

**Experiences of Mutuality in the Spousal Relationship in  
Advanced Parkinson's Disease from the Perspective of the  
Caregiving Partner**

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A thesis submitted in partial fulfilment of the requirements for the degree of Doctor of Philosophy. The candidate has already achieved 180 credits for assessment of taught modules within the blended learning PhD programme.

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I declare that this thesis is my own work and has not been submitted for the award of a higher degree elsewhere.

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*Zichronom Livracha - May their memories be for a blessing.*

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## **Abstract**

**Introduction:** Parkinson's Disease (PD) is a chronic and degenerative illness with a long trajectory involving multiple physical, cognitive, and emotional changes. In contrast to the holistic approach of palliative care, medical visits for PD patients tend to focus primarily on physical symptoms. Little attention may be paid to the psychosocial effects of PD, such as relational satisfaction and emotional and spiritual well-being of both patient and family. As illness advances, dependence on others occurs; in many if not most cases, the spouse is the primary caregiver. While research has been conducted to examine burden of care for PD spouses, the literature reveals little on mutuality, which concerns the quality of the relationship.

**Method:** This study was conducted with spousal caregivers of PD patients with advanced illness at Hoehn & Yahr stages 4 and 5. Twelve caregiving spouses to partners with advanced PD participated in a single face-to-face semi-structured interview in this qualitative hermeneutic phenomenology study. van Manen's approach to data analysis and writing for hermeneutic phenomenology was utilised, incorporating the four lifeworld existentials of spatiality, temporality, corporeality, and relationality.

**Results:** Participants' challenges to mutuality included limited enjoyable shared activities, living with a "stranger", little fun, and resentment about PD. Loss of identity, ambiguous loss, and searching for meaning are challenges for caregiving

spouses caring for an advanced PD partner; nevertheless most participants want to be with their spouse.

**Conclusion:** Understanding how PD affects the marital relationship is crucial for health professionals to provide a palliative approach to both partners living with this unwelcome “intruder” in their lives.



# 1 Introduction

This thesis is a study of the lived experience of mutuality in the marital relationship from the perspective of the caregiving partner, and the impact of Parkinson's Disease (PD) on the quality of mutuality in the marital relationship.<sup>1</sup> Mutuality is the degree to which reciprocity occurs in a relationship or the quality of interaction in that relationship (Tanji et al., 2008). The idea for this study originated in my own clinical practice in a Palliative Parkinson's clinic offering a holistic approach to care in keeping with palliative care principles to individuals living with advanced PD. These patients received physical, emotional, and spiritual support for themselves and their family from a team of health professionals. In my role as the Spiritual Care Practitioner<sup>2</sup> offering support to patients with advanced PD and their families, I was struck by what I perceived to be the unspoken tensions when one was the caregiving partner for the other with advanced PD. The husband of a PD patient said "Parkinson's affects *everything*", emphasising the word "everything". These words stayed with me.

My observations of couples in the clinic ignited my interest in this serious issue as some appeared to be engaged in a "love-hate relationship". When I asked them for examples of activities they shared together, many had little to say. This led me to wonder about the effect of PD on mutuality in the marital relationship of patients with advanced PD, when an individual loses many physical functions, communication

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<sup>1</sup> For the purpose of this research, "marital" refers to both married and common law couples.

<sup>2</sup> The Canadian model of health care uses the term "Spiritual Care Practitioner" in place of "chaplain". The Canadian Association for Spiritual Care (CASC) requires a rigorous course of study and training to be a certified Spiritual Care Practitioner that has a broader approach than that of chaplaincy with training in both emotional and spiritual counselling rather than a focus on religion alone.

abilities, cognition, and experiences personality changes. Finding little in the literature about mutuality in PD and almost nothing in advanced PD to help me support couples in this situation was the motivation for my research. The aim of this study is to understand and interpret the lived experience of mutuality in couples living with advanced PD specifically from the perspective of the caregiving partner.

I chose to focus on the caregiving partner for a number of reasons: I was aware that many advanced PD patients could not engage in an interview due to their decreased ability to speak and to concentrate due to cognitive changes. Most importantly however, I wanted to give voice to the caregiving spouse who rarely received attention during the clinic appointment other than during counseling sessions.

It is hoped that this research will provide insight into the caregivers' perspective to understand their lived experience and where mutuality can be enhanced as health providers would be sensitised to how PD affects the couple and address this in the care they provide. My research was thus grounded in my professional role with the expectation that my findings would influence my practice and that of other professionals working in PD. Understanding this experience would ideally offer me insight into how to best support caregiving spouses in advanced PD as well as contribute to the area of spiritual and emotional support for those working with couples living with other chronic and degenerative illnesses. Spiritual support has been recognized as noteworthy in its contribution to palliative care; Cobb writes that it refers to an intrinsic characteristic of personhood that can exist either within or separate from a set of religious beliefs or a faith tradition (Cobb, 2008). Spirituality refers to an individual's beliefs, values, and experiences related to meaning and

purpose; this may or may not include religion for each person and research has shown spirituality to be therapeutic in shifting emotional aspects of health such as well-being and distress (Sinclair and Chochinov, 2012). Moreover, patients stress the importance of relationships and companionship as well as meaning making. Spiritual distress is common in life-threatening illness (Edwards et al., 2010). The National Consensus Project (USA) has recommend that spiritual distress be treated with the same intent and urgency as other medical issues (Sinclair and Chochinov, 2012). Mutuality is a component of relationships and connectedness to others which is a part of one's spirituality.

Chronic illness affects the person with the illness as well as those in his/her circle of care and support. Badr et al. (2007) cite many studies that report poor functional status and cognitive decline in the PD partner as well as limited activity opportunities for caregivers with higher degrees of stress for the caregiver (Badr et al., 2007). They emphasise the importance of caregiving spouses seeing themselves as an important component of "we-ness" in their identity as a couple (Badr et al., 2007 p.212). While couple identity or "we-ness" can help reinforce relationship satisfaction, it is distinct from relationship satisfaction itself with one identity involving characteristics of the dyad and the other involving positive thoughts about the relationship (Badr et al., 2007).

For caregiving spouses, stress results from many challenges based primarily on the physical status of the ill partner and his/her caregiving needs. Secondary stressors arise as a result of a marital relationship that becomes restructured due to the illness; this is exacerbated by chronic conditions requiring demanding caregiving and

resultant dependency (Pearlin et al., 1990). Despite the possibility that caregiving by a spousal partner could strengthen the relationship, research indicates that caregiving spouses generally are at highest risk for caregiver burnout than other family members due to the long periods of time they spend with the ill person especially in illnesses like PD (Badr et al., 2007, Williamson and Clark, 1992). Dame Cicely Saunders created new approaches in the care of terminally ill patients and those close to them through her work with terminal cancer patients (Clark, 1999). She developed the notion of total pain that includes physical symptoms, mental distress, emotional, and spiritual problems experienced by patients and family (Saunders, 1964). Emotional and spiritual angst can occur in illnesses when the illness becomes the focus in the life of the couple and the relationship they once knew changes within the context of the illness that intrudes upon the life they had known before (Saunders, 1964).

While current research concentrates on caregiver burden and the tasks of caregiving, less has been done concerning mutuality with its focus on the quality of the marital relationship and feelings that ebb and flow on the part of caregiver toward his/her spouse. Hempel (2008) argues that research with caregivers is lacking and necessary (Hempel et al., 2008). This gap lends itself to the study of if and how the marital relationship is changed by the intrusion of advanced PD. Palliative care seeks to provide holistic care to the patient and their family on physical, social, emotional, and spiritual levels. The loss of a meaningful relationship and loss of equality in the marital relationship can influence the quality of life individuals experience in living with life threatening illness. Insight into the lived experience of mutuality in advanced PD from the perspective of the caregiving spouse has the potential to

provide further understanding and interventions by health professionals to assist couples living with advanced PD.

## **1.1 Thesis design**

Phenomenology was chosen as the methodology for this study, specifically hermeneutic phenomenology using the approach outlined by Max van Manen.<sup>3</sup> van Manen says phenomenology is a methodology that provides a deep understanding and insight into the meaning of everyday experience and hermeneutic phenomenology provides an interpretive opportunity for the researcher using the four existentials of spatiality, temporality, corporeality, and relationality. Rather than using the research findings to develop theory, phenomenology aims to provide insight into the lived experience under study (van Manen, 1990). This is covered in detail in the Methodology and Methods chapter.

### **1.1.1 Thesis structure**

This thesis is comprised of eight chapters that offer a comprehensive presentation of the study. Chapter 2 provides a background to the specific research in the context of mutuality for advanced PD couples and includes an overview of PD, the application of palliative care to PD, mutuality theory, and mutuality concerns in PD couples.

Chapter Three is a literature review using an integrative review method as outlined by Whitemore and Knafl (Whitemore and Knafl, 2005). The literature reviewed was comprised of both quantitative and qualitative studies examining mutuality in PD.

Since little research has been conducted in couples living with advanced PD, I examined literature of mutuality at any stage of PD as well. Chapter Four addresses

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<sup>3</sup> Max van Manen is the father of Michael van Manen, a neonatologist who has used his father's methodology in his research. It is Max van Manen's approach to researching lived experience that is referred to in this thesis.

the Methodology and Methods utilised for this research centering on van Manen's approach to hermeneutic phenomenology and his use of lifeworld existentials. Chapters Five and Six offer an analysis of the findings obtained from the interviews. These are presented within the four existentials of spatiality, temporality, corporeality, and relationality with the first three presented in Chapter Five and relationality in Chapter Six.

Chapter Seven includes a discussion of the study findings in relation to the literature and application to existing theories. Chapter Eight is the concluding chapter that provides a summary of the key findings, implications for practice, contribution to knowledge, limitations, and areas for future research.

Referencing style for this thesis is Harvard as per instructions for the 2012 cohort for the PhD in Palliative Care, Faculty of Health and Research. The guidance is followed for that provided by Endnote 6.0.

## **2 Background**

### **2.1 *Parkinson's Disease***

Parkinson's Disease is characterised by bradykinesia (slow movements), rigidity, tremor, and postural instability (Litvan et al., 2003). Involuntary jerky movements known as dyskinesia often occur with disease progression as well as countless physical symptoms, emotional dysfunctions, sleep disturbances, and falls (Haahr et al., 2010). As disease progresses, many patients also experience psychiatric conditions and neuropathic pain (Goy et al., 2007). The Hoehn and Yahr Scale (Appendix A) is used universally and describes the progressive stages of PD ranging from 1-5 (Hoehn and Yahr, 1967).

Dopamine, a neurotransmitter originating in the brain sends signals to other nerve cells. PD patients have decreased dopamine, and with disease progression, require increased doses of levodopa, a synthetic version of dopamine, several times daily. They often experience an "ON-OFF phenomenon" with rigidity and dyskinesia as the medication wears off; this ON-OFF episode can be quite sporadic (Caap-Ahlgren et al., 2002). Such lack of predictability and wanting to avoid being in public often lead to isolation, apathy, and an altered sense of body image (Caap-Ahlgren et al., 2002, Fleming et al., 2004, Haahr et al., 2010, Posen et al., 2000). Fear of humiliation, difficulty walking, pain, drooling, decreased ability to speak and swallow, the need for extra time to move, and concern about toileting when away from home can result in decreased socialisation.

Advanced illness creates dependence upon caregivers to assist with once taken for granted daily life activities (Carter et al., 1998, Husserl, 1980). The psychosocial burden in late-stage PD for some is manifested by depression, dementia, loss of

independence, self-identity and self-esteem, and changes in relationships (Calne, 2003). Loss of significant roles leaves those with advanced PD with just memories of these important components of personhood (Emery, 2013). As PD progresses, many patients lose their sense of who they once were as physical, emotional, memory, cognitive, and spiritual losses intensify over time, resulting in total dependency on others, in most cases, the spouse (Graboyes, 2012, Andes, 1998, Emery, 2013). A brief overview of the main challenges in stages 4 and 5 is seen below (Hoehn and Yahr, 1967):

**Table 1. Brief Description of clinical symptoms of Stages 4 and 5 PD (Hoehn and Yahr, 1967)**

Stage 4	Stage 5
Symptoms of rigidity and poor motor function become advanced and sometimes severe and limiting. The use of a walker is usually required for mobility. Activities of daily living are difficult or impossible without assistance. Individuals are unable to live on their own. Some people experience difficulty in swallowing and speaking and may have bowel and bladder issues. Some experience cognitive and emotional changes, including dementia.	This stage is debilitating. PD is most advanced with severe stiffness. Individuals are either bedridden or the use of a wheelchair is necessary as independent mobility is impossible. Care is required 24 hours. Some people are unable to communicate at all. Hallucinations may occur. Some require a feeding tube due to inability to swallow. Emotional and cognitive changes including dementia are common.

### **2.1.1 Parkinson’s Disease and Palliative Care**

Palliative care strives to improve the quality of life for patients and their families facing life threatening illness by addressing psychosocial and spiritual concerns as well as physical issues and pain relief (Lloyd-Williams, 2008). Due to the incurable and progressive nature of PD, palliative care is appropriate and important (Ng, 2017). The importance of palliative care principles has begun to be addressed for PD



patients and to a lesser extent for their caregiving partners (Boersma et al., 2014, Boersma et al., 2017, Miyasaki and Kluger, 2015, Ng, 2017, Fox et al., 2017). The American Academy of Neurology Ethics and Humanities Subcommittee states neurologists must understand and apply principles of palliative medicine because many illnesses in their field are progressive and incurable (Subcommittee, 1996). Patients with advanced neurodegenerative illness such as PD have needs similar to patients with advanced cancer (Low et al., 2003). Moreover, PD is considered to be a fatal disease as the fourteenth leading cause of death in the United States (Lanoix, 2009).

Palliative care is ideally provided by an interdisciplinary team of health professionals, and this is essential for patients with PD who require support in many areas.

Boersma et al. (2014) report some health professionals believe palliative care means “giving up” on their patients; however palliative care is a supportive and appropriate approach that offers assistance for the physical, psychosocial, and spiritual angst that accompany the many losses of PD and may continue for an extended period of time. Moreover, quality of life for caregivers is associated with patient quality of life (Voltz et al., 2004). Support for caregivers begins when team members assess their needs for providing care, their own self-care, and their emotional concerns (Boersma et al., 2014).

Since the team assessment is quite complex for PD patients, caregiver issues and psychosocial components are often overlooked at medical appointments; when various team members bring their unique assessment in their specific area of

expertise, the patient-caregiver dyad can offer partnership with the health care team to achieve optimum provision of care (Miyasaki and Kluger, 2015).

Lanoix (2009) argues that caregivers experience burnout with accompanying resentment, isolation, and depression due to healthcare models that do not adequately include and support them in the care of PD patients; when palliative care is initiated, it is usually too late to support the caregivers (Lanoix, 2009). She explains this has been reported for various countries including Canada and the United Kingdom (Lanoix, 2009, Fox et al., 2017). Palliative care in PD enhances medical care by addressing support to caregivers, the provision of counseling to them, and assistance in coping with psychosocial issues arising from living with PD (Boersma, 2017, Giles & Miyasaki, 2009, Hudson et al., 2011). Palliative care introduced early can assist PD patients and families in coping with many changes in their lives and their life plans (Bunting-Perry, 2006, Bekelman et al., 2011). Boersma et al. (2017) reported that when caregivers learned about palliative care as a broad model of care providing support for suffering from a variety of perspectives for patients and caregivers, and is not only restricted to end-of-life care, they expressed interest in it. Five of eleven participants requested immediate interest in search of a palliative approach for their partner, in obtaining counselling for themselves, and in the holistic approach offered by an interdisciplinary team of health professionals (Boersma et al., 2017).

Wright (2005) argues there is not sufficient research concerning the effect of illness and suffering on marriage. She proposes that chronic illness carries added emotional and spiritual distress in addition to physical disease because both men and women

believe they no longer contribute as before to their marriage. Her work indicates couples struggle with the meaning of their relationship within the context of the illness they face together (Wright, 2005). Palliative care with its holistic approach can offer support within the context of relational effects on couples facing progressive illness. My research will provide insight into the needs of the caregiving spouse with the objective of addressing the patient's total pain experience which includes family needs.

### **2.1.2 Mutuality**

The theoretical framework for this study was that of mutuality. The concept of mutuality was developed by Hirschfeld (1983), who conducted grounded theory research with the caregivers of people with dementia (Hirschfeld, 1983). Mutuality is the degree to which reciprocity occurs in a relationship or the quality of interaction in that relationship (Tanji et al., 2008). Wynne defined mutuality as the sharing of characteristics, goals, and attitudes (Wynne, 1984). As the commitment to one another in a marital relationship becomes more developed, the cognitive notion of the relationship shifts from individuals to couple (Badr et al., 2007). The notion of identity is integral to how partners relate to each other; couple identity strongly influences relationship satisfaction in married couples (Acitelli et al., 1999). Coyne et al. (2001) studied marital quality and congestive heart failure survival using a composite score comprised of marital satisfaction, useful routines, useful illness discussions, and marital disagreement. When illness severity and marital quality were analysed, they both made independent statistically significant contributions to survival prediction (Coyne et al., 2001). Based on studies such as this one by Coyne et al. (2001), Weingarten reports that marital quality is more satisfactory for couples

who see themselves as “we” (Weingarten, 2013, Coyne et al., 2001). Such a shared identity allows each partner to become a part of the other according to Hagerty et al. (1997), Acitelli and Badr (2005), and the twentieth century philosopher Martin Buber (1939) who concur that sharing a worldview is an important component of relatedness in which each partner sees themselves in relation to the other with shared goals and validating the other (Hagerty et al., 1993, Buber, 1937, Acitelli and Badr, 2005). Henson outlines the following aspects of mutuality: a feeling of intimacy and connection between the people involved; a dynamic process that transforms with a pattern of give and take that contributes to joint participation in attaining a shared goal; a sharing and satisfaction for the parties involved; and mutuality is present prior to achieving a goal that pleases all parties (Henson, 1997). Finding gratification and meaning in relationship with a person who requires caregiving is an important component of mutuality (Hirschfeld, 1983). Horowitz & Shindelman (1983) indicate that close affective relations involve sharing activities, emotional closeness, memories, and confiding in one another. Kramer (1993a) wrote that negotiation, compromise, and compassion reinforce interpersonal relationships versus criticising, ignoring, confronting, or minimising communication and Steadman et al. (2007) stress that the degree of caring, intimacy, and mutual concern for each other strongly influence mutuality (Horowitz and Shindelman, 1983, Steadman et al., June 2007, Kramer, 1993).

