. Although several genes are linked to PD, very few biological markers for PD can be identified in a living patient (Delamarre & Meissner, 2017). Thus, a diagnosis of PD is approached through clinical assessment, and confirmation of this diagnosis is somewhat difficult

(Shah, 2014)**.** A PD diagnosis can confuse patients, partly because there is little concrete knowledge of the underlying cause.

Diagnosis of PD

Approached via clinical neurological exam and history taking, a diagnosis of PD hinges on the detection of four primary symptoms: (a) bradykinesia, (b) rigidity, (c) tremor, and (d) postural instability (Bloem et al., 2021; Shah, 2014). Bradykinesia, or “slowness of movement,” is typically accompanied by symptoms of hypokinesia (i.e., small movements) and akinesia (i.e., absence of movement. This can include limited facial movement, little to no hand gestures while speaking, and hypophonic (soft) speech (Shah, 2014). Another significant symptom is limb rigidity during passive movement (Shah, 2014). A third symptom is a tremor in the limbs, typically occurring when the patient is at rest. This is the most known symptom of PD and tends to cause distress and disrupt daily activities. Lastly, postural instability is a symptom found later in the course of PD (Shah, 2014). This symptom typically manifests as difficulty in making minor adjustments with the legs to maintain balance but also can be a more general instability, which results in falls, reduced mobility, and the need for walking aids to the point of being a wheelchair user (Shah, 2014). If the patient responds favourably to levodopa treatment, this is another crucial confirmatory factor in diagnosis (Shah, 2014).

In terms of the patient’s experience, when presenting to a physician, patients may report problems with tremors or note weakness or trouble with fine motor tasks such as brushing their teeth (Shah, 2014). Other notable early symptoms include sleep problems and problems with sense of smell (i.e., hyposmia) or taste (i.e., dysgeusia). Since symptoms can be progressive and slow, many patients are not diagnosed until significant cell damage has occurred (Schneider & Obeso, 2015).

Participants in this review study (those diagnosed with PD) were likely to have encountered some of the symptoms described above. PD symptoms primarily impact movement, which can be incredibly life-disrupting. Thus, these symptoms and participants' reactions to them may hold important meanings about the lived experience of hope.

Each patient's lived experience of PD symptoms can be unique. However, the neuropathological changes that occur throughout the brain have been explored in depth, providing foundational insight into PD symptoms. The following section briefly outlines the neurobiology of PD as it is relevant to this study.

The Neurobiology of PD

To explain the neuropathology of PD, a brief outline of the motor control system is required. Human motor functioning is partly controlled by the substantia nigra and its connection to the basal ganglia. PD symptoms manifest when dopamine-producing neurons in the substantia nigra gradually die (Weiner et al., 2013). The substantia nigra delivers dopamine through what is sometimes called the *nigrostriatal highway* to the caudate and putamen, structures in the basal ganglia. When this nigrostriatal highway is disrupted, as in PD-related cell damage, less dopamine reaches other essential motor and non-motor systems in the brain. These changes disturb the neurochemical balance of neurotransmitters, such as norepinephrine and serotonin, resulting in mood changes (Weiner et al., 2013). The sequence of this neuronal degeneration in the brain is highly complex, but many researchers have attempted to document the neuronal deterioration (Braak et al., 2003).

Cell death in the substantia nigra, specifically, the substantia nigra pars compacta (SNpc) and the basal ganglia, in combination with the presence of protein accumulations called Lewy bodies, have been shown to cause symptoms of PD (Bloem et al., 2021; Schneider & Obeso, 2015). The onset of symptoms typically occurs when 50% of the dopamine-producing neurons have been lost (Schneider & Obeso, 2015). Although the substantia nigra is primarily involved in the pathophysiology of PD, it has become known as a multi-system disease as it affects many systems in the brain and body (Jellinger, 2014; Schneider & Obeso, 2015). The non-motor symptoms of PD, particularly, have become an area of focus for those working with and researching PwP. These non-motor issues are explored below.

Notable Non-Motor Features of Parkinson's Disease

PD affects various neurochemical systems in the brain stem, limbic system and cortical regions (Goldman & Postuma, 2014). Much literature has explored the pathological changes that cause non-motor symptoms (e.g., mood issues, cognitive impairment, sleep problems, and autonomic disruption) (Goldman & Postuma, 2014; Marinus et al., 2018). Non-motor symptoms can negatively impact quality of life and disease management for PwP (Connolly & Marras, 2014; Marinus et al., 2018). This section explores some of the significant non-motor features of PD and how this may impact the lives of PwP.

Depression and Anxiety. Depression affects approximately 35% of individuals with PD (Aarsland et al., 2012). Depression later in life, unexplained by other factors, is increasingly being recognized as one of the "red flags" of PD-related pathology (Bloem et al., 2021). Nonetheless, depression goes unnoticed in PD patients because depressive symptoms can be mistaken for common features of PD (i.e., poverty of movement and flat affect) (Connolly & Marras, 2014; Gallagher & Schrag, 2012).

Anxiety affects approximately 40% of people with PD, with generalized anxiety disorder, panic disorder, and social phobia being the most common (Connolly & Marras, 2014; Weiner et al., 2013). PD-related anxiety is more common in younger women with PD and tends to co-occur with depression (Connolly & Marras, 2014). Not only are these mental health issues prevalent, but they adversely impact quality of life in PwP (Tu et al., 2014).

Cognitive Impairment. About 80% of PwP develop cognitive impairment (Schneider & Obeso, 2015). Due to the eventual neurochemical changes in the neocortex, deficits in cognition are identified in executive functioning, psychomotor speed, short-term memory, and attention (Connolly & Marras, 2014; Schneider & Obeso, 2015; Dirnberger & Jahanshahi, 2013; Weiner et al., 2013). Regarding the clinical presentation of these deficits, PwP may struggle with decision-making or be slow in their reaction to stimuli. Increasingly, PwP may also have difficulty remaining focused in conversations and retaining information.

Sleep Disturbance. Some PwP experience sleep disturbances, particularly interference of the sleep cycle, excessive daytime sleepiness, insomnia, vivid dreams, and sleep apnea (Connolly & Marras, 2014; Goldman & Postuma, 2014; Schneider & Obeso, 2015). Sleep disturbance can contribute to several psychological problems (e.g., problems with focus and attention, cognitive problems) and tend to exacerbate disturbances in cognition, mood and PD symptoms. Along with sleep disturbances, several other non-conscious processes are also affected by PD.

Autonomic Dysfunction. Autonomic nervous system (ANS) dysfunction is common in PD (Connolly & Marras, 2014; Weiner et al., 2013). ANS symptoms include orthostatic hypotension (i.e., low blood pressure upon standing), drooling, excessive sweating, urinary dysfunction, gastrointestinal issues (i.e., constipation and diarrhea), and sexual dysfunction (Connolly & Marras, 2014; Goldman & Postuma, 2014; Weiner et al., 2013). Researchers have suggested that although ANS symptoms are highly prevalent in those recently diagnosed, 58% of these patients reported them as mild (Müller et al., 2011). As PD progresses, however, autonomic dysfunction typically worsens, particularly bladder control, urinary problems, constipation, sexual dysfunction and hypotension (Weiner et al., 2013). Importantly, orthostatic hypotension (i.e., low blood pressure upon standing up) can be dangerous for those with PD because it can increase the risk of falls - placing PwP at risk for bone fractures (Weiner et al., 2013). ANS dysfunction can be stigmatizing and disorienting for patients, and the symptoms may not be visible to others.

The non-motor features of PD described above vary between people but are common (Goldman & Postuma, 2014; Connolly & Marras, 2014). Non-motor symptoms are correlated with reductions in quality of life, and these symptoms are relatively poorly understood in terms of their treatment (Connolly & Marras, 2014; Goldman & Postuma, 2014). Fortunately, research has provided several effective ways to treat motor and non-motor symptoms of PD, particularly in earlier disease stages.

Treatments for PD

Pharmacological Interventions. No medication can slow down or reverse PD-related neuronal damage, but symptoms can be managed. As PwP learn about the disease, they will inevitably become aware of the treatment options available to them. Some patients can be ambivalent toward symptom-management approaches even though medications can vastly improve motor functioning (Cook & Hawley, 2014).

PD is treated primarily through dopaminergic medications (e.g., Levodopa) and medication that modulates endogenous dopamine (e.g., MAO-B inhibitors). Dopaminergic medications like levodopa (with carbidopa or benserazide to reduce side effects) are the most frequently used and most effective pharmacological treatments for PD symptoms, while dopamine agonists are less effective overall (Cook & Hawley, 2014). Medications that modulate endogenous dopamine (i.e., MAO-Bs) tend to have only modest effects relative to Levodopa (Cook & Hawley, 2014).

The patient experience of treatments like Levodopa may be complex and multifaceted. A reduction of symptoms via medications means that patients may be able to continue engaging in the activities of daily living. However, these treatments do not cure PD; thus, patients are conscious that symptoms will return when the medication wears off. PwP must take medications at multiple, often precise, times of the day. The medication regimen may be intrusive and obstructive to one's life. Additionally, because PD is progressive, symptoms tend to worsen over time with waning benefits from medication as the brain is less able to utilize them effectively. Indeed, medication in PD can become a central issue in the patient's life, impacting symptoms even on an hour-to-hour basis and thus may become pivotally connected to hope.

Surgical Treatments. There are numerous surgical interventions available for PD. One of the primary surgeries is deep brain stimulation (DBS). For ideal candidates who undergo DBS, a reduction in symptoms is expected, as is a reduction in the need for levodopa treatment (Cannard, 2014). Although DBS is effective and has lasting benefits, only patients with specific symptoms and the absence of significant cognitive problems or neuropsychiatric issues are eligible. In the likely event that a patient learns that they are ineligible for this type of treatment, they may face the reality that worsening PD symptomology will continue to be a part of their lived experience for the foreseeable future. Although this may be a challenge to hope, promising research suggests that patients can have an active role in symptom control through physical activity and exercise.

Physical Activity and Exercise. Research evidence suggests that physical activity (PA) may lessen an individual's risk of developing PD (Feng et al., 2020; Paillard et al., 2015) and significantly reduce the severity of PD motor symptoms (Shu et al., 2014). Researchers have hypothesized that exercise reduces oxidative stress, improves mitochondrial function in neurons and improves the function of antioxidant enzymes (Monteiro-Junior et al., 2015). Some also suggest that exercise stimulates the production of dopamine and promotes neurotrophic factors such as Brain-Derived Neurotrophic Factor (BDNF) and glial cell-line derived neurotrophic factor (GDNF) that serve to promote the survival and growth of brain cells (Monteiro-Junior et al., 2015). Exercise can be used in conjunction with other treatments as it may help avert some of the costs associated with medical treatments and boost patient autonomy (Monteiro-Junior et al., 2015).

Psychotherapeutic and Psychiatric Interventions. Since depression and anxiety are formidable non-motor symptoms in PD, treatments that alleviate these issues are being evaluated. Mental health symptoms in PD have a more significant role in quality of life than physical symptoms (Chrischilles et al., 2002). Thus, from a treatment standpoint, bolstering mental health and addressing mental health symptoms is critical. The two primary treatments that demonstrate effectiveness for addressing mental health symptoms in PD are psychotherapy and antidepressants like Selective Serotonin Reuptake Inhibitors (SSRIs) (Bomasang-Layno et al., 2014).

Notably, SSRIs are a frontline treatment for depression in PD despite a tumultuous debate regarding their efficacy in PwP (see Bomasang-Layno et al., 2014; Liu et al., 2013; Rocha et al., 2013). Psychotherapy is showing promise in treating anxiety (Sproesser et al., 2010), psychosis (Poewe & Seppi, 2001), and gambling issues (Gallagher et al., 2007; See Tan & Methawasin, 2013 for review). Some researchers have even tailored models of psychotherapy to PD specifically to improve mental health (Knight et al., 2016; Larsen et al., 2023; Murdoch et al., 2020).

PD profoundly affects the quality of life of those diagnosed and their families (Simpson et al., 2014). Despite multidisciplinary research efforts, there is still much more to know about PD. There has been a recent and promising shift toward understanding the lived experience of PD. The following section will review the literature on the lived experience of PwP, starting with the diagnosis itself and then reviewing studies of post-diagnostic experiences. This section also situates the current study in this context.

The Lived Experience of PD

The experience of PD holds profound significance for patients, encompassing psychological, social, spiritual, and cultural aspects. The following section first reviews the relevant literature on the lived experience of PD, including diagnosis and beyond. The last part of this section reviews the qualitative meta-synthesis literature on PD.

The Lived Experience of PD Diagnosis

The lived experience of a PD diagnosis has been explored in some depth (Peek, 2017; Philips, 2006). The major research studies documenting the experience of diagnosis are explored below.

In an early qualitative descriptive study by Phillips (2006), the author interviewed 11 people with PD about their experience of diagnosis. In this study, being diagnosed with PD was metaphorically compared to a bomb dropping on the patient’s life (Phillips, 2006). In fact, “dropping the bomb” was an overarching theme with four subthemes: (a) guarded anticipation, (b) becoming informed, (c) disease dynamics and (d) negotiating with Mr. Parkinson. The psychological and emotional significance of diagnosis was described as entirely catastrophic, leaving patients with the task of rebuilding their lives, finding answers, and rethinking their identity (Phillips, 2006).

In another study, Peek (2017) investigated 37 patient narratives of the diagnostic encounter with their medical doctor. Echoing the previous study, participants in this study described the experience of diagnosis as a life-changing event. Participants expressed that the diagnostic conversation lacked the appropriate “ceremony, " drawing attention to their medical professionals' brief and flippant remarks, leaving patients feeling abandoned (Peek, 2017). Participants described the perceived lack of empathy their healthcare professionals had for the diagnosis (Peek, 2017). While some participants noted they received no guidance or systematic care pathways, others were encouraged to buy books or learn about PD online. Some participants described that their doctors did not acknowledge them as unique people, highlighting the importance of elevating patient voices through qualitative research (Peek, 2017).

In Peek’s (2017) study, some participants described that their physicians were supportive and managed the disease with them (Peek, 2017). These patients felt at relative ease because the shock of the diagnosis was “contained” by their physician (Peek, 2017). Some patients in this study adopted a “relativist” orientation toward the diagnosis, acknowledging that PD was less severe than other diseases (Peek, 2017).

Philips (2006) and Peek’s (2017) research highlights patients’ impactful diagnostic experiences. Phillip’s (2006) study gives detailed information about the patient’s lived experiences of a PD diagnosis and the aftermath. Peek’s (2017) study highlights the importance of how a physician communicates the diagnosis and the impact this can have on hope. Although these studies shed light on the vulnerable experience of diagnosis, there is no explicit exploration of the experience of hope in the context of diagnosis or the aftermath.

Phenomenological Research on the Experience of PD

Several qualitative studies have explored the lived experience of PD. This research is crucial to understanding the lived realities of PD and identifying gaps in research and practice. Since the current QMS study aims to explore phenomenological studies, the following section will review some prominent phenomenological work in this area.

In a study by Van Der Bruggen and Widdershoven (2004), the authors analyzed print material (e.g., stories, novels, and scientific publications) written about and by PwP. The authors used existential analysis to investigate what it means to be a PwP (Van Der Bruggen & Widdershoven, 2004). Several existential themes were identified, including: "(a) corporality: monotonous and unexpectedly whimsical (b) space: established with difficulty, (c) time: always hurrying, getting nowhere fast (d) things: a difficult relationship (e) world: airport in a foreign country (f) the other: keeping in contact, keeping a distance and (g) the human being as subject: loss of identity" (Van Der Bruggen & Widdershoven, 2004, pp. 291–297). Each of these existential themes described paradoxes encountered by PwP. The authors provided a novel method of inquiry into how patients live with PD (Van Der Bruggen & Widdershoven, 2004). However, implications for hope-focused practice are not as clear. A QMS focused on hope in phenomenological studies with PwP could make clinicians more aware of how patients experience and manifest hope in their lives.

Bramley and Eatough (2005) focused on the lived experience of PD using Interpretative Phenomenological Analysis (IPA; Smith et al., 2009). Interviewing one participant, the authors offer a detailed idiographic case study (Bramley & Eatough, 2005). Two superordinate themes were constructed. The first theme, *mind and body*, included subthemes related to movement, symptoms, and medication. The second theme, *self and agency*, included subthemes associated with comparing old and new selves. The last theme, entitled *stable self*, explored how the participant described her enduring sense of self beneath obvious PD symptoms. She explained how her enduring sense of identity and familial support helped her maintain hope (Bramley & Eatough, 2005). A notable strength of Bramley and Eatough's (2005) study is its focus on the lived experience of one person, exemplifying how in-depth phenomenological research can unearth insights about hope in PD (Bramley & Eatough, 2005). However, since the experience of PD is unique between patients, a sample size of one participant may impact the transferability of the study. Additionally, although hope is mentioned in the study, an explicit focus on hope would likely provide more guidance to clinicians looking to promote hope in patients.

Another interpretative phenomenological study by Redmond and Suddick (2012) explored PD patients' lived experiences of "freezing," a common symptom of PD. Freezing involves the patient suddenly losing the ability to initiate movement and has been shown to be detrimental to quality of life (Redmond & Suddick, 2012). Interviewing six PwP, the authors hoped to learn about freezing and how it impacted the patients' lives. The authors found that patients experienced freezing as a separate, ominous entity that produced adverse emotional reactions and barriers to social functioning (Redmond & Suddick, 2012). This study then explored ways practitioners can support patients through episodes of freezing and how research should continue to explore how symptoms impact patients.

In another study focused on PD symptoms, Whitehead (2010) explored how PwP make sense of speech problems. The author interviewed patients and their spouses. Researchers found that speech deteriorated slowly over time, leading to loss of confidence and self-esteem. These changes resulted in feeling less socially competent and experiencing more social problems. Patients reported being preoccupied with idealistic visions of their past selves, especially when they felt more socially competent (Whitehead, 2010). Lastly, the study explored how the patients coped with speech difficulties (Whitehead, 2010). Indeed, hope is connected to individuals' ability to cope with illness and envision a positive future despite present difficulties (Farran et al., 1995). However, both the Whitehead (2010) as well as Redmond and Suddick (2012) studies pay no explicit attention to hope.

Qualitative Meta-synthesis in PD Research

Given the accumulating number of individual qualitative studies on PD and other chronic health conditions, attempts have been made to synthesize knowledge to guide health practitioners. Five qualitative meta-syntheses focusing on patients with PD specifically will be reviewed below. This literature will then be critically evaluated, focusing on what the current study can add.

In the discipline of rehabilitation, Soundy and colleagues (2013) conducted a meta-ethnographic review of 37 qualitative studies focusing on the experiences of people living with PD (Soundy et al., 2014). The authors concentrate on factors that impacted the well-being and hope of those diagnosed with PD. The authors utilized a theoretical lens specific to their discipline involving social identities. The authors defined social identity as PwPs' experience of belonging to a particular social group and their emotional attachment to this group (Soundy et al., 2014). Soundy and colleagues (2014) constructed five themes: (a) the effects of PD on social identity, (b) the psychosocial challenges of PD, (c) factors influencing the degree of disruption in the individual's life, (d) the strategies and factors that influence well-being, and (e) the social factors that influence well-being. From these themes, the authors developed a hope-enablement model citing the importance of social identities in promoting well-being (Soundy et al., 2014).

Another meta-synthesis by Haahr and colleagues (2021) from the field of public health used a meta-ethnographic approach to review 14 articles. The authors synthesized the literature to investigate how individuals with PD face challenges and cope (Haahr et al., 2021). The authors' theoretical perspective and research question were related to the current literature on coping (Haahr et al., 2021). The authors included only studies involving PD patients in the community and included studies with any qualitative methodology. The authors created a model of coping with four categories: (1) staying independent, (2) adapting to continuous losses, (3) avoiding unpredictable challenges, and (4) focusing on the present. Each category had a central focus on "maintaining normality" (Haahr et al., 2021). Interestingly, "Hope and acceptance" was a theme within the category of focusing on the present, but theoretical linkages to research on hope were absent (Haahr et al., 2021).

Another study conducted by Wieringa and colleagues (2021) utilized a meta-ethnographic approach to identify 21 studies. Their study aimed to answer the question: "How do individuals adjust to living with Parkinson's Disease?" (Wieringa et al., 2021, p 2). The authors included any qualitative studies that focused on individuals with PD. Further, the authors specified that at least one central theme had to focus on the adjustment process (Wieringa et al., 2021). The authors created a model of adjustment in PD with three major themes: (1) feeling in control, (2) maintaining a sense of self, and (3) holding a positive mindset.

Public health researchers in Amsterdam conducted another meta-synthesis focused on PwP. These authors utilized a meta-ethnographic approach to identify 20 studies. This study focused on any qualitative research with a focus on PD. The authors constructed a "Model of Dialectic Change" from the included studies. The authors say of their model: "[it] conceptualizes life with PD as a transformative journey, wherein PwP employ strategies intended to stabilize their changeable relationship with their external environment as well as actively engage in a continuous process of reconstituting the self" (Rutten et al., 2021, p. 148).

Taken together, these meta-synthesis studies offer diverse interpretations of the PD literature from the authors' respective theoretical perspectives. Although most of the studies do mention the word hope, none of the studies utilize hope theory to guide their synthesis. Such a synthesis would offer a nuanced experiential picture of the lifeworld of PwP from a hope-focused lens. An experiential understanding of hope may give clinicians a sensitive and ethical understanding of PwP. Counselling psychologists, specifically, are woefully short of disciplinary-specific and clinically informative investigations in the literature. A reformulation of the literature from the discipline of counselling psychology might offer clinicians valuable avenues of exploration with patients.

None of the studies to date have focused solely on phenomenological research. The current meta-synthesis of phenomenological research can offer clinicians a holistic illustration of the lived experience of PD while providing the clinician with thematic elements representing the shared experience of hope among PwP.

Hope and PD

Researchers have studied the lived experience of PD, but hope is inadequately explored. Only two prior studies have focused explicitly on hope in PD. First, Soundy, Stubbs and Roskell's (2014) study described above provides some information about hope-enablement in PD but does not have a counselling psychology or phenomenological focus. Notably, none of the studies reviewed by Soundy and colleagues focused on hope, and the authors did not review the theoretical and empirical literature on hope when conceptualizing or discussing their findings.

The only other study focused on hope in the context of PD is a quantitative study by Fowler (1997). In Fowler's (1997) study, a correlational design was used to examine the relationship between hope and health promoting lifestyle of 42 people with PD. The authors found significant, positive correlations between hope and a health-promoting lifestyle (Fowler, 1997). Notably, the authors did not provide in-depth demographic information about their sample, reducing the generalizability of their findings. Additionally, the authors collected quantitative survey information about hope but did not provide in-depth qualitative data about hope or health-promoting behaviours.

Except for the two previous studies, research focusing on hope in PD is scant. However, as will be articulated below, there is a promising avenue of research beginning to focus on the application of hope-focused psychotherapy with PwP (See Larsen et al., 2023; Murdoch et al., 2020), which has, in turn, strengthened calls for a focus on hope in medical practice with PwP (Noordegraaf et al., 2023). This research is essential in addressing the overlooked value of hope. Research on the lived experience of hope may provide theoretical foundations for researchers interested in developing hope-focused interventions with PwP. The current study aims to address this knowledge gap.

Hope is a robust field of empirical study that has virtually exploded in the last four decades. The following section explores current empirical and theoretical research on hope.

Hope

Hope has been examined and defined from multiple theoretical perspectives; however, the systematic, cross-disciplinary study of hope is relatively new. This section has four parts. First, I review the major theories of hope relevant to this study. Second, I articulate my own theoretical perspective on hope—presenting an existential understanding of hope. Third, I review the importance of hope in psychotherapy, and finally, I review the extant empirical research on hope in aging and health.

Theories of Hope

Hope has a rich philosophical foundation from which health and social science theorists have developed important applied theories. Formal research and theorizing on hope hails primarily from psychology and nursing. I first explore the relevant theories from psychology (See Scioli, 2011; Snyder, 1995). Then, I explore some prominent models of hope originating from medicine and nursing (See Dufault & Martocchio, 1985; Eliott & Olver, 2002; Farran et al., 1995). Although all these theories are unique and offer essential insights and understandings about hope, the latter theories, particularly those from nursing, inform my phenomenological understanding of hope.

Snyder. Carl Rick Snyder developed a uni-dimensional, cognitive-behavioural theory of hope that has become the most well-known and commonly used measure of hope across disciplines (Gallagher & Lopez, 2018; Redlich-Amirav et al., 2018). Snyder posited that all human action is directed toward the attainment of goals. For Snyder, to achieve goals, people must think about them, providing a cognitive target for action (Snyder et al., 2018). Snyder described hope as a cognitive process made up of agency thinking (i.e., motivational thoughts about goals) and pathway thinking (i.e., planning routes to meet goals) (1995). According to Snyder, both agency and pathway thinking are essential to the process of hope (1995). Snyder understood hope as a solely cognitive-behavioural process with emotion playing a secondary role in the experience. Emotions, for Snyder, provide information for further goal-related cognitions but are not primarily involved in hope.

Snyder developed tools to measure hope, and research has found that Snyder's version of hope is correlated with an increasing number of favourable health outcomes, convincing some authors to conclude that "higher hope virtually always is related to more beneficial life outcomes" (Cheavens et al., 2005, p. 127). Indeed, hope is correlated with positive outcomes in nearly every domain of life, such as athletics, physical health, psychological adjustment, social relationships, psychotherapy, and meaning in life (see Gallager & Lopez, 2018; Rand & Cheavens, 2009; Snyder, 2002).

Snyder's theory of hope has been criticized for being uni-dimensional and neglecting the full complexity of hope (Eliott & Olver, 2002). Snyder championed an important theory that has largely established the empirical credibility of hope in the health disciplines. Nevertheless, Snyder's theory neglects the depth and complexity of hope. I believe hope is a multidimensional concept of which cognition is only one aspect. In the proposed study, I am interested in learning about hope in all its complexity.

Scioli. From the field of psychology, Scioli and colleagues (2011) criticized Snyder's (2002) conceptualization for his focus on goals in place of the deeper, more profound origins of hope. To address these shortcomings, Scioli and colleagues conducted a review of hope literature from psychology, philosophy, nursing, and theology. Scioli and colleagues defined hope as "a future-directed, four-channel emotion network, constructed from biological, psychological and social resources" (p.79). According to Scioli, the four constituent channels are mastery, attachment, survival, and spiritual (p. 79). The authors further explain that "[t]he hope network is designed to regulate these systems via both feed-forward (expansion) and feedback processes (maintenance) that generate greater perceived probability of power and presence as well as protection and liberation" (p. 79). Scioli and colleague's theory is a complex but comprehensive, multi-dimensional model that accounts for philosophical, biological and spiritual elements of hope.

Scioli and colleagues (2011) describe hope as a "network" or a "complex system of interrelated parts" (i.e., mastery, attachment, survival, and spiritual; p. 79). Scioli compared these systems to intermingled webs, each thread supporting the structure and being supported by other threads. Scioli referred to the hope network as a "deep structure," referring to the idea that hope is deeply ingrained in human nature and spurred by universal human motives. These motives, in interaction with the environment, create a five-level interconnected structure of hope. Scioli and colleagues noted that the first level is the most basic and foundational to hope and supports each level above it, much like a pyramid. The five levels in Scioli's model are (a) hope-related motives, (b) endowments and supports, (c) hope traits – the "hopeful core," (d) the faith system, and (e) hope behaviours.

Scioli et al.'s (2011) model is a comprehensive theory that adds biological, existential, evolutionary and spiritual elements to hope theory. My own understanding of hope is informed by Scioli et al. (2011) in that I believe hope is a developmental process largely cultivated through our early learning in conjunction with natural, biological motives. Scioli and colleagues' (2011) model has influenced my own understanding of hope and provided a deeper understanding of how hope can be multifaceted.

Psychology has produced compelling insights about hope, but each one focuses on a particular component of hope while neglecting other aspects. Snyder and Scioli's theories are borne out of the discipline of psychology. Thus, their conceptualization of hope focuses more on the psychology of hope rather than the phenomenology of hope. Indeed, those trained in psychology may have a predisposition to approach and understand hope in a particular way -

privileging psychological theory. Highly abstract psychological theories may not capture the lived experience of hope in all its dimensions. Snyder and Scioli imbue hope with theoretical frameworks originating from psychology, such as goals theory (e.g., Snyder, 2002), attachment theory, control mastery theory, and terror management theory (e.g., Scioli et al., 2011). Though each sub-theory has rich historical traditions, they may also bring us farther away from the lived experience of hope.

