

Running head: THE EXPERIENCE OF PARKINSON'S DISEASE

THE EXPERIENCE OF PARKINSON'S DISEASE: TOWARD A
PHENOMENOLOGICAL UNDERSTANDING

A DISSERTATION
SUBMITTED TO THE FACULTY
OF
THE GRADUATE SCHOOL OF APPLIED AND PROFESSIONAL PSYCHOLOGY
OF
RUTGERS,
THE STATE UNIVERSITY OF NEW JERSEY
BY
JOHN WILLIAM MACHALABA
IN PARTIAL FULFILLMENT OF THE
REQUIREMENTS FOR THE DEGREE
OF
DOCTOR OF PSYCHOLOGY

NEW BRUNSWICK, NEW JERSEY

OCTOBER, 2017

APPROVED:

Louis Sass, Ph.D.

Karen Riggs Skean, Psy.D.

DEAN:

Francine Conway, Ph.D.

Abstract

Despite being the second most common neurodegenerative disorder, Parkinson's disease (PD) has received little attention in the phenomenological literature. This study aims to contribute to this limited body of research by exploring the questions of what it is like to be a Parkinson's patient and what meanings can be ascribed to their experience. To answer these questions the study thematically analyzed seven accounts of PD through a hermeneutic, phenomenological lens using a combination of Wertz's Phenomenological Psychological method (2011) and McCracken's The Long Interview method (1988). The participants of this study consisted of 6 men and 1 woman, ranging in ages 58 to 71, who have been diagnosed with PD for between 3 and 10 years. Three of these accounts were gathered via in-person interviews and the other four accounts were obtained through published, autobiographical writings. The phenomenological analysis identified four themes that appear to be characteristic of the experience of PD: (1) Denial, (2) Emotion and symptom expression, (3) Alteration of temporal perspective, and (4) Volitional and spontaneous action. The themes are reflected upon by using concepts in existential philosophy to clarify their psychological significance and to synthesize them into an account of the subjective experience of PD. The findings of the study were compared to other findings in the phenomenological literature. Limitations of the current study were discussed and suggestions for further research were posed.

Acknowledgments

As the capstone of my academic career, this dissertation would not have been possible if it were not for the many professors, mentors, supervisors and peers that have inspired me to strive for intellectual and clinical excellence. I would like to thank the GSAPP community, whose unwavering commitment to scholarship is reflected in its support of a dissertation using a philosophical method for psychological research. I would like to express my gratitude to Louis Sass for strengthening and refining my thought as both a theoretician and clinician, and for his inspiring vision of what psychological research can be. I would like to thank Karen Riggs Slean for enriching my clinical technique and for her support in pursuing a philosophical approach to clinical understanding. I also would like to thank my friend and mentor, George Atwood, for inspiring me to study clinical psychology, opening my eyes to the world of phenomenological psychoanalysis, and, above all, showing me the importance of human understanding. Finally, I would like to thank my parents, family, friends, and loved ones for their unwavering love and support, and without whom I would not have been able to accomplish this momentous achievement.

TABLE OF CONTENTS

ABSTRACT.....	ii
ACKNOWLEDGEMENTS.....	iii
INTRODUCTION	1
REVIEW OF LITERATURE	1
METHODOLOGY	26
Participants.....	26
Procedures.....	27
Analysis	27
RESULTS	35
Denial.....	36
Analysis of Denial	38
Emotion & Symptom Expression	41
Analysis of Emotion and Symptom Expression	43
Alteration of Temporal Perspective.....	47
Analysis of Alteration of Temporal Perspective.....	50
Volition and Spontaneity of Movement.....	53
Analysis of Volition and Spontaneity of Movement	58
DISCUSSION	60
Findings	60
Limitations	65
Directions for Further Research.....	67
REFERENCES	69

Introduction

This study investigates the subjective experience of what it is like to be an individual with Parkinson's disease (PD). Despite the growing body of phenomenological literature within psychology and the growing prevalence of PD, few phenomenological studies have investigated the disease. Seeking to address this deficit in literature, this paper explores the following questions: What is characteristic of the subjective experience of being a Parkinson's patient? and What meanings can be ascribed to their experience? These questions are to be answered through the use of a phenomenological method that concerns itself with the study of lived experience. The desired outcome of this study is to obtain a subjective understanding of PD and to compare its findings to the limited body of phenomenological research regarding PD. In gaining further understanding of the specific experiences and problems that Parkinson's patients face, this study hopes to help both laypersons and healthcare providers better empathize with PD patients.

Review of Literature

It is estimated that 107 per 100,000 people between the ages of 50 to 59 suffer from PD worldwide, with that number increasing with age. (Pringshiem, Jette, Frolkis, & Steeves, 2014) PD is the second most common neurodegenerative disorder after Alzheimer's disease and is expected to impose an increasing social and economic burden on societies as the population ages (de Lau & Breteler, 2006). In the United States, Parkinson's affects approximately 1 million individuals (McDonald, Richard, & Delonge, 2003). The typical age of onset of PD is between 55 and 66 years old and is characterized by slow body movements or bradykinesia, rigidity, tremors, and postural instability

(McDonald et al., 2003). The deterioration of motor abilities and verbal communication increases in severity over five successive phases. These phases are: (1) Unilateral involvement, usually with minimal or no functional impairment; (2) Bilateral or midline involvement without impairment of balance; (3) Impaired balance reflexes; (4) Fully developed motor symptoms and severe disability; and lastly (5) Confinement to a bed or wheelchair unless aided (Hoehn & Yahr, 1967).

The physical changes in Parkinson's are often described with neurological correlates and dysfunction. Over the years, researchers have identified multiple etiological pathways for an individual to develop symptoms of PD. Most contemporary research points to some combination of genetics and environmental factors as the cause of PD. Parkinson's has also been linked to exposure to encephalitis lethargica, but as the incidence of encephalitis lethargica has decreased, a diagnosis linked with the illness is now rare (Rail, Scholtz, & Swash, 1981). With the exception of encephalitis and a few other infrequent environmental toxins, the exact cause of the neurological degeneration in PD is unknown (Ascherio, Chen, Weisskopf, O'Reilly, McCullough, Calle & Thun, 2006; Giasson & Van Deerlin, 2007; Lew, 2007; Lotharius & Brundin, 2002; Warner & Schapira, 2013). What is known is that Parkinson's pathological manifestation is characterized by a loss of dopamine producing neurons in the substantia nigra and the presence of Lewy bodies in the substantia nigra and locus coeruleus (World Health Organization, 2009).

Within more recent years, diagnosticians, medical providers, and Parkinson's patients have greatly benefited from the ever-expanding body of literature regarding the etiology of Parkinson's. However, these physiological descriptions of neuropathology

and symptom progression capture little of Parkinson's patients' lived experiences and particular modes of being. A qualitative understanding that considers the subjective experience of PD patients can be of particular use to medical providers, therapists, peers, or caretakers. Better knowledge of the experience of living with PD would aid the ability to supply Parkinson's patients with adequate care that addresses their specific needs and experiences.

Literature addressing the subjective experience of Parkinson's can be traced back to some of the first documentations of the disease. James Parkinson, the man responsible for identifying "the Shaking Palsy" – later to be known as Parkinson's disease – was of the first to document some of the psychological features of Parkinson's. In his seminal work, *An Essay on the Shaking Palsy* (2002), he discussed the progression of the disease and the patient's experience of their disease's progression. He wrote:

"[In the initial stages of the disease] the patient will have experienced but little inconvenience; and befriended by the strong influence of habitual endurance, would perhaps seldom think of his being the subject of disease, except when reminded by the unsteadiness of his hand.... But as the disease proceeds, similar employments are accomplished with considerable difficulty, the hand failing to answer with exactness to the dictates of the will." (pg. 224)

In the above quote, it is evident that Parkinson paid considerable attention to the patient's lived experience. He highlights issues of will, effort, and awareness of the illness. This qualitative description of the disease is mostly likely the result of little being known about "the shaking palsy" as a discrete clinical phenomenon and was an effort to provide

a thorough description in order to establish it as such. The descriptors that Parkinson provided were meant to serve as observable diagnostic markers for other healthcare professionals. After the establishment of the disease, little attention has since been paid to the subjective experiences of PD.

The next substantial inquiries into the lived world of PD patients were not until approximately 1913, and more considerably in the 1940's. These studies took place after neurologists and psychoanalysts began to notice similarities in the types of people who suffered from Parkinson's and began to hypothesize that PD patients seem to have specific personality types. These authors posited that people with Parkinson's were industrious, inflexible, cautious, and not novelty seeking (Booth, 1948; Camp, 1913; Jelliffe, 1940; Prichard, Schwab, & Tillmann, 1951). Many researchers have since used a variety of methodologies to study if there are premorbid personality types associated with developing Parkinson's (for a review see Menza, 2000). Despite the large body of research pertaining to the personality of Parkinson's patients, it remains contested whether there are personality styles associated with the development of Parkinson's disease (Glosser, Clark, Freundlich, Kliner-Krenzel, Flaherty, & Stern, 1995; Todes & Lees, 1985). Although research regarding the personality styles of those with Parkinson's sheds light on some of the inner experiences of individuals with PD, it fails to fully capture what being a Parkinson's patient is like and how they are affected by, and ascribe meaning to their disease. It was not until more recently that that researchers became more interested in understanding the phenomenology of PD.

In the broadest sense, the discipline of phenomenology is dedicated to the exploration of lived experience and has its roots in Greek thought and the humanistic

tradition. Originally, the phenomenological method was developed as a philosophical method for the investigation of consciousness by Edmund Husserl (1990) at the beginning of the 20th century, with the intent to enable philosophical thought to overcome the objectivism (or the “natural attitude”) put forth by the natural sciences. Husserl argued that it was essential to overcome objectivism to meaningfully study philosophy and the human sciences.

Since its inception, phenomenology has been applied to a variety of fields within the human sciences, humanities, and art. In psychology, the phenomenological method is a descriptive, qualitative study of human experience that is typically applied to specific illnesses or mental states. The primary aim is to faithfully capture and conceptualize the processes and structures of mental life and their subjective meanings while withholding any preconceived evaluation of the material. More recently, the phenomenological method has been applied to a variety of illnesses, including schizophrenia, depression, anxiety, and other psychological and physiological ailments (Sass & Parnas, 2001; Fuchs, 2005; Hyde, 1980). However, there have been comparatively few investigations of the phenomenology of PD. The majority of attempts to understand the experience of Parkinson's are descriptive and behavioral. These approaches are not as much efforts to capture the subjective experience of the disease as they are diagnostic, symptoms-focused accounts (see for example: Borek, Kohn, & Friedman, 2006; Deuschl, Papengut, & Hellriegel, 2012; Wen, Zhang, Wang, Chen, Liu, & Xu, 2012). To better understand differences in phenomenological approaches, it may be of use to delineate a few subtypes of phenomenology.

Ellenberger (1958) broke down psychiatric phenomenology into three different

methodologies: descriptive phenomenology, the genetic-structural method, and categorical analysis. Descriptive phenomenology originates with Husserl and strives through phenomenological reduction to reach the essential structures of an experience. Descriptive phenomenology relies entirely on descriptions given by the patients to understand a subjective experience. Essential to this method is withholding, or “bracketing,” any preconceived understandings or biases with hopes of getting “to the things themselves.” However, the term “descriptive phenomenology” in contemporary psychiatric phenomenology, can also mean an understanding of experience through behavioral, symptomatic descriptions of a clinical phenomenon (as alluded to in the preceding paragraph). The genetic-structural method assumes a unity or theme in an individual's subjective experience and attempts to find a consistent theme, which can help reconstruct and render the whole of the person's experience more intelligible. And lastly, categorical analysis takes a system of phenomenological coordinates (i.e. time, space, causality, and materiality) and explores how the patient experiences each of the coordinates. By considering each of these dimensions separately and reassembling them into a synthesis, the researcher hopes to obtain a reconstructed, detailed account of the patient's inner universe.

Another approach to phenomenology, which may overlap or encompass genetic-structural and categorical analyses, is hermeneutic phenomenology. Hermeneutic phenomenology, as introduced by Heidegger, and later elaborated on by Gadamer, posits that lived experience itself is an interpretative process and that prejudgment is essential to understanding. In other words, hermeneutic phenomenology views understanding as a reciprocal activity in which pre-understanding and understanding are incorporated into

the phenomenological understanding to revise and refine one's interpretation of a given phenomena. (Dowling, 2007) This hermeneutic approach differs from descriptive phenomenology in its acknowledgment of the inescapability of biases, whereas descriptive phenomenology's project is an attempt to strip away the interpreter's pre-existing knowledge and biases in order to get to a phenomena's "pure" essence.

Although the majority of phenomenological studies of PD are descriptive and typically more concerned with delineating objective diagnostic descriptors, more hermeneutic phenomenological studies do exist in the PD literature. This small body of literature explores the subjective "lived world" of a Parkinson's patient and the meanings that patients ascribe to their illness. The following is a review of six examples of such hermeneutic or interpretative phenomenological literature concerning PD.