Caregiving, a component of close relationships, is accompanied by stressors of relationship quality. Rait and Lederberg (1990) outlined phases of the shared experience of illness: the acute phase is one of fear and disbelief, tests, diagnosis, and treatment; during the chronic phase, partners must adjust to role changes that

accompany daily life with a chronic disease (Rait and Lederberg, 1990). Over time, couple identity undergoes changes if caregiving becomes the focus of the relationship (Badr et al., 2007). Marck (1990) explains that in mutuality, common experiences are exchanged and shared with each other creating a feeling of shared humanness with each partner balancing the other and providing appropriate support with resulting satisfaction and shared purpose (Marck, 1990). Henson (1997) emphasises the dynamism of achieving mutuality as it changes with different situations. In illness, sometimes an asymmetry can exist with one partner dependent on the other, especially in the advanced stages when sharing becomes compromised due to physical, cognitive, and emotional changes in the ill partner (Henson, 1997). Limited research has been conducted on mutuality in PD; minimally in the early stages of illness. More research is needed on relationships, expression of feelings, and mutuality in advanced stages of illness especially when it is a degenerative one such as advanced PD (Lewis, 2004).

### **2.1.3 Parkinson's Disease and mutuality**

Most of the research on mutuality in PD has been in early or moderate stages of the illness. Little has been studied or written concerning mutuality between marital partners in advanced PD. Archbold and colleagues (1990) created the Mutuality Scale (Appendix B), a validated instrument developed to measure mutuality. It comprises four domains: love and affection, shared pleasurable activities, shared values, and reciprocity (Archbold et al., 1990). This scale provides a summary score for participants used in quantitative studies, which provided a structure that helped frame my questions for use in a qualitative study on mutuality in advanced PD.

In summary, it seems likely that mutuality in couples living with PD is challenged by a multitude of factors that include components of the illness itself as well as psychological, cognitive, and social changes. Each partner is affected in their own way as they attempt to cope with life changes due to PD; the caregiver must cope with the many demands of caring for someone with whom they have shared dreams and hopes only to realise those dreams may not materialise in the way they had planned. While studies have investigated various facets of living with PD, few have been conducted that look specifically at the lived experience of such changes in advanced PD and their effect on mutuality and the emotions of the caregiving partner.

### **3 Literature Review**

The literature review was conducted using an integrative method and synthesis (Whittemore and Knafl, 2005). This chapter presents the search strategy, PRISMA diagram, results and themes. The aim was to identify and assess current evidence in the literature to determine what is known about the impact of PD on mutuality/quality of interaction in marital couples from the perspective of the caregiving partner when one partner has Parkinson's disease and the other is the caregiver.

#### ***3.1 Literature review search question***

What is the impact of PD on mutuality/quality of interaction in the marital relationship in advanced illness from the perspective of the caregiving partner when one partner has advanced PD and the other is the caregiver.

#### ***3.2 Conducting the literature search to identify studies to include in the review***

I wanted to look specifically at mutuality/quality of interaction in marital couples living with advanced PD, however despite a very large, comprehensive search, no such studies were found. This demonstrated a research gap with no identified studies uniquely about advanced PD. As a result, a broader search was used to include mutuality in PD at any stage to identify salient issues. Other neurodegenerative conditions were discussed with clinicians to determine if the experience of couples with them might be similar to advanced PD but there are too many differences concerning factors affecting mutuality between PD and other neurodegenerative diseases and so the closest match was to general PD papers. Other conditions considered were Huntington's Disease (HD), Multiple Sclerosis

(MS), and Alzheimer's Disease (AD). Although these illnesses present similar issues in burden of caregiving and quality of life in late stage illness, they do present other concerns about mutuality which is the topic of this study. Dr. Elizabeth Slow, a neurologist with a speciality in PD and a PhD in Huntington's along with other clinicians emphasised the differences that these illnesses pose with reference to the marital relationship compared to PD when mutuality is considered.

Huntington's Disease (HD) occurs in younger adults with parenting, genetics with possible transmission to children, and finances related to an inability to work profoundly affecting the marital relationship and leading to higher rates of divorce (Rothing et al., 2015, Banaskiewicz et al., 2012). Banaskiewicz et al. (2012) report that their study showed that cognitive disturbances had a minor influence on the caregivers in their study in contrast to PD found by D'Amelio et al. (D'Amelio et al., 2009) and AD in the study by Razani (Razani et al., 2007).

Multiple Sclerosis also commonly affects younger adults with similar issues to HD and twice as often in women at the time of childbearing years or years of young parenthood (Starks et al., 2010). The caregiver is often a young adult trying to decide on parenthood, balance career development, young children at home, finances, and caregiving along with worry for the future (Wollin et al., 2013). This differs from the typical older caregiver of a loved one with PD. Murray (1995) writes of the significance of the stress of MS in marriage breakdowns with the frequency of divorce as double that of the population at large (Murray, 1995, Brooks and Matson, 1982). Since PD typically occurs later in life, such stressors in young marriages are not



as prevalent and in many cases, the partners have grown old together and are more settled into retirement years.

PD usually begins earlier in life than Alzheimer's Disease (AD) (Ellison, 2017).

Although the two illnesses have some similarities concerning cognitive changes, physical disability is a major component of PD and may or may not occur in AD.

Couples living with AD can have a lifestyle that allows outings and socialising to take place. PD caregivers must cope with the double impact of physical limitations as well as psychiatric and cognitive challenges that often begin early in PD as well as a generally longer course of illness (Weintraub et al., 2008).

### ***3.3 Review Design***

An integrative synthesis that follows the methodology for integrative reviews was conducted (Whittemore and Knafl, 2005). PRISMA guidelines are followed in review reporting (Moher et al., 2009). The integrative review (IR) approach was considered a good choice despite mixed opinions in the literature. The pros and cons of this approach are presented as follows:

Pros	Cons
<p>The IR is considered the broadest type of review allowing for inclusion of various methodologies: experimental, non-experimental, empirical, theoretical, qualitative and quantitative (Whittemore &amp; Knafl, 2005)</p> <p>This holistic approach offers a more complete understanding of research in a specific area (Grant &amp; Booth, 2009)</p> <p>The combination of various study designs and epistemological and ontological foundations is a strength resulting in a presentation of robust and valid research (Jones-Devitt, 2017)</p> <p>IR builds knowledge in a cumulative way via an integrative rather than additive method (Victor, 2008)</p> <p>Flexibility – if the topic is new with little research found, the reviewer can broaden the research question or operational definitions of variables in order to find maximum information (Russell, 2005)</p> <p>Generalisability is increased because of variability in methodologies, locations, samples, participant demographics, and times of studies because the target population is well reviewed from a variety of perspectives (Russell, 2005)</p> <p>Studies should be considered according to how relevant they are to the research question rather than by the type of method used, therefore a combination of different types of studies is advocated (Harden &amp; Thomas, 2005)</p>	<p>IR methodology has not been as well developed with clear guidance as other approaches (Russell, 2005)</p> <p>Combining diverse methodologies can result in bias, lack of rigour, and inaccuracy (Russell, 2005)</p> <p>Threat to validity include:</p> <ol style="list-style-type: none"> <li>1. possibility of a conceptual definition that is too narrow</li> <li>2. lack of attention to differences concerning details of each study or lack of transparency about the search itself (Russell, 2005)</li> </ol> <p>There is not a consensus about the order for studies to be integrated (whether quantitative studies should precede qualitative or vice versa) or whether they should be reported upon in a parallel fashion (Cooper, 1998)</p> <p>The question exists of whether one type of study should increase understanding of the other or whether integration should occur in an iterative way or as a summation (Grant &amp; Booth, 2009)</p>

The integrative review was considered a good choice for this thesis because of the multiple advantages outlined above. Furthermore, in consideration of the small number of relevant studies concerning mutuality in PD, I did not want to lose the broader literature review that the integrative review offered. In some cases, the qualitative studies were able to further explain the quantitative results as individuals could provide their lived experience such as the qualitative studies in which participants spoke about specific issues related to mutuality as they cared for their spouse with PD. This added to the knowledge obtained from quantitative studies that utilised the Mutuality Scale and others that provided frequencies and statistics of results from the Likert scales used by the specific instruments but do not explore data on lived experience.

### **3.3.1 Definitions of key terms**

**Parkinson's Disease** = A long-term degenerative movement disorder characterised by bradykinesia (slow movements), rigidity, tremor, and postural instability (Litvan et al., 2003). Involuntary jerky movements known as dyskinesia often occur with disease progression as well as countless physical symptoms, emotional dysfunctions, sleep disturbances, and falls (Haahr et al., 2010). The Hoehn and Yahr Scale (Hoehn and Yahr, 1967) describes the progressive stages of PD ranging from 1-5 (Appendix A).

**Mutuality** = The degree to which reciprocity occurs in a relationship or the quality of interaction in that relationship (Tanji et al., 2008). Other terms include reciprocity, sharing, bond, mutual exchange, responsiveness, empathy, boundedness, mutual intersubjectivity. This excludes individual wellbeing, happiness, security, comfort but

focuses on interaction in the relationship. Interaction refers to communication between the partners as reflected in the Mutuality Scale (Archbold et al., 1990) as seen in Appendix B.

**Spouse** = A husband or wife, considered in relation to their partner.

**Common law**= Non-married cohabitating partners.

**Caregiver** = A person who provides direct care, in this study, a spouse or common law partner.

### **3.3.2 Search strategy**

The PICO approach was utilised to assist in identifying search terms as outlined by Joanna Briggs Institute (Boland et al., 2014) for use in qualitative studies. This acronym represents the **P**opulation under study, the phenomenon of **I**nterest whether a condition or an intervention, and the **C**ontext of the study. Explanations of these components as they apply to this study are seen below. Due to the large volume of terms used in this search strategy, it is impossible to list them all here. The detailed and exact search strategy and results for Medline is provided in Appendix C<sup>4</sup>.

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<sup>4</sup> The extensive search strategies for the other databases are available upon request

<b>P=Population</b> - Caregiving partner of persons with advanced PD	Terms relating to spouse, partner, husbands, wives; caregiving
<b>I=phenomenon of interest</b> - Mutuality - the degree to which reciprocity occurs in a relationship or the quality of interaction in that relationship (Tanji et al., 2008).	Terms relating to interactions between partners psychosocial; quality; coping; stress; romance; love; reciprocity; sharing; affection; empathy; communication; sexual; intimacy
<b>Co= context</b> – Parkinson’s couples: couples living together in which one is the caregiver and the other is the patient with Parkinson’s disease.	Terms relating to Parkinson’s Disease and other movement disorders as a broad term; cohabitation; marriage; couples; sexual partners; common law; significant others.

The search strategy was designed with assistance from two research librarians. The themes of the search terms were mutuality, Parkinson’s, and spouse. As the concept of mutuality is quite specific and infrequently mentioned in articles concerning caregivers, other search terms were variations of those themes such as ‘relationships’, ‘husband’, ‘wife’, ‘common law’ as well as terms depicting relational interactions and emotions such as dialogue, communication, empathy, etc. were also used. The following databases were searched: Medline, CINAHL, Embase, PsychInfo, Cochrane, Web of Science, and Scopus using strategies and syntax specific to each. Reference lists of included studies were searched manually for related papers and studies citing included studies were searched using Google Scholar.

The searches were conducted beginning in April 2015 and repeated several times up until February 2018. (Appendix D for PRISMA flow diagram). Although Hirschfeld (1983) coined the term “mutuality” in health in 1983 (Hirschfeld, 1983), and Carter et

al. first published research on mutuality in PD in 1998 (Carter et al., 1998), the databases were searched with no time limit in order to determine whether earlier studies on the review topic were conducted before mutuality was developed as a concept. As mentioned above, due to no findings of studies conducted on mutuality in advanced PD, the search strategy was changed in 2015 to include all stages of PD for a broader search and the PICO framework was adjusted accordingly as seen below:

<p><b>P=Population</b> - Caregiving partner of persons with PD of any stage</p>	<p>Terms relating to spouse, partner, husbands, wives; caregiving</p>
<p><b>I=phenomenon of interest</b> - Mutuality - the degree to which reciprocity occurs in a relationship or the quality of interaction in that relationship (Tanji et al., 2008).</p>	<p>Terms relating to interactions between partners psychosocial; quality; coping; stress; romance; love; reciprocity; sharing; affection; empathy; communication; sexual; intimacy</p>
<p><b>Co= context</b> – Parkinson’s couples: couples living together in which one is the caregiver and the other is the patient with Parkinson’s disease.</p>	<p>Terms relating to Parkinson’s Disease and other movement disorders as a broad term; cohabitation; marriage; couples; sexual partners; common law; significant others.</p>

The most relevant studies (n=28) included the three main components: mutuality, Parkinson’s disease, and spousal relationship. These papers explicitly mention and address these components.

### **3.3.3 Selection criteria**

#### **Inclusion criteria**

- Studies published in English in journals
- Studies concentrating on mutuality or quality of relationship interaction in marital couples living with Parkinson's disease
- Studies describing barriers and/or help to mutuality/relationship interaction quality between marital partners in the context of living with Parkinson's disease
- Studies focusing either solely on caregiving spouses or on caregiving spouses who were included in studies with other carer/patient dyads (such as children, parents, siblings)

#### **Exclusion Criteria**

- Studies about couples in which the PD patient was living in a healthcare facility
- Studies focused on basic science related to PD, medical treatments/management, or symptoms of PD
- Studies focused on caregiver burden, individual depression or wellbeing and not concerning the dynamics of couples from the perspective of the caregiving spouse
- Studies on mutuality in PD that did not include spousal/common law partners

### **3.3.4 Data extraction and analysis**

The approach for this literature review is that of an integrative synthesis. The purpose of an integrative synthesis is to combine data from empirical studies to compare results of differing methodological designs in order to result in a comprehensive analysis (Whittemore and Knafl, 2005, Dixon-Woods et al., 2005). The integrative review is a comprehensive methodology in that it identifies, analyses, and synthesises results of independent studies on the same subject and also allows the inclusion of both experimental and non-experimental studies to gain full insight into the phenomenon being studied; moreover, a combination of data from both theoretical and empirical research is possible (Tavares de Souza et al., 2010). The guidelines for integrative reviews by Whittemore and Knafl (2005) provided a framework for this analysis. The steps followed by Whittemore and Knafl (2005) are: problem identification, literature search, data evaluation, data analysis, data reduction, data display, data comparison, and presentation (Whittemore and Knafl, 2005). Decisions concerning inclusion of papers were based on the predetermined inclusion criteria. A comprehensive search was conducted with study appraisal and interpretation of findings.

The studies were read initially for overall understanding and then again several times concentrating on the results and discussion sections to identify patterns and relationships, and coding to develop themes. Key findings and concepts were chosen from study findings for the purpose of selecting those most related to the study question. Preference was given to studies offering insight and explanation into aspects of the phenomenon under study rather than the frequency with which some themes appeared across studies (Dixon-Woods et al., 2005).



Thematic analysis was chosen for its usefulness in identifying key themes and organizing the selected findings within the contexts of these themes. Using an iterative process, thematic analysis provides flexibility and is helpful in synthesising both qualitative and quantitative findings (Dixon-Woods et al., 2005, Whitemore and Knaf, 2005). Furthermore, its inductive approach allows themes to be developed directly from the data without *a priori* categories (Dixon-Woods et al., 2005).

Descriptive data concerning the participants, the research design, purpose, outcome measure, and results of each study were extracted (Appendix E). These were chosen based on the review question and entered into a table for the purpose of observing results and methods in order to identify relationships within studies and between studies.

### **3.4 Results of Search**

This search strategy yielded 8,153 studies which were imported into Endnote. After 4,187 duplicates were removed, 3,966 remained. An additional 12 articles were obtained by a hand search of reference lists of reviewed studies and citation tracking for a total of 3,978. All studies were screened against the inclusion criteria. A total of 197 records were screened by reading titles and abstracts resulting in 78 full text articles for further screening. Of these, 28 studies met the inclusion criteria and were included in the synthesis.

Due to no separate findings of research conducted on mutuality specifically in advanced PD, the studies found in this search were conducted in early to mid-stages of PD. While some studies have some small representation of caregiving spouses of partners with advanced illness, most focus on less advanced illness. This is reflective

of the nature of PD in which mutuality changes begin to occur early in the illness trajectory as new symptoms appear and even plateau for some time (Carter et al., 1998). Moreover, understanding the issues that arise early in PD couples is critical for clinicians to be aware of nonclinical needs of couples with an important focus on the quality of their interactions as illness advances. Such understanding is essential to gain insight into the impact that PD has in earlier illness and the potential of its effect on couples as the condition advances. Therefore, the consideration of studies of early to mid-stage illness is important in understanding the dynamic quality of the relationship of PD couples as a basis upon which to study couples living with advanced PD within the context of limited evidence available from studies in advanced PD.

#### **3.4.1 Overview of the 28 studies**

The publication dates of the 28 included studies from this search ranged from 1990 to 2017. The majority were quantitative in design (n=16) with the remainder qualitative (n=12). Most were from the United States (n=16), the United Kingdom (n=4), and 8 from other countries. Many studies were cross-sectional in design with 4 longitudinal studies, 3 of which were quantitative and 1 qualitative. Of these 4 longitudinal studies, one quantitative study was conducted over a period of 10 years (Lyons et al., 2009), another over 12 months (Shim et al., 2011), and one was over 20 months (Lyons et al., 2007). The longitudinal qualitative study was over a period of one year (Haahr et al., 2013).

A variety of methods were used including mailed questionnaires, telephone interviews, secondary analysis of the control group of a randomised clinical trial,

and/or in-person completion of validated questionnaires. For all twelve qualitative studies, face-to-face interviews were conducted with most using a semi-structured approach. Eight of the twelve qualitative studies were conducted specifically with caregiving partners while two included data acquired from the PD partner as well, but reported data unique to the caregiver. Eight of the sixteen quantitative studies were specifically with caregiving partners while nine included data acquired from the PD partner as well but reported primarily data unique to the caregiver. Three of the 28 studies had a limited perspective from the patient but focused principally on the caregiving spouse (Birgersson and Edberg, 2004, Lyons et al., 2009, Hodgson et al., 2004).

### **3.4.2 Quality assessment**

Quality was assessed using the scale developed by Hawker et al. (2002) for reviewing disparate data, thus is appropriate for evaluating quantitative and qualitative studies. An outline of the scoring categories for this scale is provided in Appendix F (Hawker et al., 2002). Scores are assigned to each of four possible rankings in 9 domains. Scores of 1-4 have been assigned respectively, thereby resulting in a total score that ranges from 9 to 36 with 36 indicating the highest score. Scores for the 28 studies reviewed here ranged from 25 – 36 (Appendix G). The scores assigned in this review are used as a critique for the quality of each study and its relevance to my research question.

This quality assessment scale was chosen because it allows for a numeric score to be assigned to the study evaluated, thereby providing a more objective grading than most other methods that provide evaluation by more subjective consideration.

Despite this, it is recognised that such evaluation can be considered to be subjective as well, particularly when just one researcher is evaluating the studies. Some sections in the tool are more limited in scope than others, such as Ethics, making the evaluation of such study components more challenging. Despite these shortcomings, this tool is valuable as it allows for the evaluation of robustness of both qualitative and quantitative studies using the same parameters for both. A limitation in the quality appraisal scoring of the 28 papers is that I was the sole reviewer for the purpose of rating the papers for this thesis. Scoring by another reviewer could have offered more rigour to this component of the literature review.