Alternatively, research originating from medical contexts has produced many informative, multifaceted understandings of hope. These theories offer an understanding of hope closer to the phenomenology of hope rather than the psychology of hope. These theories align with my own existential and phenomenological understanding of hope and inform the theoretical framework for this study.

Dufault and Martocchio. Nursing researchers Dufault and Martocchio (1985) developed a theory of hope using two years of longitudinal clinical data from 35 older adults with cancer. Dufault and Martocchio defined hope as "A *multidimensional* dynamic life force characterized by a *confident* yet *uncertain* expectation of achieving a future *good* which, to the hoping person, is *realistically* possible and *personally significant"* (1985, p. 380) [italics in original].

According to Dufault and Martocchio, hope has a particularized and generalized sphere. Particularized hope refers to an investment in a specific future good and gives the hoping person a focus for their energy and resources (Dufault & Martocchio, 1985). Generalized hope is a broader, intangible anticipation toward a non-specific future development. Generalized hope can be described as a "glow" cast upon life that moves the hoping person toward a preferred future (Dufault & Martocchio, 1985).

The generalized and particularized spheres of hope each have six dimensions: (a) affective, (b) cognitive, (c) behavioural, (d) affiliative, (e) temporal, and (f) contextual (Dufault & Martocchio, 1985). The affective dimension involves the emotions that accompany hope, both positive (e.g., excitement, anticipation, yearning) and negative (e.g., fear, aching). The cognitive dimension is the thinking aspect of hope and represents how we plan, organize, prioritize, and engage our cognitive resources. Relatedly, the behavioural dimension represents the observable, measurable actions one takes to achieve some hoped-for future (e.g., eating healthily, taking medications, exercising and engaging in other self-care activities, among others) (Dufault & Martocchio, 1985). The affiliative dimension of hope is an individual's sense of hope in the context of relationships. This dimension includes "social interaction, mutuality, attachment and intimacy, other-directedness, and self-transcendence" (1985, p. 386). The temporal dimension is complex but involves the individual's sense of hope in the past, present, and future. Specifically, aspects of one's past affect one's present hopes, and this experience is directly related to one's sense of the future (Dufault & Martocchio, 1985). Finally, the contextual dimension is the circumstances that bring about, foster or act as a test for hope. For example, an interpersonal loss or a loss in physical or mental vitality can be a circumstance in which hope comes to the forefront of awareness.

Dufault and Martocchio (1985) provide the theoretical foundation for the current study and a conceptual precedent for hope to be understood in a dynamic, phenomenological way. According to Eliott (2005), Dufault and Martocchio's research has influenced virtually all qualitative research on hope in the ensuing years and laid the foundation for multidimensional models of hope in nursing. Dufault and Martocchio (1985) encourage hope to be understood as a profoundly subjective experience unique to everyone. I propose that the breadth of Dufault and

Martocchio's framework of hope allows researchers to access an ontological understanding of hope that overlaps with phenomenological frameworks proposed by others (see van Manen, 1997).

Dufualt and Martocchio (1985) propose that the six spheres of hope pervade both the particularized and the generalized dimensions of hope. Their model provides an overview and examples of how hope can be understood from the particularized dimension. However, how each of the six spheres overlaps with the generalized dimension is somewhat neglected. I surmise that this is due to the ubiquitous and implicit nature of the generalized dimension of hope. Since generalized hope is offered as a way of being, a non-specific, implicit glow set upon life, the spheres may not be easily defined for their relation to the generalized dimension.

Farran, Herth, and Popovich. Another nursing theory comes from Farran, Herth, and Popovich. This influential theory was developed from clinical data and a thorough review of philosophy and literature on hope.

For Farran and colleagues (1995), hope is multidimensional, "a way of feeling, a way of thinking, a way of behaving, and a way of relating to oneself and one's world. Hope can be fluid in its expectations, and in the event that the desired object or outcome does not occur, hope can still be present" (p. 6). For Farran et al., hope has four attributes: (a) the experiential pain of hope, (b) the spiritual or transcendent soul of hope, (c) the rational mind of hope, and (d) the relational heart of hope.

The experiential pain of hope involves instances in which individuals are confronted by suffering or captivity. Farran and colleagues conceptualized hope and hopelessness as dialectics experienced in a wave-like motion back and forth. When someone is faced with a genuinely difficult situation (e.g., a diagnosis of illness), they may encounter the depths of despair, from which they can make contact with hope (Farran et al., 1995).

The spiritual or transcendent soul of hope describes the connection between faith and hope. For some individuals, faith may be placed in the self or others around them, while others may put their faith in a higher power. Regardless of the source of faith, hope involves a sense of conviction toward an uncertain end. This faith involves believing in circumstances beyond those presented, a faith that transcends the immediate circumstances.

Another component of hope for Farran and colleagues (1995) is the rational mind of hope, which is the ability to assess reality, plan, and utilize cognitive resources to achieve goals in a timely manner. Farran and colleagues (1995) used the acronym GRACT (i.e., goals, resources, active process, control, and time) to describe the components of the rational mind of hope.

Lastly, Farran and colleagues (1995) described the relational heart of hope as the context of love and relationships. The authors argued that responsive and nurturing relationships early in life are developmentally necessary for hope to flourish. Current relationships impact hope as well. Examples of this relational aspect of hope in the medical sphere are compassionate behaviours and support from others (Farran et al., 1995).

The strengths of Farran and colleagues' (1995) work are their dialectic understanding of hope and the spiritual component of hope. Not all hope theorists propose a spiritual component, but some experience hope as a spiritual process. Farran et al.'s (1995) hope theory sensitizes me to the multidimensional nature of hope so that I am better equipped to develop a rich understanding of hope from my research. Furthering the conceptual openings offered by Farran and colleagues (1995) and Dufault and Martocchio, researchers have also provided a linguistic conceptualization of hope that has deepened my understanding of the function of hope in healthcare contexts (Eliott, 2005).

Eliott and Olver. In their research, Eliott and Olver argued that the meaning of hope can be found in understanding how people use hope in their language. Eliott and Olver examined how the language of hope was used spontaneously in end-of-life conversations, illuminating the nature and function of hope, especially in the context of immense difficulty.

Eliott and Olver (2002; 2009) examined the use of hope language in “do-not-resuscitate” (DNR) conversations with 23 patients. The findings described the ways that patients spontaneously used hope in these conversations. In the DNR discussions, the word hope was employed as a noun, an entity with both an objective and subjective quality. The objective noun form referred to hope as bestowed by medical science (i.e., hope for a cure). This form of hope was often not held by the patient but offered by medical professionals in the form of probabilities and prognoses (Eliott & Olver, 2002; 2009). The subjective noun form involved hope as an entity once again, but this hope was held by the patient and had varying degrees of resilience in the face of changing health circumstances and clinician behaviours (e.g., tumour growth or physician uncertainty) (Eliott & Olver, 2002; 2009). Patients also used hope as a verb. The verb of hope was an ongoing action for patients. As opposed to an independent entity of hope controlled primarily by medical prognosis, as is the case of the noun form, the verb form of hope was an action based upon the patient’s perception of probability and possibility.

Eliott and Olver’s discursive analysis of hope is vital for several reasons. Firstly, Eliott and Olver challenged the “empirico-realist” notion of hope proposed by theorists like Snyder (1995; Eliott & Olver, 2002). Instead, they stated that hope needs to be studied “in-action” in the context of the language. This is a perspective that I share with the authors. Although medical and psychological research has seen attempts to operationalize hope, there is little agreement on a consistent definition of hope (Eliott & Olver, 2002). In my study, I remained open to how the language and experience of hope are communicated through participant narratives. Another critical aspect of Eliott and Olver's work that is relevant to my own is the implications for clinicians and healthcare professionals. Healthcare professionals may be involved in the experience of hope for PwP. Being diagnosed with PD can lead patients to look to their physicians to protect and support hope.

Taken together, these theories have deepened my understanding of hope. Given my focus on hope as a lived experience, I must be aware of theoretical assumptions I hold to fully sensitize myself to new understandings about hope. My theoretical understandings of hope are informed primarily by the multidimensional and dynamic theories described above. In addition, I believe that hope is a deeply human concept, existential at its core. In alignment with the philosophy of Gabriel Marcel, hope is more than just goal-focused thinking; it can be a life force integrated into our being in the world. Below, I introduce an existential understanding of hope.

Hope Related to Being: Toward an Existential Understanding of Hope

In the section below, I describe my understanding of hope as an existential concept. Integrating and synthesizing the literature on hope, I provide a coherent rationale for exploring hope implicitly via this QMS study of existing phenomenological studies.

Hope is intimately tied to our being. For this QMS of phenomenological studies, I am informed by a corpus of literature along with a personal conviction that hope is an existential concept. Viewed historically, philosophers have long conceptualized the existential foundations of hope. Indeed, Cicero, a preeminent thinker and orator, proclaimed, “While there’s life, there’s hope,” indicating that hope was intimately intertwined with humanity (Smith, 2007). This sentiment is echoed by Gabriel Marcel and Ernst Bloch, prominent philosophers who understood hope as fundamentally intertwined with our humanness (Bloch, 1995; Marcel, 1951). Indeed, Marcel claimed that "hope is for the soul what breathing is for the living organism. Where Hope is missing, the soul dries up and withers" (Marcel, 1951, p. 10 - 11).

Viktor Frankl, a World War Two concentration camp survivor, wrote perhaps the most illustrative account of the importance of hope and meaning to one's life (Frankl, 1985). Many contemporary hope theorists have also articulated the existential nature of hope (see Dufault & Martocchio, 1985; Farran et al., 1995; Larsen & Stege, 2010; Scioli, 2011). This QMS study aims to answer the research question: How is hope reflected in the phenomenological literature on the lived experience of PD? Searching for hope when questions about hope are not asked is an epistemologically difficult task. Thus, it is vital to articulate my theoretical understanding of hope to provide the reader with context for my interpretations.

The analytic process for this QMS study was informed by the theoretical work on generalized hope offered by Dufault and Martocchio (1985). Dufault and Martocchio (1985) described generalized hope in the following way based on clinical data with elderly cancer patients:

> Generalized hope is a sense of some future beneficial but indeterminate developments. It is broad in scope and not linked to any particular concrete or abstract object of hope [...] Generalized hope protects against despair when a person is deprived of particular hopes and preserves or restores the meaningfulness of life - past, present and future - in circumstances of all kinds. It imparts an overall motivation to carry on with life's responsibilities and gives a broad perspective for life and thought that includes flexibility and openness to changing events (p. 380)

Emphasizing the dynamic and multidimensional nature of hope, I believe that Dufault and Martocchio (1985) articulated hope's ubiquitous and existential qualities. Generalized hope - or what other authors have defined as “hope related to being” (Benzein & Saveman, 2000) - need not be specifically focused on achieving a particular good but is instead described as a glow embodied in one’s being (Dufault & Martocchio, 1985). This version of hope is manifested through one’s actions, beliefs, emotions, and relations (Benzein et al., 2000). Benzein and colleagues (2000) describe hope related to being as an

> “inner process, belonging to life and being, and necessary for survival [...] hope is a positive experience, a will to be and to live when one can find meaning in life. It is an experience in the present and where the future is enacted. Hope is the awareness of one’s possibilities in life, the possibility of being able to make good and meaningful choices to gain independence, freedom, and inner peace. The experience of meaningful possibilities in life releases hope into energy and activates thoughts and feelings” (Benzein et al., 2000, p. 308).

Benzein and colleagues’ (2000) conceptualization of hope related to being and Dufault and Martocchios’ (1985) generalized hope share several features, both describing hope as (a) an inner motivational process, (b) connected to meaning, (c) linked to the past, present and future and finally (d) undergirding the will to live. Nekolaichuk and Bruera (1998) also discussed hope related to being (or generalized hope) in the following way:

> “The being component of hope is less tangible or visible, representing a personal inner experience that may be difficult to express outwardly. It is this part of the hope experience that is important to nurture and enhance within patients, particularly as their

> ability to engage in the action-oriented part of hope wanes with advancing disease" (p. 38)

In this QMS study, the analytic process herein was informed and guided by my understanding of hope related to being (generalized hope) as opposed to hope related to doing (particularized/goal-focused) (Benzein et al., 2000; Dufault & Martocchio, 1985). Generalized hope or hope related to being is less tangible and is often difficult to pinpoint when analyzing text or speech. Some have speculated this to be the reason hope was historically neglected in the human sciences (Webb, 2007). However, researchers have made fruitful attempts to explore the implicit features of hope. Larsen and Stege (2010a and b) found that therapists utilized hope in sessions in explicit and implicit ways. Explicit hope interventions were employed when the client and therapist intentionally discussed hope in session (i.e., the word hope was used). Implicit hope interventions were understood as interventions that addressed hope without referring to the word itself. The authors found that implicit interventions focused on the therapeutic relationship and fostering change in the client's perspective (Larsen & Stege, 2010a). In developing this idea of implicit hope interventions, the authors were informed and guided by the theoretical work of Dufault and Martocchio (1985), and their work represented crucial initial efforts to explore generalized hope.

Previous research exploring implicit understandings of hope provides essential theoretical and analytical precedence for the analytic frame of this study. In Larsen and Stege's (2010) study, they explain that hope "is a ubiquitous, if tacit, aspect of many psychotherapeutic approaches" (p. 273). Informed by an ever-growing corpus of literature on hope, I believe hope related to being (implicit or generalized hope) is a ubiquitous, if tacit, aspect of *the human experience.* It is present in each breath we take, each movement we make, and each relationship we build. It is present throughout life (as with particularized hope). However, when particularized hopes are threatened or broken down (as is the case in the face of chronic or terminal illness), hope related to being becomes more prominent. Less influenced by external circumstances, hope related to being becomes relevant when faced with an existential threat, deep despair, or captivity (Farran et al., 1995; Frankl, 1985; Marcel, 1951; Nwoye, 2011; O'Hara, 2013). When we have nothing left to hope *for,* we begin to enact hope differently – the experience of existential hope is brought into being. Hope of this kind must be resilient to the inevitable vicissitudes of the human predicament, which is why some authors characterize this hope as mature (Marcel, 1951; Nwoye, 2011).

Hope related to being is difficult to articulate. To understand this feature of hope, researchers must go beyond how the word hope is used explicitly and look to the ways we think, feel, behave, and relate to others in our lives (Dufault & Martocchio, 1985). Indeed, Stephenson's (1991) review of the literature defined hope as "a process of anticipation that involves the interaction of thinking, acting, feeling and relating" (p. 1459). It is through looking at our being that we can examine how generalized hope operates. It is perhaps this belief that has impassioned much of the constructionist and qualitative explorations of hope in the human sciences (Larsen et al., in press; Parse, 1999).

My passion for hope research lies in better understanding how generalized hope or hope related to being is experienced by those facing difficult health circumstances. For this reason, I have chosen to explore the lived experience of hope from within the phenomenological literature on PD. Phenomenology is concerned with describing the lived experience, that is, the underlying experiential structures or the universal essences of a phenomenon (Creswell, 2013; van Manen, 2014).

The roots of empirical phenomenology began with Edmund Husserl, but as a movement, phenomenology has been cultivated and refined by many important philosophers such as Martin Heidegger and Hans-Georg Gadamer (van Manen, 2014). Many of the studies chosen within this review aligned themselves with methods drawn from these philosophers. van Manen (1997) described phenomenology as the study of lived experience or "the study of the lifeworld - the world as we immediately experience it" (van Manen, 1997, p. 9). Phenomenology brings us into intimate contact with the world (van Manen, 1997). I believe phenomenology offers the best way to gain an understanding of the lived experience of hope, which psychotherapists and other healthcare professionals can utilize.

Hope has been identified as a common mechanism of positive change across therapeutic approaches (Wampold & Imel, 2015). Given that hope is essential in mental wellness and healing (Schrank et al., 2008) and medical outcomes (Rasmussen et al., 2018), a research-informed understanding of hope will likely benefit health professionals working clinically with PwP. The following section explores some of the major empirical research on hope and how it reinforces the need to examine hope in PD.

Hope and Psychotherapy

There is a wealth of research exploring the role of hope in psychotherapy, and hope-focused therapeutic approaches are being utilized with a growing diversity of individuals. In the section below, I discuss the literature on hope in psychotherapy and describe hope-focused psychotherapy interventions for those with chronic health conditions, including PD.

A considerable number of quantitative studies show that (a) hope can be promoted in therapy, (b) increases in hope are correlated with well-being and decreased distress, and (c) those higher in hope have better outcomes in therapy (Cheavens & Guter, 2018). Furthermore, hope is understood as a common factor contributing to the effects of psychotherapy (Wampold & Imel, 2015), with some researchers suggesting that “many of the benefits of [psychological] treatment occur via the installation of hope and changed expectations” (Duncan et al., 2010, p.152). Other authors suggest hope accounts for at least 15% of the variance in psychotherapy outcomes (Asay & Lambert, 1999). In a scoping meta-analysis of psychotherapeutic outcomes, hope was shown to have an effect size of d=0.24 (Constantino et al., 2011). While this literature demonstrates the importance of hope in therapy outcomes, psychotherapy researchers have also explored the experiences of hope in therapy.

Counselling psychology researchers have studied both psychotherapists’ hope-focused practices during therapy and clients’ experiences of hope in therapy (Larsen & Stege, 2010a; Larsen & Stege, 2010b; Larsen & Stege, 2012). Larsen & Stege (2010a; 2010b) found that psychologists used hope *implicitly* (i.e., without using the word hope) and *explicitly* (i.e., using the word hope) in session (Larsen & Stege, 2010a; 2010b). In terms of implicit uses of hope, therapists used strategies that fit into two categories: (a) *therapeutic relationship* (i.e., witnessing client hopelessness and highlighting client resources) and (b) *perspective change* (i.e., reframing, using metaphors, storytelling, externalizing and humour). Therapists used hope via three strategies: (a) *exploring multiple dimensions of hope* (i.e., cognitions, behaviours, emotions, and relationships), (b) teaching clients about hope and (c) *reframing problems as threats to hope.* All the above strategies provide information to help professionals mobilize and promote hope in therapy.

Larsen & Stege (2011) interviewed several clients about their experiences of hope in therapy. Clients described their experience of hope in the context of a *hope-fostering therapeutic relationship* in which their counsellor was invested, and the client felt understood. Clients also described moments of *supportive identity development* in which the client experienced positive changes in their self-understandings during therapy. Lastly, the clients described instances of *perspective change* as hopeful moments. These were moments in which the counsellor reframed their struggles from a strength-focused perspective (Larsen & Stege, 2011). These findings inform psychotherapists about how hope can be promoted in session. Indeed, the above research has led to more research attention on the application of hope-focused practices with chronic health conditions (see Edey et al., 2016; Larsen et al., 2018; Larsen et al., 2023; Murdoch et al., 2020).

Hope-focused approaches have been applied to people with chronic pain and PD (see Edey et al., 2016; Larsen et al., 2018; Larsen et al., 2023; Murdoch et al., 2020). These hope-focused approaches are rooted in the theoretical work of Dufault and Martocchio (1985) and applied research on hope (e.g., Larsen & Stege, 2010a; 2010b; Larsen & Stege, 2011). In hope-focused therapy, participants are encouraged to reflect upon and utilize hope, personal strengths, and resources. Howell, Jacobsen, and Larsen (2015) examined the effects of hope-focused group psychotherapy in people with chronic pain. Participants in this group experienced increased hope, well-being, and pain acceptance, as well as decreased catastrophizing after participating in the group.

In a recent mixed-method study, Murdoch and colleagues (2020) investigated the efficacy of the Strength, Hope, and Resourcefulness Program for People with Parkinson’s (SHARP-PwP). Employing a randomized, controlled design, researchers observed no significant outcome differences between the treatment group and the waitlisted individuals. Both cohorts demonstrated improvement in Parkinson's Disease (PD) symptoms and mental well-being. Noteworthy was the significant increase in reported hope when data from both treatment arms were combined. Qualitative analysis revealed substantial emotional, cognitive, and behavioural outcomes among participants after the groups. In another study, researchers investigated the facilitative therapeutic processes within this same group (Larsen et al., 2023). Research on hope-focused approaches with PwP is still preliminary. A synthesized understanding of hope for PwP can provide researchers and therapists new ways to think about hope in therapy.

Given that hope can be a powerful determinant of coping and well-being, the in-depth study of this experience is essential. Frank & Frank (1991) emphasized that restoring hope is one of the foundational tasks in therapy. Thus, psychologists working with PwP may benefit from an in-depth understanding of hope in PD. Knowledge gained from this QMS study may also be necessary for other health professionals, such as physicians, nurses, and social workers. Hope has also been investigated for its role in health outcomes across the lifespan. This research is summarized below.

Hope Research

There is now a large corpus of research demonstrating that hope relates to better outcomes at any age and in almost every life situation (Gallagher & Lopez, 2018). Of particular importance is the research on physical health outcomes and hope in older adults.

Hope and Physical Health. Hope has been shown to have a crucial role in favourable health outcomes. Those with higher hope may engage in behaviours and thought processes that reduce the likelihood of disease (Rasmussen et al., 2018). For example, hope has been linked to (a) not smoking, (b) eating more fruits and vegetables, (c) healthier dietary behaviours, (d) increased exercise behaviours, and (e) reduced alcohol consumption. Hope has also been shown to relate to coping, adjustment, and adherence to medical regimens in the context of disease (Rasmussen et al., 2018).

When one is diagnosed with chronic pain, cancer, or multiple sclerosis (MS), hope is correlated with one's ability to cope (Hill & Fuedner, 2018; Rasmussen et al., 2018). As in other chronic illnesses, like MS, the goal of PD treatment is not curing the disease but treating symptoms and promoting positive adjustment. In one study focusing on MS, hope was found to moderate the relationship between stress and adjustment to the diagnosis, acting as a buffer against stress (Madan & Pakenham, 2014). Hope has also been shown to predict medication adherence (Rasmussen et al., 2018). There is very little research on hope and PD, but the research described above highlights how hope is a worthwhile area of study. It also illuminates the relationship between hope and some adaptive processes that may occur in the face of disease. Further illustrating the importance of hope to PwP, there is now considerable research investigating the role of hope in older adults, revealing the developmental significance of hope.

Hope in Older Adults. Hope in older adults (> 60 years old) is related to better physical and mental health (Gum, 2018). For example, in older adults in the community, hope correlates with better perceptions of personal health and functioning (Barnett, 2014) despite having no relation to concrete physical health conditions or symptoms (Wrobleski & Snyder, 2005). Interestingly, in a longitudinal study, researchers found that high hope was related to a lower likelihood of mortality eight years later. The authors speculated that the relationship was not direct, however. They noted that higher-hope people were less likely to engage in unhealthy behaviours and more likely to engage in healthy behaviours (Wiest et al., 2013).

Research has found that high hope is related to fewer depressive symptoms (Cheavens et al., 2016; Gum et al., 2006) and suicidal thoughts (Cheavens et al., 2016) in older adults. Conversely, hope positively correlates with positive affect, life satisfaction, and well-being (Barnett, 2014; Steverink et al., 2001). Not only has hope been connected to enhanced overall mental health, but in the face of stressful circumstances, hopeful older adults can also cope in wise and adaptive ways with stressful events. For example, Ong and colleagues (2006) found that higher-hope individuals reported fewer stressful events in their daily lives and reported fewer lingering effects from stressful events. Greek researchers have also found that hope is correlated with wisdom (Moraitou & Efklides, 2013). According to these authors, wisdom was understood as combining practical wisdom (i.e., everyday problem-solving), dialectical thinking (i.e., empathic thinking), and knowledge that life is uncertain.

These findings in the context of older adulthood are relevant to the current study because the average age of a diagnosis of PD is around 50 or 60 years. Older adults are more likely to be diagnosed with PD, and research shows that older adults who are higher in hope (a) have better perceptions of their health, (b) experience higher well-being, and (c) cope better with stressful events. Given these three important findings, hope may be a crucial resource for PwP.

Chapter Summary

This chapter provided an overview of the symptoms, etiology, and treatment of PD and a summary of qualitative research on the lived experience of PD. It introduced relevant theorizing on hope and commented on the role of hope in psychotherapy and health outcomes. This QMS study aimed to investigate hope in PwP to inform practitioners so they can promote hope in their patients. The next chapter will discuss the methodology employed in this study.

Chapter 3: Methodology

In the following chapter, the method of Qualitative Meta-synthesis (QMS) is articulated to provide the reader with a comprehensive understanding of how this QMS study unfolded. Firstly, an overview of QMS methods and the general theoretical background of QMS will be presented. The role of the researcher in the interpretive process will then be articulated along with a rationale for a QMS study focused on phenomenological studies. Next, I outlined Sandelowski and Barroso's (2007) six-step QMS method, followed by a detailed explanation of how each step was applied in the current study.

Qualitative Meta-synthesis

QMS is a form of qualitative research synthesis (Sandelowski & Barroso, 2007). Qualitative research synthesis is an umbrella term representing several methods "aimed at systematically reviewing and formally integrating the findings in reports of completed qualitative studies" (Sandelowski & Barroso, 2007, p. 17). Within this umbrella, two broad methodological approaches stand out. Firstly, a qualitative meta-summary is a method oriented toward the topical summation of qualitative results. Qualitative meta-summaries offer integrations and overviews of qualitative data while adhering to quantitative assumptions and logic. These summaries may offer frequency counts and checks for validity and may adopt a positivist/realist research philosophy (Sandelowski & Barroso, 2007). This study used an alternative approach, QMS, which will be illustrated below.

QMS is an *interpretive* method whereby researchers gather data (in the form of published research papers) from qualitative studies to build a unifying but new interpretation of the data (Sandelowski & Barroso, 2007). Sandelowski & Barroso (2007) described that the results of a QMS offer more than a review of previous individual studies. Instead, QMS researchers are careful to maintain fidelity to the original findings while presenting altogether novel interpretive transformations of the data (Sandelowski & Barroso, 2007).

QMS is a qualitative research method whereby qualitative studies on a particular topic can be collected and their findings re-interpreted or thematized (Paterson et al., 2009). The process of QMS allows researchers to synthesize the existing qualitative literature on a particular topic and provide recommendations for clinical practice (Zimmer, 2006). QMS has been defined as:

> a form of scientific inquiry in which research findings about a target event, process, experience, or other phenomenon contained in written reports of completed qualitative studies are summed up, integrated, or otherwise assembled via qualitative or quantitative methods so that these research findings may more usefully serve as a basis for practice or policy or for future research (Sandelowski, 2012, p.19)

Environmental philosophers and scientists argue that the rapid consumption of materials on our planet leads to excess waste and pollution. Similarly, prominent QMS scholars argue that the rapid proliferation and production of research knowledge can lead to “research waste” in which high-quality studies are conducted but underutilized for their full translational knowledge potential (Malterud, 2019). Knowledge is a valuable and fast-moving resource in the modern knowledge economy. To build a more sustainable knowledge landscape, researchers argue we must learn to “upcycle” and utilize the knowledge base that is already available to us (Malterud, 2019). Upcycling is defined in the Oxford Learner’s Dictionary as the process of reusing (discarded objects or material) in such a way as to create a product of higher quality or value than the original (n.d). According to Malterud (2019), the goal of QMS is to analyze the knowledge products of individual studies in a way that maximizes the whole from the sum of its parts. This can develop a sustainable knowledge landscape. Malterud (2019, p. 2) elaborated:

> We are wasting research if we do not sensibly use what is already there. Knowledge is power and should be shared. Within the academic community, research evidence is regarded as a joint asset, and we can contribute to further development of knowledge capital by the best possible utilization of knowledge provided by other researchers. Instead of starting from scratch, we should therefore establish an overview of existing evidence, taking a qualified and critical perspective.

Recently, the qualitative research paradigm has had an immense increase in popularity alongside much-deserved acknowledgement for its credibility as a form of evidence (Sandelowski & Barroso, 2007). However, the epistemological and interpretive foundations of qualitative research often place little emphasis on notions of generalizability and validity - both terms perhaps inappropriately applied to qualitative studies. The point of individual qualitative studies is often not to make general knowledge claims but to make sense of a particular phenomenon and to build findings that resonate while prompting more questions.

Qualitative studies typically utilize small samples to search for the particular rather than the general. This is a strength of qualitative research. However, prominent qualitative researchers have expressed concern that results from qualitative research studies—though valuable—may lose value without concerted efforts to unify the knowledge (Estabrooks et al., 1994; Glaser & Strauss, 1967; Sandelowski & Barroso, 2007).