One of the richest and widely referenced examples of an interpretative phenomenology of PD is Van Der Bruggen and Widdershoven's paper *Being a Parkinson's patient: Immobile and unpredictably whimsical, a literature and existential analysis* (2004). The objective of their research was to obtain insight into what it is like to be ill, in particular with PD, by carrying out careful readings of four novels about Parkinson's patients. The authors assert that personal accounts and what novelists say can enrich our understanding of experience in a more poetic way than that of typical medical descriptions. Van Der Bruggen and Widdershoven continue that artists are thought to have a different, more in-depth understanding of fundamental things in life, such as being ill, recovering, or dying. They posit that artists are thought to phrase this understanding in a better, more gripping, more imaginative way than those working in healthcare generally

do. In addition to novels, the authors also utilized pre-existing personal accounts of the disease as well as research articles to supplement their investigation.

Van Der Bruggen and Widdershoven found several themes in their research. They conducted a categorical analysis of six themes: corporeality, space, time, relation to things, world, the other, and human being as subject. First, the authors found that the body is “under constant consideration,” and at times feeling strange and hostile, and reacting unpredictably characterized the corporeality of the Parkinson's patient. They remark that the Parkinson's patient's facial expressions can seem mechanical, flat, expressionless, and rigid to the other, while, paradoxically, sudden and unexpected changes may occur, enabling them to convey emotional expression. They assert that the Parkinson's patient has an evolving relationship to their body. To the Parkinson's patient, the body is first something one is, then something one possesses, and finally something one no longer has control over – in chronological order.

When investigating the experience of space, Van Der Bruggen and Widdershoven found that space is not constituted spontaneously or pre-reflectively but only constituted with cautious deliberation. Space can also be chaotic and threatening. However, as when a Parkinson's patient falls or when the patient freezes, space may not be able to be constituted at all.

With regard to the experience of time, the authors found that both past and future may take on the meanings of pain and sadness to the Parkinson's patient. The past may make the patient realize the loss that the disease has caused them. The future may represent a reminder of wishes that they will be unable to accomplish. In addition, time seems to be mediated through the use of medication and the remission and intensification

of symptoms. The authors also offered that the body is a medium through which time is constituted. So again, as found in corporeality, the experience of time may also take on a paradoxical characteristic of unpredictability and immobility (i.e. time as becoming unpredictably frozen or slowed).

The authors also found that things in the world can take on particular and potentially contradictory meanings to the Parkinson's patient. They found that things could either be regarded as "things to be conquered and controlled" or things seen as "sources of enjoyment." For example, medication and food may be seen as something to be carefully orchestrated to attain a desired outcome (symptom reduction) or may at other times be seen as a source of pleasure and nourishment. In addition, things once regarded as benign, such as a shirt, may be regarded as objects that create difficulty and stress.

When considering how the Parkinson's patient experiences the world, the authors argue that their world is dominated by feelings of "being ill" and emotions of sadness and sorrow that derive from loss and a growing constraint of the world around them. They continue that the patient's "life-world" is constituted by paradoxes. Some examples that they supply are: the world being seen as rigid while having the ever-present possibility of becoming unpredictable and whimsical (i.e. freezing or "on/off" symptoms), exerting effort to relax, or struggling to be independent yet growing more dependant on others. The authors continue that, to the Parkinson's patient, the world appears to impose itself unto the patient, with the patient being forced into a position of passivity and receptivity.

In the authors' analysis of Parkinson's patients' experience of "the other," they found relationships to be marked with the paradox of trying to avoid becoming isolated and marginalized while also worrying about becoming too dependent on others. Van Der

Bruggen and Widdershoven found that Parkinson's patients struggle with communication, often encountering trouble speaking, which could cause them to be misjudged or misunderstood. This difficulty in communication may result in isolation and alienation of the Parkinson's patient.

Lastly, the authors spoke about how the Parkinson's patient feels as if they are losing their identity. They pose that a combination of being seen as an object by others, growing dependence on others, and isolation may cause the Parkinson's patient to feel as if their identity is disintegrating without their volition. Van Der Bruggen and Widdershoven write, "at times the patient observes himself as an object in a mirror or a windowpane. Sometimes it does not look so bad, sometimes it does." (p. 297) They continue that the positive self-image the patient attempts to hold up is at times shattered and the physical decline and increasing dependence associated with the disease often wear away feelings of self-worth.

To conclude, Van Der Bruggen and Widdershoven summarize their findings in four points: (1) The Parkinson's patient's existence is characterized by both immobility and an unpredictable whimsicality. This characterization applies to Parkinson's patients' corporality, experience of time and space, relating to objects and things, sense of lived world, and being with others. (2) One of the significant features of Parkinson's is an underlying sadness, chronic sorrow, or "existential sorrow" that becomes part of a Parkinson's patient's basic attitude. (3) Another significant experience for a Parkinson's patient is the caution and deliberation expressed through control of their body, as well as the way their "well considered" body constitutes a "thoroughly thought out" world. (4) A typical phenomenon in PD is freezing, which is experienced as a sudden stiffness of the

body in a space that cannot be constituted, rendering the world unsurveyable.

In close agreement with Van Der Bruggen and Widdershoven's findings, Haahr, Kirkevold, Hall, and Ostergaard (2011) found that the experience of PD is characterized by living with and managing unpredictability. Their study analyzed eleven interviews with advanced PD patients who were eligible for deep brain stimulation surgery utilizing a hermeneutic phenomenological method. The aim of the study was to explore Parkinson's patient's lifeworld and ways of managing life with advanced PD. The authors organized their findings into two categories: "Parkinson's disease becoming a part of life: learning from and adjusting to a changing body," and "Struggling with unpredictability: aiming to stay in control." The former is seen as capturing participants' struggle over time prior to the interview and the latter seen as the patient's current struggle. The authors then broke each of these main themes down into sub-themes as will be described below.

The first theme of "Parkinson's disease becoming a part of life: learning from and adjusting to a changing body" was broken down into a sequential progression: (1) The body as acting funny, (2) Perceiving new life, and (3) Getting on with life. The first stage is characterized by confusion - the feeling that something is wrong with the actions and reactions of their body and it being unclear what is happening. This stage lasts up until a formal diagnosis is made, which could take a matter of weeks to years. Once a diagnosis is confirmed, the second stage begins, which brings a mix of relief and anxiety. On one hand, patients find relief in their symptoms being explained and treated, while on the other hand they begin to worry about what their future and the progression of the disease will bring. In this timeframe patients begin to feel stable and well treated, which leads to

the last stage of the first theme, “getting on with life.” During this period of time, patients do not require much attention as long as medication is taken as prescribed. Patients go on to function similarly to their pre-Parkinson’s selves. However, as time progresses, symptoms begin to become less responsive to treatment. The re-emerging salience of their Parkinson’s symptoms and their interference with daily life begin to erode the aspects of their body that they had taken for granted. It is at this stage where Parkinson’s begins to encroach on all aspects of the patient’s life. This is the point where Haar et al. designate a move from the theme of Parkinson’s becoming a part of life to the theme of struggling with unpredictability.

The authors posit that this second theme of controlling an unpredictable body is the most substantial component of Parkinson’s disease and they dedicate the majority of their paper to elucidating this experience. The authors analyze the theme of managing unpredictability through the “four existentials” or analytical categories: lived body, lived time, lived space, and lived other.

In regards to the lived body, Haahr et al. found that the body’s unpredictability “sets the agenda” – not only in regards to bodily function but also in everyday life. Parkinson’s patients are subject to “ON and OFF” phenomena. In “ON” states, patients are able to function normally for the most part but are also ever aware of the state’s temporary nature. In “OFF” states PD patients experience muscle cramps and limited mobility that cause difficulty in maneuvering and socializing. As result of these on/off phenomena, patients have to carefully plan and construct their days as to not find themselves stranded in a state of discomfort. The authors also found that Parkinson’s patients sensed their body as “alien,” which affects their self-esteem and sense of

identity. The incongruence between patients' mental life and their loss of strength and change in bodily sensation creates a sense of disconnect between the mind and the body. Lastly, the PD patients reported an ambiguity in whether they control their body or if their body controls them. PD patients were observed to adopt one of two coping strategies to deal with their body's inconsistent functioning: restrict their activities in accordance with their body's functioning or refuse to let symptoms control their life.

To continue, Haahr et al. found that PD patient's lived time is characterized by struggling to be on time, living in a fixed schedule, and tension between rigidity and instability. The authors explain that PD patients experience time as being fragile, never knowing when or how long they would be in control, which makes the timing of activities crucial. This point is especially important when considering medication schedules. PD patients are dependant on their medication schedule, constantly thinking ahead. However, they also desire to be in the "now" and thus experience a tension between wanting to enjoy the present while also needing to be ever vigilant of the time for fear of missing a medication dose. Lastly, the authors found that PD patients are "stuck in time," balancing rigidity and instability. The loss of spontaneity, boredom, and monotony characterize a PD patient's experience of time. The combination of activities taking aggravatingly long to complete and required periods of rest make PD patients feel stuck between the wish to live in the present and the necessity of planning for the future.

In regard to the lived other, Haahr et al. found that PD patients' relationships with others are characterized by a strain between living independently and feeling as though they are a burden. The authors found that PD patients strive to stay as independent as possible but also recognize that there are pieces of their daily living that are totally

dependent on others – especially their spouses. In addition, participants expressed a wish to minimize the burden that they placed on their spouses, and were especially aware of how their dependence on their spouses limits their partner's social life.

Lastly, the researchers found that PD patients live with a sense of restrained space and that this restriction also impacts their social life. All the participants in the study reported that they felt restricted in their ability to go out, which makes their relation to their close surroundings more important. A patient's home was found to become much more significant as a safe place. Yet, even in their home they found themselves limited in their ability to utilize some of the things that they once had taken for granted, in some instances forcing the patients to move out of their home in effort to find another, more accommodating house. This restriction or change in lived space was found also to create changes in the PD patients' social lives. Holidays, family gatherings, and social circles were required to shift as a result of the patient's requisites for space. In addition to physical space, participants also reported a narrowing of psychological space due to feelings of insecurity as result of the visibility of their illness, which caused them to isolate themselves and venture out into the social world less frequently.

In sum, Haahr et al. concluded, much like Van Der Bruggen et al., that Parkinson's is characterized by an ongoing, never-ending and increasing struggle with an unpredictable body that permeates through all aspects of everyday life. The unpredictability is equivocated with a loss of control and loss of independence. PD patients cannot take for granted the body's functioning. Over time the symptoms of PD become more prominent and are coped with by maintaining a positive outlook, living in accordance to routine, or asserting control over one's body. The progression of the illness

is understood to be a journey of loss requiring constant adjustment to unpredictable changes in the body. The authors close their paper by recommending that healthcare professionals must strive to understand the context in which PD patient's give meaning to their illness and acknowledge that PD affects all aspects of a patient's lived world.

Another interpretative phenomenological study of Parkinson's is Bramley and Eatough's 2004 paper, *The Experience of Living with Parkinson's Disease: An Interpretative Phenomenological Analysis Case Study*. This study utilized interpretative phenomenological analysis to analyze several semi-structured interviews with one female PD patient. Through their analysis, the researchers found two super-ordinate themes: the complex interrelationship of mind and body, and changes in sense of self and agency. These two themes were then broken down into sub-themes.

The authors broke the interrelationship between mind and body into the following subthemes: the challenge of movement, the cyclic experience, and medication. The challenge of movement was found in the patient's reports of struggling to communicate and think prior to taking her daily dose of L-Dopa. The absences of these taken-for-granted functions becomes salient and are made only more apparent by the stark contrast in the participant's ability to function - once her medication kicked in, she was suddenly able to communicate and think. However, restored movement is often accompanied by the side effects of involuntary movement, which are sensed as "not belonging to her." The cyclical experience in the mind-body interrelation is characterized by the cyclic oscillation between "on" and "off" periods. These two states are experienced as the body being in constant flux and unrest. The contrast between the states created a feeling in the participant that she was never able to fully enjoy relief that one or the other state offered.

In addition, these states were found to highlight the effortfulness that being in an “off” state requires, making the most routine movements an effortful task that requires careful consideration. In addition, in social settings, patients are prone to feelings of embarrassment, which exacerbate symptoms. Thus, even while functioning, one can become embarrassed and be quickly swept back into symptomatic behavior. Lastly, medication is seen to greatly affect both mind and body. At times, it seems as if medication is “in charge,” controlling the patient’s movements. At other times, when well balanced, medications allow the patient to feel a sense of control over their body. The participant offered that in some ways she feels addicted to her medication as her body becomes more and more dependent on it to function. In sum, difficulty moving, the cyclical experience, and medication requirements are all part of the PD experience that highlight the interrelationship between mind and body.

The second super-ordinate theme of Bramley and Eatough’s paper is “Self and Agency.” The researchers purport that PD and its symptoms significantly disrupt the participant’s sense of self and agency as a result of feeling that she is no longer satisfactorily represented by her body’s appearance and actions. Instead, the participant created a new, post-Parkinson’s ‘self,’ which is then in conflict with the patient’s original ‘self.’ The two sub-themes that the authors found in the interviews with the patient were: comparing the new self with the old self, and achieving a stable self. When comparing the new self to the old self, the participant recalled herself as active and competent, in certain ways idealizing her ‘former self.’ The comparison also creates a feeling of making the changes more pronounced than once felt. The change is also seen as a stolen opportunity of “making the most out of herself” and feeling as though she will never be

able to achieve the same personal ideals. To continue, the researchers noted that the participant put great emphasis that the body that they saw was not her 'real' self. The participant feared that others would perceive her incorrectly as 'old' or 'demented.' She stated that she struggles to educate others that her physical disability does not impair her inner life. As a result, the participant finds herself in constant struggle to manage the disease through an array of strategies in order to maintain an image that corresponds to her sense of self. One of the strategies that the participant used to maintain a positive outlook was to evoke humor to stave off pity or shame from others. Additionally, family and support also sustained her ability to maintain a sense of stability and reinforce the optimism needed to face the progression of the illness.