### **3.5 Themes**

Data from the results and discussion sections of the 28 studies were entered into a data extraction table. After multiple readings, data were coded using thematic analysis. This was a methodical process in which studies were read, coded for patterns, sorted in groups, and read again, codes were reviewed again and meaningful patterns were summarised and considered that pointed to content that was relevant in relation to the question being researched (Whittemore and Knafel, 2005). An example of this is the theme of Many Losses: loss of identity, loss in routine, loss of independence, extreme dependence by the patient on the caregiving spouse, decreased intimacy, speech, and communication, not feeling connected, inadequate medical monitoring, unpredictability, loss of control over daily life, exhaustion, loneliness are codes from the included articles that map to the theme of Many Losses.

This process resulted in seven themes elicited from the analysis of the 28 included studies: mutuality decreases with disease progression; living with a stranger; many losses; length of caregiving time and preparedness have variable influences on

mutuality; feeling trapped; optimism as protection of mutuality; sexuality and intimacy. With the exception of sexuality, each of these themes was evident in the included quantitative and the qualitative studies; only two sexuality studies were included and both were of a quantitative approach. Each study demonstrated at least one of these themes and in some cases, all were present. Each theme is discussed below demonstrating its relevance to the study question with a table for each outlining the description of the theme and some critique of the studies.

### 3.5.1 Mutuality decreases with disease progression

Theme	Description	Source of Theme
Mutuality decreases with disease progression	Symptoms influence how motivated the patient is to go out; Choose to stay home and not engage in meaningful activities with partner	Carter et al., 2102; Davis et al., 2011; Eriksson & Svedlund, 2006; Hudson et al., 2006; Lökk, 2009; McLaughlin et al, 2011; Shim et al., 2011, Tanji et al, 2008
	Exhaustion, unpredictability, minimal communication, and resentment by the caregiving spouse contribute to lower mutuality	Carnett Martin, 2015; Habermann, 2000; Tanji et al., 2008; Turney & Kushner 2017
	Limited social interactions due to advanced PD contributed to feelings of isolation, loneliness, loss of personal freedom and increased role strain for caregiving spouse	McRae et al., 2009; Eriksson & Svedlund, 2006; Carter et al., 2010; Lyons et al., 2009; McLaughlin et al., 2011
	Caregiving spouses experience uncertainty about future of marital relationship	Martin, 2016

The theme that mutuality decreases with disease progression was consistent across both the quantitative (Carter et al., 2012, Lökk, 2009, Shim et al., 2011, Tanji et al., 2008) and qualitative studies (Davis et al., 2011, Hudson et al., 2006, Eriksson and Svedlund, 2006, McLaughlin et al., 2010). Disease progression could be indicated

from limited movement and was significantly associated with lower mutuality (Tanji et al., 2008). Such physical symptoms of the patient influence the degree to which he/she is motivated to go out, to engage in previously enjoyed shared activities, and to socialise resulting in a decrease in previously enjoyed shared activities. Sharing time together in such activities is a key component of the Mutuality Scale (Archbold et al., 1990).

Increased caregiving in advanced illness with accompanying exhaustion, isolation, loneliness, unpredictability, and resentment by the caregiving spouse was related to decreased mutuality. However, some studies focused only on motor symptoms in early PD (Tanji et al., 2008, Martin, 2016, Carter et al., 2010, Lyons et al., 2009) and Habermann (2000) merely offered caregiving spouses' descriptions of their situation without demonstrating impact on them. Carnet Martin's (2015) study included six caregiving spouses (of a total of 23) of PD partners with advanced PD. Carter et al. (2010) studied early PD stages only comparing younger and older caregiving spouses who had different competing responsibilities contributing to lower mutuality. With the exception of one study by Lyons (2007), qualitative and quantitative studies have shown declining mutuality as illness progresses. The 10 year study by Lyons et al. (2009) of caregivers of partners with early PD showed increased strain and lower mutuality as PD progressed however this study lost many participants to follow-up and had a large gap in time of data collection between years 2 and 10 so these results must be read with caution.

### 3.5.2 Living with a stranger

Theme	Description	Source of Theme
Living with a stranger	PD partner is no longer the person caregiving spouse had known prior to having advanced PD	Habermann, 2000, Martin, 2015, Haahr et al., 2010, Carter et al., 2012
	PD entails diminished shared dreams and hopes, conversation, socialising, intimacy, and sexuality. In some cases, core spiritual values such as love, loyalty, dedication, connection, and hope are challenged	Haahr et al., 2013, Lökk, 2009, Bronner et al., 2014
	PD is a robber/intruder destroying the couple's life and caregiver feels abandoned	Eriksson & Svedlund, 2006; McLaughlin et al., 2010
	Communication problems lead to anger for caregiving spouses	Hudson et al., 2006
	Caregiving spouse is tired of holding onto hope	Hodgson et al., 2004
	Experiencing normalisation is difficult while living with a "stranger"	Eriksson & Svedlund, 2006; Hodgson et al., 2004, Carter et al., 1998, Lyons et al., 2009, Birgersson and Edberg, 2004, Habermann, 2000, Davis et al., 2014, Carnett Martin, 2015
	Physical, social, and/or emotional dependence contributes to declining mutuality	Carnett Martin, 2015, Hodgson et al., 2004

Living with a stranger was evident in many studies as caregiving spouses reported their loss of closeness to their partner, acknowledging the fragility of life, and being



concerned about the death of their ill partner. They felt abandoned by their partner due to an illness that is “an intruder”. In some cases, core values such as love, loyalty, dedication, connection, and hope are challenged (Haahr et al., 2013, Lökk, 2009, Bronner et al., 2014). A participant in McLaughlin et al.’s (2010) study said that life is destroyed by PD and its associated losses as a couple; another spoke of feeling that he and his wife were robbed of the relationship they had shared before her illness but felt he had to care for her. Living with the partner who was a changed person, did not want to socialise, and communicated less contributed to anger and bitterness for caregivers.

Finding hope was difficult for many. One caregiving spouse trying to understand who this “new person” was, expressed trying to find a spiritual reason for his wife’s diagnosis of PD, hoping and praying that “out of bad things comes good things” (Hodgson et al., 2004 p. 111). This reflection helped him to accept that the changes in her were due to the illness and not in her feelings of affection and caring for him. Eriksson and Svendlund (2006) reported Swedish caregiving wives saying every day was a struggle to live with someone they barely knew. In addition, dependence, whether physical, social, and/or emotional by the PD spouse on the caregiving partner was a contributor to declining mutuality; this was echoed in all the studies.

### 3.5.3 Many losses

Theme	Description	Source of Theme
Many Losses	<p>Caregivers' loss of self-identity and independence</p> <p>Unable to share previously enjoyed activities with PD spouse</p> <p>Family and friends are in touch less leaving couple alone</p> <p>Caregiving spouses struggle to verbalise with PD partner and fear they will lose ability to stay connected</p> <p>Enduring grief and sorrow accompany loss of affection, dreams for future, and intimacy</p> <p>Loss of equality in the marital relationship, decreased verbal interaction, inability to travel together, inability to "rescue" PD spouse, financial worry, and need to take on added responsibilities</p> <p>Alexithymia (Inability to identify personal emotions) was associated with lower intimacy and lower mutuality</p>	<p>Carnett Martin, 2015, Davis et al., 2011, Haahr et al., 2013, Habermann, 2000</p> <p>Carnett Martin, 2015, Davis et al., 2011, Haahr et al., 2013, Habermann, 2000, Hodgson et al., 2004, Martin, 2016</p> <p>Hodgson et al., 2004</p> <p>Hudson et al, 2006</p> <p>Bronner et al., 2014; Williamson et al., 2008; Carter et al., 2012</p> <p>Carnett Martin, 2015, Carter et al., 2012, Davis et al., 2011, Eriksson and Svedlund, 2006, Goy et al., 2008, Haahr et al., 2013, Habermann, 2000, Hodgson et al., 2004, Hudson et al., 2006, Lökk, 2009, Lyons et al., 2007, McLaughlin et al., 2011, Morley et al., 2012, Martin, 2016, Turney and Kushner, 2017</p> <p>Ricciardi et al., 2015</p>

	<p>Loss of stability of their home due to necessary changes</p> <p>Worry about need for institutionalisation that would involve loss of the company of the PD spouse</p> <p>Many losses that need to be mourned with need for guidance to find hope welcoming support from spiritual advisors</p>	<p>Hudson et al., 2004</p> <p>Carnett Martin, 2015; McLaughlin et al., 2011; Williamson et al., 2008; Eriksson and Svedlund, 2006; Turney &amp; Kushner, 2017</p> <p>Hodgson et al., 2004; Hudson et al., 2006</p>
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Many losses was a common theme in most studies. Due to the epidemiology of PD that indicates high prevalence among older individuals, it is often the case that the couple has been together for many years. Loss of affection, enjoyed togetherness, dreams for the future, and intimacy are losses reported in many studies that are accompanied with a kind of enduring grief and sorrow (Bronner et al., 2014, Williamson et al., 2008, Lindgren, 1996). Caregiving was related not only to worry about the partner's health condition and its accompanying losses on physical, social, and emotional levels and the future, but also to loss of control over concerns such as financial stress, the need to handle all the household responsibilities, the caregiver's own health status, fear for the future, anticipatory grief of losing one's spouse, and interpersonal changes in the relationship that may contribute to sadness, isolation, and anger. Losses associated with alexithymia include heartfelt longing and sadness

about loss of dreams, fear for the future, and anticipated additional losses (Ricciardi et al., 2015).

Loss of one's self-identity accompanied by loss of independence has been reported in a number of studies and was evident even among caregiving spouses of partners with earlier PD stages. Martin (2016) and Turney and Kushner (2017) included some data on more advanced PD and feelings about institutionalisation but such data was limited by small numbers of participants. PD individuals who cannot express emotions often leave their partner wondering if they are cared for any longer. Some caregiving spouses are aware that they are grieving their losses but many indicated their frustration without recognising the validity of such changes in their marital relationship as losses.

Longitudinal studies designed to study impact on caregiving spouses could provide important information about changes over time however the 10 year study by Lyons et al. (2007) used secondary data on frail elderly and reported much missing data and loss to follow up although they did report declining health and increased depression in spouses as PD progressed. Their other study (2009) did not address this matter. The study by Haahr (2012) reported caregiving spouses saying the losses following DBS (Deep Brain Stimulation) were less but the relationship was never the same. Shim et al. (2009) performed secondary analysis on data from a longitudinal study and showed decreased mutuality with advancing PD but did not report on losses. The studies overall included few caregiving spouses of partners with advanced PD.

### 3.5.4 Length of caregiving time and preparedness have variable influences on mutuality

Theme	Description	Source of Theme
Length of caregiving time	Longer time as a caregiving spouse was an important contributing factor in some studies to decreased mutuality and quality of life in several studies, due to exhaustion, sadness, and change of the relationship with their partner except for the study by Shim et al.	Shim et al., 2011, Carter et al., 1998, Carter et al., 2012, Morley et al., 2012
	Lack of preparedness for caregiving, uncertainty, and unpredictability were reported as factors contributing to decreased mutuality with longer caregiving time	Goy, 2008; Carter et al., 2010, Hudson et al., 2006, Williamson et al., 2008, Birgersson and Edberg, 2004, Birgerrson and Edberg, 2004, Carter et al., 1998
	Young spouses reported greater decline in mutuality due to competing demands despite fewer years as caregivers	Hodgson et al., 2004, Lyons et al., 2009, Morley et al., 2012, Shim et al., 2011, Carter, 2010,

The theme of longer time as a caregiving spouse was an important contributing factor to decreased mutuality in several studies due to the physical, emotional, and relational changes accompanying this role. However, Shim et al. (2011) reported that although mutuality was significantly lower with lower functional ability, longer caregiving had significantly higher mutuality. Lyons et al. (2007) also reported this as an unexpected finding but speculate that the major share of decline likely had already happened before the study was conducted.

Lack of preparedness for caregiving, uncertainty, and unpredictability were common themes provided by caregiving partners that contributed to the changes in the life they had once known with their partner. Goy (2008) reported that at least one third of her participants experienced such challenges (Goy et al., 2008). While some caregiving spouses saw this role as a loyalty to their ill spouse, other studies did not report this especially the young spouses in the study by Carter et al. (2010) who reported increased changes in mutuality likely due to many competing demands with children and/or elderly parents and possibly cannot envision a long period of caregiving.

### 3.5.5 Feeling trapped

Theme	Description	Source of Theme
Feeling trapped	<p>Caregiving spouses struggle with isolation due to fewer outings, watching their partner struggle, and increasing dependence by ill partner on them</p> <p>The need to spend a great deal of time together sometimes grudgingly, and a decrease in shared experiences including demonstrations of affection and sexuality led to declining mutuality</p> <p>More community and medical support is available for PD patients than for their caregiving partners, leaving partners concerned about their own ability to provide care particularly if they had health issues themselves</p> <p>Caregiving spouses felt overwhelmed and alone with no support as family and friends withdrew as caregiving took up more time.</p> <p>Less caregiver stress, fewer years as a caregiving partner, younger age for the caregiver, and better functional activity and mobility by the PD partner contribute to better individual feeling,</p>	<p>Birgersson &amp; Edberg, 2004, Habermann, 2000, Mavandadi et al., 2014, McRae et al., 2009, Morley et al., 2012, Morrow et al., 2015, Williamson et al., 2008, Martin, 2016</p> <p>Turney and Kushner, 2017, Birgersson and Edberg, 2004, Habermann, 2000, Bronner et al., 2014, Brown et al., 1990, Williamson et al., 2008, Birgerrson and Edberg, 2008, Habermann, 2000, McRae et al., 2009</p> <p>Eriksson and Svedlund, 2006, Hodgson et al, 2004, Birgerrson and Edberg, 2008, McLaughlin et al., 2010</p> <p>Hodgson et al., 2004</p> <p>Morrow et al., 2015, Morley et al., 2015, Tanji et al, 2008, Shim et. al, 2011, Carter et al., 2012, Ricciardi et al, 2015, Lyons et al.,</p>

	<p>that is, feeling less trapped, as well as rapport and agreement by both partners concerning life situation</p> <p>Caregiving spouses felt overwhelmed, sad, neglected, lonely, detached, and low mutuality due to relationship changes</p>	<p>2007</p> <p>Birgerrson and Edberg, 2008, Habermann, 2000, McRae et al., 2009</p>
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While emphasis in the PD literature tends to focus on the clinical management of symptoms of the PD partner, several of the 28 studies focused on the psychosocial aspects of caring for a partner with PD (Mavandadi et al., 2014, McRae et al., 2009, Morley et al., 2012, Morrow et al., 2015, Birgerrson and Edberg, 2004, Habermann, 2000, Williamson et al., 2008, Martin, 2016). Feeling trapped was a primary finding due to the influence of advanced PD on the sense of freedom by the caregiving spouse. The challenges of caregiving to a spouse with progressive PD often led to resentment about spending so much unstimulating time together with decreased intimate moments, minimal community support, and isolation due to decreased socialisation which were changes from the life they had once had together.

Caregiving spouses in most studies said they felt burdened by reliance their partner had on them but some had mixed emotions because they felt their partner would do the same for them. Mavandadi et al. (2014) reported spouses saying they recognised benefits of caregiving such as focusing on priorities and what had become important. However, they do not indicate stage of PD and specify that PD partners were required to have stable illness with mild cognitive impairment only (Mavandadi et al., 2014).



Martin (2016) reported some participants saying that despite facing challenges of PD, they did not feel less close to their spouse. This must be read with caution, however, as Martin interviewed some PD patients and their caregiving spouse and she does not specify whether the partner with PD or the caregiver shared this response. A very small number of participants lived with stage 4 illness and none with stage 5.

### 3.5.6 Optimism as protection for mutuality decline

Theme	Description	Source of Theme
Optimism as protection for mutuality decline	Higher marital quality and/or ability to work together to face PD related challenges perceived some benefits in terms of spiritual growth, increased empathy, and the ability to adjust life goals within the context of the illness	Mavandadi et al., 2014, Hodgson et al., 2004, Lyons et al., 2009
	Helpful coping mechanisms by the caregiving partner to maintain their optimism and contentment of life included: seeking to maintain their own life, viewing their personal issues as secondary to the illness of their spouse, encouraging their spouse to stay involved and active, attending a support group, and using social comparison as a means of coping	Habermann, 2000, McRae et al., 2009, Williamson et al., 2008
	Three studies reported some positive aspects of caregiving and mutuality	Lyons et al., 2009, Shim et al., 2011, Mavandadi et al., 2014

Optimism was found in three studies to be protective of declining mutuality. In contrast to studies that highlighted feelings of grief and loss by caregiving partners

who felt neglected and overwhelmed, the study by Mavandadi et al. (2014) examined whether PD patients and their partners recognized any benefit of having PD or being a partner of a person with PD. Those with higher marital quality and/or ability to work together to face PD-related challenges perceived some benefits in terms of spiritual growth, increased empathy, and the ability to adjust life goals within the context of the illness (Mavandadi et al., 2014, Martin, 2016, Turney and Kushner, 2017). Maintaining their own interests and contact with other caregiving spouses proved helpful for some to find hope and optimism.

While most studies found strain, frustration, and depression in the caregiving partner increased as PD stage increased in the patient with an accompanying decrease in mutuality, Lyons et al. (2009) reported optimism and high mutuality as being protective of marital quality by year 10 in their longitudinal study and Shim et al. (2011) reported longer caregiving for some was associated with higher mutuality. These studies as well as the study by Mavandadi et al. (2014), studied perceived benefits of living with PD in terms of spiritual and personal growth, empathy, and reprioritising life goals, and found that benefit finding has a direct impact on marital quality in PD, while marital quality was negatively correlated with anxiety in the caregiving partner.

### 3.5.7 Sexuality and intimacy

Theme	Description	Source of Theme
Sexuality and Intimacy	The loss of a sexual relationship was accompanied by infrequency, loss of affection, intimacy, and feeling special and valued	Bronner et al., 2014, Brown et al., 1990
	Some female spouses reported feeling “turned off” by dyskinesia and physical symptoms in their partner, resulting in “anxiety” and “disgust”, and raising important concerns for the quality of their relationship	Brown et al., 1990
	Most PD patients were satisfied but most caregiving spouses were dissatisfied with their sexual life	Bronner et al., 2014, Brown et al., 1990
	Poor communication as well as motor symptoms contributed to dissatisfaction and decline in mutuality	Brown et al., 1990
	Some female partners indicated that their husbands “excessive” demands for sex created tensions between them	Brown et al., 1990

Two included quantitative studies focused specifically on intimacy and sexuality in PD. As sexuality is an important component of the marital relationship, the loss of a sexual relationship was accompanied by loss of affection, intimacy, and feeling special and valued (Brown et al., 1990, Bronner et al., 2014). Bronner et al. (2014) reported male PD patients had significantly higher sexual desire; a side effect of

some PD medications is increased sex drive which creates tension for the spouse when sexual demands are excessive. Male patients were more dissatisfied with their sexual relationship than female patients (59% vs. 36%) but couples did not discuss sex (Bronner et al., 2014).