The Role of the Researcher

QMS is an advanced form of qualitative research. Within qualitative research studies, researchers play an active role in constructing findings. To understand the active role I took in the construction of the findings of this QMS study, I need to define what I mean by qualitative research in general. Much like the field itself, the meaning of “qualitative research” evolves in a continually developing social context. My understanding of qualitative research aligns with Denzin and Lincoln (2011). They defined qualitative research as “A situated activity that *locates the observer in the world*. Qualitative research consists of a set of interpretive, material practices that make the world visible. *These practices transform the world.”* (p. 3, Italics added for emphasis). According to Denzin and Lincoln (2011), qualitative research “locates the observer in the world” (p. 3) highlighting the active role of the researcher in the collection, analysis, and interpretation in qualitative work. Since QMS is a form of qualitative research, findings are inseparable from the person (i.e., background, biographical factors) of the researcher and this is emphasized within the structure of a qualitative study. Although qualitative approaches differ in their emphasis on this point, the general idea is that a qualitative study will be transparent and reflexive regarding the role of the researchers’ context in constructing findings. In Denzin and Lincoln’s (2011) definition, they state that research involves the collection of data to explain and understand the world around us, “mak[ing] the world visible” (Denzin & Lincoln, 2011, p.3). In making the world (or phenomena) visible through symbolic representations, the world is ultimately transformed, further emphasizing the active role of the researcher as the primary instrument in a qualitative study. This is especially true in this study. The results from each qualitative study are transformations of raw data, and my synthesis of these findings represents a further transformation in which I played an active role.

Many authors have developed guidelines in response to the proliferation of meta-synthesis projects across the healthcare disciplines (Sandelowski & Barroso, 2007; Thorne, 2017, 2019; Thorne et al., 2004). This QMS study was informed by Sandelowski and Barroso’s methodological structure for meta-synthesis. Created in the field of nursing research, this approach has now guided countless QMS studies across disciplines. Sandelowski and Barroso's (2007) method will be explored below, with specific attention to how this study was conducted.

The Method of Qualitative Meta-synthesis

There are many approaches to QMS (see Thorne et al., 2004 for review), but Sandelowski and Barroso's method is the most authoritative and widely used. According to Sandelowski and Barroso (2007), QMS is a systematic procedure comprised of six steps: (a) articulating the philosophical framework, (b) conducting an exhaustive literature review, (c) assessing the quality of each study, (d) classifying or summarizing the findings from each article, (e) combining the themes from the articles into categories and topics, and finally (f) synthesizing the information from all of the studies.

Articulating the Philosophical Framework

QMS researcher must describe their epistemological framework. Much like an individual qualitative study, the epistemological framework of the researcher must be articulated along with the methods and techniques used within the QMS. Articulating these points serves several essential purposes. First, the primary tool of interpretation is the researcher. This means that implicit assumptions and interpretive frameworks must be made known. Second, a significant part of positioning the philosophical framework within QMS is clarifying and developing the underlying rationale for the research question (Sandelowski & Barroso, 2007). Finally, a QMS study is a large-scale review of existing qualitative studies, each with its own philosophical assumptions. Therefore, a clear explanation of the epistemological position of the researchers will provide a rationale for choices made throughout the study, including the method used for analysis, the type of knowledge produced, and even the criterion for quality (Spencer et al., 2003).

Philosophically, researchers generally fit on a continuum anywhere from idealist/subjectivist and realist/objectivist orientations. It is crucial for researchers conducting a QMS study to articulate epistemological assumptions and to place oneself within this continuum (Heyvaert et al., 2017). In QMS, some researchers have postulated that it makes sense to adopt a realist stance (Sandelowski & Barroso, 2007). A realist stance means that researchers can assume that results accurately approximate the real world (Sandelowski & Barroso, 2007). The realist stance can be contrasted with idealism. Idealism - also known as constructivism - is an epistemological framework contending that there is “no shared reality alternative to multiple alternative human constructions” (Barnett-Page & Thomas, 2009). Within the realist/idealist continuum, there are several positions one can adopt as a QMS researcher, each with methods that best represent the respective epistemological position (Barnett-Page & Thomas, 2009).

Authors have noted that hope can be as unique as the clothes we wear (Jevne, 1994). Hope is also a cross-cultural phenomenon - a common thread weaved throughout the human experience (Parse, 1999). Mythological and folk representations of hope show that the concept may have some universal, shared qualities (Webb, 2007). Nonetheless, not everyone will share the same understanding of hope and experiences; beliefs and culture will mediate the experience of such. Although hope has been conceptualized and defined in realist (objectivist) terms (e.g., Snyder et al., 1995), my epistemological position in relation to hope is social constructionist (e.g., Dufault & Martocchio, 1985; Larsen et al., in press).

Social constructionism holds that knowledge is co-created by blending the interpretive paradigm of the researcher and the apparent qualities of the phenomena under study (Crotty, 1998). Within a social constructionist orientation, the objective qualities of the world blend together with the subjectivity of the researcher to create an altogether new and unique understanding of the phenomenon of interest (Crotty, 1998).

The terms ‘Social constructionism’ and ‘constructivism’ are sometimes used interchangeably, but they differ (Crotty, 1998). Constructivism posits that “individuals are continually engaged in processes of appraising their environment and acting on the basis of this sense-making process” (Mcleod, 2011, p. 52); this process takes place within the individual’s mind alone. Social constructionism adds that knowledge is co-created dialogically within a social context (Mcleod, 2011).

Applied to QMS, a social constructionist epistemological position aligns with several essential tenets. Firstly, knowledge and interpretations within the individual studies included in this review are bound by the social context of the researchers, participants, and broader sociocultural paradigm. As a researcher, I can only partially grasp the context-bound meanings that the authors wish to communicate. The analysis and writing process transformed the original data, and my interpretation of these findings is a further transformation informed by my sociocultural context. Indeed, even the retrieval and selection of the studies for this QMS review are informed by my presuppositions and social context. According to Denzin and Lincoln (2011), social constructionism acknowledges “the understanding that we are shaped by our lived experiences, and these will always come out in the knowledge we generate as researchers and in the data generated by our subjects” (p. 104).

Researchers who adopt a social constructionist orientation will likely acknowledge their presuppositions about a topic as they explore a research question. This further informs the reader and allows them to make sense of the findings based on their own backgrounds and ideas. Social constructionist research does not aim to capture objective truth but will instead offer one of many potential interpretations of a phenomenon. This is especially true in QMS research, which aims to reconceptualize existing findings within a new interpretive paradigm.

A QMS aims to produce findings with more *power* than individual studies alone (Malterud, 2019). For this QMS study, an objective truth may exist, but my access to it is informed by my previous background and foreknowledge (Gadamer, 1975). This means that I can attempt to approximate the truth, but inevitably, my findings are constructed in dialogue with the text (Zimmer, 2006). Further articulating my philosophical framework will allow the reader to be informed as they read the findings of this study. Toward this end, the following section articulates the rationale for focusing on phenomenological literature specifically in this QMS.

A Focus on Phenomenology. This QMS study aimed to investigate how hope is reflected in the phenomenological literature on PD. Researchers conducting phenomenological studies tend to adopt a subjectivist and/or constructionist epistemological position. For this reason, phenomenological studies tend to have small sample sizes and offer in-depth descriptions of lived experiences. As a result, phenomenological researchers sometimes offer tentative and context-bound conclusions. Comprehensive practice recommendations are appropriately withheld in the discussion sections of phenomenological reports.

Only phenomenological studies are included in this QMS. Synthesizing phenomenological studies allows researchers to garner concrete conclusions about the lived phenomena described in individual studies. It is important to note that meta-synthesis is not meta-phenomenology. Thus, the guidelines considered commonplace to phenomenological studies were not adhered to within this study (see van Rhyn et al., 2020). Instead, individual phenomenological studies were collated and analyzed to synthesize thematic elements.

I believe that phenomenological studies offer promise in approaching the generalized, implicit facet of hope. A brief detour into the philosophical assumptions underlying phenomenology is appropriate to provide a rationale for the appropriateness of phenomenology to the generalized dimension of hope.

Many credit Edmund Husserl for being the first philosopher to develop phenomenology into a formal philosophical system of inquiry (van Manen, 2014). Husserl took an objectivist orientation toward lived phenomena. Husserl's phenomenology aimed at describing the "essences of pure experiences… in its primordial origin or essence, without interpreting, explaining, or theorizing" (van Manen, 2014, p. 89). Husserl proposed a descriptive or transcendental phenomenology with the goal of understanding the lived nature of phenomena as they are in themselves before these lived phenomena are interpreted or explained (Dowling, 2007; van Manen, 2014). The phenomenology of Husserl was thus concerned with "the rigorous and unbiased study of things *as they appear* in order to arrive at an essential understanding of human consciousness and experience" (Dowling, 2007, p. 132, *emphasis in original*). Husserl was unconcerned with facts, generalizations, and theories in the same sense as psychological or natural science. He was also unsatisfied with the scientific foundations of his era. He thought phenomenology could establish procedures to ascertain objective knowledge (van Manen, 2014).

Although I agreed philosophically with some of Husserl's notions, for this study, I did not share his objectivist underpinnings. I believe seeking truth is a constructive, dialectic, and conversational process. My perspective on phenomenology aligned with that of Martin Heidegger, Husserl's student.

Instead of advocating for a transcendental phenomenological approach, Heidegger argued for a hermeneutic phenomenological approach focused on grasping the meaning of being

(Mcleod, 2011; van Manen, 2014). Being itself, that is, ontology, became the focus of inquiry for Heidegger instead of Husserl's pursuit of phenomenological knowledge (epistemology) (van Manen, 2014). One of Heidegger's significant contributions to the phenomenological movement was the wedding of phenomenology and hermeneutics. Unlike Husserl, who thought one should suspend one's preconceptions to gain closer contact with lived experience, Heidegger hoped to come to a clearer understanding of the essence of being. As "being" became the focus for Heidegger, he wanted to understand the essence of being – that is –the meaning of being (Mcleod, 2011).

Heidegger used the German term *Dasein*, which translates into "being-there", to describe the human being's state of presence in the world (van Deurzen, 2010). An essential characteristic of *Dasein* is that being is always situated, that is, amid a context. Heidegger used the term "being-in-the-world" to describe our embeddedness with the world. The hyphens literally illustrate the inseparable connection between being and the context of the external world (Braver, 2014).

For this study, I aligned more philosophically with Heidegger. Several of Heidegger's points are methodologically important. Instead of bracketing our assumptions and social context, researchers must acknowledge that we are always embedded within meaning. We are situated within a meaningful world upon which we must reflect to develop more sophisticated understandings.

Heidegger's ideas were important to my study for several important reasons. Firstly, in approaching the concept of hope, I recognized that my assumptions and preunderstandings (and those of individual study researchers) influenced the interpretations. Secondly, Heidegger's focus on our embedded consciousness as the primary object of study aligned with my view that generalized hope is best approached through phenomenology. Generalized hope is difficult for individuals to articulate (O’Hara, 2013). Instead, it is manifested through behaviours, thoughts, relationships, contexts, relationships, and sociocultural location. While many of the participants in the included studies did not use the term hope specifically, the journey of PD is nonetheless fertile ground for hope. For this reason, phenomenology, with its roots in the philosophical assumptions of Heidegger, was well-placed to offer innovative insights into the implicit operation of hope in the lives of individuals with PD.

Another phenomenologist that informed my work is Max van Manen. Among his many contributions to hermeneutic phenomenology, van Manen introduced four lifeworld existentials—lived time, lived space, lived body, and lived other—as a heuristic or analytical tool for interpreting phenomenological anecdotes. Lived time refers to our temporal experiences, lived space to our environmental encounters, lived body to our bodily interactions with the world, and lived other to our relationships with individuals or communities. van Manen's (2015) framework intersects notably with multidimensional theories of hope, such as Dufault and Martocchio's (1985), which identify temporal, relational, and contextual dimensions overlapping with van Manen's concepts. Since hope is a fundamentally existential concept, it is logical that it shares dimensions with these lived existentials. In my analysis, I employed both frameworks, offering a novel interpretation of the data.

Having articulated the better part of my philosophical and theoretical approach to exploring hope in the included studies, I will now transition into the practical aspects of QMS, including the search for qualitative reports, which eventually became the data for my study.

Searching for Qualitative Studies

In QMS, the process of comprehensive retrieval of published research is intentional and systematic. In this stage, the researcher should articulate essential components of the literature search, and the decisions made in the process (e.g., selection of databases, search parameters, sample parameters, temporal parameters, information management). The researcher is articulating the ‘search strategy’ that will be used to answer the research question.

Sandelowski & Barroso (2007) shared several methods for the searching process, beginning with informal browsing methods (e.g., footnote chasing, citation searching, journal runs and hand searching, area scanning, and author searches) and moving toward more systematic and comprehensive searches (e.g., searches within databases). Once the search is completed and references retrieved, the relevance of each article must be determined to make decisions about inclusion and exclusion. This is a systematic process that follows the articulated parameters closely. Still, the authors argue that if decisions are made to deviate from the articulated parameters, these decisions should be documented, and a rationale should be provided (Sandelowski & Barroso, 2007).

The search strategy can be articulated in several ways - the most prominent and commonly used being the population, intervention, comparison, and outcome (PICO) model (Malterud, 2019). The PICO method was initially developed for systematic reviews of Randomized Controlled Trials (RCTs). Since the advent of QMS procedures, some authors have modified the PICO approach to fit within QMS frameworks (Jamtvedt, 2013, as cited in Malterud, 2019). Because qualitative research is fundamentally different from quantitative research, authors within the QMS tradition have adapted the acronym PICO into an approach more suitable for qualitative research: SPIDER (i.e., sample, phenomenon of interest, design, evaluation, research type) (Cooke et al., 2012). SPIDER is a thoroughly researched method for finding literature. It has been compared metaphorically to “spinning a web for retrieval” (Cooke et al., 2012, p. 1441). The SPIDER method was used in this study.

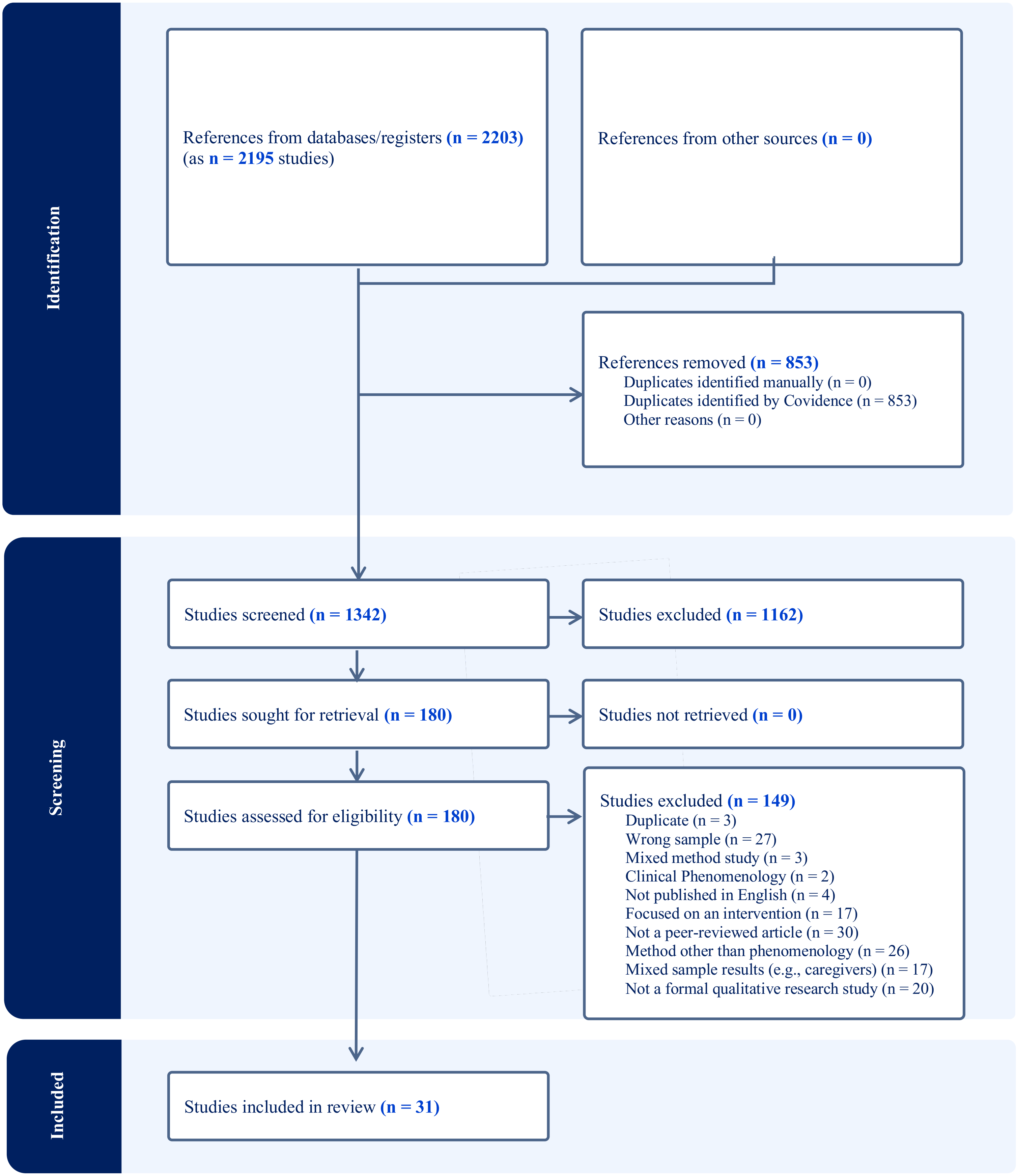
Applying the SPIDER acronym to this QMS study, only studies with samples of people with PD were included. I included studies that were conducted using interviews and text review. The evaluation of the study is the results or “outcomes” of a study. The outcomes of the qualitative data in this study could be subjective and various (Cooke et al., 2012), but I was primarily interested in studies that focused on lived experience. Lastly, it is crucial to articulate the designs of the studies one wants to include in the search. Mixed method and quantitative studies were excluded in this study, and only qualitative, phenomenological studies were included.

For this meta-synthesis, five academic databases were used to search for articles: MEDLINE, Psych INFO, EMBASE, CINAHL, and Philosophers Index. Before searching and retrieving sources, tentative inclusion and exclusion criteria were set. I chose the following inclusion criteria for article selection: (a) written in English, (b) peer-reviewed, (c) sample of only PWP, (d) phenomenological method, (e) focused on living with PD. Exclusion criteria were set as follows: (a) not phenomenology, (b) mixed method or quantitative studies, (c) mixed sample (e.g., caregivers), (e) not peer reviewed (e.g., dissertations and theses), (f) focused on treatment or intervention.

In the process of refining my search terms, I collaborated with several systematic review experts at the University of Alberta. I also took an online multi-module course on conducting systematic reviews. After careful searching using multiple combinations of terms, I eventually selected the most inclusive strategy. The following search terms were used (with corresponding suffixes for each database): Parkinson’s Disease or Parkinson, hermeneutic, phenomenolog*, lived or living, experien*, heidegger*, husserl*, merleau-pont*, colaizzi*, giorgi* ricoeur, speigelberg*, van kaam*, van manen. The search was conducted in June of 2022. While the search was completed with studies up to June 2022, no minimum date was set to maximize study data and inclusion of articles.

A total of 2203 references were located using these search terms. The references were then imported into the COVIDENCE systematic review platform. Covidence is an electronic platform used to optimize organization, screening, and evaluation for systematic reviews and QMS studies. From the 2203 references found in the search, 853 duplicates were automatically removed, leaving 1342 titles and abstracts to be screened. Upon screening the titles and abstracts, 180 studies were included for full-text review. Utilizing the inclusion and exclusion criteria identified above in the full-text review process, 149 studies were excluded from the analysis. Reasons for exclusion included the following: (a) not PwP, (b) not phenomenology, (c) not peer-reviewed, (d) not a qualitative study, (e) focused on an intervention, (f) mixed sample (e.g., caregivers), (g) dissertation/thesis, (h) not published in English, (I) duplicate, (j) mixed method study, (k) clinical phenomenology or (l) not a completed study. The complete PRISMA diagram showing the screening and study selection process (including reasons for exclusion) can be found in Figure 1 below.

Figure 1. PRISMA Diagram



Appraising & Classifying Qualitative Reports

The search and appraisal processes often occur concurrently, and they have a dynamic relationship (Sandelowski & Barroso, 2007). The appraisal process involves careful reading and documentation of the individual research reports (intrareport appraisal) followed by a structured process of comparative appraisal (inter-report appraisal). For the 31 studies included in my review study, intra-report appraisal involved reading and documenting the demographic features of the article (e.g., author information, geographical location of the study) and reading context (e.g., date of reading) of each study. From this point, I proceeded to paraphrase or extract all relevant components of the article (e.g., research problem, research question and purpose, literature review, philosophical framework, sampling strategy, sample size and demographics, data collection, data analysis, quality assurance, findings, and discussion) and collated all this information.

Comparative or inter-report appraisals present important components of included articles in a comprehensive table (Sandelowski & Barroso, 2007). I documented the 31 studies in a table that can be found in Table 1 in Appendix A. This table included the authors' information, year of publication, country of origin, study aims, participants, data collection strategy, and data analytic strategy. The process of appraising studies comparatively provides the context for the findings and allows readers to assess the significance of my interpretations given the sample I collected (Sandelowski & Barroso, 2007). The appraisals (both individual and comparative) and classification of the individual studies became the data for my study and were essential to the process of QMS.

Synthesizing Data

The next step involved synthesizing the data. This process is similar to the analytic process in individual qualitative studies. There are several approaches for the synthesis and presentation of findings. Just because one is writing a meta-synthesis does not signify any particular methodology (Sandelowski & Barroso, 2007). Indeed, Sandelowski and Barroso (2007) state: “the techniques you use to interpretively integrate the findings of qualitative research are as varied as qualitative research itself. Qualitative meta-synthesis entails leaps of imagination that you try to communicate as best you can” (p. 208).

Sandelowski and Barroso (2007) point out that the approach used to synthesize data depends on the purpose of your synthesis, the intended product of the synthesis, and the nature of the data (individual qualitative studies). The purpose of this QMS was to answer the following research question: How is hope reflected in the phenomenological research literature on the lived experience of PD? For the data synthesis process, the current study utilized thematic synthesis, a well-known and approachable form of data synthesis (Thomas & Harden, 2008). Thematic synthesis is inspired by meta-ethnography, grounded theory, and thematic analysis (Braun & Clarke, 2006; Glaser & Strauss, 1967; Noblit & Hare, 1988). Thematic synthesis follows three basic steps: (a) coding, (b) descriptive thematization and (c) analytic thematization (Thomas & Harden, 2008). Each of these steps will be outlined below in more detail, as well as the way they were carried out in the current analysis.

The initial process of analysis involved uploading the data (i.e., results or findings sections) from selected articles into Computer Assisted Qualitative Data Analysis Software (CAQDAS), much like in the process of individual qualitative studies (Thomas & Harden, 2008). For this study, I utilized ATLAS-Ti. I then read and re-read the results sections of these reports to become familiar with the data. It is important to note that the process of familiarizing myself with the data also took place during the appraisal and classification process identified above.

Once the data were collected and organized, systematic coding involved thorough, line-by-line review and coding of the data (Nicholson et al., 2016; Thomas & Harden, 2008). Even though my research question pertained to hope, I wanted to ground my coding in the data themselves instead of applying a particular theoretical framework at this early synthesis stage. This analytic stage differed from a priori qualitative analytic approaches wherein the researcher applies a theoretical position upon the data. My analysis in this study did not seek to validate theories of hope by examining the data through this theoretical framework. Instead, I employed an inductive approach, thinking deeply about how hope may implicitly appear in the extant phenomenological data on PD. To achieve this inductive approach through my coding process, I attempted to stay close to the data and to be inclusive of the original context and interpretations made by the individual researchers in each study.

In the process of coding, I also began to carefully *translate* the concepts and themes constructed within each study (Thomas & Harden, 2008). Each study contained several concepts, meanings, and interpretations (i.e., categories and thematic organizations), and it was important that these were preserved in the overall analysis. Translation of concepts, ideas, or metaphors from different studies is perhaps one of the critical products of a QMS and begins early in the analytic process (Britten et al., 2002). After line-by-line coding, I checked codes for consistency, accuracy, and correspondence with each original study.

After systematic coding, I proceeded to the descriptive-analytic stage and organized the codes into themes. Descriptive thematizing involved reviewing all the codes and grouping them based on their similarities and differences (Thomas & Harden, 2008). In this stage, I committed to a careful process of concept translation as described above (Noblit & Hare, 1988). Concepts or ideas within individual studies are considered “in-vivo” codes or concepts. These concepts from individual studies must be integrated or synthesized with other “in-vivo” ideas from other studies (Sandelowski & Barroso, 2007). At the descriptive-analytic stage, I also tentatively grouped themes into higher-order categories. Throughout the descriptive-analytic process, I repeatedly went back and forth between my codes, themes, and categories and the original data to check that my interpretations fit with the original studies.

In the last stage, analytical thematization, I analyzed the descriptive themes for overarching categories, constructs and higher-order interpretations from the data in alignment with the research question (Nicholson et al., 2016; Thomas & Harden, 2008). Thomas and Harden (2008) describe that this step in the process tends to be dependent on the “judgment and insights” of individual reviewers, implying that this stage involves interpretations that transcend the content of the original data, codes, and descriptive themes (Thomas & Harden, 2008). The analytical themes produced in a thematic synthesis have been compared to the “third-order interpretations” within the meta-ethnographic tradition (Malterud, 2019; Noblit & Hare, 1988). Third-order interpretations contain elaborations and expansions of original findings, which compose the primary interpretive products of a QMS.

Hope is the theoretical concept I imported into the analytical thematization stage in this QMS study. Sandelowski & Barroso (2007) state that "an imported concept is one that reviewers borrow from theoretical and empirical literature outside the reports in their projects to integrate findings. Imported concepts are different from in-vivo concepts, or concepts researchers [of the individual studies] themselves invent from their data to integrate them" (p. 204). During the analytical thematization stage, I imported and translated the six dimensions of the generalized sphere of hope from Dufault & Martocchio’s (1985), Farran and colleagues’ theory of hope (Farran et al., 1995), as well as van Manen’s four lifeworld existentials. Below, I explore how I integrated these theories into the overall analysis.

Theoretical Framework. The researcher of a QMS study needs to be transparent in their assumptions and biases when importing theoretical concepts. Sandelowski and Barroso (2007) state that "your selection [of imported concepts] will depend on your prior knowledge of and sensitization to relevant concepts and theories" (p. 204). I have theoretical and practical knowledge and training related to hope. This sensitivity and preparation gave me a unique positionality to identify and organize findings using imported concepts from the theoretical and empirical literature on hope. As a researcher steeped in the theoretical tradition of hope scholarship, this QMS was informed by both existential-phenomenological theory and hope theory (Dufault & Martocchio, 1985). From my perspective, the theoretical underpinnings of hope are closely tied with existential philosophy.

As a qualitative researcher, I am guided by the works of classic existential philosophers such as Husserl, Heidegger, and Gadamer and contemporary authors such as Max van Manen. As a psychologist, my theoretical framework is guided primarily by the works of Irvin Yalom, Emmy van Deurzen, and Viktor Frankl. The synthesis created in this study was informed by my reading and familiarity with these individuals' works.

Ensuring Quality

Quality in QMS is optimized using several methodological tools. In part, the tools one uses depend on the interpretive framework the author is using and the theory of knowledge or epistemological assumptions of the study (Sandelowski & Barroso, 2007). The validity of an interpretive construction thus comes from several different criteria, including the richness of the findings, the rigour of the methods, and the diversity of perspectives.

In a QMS study, authors have offered categories for assessing the validity of truth claims (Sandelowski & Barroso, 2007). First, *descriptive validity* refers to accuracy. Accuracy in a QMS is the degree to which the search and analysis identified a comprehensive article pool and the accuracy with which the reviewer documented relevant aspects of each article (e.g., appraising discussed above) (Sandelowski & Barroso, 2007). Second is *interpretive validity,* which involves the extent to which the points of view, experiences, and perspectives of the research data are fully and fairly represented. *Theoretical validity* refers to the extent to which the methods of producing interpretations and the interpretations themselves are credible (Sandelowski & Barroso, 2007). Lastly, *pragmatic validity* is the "utility and transferability of knowledge" (Sandelowski & Barroso, 2007, p. 228). Within each of these categories of validity, several methods were used in the current study, and these are described below.

To ensure descriptive validity, I conducted several hours of consultations with expert librarians to optimize search strategies and fully utilize available databases in the search stage (Sandelowski & Barroso, 2007). The search strategy was built in consultation with an expert librarian with experience and expertise in systematic reviews. In addition, I studied a detailed webinar on the use of COVIDENCE (a web-based systematic review manager) to optimize, document, and systematize the search procedures used in the study (University of Alberta, 2021).