In short, the subject's sense of self and agency were highlighted and challenged by the disease. Patients tend to compare their 'new self' to their 'old self,' which creates further disparity between their pre-Parkinson's self and post-Parkinson self. However, despite the comparison and conflict between 'old self' and 'new self,' there still remains a sense of stable self. However, maintaining this stable, core feeling of selfhood is difficult in the face of other's perceptions. This stable self is then sustained by managing symptoms of the disease, maintaining optimism, and using humor.

Another phenomenological study that explores the lived experience of a Parkinson's patient is Jo-anne Marr's article *The Experience of Living with Parkinson's Disease* (1991). For this study, Marr collected open-ended interviews with six individuals who suffered from PD. Marr found that four major themes as well as corresponding sub-themes emerged while talking with the subjects: (1) The impact of the disease, (2) Dealing with the disease, (3) Maintaining independence and normality, and (4) Effort.

The impact of the disease on the subjects was characterized by four sub-themes: (1) the diagnosis, (2) physical activity loss, (3) social activity loss, and (4) emotional loss. Marr found that Parkinson's patients have to deal with the disease before the formal diagnosis is received while they have to cope with unexplained symptoms. Once the patient is diagnosed, Marr found that patients tend to be relieved, finding comfort in receiving an explanation of their symptoms. She continued that a diagnosis sets the stage for a patient to begin to accept the illness and the reality that it entails. The loss of physical activity is characterized by the experience of progressively diminishing energy and ability to carry out routine tasks (e.g. hygiene, grooming, shopping, etc). The loss of social activity is also linked to diminished energy. The subjects in Marr's study explained that their fatigue and motor difficulties prevent them from seeking social engagement. In addition, the physiological changes that the disease causes may produce unwanted attention and feelings of embarrassment, causing them to further withdraw. Lastly, subjects' reports linked emotional loss with changes in self-concept. Subjects often reported lower self-esteem from a loss of independence. Additional emotional changes that were found were irritability and anger toward carrying out daily activities and an inability to "feel normal."

With regards to dealing with the disease, Marr found that the patients use the strategy of comparing themselves to individuals who are worse off than them to cope with their current situation. Social support, health, and medication were also seen as coping resources. Some patients reported that they try to carry on as usual and not dwell on their problem as a way to deal with their ongoing difficulties. However, Marr cites that the patients have to modify their daily routine to take into consideration fatigue,

movement limitations, and prescription scheduling, which often cause distress despite “carrying on.” What Marr found as the most important in dealing with the disease was reliable and meaningful social support. Another study found that the person that a Parkinson’s patient first tells about their disease is often the most important person in their life, and that the majority of their support comes from this person who becomes a source of strength and coping (Lazarus & Folkman, 1984). Lastly, in an unpredicted fashion, Parkinson’s patients also turn to their remaining health as a source of coping. The majority of Marr’s subjects reported that they still felt relatively healthy and prized the health and abilities that they maintain.

When talking about maintaining independence and normality, Marr’s subjects posed that they felt there wasn’t any choice but to persevere. Subjects identified the goals of obtaining independence and normality as being instrumental to carrying on. They reported a wish to do things for themselves even if it was a struggle. Accomplishing goals and having events to look forward to, reassured patients of their self-worth and ability to change their self-concept for the better.

To continue, Marr asserted that the experience of “increased effort” was consistent throughout all the interviews with Parkinson’s patients. Patients felt that overcoming fatigue, obtaining a diagnosis, establishing normality and independence, and reestablishing social and physical functioning all required deliberate effort. Marr closes by explaining that further studies should look to elaborate, validate, and explore links between the themes that she found.

Another paper that investigates the phenomenology of Parkinson’s is Todd, Simpson, and Murray’s article, *An Interpretative Phenomenological Analysis of*

Delusions in People with Parkinson's Disease (2010). This study aimed to explore what the delusional experiences that PD patients sometimes experience as a result of medication mean to the patients and to examine how psychosocial factors contribute to the development and maintenance of delusional beliefs. The researchers used the Interpretative Phenomenological Approach to study interviews of eight individuals who have PD and have experienced delusions that lasted for more than one week in the past year. Delusional experiences are most common in Parkinson's as a side effect of medications. Despite the medical explanation of delusions in Parkinson's, Todd et al. pose that delusions often receive their meaning through the psychological substrate of the individual and therefore, are of importance to explore to better understand the psychological structure of a Parkinson's patient. Todd et al. found four major themes in the delusions experienced by their subjects: (1) Emotional experiences associated with delusions; (2) A sense of uncertainty and of losing control; (3) Feeling a loss of identity and sense of self; and (4) Forming acceptance and adjustment to experience of delusions.

The authors found that the experience of emotions in their delusions was consistent throughout all interviews. The subjects described paranoid or persecutory thoughts that corresponded with negative affect. These affects typically included feelings of anxiety and fear. The subjects' accounts of negative affect were related to either living with the consequences of a chronic and debilitating illness or other difficult life circumstances, which appeared prior to the illness and worsened after the diagnosis – typically having to do with paranoia. However, it was also found in one account that delusional thought served a defensive purpose. In this example, a woman believed that she was still living with her children as she had many years prior, which served to protect

her against feelings of loneliness.

The second theme that was present in all the accounts of Parkinsonian delusions was a sense of uncertainty and loss of control. Todd et al. found that discussions of Parkinson's patients' delusional beliefs could be understood in relation to their loss of control in motor function as a result of PD. The subjects often spoke about the loss of control they felt over their treatment in regard to managing both motor symptoms and psychotic symptoms. Feelings about losing control of their treatment and their decline in motor abilities were often juxtaposed together. This was evident in an interview when a subject compared his fight against his persecutory beliefs with his discomfort with the fact that he struggles with something as simple as reading and writing.

The third theme the researchers found was that Parkinson's patients experience a loss of identity and sense of self in their delusions. Subjects often reported that they have experienced a negative change in personal and social identity. These lost pieces of identity often played an integral role in their sense of self (e.g. a busy mother, a partner in a secure relationship, a "proper" person, a non-threatening individual). However, Todd and colleagues clarify that research has found that most people with Parkinson's are able to maintain an intact identity by sustaining a sense of continuity with their pre-Parkinson's self. It is when participants had pre-Parkinson's lives that were markedly different than their post-diagnosis selves that difficulties with maintaining a sense of identity emerge.

Lastly, the theme of acceptance and adjustment to Parkinsonian delusions was characterized by an ongoing effort to maintain meaning in their lives. Participants described the process of adjustment as coming to terms with the threats posed to their

identities by delusional beliefs. One participant questioned the relevance of objective reality in day-to-day life, and instead focused on the importance of negotiating personal truths, enabling acceptance of delusions. As such, the participants described acknowledging their delusions, but resisting engaging with them. Crucial to maintaining meaning in their life, patients upheld a wish to keep active in the future despite this not necessarily being a realistic goal given the progressive nature of the disease. The researchers noted that participants in this study who appeared to be most successful in achieving acceptance of the changes in their lives were those that were the most successful in integrating the changes into their sense of self.

Focusing specifically on a more interpersonal dimension, in another study, researchers explored the subjective experience of PD's impact on couples' relationships (Hodgson, Garcia, & Tyndall, 2004). Hodgson et al. applied an interpretive phenomenological method on ten interviews with couples that had one partner diagnosed with PD. The researchers separated their data into five thematic clusters: (1) relationship and disease history, (2) impact on the couple's relationship, (3) impact on the self and other, (4) connecting with resources, and (5) strategies for survival.

The researchers found that all the participants started their accounts with a historical description of their relationship and the emergence of the disease. This is posed as an integral piece of the couple's narrative and underscores the experience of the transition from healthy to sick. Recalling the transition was painful for most couples and it was found that the diagnostic process was most difficult for younger couples. In addition, couples that had family members who suffer from the disease were just as distressed with their diagnosis as those who did not. Couples that had children also feared

for their children's future health, despite a lack of evidence for the heritability of the disease.

Hodgson and colleagues found that the couples spent the majority of the interview speaking about the impact the disease has on their relationship. They found couples experienced the impact of Parkinson's as both a blessing and a strain on their relationship. The researchers also found that themes that are characteristic of all chronic illnesses were relevant to Parkinson's patients. For example, the more stress the caregiving partner experiences, the less supported the ill partner experiences. Also similar to the effect of general chronic illness, couples noted changes in personal boundaries with their spouse as well as alterations in household responsibilities. However, the researchers found that worries about children developing the disease, uncertainty in future plans, and financial obligations were more characteristic of couples affected by PD than in general chronic illness. Strikingly, another finding was that the Parkinson's diagnosed spouse was not always the one who felt a need for support, but the caregiving partner often craved support as a result of their spouse's progressive disability. The authors continued that some of the difficulty between partners may be accounted for by the Parkinson's patient's effort to problem solve for themselves, inadvertently invalidating the caregiver's efforts and making them feel unappreciated. Conversely, the majority of couples also noted that the disease also strengthened their relationship, citing that they feel more committed to each other and that the increased amount of time that they spend together rekindled intimacy and trust within their relationship.

Another theme that arose in the interviews with couples was a tendency to digress from talking about how Parkinson's affected their relationship to how the disease affected

their individual senses of self. Some of the spouses affected by Parkinson's noted negative changes in mood, inability to talk with others about their illness, difficulty maintaining independence, being unsure of their own limits, and withdrawing from others and activities they once enjoyed. However, a few participants looked at these changes in identity as positive (e.g. spending time at home with their children). Almost all diagnosed participants noted strain in their work identity and pressure to hide symptoms from their co-workers for fear of being fired or stigmatized. As for the caregiving partner, many have to greatly modify their career identity. Some diagnosed partners reported that they suspected their caregiving partner of denying or minimizing the effect Parkinson's had on their lives. The study found that both partners' identities become stressed as a result of the disease. Most poignantly, both partners express fear and sadness for the expected future and impending losses of abilities and goals.

Hodgson and colleagues' study found the experience of connecting with resources was dependent on the availability of knowledgeable and compassionate medical providers, service providers, transportation, support groups, and other emotional outlets. All couples reported both positive and negative experiences with the above stated resources. Concerns regarding transportation were dominant in couples. They voiced an uncertainty of what transportation arrangements may look like in the future as the diagnosed partner's illness progresses. The couples noted that support groups, political outlets, and spirituality were all important to maintain a positive outlook. Many couples found a wide variety of support was necessary for successful coping. If support, in any form, had too narrow of a focus there was not enough recognition of the multi-dimensional effect the disease has on the individual and the couple.

Lastly, Hodgson et al.'s article addressed the topic which "created the most dialogue amongst couples," strategies for survival. Couples gave tips on how to maintain a healthy relationship while living with Parkinson's. Suggestions (in order of most prevalent to least) were: maintaining a sense of humor, honoring commitment to one another, seeking outside support, maintaining hope, supporting each other, living one day at a time, neutralizing conflict before it escalates, having patience with each other, maintaining open communication, not taking over for the patient, accepting losses, continuing to be physically attractive, keeping a positive attitude, allowing time apart, and never hiding the diagnosis. All participants also mentioned feeling empowered through knowledge and thankfulness. In the interviews, thankfulness took on a multitude of meanings for each subject. The authors summarized that the overarching meaning of thankfulness was a feeling of optimism and hope. Although some participants never used these words specifically, many aspects of what participants were thankful for was an anticipation of favorable outcomes.

Methodology

Broadly speaking, there is no universally accepted or "correct" phenomenological methodology. The method chosen for this study has been adopted in effort to address the strengths and limitations found in the varied phenomenological methodologies as they apply to this project. The method for this study will follow a combination of two approaches. The first is the Phenomenological Psychological method as outlined by Wertz in *Five Ways of Doing Qualitative Analysis* (2011). As such, the use of the Phenomenological Psychological method applied in this study will aim to illuminate essential subjective experiences and meanings of those experiences of individuals who

suffer from PD. In addition, the Phenomenological Psychological method will be supplemented and expanded upon by use of The Long Interview method as outlined by McCracken (1988). This method seeks to explore the mental world of an individual taking into consideration the pre-existing bodies of research that have been put forth in regards to the Parkinson's patient population and related literature. This method looks to expose the "life world" of an individual and understand their daily experience. These two approaches are highly overlapping and complementary. The reason for the combination, which will be discussed in more depth later, is to combine the strengths of each approach and mitigate any limitations that they may pose.

Participants

The participants of this study include seven individuals who have been diagnosed with Parkinson's disease for between 3 and 10 years, ranging in ages 59 to 71. Six of the participants were male and one participant was female. Four of the participants in the study were authors who have been diagnosed with PD and whose autobiographical accounts of their experience living with Parkinson's have been published. These accounts were obtained through the books: *Brain Storms: The race to unlock the mysteries of Parkinson's disease* (Palfreman, 2015), *A Life Shaken: My encounter with Parkinson's disease* (Havemann, 2002), *Old Age: A beginners guide* (Kinsley, 2016), and *Parkinson's Disease: A sniper in my head* (Verpeaux, 2013).

Three of the participants (2 male, 1 female) participated in three separate in-person interviews. The interview participants were recruited on a volunteer basis through word of mouth and use of the snowballing method. All interview subjects have received a formal diagnosis of Parkinson's disease from a physician.