Marital relationship was less satisfying for couples when the patient was male.

Erectile dysfunction, presence of a catheter, and dyskinesia are common problems in sexual activity for PD couples. Neither study indicated advanced stage of PD. Their studies included couples and responses may have been influenced by inclusion of both partners. Bronner et al. (2012) offer suggestions for alternate positions and sexual activities that might enhance the sexual relationship for PD couples and assist in preventing mutuality decline arising from this contributing factor.

### **3.5.8 Cross-cutting themes**

The relationships of the multiple variables studied across the quantitative studies are presented in Appendix H. PD stage in the patient, mutuality using Archbold's Mutuality Scale (2000), caregiving issues, and depression in caregivers were the variables most commonly studied. There was little overlap in most of the other variables, but some of the other variables did arise in some study findings where they were not explicitly studied. The qualitative studies had primarily semi-structured interviews as their research design. Aims of the studies were: understanding the impact of PD, quality of the relationship, perceived needs, psychosocial challenges, coping and managing together. Themes arising focused primarily on losses, emotional challenges, grief, impact on the relationship, losing one's identity, loss of intimacy, communication, and difficulties watching the PD partner struggle.

### **3.6 Discussion**

Chronic illness requires that partners adjust to role changes that accompany daily life (Rait and Lederberg, 1990). Caregiving, a component of close relationships, is accompanied by stressors influencing the quality of interaction or mutuality between partners. As illness becomes advanced, mutuality has been found to suffer if caregiving becomes the focus and the relationship resembles that of a nurse and patient, and/or communication is diminished due to loss of language and voice (Badr et al., 2007, Rait and Lederberg, 1990).

This literature review found the majority of literature concerning Parkinson's Disease focuses on clinical management of symptoms and medication. Little research has been conducted on mutuality or quality of the interaction in the relationship in advanced PD focusing on caregiving partners. This literature review revealed one study about being a spouse to a partner with advanced PD undergoing DBS. Four studies included small numbers (n=1-4) of caregiving spouses to partners with advanced PD. Due to this small number, it was necessary to consult studies of earlier illness as well; whether findings are equivalent in advanced illness is largely uninvestigated. Hempel et al. (2008) emphasise further research is needed in this area (Hempel et al., 2008). Furthermore, Davis et al. (2011) stress the minimal attention attributed to relational troubles in the literature. Such troubles contribute to changes in mutuality in couples struggling with PD challenges and the ways in which the many changes they face affect their shared hopes and dreams.

This literature review highlights mutuality as a critical component in the experience of couples living with PD. Research indicates numerous factors affect mutuality in PD. Physical and cognitive symptoms as well as psychosocial burden, insufficient

community resources (Birgerrson and Edberg, 2004, Hodgson et al., 2004), and decline in intimacy and communication are important contributors to poor quality in the relationship for couples dealing with PD.

The 28 studies included in this literature synthesis point to numerous important themes influencing mutuality from the perspective of the caregiving partner. Dealing with a significant change in one's life has the potential of altering the relationship between the partners when communication is minimal and feeling trapped is overwhelming. The sense of living with a stranger and feeling trapped contribute to isolation and a questioning of one's own identity. When caregiving becomes overwhelming and associated with resentment and frustration, it is potentially a step to depressive symptoms for the caregiver, reducing feelings of mutuality.

Most studies had more female than male caregiving partners in the study sample and three focused on wives only (Eriksson and Svedlund, 2006, Williamson et al, 2008, Turney and Kushner, 2017). While this is a reflection of the epidemiology of PD reflecting higher prevalence in men, more equitable numbers of male and female participants would provide important information to gain insight from male caregiving partners about needs unique to men in this role.

The Many Losses theme associated with PD was articulated by participants across the studies; such losses in turn contribute to significant life changes making the seven themes inexorably linked to each other, and affecting mutuality. With the exception of four studies, all were single interviews or times of data collection; longitudinal studies that examine changes over time in such losses would provide important insights into needs of such couples.

Several gaps exist in this area. Few studies have concentrated specifically on advanced illness, although some have included small numbers of spouses and/or couples facing later stages of PD. Detailed examination of research in mutuality from the perspective of caregiving spouses indicate that this has not been well studied in advanced illness. Therefore, studies in early to mid-stage PD were included in order to fully understand the research and findings of issues in mutuality that begins even early in PD. However, this does not truly represent the segment of the PD population who are caregivers to partners with advanced PD; one can only make assumptions that the difficulties would be exacerbated by advanced illness but empirical evidence for this is nonexistent. This gap highlights the need for research with caregiving spouses of partners with advanced PD to gain in-depth understanding of the issues concerning late stage PD.

Quantitative studies have used different sets of instruments making direct comparisons challenging. Qualitative studies, which are limited in number, tend to focus on early stages of illness, and typically involve clinical symptoms or burden of care. Therefore, this study utilised a qualitative approach with open-ended questions that offer participants opportunities to share lived experiences. This invites more reflective narrative responses than quantitative studies requiring them to respond to instruments such as rating themselves on a Likert scale.

### ***3.7 Conclusion***

Mutuality is a key component of marital partners' abilities to cope with PD at home when one is the caregiver. The 28 selected papers in this review have indicated factors that influence the quality of the relationship and sharing between partners.

The chosen studies elucidate the decline in mutuality even in earlier stages of illness. Although such information can be used to extrapolate the cumulative effect, less is known specifically about mutuality in advanced stages of PD.

Caregiving partners play important roles in the physical care and emotional and spiritual security of an individual with PD. Patient-centered care involves the stability and morale of family members also as they strive to cope with the many changes that accompany this neurodegenerative illness. This literature search has shown that the majority of papers about PD focus on clinical components and treatment with some research on burden of care but far less on mutuality. Moreover, such studies focus on early to mid-stage illness; as illness advances and patients require a palliative approach in their care, clinicians are challenged to understand the family unit with needs for emotional and spiritual support to assist them in preserving a level of mutuality that will help maintain a meaningful life despite advanced illness. Recognising this gap in the literature, and my interest in understanding the impact of PD on mutuality for my own professional work, I chose to study mutuality in advanced PD using a qualitative approach. This literature review has indicated a need for work in the area of advanced PD and has informed the design of my study which is described in detail in Chapter 4.



## **4 Methods and Methodology**

The methodology used in this study is van Manen's approach to hermeneutic phenomenology (van Manen, 1990). This chapter outlines methodological components of phenomenology and hermeneutic phenomenology with emphasis on van Manen's use of lifeworld existentials and the importance of language. The epistemology and ontology of phenomenology are presented as well as van Manen's view on rigour in research. This section is followed by the methods I used for my research: recruitment strategy, the study sample, data collection, data analysis plan, rigour, and ethical issues.

### **4.1 Phenomenology**

Phenomenology is the study of the lifeworld as the world of lived experience, defined as the world as it is experienced in the moment, in contrast to how people conceptualise or theorise about it (van Manen, 1984). It is the study of lived experience which is concerned with the immediate, pre-reflective aspects of experience (van Manen, 1990). Phenomenology seeks to find the essence of a phenomenon; essence is defined as the nature, rather than trends, of a phenomenon that exposes the structure of the lived experience allowing the researcher to understand its significance (van Manen, 1984, Rutberg and Ohrling, 2012). Phenomenological research is a means of investigating and understanding the fullness of living within the given phenomenon and provides a deeper understanding of the individual's experience (van Manen, 1984).

There are two categories of phenomenological research with multiple nuances developed by followers of each approach: firstly, Husserl's descriptive (eidetic) and

secondly, the interpretive (hermeneutic) approach founded by Heidegger. In Husserlian phenomenology, the researcher brackets personal previous knowledge about the phenomenon under study to avoid bias. Findings are thus descriptions of the phenomenon studied. However, a critical issue arises about whether research can be truly free from bias given that researchers cannot help but bring an element of their prior assumptions and experience to their research even when attempting to bracket. On this basis, van Manen rejected Husserl's approach and was influenced by Heidegger, who used the concept of *dasein*, defined as the situated meaning of humans in the world acknowledging influences from the world they live in (Flood, 2010, van Manen, 1990). For van Manen (1990), hermeneutic phenomenology uncovers the internal meaning of lived experience by studying individuals' experiences that are described and interpreted to understand their meaning (van Manen, 1990, Woodgate et al., 2008). Hermeneutic phenomenologists believe researchers cannot bracket previous knowledge and assumptions; rather, these are made explicit and contribute to data interpretation by the researcher (Rutberg and Ohrling, 2012, van Manen, 1990).

#### **4.2 Hermeneutic Phenomenology**

Hermeneutic phenomenology focuses on the lifeworld or lived experience to create meaning and understanding (Kafle, 2011). Hermeneutics are used to interpret an individual's language to capture the essence of the lived experience (Webb and Pollard, 2006). Following Heidegger, Gadamer used hermeneutics to show how *being* is revealed through language (Sloan and Bove, 2014, Gadamer, 1989). van Manen developed this further by indicating that language reveals *being/existence* through the contexts of history/time and culture (Sloan and Bove, 2014, van Manen, 1990).

The notion of *being/existence* is understood through language shared between the researcher and the participant and plays an important role in understanding the relationship between *being/existence* and practice because it helps to inform, reform, and transform this relationship (van Manen, 1990). van Manen writes “everything is soaked through with language” (van Manen, 2007 p. 38, van Manen, 1990). The vocative component of language, that is the addressing of vital parts of a story, is not only about speaking but about the skill with which the researcher listens. Something can only speak to us, van Manen says, if it is listened to.

Sound, language, and tone contribute to the language that the researcher uses in the reflective process of phenomenological writing (van Manen, 2014). In addition to the researcher, the speaker must be attentive to tonalities of language that indicate the way their lifeworld speaks to them (van Manen, 1984). Hermeneutic phenomenology involves the interpretation of meanings articulated by participants and exploring the data for themes leads to interpretive engagement with the data with the ultimate goal of understanding the experience of the participant (Langdrige, 2007).

#### **4.2.1 Language**

Hermeneutic phenomenologists interpret stories told by people living with a particular phenomenon by delving into deep and layered reflection of descriptive language to understand its meaning (Kafle, 2011). It is through language that the text provided by participants reveals the world as “we live in it” (Van der Zalm and Bergum, 2000). van Manen (2000) says hermeneutics facilitates understanding human experiences through language; communication and language are entangled together (Ajjawi and Higgs, 2007). van Manen stresses the importance of pathic

knowledge; the term “pathic” relates to aspects of a discourse such as empathic interactions incorporating a relational understanding of another person. He emphasises understanding that terms such as empathy and sympathy are not primarily intellectual but rather pathic, that is, derived from the lifeworld existentials. The language of the interview must be oriented to experiential aspects of one’s world (van Manen, 2007). He proposes that it is less easy to describe pathic life aspects than cognitive ones, therefore a language that is pathic is needed to reflect and elicit pathic meanings; such a language must be sensitive to experiential, emotional, and personal dimensions (van Manen, 2007). During my research, I was aware of the importance of allowing participants to feel emotions that arose for them during discussion of sensitive topics, and recognized the importance of experiential dimensions such as showing me pictures and items in their home or reminiscing about past experiences they had shared with their spouse in easier times.

While not all experiences are easily expressed verbally, van Manen stresses the ability of language to make such experiences intelligible and understandable (van Manen, 2014). He argues that a phenomenological text offers more than just information; it can evoke even ambiguous or poetic forms of meaning (van Manen, 2014). He proposes that phenomenological research is a poetising activity where the conclusion is not of prime importance; the poem or process itself is the result (Lindseth and Norberg, 2004).

The researcher must pay attention to silence which may occur as the participant contemplates or faces the unspeakable or ineffable; such silence, he says, is as important as spoken words and sometimes reveals truth (van Manen, 1990). Furthermore, lived experience must always be solidified in texts that require interpretation in order to understand the story a person tells at a deeper level (Lindseth and Norberg, 2004).

#### 4.2.2 Use of existentials in PD related research

van Manen elucidates everyday life as the lifeworld, and names four lifeworld themes or existentials that are interdependent and form a unity for each person, making up one’s lived world as seen in the following table (van Manen, 1990, Haahr et al., 2013):

**Table 2. Lifeworld existentials as Described by van Manen (van Manen , 1990, pp. 103-106)**

Existential	Description
Spatiality (lived space)	Personal safety and security in our personal world
Temporality (lived time)	Personal perception of time focusing on our past, present, and future
Corporeality (lived body)	Our sense of how others see us through our body and our subjective response to this
Relationality (lived other)	Our relations with others

van Manen (1990) says all humans experience the world through these four existentials in ways unique to each person, and each existential influences the others. The four existentials are especially relevant to PD, an illness with many dimensions.

The four existentials are interdependent and at times intertwined with each other. They offer a holistic framework in understanding the phenomenon under study for the researcher to explore layers of meaning in the four unique contexts. They help the researcher to promote the uniqueness of each individual as he/she experiences their lifeworld (del Pilar Camargo Plazas et al., 2016).

#### **4.2.3 Epistemology and ontology**

As outlined above, language is an essential component of hermeneutic phenomenology. The epistemological goal of Husserlian phenomenology focuses on *knowing* by descriptions of what individuals experience in their lifeworld. Husserl said phenomenology is a rigorous study of things as they appear for participants in order to understand human experience (Dowling, 2006). Husserl used the concept of intentionality which relates to being conscious *of* something; by researching, questioning, and theorising about the world, we become more a part of it (Earle, 2010, van Manen, 1990). For Husserl, intentionality is critical to understanding human experience (Earle, 2010). He argued that with the use of bracketing, the phenomenon studied shows itself as described by the participants through the process of reduction which is a process that reduces a person's world to the pure phenomenon; the result is free from bias by the researcher (Dowling, 2006, Valle et al., 1989). Bracketing one's preconceptions allows the researcher to separate

himself/herself from the essence of the phenomenon under study and thus acquire a new understanding of it (Flood, 2010). Both Heidegger and Gadamer rejected bracketing (Lavery, 2003). Since I had background knowledge of PD, I chose the approach espoused by Heidegger and Gadamer.

Whereas Husserl had an epistemological focus, hermeneutic phenomenology is ontological (Annells, 1996). Ontology is about the study of *being* (Kafle, 2011). The factors that make something uniquely different from other things is an important aspect of ontological research (Converse, 2012). Heidegger said humans live in a world that they experience and interpret and was interested in the meaning of *being* in their respective world (Heidegger, 1962). Husserl's view of intentionality for the purpose of uncovering the essence of a phenomenon was rejected by Heidegger and his students of hermeneutic phenomenology for *dasein*, the 'meaning of being in the world' (Earle, 2010). He focused on what it means to be human in the world (Annells, 1996). Heidegger said temporality is the sphere that provides the understanding of all being which makes sense within the time frame of past, present, and future (Earle, 2010). Koch (1994) explains further that the concept of *dasein* implies that a person and the world exist in tandem and thus are a single unit. In this ontologic approach, one makes sense of his/her world from within his/her existence rather than detached from it, as Husserl had conceptualized in epistemologic descriptive phenomenology (Annells, 1996).

Researchers have knowledge by virtue of 'being in the world' and must examine their own pre-understanding of the phenomenon under study, moving from the whole to the parts and back again in a reciprocal way (Earle, 2010). Hermeneutics is a

methodology founded on the ontological view that lived experience is a process of interpretation (Racher and Robinson, 2003). This view of phenomenology therefore is ontological, concentrating on the meaning of *being*; van Manen said understanding the *being* of something is to ask for the meaning of that phenomenon (van Manen, 1990, Dowling, 2006).

While Heidegger insisted that the use of language and the interpretation of a person's experience are inseparable, Gadamer focused on how language reveals *being*. He said all understanding is phenomenological and understanding is made possible only through language; the world is represented by language (Sloan and Bowe, 2014). In this way, he connected hermeneutic phenomenology and language with ontology with its focus on *being* rather than the mode of epistemology that focused on *knowing*. According to van Manen (1997), revealing meaning is the focus of phenomenology; this differs for him from the act of developing abstract theory.

#### **4.2.4 The interview**

For phenomenological research, the primary method for data collection is the interview (Flood, 2010). The interview provides a rich source of language and has several purposes: it is a method for collecting personal stories of participants' lived experiences; participants share a conversation with the researcher about the meaning of their experience; and participants tell their story from their own perspective (van Manen, 1990). The interview is comprised of interaction and shared speech in which the interviewer and interviewee share an exchange about the phenomenon (Lindseth and Norberg, 2004). The formation of trust with the researcher is critical; within the safe relationship that develops, the text emerges



from the participant to be interpreted by the researcher (Laverty, 2003). The interview offers sharing, probing and illumination of participants' experiences as the interviewer asks for examples and uses listening skills (Jasper, 1994, Flood, 2010).

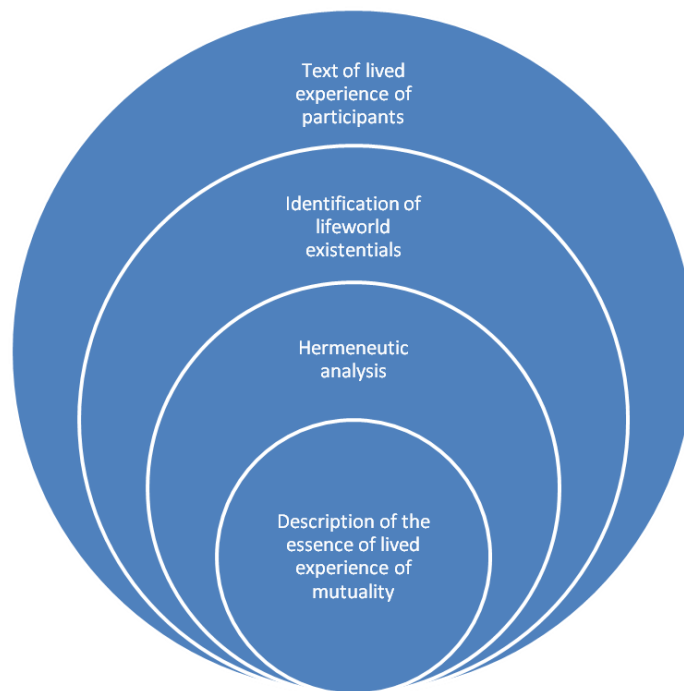
Interviews can be structured, semi-structured, or unstructured, with attention paid to what is said and is not said as well as to silence as participants ponder on what may be unspeakable (Kvale, 1996, van Manen, 1990).

#### **4.2.5 van Manen's approach to data analysis**

The researcher must be involved with the material obtained from research participants and in the data analysis (van Manen, 1990). The goal of hermeneutic phenomenological data analysis is to "transform lived experience into a textual expression of its essence – in such a way that the effect of the text is at once a reflexive re-living and a reflective approbation of something meaningful" (van Manen, 1990 p. 36). The process of interpretation and re-interpretation continues until the researcher attains meanings of the phenomenon that make sense without contradictory thoughts (Kvale, 1996).