In this study, I was also rigorous and systematic in documenting each step I took in the appraisal and extraction process. I kept a detailed audit trail of each decision I made, and my studies were extracted with meticulous care and integrated into an Excel spreadsheet that I referred to repeatedly throughout the analytic process. According to Sandelowski and Barroso

(2007), an audit trail is a fundamental tool for optimizing all four types of validity in QMS. An audit trail provides documentation and evidence of decisions made at every level of the research project, from developing a research question, study rationale and philosophical framework to decisions made about data representation in the writing process (Sandelowski & Barroso, 2007). It is important that an audit trail documents the rationale and process behind the implementation, optimization or change in techniques or methods (Sandelowski & Barroso, 2007). The audit trail becomes a form of data in the study while serving concurrently to ensure transparency and reflexivity (Sandelowski & Barroso, 2007).

Since the goal of QMS is to offer synthesis for a large body of research to create something new - both theoretical and pragmatic validity are essential. One way of promoting both forms of validity is through expert peer review (Sandelowski & Barroso, 2007). Sandelowski and Barroso (2007) describe the peer review process as a way to “translate” one’s findings into usable clinical knowledge and practical guidelines. In the peer review process, research reviewers consult with experts in the field. To manage theoretical validity in this study, I maintained consistent contact with my research supervisor (Dr. Denise Larsen), an expert in hope studies fluent in the theoretical lenses of hope I applied in my analysis. Together, we read and re-read my analysis for theoretical fidelity and coherence. This study was a dissertation, and my expert team of reviewers was my supervisory committee (two psychologists and one neurologist), who were asked to provide feedback on the transformation of findings into practice recommendations (Sandelowski & Barroso, 2007).

Lastly, to ensure interpretive validity, I engaged in a back-and-forth process of checking my codes, themes, and categories with the original studies. In this way, I could maintain the integrity of the whole while maintaining adherence to the parts. This process was reminiscent of the hermeneutic circle described elsewhere (Ellis, 1998; McLeod, 2011). Perhaps the most crucial aspect of interpretive validity is fidelity to the voice of the individual studies. In this QMS, the reader will notice an extended results section with many quotations. This aimed to enhance the trustworthiness of the findings and demonstrate the rigour of my analytic strategy. As has been articulated by several authors, QMS is typically conducted with a team of researchers due to the time-intensive nature of the research. For this study, assembling a research team was not feasible, and to protect validity, I offered many quotations in writing the findings.

Chapter Summary

This chapter served to articulate the basic structure of this QMS study. I utilized Sandelowski and Barrosso's (2007) step-by-step method for meta-synthesis. This approach utilized the following steps: (a) articulating the philosophical framework, (b) searching for qualitative studies, (c) appraising and classifying the qualitative reports, (d) synthesizing data (Thomas & Harden, 2008), and (e) ensuring quality. A total of 2203 studies were located in the search process. The final data for this QMS study included 31 studies comprising data from 289 individuals with PD. In the next section below, I present the findings of this meta-synthesis study.

Chapter 4: Findings

Description and Appraisal of Included Studies

The following chapter outlines the findings from my review of 31 phenomenological studies. Each article was read to appraise the quality of the studies, and relevant information was extracted from the articles, including demographic information (e.g., author information, country of origin, and sample characteristics) (See Sandelowski & Barroso, 2007). Next, relevant individual components of the research study (e.g., study aims, research problem, research question, techniques for quality assurance, methodology) were extracted and paraphrased/compiled. After extracting the data, all relevant information was compiled in a table to assess each study comparatively. A summary table of basic study information can be found in Table 1 in Appendix A. General information about study quality was gleaned from this process; however, ratings of each individual study were not used to exclude studies in this dissertation, and instead, the appraisal process was used to increase my familiarity with the studies and inform the analytic process (Sandelowski, 2012). Information gleaned from the extraction and appraisal process is summarized below.

Studies included in the review were published between 1991 and 2021. Almost half the studies were conducted in the United Kingdom (n=13), while others were conducted in Sweden (n=5), The United States of America (n=3), Canada (n= 2), France (n=2), and one each from Denmark, Netherlands, Slovak Republic, Jordan, and Spain. The findings of this review are based on a total sample of 289 individuals with PD (male = 142, female = 146, unknown = 1). The sample sizes of the individual phenomenological studies ranged from one participant to 14 (M=8.5), with ages ranging from 30 - 86. Due to inconsistent age reporting (some studies only reported the range without detailed individual data), a mean age for the entire review was not calculated. Twenty-six studies in this review did not include any information about the ethnicity of participants. In the studies that included information on ethnicity (n=5), all 42 participants were white.

Most of the studies (n=30) employed some variation of an interview to collect data, while one study utilized text review (see Van Der Bruggen & Widdershoven, 2004). While all studies used a phenomenological methodology, almost one-third (n=9) of those studies utilized Interpretative Phenomenological Analysis (Smith et al., 2009).

Almost half the included studies (n=15) did not describe methods to ensure trustworthiness or quality. Of the studies that included documentation of trustworthiness and quality assurance techniques, six utilized member checking, while nine utilized expert peer review or supervision. Most studies (n=27) noted detailed information about their sampling strategy, while four studies did not describe their approach. For those studies with a documented sampling strategy, 11 studies utilized purposive sampling; ten studies utilized convenience sampling, three used maximum variation sampling, and three used a critical case or single case. In all studies, the goal was to collect data from individuals with a current diagnosis of PD.

Conceptual Framework and Imported Concepts

For this QMS study, I was informed by Dufault & Martocchio's (1985) theory of hope, Farran and colleagues' theory of hope, and van Manen's lifeworld existentials. The reader will recall that Dufault & Martocchio's (1985) multidimensional model of hope contains two broad dimensions of hope (particularized and generalized). Within each of these dimensions are six spheres of hope (Cognitive, Affective, Affiliative, Contextual, Temporal & Behavioral). For Dufault and Martocchio (1985), hope is a multidimensional and dynamic construct that can look different from person to person.

Dufault and Martocchio's (1985) theory of hope served as a scaffold to organize the codes and themes. This model allowed me to apply a lens of hope to my analysis, offering theory-informed interpretations in response to my research question.

The constructed findings for this study were divided into five categories, including (a) Encounters in the Medical Context: Hope and Hopelessness in PD; (b) Unfamiliar Being: Hope Wilted, Strengthened, and Transformed; (c) Being Seen: Hope Reflected Through Relationships (d) Enacting Hope (e) (Re)Constructing Hopeful Narratives. A table with the categories, themes and subthemes can be found below in Table 2.

Table 2. Categories, Themes and Subthemes

Categories	**Themes and Subthemes**
Encounters in the Medical Context: Hope and Hopelessness in PD	Diagnosis ● *"Something is wrong": A Hope for Coherence* ● *Hope & Hopelessness Entwined* Medications ● *Hope Promised* ● *Hope in Captivity*
Unfamiliar Being: Hope Wilted, Strengthened, and Transformed	Shame: A Hiding Place for Hope Symptoms as Threats to Hope Lived Time (Temporality) ● *Grieving the Future and Reconstructing Hope* ● *Hope Reignited in the Present* Lived Body (Corporality) ● *The Uncooperative Body: Negotiations with Hope* Lived Space (Spatiality) ● *Space-Body-Time*

Being Seen: Hope Reflected through Relationships	The Captivity of Being Seen Maintaining Hope in Relation ● *Dependence vs Independence* ● *Encouragement* ● *Understanding* Social Stigma Disconnection and Withdrawal Healthcare Providers
Enacting Hope	Seeking Continuity & Acting Normal Constructing Self-Management Strategies
(Re)Constructing Hope Narratives	Identity Acceptance and Denial Personal Responsibility

Each of these constructed categories contained themes and sometimes sub-themes. Each category is described below, and themes are presented. Where appropriate, illustrative quotations are provided to demonstrate grounding in the data. Although each study utilized different ways of naming participants and citing quotations, a unified and consistent citation style was employed in this study for ease of reading. Each category and theme are described, and illustrative quotations are included with APA citations indicating the corresponding individual study. Although many of the original studies utilized pseudonyms for their participants, I chose to exclude pseudonyms in the findings section of this review. All the quotations below came directly from the results or findings sections of the original studies. When a participant's voice from the individual study was relayed via a direct quotation, this was clearly articulated using the term "participant." Occasionally, I utilized a quotation from an individual study that relayed the authors' interpretation of the data, and when this occurred, it was made explicit in the text.

Encounters in the Medical Context: Hope and Hopelessness in PD

Being diagnosed with PD and pursuing treatment for the incurable disease can offer a promise alongside threats to hope. The theme *Encounters in the Medical Context* highlighted how the experience of diagnosis and treatment for PD was understood in the context of the experience of hope. This theme was informed by the contextual dimension of hope conceptualized by Dufault & Martocchio (1985). The contextual dimension of hope describes the inevitable life circumstances that “surround, influence, and challenge” hope (O’Hara, 2013, p. 16). The initial context in which hope arose in a PD journey was often the first appointment with a medical professional who diagnoses the disease and prescribes treatment.

This category described the context in which PD diagnosis and treatment occurred within the broader story of a person’s life. A diagnosis can make sense of perplexing symptoms and offer explanations that provide coherence and meaning to the early experience of PD, offering hope. Concurrently, a diagnosis can also feel like a critical threat to hope. Similarly, a medical treatment strategy that includes medication may leave some feeling hopeful about managing symptoms. However, the necessity of taking medications with no end in sight alongside the side effects experienced (e.g., on/off periods) can be discouraging. The duality of hope and hopelessness was demonstrated in these conflicting experiences when first diagnosed with PD and beginning active medical treatment. The following category highlighted the prominent phenomenological features of diagnosis and treatment and how these experiences impacted hope.

Diagnosis.

The experiences of being diagnosed with PD had common elements woven throughout the studies examined. While some participants described a process by which they slowly came to realize something was wrong with their bodies, others shared that the diagnosis came as a sudden shock.

“Something is wrong”: A Hope for Coherence. Prior to diagnosis, many participants described a sense that “something was wrong.” While some participants described a marked increase in strange and unexplainable symptoms, others described it as more of a slow and insidious process. In the cases of more gradual realizations, frequently, participants described a sense that something was wrong but may have explained it away or rationalized the experience (Habermann, 1996). In either case, participants often described a moment when they recognized that their symptoms may be a sign of something more significant, and they sought an understanding and an explanation. In the PD journey, this may reflect the beginning of hope. The awareness of a need for an explanation may not be explicitly identified by those with PD. Instead, during this time, a sense of confusion and despair may indirectly lead to a hope for the expertise of a health professional.

In one study, authors described a participant’s experience of “losing grip” and realizing that something was wrong:

> “[I] knew there was something wrong’’: ‘I was glad to have a name on [sic] it. I thought I was going nuts; I really did think I was beginning to lose my grip because I was crying. Well, I wasn’t crying. I would get up in the morning and go make a cup of tea, and my eyes would start to cry. I didn’t feel unhappy, sad or upset in any way, but my face would cry...I’d just be standing there having a cup of tea and start to cry and I thought this is mad, I’m losing my grip’. (Eatough & Shaw, 2019, p. 53)

For some participants, the journey from noticing symptoms to being diagnosed was a long and drawn-out process. This process was often described as an immensely difficult time, ridden with confusion and chaos, followed by an initial hope - a determination for explanation and answers. Participants were usually able to recognize something was different about their functioning, but sometimes consultations with medical professionals felt invalidating and threatening to hope. One participant explained:

> “The same year I was diagnosed with Parkinson’s, I went to a neurologist who told me that my shakiness was psychosomatic . . . this thing is always being questioned because I have the wrong disease for my age and then I have other chronic conditions. I often hear that it’s not possible. I can’t have both. (Rosengren et al., 2021, p. 8)

In another study, the authors summarized the process of seeking a diagnosis:

> Consistently, participants spoke about "something being different," although this frequently was not affirmed by healthcare providers. Many participants went to their primary providers seeking an explanation for what they were experiencing only to have their experiences negated by their physicians, who suggested that their experiences were insignificant. It was not uncommon to have to experience further or worsening symptoms before they gained the attention of their primary physicians. Several participants shared that they were deeply concerned by the time their physicians acknowledged there was a problem. They had begun to wonder whether they had brain tumors or had experienced strokes. Obtaining or securing a definitive diagnosis was essential for participants (Habermann, 1996, p. 402).

Both studies above (i.e., Habermann, 1996; Rosengren et al., 2021) offer an illustrative account of this initial and wavering experience of hope and hopelessness prior to receiving a diagnosis. Initially confused by early PD symptoms, one of the first signs of hope was an active search for validation and answers. Unfortunately, this early search for hope was sometimes met with a magnified vulnerability when complaints were not taken seriously.

Hope and Hopelessness Entwined. Although many participants described the diagnosis as distressing and confusing, others expressed great relief as the diagnosis provided a sudden sense of understanding and an explanation. For those describing a sense of relief, receiving a diagnosis offered them a reprieve from the captivity of confusion and despair. Receiving a diagnosis provided by a health professional offered a coherent rationale for symptoms and a way to begin thinking about a way forward. One woman even described a sense of elation and excitement: "[The doctor said:] 'You've got Parkinson's.' I could have kissed him. He put a name to what was wrong with me" (Marr, 1991, p. 326). Another participant shared that they felt even comforted by the diagnosis: "I was so comforted when I knew my diagnosis … At least I finally knew what my diagnosis was and what the management was" (Nazzal & Khalil, 2017, p. 78). The power of a medical diagnosis to legitimize and validate participants' experience was profound, and often, it permitted participants to begin processing their future with the disease (Habermann, 1996). In this way, a diagnosis may have served as an occasion in which they felt their concerns validated and their hope acknowledged - especially after an often long and confusing process of trying to understand a baffling array of symptoms.

While some participants described the diagnostic encounter as relatively positive, others described the diagnosis as a significant hope-threatening experience. Some expressed a feeling of bafflement and confusion about how this could happen to them. For example, one participant shared: "I felt pity [for] myself when I knew about the diagnosis; all kinds of questions came to my mind … why me? The moment when I've been told about the diagnosis was a very tough moment in my life." (Nazzal & Khalil, 2017, p.77). Other participants described difficulty accepting the credibility of the diagnosis (Twomey et al., 2011; Whitehead, 2010). A diagnosis of PD was sometimes seen as an injustice and as something undeserved - a participant shared: “I feel sorry for myself, I suppose, sorry for me and a bit angry because I think, well, you know, what’ve I done to deserve this?” (Twomey et al., 2011, p. 8). Amongst the shock and confusion of the diagnosis, the sense of anger at a perceived injustice may have contributed to the difficulty many reported in accepting the credibility of the diagnosis. One participant described the difficulty he had in accepting the diagnosis because it was based on a clinical exam: “Because there’s nothing you can measure. It can’t show up on X-ray, they can’t do anything to find out that it’s that, but they know it’s that.” (Eccles et al., 2011, p. 1413). Difficulty accepting a diagnosis made by a health professional may be perceived as a way of denying reality. It may also be an expression of hope (often unshared with their physician) that the diagnosis was an error.

Being diagnosed with PD is a sensitive and vulnerable time to hold hope. Participants often commented on the support (or lack thereof) they received during this time as particularly crucial. Some participants shared troubling experiences related to the abruptness of the diagnosis and the lack of support offered by their physicians, which impacted their hope.

> I began to ask questions. He said, "Well, it's an incurable disease." Told me the classic symptoms and these kinds of things [...] And after about 5 minutes, he abruptly stood up and said, "Well, that's all the time I have today, and obviously this is a complex discussion, and you won't remember this anyway, so you'll just have to come back another time.” I was shocked: in maybe 12 minutes of his total time seeing me, he diagnosed me with an illness and gave me no hope [and] told me to take some medicine... And then he dismissed me. (Habermann, 1996, p. 404).

This participant remarked specifically about how hope was not offered in this consultation. Further, the participant shared that they felt dismissed and invalidated by their physician, further threatening hope. The perceived role of the physician in offering hope to the patient is implied in this quotation, with the participant feeling shortchanged in the interaction. In meeting with a physician, there is often an implicit hope for a cure or an explanation. Participants were also attentive to the way the physician treated them. Indeed, some participants held several expectations, beliefs, and needs during the diagnostic encounter. Unmet needs in the context of this encounter were threatening to hope.

Like the experiences relayed above, another participant shared: "He prescribed the medications ... and when I asked: What can I do as a patient? ... He said: With this diagnosis?! Nothing (?!)." (Tomagova et al., 2021, p.277). The authors of this study went on to explain: "She [participant] experienced a degrading style of communication, reflecting the dominance of paternalism and leading to a violation of her dignity, which hindered the development of hope." (Tomagova et al., 2021, p. 277). The above participant quotations illustrated how hope may be connected to having one's dignity respected and maintained in diagnostic conversations.

Medication

Many participants described their relationship with medications as complex and multifaceted. For some, medication offered a promise of hope, providing control and near instantaneous benefits (Gibson & Kierans, 2017), while others described that medication threatened their hope, citing a loss of control, medication dependence, medication ineffectiveness, and unpredictability as critical features of this experience.

Hope Promised. Amongst the hope-promoting experiences with dopaminergic medications, some participants described the feeling of freedom that they were afforded by taking their medication at the right time:

> When they kick in, you feel as if a weight comes off your body, and you feel, ahh, I can move. But it isn't a weight, it's like a restriction, and it frees itself, gradually, and [suddenly] you find you can move your legs much more easily, and you can walk more naturally. It comes on very quickly (Gibson & Kierans, 2017, p. 541)

With near-instantaneous relief coming from medications, many participants stated that medications became essential to hope and life - as one participant shared: "Well, the tablets keep me going. Without them, I can't function." (Suddick & Chambers, 2010 p. 297). Another participant described:

> It just comes on like a light switch. One minute, you'll be fine; the next minute, you're like a zombie. And my partner notices it straight away. She's only got to look at me, she can tell. They feel terrible, to be honest ... When you are in an off period, you feel so lousy. It's unbelievable. Your coordination, you're like, you are stiff more or less, you can't get going properly. So, you just wait for (medication) to kick in and then get back going again (Gibson & Kierans, 2017, p. 542).

For many, medications offered an immediate sense of personal control, agency, and hope. When medication wore off, participants described profound helplessness and disconnection from hope. Although medications were intimately connected to one's experience of hope, the benefits of medications were sometimes outweighed by the experience of existing on a knife's edge between hope and despair. Medications were a dichotomy between promising hope and holding hope captive.

Hope in Captivity. While most participants appreciated that medications reduced their symptoms, many participants shared that medications made them feel uncertain, without control, and dependent (Bramley & Eatough, 2005; Nazzal & Khalil, 2017). This combination often left participants in a vulnerable and restrictive relationship with medications. Medications frequently became a source of stability and instability as if hope was held captive:

> The medication is really great, but it has restricted my life; I cannot go anywhere unless I have my tablets … my life has flipped over, I was doing a lot of work without the need of anything. But now I have to take it with me all the time … Sometimes I miss a dose and totally forget that I need it till the symptoms get worse. (Nazzal & Khalil, 2017, p. 77).

This participant illustrated how quickly they can feel dependent upon the effects of medication. Whereas before, participants may have lived a life of unacknowledged freedom, with the medications arose a feeling of being dependent and tethered to an external support.

One participant described: "It depends whether I'm "on" or "off." When the tablets are working, I'm on, and when the tablets aren't working, I'm "off," so I can't really do much. I just sort of sit around waiting for them to come "on." (Murdock et al., 2015, p. 1367). This participant described that medication effects were often unpredictable and uncertain. This often led to a feeling that one was trapped. One participant described this sense of uncertainty:

> it's all depending on whether they produce the dopamine or not; they can control me because I can take the tablets, and if they don't work, there's nothing I can do about it, not a damn thing; I can just sit there and wait for it, the next lot of tablets, I can't keep taking them and taking them because I think my head would explode if I did. (Bramley & Eatough, 2005, p. 228)

With the fluctuating nature of medication effectiveness, sometimes patients described a sense of frustration at the unpredictability of their lives. To cope with this, some participants began to measure their lives within the increments of their medication. This complex and regimented lifestyle was seen as a necessary component of reclaiming their freedom and hope (Haahr et al., 2010). As time would be measured in medication dosages, participants adapted by modifying their activities. This was a common strategy employed and illustrated how hope in PD became a constant balance between certainty and uncertainty.

Medications were like an unpredictable gatekeeper to hope and freedom. Paradoxically, medications were understood as a major promise of hope. However, medications also placed strict yet unpredictable restrictions on this freedom. In the lives of those with PD, medications offered, at once, the promise of hope, but they also served to hold hope ever captive.

Unfamiliar Being: Hope Wilted, Strengthened, and Transformed

The category *Unfamiliar Being* offered a window into the experiential world of participants. Within the accounts of PwP in the studies, many participants discussed the vulnerability of having PD. Each participant described how their life and hope underwent a profound change in the context of PD. With PD, one’s bodily connection to the world felt unfamiliar, which presented a formidable challenge to the growth of hope. Yet, some experiences helped foster and transform hope amid this unfamiliarity. This category reflected participants' descriptions of negative emotional experiences like shame, anxiety, and grief and positive emotions adjacent to hope, like interest or curiosity. This category also depicted the profound shift in individuals' lived experience of time, body and space and how this transformed hope.

My interpretations in this category are informed by Dufault and Martocchio’s (1985) affective dimension of hope, which involves the positive or negative emotions that impact one's experience of hope. It was also informed by Farran and colleagues' (1995) experiential dimension of hope. Farran and colleagues (1995) describe the experiential dimension of hope as "the pain of hope," illustrating that hope often arises in highly challenging circumstances such as a difficult medical diagnosis. Farran and colleagues (1995) also describe the experience of hope as a dialectic between hope and hopelessness. Informed by these theories, the themes within this category are: (a) Shame: A Hiding Place for Hope, (b) Symptoms as Threats to Hope, (c) Temporality, (d) Corporality, and (e) Spatiality.

Shame: A Hiding Place for Hope

A significant theme for participants was shame, followed by the desire to avoid situations where their symptoms would be displayed. Many individuals reported feelings of intense psychological pain associated with others perceiving them in a negative light. Shame dampened hope and left many participants less willing to participate actively in their lives and futures. One participant shared: "It was going from being a strong, healthy woman to somebody you looked at and you thought… kids stared at you, and you felt a freak." (Bramley & Eatough, 2005, p. 229). As can be gleaned from this quote, the experience of shame was connected to the ongoing construction of identity. Shame can be conceptualized as a threat to participants' implicit hope to feel acknowledged and accepted. The experience of shame brought into sharp focus how one hoped to be seen by others. When expectations for how participants hoped to be perceived were not met, it resulted in grief and hopelessness. For those experiencing PD symptoms, shame revealed an implicit necessity and hope to be acknowledged, accepted and valued by others. The authors of one study shared:

> Going for a walk is troublesome. The women felt that people in the neighbourhood stare at them and seem to wonder 'What's wrong with her, is she in pain?' They feel like idiots, are

> ashamed of the disease, and believe people think them incompetent (Caap-Ahlgren et al., 2002, p. 90)

A participant from another study shared: “The staring is what hurts me the most … psychologically I am very down. This of course affected badly my daily life. I do not like to go out so people will not notice my shaking.” (Nazzal & Khalil, 2017, p. 76). When people would stare, participants often reported embarrassment with a corresponding wish to isolate themselves. Frequently, participants commented on their lives becoming ever smaller - compounded by anxiety about how people would view their symptoms. Further commenting on the painful experience of shame:

> When I go to the store, people look at me out of the corner of their eyes. Often, I have problems with walking, I freeze and sometimes I stumble. When it happens, people look at me bizarrely. If it happened at home, it wouldn’t bother me at all. It’s more in front of other people. Sometimes I see them laughing at me. That hurts, actually (Parry et al., 2022, p. 10).

Shame was a critical emotional experience for those with PD and had a significant impact on their life and hope. Some individuals modified the way they conducted themselves in public, while others avoided social situations altogether. One participant offered: “Over the last year, I’ve become more withdrawn. I don’t want people to see me. I’m afraid to see how people look at me.” (Parry et al., 2022, p. 16). When feelings of shame were present, it became difficult to envision a future in which things would be different, especially considering the gradually worsening symptoms of PD.

While the reactions to shame differed between participants, the psychological pain associated with being judged for PD was shared by almost all participants. Two participants offered a stark and frank disclosure of adverse reactions in the public. “People tell me that I don’t look good, I’m haggard… they say, ‘She’s drunk!’” (Tomagova et al., 2021, p. 277). Another participant shared: “You can feel those looks; they’re almost poisonous, condemning” (Tomagova et al., 2021, p. 277). This quote illustrates the negative and palpable fear of being judged harshly by others. Hope was difficult in the context of feeling condemned and poisoned. Shame seemed to serve as a barrier to hope and, even more, a contributor to feelings of hopelessness and despair. Yet shame also revealed in participants the deep and human need to be seen for who they were.

Symptoms as Threats to Hope

Participants reported several common symptoms of PD (e.g., fatigue, cognitive problems, apathy, freezing, sleep problems, slowness of movement, balance problems, facial masking, and speech problems). Symptoms were central to the lived experience of people in this study, and the symptoms fluctuated and were yet ever-present barriers to hope. For example, one participant described:

> It sounded great, you know, rehab because I have pain. I was accepted for rehab, but I work 75 percent in home care, I mean I just didn’t have the energy . . . I was supposed to go twice a week, and it was so hard, you know I have to walk the dog too; I mean, I got completely stressed out, so I had to quit. (Rosengren et al., 2021, p. 7).

Another participant described how cognitive symptoms compounded difficulties connecting to others:

> You are in conversation with somebody, and all of a sudden, you’ve forgotten the name completely. It could be somebody well known, who you’ve worked with, and you just can’t. I go through the alphabet sometimes trying to memorise names... It’s unpredictable,

> if you start a conversation and halfway through, ‘oh what’s he talking about’, it’s gone from your mind. It happens quite often (Gibson & Kierans, 2017, p. 540).

Since symptoms were an ever-present experience of the disease, disrupting the mind and body, participants described a loss of agency and hope. One participant shared:

> ‘‘I can’t be bothered ... it doesn’t hold any interest for me. Perhaps because I can’t do them as well. It would take me two hours to do a job that was 15 minutes if it involves dexterity’’. (Simpson et al., 2015, p. 613)

Another prominent symptom described by participants was freezing (i.e. when the body suddenly becomes rigid and unable to move). It was a deeply uncomfortable experience for many participants. One participant described how freezing often came about in situations in which they were under stress:

> “It’s unpredictable it can happen erm when I run out of medication, or it can happen when I’m under stress ... If the telephone rings and I’m in a sort of freezing mode, then everything becomes much more difficult because I know I’ve got to get to the telephone to answer it. (Redmond & Suddick, 2012).

Without having experienced this symptom oneself, it can be difficult to imagine the fear and panic freezing would instill. The unpredictable nature of freezing meant that participants often could not anticipate an episode. The future became a place of sudden unpredictability. One participant described it vividly:

> “Yes, I can feel it coming on; I can be walking along the road or sitting in a chair. It comes on at random; it’s unpredictable, you never know when it’s going to hit you it just comes on, and I think oh no, no, no, please go away, but it doesn’t go away, it stops me in my

> tracks I have to sit and let it out till it leaves me again and changes my body again. It's horrible, really horrible, it's interfering." (Redmond & Suddick, 2012)

This quotation illustrated the unwelcome nature of symptoms and how they seemed to disrupt participants' connection to the future and hope.

Individuals with PD described a broad range of reactions to their PD symptoms. The lived experience of PD symptomatology was experienced as challenging and unpredictable due to their inconsistency, leading to feelings of uncertainty and a struggle for control.

> It seems odd … when I go bowling, I can lift a bowling ball that weighs about 16 pounds. I can easily hold that with my fingers, but I cannot, when I am [at my] worst, pull a 1000 g duvet into place. That's just the way it is (Haahr et al., 2010, p. 412).

When uncertainty became the rule rather than the exception, envisioning a future became difficult, which led to frustration and helplessness.

Participants described time without symptoms as free, life-promoting and potent, while the experience of some symptoms was equated with death and hopelessness. One participant described her experience of freezing:

> "[in on periods, I feel] better, elated, jump up and down can get things done, run around like a headless chicken doing stuff, feels good again, feels good to be alive again, feel free again... I feel dead when I'm freezing… [when I'm not frozen, I] feel alive again it's wonderful ... feel like I'm happy (Redmond & Suddick, 2012, p. 172).

The fluctuating and life-interfering nature of symptoms sometimes led participants to experience a deep and persistent sense of hope for symptomatic relief (Olson et al., 2013). While time without symptoms may have felt relatively brief, these moments of aliveness were sometimes imbued with a potent hope and expectation. The contrast between symptomatic and symptom-free periods meant that participants were living in a complex and ever-changing relationship with hope.