Procedures

Four written, autobiographical, first-person narratives of subject's experience of Parkinson's disease were obtained through various pre-existing publications. These publications include: *Brain Storms: The race to unlock the mysteries of Parkinson's disease* (Palfreman, 2015), *A Life Shaken: My encounter with Parkinson's disease* (Havemann, 2002), *Old Age: A beginners guide* (Kinsley, 2016), and *Parkinson's Disease: A Sniper in my Head* (Verpeaux, 2013). These books were read and reflected upon in a combination of both Wertz and McCracken's methods.

Interview accounts of PD were obtained through a sample of 3 subjects whom volunteered to be interviewed by the researcher in an effort to better understand the experience of Parkinson's disease. All participants were asked to sign a notice of confidentiality and participant rights, consistent with Rutgers University IRB requirements. Interview participants were interviewed individually and responded to a semi-structured interview, following McCracken's Long Interview Method that investigated their general experience of their disease and daily life. All interviews were recorded on a digital voice recorder and manually transcribed by the researcher. All confidential materials were stored and transported in accordance to IRB confidentiality guidelines. No identifying information was collected or included in the manuscripts of this study.

Analysis

The study's analyses will follow a combination of Wertz's Phenomenological Psychological method (2011) and McCracken's The Long Interview method (1988). Each method will be described below in their unadulterated forms, followed by a

synthesis of the two methods as well as a rationale for the synthesis. Lastly, the technique used for conducting the interviews is explained.

In the Phenomenological Psychological method proposed by Wertz, there are two primary analyses, intentional analysis and eidetic analysis. Intentional analysis is the procedure of reflecting on, gaining insight into, and describing the “how” and “what” of experience, or how experiential processes proceed and what is experienced through them. This includes investigating the intentionality of the subject’s consciousness, or what the person’s consciousness is directed toward. This is meant to illuminate the person’s psychological processes and how they relate to their and other’s lived worlds. To accomplish this, narratives of people’s experiences are listened to or read. Then the structures of various types of experiences and the ways the world is experienced are descriptively elaborated on and recorded by the researcher.

Eidetic analysis is a qualitative analysis that utilizes the human capability of what Edmund Husserl called “the intuition of essences.” The eidetic analysis begins with the written narratives of the subject’s experience. The investigator then applies what is called “free imaginative variation” to each example to conceptually clarify its essence. If, after a particular theme or aspect of the report is imaginarily removed from the description, the instance is still an example of the studied phenomenon, what was removed is deemed not essential to the experience. By comparing many imaginatively varied experiences, the investigator can conceptualize what themes or experiences are invariably present in most or all examples of the experience - thereby achieving a realistic, general knowledge of the experience.

In agreement with Giorgi's (1975, 2009) attempt to make phenomenological analyses (intentional and eidetic analyses) explicit, systematic, and accountable, the Wertz's analysis progresses in four steps: (1) reading and listening for a sense of a whole; (2) extracting units of meaning from the text or interview; (3) reflecting on the psychological significance of each meaning unit; and (4) clarifying the psychological structures of the investigated phenomena.

The first step of reading or listening to the accounts of the phenomena is an exercise in "open reading." In this, the researcher follows the narration of the subject with no agenda, aim, or judgment of the report. Open reading lays the ground for the next step, discriminating meaning units. In finding meaning units, the researcher differentiates segments of the description that are relevant to the research interests. Specifically, in the study of PD, the researcher listened for content concerning the experience of will, corporeality, patients' relationship to the disease, intersubjectivity, and temporality. These meaning units can be combined or further differentiated in order to facilitate a more fruitful analysis. The third step is psychological reflection in which the researcher pays attention to what the expression in each meaning unit seems to reveal about the psychological process of a patient. The researcher analyzes and develops in detail what each meaning unit reveals about the example of the experience by using free imaginative variation. Finally, the researcher will develop a structural understanding and description by integrating and making a statement on what was learned in the various reflections on the meaning units. This requires the articulation and meaningful organization of the Parkinson's phenomena as a structured whole.

McCracken's Long Interview method is seen as complementary and highly overlapping to the above phenomenological approach. This approach requires the researcher to perform a four-step methodology. First is a review of analytic categories. Second is a review of cultural categories. Third is the discovery of cultural categories. Fourth is the analysis of the interview and discovery of analytical categories.

The review of analytic categories begins with an exhaustive literature review. This enables the researcher to identify problems, assess data, and provide the concepts on which the study's precepts depend. It also allows the researcher to notice discrepancy between the researcher's collected data and the current theories present in the field. This can allow the researcher to be aware of the assumptions that are present in the current literature. This step also aids in the construction of the questions that are to be asked by the researcher and the areas of experience that need to be investigated.

The review of cultural categories is an exercise in self-reflection. The investigator must examine the associations, incidents, and assumptions that surround the topic at hand. This prepares the researcher for the construction of interview questions, making them more aware of what pre-conceived ideas to which they may try to "match" interview data. The awareness of preconceptions is also used to distance the researcher from the data so they can become more objective in the themes that they find.

The discovery of cultural categories begins with the construction of the interview questions. These questions aim to gather general details of the subject's life through biographical inquiry. Next, questions are posed regarding subjects' general overview of experience. These non-directive questions regarding general experience are open-ended so subjects can speak freely and without constraint. Then, further specificity is sought

through “floating prompts,” which seek further detail about a specific account. Planned prompts are then used to illuminate experiences that are typically in the realm of the self-evident or imponderable. Through the construction of a sequence of questions that begins with biographical data, moving toward the general, and then seeking out the specific, the researcher is provided with an interview itinerary that guides the interview but does not intrude on the content presented. After this, the interview is conducted with the interviewer listening on multiple levels. The researcher listens for key terms, impression management, topic avoidance, deliberate distortion, minor misunderstanding, and incomprehension. In sum, the researcher must listen for both explicit and implicit material.

Lastly, the interview analysis and discovery of analytic categories begins with taping the interviews and transcribing them. The investigator then, at first, judges each interviewee's utterances based on their intended meaning. This is a way to sort material by importance. This material is then reflected upon by the researcher as a means to gain thematic insight into the data. The researcher then continues to develop these observations and use each separately to understand other sections of the interview. Next, the researcher has to attempt to investigate the relationships between each of these observations. The researcher then distills each of these interrelated observations into themes. These themes are then sorted in a hierarchical manner using subthemes as evidence for larger themes. Finally, themes from all the interviews are synthesized to talk about the general experience of the condition that is being studied.

The reason for the combination of Wertz and McCrackin's methodologies is to address what is seen as the limitation of the Husserlian eidetic analysis. As viewed from

this study's vantage point, the Phenomenological Psychological method's heavy reliance on the eidetic reduction is problematic. As Husserl views it, the eidetic reduction strips away all of the nonessential components of a phenomenon to arrive at the essence of the phenomenon. However, if the eidetic reduction was to be applied to Parkinson's, it would have to presuppose knowing what experiencing PD is like. In other words, the eidetic reduction would be useful in a phenomenological study of something that is essential to an experience that the researcher has already experienced but has not yet reflected upon. However, if the phenomenon being studied is radically outside of the typical experience of the researcher, such as PD, how could the researcher know, after systematically stripping away components of the described experience, what is still essential to the PD experience? As Sass & Fishman (In Press) noted, Husserl himself recognized this as a limitation of studying experiences that are outside of one's own cultural vantage point. To address this limitation, one can employ a more hermeneutic method where one acknowledges cultural biases and pre-existing knowledge of specific phenomena and incorporates them into new accounts of the phenomena in effort to enrich their understanding. In doing so the project's aim is not to arrive at a definitive "essence" of the experience of PD, but rather hopes to create a dialogue between the researcher's pre-existing biases and knowledge and subjects' reports of the phenomena to refine as well as broaden the understanding of PD. In this way, The Long Interview method is seen as a methodology that allows the investigator to understand the experience of PD through incorporating the pre-existing literature, the researcher's biases, and the information gathered through published first-hand accounts and interviews. To balance the introduction of the researcher's biases, this study analyses the multiple accounts of PD,

which serves as a means of “imaginative variation.” Having multiple accounts of the disease allows the researcher to deduce similar, essential aspects of the experience that are present across all of the subjects’ reports.

As for how these methodologies are combined, the sequence of each technique is maintained while components of each methodology that are seen as overlapping or enriching are combined. The first steps of The Long Interview method are seen as measures to address the researcher’s deficit of knowledge as to what the experience of PD is like. The review of analytic categories and cultural categories is seen as an acknowledgment of the preexisting biases and perceptions of the current body of literature and the researcher, respectively. Addressing and acknowledging pre-existing biases, as is included in each of the aforementioned steps, is seen as paramount to begin to formulate an approximation of what is to be expected as well as what needs to be “bracketed” in the proceeding steps, and thus must be preformed first.

Secondly, “reading and listening for a sense of a whole” and “the discovery of cultural categories” are seen as complementary, if not overlapping techniques. In both of these techniques the reader/listener takes an initial pass over the information. While doing such, the reader is attempting to get the broadest sense of the phenomena being described. The “discovery of cultural categories” elaborates on this by looking for “the obvious” or the “self-evident.” And both techniques are an attempt to lay the groundwork for “meaning units” to be found and extracted from the data.

To continue, The Long Interview’s technique of discovering analytical categories is seen as a combination of extracting “meaning units” and reflecting on the psychological meaning of each of the units. Firstly, each utterance is read based on their

intended meaning, sorted by significance (or meaning units), and then reflected upon by the researcher as a means to gain thematic insight into the data through relating the observed phenomena to concepts in existential philosophy (or finding psychological significance). Last of all, both studies conclude with the researcher synthesizing and processing the findings in a way that illuminate the subjective experience of the given phenomena.

Turning to the issue of conducting the interviews, although both the Phenomenological Psychological Method and The Long Interview method rely heavily upon gathering thorough, cogent, and vivid descriptions of the participants' experience, little instruction is given on how to execute interviews beyond the types of questions to ask and their sequential progression. To address this limitation, the Explication Method will be used during each interview. The Explication Method was created by phenomenologically oriented proponents of introspection as a methodological way to prompt subjects to observe their experience (Bitbol & Petitmengin, 2013; Maurel, 2009; Vermersch, 2009). In the Explication Method, the researcher follows a series of steps and guidelines to enable a subject to recall experiences in more vivid detail. The components of the technique are described below.

First, the interviewer and subject create a communication contract. This contract consists of an explicit statement regarding what information is being sought in the interview and how the subject may go about recalling that information (e.g. "I suggest that you take the time to notice what comes to you after the question is asked and you report it just as it comes back to you"). (Maurel, 2009) After the communication contract is established, the interviewer tries to evoke specific experiences. One of the ways this

can be done is by repeatedly attempting to evoke selected time-slices of this singular experience. The subject should be guided towards these acts by helping them to retrieve a specified moment of the experience and the sensations associated with the experience, or systematically using the present tense (Bitbol & Petitmengin, 2013; Vermersch, 2009). Once a specific moment of experience is evoked, the interviewer tries to stabilize the subject's attention to the experience by: (1) inviting the subject to suspend any other concern than the present interview, (2) reformulating the last pieces of report given by the subject (e.g. an answer to a previous question) and inviting them to check the accuracy of the reformulation, and (3) bringing the subject back to the thread of her description each time she stops describing the experience and starts judging or explaining it. (Bitbol & Petitmengin, 2013) Lastly, the interviewer tries to have the subject move their attention from the narrow content to the complete act of consciousness by relaxing any attention focused on the "what" and "why" of experience and progressively expanding it to appreciate the "how" of experience. (Bitbol & Petitmengin, 2013).

Results

The study's findings are presented below, separated by theme. Each theme is first presented in its raw, un-interpreted form. The un-interpreted forms of each theme are seen as the distillation of "meaning units" with minimal reflection added by the researcher. Following the un-interpreted data, the reports will be reflected upon and compared to pre-existing existential or phenomenological concepts. These existential analyses are used as a means for the researcher to reflect on the meaning units and clarify each theme's psychological significance as well as attempt to synthesize the meaning units and reflections into an understanding of the subjective experience of each of these

themes.

Denial

One of the most prominent aspects in the experience of coping with PD was found to be assuming a certain level of denial when accepting the diagnosis. When writing about the use of denial and initially receiving a PD diagnosis, one subject explained,

“Even when the warning signs are undeniable, [PD patients] try to deny them—in part because the disease is so far out of the public conscious, in part because we naturally reject the prospect of living out the rest of our lives with a degenerative disease.” (Havemann, 2002, p. 7)

Denial first appears as a response to the PD diagnosis itself. In nearly all the written and verbal accounts, subjects reported that upon noticing their first symptoms they resisted entertaining the idea of having PD. In two of the written accounts, the subjects stated that even their doctors colluded in their denial, telling the patients that there must have been a diagnostic error or that the prognosis was nothing to worry about. However, even after their doctors confirm their diagnosis, on some level the patients' denial continues. When talking about his “choice” to deny his illness, one subject explained:

“There are three ways to deal with [receiving a diagnosis of PD]: acceptance, confrontation, and denial. Acceptance is an aspiration, not a strategy. Confrontation means putting the disease at the very center of your life... Denial, on the other hand, means letting the disease affect your daily life as little as possible. In fact, it means pretending as best as you can that you don't even have it.” (Kinsley, 2016, p. 20)

To this subject, and many others, denial seems like the most attractive option.