The hermeneutic circle is a methodological technique that addresses understanding and interpretation by moving back and forth between the parts and the whole (Ajjawi and Higgs, 2007). The whole and the parts have a circular relationship that is iterative as meaning derived from each section gives meaning to the other. Reading, reflective writing, and interpreting are fundamental in the hermeneutic circle of data analysis (Laverty, 2003, Kafle, 2011, van Manen, 1990). Questions emerge from studying the phenomenon, and the answer is found in the text through use of the hermeneutic circle (Ajjawi and Higgs, 2007). The text is created from the data

provided by the participant and understanding by the researcher moving back and forth between the questions and the text, leading to insight in partnership with the text as seen below (Ajjawi and Higgs, 2007):



**Figure 1. The whole and the parts of the hermeneutic circle that lead to the essence of the phenomenon under study**

#### **4.2.6 Themes**

Thematic analysis for van Manen is about finding structures of meanings of lived experience in the text provided by the interviewee. Rather than coding data, he proposes various levels of reading: holistic reading of the entire text; selective reading of highlighted statements that are revealing about the phenomenon under study; and detailed reading of each sentence or sentence cluster that gives rise to the meaning of the phenomenon in the text itself (van Manen, 2014). He outlines how themes are then identified from data related to the studied phenomenon. The

theme uncovers the kernel of the expressed idea; offers the essence of that which has been expressed; helps to describe the content of the idea expressed; and assists in unlocking the depth of the kernel (van Manen, 1990). Within this structure, van Manen describes two categories of themes: essential and incidental. Only some meanings are uniquely attributed to the phenomenon under study and these are essential themes; others are just incidentally related to the phenomenon such as giving medication to the spouse as an aspect of the larger caregiving role (Fielden, 2003, van Manen, 1990). He stresses focusing on essential themes utilising the hermeneutic circle to write, reflect and re-write in a cyclical way to adjust the accuracy of how themes reveal lived experience. This thesis highlights the essential themes from the data.

#### **4.2.7 Phenomenological writing**

For van Manen, writing requires sensitivity to how language speaks “when it allows the things themselves to speak” (van Manen, 1984 p. 24). Understanding a person’s experience requires the researcher to listen to “the language spoken by the things in their lifeworld” (van Manen, 1984 p. 24). The researcher then learns the meaning of lived experience at a deep level significant to the participant. Writing provides the opportunity for the researcher to “discover the existential structures of experience” (van Manen, 1990 p. 127). van Manen outlines five approaches to writing that could be utilised either independently or in combination with one another:

**Table 3. van Manen's approaches to writing (van Manen, 1984)**

Approach	Style
Thematically	Presenting themes arising from findings.
Analytically	Digging deeper into themes for more thoughtful understanding.
Existentially	Interlacing participants' description against the existentials of spatiality, temporality, corporeality and relationality.
Exemplificatively	Use of varying examples to illustrate themes.
Exegetically	Engaging one's own writing with that of another phenomenologist.

Whichever style or combination of styles used, phenomenological writing requires a 'dialectical going back and forth' among questions that arise from the original research question and those surfaced during the study (van Manen, 1984, p. 28). The combination I used is primarily existential utilising the four existentials of spatiality, temporality, corporeality, and relationality with some use of the thematic approach. This combination involved identifying relevant essential themes within each existential.

### 4.3 Methods

Human science is the study of meaning and human science research is the “activity of explicating meaning” (van Manen, 1990 p. 181). Although van Manen rejects a fixed research methodology, he outlines six necessary activities of research in interaction with each other (Earle, 2010). The application of these to my research is seen as follows:

**Table 4. Six necessary activities of research according to van Manen (1990)**

Activity	As applied in my research
1. Turning to a phenomenon that holds particular interest to the researcher.	I observed in my clinical work that many PD couples experienced friction in their relationship when one was the caregiver in advanced PD.
2. Investigating the experience as it is lived rather than conceptualized.	I collected data on the lived experience directly from participants.
3. Reflecting on essential themes that are unique to the phenomenon under study.	I conducted the interviews and data analysis myself to best understand the essential themes that arose.
4. Describing the phenomenon through writing, reflecting and writing again.	I analysed the data, wrote, reflected, had supervision, reflected and wrote again many times.
5. Maintaining a strong relation to the phenomenon being studied.	I continue to work in the field of PD and have been able to apply my findings to my work.
6. Considering the parts and the whole of the research findings.	I used the hermeneutic circle.

#### **4.3.1 Addressing my pre-understanding**

van Manen (2014) emphasises using reflexivity to help interpret meanings discerned in research data. In doing so, the researcher uses his/her subjective views, knowledge, and experiences to assist in analysis and interpretation of the data, rejecting bracketing (van Manen, 2014). Instead of bracketing, van Manen requires researchers to explicitly state their knowledge of the phenomenon they are studying (Heinonen, 2015, Sloan and Bowe, 2014, Earle, 2010). The researcher may have assumptions, pre-existing knowledge, and pre-conceived thoughts about the research question that can be influential in interpreting the phenomenon before understanding the meaning of the participants' shared lived experiences; these must be overtly stated (van Manen, 1990). Consequently, it was important to acknowledge my pre-understanding of mutuality in advanced PD.

My role as the investigator for this research raised several issues. I worked in the Palliative Parkinson's clinic and knew many patients and their spouses within the context of their clinical situation. I was mindful that face-to-face interviews might allow participants to divulge unexpected information. Thus, I intentionally developed broad, open-ended questions for a semi-structured interview and presented myself as researcher rather than a Spiritual Care Practitioner. My work as a Spiritual Care Practitioner entails meeting individuals where they are concerning their spiritual and emotional status. Using therapeutic techniques, I facilitate exploration of emotions arising from the challenges they face. As a researcher, I adhered to an interactive research methodology that used questions that enabled participants to reflect on their own lived experience of mutuality. The interview data were thus the result of a shared and jointly produced method.

I was aware that researching lived experience might elicit emotional responses. The research questions were focused yet open-ended, inviting a range of responses without therapeutic intervention on my part; at the same time, the open-ended questions allowed for emotional expression as participants told their story. I assumed that caregiving spouses would be interested in participating and sharing their lived experiences. Caregiving spouses want to be heard and a phenomenological study offers this opportunity (Moore and Miller, 2003). These assumptions proved true. I hoped that participants would talk about their emotions and share other experiences.

#### **4.3.2 Insider researcher**

An insider researcher conducts research as a member of a group and has *a priori* knowledge of characteristics of that group (Greene, 2014). Insider research has the advantages of greater acceptance, accessibility, and relational intimacy but concern exists about bias (Breen, 2007). Precisely what constitutes a member is difficult to ascertain. Although I worked in the clinic and knew potential participants and some of their issues, I was not a caregiving spouse to a patient with advanced PD. Dwyer and Buckle (2009) explain the binary terms of insider and outsider can be bridged; it is not imperative that the researcher be a member of the group being studied to characterise the lived experience of its members but rather, the commitment to carefully and caringly study and represent their lived experience is paramount. The identification by researchers with the population of the participants plays a vital role in accurately understanding their stories (Dwyer and Buckle, 2009).

My position was what Breen describes as ‘the researcher in the middle’ (Breen, 2007). Although not a true insider, it was not entirely possible as a researcher to be a true outsider to the experience of caregiving as a spouse because I had pre-existing knowledge of concerns that some participants had discussed during clinic visits. I recognized that my spiritual care work might result in assumptions and preconceived expectations, introducing a potential bias if I asked leading questions. Furthermore, due to my clinical work, I had read literature about caregiving in PD and mutuality and had had discussions with physicians and team members. As a result, I was neither an insider nor a true outsider; I dwelled in ‘the space between’ (Dwyer & Buckle, 2009, p. 61). This space between the two perspectives allows for deep understanding of the experience I was studying with participants who had already placed their trust in me. Because I was known to some potential participants, it was important to minimise perceived obligation to participate to avoid disappointing me. To minimise this possibility, the study was explained and they were informed that there was no obligation to me or the hospital to participate. Furthermore, if they declined, this decision would not affect the medical care their spouse continued to receive.

#### **4.3.3 The study sample**

Participants were recruited for this qualitative study with purposive sampling from a site of Canada’s largest teaching hospital that hosts a comprehensive Movement Disorders department. A multidisciplinary team offers a holistic approach to the care of patients diagnosed with a variety of movement disorders, PD being the most prevalent. The Palliative Parkinson’s clinic was created to care specifically for people with advanced PD.



Caregiving spouses of a PD patient with stage 4 or stage 5 of the Hoehn & Yahr PD scale comprised the study sample. Thirteen of fifteen people approached accepted the invitation to participate. One changed her mind prior to the interview, yielding a total of 12 participants. Inclusion and exclusion criteria were as follows:

#### **4.3.4 Inclusion criteria:**

- Caregiving spouse/common law partner to an individual with advanced PD (stage 4 or 5) as designated by the physician.
- Both partners residing together in their home.
- English fluency.
- Able to participate in a one hour interview.

#### **4.3.5 Exclusion criteria:**

- Residence for the PD partner outside of the home (such as nursing home, hospital, etc).
- Hoehn & Yahr classification of the PD partner less than stage 4.
- Inability to speak English.
- Unable to participate in a one hour interview.

van Manen does not indicate a recommended sample size as the nature of the lived experience of the phenomenon under study is the key factor with the goal of understanding the experience (van Manen, 1990). However, suggested sample sizes for phenomenological studies range from 6 – 50 depending on the phenomenon

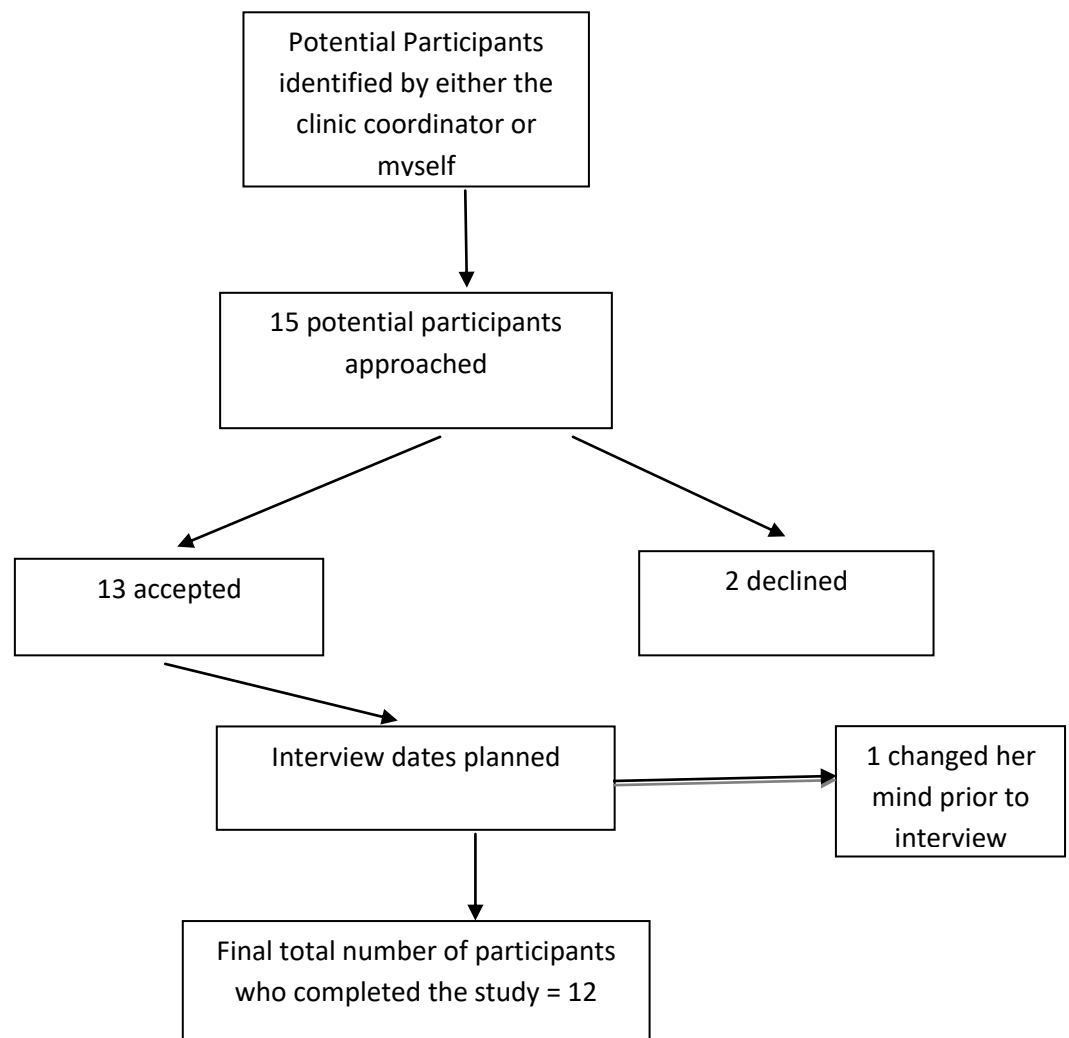
under study and the purpose of the research (Sandelowski, 1995, Schumacher, 2010). My study sample included 7 caregiving wives and 5 caregiving husbands, reflecting PD epidemiology that reports higher PD prevalence in men, although an attempt was made to have as equal as possible gender representation. All twelve participants were married to their partner, ranging from 26-65 years of marriage. Participants' ages ranged from 70-86 years of age. Their spouses had PD ranging from 2-32 years duration. All 12 participants were retired.

#### **4.3.6 Recruitment & consent**

Participants were recruited and interviewed between April and December 2015. Initial plans for the clinic coordinator to approach potential participants were rejected by the Research Ethics Board (REB); I was required to undertake the recruitment myself to avoid participants being approached by somebody unfamiliar. The REB indicated no concern about possible perceived obligation arising from my approaching potential participants and stated that due to the sensitive nature of the research, familiarity with me was beneficial. Therefore, I approached individuals who met the inclusion criteria. After I spoke with each potential participant, he/she received an information pack about the study. I contacted them two weeks later by telephone to follow up about their interest in being interviewed and to answer any questions.

When willingness to participate was verbally expressed by the participant, we arranged a meeting time that would be convenient for them (Braun and Clarke, 2013, Silverman, 2011). I introduced and conducted the informed consent process, and initiated the interview after obtaining consent (Appendix J). A statement

indicating no conflict of interest between my clinical and research roles was provided according to research ethics requirements (Silverman, 2011). These actions were designed to assist potential participants in making a voluntary decision about participation. The informed consent process followed the processes required by both Lancaster University (UK) and the study hospital. Eleven participants chose to be interviewed at home and one came to the hospital. Figure 2 provides a flow chart of the recruitment process:



**Figure 2. Flow chart of recruitment process**

The three individuals who declined to be interviewed were all caregiving wives. One felt her husband would not approve, one expressed no interest, and one changed her mind due to lack of interest as the interview date approached.

#### **4.3.7 Data collection**

After outlining the study, risks, benefits, confidentiality, data storage, and contact information for the appropriate Research Ethics Boards, I asked the participants to sign a consent form they had seen previously in their information pack; they then participated in a single face to face semi-structured interview. Participants were asked initially to provide demographic information, specifically: birth date, length of marriage to their spouse, and number of years their spouse had PD. This allowed for both obtaining necessary baseline demographic data and to ease them into the more sensitive study questions that followed. I created an interview guide of open-ended questions concerning mutuality to guide my interview with participants (Appendix K). Sometimes participants would veer away from the question and I encouraged them to continue on tangents that were relevant; they were gently guided back if necessary to resume their train of thought (Silverman, 2011).

Interviews were conducted on a one-to-one basis with the participant; when the PD partner was home, the interview took place in a separate room while the PD partner slept or was with somebody else. Interviews lasted 60-75 minutes and were digitally recorded; they were transcribed by a transcriptionist who signed a confidentiality agreement. Participants were not invited to read their transcripts, however most expressed interest in the study results.

In order to ensure the collection of pathic knowledge, I often mirrored responses provided by participants and was sensitive to times when they were emotional or cried at poignant moments. We paused for a few moments if needed. One participant would hold up her hands to indicate that she needed time to think or to pause. As per van Manen's guidelines, silence and the request to pause are important contributions to the data collection (van Manen, 1990).

#### ***4.4 Confidentiality and Storage of Research Data***

Participants were informed that the data they provided would be seen only by me, the transcriptionist, and my academic supervisors at Lancaster University. I provided contact information for each supervisor in the UK and the hospital REB. They were informed that their name would not be attached to the interview data, that the signed consent forms and demographic data would be kept separate from the transcripts, and that the interview would be recorded and transcribed. Recordings were transferred to a confidential server of the hospital; data are stored in a locked cabinet in a locked office at the hospital and on a secure hospital server for 7 years according to hospital REB standards and will be destroyed at that time.

#### ***4.5 Data Analysis***

van Manen's approach to hermeneutic phenomenology with the use of existentials was used as the framework for analysis in this study. I conducted analysis of the texts using his methods of reading, reflective writing, and interpretation as components of the hermeneutic cycle using pathic language to reveal the lived experience of mutuality as a caregiver to a spouse with advanced PD. Attention was paid to silences, tears, and changes in voice tone as these were included in the transcriptions.

Analysis for this thesis utilises a data driven approach with a two-step process as follows: the iterative process of coding and identification of themes began with a thorough holistic reading of the transcripts for full understanding, selective reading, and detailed reading as van Manen (2000) outlines to determine themes from meaningful patterns of responses and reflections. Transcribed texts were compared to the audio recordings to ascertain emotions and nuances of language. Comments were made in the margins as needed. Themes were then identified and mapped to the lifeworld existentials of spatiality, temporality, corporeality, and relationality to which they related (Thome et al., 2004, Sloan and Bowe, 2014). I used a combination of thematic and existentialist analysis (van Manen, 1984). This approach provided an understanding of mutuality in advanced PD by in-depth study of the meaning of the lived experience of the 12 participants. The hermeneutic circle was used until the themes were robust. An example of the analytic process showing how data evolved into themes through the selective reading approach for one theme (Where can we go?) as outlined by van Manen is seen in Appendix I. The selective reading approach involves the identification of statements or phrases that seem especially revealing about the phenomenon under study; these statements are underlined or highlighted (van Manen, 1990).

The order of analysis for the existentials was spatiality, temporality, corporeality, and finally relationality. Data were analysed separately for each existential following the steps outlined above and upon completion, cross-cutting and common themes across all transcripts were identified for each existential. Upon initial holistic reading of the transcripts, I saw that relationality appeared to exert the strongest influence, so chose to concentrate on the other existentials earlier in the analysis to see their

unique contribution on their own as much as possible without the effect of relationality. Given this strong influence of relationality and the large number of themes within this existential, a separate chapter has been dedicated to the presentation of themes of relationality.