Lived Time (Temporality)

van Manen (2015) explained that lived time can often feel different from time as objectively measured (e.g., seconds, minutes, hours). One can impatiently wait for 20 minutes, which feels like an hour, while on the other hand, one can be absorbed in an activity as time quickly slips away. For participants in this study, understandings of the past, present and future had a tangible impact on hope. In their multidimensional theory of hope, Dufault and Martocchio (1985) described the temporal dimension as how our perception of time can influence and impact hope. Although hope is typically conceptualized as a future-focused experience, it is also influenced by our past and present. The theme of lived time and its subthemes were informed by Dufault and Martocchio's (1985) temporal dimension.

Reflections on lived time weaved throughout the individual studies. As participants encountered the various difficulties of PD, their lived experience of time was also affected. Typically understood as a future-focused experience, hope was informed by participants' constructions of the past and present. The theme of temporality is explored below, including how participants experienced the present and future.

Grieving the Future and Reconstructing Hope. For participants in this review, a diagnosis of PD represented a sudden change to the constructed narratives about their hope and the future. Many participants described that living with PD changed how they envisioned their future, and this weighed heavily upon their experience of hope. The future seemed tentative and unfocused, lacking the cohesion it possessed before the diagnosis. Some participants found it extremely difficult to envision a livable future with the disease: ''Everything I had planned about what my life would be like is not going to be like that, and this stresses me out'' (Duran Bermejo et al., 2019, p. 258). Other participants even denied having a future altogether, emphasizing the present: “I am a person without a future. Neurodegenerative patients have no future; we have a present'' (Bermejo et al., 2019, p. 258). Participants shared that PD was an unanticipated interruption to their expected life course.

Some participants' understanding of their future was so threatening that they could not think about it. Participants also described their perception of the future as permeated with feelings of fear, foreboding, and uncertainty. One participant expressed: “In the early stages, Parkinson’s is mainly a matter of foreboding—fear of what is ahead—as opposed to any painful or debilitating symptom at the moment” (Machalaba et al., 2020, p. 34). Thinking of the future caused such feelings of anxiety, uncertainty, and even dread that it stole opportunities for participants to enjoy and value the present moment:

> “The present is stolen away by the future … How are you going to live now with the knowledge of what’s ahead? I want to look toward the future, see my children get married, and see my daughter’s baby brought into the world. But if I’m busy controlling the future menace from stealing the present, I can’t think about those things… So, I’ve noticed I don’t think about the future to preserve the present, but I’ve noticed that I’ve knocked off a lot of good things too (Machalaba et al., 2020, p. 35).

This participant felt that PD stole away meaningful potential futures. The participant also described a desire for hope but felt that PD was a barrier to envisioning a future with any value. Another participant also expressed an outright refusal to acknowledge a future with PD, instead imbuing the present with as many opportunities as possible:

> I realize psychologically that it could bear on you, and it could make you depressed. Especially when you realize that it's never going to go away . . . I have refused in my own mind to look to the point where I am immobile. . . We do as much normal activity as we possibly can. I read with my wife. We go to the movies a lot . . . [and] we travel whenever both of us are in condition to do so (Whitney, 2004, p. 33).

Difficulties envisioning the future also influenced participant's interactions with healthcare providers:

> Well, [the physician] didn't really give me a prognosis. They said, they don't really want to tell you what's going to happen, but you know it's going to be terrible, you know, and er, I didn't press it, 'cos I didn't really want to know (Delaney et al., 2012, p. 528).

Participants reported that foreboding feelings about the future and being reminded of their mortality caused them to shift their perception of time. Participants' outlook on the future became constricted and oriented to the immediate and near future (i.e., planning the next movement of their body or the timing of their next dose of medication, etc.). Furthermore, thoughts beyond the near future become uncertain and posed a possible threat to hope, one participant shared:

> "I stopped thinking about the future; I only want to think a year ahead of time. I don't think it's sensible to think, 'Where am I going to be in five years? Where am I going to be in ten years?' Because I really don't know. I could be worse off; I could be the same. (Machalaba & Sass, 2020, p. 35)

Instead of being extinguished, hope for the future was transformed as the participants' relationship with time shifted. Thinking about the future sometimes involved coming to terms with the limitations placed upon them by the disease and the possibilities available to them.

Some participants described a feeling akin to grief as they were forced to construct new ideas about the future and leave others behind. PD changed participants' perceptions of the future, and some individuals were forced to reconstruct what was possible; one participant stated:

> It’s a kind of grief, in some way you’re mourning for the life you thought you had, and you feel like you won’t be able to do this and that, and then suddenly you realize that yes, I can, there’s nothing stopping me. (Rosengren et al., 2021, p. 8)

As the above participant contemplated the limitations placed upon their future, an active reconstructive process was also occurring. A changed perception of the future led some participants to take an active role in constructing the future they wanted. This led some participants to experience a sense of gratitude for where they were in life. Others still attempted to cope with imagined futures by outlining their personal control, agency and autonomy in determining their future.

> I’ve accepted that I got it, and I know the reality of what I’m going to be like in 30 years. I could be really bad, [and] I might not be . . . but if I keep exercising, maybe I can slow the progression down. I mean, it’s something I can’t change. It’s not like I broke my leg [where] I can change that in 6 months . . . but PD it’s a disease that right now there is no way we can cure it. We can slow it down a bit and I figured okay, let’s slow it down; work really hard and get it slowed down (Ravenek & Schneider, 2009, p. 1933).

Through the process of constructing and reconstructing their hope, some participants described coming to a different perception of the future. In one study, authors offered their interpretations alongside a quotation from one of their participants:

> “I think not about what lies ahead for me but about what awaits,” wrote one patient

> Here, “what lies ahead” signifies knowledge of inevitable disability, whereas “what awaits” alludes to the unknown experiences and opportunities that can still be pursued. As another subject wrote regarding his sense of hope, [It is] not a naive hope that I will, by some miracle, have my former self restored but hope that tomorrow, and the day after, can still be a day from which a measure of joy and meaning can be derived. And from hope springs optimism that, even with great limitations, there is life to be lived (Machalaba & Sass, 2020, p. 36).

This participant explicitly commented on their changed ideas about the future and hope. They acknowledged how refining their view of the future and nourishing a vital and hopeful experience of the present as a result.

Hope Reignited in the Present. Adjusting to PD often meant that the present moment was imbued with great significance. With a future uncertain, many participants emphasized the importance of living an authentic and joyful life in the present. Some participants articulated that life felt more urgent and saturated with immediacy since they were unsure what tomorrow would bring. This feeling of immediacy brought renewed hope to use one’s skills and capabilities before they might be lost. One participant explained: “This is my life, one and only life I’ll get, so live it, as long as you can and just put as much into it as you can” (Bramley & Eatough, 2005, p. 231). Another participant described: “This is my goal: to get everything that I want to do started before Parkinson’s gets too bad” (Murdock et al., 2015, p. 1370). For some, realizing the importance of the present was a lesson learned too late in life: “Life is more... live as you are today because you never know what tomorrow will bring. And I wish more people would do that. You don’t have to become ill to realize that you have to enjoy life.” (Rosengren *et al., 2021, p. 9).* Another participant shared his recommendations for those with PD:

> Keep busy. Try to ignore it. Try to live like you've always lived except, if you want to do anything, do it. You know like the Nike commercial "Just Do it" I added one word "now." Don't postpone anything. . . Just do it now (Whitney, 2004, p. 33).

Sometimes living in the present led to engaging more joyfully in life, but sometimes participants described apathy for the future, which led to more hedonistic or impulsive lifestyle choices as one participant shared: "I always feel a bit guilty about what I'm eating these days, but if it's unhealthy I don't care 'cos it doesn't matter, you know? (Delaney et al., 2012, p. 529). In either case, the present was a central concern for PwP.

Connecting more deeply to the present moment allowed participants to navigate previously unexplored avenues in their lives. While the present moment was imbued with a sense of meaningful urgency and immediacy, a simultaneous sense of bodily slowness gave some participants the impression that their sense of time and opportunity was narrower than before. This dialectic between urgency and slowness was an important precursor to refocusing on aspects of their life that were readily accessible. The relationship between the meaning of PD for one's future and the urge to connect more deeply to their surroundings led to a richer and more focused connection to the present. As was demonstrated by one participant, this seemed to ignite a refined hope:

> "Now, my world has shrunk, and my perspective has gotten a little bit deeper. I don't have to go so far away for experiences anymore. I mean my life and my world: it was the world because I worked with people in so many parts of the world. So, it's as though there has been a new opening / you know, those cabinets that you can open, and there are new pictures? It's like that (Sunvisson, 2006, p. 97)

Another participant described how acknowledging their limitations offered space to consider new opportunities:

> Earlier, you lived an unlimited life; you thought you would live forever. And you don't anymore. Not me, anyway. I'm always conscious about limits. […] I think people look at things in a narrow-minded way. Maybe I see things a little bit deeper. I see other dimensions. And then ... a lot of things aren't that important anymore (Sunvisson, 2006, p. 97).

Acknowledging limitations while reconsidering one's future allowed participants to reconstruct their experience of the present. Hope was ignited in the present when participants permitted themselves to examine avenues nearer to them in both time and space.

Lived Body (Corporality)

PD changes one's relationship to the body. The theme of Lived Body described participants' experiences navigating a changed relationship with their bodies. Phenomenological thinkers state that we experience the world through our body, and in turn, the body shapes our lived experience (van Manen, 2015). Hope, as a lived experience then, can be intimately linked to our ability to control and navigate the physical world. The corporality theme described how PD changed participants' relationship with their bodies and how this may have impacted their experience of hope.

The Uncooperative Body: Negotiations with Hope. This subtheme described participants' relationship with their bodies - mainly the difficulty they had in enacting their hope and agency through their bodies. PD changes one's relationship with the body, and some participants described that their bodies felt uncooperative, foreign, or "alien." Most participants described a disconnect between their mind and body and shared that it was difficult to engage in everyday tasks because they felt their bodies would not cooperate. For most participants, this unfamiliar relationship with the body prompted a new and unfamiliar relationship with hope. Whereas before the PD diagnosis, participants described experiences of unacknowledged bodily autonomy, PD tended to interrupt this process, presenting a new barrier to hope. Individuals differed in the images and metaphors used to describe this feeling. Some described the feeling as if the body was a malevolent presence:

> It’s like having an evil twin. I go to bed at night, and I think ... I’m going to get up and I’m going to hoover the floor and I’m going to do some washing. I get up in the morning, and I go and get the hoover out, and I can’t do it. I just stand there. I know what to do, I know exactly how to hoover, but my hands won’t do it...it’s things like that I feel like I’ve got this evil twin that won’t let me do what I want to do, it stops me when it finds out what I’m trying to do (Eatough & Shaw, 2019, p. 54)

Some participants described negotiating with their body as if it had a mind of its own:

> When we have drinks, she can’t carry them, so I carry them in, and what I find interesting, whenever I’m holding something. Now I used to just let go, but sometimes he doesn’t let go. I have to say, ‘let go hand’, so to speak ...It’s definitely different. (Gibson & Kierans, 2017, p. 540)

In Machalaba and Sass’ (2020) study, participants described the uncooperative body and the experience of “silently … coaxing an unruly antagonist” (p. 32). One participant explained: “I make one move, and [PD] makes another” and: “[PD] is like a cat and mouse game; Parkinson’s is the cat, and I’m the mouse.” (Machalaba et al., 2020, p. 32).

The unpredictability of the body was unsettling for many participants:

> Yeah, you know I slide like this sometimes. It also happens when I'm washing up. Suddenly, I find myself half standing up at the sink. And I don't know why it's like this. And it happens when I must stand and wash up and at the same time know where I have all the parts of my body. It isn't easy. Or when I don't understand because this is happening against my will (Sunvisson, 2006, p. 94).

Clients described this experience of the uncooperative body in many ways, but threaded throughout each experience, a common thematic element was a disconnection between the will of the mind and the expression of will via the body. In Van der Bruggen & Widdershoven's (2004) study, many of the participants illustrated this phenomenon: "[My hands] don't do what I want [... my mouth] chatters if it pleases him' (Van Der Bruggen & Widdershoven, 2004, p. 291). Another author described: "It's my machine. My brain (...) I just can't make my mind ... stay on it. I want – or my mind wants. To go its own way. I just stop." (Van Der Bruggen & Widdershoven, 2004, p. 291). Feeling limited control over the body, many participants felt despair and helplessness:

> It's getting too hot; he wants to get out of his easy chair. Again, he doesn't succeed, probably because he is afraid he won't manage, which makes his muscles go rigid. Damn, damn. He has lost control over his body, it follows its own whims, not his will. It makes him depressed (Van Der Bruggen & Widdershoven, 2004, p. 292).

The interrupted connection between one's hope and the expression of this hope through the body presents a highly challenging barrier that only those with physical limitations can understand. It seems that for PwP, one needs to continually renegotiate their relationship with their body using an immense amount of determination and hope.

Lived Space (Spatiality)

In this study, PwP gradually adapted to a new way of existing in and navigating through space. As participants described above, the fractured relationship between their mind and body affected how they continued to occupy and navigate space. Movement through space can be taken for granted by the able-bodied, but with PD, movement through space is carefully considered and sometimes painfully deliberate (Parry et al., 2019). Contemplating time necessarily invokes contemplation of both the body and space. All these constructs seem to also overlap with the experience of hope. The overlap between hope and these existential constructs will be described below.

Space-Body-Time. This subtheme describes how participants' experience of spatiality impacted their experience of their body and time. In some ways, participants with PD described an intimate relationship with the space around them; they concentrated on aspects of the environment that may have been previously taken for granted. The boundary between characteristics of space and feelings in the body seemed to blur for some participants. Participants recognized that their external environment would influence their internal experience. One participant described the difference between being indoors and outdoors:

> It's a question of space. Inside, I walk one way, outside another way. Straight away, I feel different. It's incredible; I'm more at ease. Inside, I feel suffocated. …. I feel completely suffocated here. (Parry et al., 2019, p. 2786)

Similarly, negative memories held by participants from a familiar environment caused some participants to notice increased symptoms in a space when they returned. In this way, the meaning of a space had implications for the capability of the body to navigate the space in the context of their symptoms:

> I find myself in situations I've already lived. I remember having problems and that makes me afraid. I tell myself, 'Look out,' 'don't freeze'—and then it happens. I bring it upon myself. If I don't think about it, sometimes I walk better (Parry et al., 2019, p. 2788)

Reflected in the closer relationship individuals developed with space, individuals described a more conscious relationship to their bodies navigating space. To successfully navigate a space, some participants paid more attention to how their bodies (specifically their feet) navigated the space. Navigating objects in space demanded that participants modify their relationship to obstacles in the room. The language used by the following participants evokes the sense of a careful, pre-planned journey: "I look where I want to go, and then I set off. Once I'm moving, I watch my feet. My eyes are always on my feet." (Parry et al., 2019, p. 2788). Language commonly used to refer to simple bodily acts could no longer be used in the same way as one participant illustrated: "Getting in and out of bed or turning in bed are 'acts I have to perform and no longer acts that simply happen' 'Jumping out of bed' is not an option anymore" (Van der Bruggen & Widdershoven, 2004, p. 293).

Just as the feeling of space was intimately connected to one's sense of body, similarly, one's experience of space and time seemed to be intimately intertwined for participants. Individuals described that their world was metaphorically and literally shrinking: "You can just see your life getting smaller all the time, you know?" (Twomey et al., 2011, p. 11). As PD limited their capability to access certain aspects of their world, participants described feeling constrained. As this feeling of being physically constrained grew, so did their sense that time was going faster than they could manage. While some participants grieved their shrinking spatiotemporal world, others adapted by paying attention to features in their environment that were near in time and space. Sunvisson and colleagues (2006) shared their interpretation:

> [W]hen she had the energy and capabilities, she was involved in larger ‘‘external’’ projects / the wide world. Home was a place to eat, sleep and meet people. As she increasingly required more peace and quiet, she started to notice the birds outside her windows and the changing of the seasons. These things captured her attention when larger project no longer occupied her (p. 96)

For participants, hope was transformed by changes to their temporal, spatial, and corporeal existence. For example, when participants experienced their spatiotemporal world shrinking, hope tended to involve goals nearer to them in space and time. As time felt rushed and space constrained, so too can the notions of possibility and capability – transforming hope.

Being Seen: Hope Reflected Through Relationships

As Dufault and Martocchio (1985) explained, the affiliative dimension of hope is the “sense of relatedness or involvement beyond the self as it bears upon hope” (Dufault & Martocchio, 1985, p. 386). O’Hara (2013) explained that this dimension is about otherness and can encompass familial and extra-familial relationships as well as relationships with larger society and even animals. According to O’Hara (2013), the affiliative dimension is manifested through hope for mutuality, connection, and shared humanity.

The category *Being Seen: Hope Reflected Through Relationships* included participants’ relationship with others and encompassed feeling seen or observed, experiencing inner conflict between autonomy and dependence, social stigma associated with PD, and finally, withdrawal and disconnection. Within each of these themes, several concepts and polarities are described.

The Captivity of Being Seen

One of the most prominent themes within the data was the feeling of being seen. Participants described an acute sensitivity to others watching them. In reaction to this sense of being observed, many participants felt conspicuous or a sense of being on display, which influenced hope in several ways. The knowledge of being seen and the resultant emotional reactions, such as anxiety and even tension, seemed to have a dampening, constricting, and compressing impact on hope. One participant shared: "if I'm fidgety, you think everybody sees it, you know. I think everybody's looking at me, [because] I know they are." (Gibson & Kierans, 2017, p. 536) For some participants, they described a sense of discomfort in displaying characteristics of PD:

> I will stand there like a statue unable to move anywhere. People are looking strangely, they really are, and I don't like it. Even if people in town know that I am slow …you really don't feel good… I simply don't want to advertise for the disease. (Haahr et al., 2011, p. 412)

Another participant expressed that this was one of the most challenging aspects of living with the disease: "People staring… I try not to pay too much attention, but I can still feel them looking. It hurts all the same" (Parry et al., 2022, p. 10). In a study on the experience of delusions in PD, a participant described the discomfort and fear that can be aroused in being seen: "Even when I was walking, I felt like they were keeping tabs on me, and I'd run miles to keep out of the way" (Todd et al., 2010, p. 1294).

For some participants, the feeling of being watched by those around them was paired with awareness of how this was changing their communication with others:

> I am very conscious of speaking … differently to you now, for instance … I am conscious that I am [s]lurring a bit … it's not as clear as it should be ... gets stuck in my mouth I don't know why that should be… but … yes that's becoming more common, people saying 'umm?' or 'say it again…' or whatever… (Whitehead, 2010, p. 32).

In terms of its impact on hope, being seen was a threat to hope in that participants felt anxious and less able to connect with others. Being seen also made participants feel overwhelmed and suffocated, which exacerbated the expression of symptoms. The worsening of symptoms made participants feel less in control of the image they hoped to portray in the public domain.

Maintaining Hope in Relation

This theme encompassed participants' experiences of personal relationships in living with PD. It specifically outlined how hope was maintained through relational experiences.

Dependence vs Independence. A major internal conflict described by participants was that of dependence vs independence. Accepting increased support from others came at the expense of autonomy, dignity, and sometimes hope. Many participants were acutely aware of the eventual burden that PD would have on their partners and caregivers: "Well, I suppose it affects my wife ... [you're] reminded you're on a downward spiral, I'm worried about how it will be for her at the end" (Redmond et al., 2012, p.173). Depending on others is a vulnerable relational process, as one participant relayed:

> "I think there comes a time when … you need to let the children, well, they're not children anymore, you need to step back, it's their turn to take on some of their responsibilities and that kind of thing … I just hope that I'm not becoming a burden, you know I'm not becoming somebody who's …a drag (Eatough & Shaw, 2019, p. 56).

One participant described the process of growing dependence and what it meant for his sense of identity and hope:

> I hate it ... from doing so much and doing things for other people, and now needing to stand back and let other people do the work for me is a hard thing to accept having been an active

> person. So, you don’t put yourself into that position of having to feel that feeling, so again, that’s where the apathy creeps in ... it’s easier not to do it. (Simpson et al., 2015, p. 614).

Increased dependency challenged this participant’s identity, which threatened hope, leading to apathy. Another participant described:

> You get really frustrated. You feel that you can’t manage because you want to feel independent. You want to do things by yourself, to do what you want, not being forced to ask someone else to do things for you. Instead, you want to feel that you can manage. (Olsson et al., 2013, p. 744)

While most participants expressed a clear preference to remain independent, some participants even shared explicitly negative reactions to compassion from others: “I hate compassion, I say: That’s enough, friends and family! I have Parkinson’s, but my head still works fine.” (Tomagová et al., 2021, p. 277). Maintaining independence was highly important, as another participant expressed: “I have to do it on my own ... If someone starts to help me, I just stop being self-sufficient ... Dependent individuals can’t do anything freely … I will stop existing.” (Tomagová et al., 2021, p. 277). Interestingly, this participant equated dependency with ceasing to exist. Striving for independence and autonomy was seen as worthy moral and existential striving in and of itself.

Even if independent action was nearly impossible, striving for independence was still a worthy aspiration and continually negotiated. In this negotiation process, participants described strategies to protect their autonomy or provide help to others in exchange for the help they received. In negotiating their independence, participants attempted to maintain agency and dignity despite undesirable circumstances. In one study, a participant described a negotiation

> with their neighbour: “I’ll make a deal with you. I’ll provide the snow blower, and you provide the labor. You do yours, and you do mine, and we’re very happy.” (Whitney, 2004, p. 32)

For participants, meeting the needs of others and fulfilling interpersonal roles seemed to maintain a sense of social value. When this social value was internalized, perhaps participants felt more willing to accept help. Conversely, feeling unable to fulfill their social roles threatened hope, causing participants to feel disconnected, discouraged, and apathetic.

Encouragement. This sub-theme described participants' experiences of encouragement from others and the hope-promoting support they received. Amongst the experiences, participants found most supportive of hope were experiences of genuine, patient and non-patronizing concern. Participants also described the importance of being held accountable for their own progress. One participant explained: “She encourages me. Even when she’s helping me, she’s still encouraging me to be independent, you know, to get up and go out, you know. She’ll not sit and say, “Oh, you poor thing.” (Murdock et al., 2015, p. 1369). Another participant described: “Well ... it feels good … they [friends in the choir] accept me for who I am ... and yes ... they are so thoughtful, and if I don’t show up, they phone me and ask me how I’m feeling” (Olsson & Nilsson, 2015, p. 5). Yet another participant described how encouragement was motivating:

> They encourage me, goad me, embarrass me into doing some [activities] and they also will alter their activities to accommodate me which is very good. [My husband] just you know, like he always is trying to get me into doing more. He probably encourages me and gets me going more than I would do myself. (Ravenek & Schneider, 2009, p. 1929)

Many participants described that supportive others were an essential component of taking risks and pushing past anxiety. One participant described: “I think they’re all supportive, and if you have a positive attitude, they're willing to help you participate, or you know they don't discourage going to do things because it's too risky or something like that." (Ravenek & Schneider, 2009, p. 1929). Another participant described:

> So, my friends and my family just drag me out and say, you know, 'Don't worry about what other people think or whether they look at you funny or not,' because I shake incredibly in class because I get tired . . . I don't think I could ask for much better support . . .. You need people around you to get you going and say, 'It's okay, don't worry about it, we'll do whatever you can.' So yeah, they've been incredibly helpful in exercise. (Ravenek & Schneider, 2009, p. 1930)

The support and encouragement they experienced from others helped participants manage shame and bolster hope. Encouragement and support were vital in maintaining their lifestyle and engaging in positive, health-promoting behaviours. Experiences of encouragement and support seemed to be essential to maintaining hope in the face of difficulty.

Understanding. There were several references to feeling meaningfully understood by others in the participants' lives. Some participants described that feeling understood was a source of strength, while others described warm and positive feelings. One participant provided an illustrative account:

> I went to get out of the car, and I was soaking wet. Absolutely soaking wet, my bladder had let loose ... So now I'm in a position I'm soaking wet, I'm a long way from home, I'm fed up, so do I go home or what. So, I rang them, and I said, 'Look, I'll tell you straight now, I've got Parkinson's disease, I've just had a mishap in as much as my bladder's just let go, I'm soaking wet, if you don't want to see me I quite understand, but I can't come back all this way again, so it's now or never sort of thing.'... I can honestly say coming

> away from there they were very friendly people, ... there were three men there that I was dealing with, two of them had got experience of Parkinson's in the family, and they wanted to know more. (Gibson & Kierans, 2017, p. 537)

For this participant, the understanding they experienced from these three individuals seemed to be memorable, meaningful, and protective of hope. It was important for participants to spend time with others who understood PwP. One participant described:

> "Parkinson's is a big neurological disease. No one knows how it's going to pan out, and there's a certain amount of nervousness about it. But if you're with other people who are similarly affected you can discuss, talk to them, their carers, their wives, their husbands. There [are] a few people younger than me, not many. And we share experience… you become very friendly with them." (Lovegrove & Bannigan, 2021, p. 6)

Another participant described specifically the understanding they experienced from others: "They'll come out and walk with me sometimes, or friends will come out and bike with me . . . it's nice to have friends who are compassionate and … understand what you are going through" (Ravenek & Schneider, 2009, p. 1930).

Many participants valued finding others who were aware of their PD struggles. Feeling understood was described as a crucial relational process that supported the maintenance of relational hope.

Social Stigma

Contrasting with the subtheme of understanding, many participants referred to a sense of social stigma about PD. Social stigma - the feeling of being misunderstood - was a significant threat to hope. Most participants described that society misunderstands PD or holds stereotypes about the disease. This would challenge participants' hope, leaving them frustrated, misunderstood, and isolated. One participant shared: "For people, Parkinson's means shaking, and that's it ...it is not seeing how you get up in the morning and how your husband has to help you with everything.'' (Durán Bermejo et al., 2020, p. 257).

Several participants described a feeling of being misunderstood and made specific comments about how others had preconceptions about PD. One participant explained: ''For people, a person with Parkinson's is an elderly person who shakes. . . and it is very difficult to change a person's [understanding]'' (Durán Bermejo et al., 2020, p. 257). Being misunderstood was a significant barrier to hope via feelings of disconnection and isolation that followed. However, sometimes misunderstandings prompted a hope to correct misconceptions and self-advocate. One participant shared: "it's as if I was an old lady that couldn't manage and I'm not old, and I want to say ''I'm not old, I'm young, I'm young at heart, that isn't affected." (Bramley & Eatough, 2005, p. 230). This participant's inner experience was at odds with others' apparent conceptions, evoking dissonance and an urge to correct these misunderstandings.

Societal misconceptions were difficult for participants, prompting some to keep their diagnosis of PD a secret from others. One participant described:

> My wife and I reached the conclusion that if you tell people [they often say] ''poor thing. . . I wonder if he will fall!'' or they treat you as if you were a child and so we decided to not tell people until it was noticeable. (Durán Bermejo et al., 2020, p. 258)

It was common for participants to describe how a lack of understanding paired with societal stigma made them feel isolated and confused. Some participants felt stymied by the predicament of educating others about the disease. A participant shared:

> There’s not enough information about PD. People don’t talk about it enough. People think PD is just people who tremble. They don’t know. Me either, I didn’t know. When you have a disease like that, you don’t know where to turn to. (Parry et al., 2022, p. 13)

Another participant added that education might improve the way others think about PD: ‘‘A lot of people don’t understand, and I’m sure if they were educated, they’d think differently’’ (Simpson et al., 2015, p. 616).

It was often difficult for PwP to encounter rudimentary understandings of PD held by others. Stigma and misunderstanding were common barriers to connection and hope in the participants' experiences. While some participants expressed a willingness to battle stigma, others felt frustration and a sense that the problem was larger than themselves. In either case, participants felt stigmatized, and education and awareness were offered as hopeful pathways toward destigmatizing the disease.

Disconnection & Withdrawal

Many participants felt disconnected and withdrawn from the world. Disconnection and withdrawal were sometimes attributed to a lack of motivation to connect with others, a desire to hide oneself due to shame, or even a lack of self-efficacy for social relations. One participant shared: “Over the last year, I’ve become more withdrawn. I don’t want people to see me. I’m afraid to see how people look at me.” (Parry et al., 2022, p. 16).