Confrontation of the illness seems fraught with effort and entails committing a large portion of your life to the illness itself. Acceptance seems like a lofty goal, which, at least initially, seems unobtainable. Whereas denial seems like the most attractive option, you get to live comfortably, as you had pre-diagnosis, and the aspiration of acceptance gets to be put on the back burner.

However, the pervasiveness of the disease throughout one's life make's maintaining denial difficult for a PD patient. Specifically, all the subjects reported that PD significantly affects their interpersonal interactions, which in turn can become a reminder of the diagnosis' existence. As one subject wrote, "To work effectively... denial requires secrecy, and secrecy pretty much requires deception. It's simply easier to go through the day not thinking about Parkinson's disease if the people you interact with don't know you have it." (Kinsley, 2016, p. 24) Not only does disclosing your diagnosis to others compromise one's ability to maintain denial, but sympathy or reassurance regarding the PD diagnosis (or symptoms) can also be seen as threatening. One interview subject explained such an encounter with a friend after being recently diagnosed,

"[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.”

In summary, the presence of the theme of denial in the experience of PD first was found to emerge upon PD patients receiving their diagnosis and resisting that the diagnosis of PD was a viable option or explanation. This denial continues as a way of self-preservation and to maintain a semblance of “normalcy” and their pre-Parkinson’s selves. However, to effectively deny their condition and to eradicate the idea of having PD from their daily life, patients need to enlist others to support them in their denial. In other words, to maintain their denial, PD patients need to effectively conceal their symptoms from others to prevent external acknowledgement of their PD diagnosis. In addition to not wanting others to know about their disease, reassurance or comfort regarding PD symptoms can be seen as a threat to their ability to maintain their denial and semblance of normalcy.

Analysis of Denial

Denial, as typically defined, is when an individual declares something as untrue. The psychoanalytic definition of denial is a psychological defense mechanism in which confrontation with a personal problem or reality is avoided by rejecting the existence of the problem or reality, or in other words, a form of self-deception in the effort to cope. The denial observed in the Parkinson’s patient’s experience is closer to the latter. The PD patients that were studied, nearly unanimously, considered their efforts to deny the existence or ramifications of Parkinson’s as a coping mechanism – a way by which they were able to assume some semblance of normalcy and continue living without feeling disabled. However, the label “denial” in either the conventional or psychoanalytic understanding does not seem to fully capture the complexity of this coping strategy. The

denial observed in PD does not seem to have the full connotation of self-deception. One does not deny *having* Parkinson's and therefore refute that they objectively have the disease, but rather they resist identifying with the disease. Through this lens, denial as found in PD functions on a much more subtle, but no less impactful, way.

To understand denial in PD, one must consider what is being denied as well as what utility is in denying those certain aspects. In the accounts of Parkinson's that were given, no one denied that they objectively had the disease. The "conventional" denial of the actual diagnosis was only observed to be present when patients initially received the diagnosis (perhaps because the disease was too far out of the culture's consciousness or perhaps the prospect of living with a progressive neurological illness was unfathomable, as suggested by one interview subject). However, throughout the accounts, once a physician confirms the diagnosis, patients eventually accepted that they have the disease (within varying lengths of time). From this point, PD patients carry on the "denial" in a more subtle way. This denial is not that they *don't have* PD, rather they deny that their identity and their lives are *defined and constrained by* PD. In this way, patients wish not to acknowledge the presence of their illness in effort to maintain the sense of autonomy, selfhood, and freedom they experienced pre-diagnosis. However, the maintenance of this sense of self and autonomy is also influenced by the perceptions of others, which is why enlisting others within their interpersonal sphere in their denial is important to maintain their sense of self.

In many ways the "denial" observed in PD appears to be related to Jean Paul Sartre's notions of good and bad faith (Sartre, 2012). To Sartre, a person is in bad faith when they lie to themselves to spare themselves from angst. In its most fundamental

form, bad faith is when a person denies their freedom or the possibility to take other options in order to escape the weight of responsibility that freedom entails. Sartre argues that one of the most prominent ways in which people do this is to tell themselves the way they are at the current moment is the only way that they can be, which closes down the options of freedom. One of Sartre's most famous examples of bad faith is in his description of a waiter in a restaurant, who simply tells himself that his lot in life and destiny is to be a waiter. As such, the waiter becomes a reified caricature of what he envisions a waiter to be. In assuming this identity, the waiter loses his innate freedom to prescribe meaning to his life and the possibility to transcend himself in his role as a waiter. In essence, the waiter becomes an object (a being-in-itself, or *être-en-soi*), which negates his existence as a subjectivity (a being-for-itself, or *être-por-soi*). On the other hand, acting in good faith, as Sartre argues, is to embrace the radical freedom that we possess. Being in good faith means to recognize that you are primarily a subjectivity (being-for-itself) with no fixed nature, or essence, that is constantly recreating and transcending itself.

Taking good and bad faith in mind, one can better understand how the denial in PD functions. At first glance, one might assume that a patient "lying to themselves" by denying their identity as a PD patient would be in bad faith – they are, after all, lying to themselves to prevent short-term pain. However, to the contrary, when choosing the sort of denial discussed in this paper, a PD patient is acting in good faith. Sartre is not concerned with lying about objective facts. Rather Sartre is concerned more about people lying to themselves to escape their condemnation to be free. By denying their identification with the disease, they are trying to avoid the closing down of possibilities

that PD can represent. In refuting *to be* a PD patient, patients are utilizing their freedom to escape being defined as merely a Parkinson's patient, a being-in-itself, and trying to maintain their identity as a free subjectivity, a being-for-itself, that just so happens to be playing, but not confined to, the role of a PD patient.

Emotions and Symptom Expression

Emotions were found to play an integral role in the experience of PD symptoms. Subjects expressed an intimate connection between tremor severity and their emotional states. As such, when a Parkinson's patient experiences negative emotions (i.e. agitation, stress, anxiety, anger, sadness) their tremors become more pronounced and more severe. This phenomenon was observed multiple times throughout the interviews conducted for this study. During one interview, a subject became uncomfortable while talking about a difficult topic and expressed the following; "The stress manifests itself in a tremor. If I relax, which I can do voluntarily, I can stop it. I don't have to suppress it exactly, but I can reduce it tremendously." As the conversation continued the subject began to relax and further remarked, "I'm very calm right now, see [the tremor] is gone. As you and I have gotten into the discussion, my calmness has increased and deepened. I'm fine."

This connection with negative affect was also reported to be cyclical. As stated, when a PD patient becomes anxious, their symptoms become more pronounced. This increase in symptom severity can cause the patient to become more self-conscious, agitated, or stressed because their ability to function, control their body, and conceal their condition to others is compromised, which causes further agitation of their symptoms. When talking about the inability to control symptoms, one subject stated,

“I know sometimes when I get upset... I can't sit still. I get antsy; I guess you could say. You want to get control of the situation, get control of yourself. And wanting to gain control makes me more antsy. I want to stop this nonsense, but I can't.”

In another interview one subject, in an expression of familiarity to this cycle of emotions, labeled this phenomenon the “snowball effect” of Parkinson's.

Parkinsonian tremors are not limited to having a relationship to negative emotions. Positive affects (i.e. happiness, calmness, captivation) have a quelling effect on tremors. In effort to explain this experience one subject offered, “When I'm laughing or enjoying something, I feel better. I find that if I am spellbound by a movie or a book or something, I get a lot of enjoyment from, my symptoms vanish.” This “vanishing” of symptoms seems not to be a hyperbole. One subject reported in his writing that becoming enthralled with a creative activity enables him to paint or play piano – activities one would think to be near impossible with Parkinson's tremors. The subject explained,

“When I am engrossed in creativity, I have no time to pay attention to my condition. At those times, life seems to have returned to normal, as if the disease had never happened. It's a little like being able to freeze-frame a nightmare, to hold it in stasis for a while.” (Verpeaux, 2013)

In summary, emotional states were found to have great influence in the expression and presence of PD symptoms, especially Parkinsonian tremors. Negative affective states were reported to increase symptom severity, whereas positive affective states were seen as reducing the severity and presence of tremors. Furthermore, the connection between emotional states and symptom expression has the ability to become cyclic in nature.

When someone is feeling poorly, their symptoms increase, making them feel worse, which maintains the symptom expression. Likewise, entering a positive affective state can calm symptoms, helping the patient feel better, which further decreases symptom severity.

Analysis of Emotion and Symptom Expression

There is much debate in the literature regarding the role of the body in creating emotional states (Cornelious, 1996; Frijda, 1986; Prinz, 2004). However, a discussion of this debate exceeds the scope of this paper. Instead, what is more relevant to this project is how the body is experienced in emotional states and in what ways this may be affected by PD. As observed in the above accounts of PD, experiencing a change in symptom severity causes one to call into attention both the state of their body (e.g. presence of shaking, absence of shaking) and emotional experience (e.g. stress, sadness, relaxation, happiness, etc). An understanding of these states of self-awareness in PD may be enriched by relating them to the phenomenological concepts of pre-reflective and reflective self-awareness, bodily self-awareness, and foreground and background bodily feelings.

Pre-reflective self-awareness is a state in which one's self is experienced or lived through as the subject of awareness, without any process of reflection on itself. Within all experiences there exists pre-reflective self-awareness in that all conscious experiences are given as "mine," or in other words they are directly experienced in the first person (Zahavi, 2005). In reflective self-awareness, one's own self is reflected upon and objectified. One can then make the pre-reflective experience of "mine-ness" into a reflective self-awareness by calling this phenomenon to the fore of attention. In a similar

fashion, bodily self-awareness can also be pre-reflective and reflective. Pre-reflective body awareness is when one directly and immediately lives through one's own body, whereas reflective body awareness is a thematic, observational consciousness of one's own body.

Colombetti (2011) expands upon these ideas and links them to emotion by introducing the idea of bodily feelings being in the foreground or background of emotional states. Colombetti explains, "In many emotional experiences one's own body can somehow "stand out from the field of awareness and engross one's mind." (pg. 294) The experience of bodily sensation "standing out" is conceptualized as bodily experience being in the foreground of experience. Foreground bodily sensation can be either localized (e.g. the pain of a pin prick on your finger tip) or diffuse (e.g. the weight of your body when depressed). In contrast, background bodily feelings do not "stand out" and are not made apparent. However, they are still *felt* in the sense that background bodily sensations contribute to the specific quality of experience. Colombetti explains, "Background bodily feelings are best characterized as that *through which* a situation in the world is experienced by the subject as possessing a specific quality." (pg. 297, emphasis in original) Although one could easily assume that background bodily feeling would be pre-reflective and foreground bodily feeling would be reflective, Colombetti argues that both types of bodily experience are primarily pre-reflective. She agrees that background bodily feelings would be characterized as pre-reflective, as was we experience emotions *through* the body in a non-thematic way. However, foreground bodily feeling cannot be assumed to be reflective. This is because these feelings are not attended to as *objects*, and the body is still *subjectively* lived. These bodily experiences

can come to the fore of awareness, but they do so in a non-mediated and non-reflective way.

In many ways, the experience of emotion in PD is related to the distinctions between pre-reflective and reflective body awareness as well as foreground and background bodily feeling. In subjects' writings and interviews, they often noticed changes of intensity in their "resting tremors." As the name suggests, these resting tremors are most present in states of rest and less so when taking action. These tremors become PD patient's baseline and as such are most often in the background of bodily feeling, in the margins of awareness. These tremors are sensations that no longer "stand out," but never the less still contribute to the specific quality of experiences. However, when the intensity of the tremors change, they become foreground bodily feelings. The atypical quality of the tremor "stands out" and come to the fore of one's attention. Just as Colombetti explained that foreground bodily feelings can be either localized or diffuse, so too can the foreground feeling of tremors – the tremors can be limited to a specific limb or digit, or be felt as a diffuse sense of "antsy-ness," as one subject stated.

Similar to the discussion in Colombetti's paper, foreground and background feelings of tremors are also linked to reflective and pre-reflective self-awareness, but this relationship develops in a slightly different, more complex way. First, Colombetti asserts that in most circumstances, foreground bodily experience is pre-reflective because the body is still *subjectively* lived, whereas reflective self-awareness requires and objectification of the body. This seems true for the normative population, and Colombetti does make room for the idea that foreground bodily feeling can be reflective, but the PD population seems to make this possibility into an actuality. When PD tremors come to the

fore of bodily attention, PD patients report seeing their disease as “other” or as a counterwill of sorts. This distinction seems to require an objectification of the body (see “Volitional and Spontaneous Action” for more detail). As such one could argue that, at least initially, the changes in tremor intensity create an objectification of the body and therefore bring about a reflective self-awareness.

Furthermore, the experience of PD tremors in the foreground of bodily feeling also causes a shift in emotional self-awareness. In the interviews and written accounts, it was found that as patients notice the change in their tremors (when not linked to medication), they also reflect on their emotional states. Emotions that were once pre-reflective become reflective. In other words, the emotions that the subjects experienced as in the margins of experience, “living through them” in a direct, non-thematic way, became the *objects* of conscious intention. As result, a cyclic pattern emerges. The experience of the tremors in the foreground of bodily awareness brings their emotional state to reflective consciousness, which then sustains the reflective nature of foreground bodily feelings, and the cycle continues.