#### **4.6 Rigour**

Rigour ensures the quality of the research process. Guba and Lincoln (1989) coined the phrase “trustworthiness,” which is comprised of credibility, transferability, dependability, and confirmability (Guba and Lincoln, 1989). While this model is used by many qualitative researchers, van Manen proposes a different set of criteria for quality that utilise participants’ lifeworld stories: 1) orientation 2) strength 3) richness and 4) depth (Kafle, 2011, van Manen, 1990). Orientation concerns the degree of immersion of the researcher into the world of his/her participants and their stories of their lifeworld; strength indicates the ability of the text to offer understanding of its meaning expressed by these stories; richness offers the visual quality of the text that tells the researcher the meanings as perceived by the participants; and depth refers to the ability of the text to present deep exploration that best expresses the intentions of the participants (Kafle, 2011, van Manen, 1990).

I used van Manen’s four criteria to obtain rigour as follows: 1) orientation was applied by my deep immersion in the data through reading each transcript and then reading across transcripts for codes; identifying themes and mapping them to existentials and using the hermeneutic circle and self-reflection following each interview; 2) strength was applied by the use of direct questions that utilised straight forward and easy to understand language that allowed participants to understand

what was being asked. I created the interview questions based on my literature review. To obtain user involvement, the questions were field tested with spouses of patients with less advanced PD to ascertain comprehension and clarity of the questions and adjusted according to recommendations prior to the start of data collection to ensure they captured appropriate and relevant information; 3) richness concerns quality of the text that tells the researcher the meanings as perceived by the participants – I wrote notes on the transcripts in margins about codes or observations; transcripts were compared against the recordings to observe tone of voice, silences, emotions, crying, laughter, and pauses; and 4) depth was attained by the use of questions that initiated opportunities for participants to think deeply of their experiences and provide reflective thoughts and lived experiences of what it meant to be a caregiving spouse; moreover, the open-ended aspect of the questions allowed for opportunities to think broadly and offer responses that could reflect their unique lifeworld. This in turn resulted in rich texts that provided the opportunity for meaningful analysis.

#### ***4.7 Approval by Research Ethics Boards***

Hospital REB approval was received via letter dated December 23, 2014, study number 14-8438-AE. The hospital requires annual REB renewal and this has been granted yearly. Ethics approval was received from the Lancaster University Research Ethics Committee via letter dated February 16, 2015. Relevant ethical concerns for this study included: a) interviewing the caregiving spouse only; b) location of the interview; c) support for the participant, researcher, and transcriptionist; and d) safety of the researcher. Each of these is discussed in the section below.



#### **4.7.1 Ethical concerns**

a) This study focused on the perspective of the spouse who is the primary caregiver.

PD affects the spouse as well as the patient, but several concerns arise if both parties are interviewed together: one interviewee may dominate, the patient may feel his/her opinion is not important, the focus of discussion may take an undesired shift and lose sight of the research questions, and antagonisms between spouses may arise (Arksey, 1996). Discussing difficult topics may be avoided in order to maintain the stability of that relationship (Morris, 2001). Moreover, data derived from a joint interview provide a picture that is a combined result of separate perspectives while an individual interview provides data from a single person's lens (Seymour et al., 1995). This study sought the individual perspective. Understanding meaning is essential in the development of assistance and interventions that can assist those caring for a close relative living with a progressive illness (Ohman and Soderberg, 2004). The objectives of this research were best met by interviewing just the caregiving spouse. It was planned that if patients questioned why their spouse alone was included, that information would be provided to them about the rationale for this study. This concern never arose.

b) Location of the interview concerned the issue of privacy for the spouse who was being interviewed as well as the needs of the patient who was in the home at the time of the interview. Issues arising included the need for the patient to be in another room and excluded which carried possible feelings of feeling physically unsafe and excluded from the experience (Morris, 2001). Some required someone else to be with them. Although the ideal location was the hospital before or following a clinic appointment, logistics determined that the home was easier. For some

participants, the interview was conducted at the home while the patient was at a day program. Once again, this required some planning in order to be sure the patient was safe and the location ensured privacy.

c) Privacy for the interviewee as well as the needs of the patient at home during the interview was paramount. The ideal interview location was at the hospital, but most chose to be interviewed at home sometimes while the patient was at a day program, if applicable. Engaging in dialogue about the spousal relationship with a PD partner may induce feelings of anxiety, sadness, anger, or impatience. Participants were informed that they could end the interview at any time or change their mind about participating. I was concerned that questioning participants about their sexual relationships might be taken as encroaching upon their privacy, but this never was the case and I felt more confident with each interview about this.

In order to protect the confidentiality and privacy of study participants, pseudonyms were assigned. I assigned them randomly; one participant wanted to choose her pseudonym and for one participant, I chose a pseudonym that reflected her cultural background.

d) It was possible that I could be triggered emotionally. Similarly, the transcriptionist might have this experience while transcribing interview data. I arranged for emotional and spiritual support for participants, the transcriptionist, and myself should it be required. This situation never arose. The REB concern about safety for the researcher was addressed by the clinic coordinator knowing when I was going to the participants' homes for the interview with planned check in times.

## **4.8 My Dual Role and Professional Boundaries**

I was aware of my dual role early in the study and this understanding developed further in all the methodological decisions I made from conceptualisation of the issue, design, recruitment, and analysis that I outline in this section.

### **4.8.1 Conceptualisation of the issue**

Mutuality reflects connection to a significant individual. As a Spiritual Care Practitioner, I observe and question individuals about their sense of connectedness to others. It was no surprise that I noticed patterns of interactions between some PD patients and their caregiving spouse that led me to wonder about the impact of PD on their marital relationship. While I recognised that there are other contributing factors that influence the quality of the marital relationship, I learned this was not well explored in advanced PD. Engaging in this research, it was imperative that I remained aware of my role as researcher in this endeavor and not slip into the role of Spiritual Care Practitioner.

### **4.8.2 Design**

In choosing to conduct a qualitative study, I realised the sensitivity of my questions might lead participants to consider the interview as a counseling session; this was how they knew me as Spiritual Care Practitioner at the clinic. It was important to establish my role as a researcher in this interaction with them. It was imperative that I not allow the research interview to focus on the clinical or supportive aspects they experienced at their appointments. Participants appreciated the opportunity to talk about themselves and were informed that this would be about them in relation to their PD partner. The blurring I was concerned about occurred in a small way with only one participant who said she wanted to know the prognosis of her husband. Not

only could I not provide this as I am not a physician, but I told her this question could be raised at her husband's clinic appointment.

The reality that people knew me likely made very sensitive questions easier to raise. This is an assumption as it is only questionable if talking to a stranger about sexuality, intimacy, and love would provide the same honesty and openness. Conducting the interview in their home and not during working hours allowed me to remove myself from my professional role in the clinic which otherwise might have contributed to blurring of boundaries. This was encouraged for all participants but one insisted on coming to the hospital.

I could have recruited participants living with an advanced PD partner from practices of other neurologists, however, this clinic is known for its specialty and receives patients from across Ontario. I was aware that participants might refer to their spouse's medical appointments during our interview or expect a counseling session. I informed them during the introduction and consent process that the interview was intended to collect data pertinent to the research question.

#### **4.8.3 Recruitment**

Although a third party would mitigate potential bias, the REB insisted that I approach potential participants due to the sensitivity of this study. I had concerns about this and reassured participants about not feeling obligated and that their partner's treatment would continue as before. On the other hand, participants were very pleased to participate in research by somebody they knew, with whom they received treatment, and knowing the research was supported by this important clinic.

#### **4.8.4 Analysis**

I was aware that I had some knowledge about some of the participants from clinic appointments but I knew less about their marital relationship as the clinic focuses on PD symptoms and treatments. My dual role might have allowed me to slip into advanced clinical symptoms rather than mutuality so I was challenged to maintain my role as researcher at all times rather than Spiritual Care Practitioner and conduct the analysis from the vantage point of the research question itself using the existentials as the analytic framework. In order to offset this possibility, I kept field notes during the interviews and memos to myself during analysis of the data.

#### **4.9 Self Reflexivity**

Reflexivity requires the researcher to be intimately involved in both the process of the research and the study results (Dowling, 2006, Etherington, 2004). Throughout the various steps of my research, I have recognised that my background and experience as a Spiritual Care Practitioner contributed to my interest in the relationship between spouses in advanced PD as I was aware of some (but not all) of the challenges of advanced PD. This stemmed primarily from the work I have done in palliative care, bereavement counseling, and my interest in providing support to families receiving palliative care approaches as they live with chronic and degenerative illness. I was aware of the importance of checking in with myself prior to and following each interview and kept a journal for this purpose. I examined my feelings about each interview prior to the date as well as afterwards.

Reflexivity is a process that is both introspective as one examines oneself, and intersubjective involving feedback from others, ideally a research supervisor(s) (Dowling, 2006). My monthly supervision meetings with my thesis supervisors

assisted me in examining my thoughts about the progress of the design, the interviews, and analysis of my research. One interview with a participant left me feeling disappointed that she had not given me what I had hoped would be substantial data. I thought she avoided answering the questions directly. However, upon reading the transcript, my supervisors helped me see the rich data she had provided. I learned that responses are different based on the lived experience of each participant; in my eagerness to obtain comparable data from each participant, I had lost sight of this.

Although I wondered if my pre-understanding would challenge my objectivity, I came to appreciate van Manen's rejection of bracketing as I realised that I could understand some of the issues participants identified because of my experience of working in the PD field. I believe this pre-existing knowledge influenced how I designed my study, specifically choosing a hermeneutic phenomenological approach that requires interpretation. Koch and Harrington (1998) stress the importance of the researcher's background and situation as fundamental in the interpretation of participants' stories; we make something understood by comparing it to something that is already known (Koch and Harrington, 1998). Moreover, understanding is achievable because of the researcher's pre-understandings rather than in spite of them (Rabinow and Sullivan, 1987). I utilised the hermeneutic circle as I engaged in the writing of results and discussion, immersing myself in the texts to the extent that I sometimes felt like I was drowning in the transcripts. van Manen proposes that we "step out of one world, the ordinary world of daylight, and enter another, the textorium, the world of the text" (van Manen, 2014 p. 359). I felt reassured in reading this that I was not losing myself in the words of my participants but rather

developing the “special relation to language” that van Manen encourages (van Manen, 2014 p. 359).

This chapter has outlined van Manen’s approach to hermeneutic phenomenology and the use of the four lifeworld existentials as a framework for understanding lived experience. The interview, which van Manen promotes as the gold standard method for data collection and his use of the hermeneutic circle for data analysis, writing, and rigour have been outlined. Application of his methodology to this study has been presented. Detailed results of this process are reported in Chapters 5 and 6.

## 5 Results

The study results are presented in both this chapter and the one that follows.

Spatiality, temporality, and corporeality existentials are presented in this chapter.

The relationality existential is covered in Chapter 6.

### 5.1 *Spatiality themes*

van Manen explains lived space, spatiality, as “felt” space. Lived space refers to aspects in our environment that affect how we feel relative to where we are. PD can have a profound influence on lived space as people realise their home may need re-configuration and outings become more challenging. Three themes were identified: home is no longer the sanctuary it once was; where can we go?; and, feeling trapped at home.

#### 5.1.1 **Home is no longer the sanctuary it was**

Mutuality and shared love of home create a strong bond between partners as they create a unique space that represents their relationship and commitment. PD affects not only where participants live and feel most themselves, but also their place of shared activities. Adjusting their home to the partner’s needs was mentioned by most participants, accommodating aids such as wheelchairs, walkers, poles, and hospital beds. Participants expressed frustration, sadness, and disappointment despite accepting the necessity of such changes.

Illness can “rob” couples of the sanctity they have known in their home. Some participants felt PD had turned their home “upside down” and it looked more like a hospital. Several reported sleeping in separate beds, and some PD partners required a hospital bed thereby losing the intimacy of their shared marital bed. Due to the size



of the hospital bed and the need to have it in an accessible space, these couples were challenged with finding arrangements that worked for both of them. Ann was frustrated over a friend whose unsolicited advice to move her husband's hospital bed left Ann wondering if she had made a mistake placing it where it was. Ann wanted to do the best for her husband, but he was unable to speak and she felt moving the bed would be disruptive to their preferred calm home setting. She said PD took over their routine, relationship, and their shared space. She resented someone making suggestions when she, was the one living in a shared space already altered to meet her husband's needs:

*"...with this hospital bed in the living room, the other night somebody came over and they had an idea of putting it in the dining room so the next day I'm out with the measuring tape trying to figure out what's good, what would be better for him...we need so much floor space and I don't think we have it in there...I don't like him having this; it's not nice for him; it's not nice for me but I can't make it go away so you try to do the best you can for him, with him, around him, because of him, whatever." (Ann)*

One's home is ideally a space of comfort and welcoming others. PD can contribute to isolation because of decreased social interactions; home can become a place of quiet and boredom. Jim spoke of his wife's difficulty coming home from the hospital:

*"...she was enjoying being in the hospital ... seeing different people every day and ... she met different nurses, doctors, and she was happy. Now ... she says 'take me back to the hospital'." (Jim)*

Jim shared this story sadly; despite everything he did for her, his wife longed to engage with more people beyond the confines of their home. He was surprised that she preferred the hospital, and he took this personally. Jim's story represents others in which caregivers can feel less important in the relationship due to the focus on the ill partner.

Going out posed multiple transportation challenges. Maneuvering in and out of a car is difficult for individuals with advanced PD due to rigidity and tremors. Most participants were older themselves, often unable to assist their partner. Steps at the front door made leaving home difficult and presented numerous hardships, limiting the amount of time couples enjoyed shared outings; this in turn contributed to social isolation and anger at being stuck at home a great deal. Some used WheelTrans<sup>5</sup> but Robert purchased a special van as their community is not serviced by WheelTrans. Robert felt lucky he could afford this vehicle, and as a car mechanic, could maintain it. None of the women spoke of such a creative approach to going out; gender may play a role in finding possible solutions. Life had become unstimulating for many partners as they were confined to their homes. Resultant boredom and disappointment contribute to poor mutuality with the caregiver feeling alienated from the PD partner.

The need to feel safe is important; for PD patients, moving safely is paramount. Home can become less safe than it had been before advanced PD; many spouses said they had to watch their partner constantly because of fall risks. For some, this created anger; they resented being the watch keeper and disliked rearranging their home, removing obstacles, or installing aids that were not always of assistance. Mary resented her home being different, and that sometimes costly, installed equipment which changed the aesthetics of their home did not even provide the expected

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<sup>5</sup> WheelTrans is a service provided by the Toronto Transit Commission, the public transportation company that serves the needs of individuals with mobility issues. This bus, designed to transport people in wheelchairs, requires a physician's referral and must be reserved by the individual in advance. There is a nominal fee.

assistance; she often found her husband on the floor. These were barriers to jointly enjoying their home as they once had:

*“Sometimes I’m waking him up; sometimes I go towards where he is in bed and I can’t find him; he is on the floor. Sometimes it takes me twenty minutes to half an hour to get him off the floor. I try to get him to hold onto the pole and to pull himself up...I left him because sometimes I get him his six o’clock medication and I leave and come back in ten, fifteen minutes to see if the medication will work. I don’t want to leave him too long because that means he will pee in the area he is in.” (Mary)*

### **5.1.2 Where can we go?**

Patients with advanced PD are often unaware of their medication waning and the “OFF” experience beginning. As a result, couples have minimal outings because space outside is not ideal for mobility, and the disappointing reality is that it is easier to stay home. However, this restricts the frequency of outside activities together. Some participants were willing to try outings together that they thought might be possible, but often experienced profound disappointment. Barbara reflected on seven challenges of going out:

*“He has a transport chair but that’s – he likes Tim Hortons (a popular coffee shop) and periodically I am so fed up with making lunches every day so once in a while if we have been to a doctor’s appointment and we’re finished and it coincides with a lunchtime so let’s go to Tim Hortons for a treat.*

*... you get him in that transport chair which isn’t bad; it’s getting him into Tim Hortons and a person in a transport chair is like a dead weight and he is not a big heavy man to start with but now he feels like he is five hundred pounds because he is dead weight...*

*Fortunately, the odd time there have been some people who have been courteous and held the door for us while we get in. And I feel Tim Hortons with the millions that they make, their restaurants need revamping for people with wheelchairs. And once you’re inside and you get these young girls in there with these big bulky baby strollers, you cannot move.*

*Then some places have inadequate parking spaces. There is only one or two token parking spaces and if they're already taken, now what? Then you have to park way at the other end of the parking lot and then you have to shuffle this person... so you finally say 'the heck with this; I'm going home, forget it.'*

*The last time we were at Tim Hortons it was such a thrash to get in and out of that building and the same with the washroom. They have a little handicap sticker on the door. What a joke. There is a narrow door and then I have to go into the men's washroom because I have to assist him. No one has said anything but I'm kind of thinking that people think what's going on that this woman is going in the men's washroom... I'm thinking 'what are people thinking?'"*

Barbara demonstrated anger, disappointment, and helplessness as she felt the world closing in on her and ordinary, everyday experiences become almost impossible. The small pleasure of going out for lunch together was problematic in almost every way and not worth the trouble; yet Barbara spoke about how much she would love to go out with her husband and do activities they had once shared. All the participants shared difficulties about going to restaurants; the amount of work involved overpowered the enjoyment of having a meal out and it lost its appeal. Many participants spoke of this difficulty with disappointment. The embarrassment of spilled food, having to cut their partner's food into small pieces, and toileting concerns all contributed to this as something they no longer looked forward to together; rather it was just one more thing to do for their partner.

Many expressed wanting to go out but feared unexpected events such as toileting issues, inability to move, or falling. As Elizabeth articulated:

*“My son says ‘let’s go here, let’s go there’ but I am not going because I don’t know when he (husband) is going to faint; when he is going to fall; I don’t want to go”. (Elizabeth)*

Going on outings with someone with advanced PD requires bringing equipment, changes of clothing, and medications. Moreover, there may be an element of embarrassment in possible falls or incontinence. This fear of unpredictable events causes anxiety for many participants so they chose to simply stay home where their partner would be most safe with minimal inconvenience. This however, has a detrimental impact on mutuality as resentment is increased as lack of interesting outings became minimal as in Mary’s case; she reported being so burned out that she did little with her husband at all. As couples participate less together in activities, mutuality is at risk.

Participants indicated having to change how they spend time together. Some modified ways to engage in activities they previously did, but were restricted space-wise. Barbara and her husband had spent years going on birdwatching trips; the only birdwatching they currently do is looking out of their backyard window. Many participants missed attending church together as an important component of their mutual spiritual connection. This held importance to each as individuals and to their joint connection to the universe and their shared community. Most spoke about missing the sacred space of the church and being there together – a space that was holy for each of them.