Some participants felt incompetent in social situations, often letting others take the lead in their social circle. Describing the increasing difficulty in handling communication, one participant shared:

> "It seems to me … when an argument ensues in the family for some reason or other, I tend to let somebody else handle them and not myself because they can cope with it better than I can." (Elliott & Velde, 2005, p. 70)

Other participants described concern that their symptoms burdened others in their lives. One participant described a persistent belief that she would be a "drag" to her friends:

> I was always out with my friends…visiting garden shows, garden centres...and all those things have been very much curtailed because I'll slow them down and although they're quite happy for me to go with them, I know that I'm going to be a drag on them. (Eatough & Shaw, 2019, p. 56)

PD can feel profoundly isolating and threatening to hope. Although many factors contributed to this sense of isolation - shame and distress about symptoms were important contributors. Isolating oneself left participants feeling alone and disconnected from important cultural and community activities. One participant in Nazzal and Khalil's (2017) study illustrates:

> The disease has affected me the most. The problem of moving has all the effect on my psychological being. Slowly, I [find I] cannot leave the house. I became unable to go to mosque or even to communicate with my neighbors. (p. 78).

Isolation and withdrawal were common experiences for PwP in the studies. For some participants, this withdrawal was prompted by feelings of shame and embarrassment, while others were concerned that their symptoms would be a burden in their social circles. Isolation and withdrawal were clear barriers to hope for participants –leading to feelings of grief and loss.

Healthcare Providers

Participants emphasized the pivotal importance of the relationship with their healthcare providers (i.e., neurologists, family physicians, and nurses). Positive and hope-promoting relationships with healthcare workers were relationships wherein patients felt their autonomy and dignity were respected. One participant elaborated:

> "The staff's communication is pleasant, their approach is responsible, they don't turn patients into objects, and they approach them with respect like humans, living beings" (Tomagová et al., 2021, p. 278)

Participants had many hopes and expectations for their meetings with healthcare providers, often anxiously awaiting these appointments. One participant shared:

> "You're counting the days . . . you're putting life totally on hold and simply waiting. I mean, there is nothing more important than seeing a neurologist. At least, that's how it was for me, and I don't know if I'm over-sensitive or something. But that's how it was for me." (Rosengren et al., 2021, p. 5)

While some medical consultations were helpful, some participants explained that medical consultations were overly focused on medication and symptom management. In contrast, crucial conversations about hope, humanity and the participants' subjective experience were absent. Further, some participants even described relationships with healthcare providers wherein they felt invalidated, undignified, and unacknowledged (Tomagova et al., 2021). One participant described:

> My doctors they were more for illness treatment . . . you get your five minutes. So, I mean, they were good, and when you'd say something, they'd say, 'Okay, what do you need?' Like there was no suggestion of activity or exercise or umm keeping you know mobile or whatever. It was, you know, 'How are you doing on the pills?' and 'How are you managing?' and 'Do you have a question?' (Ravenek & Schneider, 2009, p. 1931)

Another participant felt his viewpoint was not considered:

> “The starting point was always his [the neurologist’s] perspective. I really wished for someone who adopted my viewpoint, paid attention to how it works for me and asked about my family, what causes stress in my life. I’m a human being, you know. But for him, I was a diagnosis, and that’s not the same thing.” (Rosengren et al., 2021, p. 8)

When participants sensed that their subjective experience was dismissed, they felt disconnected from their healthcare provider, which was a significant threat to both dignity and hope. The authors of one study offered: “Degrading style[s] of communication, reflecting the dominance of paternalism and leading to a violation of… dignity... hindered the development of hope” (Tomagová et al., 2021, p. 277). These researchers make an explicit connection between the quality of the relationship with the healthcare provider and hope.

Although participants described negative experiences with healthcare providers, they also often expressed hope and willingness to pursue positive relationships. When relationships with physicians and healthcare providers were positive and supportive, participants felt more hopeful and motivated.

> [My new neurologist] is very supportive. He’s glad I’m doing [physical activity], and he’s the one that set it up for me to come [to the research centre] ... Like I just had an appointment with him, [and] I was in there for 45 minutes, and it was first thing in the morning. Usually, you get 10 minutes, and you’re kicked out the door. (Ravenek & Schneider, 2009, p. 1931)

This participant highlighted some of the essential and positive aspects of the medical consultation, namely, support, resources, and extra time. This subtheme illustrated the importance of one’s relationship with their healthcare provider. It underlined essential features of the relationship that can cultivate and enhance hope in the lives of those with PD.

Enacting Hope

In this review study, several participants described behaviours and actions that reinforced hope and helped them cope with PD. Participants engaged in several actions that maintained their connection to the future. As Dufault and Martocchio (1985) described, the behaviour of hope need not be observable. Instead, action can be cognitive, such as reframing reality or changing perspective, which allows for more positive coping.

Seeking Continuity & Acting Normal

Many participants described determined efforts to continue living normally and engage in activities that promoted continuity in their lives and abilities. Individuals described this as effortful action (both cognitive and behavioural) focused on continuing and maintaining a sense of normalcy. One participant shared:

> I tend not to sit at home and go, ‘oh poor me this is horrible, let’s just sit here.’ Like I’m by nature kind of a doer, so I don’t let the disease get the best of me . . . I plan to continue [physical activity] as much as I can at whatever level, like as I get worse . . . I think I will keep on being active to some degree until I die . . . It’s more of a health thing than just a fun thing . . . I’ll do it because I need to do it. (Ravenek & Schneider, 2009, p. 1933)

For this individual, dedication to their health seemed to be a vital value keeping them committed to exercising. For another individual, a sense of normality meant maintaining proficiency at work:

> ‘I worked till I turned 60. So, I stopped working in a nice way… worked for 10 years [whilst having PD] … there was nothing to say about my work. If I wasn’t finished, I brought work home. You do that today, but it wasn’t as common then… so I probably did

> some extra hours to get things ready, because maybe you worked a little slower'. (Haahr et al., 2011, p. 412)

Another participant put it firmly: “My idea with Parkinson’s is I’ll do what I was doing beforehand… as best I can, and if it holds me up, it holds me up.” (Murdock et al., 2015, p. 1368). A participant from another study described some of the activities that she was able to maintain in the face of PD symptoms:

> Well, I continue doing most of my housework, not all of it . . . I still do all my cooking. I do my washing and not too much ironing anymore ... It’s just that I have that little tremor in my left side. If I could stop these tremors altogether, my life would be better. But they’re not too bad. I can still button my buttons. (Whitney, 2004, p. 31)

At times, acting in ways that were considered normal before a PD diagnosis was protective of hope:

> You’ve got to do things as long as you can ... otherwise, I’m going to be giving up… I started trying to do some decorating ... and did too much just to prove I could still do it ... I’ll push myself that extra bit, and then it won’t be just low in energy; I’ll need to go and sit down because I’ll not be able to stand up hardly (Simpson et al., 2015, p. 616).

This participant described that efforts to maintain pre-illness standards would leave them feeling somewhat debilitated. Still, the importance of preserving the continuity of these standards outweighed the negative impacts.

Maintaining continuity for certain valued behaviours often required a gentle refusal to surrender to the limitations of PD. One participant advised: “Live a normal life. You know, don’t let the thing overwhelm you. It’s not that difficult. It’s not that much of a burden to carry.” (Whitney, 2004, p. 33).

Participants described several important methods for maintaining continuity and normality in their lives even while considering the significant limitations imposed by PD. The determined effort to maintain continuity and normality was a crucial action of behavioural coping and a pathway to hope for participants in this review study.

Constructing Self-Management Strategies

Participants were creative in their continual search for strategies to navigate their lives with PD effectively. For some, this meant developing ways to cope with symptoms, while for others, it meant developing personal theories about how to stay well with PD. This continual process of adjusting to difficulties and maintaining wellness was an inherently hopeful act that each participant seemed to learn independently. One participant described this process: “everyone has to decide for themselves how they’re going to handle…adjusting to their illness.” (Elliott & Velde, 2005, p. 68).

Many participants described their experience of constructing strategies to engage with everyday activities:

> It was wiring a plug, that’s the simplest thing in the world... But because of the way I couldn’t grip properly, I had to find all sorts of ways of manipulating the screwdriver, very frustrating. Over the years I think I improved, I can still put a wire in a plug, purely and simply because of what I’ve learnt. What I’ve learnt is that the body, and the brain, can be trained to organise a job, to do it in a different way. (Gibson & Kierans, 2017, p. 539)

Like this participant’s discovery of unique ways to wire a plug, a different participant described their use of relaxation strategies to decrease symptoms: “I tell myself ‘woooooo, breath, need to relax,’ then I can go.” (Parry et al., 2019, p. 2788) and another participant added “When I freeze at the door, I try to think 'Zen,' I try to relax myself. Just for a second. And then I try to set off again." (Parry et al., 2022, p. 2788).

One participant described their unique process of utilizing a tremor in one limb to lessen the tremor in another:

> For example, if I'm in the post office and must sign something. I cannot write. I just can't. There is no point in trying; I start with big letters, and then they become so small, and the whole paper becomes entangled. But if I really concentrate on what I'm doing and let my leg go instead of my hand, then I can write. (Sunvisson, 2006, p. 96).

When participants described their coping strategies, a sense of pride often emerged from having conquered a daunting and challenging task. As one participant shared: "I'd close my eyes, take a deep breath and just let the air out slowly, and it controls your body; it's like a mind over matter sort of thing… I figured that out myself" (Twomey et al., 2018, p. 10).

While often self-management strategies involved developing practical strategies to overcome symptoms, sometimes they involved constructing and reconstructing personal theories about wellness in PD. These understandings about PD were usually important to the participant and led to strategies focused on wilfully combating the symptoms of PD. One participant explained: "They reckon your brain stops making a chemical, but they don't know why it stops. So, if they don't know, why can't they tell the brain to start making it again, just tell it. So, I did." (Whitehead, 2010, p. 33). Another participant shared his understanding of how to cope with PD and its impacts: "My brain is slower…and any way to make … keep it going as fast as it can ... is keeping it occupied, I think. I keep reading and doing things." (Whitehead, 2010, p. 33). Personal theories about the origins of PD and its management seemed important to maintaining hope throughout the PD journey.

Many of the self-management strategies were effortful cognitive or perspectival shifts that made a meaningful difference in behaviour. Whether one was developing personalized coping strategies or acting on personal theories of PD, this active and constructive cognitive process often encouraged stability, control, and hope.

(Re)Constructing Hopeful Narratives

The cognitive dimension of hope, as described by Dufault and Martocchio (1985), illustrates the practical, rational, and creative processes that surround hope. The cognitive dimension is focused on the assessed reality of a hoped-for outcome or state of affairs. It also focuses on the processes of meaning-making in evaluating the likelihood of a positive outcome (Dufault & Martocchio, 1985). The category (Re)*constructing Hopeful Narratives* was informed by the thinking of Dufault and Martocchio (1985) and described how PwP made sense of PD in the context of their life narratives and how they accommodated the disease within their identity and life narrative. This category included the way in which PwP enlisted their cognitive resources to (a) construct and reconstruct their sense of identity, (b) navigate the tension between acceptance and denial of PD, and (c) assume responsibility and construct meaning. These processes can be seen as concurrent and necessary processes in the development of hope. The following section will elaborate upon these processes and provide illustrative quotations.

Identity

PD challenged some participants to deconstruct previously held self-understandings or accommodate new identities into their life narratives. The process of identity development and maintenance was an ongoing and dynamic process for people with PD and was crucial to hope. Many participants described how they contrasted their pre- and post-diagnosis self. This process of comparing and contrasting seemed essential for processing significant identity changes. For example, one participant looked back fondly on their sense of capability:

> I used to be so confident; I could get up, get my children ready, clean the house, get them to school, get home again for when they came out of school, and work till early hours of the morning doing outdoor work to make some extra money. Go to markets and away for weekends, I could do all that and not feel tired or anything, I never felt tired, I always felt exhilarated by work and children. (Bramley & Eatough, 2005, p. 229)

Some participants felt disconnected from their previous identity following diagnosis. Reconciling current behaviours with their previous identity was a complicated process, leaving some with the feeling that their previous self was alien:

> It's as alien to me now as if it was someone else [. . .] It's murkied the water so much that I don't really know what I was like before, or really have much faith in what I was like before (Delaney et al., 2011, p. 528)

For many participants, identity was closely tied to their occupation. Some participants were forced to leave their jobs, and this loss challenged both their identity and hope. One participant described the loss of their occupational identity: "It's a misery; I have such a strong occupational identity. Most of my friends don't call me N.N; they call me by my occupation. That says a lot... so it's kind of a big fall." (Rosengren et al., 2021, p. 9).

Another participant described adjusting to occupational loss:

> I was surprised when I had stopped working, that I missed the sense of purpose. I still do miss having something to get up for. Although I've got bits and pieces that I do, plenty to keep me busy but, I still miss having that goal because I worked [for] 25 years. I was never

> previously off sick. I was the sort of person who was never ill and worked most of the year without any days off sick. So, it was a bit of a shock. (Lovegrove & Bannigan, 2021, p. 8)

For several participants in this study, navigating a changing identity was both a personal and interpersonal process. Participants contrasted their identity as observed by others, which they discovered was dynamic and subject to interpretation with the internal sense of self with which they were familiar (Sunvisson, 2006; Todd et al., 2010). Sometimes, participants described that they felt misunderstood by others around them as if their identity was not mirrored accurately back to them. Participants said these misinterpretations threatened their identity, making them feel isolated and alone. Alongside this feeling of misunderstanding was an implicit hope to be seen and understood on the inside. Some individuals made efforts to attend to their values and build awareness of the identity they wanted to portray to others. They made concrete efforts to reflect this aspect of their identity outwards. One participant described how his clothes offered him a way to communicate a preferred identity:

> Yes, I think I usually have put on these socks with 'Taz', or 'Tigger' or 'Scooby Doo'. It's just that I appreciate that my face doesn't work, so I feel that people judge you by what they see so I'd rather be known as I wear outrageous ties as well. If I put a tie on, it won't be a serious one unless it's a funeral, so I'd rather be known as the idiot who wears stupid ties or wears stupid socks rather than the miserable old bugger (Whitehead, 2010, p. 33)

Another participant described her hope to project her inner sense of self to others:

> You don't accept erm that I'm any different because inside I'm not, from that young girl to a mother, to a grandmother, that's *me* [authors' emphasis] that's all I can think of projecting, not this illness (Bramley & Eatough, 2005, p. 229)

Another participant described the difference in how others perceived her versus how she wanted to see herself.

> I feel like I'm a hunchback, a bent old woman. And maybe I am just that – but not in my mind. I'm very proud, I don't want to be diminished with respect to others.
>
> I am equal, I don't want to be inferior (Parry et al., 2022, p. 14).

In response to being misperceived or misunderstood by others, participants described a feeling of dissonance they hoped to resolve. Some participants chose to behave in line with their preferred identity despite symptoms, while others attempted to communicate their preferred self-understanding in some way.

For participants in this study, PD had a substantial impact on identity. Alongside a changing sense of identity, participants negotiated this change with the world. This was an important and complex process that appeared to be crucial to the maintenance of hope. Alongside this process of identity construction and reconstruction, participants also reported a dynamic and dialectic process of acceptance vs denial of PD.

Acceptance vs Denial

Being diagnosed with PD can be a shocking and harrowing experience. Some participants began the process of accepting that they had PD, while others may have made efforts to actively reject, deny, and ignore PD. Still others fluctuated back and forth between acceptance and denial as they processed what the diagnosis meant. For example, participants may have accepted the disease internally on one hand, but on the other, they explicitly and actively denied the prospect of being defined by their illness (Rosengren et al., 2021). The processes of acceptance and denial seemed to have the purpose of helping the person adjust, cope and maintain a connection with hope in a life that no longer felt familiar.

Importantly, participants were able to articulate how denial of PD impacted their experience of hope. For example, some participants described that PD caused them to feel a lack of control over their lives, and therefore, they felt less able to participate in education and health-promoting behaviours. One participant shared:

> I actually hide my head in the sand. The thing is, I only know what I have seen at work. I can't even read about Parkinson's disease. I have problems with my thyroid as well, and I know all about that; I mean absolutely everything. But I know nothing at all about Parkinson's. I simply don't have the energy to read about it. (Rosengren et al., 2021, p. 6)

Some participants had trouble accepting their disease, while others acknowledged the presence of the disease was threatening. One participant explained:

> [My friend] took me aside and grabbed my trembling hand, grabbed it firmly and said, 'I love you.' The message was, 'maybe you have your tremors, and maybe you don't, whatever it is, but I'm with you.' But I found this tremendously upsetting when he did this. I didn't find it reassuring … I was fighting against that it was even happening to myself. And when I saw it reflected in other people … that confirmed that the tremor was there. I was not helped by reassuring love. In fact, I was alarmed by it because it confirmed what I had not wanted to see (Machalaba & Sass, 2020, p. 25)

Perhaps this participant was not ready to acknowledge the emotional reality of the disease, and thus, compassion felt overwhelming. Interestingly, some participants described being more able to benefit from compassion when they were more accepting of their disease.

In contrast to denial, participants described that acceptance of PD was a crucial step in the cultivation of hope. To process and understand the diagnosis meaningfully, participants explained that they needed to accommodate PD into their life narrative. Accepting PD then permitted participants to move forward with hope and possibility. To some participants, accepting PD also meant taking back responsibility - perhaps becoming active in deciding what was within and outside their realm of control. Indirectly, this process seemed to foster autonomy, agency and hope.

One participant shared their experience of accepting the disease: ". . . I just thought you've got to get on with it as much as you can, as well as you can. And try not to let it rule your life." (Lovegrove & Bannigan, 2021, p. 7). Participants were careful not to equate acceptance with surrender – implying a lost hope. Instead, acceptance was a process of integrating the disease into one's life story and maintaining autonomy. One participant described:

> You have to learn to live with your disease, and if it demands a certain kind of food or that you have to do things differently, then that is what you have to do to live your life. So, I guess that if Mr. Parkinson has decided that I must work out every day, then that's what I do. He can decide that, and I decide the rest. (Rosengren et al., 2021, p. 4)

For some, acceptance meant being able to live their life more authentically, as one participant offered: "This is my life, one and only life I'll get, so live it as long as you can and just put as much into it as you can." (Bramley & Eatough, 2005, p. 231). Some participants described that acceptance led them to acknowledge and accommodate different abilities and roles, bolstering their hope. For example, one participant offered advice to others with PD:

> Just try to do the things that you have been doing all along. If there is something you can't do—forget it. For example, I can't work . . . I understand the reason for that . . . I am beginning to realize there is stuff I can't do. [So, I] just put up with it. Don't sweat it. You got to live! (Whitney, 2004, p. 32)

Acknowledging and accepting the disease was explicitly connected to hope. Individuals described that acceptance allowed them to more readily engage in positive health behaviours.

> "You can never lose hope, you know. That's when you can't cope. I have switched focus from being healthy to try to be as healthy as possible with Parkinson's disease. So, it has limited my future a bit, it's more framed by the disease. I guess I like to know when I'm making progress. When I succeed in stopping the decline. That's the only thing. It's my biggest goal, actually: not getting worse." (Rosengren et al., 2021, p. 6)

Similarly, one participant explicitly described acceptance as a pathway to hope: "I think if you can accept pain and get on with life as bad as its going to be than least you've got something to look forward too." (Twomey et al., 2018, p. 9)

Acceptance and denial were powerful processes for participants in this review. For them, the process of hope meant accepting limitations and prioritizing personal responsibility, agency, and meaningful engagement with life.

Personal Responsibility

Participants described a gradual process of taking personal responsibility for their health in the face of PD. Adopting personal responsibility was closely connected to rebuilding hope. Accepting that one has PD can sometimes be a precursor to adopting personal responsibility for coping with it. Although a diagnosis of PD was an unwelcome intrusion and outside one's realm of control, a pivotal decision was often made by participants to take personal responsibility for one's attitude in the face of this new reality – an essential ingredient for the development of hope. One participant described the process of reclaiming responsibility:

> In the end, I've got to be answerable for myself. Other people cannot be responsible for me. And I think you've got to have trust in yourself. Faith in yourself. In the long run, it comes to you. (Lovegrove & Bannigan, 2021, p. 7)

This participant discussed the importance of taking personal responsibility and having faith and trust in oneself. Similarly, another participant commented: "Yes, it's this body that I inhabit; it's mine, and it's up to me to keep an eye on it" (Sunvisson, 2006, p. 96). In the face of disruptive symptoms and increasing medical needs, some participants felt their dignity, control, and hope slipping away.

In contrast to taking personal responsibility some participants described that they externalized responsibility, which sometimes led to self-pity, an experience participants mostly denigrated. Participants described taking responsibility as a moral and existential imperative in the face of PD. One participant noted: "I did ten minutes of 'why me, why me?' and then there's no point in that and just got on with it." (Whitehead, 2010, p. 34).

In Todd's (2010) study on the lived experience of delusions in PD, one participant described his ability to adopt personal responsibility through imagination and writing:

> "Well, I write, so a lot of the things that are passing in my life, I'm really interested in... Yeah, my imagination's going overtime most of the time. That's a lot how it's always been, so it's normal and natural for me. . . I mean, you can lie in bed and look at the walls and die, or you can manage as best you can. (Todd et al., 2010, p. 1297).

Although PD felt disempowering at times, many participants looked for ways to reclaim control and agency. Many acknowledged that they had the disease but felt keen to maintain a hopeful attitude: "You've got to, […] make the most of it, because you can alter it. Don't sit back and let it tell you what to do. Try and tell it what […] to do. Your life, I mean, rather than the disease." (Eccles et al., 2011, p. 1416).

For participants, taking personal responsibility meant reclaiming autonomy over their attitudes and values in the face of PD. Some clients described a process of renegotiating their values and priorities (Durán Bermejo et al., 2020). For some, this meant valuing their health; for others, it meant deciding how best to spend their time (Olsson & Nilsson, 2015). For example, one participant described: ''Health comes first. . . and you don't know that until you lose it. . . I always said the family but. . . what's the use of it if you don't have your health'' (Durán Bermejo et al., 2020, p. 257). A participant in Olsson and Nilsson's (2015) study described her change in priorities:

> Well, it is different sorts of things, and it depends on what mood you're in, and […] I need to do the things that give me satisfaction ... I need to get rid of the stress ... and that becomes more and more important to me ... there is a calmness in the colors and in what you are going to paint, and then you don't think of anything else than that. (Olsson & Nilsson, 2015, p. 5).

When participants described taking responsibility for PD, this process often coincided with the process of seeking information about PD. Sometimes, health professionals would provide information, but the personal search for information frequently appeared more psychologically and emotionally fruitful. Perhaps it was the process of searching for comprehensible information about PD that helped participants reclaim a sense of personal control and hope:

> If you have to live with it, you ought to understand what it is . . . I wish someone had assured me that this is a long-range illness. . . That there is some help for it. . .But I had to learn it myself through reading . . . It took me some digging . . . in the very beginning; I

> didn’t know what I had or how serious it was or what the ramifications were going to be, and as a problem solver, I had to get to the bottom of that as much as I could. That was a difficult time. . . The reaction is a: what have I got? How serious is this, and what do I do about it? (Whitney, 2004, p. 32)

One participant shared that it was imperative to take personal responsibility for learning about PD:

> “I decided to make it work by assuming my responsibility. I must be in charge of this process because nobody else can. As soon as you hand it over to someone else, a physician, for example, you fail. You must take control. That’s the only option, unfortunately. It’s a difficult process, but you have to do it.” (Rosengren et al., 2021, p. 6).

The process of building personal responsibility revealed a natural inclination for participants to reclaim lost autonomy. In the case of PD, where individuals can feel a gradually diminishing sense of grip upon their lives, claiming responsibility was foundational to hope.

Chapter Summary

This qualitative meta-synthesis explored how hope is reflected in the phenomenological literature on PD. This chapter described the results of this qualitative meta-synthesis of 31 primary phenomenological studies. Five categories informed by Dufault and Martocchio’s (1985) theory of hope were represented, including (a) Encounters in the Medical Context: Hope and Hopelessness in PD (b) Unfamiliar Being: Hope Wilted, Strengthened, and Transformed; (c) Being Seen: Hope Reflected Through Relationships (d) Enacting Hope (e) (Re)Constructing Hopeful Narratives. Several themes and subthemes were described within these categories with illustrative quotations. As the author's conceptual framework and academic inclination was to focus on hope, the following chapter will discuss the implications of these findings for research and practice with hope and counselling psychology, with a particular focus on PD.

Chapter 5: Discussion

Introduction

This QMS study aimed to answer the following research question: How is hope reflected in the phenomenological literature on the lived experience of PD? The following chapter outlines each category, focusing on situating the findings within the empirical and theoretical research on hope. Understanding the findings in the context of hope has implications for research and clinical work. First, this study may equip researchers with a better understanding of the lived experience of PD through a theoretical lens of hope. Others in the field have pointed to hope research as a promising avenue yet to be explored in depth but with many potential benefits (Noordegraaf et al., 2023). Hope has been shown to be an influential facilitative factor in human change processes (Cheavens & Guter, 2018; Constantino et al., 2011). With respect to PD, there is a dearth of research examining the role of hope in the clinical outcomes of this population (Murdoch et al., 2020; Noordegraaf et al., 2023). Clinicians would be well-served with a sensitive and coherent understanding of hope in the everyday lives of PwP.

In the following chapter, findings from this meta-synthesis are reviewed and discussed. Findings are explored for the (1) theoretical and empirical connections to relevant hope research, (2) practical and clinical insights that can be gleaned from experiential themes, and (3) potential avenues of future research at the intersection of PD, counselling psychology, and hope research. Each finding will be explored, and implications will be offered throughout the text. The chapter concludes with a brief review of practice and research implications, as well as the limitations of this QMS study.

Summary of the Findings

Informed by prominent theories of hope (See Dufault & Martocchio, 1985; Farran et al., 1995), findings constructed in this QMS study spanned five categories of experience. The five constructed categories were (a) Encounters in the Medical Context: Hope and Hopelessness in PD (b) Unfamiliar Being: Hope Wilted, Strengthened, and Transformed; (c) Being Seen: Hope Reflected Through Relationships; (d) Enacting Hope, and (e) (Re)Constructing Hopeful Narratives. Each of these categories will be explored below.

Encounters in the Medical Context: Hope and Hopelessness in PD

The contextual component of hope, from Dufault and Martocchio's perspective, concerns the circumstances that occasion hope (1985). To understand the challenge of hope from the perspective of a PD patient, it is first important to understand the broader medical context of diagnosis and treatment from the patient's perspective.

Diagnosis

Participants described varying reactions to the diagnostic encounter. Sometimes, participants stated that a diagnosis with a physician offered validation and understanding for the troubling symptoms they had been experiencing. However, some participants had negative experiences. Research has begun to focus on the experience of diagnosis for patients (Schrag et al., 2018; Phillips, 2006). This research is crucial to learning practical strategies to support patients through this vulnerable experience. Indeed, the results of this QMS study suggest that healthcare professionals can support patients' hope in the diagnostic process by an explicit and sensitive focus on patients' subjective experiences.

Participants described hopeful diagnostic consultations as those in which they felt seen and validated, had an opportunity to ask questions, and discussed coping strategies. Participants explained that degrading communication, paternalism, and violation of dignity in diagnostic conversations were factors that impeded hope (Tomagova et al., 2021). Indeed, research on other diseases (e.g., cancer) demonstrates that individuals receiving a diagnosis can oscillate between feelings of hope and hopelessness (Hammer et al., 2009). In a study of women diagnosed with gynecological cancers, hope was described by participants as the following: (a) being cured, cared for, and returning to normal, (b) being active and feeling well, (c) maintaining integrity, (d) love and connectedness, and (e) fighting against hopelessness (Hammer et al., 2009). In Hammer and colleagues' (2009) study, it is notable that only one aspect of hope was related to medical treatment for the disease. This highlights that medical treatment is only one among many hopes a patient may have during a diagnostic consultation.

For many patients, hope and hopelessness were weaved throughout the experience of diagnosis, demonstrating that it can be an emotionally vulnerable time. The findings of this study revealed that diagnosis may be more like a process of coming to an understanding rather than a single isolated event. Healthcare professionals who offer patience, sensitivity, and warmth during this process may be able to nurture hope in their patients. Current PD research demonstrates that about 50% of patients feel their diagnosis was communicated in a sensitive and empathic way. Satisfaction with the diagnosis was correlated with the sensitivity of delivery, the amount and helpfulness of information provided, and the amount of time given for the diagnostic conversation (Schrag et al., 2018).

Diagnostic conversations can be a sensitive process for healthcare professionals to navigate with patients. Further, health professionals who diagnose and treat PD face incredible demand on their time and resources (Miyasaki et al., 2017). Some clinicians may not have the time to address hope, while others may feel limited in their ability to provide hope for a cure, leaving them cautious about discussing the topic. However, hope is an impactful avenue of exploration, even in the context of an incurable disease (Eliott & Olver, 2009; Harris & Larsen, 2008).