Lastly, in her paper, Colombetti also uses the example of “absorption” to illustrate how foreground and background body feeling relate to pre-reflective and reflective self-awareness, which, when seen in light of this paper, enriches the phenomenological understanding of how patients can mitigate their tremors and deescalate their emotional states. In two interviews, subjects offered that when they are “spellbound” or “engrossed” by an activity, their tremors nearly disappear. Because PD symptoms are exacerbated by bodily feelings coming to the foreground and body self-awareness becoming reflexive, having experience fade to the background of experience helps quell PD symptoms.

Colombetti states that when one is absorbed in an activity the bodily feeling is still in the foreground of bodily feeling, but the self-awareness of the body is not objectified or thematized, but rather lived through (pre-reflective). This shift in self-awareness in absorption allows a PD patient to break the cyclic experience by becoming absorbed in an activity and no longer sensing their body as an object, but rather as a medium to live through. With this in consideration, PD patients who are able to allow their attention to shift to the absorbing task allow their reflective body awareness fade to a pre-reflective state. This allows their bodily feeling to remain in the foreground of experience but no longer feel pushed to reflect on their emotional state, which reduces their tremors' intensity.

Alteration of Temporal Perspective

An alteration in temporal perspective was also found to be present in the experience of PD. As reported by the subjects, one of the most troubling aspects of receiving a PD diagnosis is the progressive nature of the illness. The initial symptoms of Parkinson's are easily treated. However, as the symptoms worsen, the relief provided by medication becomes more inconsistent and problematic. In the most advanced stages of PD, relief provided by medication can be short lived. In addition, the more medication you take, the stronger the side effects become, which can be debilitating in their own right. Patients need to come to terms with the realization that PD will follow them to their death – if not the cause of death, PD will be an undeniable and debilitating component to the patient's end-of-life experience. As one subject wrote, "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.” (Kinsley, 2016, p. 23) Another subject, as he explained his feeling toward medications and the future wrote,

“Viewed from the patient’s perspective, L-Dopa therapy seems like a Faustian bargain: You trade a better ‘now’ for a worse ‘later.’ You change moving well in the immediate future for complications—like moving too much and suddenly switching off—down the road.” (Palfreman, 2015, p. 33)

Patient’s reported that this feeling of foreboding and being reminded of their mortality causes them to shift their perception of time. Parkinson’s patients’ outlook on the future becomes constricted and oriented to the immediate and near future (i.e. planning the next movement of their body, when their next medication dosage is, when their next doctor’s appointment is, etc.). Furthermore, thoughts beyond the near future become uncertain and pose a possible threat. One interview subject stated this dilemma quite succinctly,

“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.”

Another interview subject expanded upon the idea while also giving voice to the inherent paradox in assuming this constrained temporal position,

“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."

In the above quote, the subject not only lays out the constriction of his outlook on time, but he also expresses the emotional deficit he feels by having to only look at the present. In this way, when a PD patient looks toward the future, they see disability and hardship. To avoid the emotional pain that comes with the future, they cut it off to the present or immediate future. However, in doing so they run the risk of losing sight of their goals, wishes, and dreams.

However, there seems to be a resolution to the tension between fearing the future and wishing to still be future-oriented. Throughout all the interviews and written accounts of PD, despite the negativity associated with the future, there is a strong presence of optimism. This optimism does not represent the thought that patients will no longer have PD or be cured, but rather represents a shift in the way they are oriented toward the future. While explaining this shift toward optimism one subject wrote, "I think not about what lies ahead for me but about what awaits." (Havemann, 2002, p. 158) In this quote "what lies ahead" is a signifier for the knowledge of inevitable disability, whereas "what awaits" symbolizes the uncertain experiences and opportunities that one can still pursue. Instead of focusing on the inevitable losses that will be dealt by PD, patients who have resolved this conflict focus on the opportunities and experiences that are to be had in order to foster a sense of hope. 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.” (Palfreman, 2015, p. 149)

In summary, having PD alters the experience of time for PD patients. To many patients, PD signifies having a progressive, debilitating disease that will increase in severity until death, whether from PD or other causes. This looming threat of debilitation and suffering causes PD patients to constrict their sense of time to the near future out of fear and uncertainty. The dismissal of the more distant future serves as a way to “save” the present from being contaminated by the anxieties that thinking about the future represents. However, as a result of avoiding thinking about the more distant future, PD patients find themselves robbed of life-long goals and aspirations to which they had once looked forward. In effort to resolve this tension between trying to avoid the anxieties of the future while maintaining their desires and aspirations, PD patients selectively alter what pieces of the future are paid attention. The impending disability that the future holds is downplayed, while the richness of possible experiences is maintained in order to restore a sense of hope and optimism.

Analysis of Alteration of Temporal Perspective

The alteration of temporal perspective observed in PD is intimately connected with subjects' outlook on the progression and prognosis of the disease. Salient in all the subjects' accounts was a keen awareness of their increasing level of disability and the inevitability of their death. As result of these expectations, PD patients found focusing on their distant future threatening and disconcerting whereas constraining their temporal experience to their immediate experience and near future was much less of a threat.

However, this constrained outlook eventually leads to the recognition of their current abilities and aspirations for their life that are still obtainable. A richer understanding of this temporal alteration can be obtained when juxtaposed against Heidegger's phenomenological analysis of the temporal experience of being-toward-death (Heidegger, Stambaugh, & Schmidt, 2010).

For Heidegger, there are two ways people can live, authentically and inauthentically – with most of life being lead in an inauthentic manner. Although the scope of this paper does not permit a full discussion of Heidegger's concept of authenticity, it is important to examine what Heidegger considered an inauthentic existence in order to achieve a rudimentary understanding of what is meant by living authentically. To Heidegger, living inauthentically means to live non-reflectively according to the demands dictated by societal forces while avoiding responsibility for contributing to the emergence of possibilities for one's own existence. (Guignon, 2008)

Heidegger posed seven characteristics of living inauthentically: (1) Being-with-one-another, or blindly identifying with an other's point of view; (2) Distantiality, or artificially distinguishing oneself from others by use of status; (3) Averageness, or lack of distinction between shared possibilities with others; (4) Publicness, or assuming the public worldview to be right; (5) Leveling down of possibilities, or the result of averageness, which restricts one's choices to the safe, tame things that others do; (6) Disburdening, or the abdication of one's responsibility to interpret the world from one's own perspective; and (7) Accommodation, or deceiving oneself that shared views are their own (Heidegger, Stambaugh, & Schmidt, 2010; Steiner & Reisinger, 2005). By assuming an inauthentic way of being, the meaning of, or possibilities for, existence is

lost or “covered up.” In addition, as is pertinent to our discussion, inauthenticity allows a person to avoid the realization that non-existence is an ever-present possibility.

Heidegger argued that to live authentically, and uncover the meaning of being, one must acknowledge one is a “being-toward-death.” In this mode of being, one does not see their death as an event but rather as a possibility. Seeing death as an event objectifies death as something in the future, to see life as a linear experience with a beginning and an end. If death is seen as a discrete event, one can dismiss it as being only present at the cessation of life or as happening to someone else. Assuming the mode of being-toward-death is to see death as an ever-present possibility, to constantly be seeing the possibility of non-being in being. To Heidegger, when one acknowledges the possibility of non-being, one’s being-able-to-be is revealed. To understand the meaning of being is to be aware of the possibilities of existence. Once the possibility of non-being and being-able-to-be are made salient, new possibilities of being emerge and one becomes more aware of one’s ability to create and re-create their future.

With Heidegger’s concepts in mind, it is possible to understand PD patients’ alteration in temporal perspective as a recognition of being-toward-death, or perhaps more apt here, being-toward-disability. This signifies a progression from seeing disability as a discrete, objective event that happens to others to disability as an ever-present possibility. Subjects’ initial dismissal of symptoms or, as the disease progresses, aversion to contemplation of their distant future can be understood as an objectification of their impending disability – a discrete event in the future that is feared and to be avoided, but not existing in the present. As such, in this initial stage, PD patients detach themselves from their progressing disability and eventual death. As a result of not recognizing the

possibility of non-being in being, subjects are constrained to the present and the meaning of existence (i.e. possibilities of being) is covered up. However, as PD patients begin to recognize the ever-present nature of disability as possibility, their being-able-to-be is brought to light. It is only after PD patients can recognize their being-able-to-be and the possibility of non-being that they can look toward the future as a source of experience and possibility, thus relinquishing the constraints on their temporal perspective.

Volition and Spontaneity of Movement

Another theme throughout PD patients' reports of their experience was a tension between actions being volitional or spontaneous. Paradoxically, patients reported both feeling as if their body was "not under [their] control," while also reporting the experience of having some power over their symptoms. One of the interview subjects noticed this phenomenon early on in his diagnosis and supplied the anecdote below, which was followed by an in-the-moment example while talking with the researcher:

"I noticed with my wife that my hand was jumping around, this is 5-6 years ago. She said, 'Are you doing that on purpose?' And I said that I was, but I wasn't... It actually subjectively felt between the two. I thought I was doing it on purpose. Right now, when you see the tremor [in my hand], it's not entirely involuntary. I can control it; I can quiet it down. [The subject then stops the tremor in his hand] Then I can reenact it. [The subject's hand begins to shake again] There is a weird boundary line between intentionality and spontaneity. It encompasses every part of Parkinson's."

As this subject stated, and then demonstrated for the researcher, he is capable of impacting, if not controlling, the presence of his tremors. This subject asserted that this control was accomplished with careful concentration and effort. In this way, the tremors in Parkinson's are, to some extent, under the patient's volition. Another interview subject described a similar phenomenon while talking about the connection between emotions and the presence of her tremors. As stated above, PD tremors are exacerbated by emotional stress and this patient used her ability to control her emotional state to control her tremors. As she spoke with the researcher about a sensitive subject, she became uncomfortable. As she attempted to control the tremor she said the following, "I'm talking and I'm getting too excited. My left side wants to shake. And what I do for that is I lay in my chair here. I put my feet up there, up against the seat. I'll just relax." As the subject reclined into her chair, she took deep, deliberate breaths and slowly her tremors began to dissipate as she became relaxed.

PD patients also control their tremors by means of "tricking" their bodies into restored movement. One interview subject described the difference in using a four-legged walker as opposed to two canes. She reported that when using the walker, she would begin to walk and her feet would "want to go faster" in anticipation of arriving at her intended destination. This forced her to stop and slow herself down for fear of falling. However, when she used two canes to aid her in walking, one in each hand, she no longer experienced the problem of her feet moving too quickly. Instead, she stated that when she swung the canes "like you would do with your arms when walking" she was suddenly able to control the speed of her legs. The patient said that she exploits this "trick" to move around more effectively. Another interview subject described "freezing in

doorways” when entering one room from another. This patient reported that, to avoid “freezing,” he focuses on the floor ahead of him as opposed to the doorway itself. He stated, “If I look at the doorway, I freeze. But if I look at the floor in front of me, especially if it is the same type of surface, I can enter the room much easier.”

However, there would not be a conflict between the volitional and spontaneous nature of PD symptoms if the symptoms were not also resistant to the PD patient's will. Subjects described that when the disease exerts its control over their body it is as if they are captive to the disease's will. As one subject wrote, “It's like being a prisoner, and the jail cell is my body.” (Havemann, 2002 p. 14)

Many others echoed this sentiment. In these instances, PD patients describe their bodies as feeling radically “Other” specifically as an Other that is in opposition to their will. As one interview subject described the experience of walking, she reported, “My body just stops. I can see [my destination]. I can anticipate any obstacles. But when I go, [my body] doesn't.” When she experiences this phenomenon, she describes silently talking to her body saying, “Okay c'mon. Come on, let's go!” as if she needs to coax an unruly opponent. Or as another subject described,

“Parkinson's is continually taking out his temper on me for being his unwilling captor; he is still like an adolescent who likes to play naughty games with my brain and delights in tricking me when he gets bored.”

(Verpeaux, 2013)

Similar to the above statements, subjects personify PD when describing the control that it has over them, saying things like, “I make one move, and [PD] makes another,” or “[PD] is like a cat and mouse game; Parkinson's is the cat and I'm the mouse.”

The deliberateness and effortfulness that it takes to combat and control PD symptoms is also salient throughout the subjects' reports. One subject likened the experience of functioning with PD to an American driving in England:

“Having Parkinson's is a bit like going on vacation in another country and having to drive on the 'wrong' side of the road. Driving is one of those activities that we outsource, in large part, to the basal ganglia. The American driver's basal ganglia as picked up the habitual behavior of driving on the right-hand side of the road through thousands of hours of practice navigating a car through the streets of the United States. When he tries driving in England, these learned habits are a liability. To compensate, the motorist must evoke the conscious, deliberate, mindful and goal-oriented part of his brain—the cortex—to override the basal ganglia.” (Palfreman, 2015, p. 61)

Not only is the activity of movement effortful and deliberate, but the deliberateness of these acts feels embarrassing. As another subject put it, “Having Parkinson's Disease is like pedaling a bicycle with the brakes on full all the time. Not only do you advance extremely slowly, but it is frequently very tiring and is sometimes even laughed at by passers-by.” (Verpeaux, 2013)

Lastly, it should be noted that the tension between the volitional and spontaneous quality of PD symptoms is, for the most part, quite unpredictable and inconsistent. Subjects described that their ability to function and control their symptoms throughout the day can have a roughly predictable rhythm – especially for those who take their medication promptly and regularly. However, even within this rhythm there is great

variability and unpredictability. If one is unable to take a dose of their medication on time, if they become emotionally activated, or if they deviate from their typical schedule, the fragile rhythm is lost and the day can become markedly less controllable or predictable. One subject remarked that that predictability of functioning with PD is mostly an “illusion” and a transient state, stating that no one can ever anticipate the events of the day that may mark the resurgence of symptoms. As one interview subject put it,

“...It’s a rollercoaster. There are some highs and lows. There can be highs and lows in the course of a day, highs and lows in the course of a week, highs and lows in the course of a month when you’re dealing with [PD]. The only thing that is predictable about Parkinson’s is the unpredictability.”