Due to cognitive, behavioural, and social changes in advanced PD, there is decreased ability to engage in active conversation, especially in a group setting; socialising with friends becomes increasingly difficult. Because of problems leaving the house,

couples often find themselves isolated from their friends with limited meaningful and shared socialising. Participants spoke about their changes in socialising. Some were disappointed in having to socialise only in their own residence:

*“...we very seldom have friends in...we are in a bible study group together and they meet here in the winter which makes it easier for us...I will take him down and we play (bridge) in the party room and he sits in the TV lounge and reads...” (Susan)*

Susan acknowledged that playing bridge with friends downstairs in the party room was a reasonable adjustment, but she disliked appearing like the “babysitter” for her husband, implying their relationship is no longer an equal one; this was problematic for both partners as they felt resentment toward each other.

Due to the many challenges arising from going out, staying home became the logical, but not necessarily desired, choice. Most of the participants recognised this as their reality. Sam, like others, talked about planning to go out but their plans were often thwarted and failed. Despite the desire to go somewhere, PD symptoms often interfered, creating confinement within the walls of their home with life almost closing down for them as a result and resentment building. Most participants said they want to go out and admitted a change of scenery and a new activity would also be nice for their PD partner, but leaving home posed more challenges than they could handle. Fatima said taking her husband out was difficult but important; she learned to be selective about the best type of outing for him.

The need to plan was important for most participants. Not only did they need to carefully plan simple outings, but most spoke about retirement ideas they had planned together that could no longer be realised. The changed shared space also

affected the shared hopes of mutuality. After working a lifetime, with dreams for retirement years, life became sedentary and unstimulating with travel an impossible hope. All the participants were retired having dreamed of exploring the world together:

*“I sit and dream about wouldn’t it be nice to go here or there...We had planned our retirement...we were going back to Hawaii... to go back to New Orleans; I wanted to do some other countries.” (Barbara)*

This dream was dashed; moreover, some had to assume a role they loathed. Making plans had become futile as they could not count on plans to materialise on a daily basis or in the future, often inciting anger and a decrease in mutuality between the partners.

### **5.1.3 Feeling trapped at home**

Home is ideally a sanctuary, but when a balance between staying home and going out is nonexistent, a sense of feeling trapped may ensue. Some participants indicated they did not appreciate being home and resented feeling trapped, sharing little together. Mary also spoke of feeling unsafe in her home because of her husband’s unpredictable behaviour due to dementia from PD:

*“If I’m alone with him, I don’t go on the balcony...I don’t want to be pushed off the balcony...I go out on the balcony either when he is asleep or when somebody is there”. (Mary)*

She expressed feeling trapped both inside and outside their home; the balcony was the only space that might provide her some ‘freedom’ but became a danger for her if they were there together. While others did not articulate feeling unsafe, many expressed frustration at being restricted to home. Barbara felt like a prisoner in her

home, saying she felt like she was “*in prison here without bars*”, longing to get out and have ordinary experiences she had once enjoyed.

A common component of feeling trapped for participants was diminished social life.

Outings with friends became difficult to arrange:

*“...I miss my friends. I’ve often said to X ‘I wish I could go into the city and take a bit of time and see some old friends or go back to some old familiar parts of the city that I like...but I guess I’m dreaming. I’m stuck with what I have. When he could drive a car, periodically we would take a day and go into the city, pack a lunch and go to different parts of the city.” (Barbara)*

Caring for a spouse with advanced PD generated negative feelings about the enforced quieter and limited lifestyle. If participants could go out, it often meant doing so on their own and not as a couple. Craig was frustrated because he could not go to the gym, and Natalie expressed disappointment at moving from an athletic life to a more sedentary one. Larry said he could not go out alone to socialise knowing his wife was crying at home without him. He expressed desperation at realising his life no longer offered enjoyment with her:

*“What I do now is not participate in any social events by myself. I feel kind of guilty if I go somewhere to enjoy an evening and she is crying at home. That makes me feel bad. I don’t go anywhere except in the evenings...while she is sleeping. But if I had to go to a dinner or dancing or a picnic or somewhere, no I wouldn’t go.” (Larry)*

Some PD partners attended day programs, but caregivers felt they must be home when their spouse returned in mid-afternoon. They experienced a lack of an active lifestyle together and feeling tied to the house because they could not leave their PD partner alone, and deprived of activities important to them as individuals as well. This need to be at home was for some like being a parent to children coming home



after school. Such restrictions easily contribute to a sense of entrapment with accompanying resentment and low mutuality.

## **5.2 *Temporality themes***

Lived time, temporality, entails subjective time that links us to the past, present, and future (Linschoten, 1953, van Manen, 1990). In a progressive illness, time is compared between how life was before and after the diagnosis, before and after the illness became classified as advanced, and in daily life. Five themes of temporality were identified: before and after PD became advanced; acceptance over time by the caregiving spouse; daily experience; negative self-regard over time; most time is spent together now.

### **5.2.1 Before and after PD became advanced**

PD and changes in the marital relationship over time result in modifications to how a couple relates and shares experiences. Couples encounter multiple losses that impact mutuality. Opportunities for shared experiences wane and spending time together may be less pleasurable as the partner with advanced PD can look progressively different, speak less, and demonstrate apathy, behavioural changes, and cognitive dysfunction. The difference between before and after PD became advanced are highlighted here for three selected participants:

**Craig**

**Before**

*"We would go out on weekends to visit friends all over the place or family or whatever."*

*"I can show you pictures of the holidays we've had together with our friends at the beach and she's taking the sun and we would be dancing under the palms..."*

**After**

*"What do we do? Watch TV. We both read the papers together in the mornings here. We both watch the news; we're both big news fans. Her attention to focus is not 100 percent, like she cannot sit down and watch a movie because she can't concentrate."*

**Natalie**

**Before**

*"...it was kayaking, it was bicycling, it was hiking, very active physically; it was philosophical; it was political....discussing and reviewing. We have been very engaged citizens ... with the neighbourhood ... Sometimes we went to concerts; we went to theatres."*

**After**

*"Together now we do go for a walk every day. All of the meals are together...and going to the movies or concerts or activities but to a large extent the relationship now is one of pretty well dependence on his part, on me...we have always had very active political, philosophical, cultural discussions and we didn't always agree but right now to a large extent ... he cannot keep... two thoughts in his mind at the same time."*

**Mary**

**Before**

*"The real Bill I knew was a very kind person that used to help people, but I don't see him [now]...we used to work around the house and we went on holidays."*

**After**

*"I can't remember the way it used to be; I just remember how it is now and it has taken over. When you see the Bill that I have to deal with, it's unreal...what's the point of missing [the good times]; they're gone. I see this person here; there is no point thinking about it. You just have to move on so I've moved on."*

These couplets express significant lifestyle changes as PD progressed. Craig lamented lost romantic times with his wife, who has reduced vitality. Natalie longed for the political and community involvement that had once been fulfilling for both of them; as very engaged individuals their involvement in decisions affecting municipal matters had been stimulating. In fact, not always agreeing with her husband was exciting for her and this was lost. Mary described personality changes that transformed her husband from a once considerate individual to someone she no longer enjoyed being with because PD has “taken over”. After many disappointments, she gave up trying to even remember what had once attracted her to him. She indicated she was exhausted and no longer interested in caring for her husband, who she resented and felt no affection for. Disappointment in how their “golden years” turned out is a struggle:

*“I’m tired. I don’t want to spend the rest of my life doing what I’m doing... I just can’t take it anymore.” (Mary)*

Her statement sadly expressed that time is precious, and her expectation for retirement was not to be a caregiver to someone she no longer cared for. Such loss of shared experiences carries the risk of each partner becoming a loner in their relationship. This lost feeling of togetherness was grieved by all the participants. Mary said there was no use in remembering what life had once been like; those days were long gone.

As PD advances and life becomes duller, mutuality can be deeply affected with enforced lifestyle changes for the caregiving partner. Several demonstrated anger that over the years PD has dramatically changed them as a couple:

*“Oh we do not resemble ourselves to how we used to live; how we used to be until now. Now we look like a couple of deadbeats that are always home and we are like a couple of recluses. But that is not who we are but this illness has ground us to a halt...this has ruined our lives, my life, his life...” (Barbara)*

Although couples prepare to grow old together, and expect some illness as they age over time, most participants did not expect this degree of change. Some were more accepting, such as Fatima who said upon reflecting about the passage of time, *“everybody has to get old”*.

### **5.2.2 Acceptance over time does not occur for all**

PD is all encompassing as it progresses, often taking a spouse by surprise; Jim shared his initial lack of preparedness for “this kind of disease”. With the passage of time and years of caring for his wife with advanced PD, he is worn out and admitted feeling dissatisfied. Caregiving partners’ eventual acceptance of their partner’s physical, emotional, and spiritual changes may be accompanied by resentment and a decline in mutuality. Acceptance however, does not imply satisfaction. In time, the caregiving partner recognises that some dreams will not be realised, but acceptance of the present situation is not easy for most. Some participants accepted that life is different with their spouse and tried to make the best of *“dealing with the cards”* (Ann) they were presented.

Recognising that lifestyle changes as PD progresses brings disappointments for caregivers. Natalie tried to change her husband until eventually realising that she had to accept his medical status and the changes that impacted both of them:

*“...I made the decision there is no use my trying to change him. I still try from time to time, but in this partnership, the only person that can be changed is me...” (Natalie)*

This acceptance was a loss that Natalie initially resented, until she became aware that she must find fulfillment in different ways with her husband and for herself.

Conversely, Mary indicated that she did not enjoy her relationship with her husband any longer, and was tired of caring for him; she looked to the future when he will be well cared for in a pleasant nursing home, but would not commit to being his caregiver forever, thus limiting the time which she is willing to be committed at all. In her case, PD significantly contributed to the breakdown of the marriage.

### **5.2.3 The daily experience**

Daily life affects time spent together and ultimately, experiences of mutuality. Caring for a person with advanced PD entails monitoring medications, attending medical appointments, physical care, and dealing with daily behavioural fluctuations. Sam tearfully spoke about his wife continually being different as she expresses anger toward him one moment and then forgets what she said. Such unpredictability requires dealing with one day at a time and prevents planning ahead. After spending many years running a business together, he was sad to see these changes in a woman who was once so astute in business affairs. Similarly, Susan said before her husband's PD became advanced, that he had run a company but can no longer do so as he is dependent on her almost all the time for everything, emphasising the dramatic changes over time.

Nights are often difficult due to the PD partner's medications, incontinence, and poor sleeping patterns, requiring the caregiving spouse to be awakened frequently to care for their PD partner, often resulting in little sleep and exhaustion the next day.

*"Last night he woke me up at one-thirty. I got up, changed him, and I couldn't go back to sleep...from one-thirty to four-thirty I didn't sleep." (Elizabeth)*

For many participants, exhaustion resulted in increased anger toward their spouse, who deprived them of sleep.

For many, the days often have little variety with the caregiving spouse spending much time alone as the PD partner sleeps more. Some mentioned knowing the time of day or night when the OFF syndrome became more obvious and communication or activities were minimal. This varied for each person with PD, but for each caregiver, there were lonely periods of time. With significant changes in movement, cognition, and social engagement over the years, activities become more challenging and almost nonexistent, and many days had few pleasant activities to do together. Ann mourned the loss of stimulation she and her husband have experienced as their level of activity decreased to virtually none over the last several years.

As couples spend more necessary time together but speak less, the days become long and the partners become distanced from each other. On the other hand, some said they needed time to themselves when they did not feel like a resentful caregiver rather than an equal partner in their relationship. The steady decline in communication between partners over time contributes to the decrease in mutuality in advanced PD. Natalie spoke of a creative approach to providing herself with meaningful segments of the day:

*“...I have been much more proactive ... I have a sign that I put up and he doesn't interrupt...that's my time and I put the sign up there ... And the rest of the time is devoted to him”. (Natalie)*

Natalie indicated her need for balance between time for herself and time for caregiving, something often overlooked by caregivers and others; this can be a source of resentment as most participants indicated they must be active caregivers for the bulk of their day.

#### **5.2.4 Negative self-regard over time**

Participants needed to reinterpret themselves as the caregiving experience intensified over time with PD progression. Conflict can arise as each partner deals with impatience, sadness, and anger, contributing to feelings of isolation. Coupled with inequality in the relationship, a change in self-identity may take place. Many participants expressed negative self-regard as they reflected on their relationship with their PD partner. Most were aware that years of caregiving influenced how they currently viewed themselves as a partner in the relationship.

Various aspects of negative self-regard were experienced. It is not unusual for caregivers to feel frustrated and intolerant due to the many demands on them. Recognition of negative behaviour and feeling sorry about it was a common theme. Several participants, including Craig, felt bad about being impatient because of their spouse's slow response and/or movements. Barbara admitted to having a short fuse and being easily irritated; the years of coping with her husband's declining condition made her recognize that she has changed and not to her liking:

*“...I'm more short tempered; I'm more irritable. I was never big on patience but I have none at all. I have no patience. I'm irritable, I'm grouchy, and I'm snarky” (Barbara)*

Changes over the years made some caregivers hard on themselves, and they saw themselves as unlikeable because of their behaviour. Elizabeth felt bad about screaming at her husband because he did not listen otherwise; this was a marked personality change for him that she had not seen in her husband in their earlier married years. Natalie admitted that since the PD became advanced she resented both the PD and her husband for the changes in their relationship, until she accepted she could not continue this way and said she had to be the one to change. Mary wondered how others might judge her because of how her negative attitude had materialised over several years, while Jim judged himself concerning his dissatisfaction with his life and his marital relationship that was so very different from what it had been years ago:

*“...sometimes I feel dissatisfied but I try again to be on the right way and say it’s wrong. I should be patient...” (Jim)*

He articulated a self-admonishment that he “should” be patient and behave in the “right way”. Many participants confessed to negative feelings toward themselves, saying their marital relationship no longer offered equal partnership. The imbalance of one partner being dependent on the other changed the dynamic for many, and mutuality took a nosedive due to negative feelings toward both the PD partner and self. Years of living with PD and especially advanced illness brought changes to their relationship that for many were unpleasant and unanticipated in their earlier marital experience. The years of being a caregiving spouse took its toll on many participants as they experienced a relationship focused on the illness of the PD partner, creating a relationship that lacked equity and sharing, running the risk of eroding the self-



esteem of the caregiver who may feel less important or invisible. This is yet one more pressure to contend with that erodes mutuality.

### **5.2.5 Most time is spent together now**

Time was a luxury that often seemed elusive to the participants. Personal time was challenging for most because their spouse could not be left alone for long if at all, and caregiving was all encompassing of their time. This resulted in little attention to oneself, often with accompanying antipathy, as they wondered if they mattered any longer in the relationship:

*"I don't have time to be me. Me doesn't exist; I'm not even on the page; I'm not even in the book because in my opinion, other things take priority. He takes the biggest priority." (Barbara)*

Juggling time is necessary to maintain a household and be a caregiver. Robert went out only when the home care nurse was there which provided only two hours to accomplish errands. Any mutually enjoyed time they once had together became necessary to provide care or to be in the house for safety purposes. Due to difficulties in going out, couples are forced to spend almost all their time together as Fatima said:

*"I'm with him twenty-four hours a day."(Fatima)*

Although Fatima accepted this, many echoed these exact words with resentment. Personal time had become a precious commodity. Most participants were tired and unstimulated and expressed the worry that time was marching on but their lives remained stagnant:

*"I'm old now. I don't know when I will get sick" (Fatima)*

Many of the PD partners experienced apathy, which hindered the expression of appreciation for the time their partner spent providing care for them:

*“He just sits in a chair, looks asleep, and has nothing to say, and just sits slumped in a chair...he never compliments.” (Barbara)*

This lack of expressed appreciation contributes to a decline in mutuality.

### **5.3 Corporeality Themes**

Corporeality concerns one’s lived experience by feeling the world through the senses, movement, and awareness of one’s body (van Manen, 1990, Wilson, 2014).

Corporeality in this study focuses on that of the caregiving spouse rather than the person with PD. Mutuality experienced by caregiving spouses has been interpreted through data they provided about their body and sensory and sensual perceptions in response to their PD partner.

#### **5.3.1 Awareness of one’s own physical limitations**

Due to older caregivers’ physical changes, mutually satisfying shared activities with PD partners become more difficult because of their own age related limitations as well. Most participants also expressed concern that caring for their spouse takes a serious toll on them:

*“My body is falling apart...I’m also aging so I think the stress is having an impact... I’m starting to see what it does to my body.”(Susan)*

In addition to Susan’s concern, echoed by almost everyone, many were apprehensive concerning how long they will be in good enough health to care for their spouse.

Sam, 86, and Fatima, 66, both recognized the need to consider future caregiving limitations. After a lifetime of marriage, they expressed devotion to their spouse but had not anticipated functioning as a “nurse.” Many participants envisioned

retirement as something different from being worn out. Robert said retirement is “supposed to be a little bit more relaxing.”

Caregivers for a partner with advanced PD are pulled in many directions balancing caregiving, a household, and self-care. Barbara said her body is physically exhausted; when she finally relaxes, she is disappointingly alone late at night and exhausted. She wants to watch a movie with her husband, but knows he cannot follow the story line; moreover, he would have already gone to bed. She added that her own appearance is less than ideal because of minimal time to care for herself:

*“...I don’t have time. My nails look like the rats have been chewing them .... My hands are always in water... I don’t bother even putting nail polish on my own nails. I figure what for - they are so unsightly so I try to hide my hands, and then as far as my hair is concerned...” (Barbara)*

Barbara lost her desire to be pampered, even saying it is worthless since she receives no compliments from her husband, contributing to her experience of low mutuality.

### **5.3.2 Sensory and sensual responses affecting mutuality**

The sensory experience of participants not hearing their partner’s voice due to the loss of ability to speak, seeing their partner decline, smelling bodily odours such as urine due to incontinence, or issues with touch all contribute to changes in mutuality. Furthermore, decreased sensuality in and a perceived lack of desire from the partner can contribute to declining mutuality.

Many participants struggled with their partner’s inability to communicate and their own adaptation to the silence. Not hearing their partner speak and living with such silence can be disheartening to a caregiver. Their partner is physically present, yet

conversations become one-sided; some felt isolated due to both the silence and the basic level of conversation that does occur:

*“It is more and more silent time...we have a lot of quiet time ...the loss of his partnership in the daily conversations...we do have conversations but often they are so pedestrian.”(Natalie)*

Natalie, who had experienced stimulating times with her husband, was dismayed by the simple conversations they now had, no longer debating political and philosophical points of view. Larry expressed his sadness about not having conversations anymore with his wife; this was even more difficult than the loss of their sexual relationship. For him, it was their connection through dialogue that brought meaning to their relationship; sharing this poignant loss brought up sadness for him because he had lost both the verbal and physical intimacy of their once close marital relationship.

Almost all participants felt frustration about not understanding when their PD partner spoke: a reminder that the illness has changed the spouse quite dramatically:

*“... she would be telling me something and all I would get is something out of the middle of the sentence and try to get the tail end ...and I still didn't know what it was and then she would say 'well, I don't remember'... it is extremely difficult because you don't know what she wants and she's not able to put anything together...” (Robert)*

Robert's story highlights two important issues concerning mutuality: he often does not understand what his wife is telling him, and he cannot share her experience, making this yet another example of lost sensory connection. Some participants mentioned forgetting what their spouse's voice sounded like; this was a sad indication of one of the many losses experienced in PD.