Current literature suggests that time can be spent encouraging PD patients to develop personalized hope and resources (Noordegraaf et al., 2023). Although a diagnosis of PD is a momentous experience, a diagnosis is only one component of an individual's life. Patients with PD possess many strengths, hopes, dreams, and stories that are much more interesting (if not more consequential) than their diagnosis. When thinking about fostering hope in diagnostic consultations, it may be necessary for clinicians to invite patients to develop ideas about their hope and strengths collaboratively.

Medication

While some participants described hopeful experiences with medications, such as a sense of control and rapid benefit, others described significant threats to hope with medications, such as dependence, ineffectiveness and unpredictability. Most medical treatment for PD takes the form of dopaminergic medications such as Levodopa and other alternatives (Cook & Hawley, 2014). Understanding how patients make sense of medications is crucial because it can impact patients' hope and potentially the therapeutic efficacy of a given treatment.

Participants in this study described medications as a crucial promise of hope in their lives and an essential ingredient to positive functioning. Dopaminergic medications have significant biological effects that produce measurable differences in PD symptoms. However, the power of the clinician-patient interaction on the impact of medications has been well-established in PD and countless other conditions (e.g., pain and irritable bowel syndrome) (Colloca et al., 2004; Petrie & Rief, 2019; Wampold, 2018). More research is needed to examine how the patient-clinician relationship can hinder or enhance outcomes in the dopaminergic treatment of PD. Hope may play a crucial role in promoting positive outcomes in treatment.

The primary difficulty described by participants in this study was uncertainty and lack of control. Although medications were a stabilizing force offering a vital avenue of hope, this was paired with a sense of uncertainty due to medication ineffectiveness, dependence on medication and a corresponding loss of control in their lives. While some patients may be able to cope with these issues by adjusting their lives to accommodate medication, others may feel the inclination to abandon medications altogether.

Research shows that adverse events and lack of efficacy are among the most common predictors of discontinuation of medications (Grossett et al., 2005). Alternatively, hope has been shown to be a predictor of both medication adherence and positive health behaviours (Rasmussen et al., 2018). Reflecting upon the findings in this review, a lack of control or a feeling of giving up control was a common and frequently negative experience brought up by participants. Taking dopaminergic medications may mean that patients must surrender some of their autonomy and agency. This can quickly and easily turn into disempowerment and even feelings of resentment and hopelessness.

Interestingly, research in other chronic diseases (e.g., diabetes) has shown that experiences of autonomy and personal empowerment are correlated with positive health behaviours, increased self-efficacy, and medication adherence (Lee et al., 2019). Little research exists on specific ways to promote autonomy and personal empowerment in the context of PD treatment. However, perhaps the current research on hope-focused strategies in PD (Murdoch et al., 2020; Larsen et al., 2023) can provide a framework for developing patients' autonomy, personal empowerment, and hope in the context of their medical care. Supporting patient empowerment and independence in the context of treatment for PD may ameliorate and perhaps address some of the negative experiences with medications.

Unfamiliar Being: Hope Wilted, Strengthened, and Transformed

Living with PD is a state of unfamiliar being, particularly shortly after diagnosis. Throughout the journey with PD, hope can shrink, grow, and change in significant ways. This category captured a wide array of experiential themes encompassing the emotional experience of PD. The category *of Unfamiliar Being* was informed by Dufault and Martocchio's (1985) and Farran and colleagues' (1995) multidimensional theories of hope. This category encompassed participants' emotional reactions to PD and the transformed lived experiences of time, body and space. The following themes within this category are discussed in the context of current literature: (a) Shame: A Hiding Place for Hope, (b) Symptoms as Threats to Hope, (c) Lived Time, and (d) Lived Body.

Shame

Many of the participants in the review described shame as a pervasive and painful experience. Participants often perceived that others were viewing them negatively, and many described embarrassment and shame as well as the corresponding impulse to hide away from others or isolate themselves (e.g., Bramley & Eatough, 2005). Some participants even feared seeing others' reactions to their symptoms (e.g., Parry et al., 2022). For many of the participants, shame was a critical experience at the center of their social and emotional experience of PD and a significant threat to hope.

Shame has been explored across the disciplines of sociology, psychology, nursing, philosophy and beyond (See Shaughnessy, 2018, for a review). In psychology, shame has been defined as a negative emotional response related to a perceived devaluation of the self or one's sense of social status (Tangney & Dearing, 2002; Van Vliet, 2008).

Researchers have highlighted and explored the concept of shame in those with PD (Angulo et al., 2019). Angulo and colleagues (2019) interviewed PwP. They found that shame for PwP was explicitly related to the experience of PD symptoms, increasing physical dependence, failure to comply with social rules or norms, and negative body image. Participants in this review echoed these sentiments and provided many illustrative accounts specifically related to how their symptoms contributed to shame. Some authors have described shame as a reaction to experiences of misunderstandings and stigma, which lead to experiences of "psycho-emotional disablism" (Simpson et al., 2013, p. 5). At the core of the experience of psycho-emotional disablism is the internalization of harmful or damaging attitudes held by society. Put simply, stigma, as experienced by the stigmatized person, can be internalized and integrated into one's identity. As a person with PD, social experiences of misunderstanding and stigma can be incorporated into one's self-concept, and this can negatively impact one's quality of life (Simpson et al., 2013).

Shame overlaps with one's sense of identity and selfhood. Shaughnessy (2018), citing Kaufman (1996), highlights that shame is intimately connected to identity formation. For Shaughnessy (2018), shame is experienced when one fails to live up to a valued self-ideal or feels unable to sufficiently manage public perception of themselves. Shaughnessy (2018) describes that shame is often evoked when the aspect of oneself being shamed is central to our identity. Like shame, hope has been shown to have an intimate connection to our identity development (Eliott, 2005; Murdoch & Larsen, 2018). Indeed, Eliott (2005) asserts, "Hope does seem to be part of who we deem ourselves to be, with relevance to the best and the worst of what we are. And as we wish to know about ourselves, so we wish to know about hope (p. 38). Informed by previous research on shame as well as the findings of this study, perhaps we can learn much about what is important, valuable and hope-promoting to an individual with PD.

Participants in this study expressed feelings of shame and the corresponding desire to hide. However, participants also provided some implicit and explicit information about how they were hoping to be seen by others. Many participants described the implicit hope to be seen in a way that preserved their dignity and sense of identity. For clinicians working with PwP in clinical practice, it may be valuable for clinicians to be attentive to shame in their patients. While exploring the feelings of pain associated with shame, perhaps in the same conversation, it would be important for clinicians to open conversational avenues about who patients hope to be and how this might have changed since being diagnosed with PD. More research is needed to examine and explore the intersection between hope and shame, their relevance and role in identity formation and changes that occur in the face of disease. Research in this area may provide healthcare professionals with concrete strategies to pivot conversations about shame into hope-focused directions. This may mitigate the impact of shame so that it can be less threatening to patient hope.

Symptoms as Threats to Hope.

It was common for participants to describe ebbs and flows in their symptomatic experience. Many participants shared that they experienced their symptoms as explicit threats to hope, interrupting the ordinary and everyday flow of their lives and sometimes severely impacting their communication. Many participants described that they equated symptom-free periods with freedom, while symptomatic periods were commonly associated with death and despair. The frequent and sporadic changes in symptoms made participants intimately familiar with both despair and hope – sometimes on the same day, if not at the same hour.

On the surface, it seems intuitive that symptoms would impact hope. Nonetheless, it is worth exploring the connection between hope and symptoms more deeply. The sporadic nature of PD symptoms meant that individuals had a complex relationship with hope. The ever-present and sometimes fluctuating symptoms of PD meant that each patient experiences moments in which their full personal agency returns to them. However, as symptoms from moment to moment, a cautious sensitivity was garnered toward the future. Symptoms can overpower the individual at any moment, making them feel helpless and hopeless. As many participants noted, resisting symptoms was often fruitless as they had little control over how and when symptoms occurred.

Research has shown that the severity of symptoms (as perceived by the patient) significantly impacts the well-being of patients and the burden experienced by caregivers in PD (Macchi et al., 2020; Zhao et al., 2021). Patients with PD are more likely to experience depression than healthy controls, and symptom severity has been shown to correlate positively with depressive symptomology (Jiménez-Cebrián et al., 2021). Individuals with PD are likely to view their symptoms through a pessimistic lens, furthering a cycle of negative emotionality, often leading to more depressive thoughts and behaviours (Lerman et al., 2019). The psychological meaning of symptoms with respect to hope in PD is an important area of research that has yet to receive any attention. Further exploration of the connection between hope and symptomatic expression may provide a framework for hope-focused coping strategies to use with patients.

Research is now exploring the impact of hope-focused interventions for PD (see Larsen et al., 2023; Murdoch et al., 2020). Findings show that although symptoms cannot be changed, how one constructs and understands themselves in relation to their symptoms and PD is flexible and constantly evolving. Specifically, as opposed to focusing on the symptoms of PD and the immense suffering these can cause, hope-focused treatments focus on utilizing existing strengths, resources and capabilities to reignite hope. Although discussion of symptoms can be a meaningful experience, in some hope-focused interventions, they are intentionally put aside for a moment to consider the capabilities, identities, and resources that may help the patient engage with their lives meaningfully (Larsen et al., 2023).

Many medically focused PD treatment programs focus on symptom management. However, far less research has explored intentional ways to support PwP to live with hope amid their symptoms. Some researchers (e.g., Noordegraaf et al., 2023) argue that hope-focused interventions are a crucial new frontier in PD research, offering patients ways to break the negative emotional cycles associated with symptoms. Hope interventions focused on other patient populations have shown promise in modifying patients' relationships with themselves and their symptoms (Howell et al., 2015). This research provides initial evidence for the benefits of hope-focused strategies to cope with symptoms. More research is needed in this area so clinicians can be better equipped to support their patients in the context of challenging symptoms.

Lived Time (Temporality)

van Manen offered the lived existentials*,* as a heuristic for conceptualizing and understanding lived experiences (2014). One of these lived existentials was lived time. In exploring one's relationship to time, much insight can be gleaned about hope. Many of the participants in this study felt that they could no longer view their future in the same way as before they were diagnosed with PD. Many participants felt that the future (especially the distant future) was threatening (e.g., Durán Bermejo et al., 2020). For many participants, this led to a shift of focus from the future to the present. Indeed, some participants even shared that they became much less focused on the future to preserve their present-moment experiences, which held more potent value (e.g., Machalaba et al., 2020).

This shift in time perspective, from focusing on the future to a deeper connection to the present, represented a meaningful change in orientation toward hope. Hope is typically conceptualized as a future-focused emotion (e.g., Snyder, 1995); however, multidimensional models of hope clarify that our past and present experiences can be relevant to hope (e.g., Dufault & Martocchio, 1985). Indeed, participants in this study described a feeling of grief and loss for their potential future selves and instead elected to focus on the present. In processing this grief, some participants were able to construct a new narrative for their future. Taking an active role in this reconstructive process helped those with PD enliven a sense of hope for the future. Indeed, recent clinical research has highlighted the crucial importance of developing a clinical care “roadmap” for the future with patients and their families (Jordan et al., 2020).

Nekolaichuk and Bruera (1998) wrote about hope in palliative care. The authors argued that hope is a concept oft marginalized in the context of palliative medicine, highlighting three important myths that pervade current conceptualizations of health and illness. One of the myths, the myth of immortality, relates well to the theme above. Nekolaichuk and Bruera (1998) argue that healthy individuals typically deny the reality of mortality, and hope tends to be focused on goal setting for a “timeless” or infinite sense of a future. Once someone is diagnosed with a significant illness, one is confronted with the reality of mortality and the infinite time perspective may collapse or change, leaving behind a much more tentative and uncertain future. The authors caution clinicians against an excessive future focus and invite readers to consider how hope can be approached through thoughtful construction and reconceptualization of the past and present (Nekolaichuk & Bruera, 1998).

PD is not a terminal illness per se; however, patients are often confronted with a future that no longer feels familiar and may feel foreshortened. In fact, researchers have found that patients benefit from palliative models of care, even early in their illness (Kluger et al., 2020). The participants in the current QMS study clearly articulated that their hope for the future was challenged, encouraging them to hope more deeply for present-moment opportunities that were afforded to them while accounting for their PD symptoms. Some participants opened themselves to a more curious and exploratory connection to the aspects of their lives that were nearer and more accessible. Perhaps participants were diversifying their emotional investment, and instead of solely focusing on the future, they took more opportunities to consider offerings in the present. Looking at the present moment through a hopeful lens has the potential to reinvigorate the present and, in turn, can influence our understanding of hope in the past and future.

Examining the linguistic structure of DNR conversations in the terminally ill, Eliott and Olver (2002) demonstrate that hope is not always focused on the future. The researchers explain that those who are terminally ill use the language of hope in different ways. As a noun, hope could be understood as an entity that can be possessed in lesser or greater amounts (i.e., I still have hope; I was given hope). As a verb, hope is an action that occurs in the present with a focus on probabilities and possibilities (i.e., I am still hoping) (Eliott & Olver, 2002). The verb of hope seems less influenced by constructions of the past and future and seems to focus more on hoping as a meaningful process in and of itself. The findings of this QMS study aligned with Eliott and

Olver's (2002) research and further reinforced the importance of a hopeful focus in the present moment. I contend that the participants in this study may have been discussing hope as a verb – closely tied to the being dimension of hope. Participants in this study seemed to access generalized hope when particularized, future-focused hope was threatened.

Hope is a temporal concept. Within this study, participants shared that it was sometimes immensely difficult to envision the future. For participants in this study, the future sometimes became challenging to imagine, which caused feelings akin to grief in some participants. However, it also prompted a search for hope in the present moment. I believe this was an intentional investment in generalized hope or hope related to being, as discussed by the scholars above. Nekolaichuk and colleagues (1998) highlight that hope related to being is a worthwhile focus for healthcare professionals – especially when a patient faces advancing disease and a future threatened. Results such as this allow clinicians and researchers to think about hope and time more flexibly and dynamically. More research is needed to explore this way of conceptualizing hope and time – specifically in those facing life-changing diagnoses.

Lived Body (Corporality)

Another lived existential introduced by van Manen (2014) is the Lived Body or Corporality. Many theorists have commented on the embodied nature of our being (e.g., Merleau-Ponty and others). Indeed, many of the participants in the review provided detailed descriptions of their relationship to their body and how it transformed when they were diagnosed with PD. This makes sense, given that the cardinal symptom of PD is movement-related changes. In the following section, I discuss the subtheme, *The Uncooperative Body: Negotiations with Hope.* Empirical and theoretical implications are discussed for hope and clinical practice.

The Uncooperative Body: Negotiations with Hope. This subtheme illustrates how participants no longer felt in complete control of their bodies but had to continually negotiate for their bodily autonomy. Participants shared that their body had a “mind of its own.” While some participants shared how they managed their body's unpredictability, others described a sense of despair in response to this loss of control. While PD originates in the body, so too, I believe, does the experience of generalized hope. Thus, a compromised relationship with our bodies also places us in a complex and challenging relationship with hope.

Generalized hope or hope related to being is closely related to our sense of self and will (Benzein et al., 2000; Dufault & Martocchio, 1985). Others have argued that our sense of self is embodied (van Rhynn et al., 2020). As participants in this QMS study articulated, when one’s body no longer operates in its taken-for-granted ways, it can be a significant threat to hope (e.g., Machalaba et al., 2022). In the study, participants described that they continually negotiated with their bodies to navigate the world. I argue that PD fundamentally transforms one’s relationship to the body and hope.

Current research provides evidence that hope has embodied qualities (Khatin-Zadeh et al., 2023; Olsman et al., 2014). Khatin and colleagues (2023) examined “embodied conceptualizations of hope through metaphors” and found that participants associated hope with “forward hand gestures, rightward head gestures, and upward eyebrow gestures,” indicating that we have bodily gestures for hope (p. 1). Similarly, in studying palliative care professionals’ use of metaphors to describe hope, researchers posited that hope could be understood through embodied metaphors (Olsman et al., 2014). The authors found that hope was expressed through the metaphors of grip implying strength (e.g., holding onto hope; letting go of hope; falling down), source implying strength (e.g., hope lights you up inside; comes from the heart), tune implying harmony (e.g., attuning to others; accompanying others), and vision implying a positive perspective (e.g., looking forward to; seeing perspective).

With respect to the findings of this study, participants experienced a disrupted relationship with their body. Some participants noted that they had to coax their bodies to perform straightforward tasks. Indeed, the shuffling gait and postural instability of PD, in and of itself, presents a threat to patients' embodied relationship to the world and to hope. The evidence from this QMS study and the current research literature reveals that PD, in its disruption of motor control, is perhaps the ultimate challenge to the embodied expression of hope. For instance, the typical behavioural and bodily presentation of PD patients is hunched and unstable with rigid or slow movements. The barriers to hope experienced by PD patients are fundamentally tied to their physical embodiment in the world. Thus, improving patients' connection to their bodies and movement may be an essential pathway to hope. It is unsurprising that physical exercise has been shown to provide profound physical and psychological benefits to PwP (Ahlskog, 2018; Frazzitta et al., 2013; Rodrigues de Paula et al., 2006).

There is ample evidence that exercise can improve quality of life and symptom progression (Feng et al., 2020; Rodrigues de Paula et al., 2006). While the neuroprotective effects of exercise have been explored at length in PD, other psychological mechanisms of change should be explored in more depth, particularly the potential of exercise as a pathway to hope. The value of gaining (or regaining) a sense of bodily autonomy and hope cannot be overstated with respect to PD, as evidenced by participant narratives in this study. Findings from this study invite researchers and clinicians to further examine the relationship between the body and hope. There is little to no research focused on the relationship between hope and embodiment in those with PD. Research in this area would provide clinicians and researchers with a better understanding of hope in general, and it may even open avenues for nuanced discussion of the relationship between physical exercise and positive outcomes in PD.

Being Seen: Hope Reflected Through Relationships

The category *Being Seen: Hope Reflected Through Relationships* reflects how participants experienced relationships with others in the context of PD. In Dufault and Martocchio's (1985) conceptualization of hope, the affiliative dimension is the "person's sense of relatedness or involvement beyond the self as it bears upon hope" (p. 386). O'Hara (2013) notes that hope in relationships includes close interpersonal connections like family and friends or more abstract realms such as the spiritual realm, natural world, or society. O'Hara (2013) states that the affiliative dimension involves our hope for a particular response from others. O'Hara (2013) uses a relationship with a healthcare provider as an example: "It may be the hope invested in a doctor's response by a person suffering from a difficult illness, in particular, that the doctor will see them as a person and not just as a patient" (2013, p. 15). He emphasizes that our relationships can have a tangible impact on hope.

Indeed, participants in this study specified that hope was intimately connected to their relational experiences. The findings revealed important facets of relationality and how this impacted hope. The following themes are explored in depth for their implications for hope and PD: (a) The Captivity of Being Seen, (b) Social Stigma, (c) Disconnection and withdrawal, and (d) Healthcare Providers.

The Captivity of Being Seen

The felt sense of being observed was disturbing for some of the participants in this study. While some participants felt that their symptoms were on display and this may have caused momentary discomfort (e.g., Parry et al., 2022), others described feelings of intense fear and anxiety (e.g., Todd et al., 2010). Many participants reported the sense that others were looking, staring or witnessing them, which sometimes exacerbated their symptoms (e.g., Nazzal & Khalil, 2017). The participants in this study shared the objectifying and paralyzing experience of being seen and how it impacted hope.

Philosophers and contemporary researchers have explored the phenomenology of being seen, allowing a deeper understanding of this experience. Jean-Paul Sartre articulates his perspective on the lived experience of the gaze of the other. Sartre argued that the awareness of being observed by another conscious subjectivity led to feelings of being objectified, defined, or fixed, effectively limiting one's sense of freedom (Stack & Plant, 1982). Sartre asserted that reclaiming freedom from the gaze of another is achieved through acts of resistance (Stack & Plant, 1982). At the core of Sartre's treatise on "the look" is the idea of power relations. According to Sartre, shame and pride are experienced when one becomes the object of evaluation or judgment in the eyes of another. Suppose someone consents to being an object of evaluation or judgment from the other. In that case, they also consent to live their lives for others, which Sartre associated with living in bad faith (Stack & Plant, 1982).

Within the affiliative dimension of hope proposed by Dufault and Martocchio (1985), our relationships with others or even our perceived relation to an abstract "other" (i.e. society as a whole) can influence hope. In line with Sartre's exposition on "the look" and how it objectifies, I argue that the gaze of the other can invite objectification of one's hope. Discourse researchers highlight that, in English, hope can be used as an object or noun (e.g., "hope exists out there") and as a process or an action (e.g., "I am hoping") (Eliott & Olver, 2002). Examining power relations in a similar vein to Sartre, Eliott and Olver (2002) investigated discourses of hope in medical contexts and found that those who hold power (e.g., healthcare professionals) can influence patients’ hope through their medical judgments and opinions.

Participants in this study articulated a feeling of being objectified by the judgment and evaluations of others. Participants described that objectification occurred in many contexts, including those in public and even with their healthcare professionals. Medical doctors and other professionals have been historically granted power and control over hope, giving hope a paternalistic status, where it can feel like a patient’s rationale for hope rests solely on the shoulders of the medical professional (Eliott & Olver, 2002). For example, the physician must objectify the patient somewhat to diagnose and classify PD. Perhaps extensive education and training imbue physicians with the authority to objectify hope (i.e., the likelihood of a favourable prognosis) for each patient. However, in objectifying patients and their hope, perhaps we are also violating their autonomy and dignity to define hope for themselves.

As articulated by a few of the participants in this study, dignity-violating interactions with health professionals were seen as paternalistic, authoritative, and brief interactions, leaving participants feeling hopeless and devalued (e.g., Tomagova et al., 2021). I posit that these paternalistic interactions with medical professionals can rob the individual of dignity and remove the patient's agency to define and understand hope on their terms. Regardless of the medical feasibility of patients’ hopes, Eliott and Olver (2002) posit that this hope can still be a crucial resource for patients to navigate a challenging time. Participants in this study described satisfying healthcare relationships as those in which their dignity and subjectivity were honoured. To acknowledge the patient's subjectivity is to allow space and time to explore the subjective hopes of the patient, even if these are unshared or unrealistic (Eliott & Olver, 2002; see Larsen et al., 2014 for a review of unshared hope).

Of academic and clinical significance would be research exploring how one's relationship with others impacts the experience of hope. Although much research points to a relational component of hope (e.g., Larsen et al., 2023; Scioli, 2011), more formalized research on the relationality of hope may provide concrete strategies for healthcare professionals. Psychotherapy literature, particularly within the existential tradition, has long acknowledged the therapeutic value of promoting authenticity, choice, and agency while recognizing and embracing human limitations (van Deurzen, 2010). Psychotherapists and healthcare professionals may benefit from more research on how to honour and promote subjective (i.e., the verb or process) hope in their interactions with patients. Indeed, researchers have made initial calls for research and policy to this effect (Larsen et al., 2023; Murdoch et al., 2020; Noordegraaf et al., 2023).

Social Stigma

Many of the participants in this review described the sense of stigma facing those with PD. At the core of the experience of stigma was the perception of being misunderstood by others and society (e.g., Durán Bermejo et al., 2020). While some participants described that being misunderstood led them to feel lonely and isolated, others expressed a sense of dissonance and a desire to speak for themselves and correct assumptions made by others (e.g., Bramley & Eatough, 2005). Stigma often led participants to feel an acute sense of frustration and a related hope that work could be done to alleviate stigma (e.g., Parry et al., 2022).

Stigma has received much research attention in recent decades (Link & Phelan, 2001). Goffman (1963) originally defined stigma as an attribute of an individual who is seen as "bad, or dangerous, or weak. She/he is thus reduced in our minds from a whole and usual person to a tainted, discounted one" (p. 3). Others have emphasized that stigma is a "mark" applied to someone who appears to exist or behave outside of an acceptable norm (Jones et al., 1984; Stafford & Scott, 1986). Participants in this study described the lived experience of stigma and how it led them to experience self-consciousness and shame in public.

Researchers have now begun to develop an understanding of the stigma faced by PwP. Stigma is a pervasive experience for PwP, and some researchers have even suggested that it should be considered a non-motor symptom of PD (Maffoni et al., 2017). In a recent meta-synthesis, Maffoni and colleagues (2017) found that stigma revolved around the experience of symptoms, communication problems, perceptions of others, and the changing relationship with their caregiver (Maffoni et al., 2017). Stigma has been associated with decreased hope in PwP and has the potential to interrupt treatment and even worsen non-motor symptoms of PD (Maffoni et al., 2017; McDaniels et al., 2023). Maffoni and colleagues (2017) call for more research exploring interventions targeting stigma, and others call for a more holistic, biopsychosocial approach to addressing stigma and other psychosocial factors (McDaniels et al., 2023). Researchers have found that hope-focused interventions hold promise for reducing stigma in those with other chronic diseases (Ge et al., 2021). Hope has also been found to be a valuable resource for both counsellors and patients in navigating the complexities of other diseases that face stigma, such as HIV (Harris & Larsen, 2008).

Much is needed to dismantle and transform societal perceptions of PD. As others have noted, stigma would ideally be included as a part of a comprehensive and holistic clinical assessment of the person with PD (Subramanian et al., 2024). In fact, stigma was included in a recent list of clinical guidelines for providing hopeful and compassionate diagnoses to patients (Subramanian et al., 2024). Interestingly, Subramanian and colleagues (2024) spoke about hope explicitly, indicating that encouraging patients to develop their hope is an integral part of the treatment process with PwP (Subramanian et al., 2024). The current QMS study provides further evidence of the impact of stigma. It may provide clinicians and researchers with the impetus to further investigate the role of hope in addressing stigma.

Healthcare Providers

Participants in this review identified their relationships with healthcare providers as fundamentally important. As described by participants in this review, the relationship between a PD patient and their physician can be emotionally charged with a pivotal impact on their hope (e.g., Rosengren et al., 2021; Tomagova et al., 2021). Of critical importance to participants in this study was the feeling that one's subjective value as a human being was respected and valued by their healthcare providers (e.g., Ravenek & Schneider, 2009; Rosengren et al., 2021). While negative experiences with providers were characterized by the feeling of being devalued or belittled through the words or actions of their healthcare providers, participants also described close, attentive, and valuable interactions with healthcare providers (Ravenek & Schneider, 2009).

When a patient visits a healthcare provider, the medication or active treatment may not be the only "active ingredient." Indeed, individuals' relationship with their physicians is a meaningful cultural phenomenon. In the psychotherapy literature, many studies have demonstrated some of the relational factors between the patient and clinician that lead to an improvement of symptoms (e.g., empathy, genuineness, trust; Wampold & Imel, 2015). With respect to PwP, participants in this study described some of the qualities they appreciated in their healthcare providers, including care, concern, and patience. When patients felt seen and heard in their appointments, they noted that this reinforced their self-efficacy and hope for coping with the disease. There is now a substantial area of research demonstrating the quality of the patient-clinician relationship in the health outcomes of PD (Colloca et al., 2004) and other conditions (Petrie & Rief, 2019; Wampold, 2018).

In the psychotherapy literature, the therapeutic relationship has been identified as a crucial factor in the development of hope in those seeking treatment (Flesaker & Larsen, 2012; Larsen et al., 2013; Murdoch & Larsen, 2018). Interestingly, there has been little to no research on factors in the patient-clinician relationship that influence hope in PD. There is also no research on how hope can be promoted or inhibited in interactions with physicians. In psychotherapy research, however, it is well established that transmitting hope and expectations is a crucial and essential building block for change (Larsen et al., 2013).

Given the pivotal nature of patients' relationships with physicians, as demonstrated in this review, research on the relational development of hope needs to be conducted to better understand the nature of hope-fostering interventions. Clinically, research on the patient-clinician relationship may provide healthcare providers with research-supported tools to engage and support the hope of their patients. The viewpoint that physicians can utilize the relationship to support patient hope has only recently been identified as an important and clinically significant area of focus (Noordegraaff et al., 2023; Subramanian et al., 2024). Clinicians and researchers may benefit from searching across disciplines (e.g., psychotherapy) for insight into how hope can be harnessed and mobilized in the context of professional healthcare relationships (Larsen et al., in press).

Enacting Hope

According to Dufault and Martocchio (1985), the behavioural component of hope focuses on actions that influence, maintain, or develop a desired future (O'Hara, 2013). While some actions directly influence the likelihood of a future outcome, others may seem indirect or unconnected (O’Hara, 2013). Although the behavioural dimension focuses on action, one can engage in different types of action (e.g., psychological, physical, social, and spiritual) (Dufault & Martocchio, 1985; O’Hara, 2013). Participants in this review study described two primary actions that reinforced their hope: (a) seeking continuity and acting normal and (b) constructing self-management strategies. These aspects of the behavioural category will be explored below in detail.