In summary, the experience of PD tremors is permeated with a tension between volitional intent and spontaneity. PD patients report that with careful attention and effort they can control or manage the expression of tremors. Patients report using their emotional states, relaxation techniques, and cognitive “tricks” to control or quell their symptoms. Yet at other times, PD patients experience their symptoms as outside of their volition and radically “other,” which is often expressed as a personification of PD as an opposing force to their will. Lastly, the level of control they may have over their tremors is unpredictable.

Analysis of Volition and Spontaneity of Movement

Volition is the process by which an individual decides on and commits to a particular course of action. In this way, action is willful and is conducted in the context of

freedom of choice amongst other actions. Under “normal” circumstances, people are only limited in their volition by outside constraints (i.e. laws of physics, the opposition of other's will, etc.). However, in Parkinson's, one's will over their functioning is not only limited by external constraints but is also limited by their own neurological functioning. In the experience of PD, the effort to control and being controlled by your symptoms creates a conflict that makes patients assume both the position of a subject who is exerting their will as well as an object to be overcome.

The split within the PD patient as both subject and object is related to existential philosophers' conception of the ontology of human experience. Sartre (2012) believed that there are two fundamental ways of being, being-in-itself and being-for-itself. Being-in-itself is the mode of being that *things* (i.e. non-human things) in the world possess. A being-in-itself does not possess the ability to reflect upon and be aware of itself and its own identity. Sartre poses that a human's central way of existing is as a being-for-itself. As such, humans are wells of subjective experience for which their own existence matters. A being-for-itself also possesses the capability and freedom to reflect on their existence in whatever manner they choose. The split between being-for-itself and being-in-itself represents the split between subject and object, respectively. Sartre also realizes that a large part of being-for-itself is being-for-others (or existing in a social context), in which a tension is created between being-for-itself and being-in-itself. This is to say, when one person (a being-for-itself) looks at an Other, the Other becomes objectified (a being-in-itself) by the subject's “gaze.” Within this social context, a being-for-itself experiences themselves as a being-for-itself while also being a being-in-itself to others.

In the case of PD, patients are immersed in the tension of being both a being-in-itself and a being-for-itself. They are both a subject that can willfully act and exert their freedom, while also experiencing themselves as an object, limited in or devoid of freedom and will. As such, a PD patient does not need an Other to objectify them. The patient, as a subjectivity, is persistently manipulating or tricking their body as an object (a being-in-itself) in order to exert their will. The split between the subjectivity of the patient and the objective qualities of their bodies creates a sense of otherness – which becomes reified and personified in the subjects' reports of their bodies as being an opposing will.

However, it should be mentioned that the experience in PD of being both a being-for-itself and a being-in-itself simultaneously may not represent a fundamental divide as much as it represents a fundamental connectedness between subject and object, as suggested by Heidegger (Heidegger, Stambaugh, & Schmidt, 2010). Heidegger found the distinction between subject and object as an illusion created by the Cartesian worldview. To Heidegger, subject and object are inseparable and conceived the basic ontology of humans as *Dasein*, or “being-there.” One basic mode of being for *Dasein* is “being-in-the-world,” which denotes the connectedness of being (subjectivity) to the world (objects) around them. In this line of thinking, PD patient's experience of the inescapable tension of existing as both subject and object as well as “tricking” and manipulating one's body to exert volition can be seen as underscoring the intimate interdependent nature of subject and object. In this way, the volition of a patient (as a subject) influences the body (or object), while the body reciprocally the body influences volition in a co-dependant manner.

Discussion

Findings

The four themes found to characterize the subjective experience of PD patients are (1) Assuming a stance of denial to prevent one's identity from becoming defined by Parkinson's disease; (2) Emotional states being connected to symptom expression and the awareness of one's own body; (3) An alteration of temporal perspective that, at first, is limited to the present and near future and expands to the more distant future through recognition of the possibility of non-being and being-able-to-be; and (4) A tension between movement being volitional versus being spontaneous, which mirrors the human condition of being both a subject and object.

Although many of the thematic categories may seem to be novel, existential analysis shows them to overlap considerably with those described in previous literature. Two of the most common themes in the phenomenological literature on PD are unpredictability (Caap-Ahlgren & Lannerheim, 2002; Haahr et al., 2011; Van Der Bruggen & Widdershoven, 2004; Wressle et al., 2007) and loss of control (Todd, Simpson, & Murray, 2010). These themes correspond closely to the tension between volitional and spontaneous movement found in the current study. Participants often reported feeling as if their bodies were "out of [their] control," going so far as to say that they felt captive to their bodies. Yet, subjects also reported feeling as though they did maintain the ability to control their symptoms and that their tremors were "not entirely involuntary." These patients asserted control over their tremors through the use of will-power, emotional states, or perceptual "tricks." In addition to fluctuations in perceived control over movement, subjects also reported that periods of volition and spontaneity

oscillate unpredictably. Previous literature has found these themes to relate to PD patient's perceptions of space, temporal experience, medication management, and the presence of symptoms. However, in this study, control and unpredictability were predominantly described in reference to physical movement.

Other authors have also identified changes or threats to the sense of identity of a person with PD as a prominent theme (Bramley & Eatough 2004; Marr, 1991; Todd, Simpson, & Murray, 2010; Van Der Bruggen & Widdershoven, 2004). However, the participants in this study described how although their identity is threatened, patients do maintain a stable sense of identity throughout the experience. Despite "changes in identity" not being used as a thematic category, subjects described using denial to preserve or adapt their identity in the face of PD. Subjects' denial, as conceived in this study, was not oriented to denying the diagnosis of PD, but rather was a way to reject PD as the sole source of their identity. Bramley and Eatough (2004) observed that the experience of identity in PD is characterized by what seems to be a dialectical process. As such, an "old self" (pre-Parkinson's) gets compared to a "new self" (post-Parkinson's) and a tension between "new self" and "old self" remains until a stable sense of self is reestablished. This study provides further support for this concept, given that denial was employed as a way of preserving a stable identity. However, this study differs by finding considerably less emphasis on comparing a "new self" to an "old self." Rather, subjects reported assimilating new, post-Parkinson's characteristics to a pre-existing, stable sense of self. In light of this study's existential analysis of denial, creating the concepts of "new self" and "old self" might be considered an example of acting in "bad faith" by viewing their identity as being defined and confined by their state of health. However, subjects'

refusal to be defined by their state of health while integrating new, post-Parkinson's characteristics often seemed to be an effort to expand upon their identity to accommodate new traits into their pre-existing personhood. In this way, PD patients do not seem to have to create an entirely "new self" to achieve a stable sense of self. Instead, PD patients become aware of possessing a dynamic, ever-changing constellation of attributes that make up their identity. Some possible causes of these contrasting results may be linked to differences in the theoretical perspectives or interpretative emphases adopted by the various authors. The difference may also be the result of genuine discrepant experiences between participants. However, in the absence of a clear explanation, further research regarding the experience of identity in PD is warranted.

The literature regarding the temporal experience of PD is sparse and seemingly contradictory. In their investigation, Van Der Bruggen and Widdershoven's (2004) found that PD patients' temporality is colored by sadness and as a result becomes constrained. The authors found that PD patients see their past as a reminder of what they have lost and see their future as a reminder of things that they will be unable to accomplish, which confines the patients to the present. However, elsewhere in the literature, hope and optimism regarding the future are seen as characteristic ways of coping with PD (Haahr, et. Al, 2011, Hodgeson, et. al, 2004; Marr, 1991; Todd et. al, 2010). The juxtaposition of these concepts highlights a conflict within the literature. Some researchers have found PD patients' experience of the future is cooled by sadness, while others pose that PD patients see their future with optimism and hope.

This study helps clarify these seemingly contradictory findings. Similar to Van Der Bruggen and Widdershoven's (2004) findings, initially subjects reported that their

experience of time was constrained to the present as result of fearing future debilitation. However, because of the imminence of their disease and mortality, PD patients realize the ever-present possibility of “non-being,” which illuminates their current “being-able-to-be.” This realization of their relative health and ability allows PD patients to enjoy the current moment while not being overly preoccupied with fear of the future. In this sense, the future becomes a signifier of possibilities as opposed to disability or death. However, the comparison of this study’s findings with the literature raises the question of whether these different temporal outlooks represent distinct outcomes, or if the different findings might represent stages in a progression of temporal perspectives toward optimism and hope.

Finally, this study identified the link between emotional states and PD symptom expression as a novel salient theme. Although there exist many non-phenomenological studies that focus on emotion in PD, especially concerning depression and facial affect recognition (Reijnders, Ehrt, Weber, Aarsland, & Leentjens, 2008, Gray & Tickle-Degnen, 2010), the phenomenology of emotion in PD and the effect of emotional states on symptom severity is not well researched. Bramley and Eatough (2004) found that Parkinson’s symptoms have a “cyclic” nature. The authors found that embarrassment cyclically exacerbates symptoms, noting that PD patients reported that they often became embarrassed by their symptoms and that this caused their tremors to become worse, which caused further embarrassment. Similarly, Todd et al. (2010) found that negative emotional states intensified delusional states associated with PD medication or neurodegeneration. The current study lends further support to the theme of reciprocity between emotional states and symptom severity, finding that negative emotional states

(i.e. anxiety, sadness, anger) increased the intensity of tremors, which reciprocally made subjects feel worse, which further exacerbated subjects' tremors. However, unique to this study is the finding that this cyclic experience also occurs in its inverse. Subjects indicated that relaxation and positive affects (i.e. happiness, enjoyment) can mitigate symptoms, thus creating further positive affect, which sustains tremor reduction.

Aside from thematic findings, another original aspect of this study is the comparison of thematic findings to concepts in existential philosophy. By comparing denial, the connection between emotion and symptom expression, alteration of temporal perspective, and action as both volitional and spontaneous to the existential concepts of bad faith, self-awareness, authenticity, and being-for-itself and being-in-itself, respectively, the understanding of PD phenomena is deepened and enriched. By making these comparisons, the researcher is able to reflect upon the experience of interviewing and thematizing the subjects' reports with their own understanding of related philosophical concepts, which helps enrich the understanding of the thematic content. These existential analyses are not to be taken as definitive "essences" of the experience of PD or as arriving at a "Truth" about the experience, but rather are meant to be seen as the beginning of a dialogue between the author of this paper, other researchers, and PD patients in order to better understand the experience of PD. In line with the notion of the hermeneutic circle, it would be useful for PD patients and future researchers to compare their experiences and findings with those reported in this paper in order to further refine and/or expand our understanding of the subjective dimensions of PD.

Limitations

Some limitations of this study are clarified by Finlay's 2009 paper, *Debating Phenomenological Research Methods*. Finlay poses various critiques and questions to phenomenological researchers as a way of fostering dialogue and openness, while also clarifying phenomenological methodology. Three questions raised by Finlay highlight potential limitations of this study: (1) Should phenomenology aim to produce a normative description of the phenomenon, or is idiographic analysis a legitimate aim? (2) To what extent should interpretation be involved in phenomenological description? and (3) Should we set aside or bring to the foreground a researcher's subjectivity? While the remainder of Finlay's questions are essential to the advancement of phenomenological methodology, their consideration is beyond the scope and aim of this study.

Let us first consider the question of whether the study strives to be a normative or ideographic description of PD, and whether the participants for this study can be considered a normative sample. The sample of participant reports that were analyzed may represent a subset of the Parkinson's population that find themselves articulate enough or in good enough cognitive standing to report their subjective experience either through writing or verbal report. As such, this sample may be biased and unrepresentative of the general or normative spectrum of the disease's symptomatology, which obviously involves cognitive decline (Muslimovic, Schmand, Speelman, & De Haan, 2007). In addition, because participation was voluntary, the subjects may be self-selecting in level of interest or openness and therefore, not fully representative of the overall population. However, the aim of this study's methodology is not to arrive at a definitive or normative understanding of the experience of PD, but instead seeks to explore possibilities of how

the experience of PD can be understood. Although, because of the nature of the PD patient population, it is unclear if this study's findings can be seen as capturing the general essence of PD or if a subset of these findings may be attributed to co-occurring phenomena. For example, it is unclear what characteristics of the PD experience can be attributed purely to the disease itself versus the experiences of aging, living with a chronic illness, or a having movement disorder in general.

Another limitation of this study concerns the objectivity of the study's findings or how much interpretation and subjectivity of the researcher should be included in the findings. Although the study's methodology attempts to address the issue of the researcher's biases based on pre-existing knowledge about Parkinson's or the existential concepts used in the analyses, the effect of biases cannot be entirely excluded. In an effort to minimize the impact of the researcher's interpretations on the thematic findings, the study purposefully separated the thematic findings from their respective existential analysis. However, even in the act of listening to or reading the accounts of PD and organizing them thematically, it can be argued that the investigator, in one way or another, was interpreting the content and therefore introducing biases to the themes found. One of the ways in which this limitation might be addressed would be by utilizing multiple researchers to conduct separate thematic analyses, identifying areas of convergence and divergence. However, even in recruiting more investigators, groups are still susceptible to cultural biases or being influenced by groupthink. It would however be prudent, and consistent with the hermeneutic circle, to gather post-analysis reflections from the subjects on the findings, thereby allowing participants to confirm or deny the fidelity of the study's findings to their experience. Gathering post-analysis reflections

would allow the subjects and investigator to engage in a conversation to refine the themes found to be present in their reports and to ensure agreement between the subject's experience and the study's findings.