Seeking Continuity and “Acting Normal”

Participants described a continual striving to live a normal life in the face of PD. Participants shared that they engaged in intentional cognitive and behavioural action toward the end of maintaining hope (e.g., Ravenek & Schneider, 2009). Participants attempted to maintain normality in different ways, with some identifying a continued sense of mastery at work as a pivotal component (e.g., Haahr et al., 2010). Others described the continued hope to engage in recreational activities or activities of daily living (e.g., cleaning and housework) (e.g., Whitney, 2004). Most participants acknowledged that PD symptom progression might inhibit these activities in the future. Nonetheless, participants were keen to continue as normal for as long as possible (e.g., Whitney, 2004).

In a recent meta-synthesis of qualitative PD research, Haahr and colleagues (2021) investigated coping strategies used by those with PD. The results identified 18 strategies people with PD used to cope with the disease. The primary and overarching strategy, as determined by the authors, was “maintaining normality and preserving the self” (Haahr et al., 2021, p. 4). Consistent with findings from the current review, Haahr and colleagues (2021) also described several coping behaviours participants engaged in to maintain a sense of normal. Effortful coping behaviours included (a) an intentional focus on the present, (b) altering performance in desired activities to keep participating, and (c) maintaining a positive outlook. The strategies identified in Haahr and colleagues' (2021) review echo similar sentiments in the current findings.

Much of the previous literature on PD has been deficit and symptom-focused. However, researchers have recently attempted to better understand hope and strengths in the context of PD (See Larsen et al., 2023; Murdoch et al., 2020). For example, several authors have identified "preserving the self" as an essential process in the lives of those with PD (Haahr et al., 2021; Vann-Ward et al., 2017). This is echoed in the findings of the current review as participants made efforts to seek continuity and maintain normality. These strategies employed by participants align with the therapeutic philosophy underlying hope-focused approaches to working with PD. Within hope-focused work, deficits and struggles are acknowledged, but the aim is to help participants connect with their strengths, resources, and valued activities nonetheless (Larsen et al., 2023; Murdoch et al., 2020). More research is needed to identify and evaluate methods for assisting PwP with coping strategies that are already present. Future research could focus on methods to promote this adaptive tendency to preserve the self and find normality in one's life. This research might offer healthcare professionals methods to promote valued identities and activities in the context of the patient's life and help them think about ways to maintain these activities in the future with PD.

Constructing Self-Management Strategies.

Participants in this review described that they had developed unique methods to cope with their illness in their daily lives. Some participants explained that each person needed to find personal ways to cope with the disease (e.g., Elliott & Velde, 2005). Participants described creative ways to get into a car, wire a plug, and relax their bodies to cope with a freezing episode (e.g., Elliott & Velde, 2005; Gibson & Kierans, 2017; Parry et al., 2019). Because PD symptoms can fluctuate and look different between individuals, each participant described a personal understanding of their disease and methods to cope with it.

Using coping strategies has been shown to correlate with health-related quality of life (HRQoL) (Bucks et al., 2011). Specifically, researchers have found that problem-solving approaches to coping were related to improved scores on some facets of HRQoL (i.e., cognitive impairment, communication and bodily discomfort). Conversely, coping strategies that utilized escape or avoidance were correlated with decreased scores on some facets of HRQoL (emotional well-being, mood, and social support) (Bucks et al., 2011). This research demonstrates the importance of specific coping styles on HRQoL.

Research is beginning to highlight the patients' critical role in developing unique and effective coping strategies (Haahr et al., 2021; Mulroy et al., 2021).

In a correspondence article by Mulroy and colleagues (2021), the authors document and describe the creative and self-concocted coping strategies patients have used to overcome difficult experiences with PD. Interestingly, the authors differentiate between disease (i.e., pathophysiological processes in the body) versus illness (i.e., subjective negative changes in one’s perception of their functioning). Disease tends to be concrete, tangible, and an object of focus for physicians; however, patients typically seek medical treatment to relieve illness, which can be subjective, dynamic and influenced by personality and coping style (Mulroy et al., 2021). The authors encourage clinicians to work with patients to develop personalized coping strategies and emphasize patient agency over their illness. They also point to the promise of psychological therapies to create and maintain patient coping skills (Mulroy et al., 2021).

Activating the client’s internal resources (i.e., coping strategies and strengths) is a valuable and potent psychotherapeutic process utilized across therapeutic approaches and modalities (Flückinger & Holtforth, 2008; Flückinger et al., 2014). Hope-focused approaches to psychotherapy encourage individuals to articulate the strategies and resources they have utilized to overcome obstacles in the past (Larsen et al., 2023; Murdoch et al., 2020). Assisting individuals to reify these coping strategies and reinforce personal solutions is a key therapeutic strategy that can help individuals to implement these adaptive solutions. Inherent to a hope-focused philosophy in psychotherapy is a trust in the client and their capabilities to overcome obstacles (Larsen et al., 2023). There is a growing corpus of literature exploring the use of hope-focused practices with PWP. This research now offers promising strategies for clinicians to engage and promote the internal resources of clients. More research is needed to evaluate therapeutic approaches that can be utilized to promote personalized coping in those with PD. As Mulroy and colleagues as well as others (2021; Noordegraaf et al., 2023) have emphasized, clinicians may then be more equipped to support patients in developing personalized and effective strategies that address illness without side effects.

(Re)Constructing Hopeful Narratives

Participants described certain thought processes that promoted hopeful self-understandings and narratives regarding PD. Dufault and Martocchio (1985) describe the cognitive dimension of hope as the processes of thinking, imagining, and assessing reality in relation to hope. This dimension often involves evaluating the grounds for hope (i.e., resources, plans, goals, outcomes and boundaries) related to hoped-for outcomes in one’s life. Within this category is the cognitive strategies one uses to realign oneself with future goals and personal values. There were three themes constructed within this category: (a) identity, (b) acceptance vs denial, and (c) personal responsibility. Each of these themes will be explored in-depth below.

Identity

Many participants in this study shared that their diagnosis of PD caused them to reassess and explore their self-understandings and life narratives. Some participants contrasted their current functioning with previous understandings of themselves and this caused an uncomfortable dissonance or a sense that life had lost purpose (e.g., Eatough & Shaw, 2019 Lovegrove & Bannigan, 2021; Rosengren et al., 2021). Participants also differentiated between their identity as constructed by others versus their inner identity. Incongruence between perceptions of others and internal self-understandings often left participants feeling the need to maintain, protect, or communicate inner self-understandings to the world (Bramley & Eatough, 2005; Gibson & Kierans, 2017; Whitehead, 2010). The act of constructing and reconstructing identity is a difficult task and yet it seemed to be essential in the maintenance of hope.

In a meta-ethnographic study, Soundy and colleagues (2014) utilized social identity theory to understand the role of identity in the enablement of hope and well-being. The authors specifically explored the extent to which hope was important to social identity with PD as well as the factors that inhibit or promote hope. The authors then developed a model of hope-enablement undergirded by social identity theory.

In the Soundy and colleagues (2014) study, the authors found that indeed, PD had a significant impact upon one's experience of social identity. Some of the findings from this meta-ethnographic study overlap with findings in the current review. For example, the authors found that participants reported an "unchanged core of who they were" in which they had different roles and abilities but still felt like the same person inside (Soundy et al., 2014, p. 11). Additionally, the authors found that individuals sought to retain "old" identities (i.e., who they were before PD) and grieved the loss of valued social identities (Soundy et al., 2014). Many themes within the Soundy and colleagues' (2014) study lend confirmatory support to the categories and themes constructed within the current review - most especially regarding identity formation and maintenance and how it can impact hope.

Another meta-ethnographic study examining individual's adjustment to PD, Wieringa and colleagues (2021) found that maintaining a coherent sense of self was a key theme. The authors shared that participants recognized that PD involved a disruption to pre-illness identity and as the disease progressed, individuals made efforts to maintain important aspects of this identity and accept those which they had lost (Wieringa et al., 2021). Acceptance was seen by the authors as a theme underlying the maintenance of a coherent sense of self.

To be sure, adjusting to a diagnosis of PD involves a change in identity. For healthcare professionals, caregivers, and those affected by PD themselves, acknowledging the impact of PD on one's identity is likely a crucial process, and one identified specifically in the current review. The extent to which one can process, navigate, and traverse identity changes may have a significant impact on hope. Indeed, hope has been shown in both theoretical and empirical research to be intimately tied to identity. Prominent hope scholar Jaklin Eliott (2005) offering the following:

> Hope does seem to be part of who we deem ourselves to be, with relevance to the best, and the worst of what we are. And as we wish to know about ourselves, so we wish to know about hope (p. 38).

Being attentive to the ways PD has disrupted valued pre-illness identities may allow healthcare providers and caregivers to assist those with PD in managing these changes and exploring new and changed identities. Although the process of navigating identity change is difficult, the process of constructing a valued identity in the face of PD is hopeful. The research is clear that identity is a crucial concern for those with PD, however, there is a dearth of research regarding how this knowledge may best be applied in the context of supporting someone with PD. Psychotherapy may be a starting place for patients navigating identity changes. Indeed, researchers have found that interventions in therapy focused on supportive identity development were seen as hope-promoting (Larsen & Stege, 2010). Hope-focused therapeutic approaches offer promise in assisting patients to navigate identity changes in PD (See Larsen et al., 2023; Murdoch et al., 2020). However, more research is needed to evaluate interventions focused on helping those with PD navigate the process of identity change, loss, and transformation. This may offer clinicians additional strategies to support patients with this process.

Acceptance vs Denial

Many of the participants in this review described a conflict between acceptance and denial with respect to their diagnosis of PD. Some participants described a strong urge to avoid acknowledging the implications of PD for their future (e.g., Machalaba et al., 2020; Rosengren et al., 2021). For these individuals, it was more difficult for them to receive support from others or research the disease (e.g., Machalaba et al., 2020; Rosengren et al., 2021). Other participants in this review described that they were eventually able to accept the illness and its implications for their future (e.g., Bramley & Eatough, 2005; Lovegrove & Bannigan, 2021; Ravenek & Schneider, 2009). Acceptance was seen as a difficult but necessary process to encourage hope (e.g., Twomey et al., 2011; Whitney, 2004). Participants articulated that both denial and acceptance have their place in adjusting to a PD diagnosis, but most participants described that acceptance was more conducive to hope.

Many studies have explored the idea of acceptance in relation to illness narratives. In a qualitative study exploring hope and hopelessness in terminal cancer, Sachs and colleagues

(2013) found that hope was connected to acceptance of the disease, including one’s prognosis, symptoms, and future. Participants in the Sachs and colleagues (2013) study found that acceptance of their illness helped them to reassess and readjust their hope. Acceptance was also understood by participants as protective against hopelessness as participants described the feeling that their hope was more realistic (Sachs et al., 2013). Findings from the current review in relation to acceptance align with Sachs and colleagues’ (2013) study. Acceptance of PD allowed some participants to think about their life direction, future, and hope flexibly and openly. In contrast, difficulty with acceptance made it difficult to envision the future.

Researchers have also been examining the role of illness acceptance in the lives of those with PD. Several qualitative studies (including some included in this review) highlighted acceptance as a key theme in the lived experience of PD (e.g., Machalaba & Sass, 2020; Rosengren et al., 2021; Tomagova et al., 2021). Further, in Haahr and colleagues’ (2021) meta-synthesis exploring strategies for coping with PD, the authors found that a key coping strategy involved hope, acceptance, and denial. Although the authors did not explore the theoretical linkages between hope, acceptance, and denial, they did cite other authors (see Gardenhire et al., 2019) who provided important theoretical exploration of the role of acceptance in the experience of hope.

Gardenhire and colleagues (2019) conducted a grounded theory study examining how individuals cultivate optimism in the process of adjusting to PD. The authors found that acceptance was an important phase in the journey toward optimism. Gardenhire and colleagues (2019) explain that accepting the disease and the associated lifestyle changes allowed the participants to adopt healthy life changes, engage in hobbies, pursue valued activities, and face the challenges of PD. Interestingly, acceptance was the penultimate phase before that of “living with optimism" illustrating the connection between acceptance and hope-adjacent constructs (Gardenhire et al., 2019). Although quantitative research on disease acceptance in PD is still in its infancy, researchers are beginning to acknowledge the role of illness acceptance in the well-being of those with PD. For example, a preliminary study by Rosinczuk and Koltuniuk (2017) found that illness acceptance in PD patients was negatively correlated with symptoms of depression and positively correlated with quality of life.

For participants in this study, acceptance played a key role in hope and forward movement in life. Future research should explore whether illness acceptance as a construct can be bolstered in individuals with PD. Indeed, contemporary approaches to psychotherapy show promise - namely Acceptance and Commitment Therapy – which emphasizes acceptance of difficult experiences and commitment to valued action (Hayes et al., 1999). Supporting patients from the perspective of acceptance may support these individuals to maintain a hopeful future focus while acknowledging the realistic limitations of PD.

Personal Responsibility

Participants described a gradual process of adopting personal responsibility for their journey with PD. The participants described a sense of initial shock at the intrusion of PD into their lives and described a process of reclaiming personal responsibility for the way they coped with the disease (e.g., Lovegrove & Bannigan, 2021; Nazzal & Khalil, 2017). Participants described that externalizing responsibility for one's well-being could become a difficult and slippery slope into feelings of victimhood, inaction, and hopelessness (e.g., Ravenek & Schneider, 2009). Interestingly, the participants described adopting personal responsibility as a kind of moral imperative, wherein one could derive a sense of meaning, accomplishment, integrity, and hope. Indeed, adopting personal responsibility often also meant reprioritizing values, engaging in health-focused action, and reclaiming a sense of personal agency in the context of their disease (e.g., Lovegrove & Bannigan, 2021; Nazzal & Khalil, 2017; Sunvisson, 2006; Whitehead, 2010).

Viktor Frankl provides perhaps the most notable exploration of the importance of personal responsibility in his reflections on the extreme captivity he experienced in the Second World War. Frankl (1985), himself a psychiatrist and concentration camp survivor, famously wrote:

> Man should not ask what the meaning of his life is, but rather must recognize that it is he who is asked. In a word, each man is questioned by life; and he can only answer to life by answering for his own life; to life he can only respond by being responsible (masculine identifiers in original, p.131)

This quotation highlights the moral imperative toward personal responsibility described by participants in this review. The topic of personal responsibility in the context of PD is itself riddled with ethical dilemmas. Though adopting personal responsibility may support those with PD in developing a sense of personal agency, conversations aimed at supporting personal responsibility have the potential to be interpreted as blaming and condemning. Healthcare professionals who approach this issue will be best equipped by paying close attention to the current literature and findings from this study.

There has been little to no research that has explored the theme of personal responsibility as it relates to PD or hope. However, there has been a growing research corpus focusing on Perceived Control (PC) in the context of PD (Verity et al., 2020). Verity and colleagues (2020) define PC as the degree to which someone feels control over their life and health. The authors found that PC is a predictor of well-being and mental health outcomes, and PD mediated the relationship between stigma and wellbeing in those with chronic disease (Verity et al., 2020). Verity and colleagues (2020) suggest that interventions aimed at reducing stigma and increasing personal control would be productive avenues of future research. Although personal responsibility and PC are different concepts, adopting a personal responsibility could ostensibly lead to greater PC, which may be another fruitful area of research.

Researchers are also beginning to explore the connection between hope, uncertainty and control in the context of serious illness (Salamanca & Merluzzi, 2021). Hope can be difficult in the context of navigating medical treatment with chronic illness, because hope has historically been equated with the likelihood of a cure (Eliott & Olver, 2002). This is understandable given the advances of medical science, but it also risks placing hope firmly outside the patient's control (Eliott & Olver, 2002). In the context of diseases without a known cure, focusing solely on a hope for a cure can perhaps begin to feel like a wish.

Researchers in the context of hope studies have been examining how individuals with advanced and terminal illness understand and talk about hope (See Eliott, 2009). This research has led to constructionist understandings of hope. Driven in part by a need to define hope in patient-focused terms, researchers have discovered that hope is often used in multiple ways. Individuals will often discuss hope for a cure (e.g., “there is hope for a cure”) and patients will also talk about hope as a verb (e.g., “I am continuing to hope”) (Eliott & Olver, 2002). Whereas hope for cure is primarily dictated by the scientific progress, the active process or orientation of hoping is resilient to the vicissitudes of existence. Perhaps this is why some have called hope a mature emotion (Nwoye, 2011). With respect to the current review, it is perhaps this mature hope that participants are articulating. Facing an incredibly difficult diagnosis, patients must build hope in a situation in which they have little control, perhaps a choice must be made to place hope within one’s control. This can be a liberating and empowering decision but demands significant internal strength and resources.

More research is needed to explore discourses of hope in the context of PD. PD is a unique and debilitating illness with no known cure. Healthcare providers and clinicians are in a difficult position, often perceived as a fulcrum for hope in patient’s lives. Although current medical discourse can place medical professionals in this position, clinicians may be able to help empower their patients to foster unique and personal hopes even in the face of difficult and disempowering circumstances. In the field of hope research, methods are currently being evaluated that aim to locate the patient’s story outside of their illness and encourage clients to envision a future even in the face of adversity (See Larsen et al., 2023). If more research is conducted in this area, healthcare professionals working with those with PD may feel more equipped to converse about hope with their patients to enhance the outcomes of their care.

Implications & Recommendations

Applications and recommendations from this study to the medical field are plenty and even more to the field of counselling and psychotherapy. For the purposes of this section, I will focus primarily on the recommendations that can be made for all healthcare providers who serve the PD population, but I will pay specific attention to the way counselling psychologists can be informed by the findings. As the population steadily ages, it is expected that the number of individuals with PD in the world will increase (Pringsheim et al., 2014; Schneider & Obeso, 2015). In a disease with no known cure, this will likely lead to an increase in demand for interventions that support individuals to live with this disease for many years. Although medical treatment for PD is a flourishing area of research, adjunctive therapies and the development of cross-disciplinary collaborations must become the norm.

Research teams are beginning to collaborate across seemingly large disciplinary gaps (e.g., counselling psychology and clinical neurology) to explore promising and innovative methods to work with PD (Murdoch et al., 2020; Larsen et al., 2023). Indeed, this work is now being recognized in the realm of neurological practice (Noordegraaf et al., 2023). As the population of PD patients continues to grow, the burden of providing innovative care to this population will not lie with neurologists alone. Given the considerable psychiatric needs of the PD population, it is my belief that counselling psychologists working in diverse settings will be called to provide care to an increasing number of those with PD. To be successful in working with this population, clinicians will need access to informative and authoritative explorations of patient's experiences such that they can provide ethical and sensitive care. Studies such as the review conducted here, can provide clinicians with access to synthesized information from years of informative research. Meta-synthesis itself offers clinicians with up-to-date and digestible information that can be utilized to build empathy and understanding for broad and complex issues.

Because qualitative research tends to be context-bound, the implications of this research are understandably limited. With now thousands of qualitative studies in the context of counselling psychology, clinicians are faced with a staggering amount of data to sift through. The gap between research and practice will continue to widen if this proceeds unchecked. Meta-synthesis offers important methodological opportunities to the profession of counselling psychology, specifically. Counselling psychology as a profession is tasked with providing care to a broad range of clients in a way that is research-informed and empirically supported. Qualitative meta-synthesis, in many ways, can be the new frontier in counselling psychology research - offering clinicians a renewed connection to a corpus of research at risk of being lost in cyberspace. More research is needed, specifically meta-synthesis research that begins to comb through the now staggering amount of qualitative research in counselling psychology to develop strategies, guidelines and practice recommendations grounded in lived experience.

From each of the categories above, counselling psychologists and other healthcare professionals may be able to glean insight into the pathways their patients walk with hope. Building hope in the context of chronic disease is rarely a linear process. There are several significant barriers to hope, as identified in the review above (e.g., negative interactions with healthcare providers, shame, stigma, disconnection and withdrawal, and difficulty with acceptance). Alternatively, there are also important experiences identified above that can be said to develop and reinforce hope (e.g., compassionate and humanizing interactions with healthcare providers, encouragement and understanding from others, processes of identity construction and reconstruction, acceptance, or adopting personal responsibility). Further delineation and study of these experiences and how they influence hope can offer clinicians and other healthcare providers important themes to guide hope-focused conversations with their clients and patients. With these implications in mind, the limitations of this study are described below.

Limitations

There are several limitations worth articulating in this meta-synthesis study. First and foremost, meta-synthesis research is typically conducted with a team of researchers. In this study, I conducted a meta-synthesis alone with the mentorship and support of my graduate supervisor, my supervisory committee, and the search consultants at my academic institution. For this reason, it is important to suggest that some potentially important aspects of a research team were not utilized in this study. For example, a team of researchers will typically assign more than one individual to the study selection process to provide consensus checks. This was not feasible in this study, and the responsibility for study selection was my own.

Another limitation worth considering in this project is the fact that this project focused only on phenomenological research studies. This provided a limited sample of articles that examined the lived experience from a particular phenomenological and existential perspective. Readers are cautioned to read the studies with this in mind and carefully decide whether the findings apply to their specified clinical settings. The interpretations I constructed in this study were informed by experience in counselling psychology and specialized expertise in hope and phenomenological methods of psychotherapy and research. This makes these interpretations unique and disciplinarily specific. For those reading this review, exploring the findings and deciding whether and how they may be ecologically valid in their given contexts will be especially important.

Another limitation of this study involves the heterogeneity of each study. Although this study initially aimed to explore how hope was portrayed in the phenomenological literature conducted on those with PD, each study explored a different experience from the perspective of PwP. Although the methodology was intended to be similar between studies, this varied considerably between studies. As such, the interpretations made by the primary researcher need to be considered in this context of study heterogeneity.

Notably, not all studies or data in this review were heavily represented in the findings. In the data analysis process, I primarily examined data related to the specific research question. Some studies offered more informative data in response to the research question than others. Studies also varied in quality. Although quality was not discussed in-depth in this review - perhaps another limitation - it would be wise for the reader to interpret the findings while acknowledging that the primary researcher (myself) served as the primary interpretive tool in synthesizing these reports into categories and themes. Should another researcher have conducted this study, it is likely that their background, training and foreknowledge would have resulted in an emphasis on different ideas, themes and concepts.

Conclusion

This meta-synthesis study aimed to answer the research question: How is hope reflected in the phenomenological literature on the lived experience of PD? Utilizing strategies informed by thematic synthesis and thematic analysis (Braun & Clarke, 2012; Thomas & Harden, 2008), 31 studies were extracted and synthesized in answer to the research question. Five categories were constructed based on these 31 studies: (a) Encounters in the Medical Context: Hope and Hopelessness in PD (b) Unfamiliar Being: Hope Wilted, Strengthened, and Transformed; (c) Being Seen: Hope Reflected Through Relationships (d) Enacting Hope (e) (Re)Constructing Hopeful Narratives. These findings were explored for theoretical and clinical implications in medicine and counselling psychology. Lastly, theoretical linkages were made between the findings and present and future avenues of hope and PD research. Findings from this study may be used to offer informative and concrete recommendations for clinicians to enhance their sensitivity and knowledge concerning the lived experience of PD patients.

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Appendix A

Table 1. Characteristics of Included Studies

Author (s)	Year	Country	Study Aim	Participants/Gender	Data Collection	Data Analytic Strategy
Bramley & Eatough	2005	UK	Explored one individual's personal experience of living with Parkinson's disease	1F	Semi-structured interviews	Interpretative Phenomenological Analysis (IPA)
Caap-Ahlgren et al.	2002	Sweden	To explore women's experiences of living with PD, and analyze how the symptoms influence quality of life	8F	Narrative Interview	Phenomenological-Hermeneutic (Informed by Ricoeur)
Delaney et al.	2012	UK	Explore perceptions of cause and control for individuals with PD who have ICBs	7M/3F	Semi-structured interviews	Interpretative Phenomenological Analysis (IPA)
Duran Bermejo	2020	Spain	To explore the process of coexisting with Parkinson's disease	3M/3F	Semi-structured interviews	Phenomenological Thematic Analysis
Eatough & Shaw	2019	UK	Explored one individual's personal experience of living with Parkinson's disease	1F	Semi-structured interviews	Interpretative Phenomenological Analysis (IPA)

Eccles et al.	2011	UK	Investigate how people with PD perceived both the cause and their control of the disease.	4F/7M	Semi-structured interviews	Interpretative Phenomenological Analysis (IPA)
Elliott & Velde	2005	United States	The purpose of this study was to describe the essence of occupation for community living adults affected with PD.	3M/4F	Semi-structured interviews	"Cut and put" method (Morse & Field, 1995)
Gibson & Kierans	2017	UK	Explored men's experiences of PD in terms of a masculine, ageing embodiment.	15M	Semi-structured interviews	Custom/Novel Approach
Haahr et al.	2011	Denmark	Exploration of patients' lived experience of advanced PD prior to a Deep Brain Stimulation and expectations following treatment.	8M/3F	Semi-structured interviews	van Manen (1990)
Habermann	1996	United States	The goal was to explicate the day-to-day demands experienced by those living with PD in middle life.	9M/7F	Semi-structured interviews	Thematic analysis, Analysis of exemplars, and Search for paradigm cases.
Lovegrove & Bannigan	2021	UK	This study explored the lived experience of anxiety for people with PD.	3M/3F	Semi-structured interviews	Thematic analysis

Machalaba & Sass	2020	United States	Aimed to develop an understanding of PD by creating a dialogue between the researcher's pre-existing knowledge and subjects' reports of the phenomena.	6M/1F	Semi-structured interviews; Autobiography	Hermeneutic Circle
Marr	1991	Canada	Explore the lived experience of living with PD.	3M/3F	Semi-structured interviews	None stated
Murdock et al.	2015	UK	Explore how people with advanced Parkinson's disease experience the phenomenon of occupation in their daily lives.	6M/4F	Unstructured, open-ended interview	Heideggerian Phenomenology, Inductive, Thematic Content Analysis
Nazzal & Khalil	2017	Jordan	Explore the lived experiences of Jordanian individuals with PD and how the disease affects their daily life.	4M/4F	Semi-structured interviews	Content Thematic Analysis
Olsson et al	2013	Sweden	Elucidated meanings of fatigue for women with PD.	11F	Narrative Interviews	Phenomenological Hermeneutic Interpretation (Custom)
Olsson & Nilsson	2015	Sweden	Described meanings of feeling well among women with PD.	9F	Lifeworld interviews	Custom/Novel Approach

Parry et al.	2019	France	Characterized the way patients with Parkinson's disease consciously perceive and respond to their surroundings while walking in everyday situations.	11M/3F	In-depth Interviews, Behavioral Observation, Self-Confrontation (reviewing videotapes)	Interpretative Phenomenological Analysis (IPA) Thematic Analysis
Parry	2022	France	Examined the experience of people with PD when walking in different social situations.	11M/3F	Interviews, Video Recording, Self-Confrontation (reviewing video tapes)	Interpretative Phenomenological Analysis (IPA) Thematic Analysis
Ravenek & Schneider	2009	Canada	Investigated how social support influences physical activity participation, as perceived by people with early PD.	4M/3F	Semi-structured Interviews	Creswell guidelines
Redmond & Suddick	2012	UK	Explored the experience of freezing for people with PD	5M/1F	Semi-structured Interviews	Thematic Analysis
Rosengren et al.	2021	Sweden	Explored the meaning of Life Satisfaction and adaptation in persons with PD.	3M/9F/1NB	Open-ended In-Depth Interviews	Phenomenological–Hermeneutic Method
Simpson et al.	2015	UK	Explored the lived experiences of apathy in people with PD	7M	Semi-structured Interviews	Interpretative Phenomenological Analysis (IPA)

Suddick & Chambers	2010	UK	Explored the lived experience of sleep disturbance in a group of men with PD.	5M	Semi-structured interviews	Thematic analysis
Sunvisson	2006	Sweden	Explored the lived experience of late-stage PD	1F	Unstructured interviews	Phenomenological Method
Todd et al.	2010	UK	Explored the meaning of delusional experience for people with PD	7M/1F	Semi-structured Interviews	Interpretative Phenomenological Analysis (IPA)
Tomagová et al.	2021	Slovak Republic	Explored the lived experience of outpatients with PD and its impact on dignity	4M/7F	Semi-structured Interviews	Interpretative Phenomenological Analysis (IPA)
Twomey et al.	2018	UK	Explored the lived experience of pain in PD.	2M/2F	Semi-structured interviews	Custom
van Der Bruggen & Widdershoven	2004	Netherlands	Explored what it means to be a PD patient.	None stated	Text review	None stated
Whitehead	2010	UK	Explored communication difficulties in people with PD.	3M/1F	Semi-structured Interviews	Thematic Analysis
Whitney	2004		Explored practices used by older adults with PD to sustain quality in their lives.	6M/6F	Unstructured Interview-s	Custom