Directions for Further Research

After taking into account the results of this study, its limitations, the questions it raises about phenomenological research, and the limited body of phenomenological research regarding PD, further investigation into the subject matter is warranted. Considering the relatively small body of literature on the topic, further phenomenological studies of PD are needed to clarify what is seen to be characteristic of the experience of PD.

The literature would also benefit from studies that have PD patients reflect upon the findings of this study and others in effort to find points of agreement and contention between researcher's perceptions and patients' experience of PD. Variations of these follow-up studies may also be beneficial, such as having the subjects reflect upon the findings of the study in which they participated, as well as having PD patients reflect on the findings of other studies. Executing these types of studies can act as a way to check for both inter- and intra-study validity.

Additionally, the literature would benefit from a qualitative meta-analysis (Timulak, 2009) of the pre-existing phenomenological literature on PD in an effort to consolidate findings regarding prominent themes and raise questions regarding findings that are outliers. By conducting a meta-analysis, one could obtain an enhanced normative understanding of PD. Through this lens, the current study should be looked upon as a part of a conglomeration of studies whose findings can be synthesized and analyzed for

overarching thematic similarities. In this way, the comparison of studies can be seen as analogous to conducting Husserl's method of "imaginative variation" in which one hopes to obtain general knowledge and clarify the essence of the experience of PD without necessarily having a fully representative sample in each study.

Lastly, further clarity and differentiation is needed between the phenomenology of PD and other co-occurring phenomena. One example is to seek comparisons between the phenomenological literature of PD and other chronic illnesses. Such a comparison would shed light on what findings are specific to Parkinson's and what aspects can be attributed to living with a chronic, degenerative illness. Similar comparative studies would also help in further delineating what phenomena are specific to PD as opposed to movement disorders, terminal illness, aging, and other neurodegenerative diseases.

References

- Ascherio, A., Chen, H., Weisskopf, M. G., O'Reilly, E., McCullough, M. L., Calle, E. E., & Thun, M. J. (2006). Pesticide exposure and risk for Parkinson's disease. *Annals of Neurology*, 60(2), 197-203.
- Belgum, D. (Ed.). (2008). *Living with Parkinson's Disease* (1st ed.). Lanham, Maryland: Hamilton Books.
- Bitbol, M., & Petitmengin, C. (2013). A defense of introspection from within. *Constructivist Foundations*, 8(3), 269-279.
- Booth, G. (1948). Psychodynamics in parkinsonism. *Psychosomatic Medicine*, 10(1), 1-14.
- Borek, L. L., Kohn, R., & Friedman, J. H. (2007). Phenomenology of dreams in Parkinson's disease. *Movement Disorders*, 22(2), 198-202.
- Bramley, N., & Eatough, V. (2005). The experience of living with Parkinson's disease: An interpretative phenomenological analysis case study. *Psychology & Health*, 20(2), 223-235.
- Caap-Ahlgren, M. (2002). Older Swedish women's experiences of living with symptoms related to Parkinson's disease. *Journal of Advanced Nursing*, 39(1), 87-95.
- Camp, C. D. (1913). Paralysis agitans and multiple sclerosis and their treatment.
- Colombetti, G. (2011). Varieties of pre-reflective self-awareness: Foreground and background bodily feelings in emotion experience. *Inquiry*, 54(3), 293-313.
- Cornelius, R. R. (1996). *The science of emotion: Research and tradition in the psychology of emotions*. New York: Prentice-Hall, Inc.

- de Lau, L. M., & Breteler, M. M. (2006). Epidemiology of Parkinson's disease. *The Lancet Neurology*, 5(6), 525-535.
- Deuschl, G., Papengut, F., & Hellriegel, H. (2012). The phenomenology of parkinsonian tremor. *Parkinsonism & Related Disorders*, 18, S87-S89.
- Dowling, M. (2007). From Husserl to van Manen. A review of different phenomenological approaches. *International Journal of Nursing Studies*, 44(1), 131-142.
- Ellenberger, H.F. (1958). A clinical introduction to psychiatric phenomenology and existential analysis. In R. May, E. Angel, & H. F. Ellenberger (Eds.), *Existence: A new dimension in psychiatry and psychology* (pp. 92-104). New York: Basic Books.
- Finlay, L. (2012). Debating phenomenological methods. In *Hermeneutic phenomenology in education* (pp. 17-37). SensePublishers.
- Frijda, N. H. (1986). The emotions: Studies in emotion and social interaction. *Paris: Maison de Sciences de l'Homme*.
- Fuchs, T. "The phenomenology of body, space and time in depression." *Comprendre* 15 (2005): 108-121.
- Giasson, B. I., & Van Deerlin, V. M. (2007). Mutations in LRRK2 as a cause of Parkinson's disease. *Neurosignals*, 16(1), 99-105.
- Giorgi, A. (1975). An application of phenomenological method in psychology. *Duquesne Studies in Phenomenological Psychology*, 2, 82-103.
- Giorgi, A. (2009). *The descriptive phenomenological method in psychology: A modified Husserlian approach*. Pittsburgh, PA: Duquesne University Press.

- Glosser, G., Clark, C., Freundlich, B., Kliner-Krenzel, L., Flaherty, P., & Stern, M. (1995). A controlled investigation of current and premorbid personality: characteristics of Parkinson's disease patients. *Movement Disorders*, 10(2), 201-206.
- Gord, C. (Ed.). (2007). *Surviving Adversity--living with Parkinson's disease* (1st ed., Vol. 1). Surviving Adversity.
- Gray, H. M., & Tickle-Degnen, L. (2010). A meta-analysis of performance on emotion recognition tasks in Parkinson's disease. *Neuropsychology*, 24(2), 176-191.
- Guignon, C. (2008). Authenticity. *Philosophy Compass*, 3(2), 277-290.
- Haahr, A., Kirkevold, M., Hall, E. O., & Østergaard, K. (2011). Living with advanced Parkinson's disease: a constant struggle with unpredictability. *Journal of Advanced Nursing*, 67(2), 408-417.
- Havemann, J. (2003). *A life shaken: my encounter with Parkinson's Disease*. JHU Press.
- Heidegger, M., Stambaugh, J., & Schmidt, D. J. (2010). *Being and time*. SUNY Press.
- Hodgson, J. H., Garcia, K., & Tyndall, L. (2004). Parkinson's disease and the couple relationship: A qualitative analysis. *Families, Systems, & Health*, 22(1), 101.
- Hoehn, M. & Yahr, M. (1967). Parkinsonism: onset, progression, and mortality. *Neurology*, 17 (1967), pp. 427-442
- Husserl, E. (1990). *Ideas pertaining to a pure phenomenology and to a phenomenological philosophy: Second book studies in the phenomenology of constitution* (Vol. 3). Springer Science & Business Media.
- Hyde, M. J. (1980). The experience of anxiety: A phenomenological investigation. *Quarterly Journal of Speech*, 66(2), 140-154.

- Jelliffe, S. E. (1940). The parkinsonian body posture: some considerations on unconscious hostility. *The Psychoanalytic Review* (1913-1957), 27, 467.
- Kinsley, M. E. (2016). *Old age: a beginner's guide*. New York: Tim Duggan Books.
- Lazarus, R. S., & Folkman, S. (1984). Stress. *Appraisal, and coping*, 725.
- Lew, M. (2007). Overview of Parkinson's disease. *Pharmacotherapy: The Journal of Human Pharmacology and Drug Therapy*, 27(12P2), 155S-160S.
- Lotharius, J., & Brundin, P. (2002). Pathogenesis of Parkinson's disease: dopamine, vesicles and α -synuclein. *Nature Reviews Neuroscience*, 3(12), 932-942.
- Marr, J. A. (1991). The experience of living with Parkinson's disease. *Journal of Neuroscience Nursing*, 23(5), 325-329.
- McCracken, G. (1988). *The Long Interview* (Vol. 13). Sage.
- McDonald, W. M., Richard, I. H., & DeLong, M. R. (2003). Prevalence, etiology, and treatment of depression in Parkinson's disease. *Biological Psychiatry*, 54(3), 363-375.
- Menza, M. (2000). The personality associated with Parkinson's disease. *Current Psychiatry Reports*, 2(5), 421-426.
- Maurel, M. (2009). The explication interview: examples and applications. *Journal of Consciousness Studies*, 16(10-1), 58-89.
- Muslimovic, D., Schmand, B., Speelman, J. D., & De Haan, R. J. (2007). Course of cognitive decline in Parkinson's disease: a meta-analysis. *Journal of the International Neuropsychological Society*, 13(06), 920-932.
- Palfreman, J. (2015). *Brain Storms: The Race to Unlock the Mysteries of Parkinson's Disease*. Macmillan.

- Parkinson, J. (2002). An essay on the shaking palsy. *The Journal of Neuropsychiatry and Clinical Neurosciences*, 14(2), 223-236.
- Prichard, J. S., Schwab, R. S., & Tillmann, W. A. (1951). The effects of stress and the results of medication in different personalities with Parkinson's disease. *Psychosomatic Medicine*, 13(2), 106-111.
- Pringsheim, T., Jette, N., Frolkis, A., & Steeves, T. D. (2014). The prevalence of Parkinson's disease: A systematic review and meta-analysis. *Movement Disorders*, 29(13), 1583-1590.
- Prinz, J. J. (2004). *Gut reactions: A perceptual theory of emotion*. Oxford: Oxford University Press.
- Rail, D., Scholtz, C., & Swash, M. (1981). Post-encephalitic parkinsonism: current experience. *Journal of Neurology, Neurosurgery & Psychiatry*, 44(8), 670-676.
- Reijnders, J. S., Ehrt, U., Weber, W. E., Aarsland, D., & Leentjens, A. F. (2008). A systematic review of prevalence studies of depression in Parkinson's disease. *Movement Disorders*, 23(2), 183-189.
- Sartre, J. P. (2012). *Being and nothingness*. Open Road Media.
- Sass, L. & Fishman, A. (in press). "Introspection, phenomenology, and psychopathology." In G. Stanghellini, M. Broome, A.V. Fernandez, P. Fusar-Poli, A. Raballo & R. Rosfort (Eds.). *The Oxford Handbook of Phenomenological Psychopathology*. Oxford University Press.
- Sass, L. A., & Parnas, J. (2001). Phenomenology of self-disturbances in schizophrenia: some research findings and directions. *Philosophy, Psychiatry, & Psychology*, 8(4), 347-356.

- Sanders, N. E. J. (1999). *An assessment of coping and adjustment in individuals with Parkinson's disease and their caregivers* (Doctoral dissertation, ProQuest Information & Learning).
- Steiner, C. J., & Reisinger, Y. (2006). Understanding existential authenticity. *Annals of Tourism Research*, 33(2), 299-318.
- Timulak, L. (2009). Meta-analysis of qualitative studies: A tool for reviewing qualitative research findings in psychotherapy. *Psychotherapy Research*, 19(4-5), 591-600.
- Todd, D., Simpson, J., & Murray, C. (2010). An interpretative phenomenological analysis of delusions in people with Parkinson's disease. *Disability and Rehabilitation*, 32(15), 1291-1299.
- Todes, C. J., and A. J. Lees. "The pre-morbid personality of patients with Parkinson's disease." *Journal of Neurology, Neurosurgery & Psychiatry* 48.2 (1985): 97-100.
- Van Der Bruggen, H., & Widdershoven, G. (2005). Being a Parkinson's patient: immobile and unpredictably whimsical literature and existential analysis. *Medicine, Health Care and Philosophy*, 7(3), 289-301.
- Vermersch, P. (2009). Describing the practice of introspection. *Journal of Consciousness Studies*, 16(10-1), 20-57.
- Verpeaux, J. (2013). *Parkinson's Disease: A Sniper in my Head* (1st ed.). Lulu.
- Warner, T. T., & Schapira, A. H. (2003). Genetic and environmental factors in the cause of Parkinson's disease. *Annals of Neurology*, 53(S3), S16-S25.
- Wen, H. B., Zhang, Z. X., Wang, H., Li, L., Chen, H., Liu, Y., ... & Xu, Q. (2012). Epidemiology and clinical phenomenology for Parkinson's disease with pain and fatigue. *Parkinsonism & Related Disorders*, 18, S222-S225.

- Wertz, F. J. (2011). A Phenomenological Psychological Approach to Trauma and Resilience. In K. Charmaz & L. M. McMullen (Authors), *Five ways of doing qualitative analysis: Phenomenological psychology, grounded theory, discourse analysis, narrative research, and intuitive inquiry* (pp. 124-164). New York, NY: Gilford Press.
- World Health Organization. (2009). International statistical classification of diseases and related health problems.
- Wressle, E., Engstrand, C., & Granérus, A. K. (2007). Living with Parkinson's disease: Elderly patients' and relatives' perspective on daily living. *Australian Occupational Therapy Journal*, 54(2), 131-139.
- Zahavi, D. (2005). Subjectivity and selfhood. *Investigating the First-Person Perspective*. Massachusetts: Bradford Books.