Lack of predictability creates tension in a relationship where the caregiver is taken by surprise. Craig explained the frustratingly unpredictable moments when in the middle of a conversation, his wife is suddenly unable to proceed, bringing things to a halt as he waits for her to respond to a statement; sometimes there is no response at all. However, verbosity can also be a problem as indicated by Mary, who said her husband's incessant chattering contributes to the conflict between them. This is a more unusual situation with advanced PD, but Mary said that hearing her husband's incessant speaking, which often makes no sense, creates distress for her.

For caregiving partners, seeing the visual evidence of their partner's deteriorating physical condition is disheartening. Living with somebody who is declining influences how caregiving spouses observe their PD partner:

*"...when she's in a mood where she is slow – I don't want to use the word retarded ... I can't believe it that this is happening to her ...because she was a very, very intelligent woman..." (Craig)*

Craig was aware that his wife seemed different from the intelligent woman who now appears drastically changed. He realised that in his struggle to see how different she is, he may be judging her. As caregiving spouses observe the changed physical appearance of their PD partner, some reported not wanting to be seen with them in public places, thereby threatening their mutuality. Ann wanted to see her husband have a sense of pride in looking good and well groomed, but was annoyed at changing his clothing multiple times daily; feeling annoyed with one's partner is another risk to the integrity of their mutuality. In discussing coping skills, Sam said simply closing his eyes and not seeing how his wife has changed helps him on some days. Sometimes, seeing is too much as Mary said:

*“He tires himself out and he mentally tires me out. So I am mentally exhausted watching him.” (Mary)*

Mary was no longer interested in or able to handle her husband to the extent that just watching him exhausted her. She said a mutual relationship no longer exists for them.

Caregiving spouses often take the lead for their spouse as they watch and record outcomes. Natalie accompanied her husband to a physiotherapist, who gave him exercises that would assist him, only for him to not bother practicing:

*“I said ‘I haven’t seen you practice the exercises’ and he said ‘what I am really angry about is that she never gave us any homework’ and I pretty well hit the roof...we went through all of that and he had forgotten.”*

Despite Natalie’s attempt to assist her husband, his lack of comprehension at times required her to withdraw for a period of time, frustrated, and not wanting to be the one to lead. Susan worried about seeing her husband unsteady on his feet; she must have a keen eye watching out for him at all times and be on high alert to prevent falls. She said this continuous vigilance contributes to her resentment, making this another aspect of caregiving that is aggravating for her.

PD can cause changes in social behaviours that are not acceptable. Advanced PD is usually accompanied by incontinence. This affected how many participants felt toward their spouse:

*“...he doesn’t do what I want him to do. So he has to get out of bed to go to the washroom and ... have his medication. He pees on the hall carpet at six o’clock in the morning. I have to clean up; there are stains, there is smell. Do you know how many times I have to clean it – sometimes four or five times to get the smell away? “(Mary)*

Mary was concerned about accusations of damage to the communal space where they live. Not only does she resent having to clean up, but she must deal with the smell of urine in her home; this was repulsive to her, contributing to her frustration and exhaustion and already existent resentment toward her husband. Elizabeth's husband cannot feel the need to urinate; she must be intuitive about his needs with her sense of touch. His incontinence and inability to feel when he is wet requires her to judge when he needs changing: an unpleasant event for her as she has to place her hand in his diaper to determine this.

Touch was usually expressed with reference to caregiving and not to intimate touch:

*"Sometimes five times a night I must take her out of bed and she is losing strength completely like a potato bag." (Sam)*

Sam referred to the difficulty of moving his wife; she is like a dead weight and feels limp to him; gone is any sensuality he had once felt with her. The loss of sensual touch was articulated by some participants who said having sexual intercourse is no longer feasible due to the loss of erectile function and the need for an indwelling urinary catheter. The ability to have sexual intercourse is virtually nonexistent in advanced PD, contributing to loss in mutuality between partners due to the loss of sensual connection. For some caregiving spouses, loss of physical intimacy can feel like decreased love from the PD partner, contributing to rejection and sadness.

Some caregiving spouses experience painful injury while providing care, or worry that physical injury may occur due to either the effort needed to move the person with PD or confusion or dementia that accompanies advanced PD. Mary experienced such pain when her husband grabbed her arm:

*“...it’s a brace so if he sees this on my hand he doesn’t act up...he squeezes my hand so that I’m in pain...so any time I go to help him, I have the brace on...I had to take physio.”(Mary)*

Her husband’s PD dementia has caused her physical harm, resulting in decreased affection for him. Susan expressed concern about how she would manage in the event of an incident with her husband, who towers over her. While Susan had not yet been injured, she is on “high alert” because she worries about not being able to assist her husband if he falls. As a result, they both resent her continually watching him.

The caregiver’s sense of taste was not explicitly affected as the other four senses were. However, taste is tied to eating, which is a component of mutuality very much affected by PD, as partners cannot share and enjoy meals. Eating becomes challenging and meals may not be shared due to distaste of food that must be pureed or fed to the PD partner. The PD partner’s lack of interest in eating and increased apathy concerning compliments and appreciation of cooked meals can lead to disappointment and resentment for the caregiver. Elizabeth once enjoyed cooking for her husband and sharing special home cooked meals together. Despite how much pleasure she used to derive from cooking, the many demands of her husband’s care and her exhaustion have eliminated such fulfillment. Sharing a beautiful meal with him hardly happens due to his swallowing challenges, thus his physical impairment impacts her sensory enjoyment of something that was once special for both of them.



## **6 Results**

### **6.1 Relationality Themes**

Relationality, or lived other, is van Manen's approach to understanding how relationships are created and experienced. Marital partners share significant individual contributions and interactions. Humans also use relationality in an existential context in their relationship with God (van Manen, 1990). Relationality is the most complex of the four existentials in this study relating to mutuality. Spatiality and temporality can be expressed in somewhat measurable units (space and time) and corporeality can be described in terms of physicality; relationality is less tangible focusing on personal emotions.

Seven relationality themes influencing mutuality were identified: 1) the challenge of finding enjoyment in each other; 2) activities shared together now are very dull; 3) the PD partner has become like a child; 4) impact of PD on the marital relationship; 5) the wish to recreate the past; 6) relationality with God; 7) love. Some overlap with the other existentials is seen; relationality permeates the other existentials and it is in this chapter that the issues are brought together.

#### **6.1.1 The challenge of finding enjoyment in each other**

Most participants found engaging their spouse in previously enjoyed activities was difficult. At a time when the partners expected to have fun in their retirement years together, their spouse appeared to be a stranger due to clinical and cognitive changes. Caring for a person with profound physical limitations often brings substantial disappointment as the simplest of activities and fulfillment of dreams are difficult. Notwithstanding, some couples continue to enjoy their relationship relative to the activities in which they can participate. For most, this means sedentary

schedules involving reminiscing, spending joint time with family, and watching television. Participants pondered whether they enjoyed spending time with their spouse. The complexities of caregiving and meaningful time together not impeded by PD made this question difficult. Participants articulated frustration with the difficulties of going out, minimal socialising, and focusing on the illness most of the time. When Natalie was asked if she enjoyed spending time with her husband, she said:

*“No, not very much...he has to concentrate on one action at the time. We cannot have a conversation when we walk because he has to concentrate on actually walking...sometimes we went to concerts, to theatres...the last time we went we had to leave because he was just in a panic.” (Natalie)*

Many said they wished for past activities before PD interfered in their lives; they got along better with their spouse when they did not have to be caregivers or go to medical appointments that aggravated frustration levels and contributed to decreases in mutuality. Many resented their spouse when they heard complaints, dealt with unstimulating interaction, or grieved the partner’s former personality. Susan felt torn between her husband’s slowness and wanting to be with him. She admitted she enjoyed his company only when he was well and when caregiving was not the focus. Ann enjoyed time with her husband conditionally because his tremors and slowness frustrated her. This occurred despite understanding this as symptoms of his illness. Natalie said spending time together is *“hard work,”* having lost stimulating conversations to those that were now *“so pedestrian”*. Stress and disappointment, often resulting in resentment and decreased mutuality accompanied such changes.

Barbara admitted to not enjoying the company of the changed person her husband had become:

*“Yes ... when the old Max - not aged old Max but the Max I used to know - comes back and I enjoy that, but the Parkinson Max frankly, I don’t like.”  
(Barbara)*

Although there were moments that Barbara enjoyed with Max, they were not enough. Mary expressed her resentment toward her husband with PD-related dementia that destroyed their partnership, creating an unpleasant nurse/patient relationship.

Participants struggled to enjoy time spent with a partner so changed as seen in the couplets in the temporality section. That person had been someone with whom they shared dreams and life experiences; life now offered little fulfillment of those dreams and was dull. Such dullness and changes in relating to each other brought decline in mutuality for many as they shared little and found time together lost meaning as seen in the following theme.

### **6.1.2 Activities shared together now are very dull**

Mutual activities for most couples living with degenerative illness become minimal as interaction lessens, creating shared times that are silent or illness oriented; mutuality is affected by such changes. Participants reported mundane shared activities with watching television as the most common one. However, many of the PD partners could not follow the story line of a television show and caregivers found it tedious simply watching and not sharing in discussion about the show. Some participants did practically nothing together. Ann longed for something interesting to do together; life became empty as a cruel illness interfered:

*“Now nothing much really...It would be nice if he could for example, play crokinole.” (Ann)*

For many participants, occasional outings were usually limited to medical appointments. Few couples went on other outings together or engaged in meaningful conversations thereby risking a steady decline in mutuality. As stated in other existentials, caregivers usually found themselves at home, struggling with a changed relationship because of PD. Larry sadly described sitting next to his non-communicative wife:

*“Every morning I spend two hours ... sitting side by side. I just sit; sometimes I fall asleep; sometimes she falls asleep.” (Larry)*

Larry understood the trajectory of PD but was saddened by the life changes imposed by PD. The quietness of their relationship made him continually miss vibrant times they once had. He could only experience such happy times in memory due to her lack of communication.

Participants articulated their relationships as complex, sometimes resulting in a “love/hate relationship” usually with few fun activities. Several participants said fun with their spouse is hardly imaginable while others talked of past fun experiences. Whereas Mary said, “no, none whatsoever”, others considered ordinary conversations about their children or grandchildren as fun. Robert tried maintaining his sense of humour, trying to understand his wife who struggled with being unable to speak clearly and then forgetting what she wanted to say; they laughed together over this. Others, however, indicated that fun barely existed any longer:

*“Not much anymore. His sense of humour is pretty well shot in terms of laughing about something. Our fun together was kayaking; it was bicycling; it was philosophical; it was political... those were really fun times.” (Natalie)*

Natalie found the loss of shared intellectual engagement previously enjoyed to be very painful; she grieved such losses. Mutuality can diminish when levity disappears in a relationship. For some, fun was merely a temporary relief from difficult times; fun was a concept that was lost. Sam said life was so challenging that fun was simply a moment without complaints. Several participants could not think of activities with their PD partner that constitute fun; as Susan said, *“fun is a bit of a stretch.”*

### **6.1.3 The PD partner has become like a child**

With dependence comes a tendency to treat the PD partner in a childlike way. This change in how partners relate to each other leads to a relationship that lacks equality, intimacy, and maturity. Marriage became a new kind of parenting experience. Craig described a bedtime ritual similar to a child learning the skill of not bedwetting. Whereas children eventually acquire this skill, caregivers despair that it will worsen as PD advances. This increases stress for the caregiver and humiliation for the PD partner. Some caregivers become possessive: Ann described watching over visiting nurses due to her husband’s vulnerability and inability to speak for himself. She felt compelled to treat her husband’s care similar to caring for children, taking responsibility for him.

Several participants articulated resentment for what PD has done to their relationship and harbored resentment toward their spouse who needed constant supervision. Natalie and Barbara both shared their frustration of coping with childlike behaviour:

*“He is like a toddler but with a toddler you say ‘go in the playpen’.... You can’t say that and he forgets anyway...”(Natalie)*

Natalie expressed a lack of patience for her husband, an older individual who was often childlike. While she was accepting of such behaviour in a child, she was embittered about her husband's similar conduct knowing she could not "contain" him as one could with a child in a playpen. Because of the inability to change behaviours, anger and resentment ensue for caregivers. Expressing a different emotion, Larry said he kisses his wife as he would kiss a baby: no longer with passion, but sorrowfully accepting the changes:

*"Yes, sometimes I kiss, yes, just like you would kiss your baby. You understand it is not a love kiss." (Larry)*

#### **6.1.4 The wish to recreate the past**

The couplets in the temporality existential show participants' expressions of sadness about PD progression robbing them of opportunities to enjoy life together as previously. Many spoke proudly about their spouse's accomplishments including recognition of their spouse as a published author, a working partner in a shared business, joint volunteer community work, and their spouse as an attentive parent. Some reflected on their spouse's kindness and dedication to others in their healthier times. Such pride was bittersweet as these accomplishments became lost other than in memory. As participants grieved those events, most wished these times could still occur. Partners' pride in each other strongly reinforces mutuality, as seen in Robert's comment:

*"...she was an avid writer at one point. Yes, she has been published ...she did win a prize. She was a runner up in the Stephen Leacock Short Stories."(Robert)*

Robert lamented the loss of his wife's ability to write recalling the person she had once been, and with whom he had shared such success; this had contributed to their earlier mutuality.

Several participants referred to their "take charge" role as significantly affecting how they related to each other within the context of advanced illness. Susan wanted her husband to take charge of his life more but he continually depended on her, creating friction between them. Some had attempted to change their spouse into the person he/she used to be to no avail. Encouraging their spouse to be proactive or teach him/her new skills was unsuccessful and disappointing, usually resulting in frustration by both parties and represented yet more loss. Natalie indicated how she tried to change her husband, but there was no use, recognizing that PD stole his ability to achieve past successes. Barbara tried showing her husband how to use the computer, a once simple task for him but his inability was accompanied by frustration and resentment on her part:

*"...I tried to show him how to do things ...I have a husband but there is nobody here." (Barbara)*

Especially poignant in this was Barbara's sadness as she said these were previously everyday skills for him. Each participant who spoke about teaching their spouse skills experienced unsuccessful results and lamented the loss of a component of the personality they had once been attracted to.

### **6.1.5 Impact of PD on the marital relationship**

Participants had a range of feelings concerning how PD affected their relationship with their PD spouse. Craig and Fatima both accepted the negative changes despite

alterations in mutuality, and saw caregiving as their duty as a spouse. Others, however, expressed disappointment at the stranger their spouse had become:

*“I feel the partner, the intellectual, mental partner is not there.” (Natalie)*

Some participants expressed confusion or anger, attempting to make sense of profound and unexpected changes due to advanced PD. Barbara angrily referred to herself as the “sergeant major,” with a resultant power imbalance.

Caregivers must make sense of their new reality after years of marriage. Some PD couples can no longer experience intimacy. Not sleeping in the same bed and losing physical closeness had a strong negative influence on mutuality for some participants:

*“Well I get nothing [sexually] from him...kiss maybe” (Ann)*

For others, constant togetherness contributed to a decrease in mutuality because of the focus on caregiving rather than shared pleasurable time:

*“It’s hard...I’m starting to see some stubbornness which I don’t blame him for because I’ve become the nag, really. No matter how you sugar coat it, they can call it cueing all they like. When we have to get to an appointment and he still hasn’t done his exercise...he falls asleep. It takes him two hours to get ready. (Susan)*

Both situations contributed to the caregiver feeling their relationship had changed dramatically, with life not materialising as they had intended.

When daily life entails caregiving, housework, and running a household, caregivers feel stretched. Several resented losing shared household responsibility. The combination of handling all household requirements, nominal communication, and



minimal intimacy can lead to resentment. Attention is focused on what must be done rather than on the relationship:

*“Chief cook and bottle washer; I do everything.” (Robert)*

Some were overwhelmed by the demands and their anger was at times directed at their spouse, creating added pressure and relationship strain.

Most participants recognised the disease as the culprit of their strained relationship. Although understanding their partner’s physical limitations on an intellectual level, living with isolation, apathy, increased dependence, and minimal communication created annoyance and decreased mutuality. Ann struggled with her husband’s tremors, and became irritated despite a solid understanding of PD:

*“...sometimes he can’t cooperate... it’s a physical thing... he’ll start scissoring with his hands and arms and legs ... it can be very frustrating...” (Ann)*

Mary expressed having no feelings of affection toward her husband, despite knowing his dementia is due to PD. Larry described their relationship as one-sided without responses from his wife except for an occasional smile yet he articulated deep devotion and love for her; decreased mutuality is mingled with sadness and isolation:

*“...it’s a different kind of love. It’s not love to make love; it’s love for compassion, humanitarian love. I don’t know; I don’t have the right words.” (Larry)*

Feelings of resentment, sadness, and disappointment contribute to already declining mutuality as the caregiver experiences a “pressure cooker” situation, knowing the PD will become progressively worse.

Caregiving spouses often struggle to see their spouse's appreciation of them. A vicious cycle of resentment can result, seriously affecting mutuality as the PD partner provides little verbal acknowledgment and the caregiving partner feels invisible.

Expressions of intimacy between marital partners include sexual relations as well as feelings of affection. As discussed in the corporeality section, none of the couples have sexual intercourse any longer. Moreover, decreased mutuality in a strained relationship can affect the expression of affection. Some said they hugged and kissed or just held hands with their partner. Several said they did not miss having a sexual relationship as they were exhausted most of the time; among the men, Robert and Jim rationalised: Robert's wife had a catheter so they had only occasional hugs and kisses. Jim said his spiritual discovery became more meaningful than physical intimacy:

*"No, not anymore...we are both satisfied...once you discover the spiritual life you feel that it is something great...we both don't feel anymore about that (intimacy)." (Jim)*

While some did not miss a sexual relationship, participants of both sexes were saddened at the lessened expressions of intimacy. With sexual intercourse absent, lack of intimate physical contact can be a serious threat to already reduced mutuality. Whether lack of intimacy occurred as a result of a strained relationship, or the strained relationship was caused by a lack of intimacy can be complicated and confusing. As Mary said:

*"I had a hard time buying a birthday card or Christmas card because half the things in the cards don't relate to how I feel." (Mary)*

### 6.1.6 Relationality with God

Some people search for meaning, connection, and a sense of purpose in relationality with God (van Manen, 1990). Eleven of the twelve participants stressed the importance of God and/or spirituality in both their spousal relationship and individually. For some, relationality with God helped them to cope with the pressures of caregiving. Some were active in their faith community: for Fatima, a devout Muslim, and Jim, a devout Christian, their religion presented a supportive framework for coping:

*“We are Muslims so I have to do my study, Holy Koran and pray most of the time...Muslim peace... yes, a very strong faith...I believe if your husband is happy and when he is sick and when he needs you, if you take care of him, God will send you to heaven ...” (Fatima)*

Fatima’s faith grounded her. Despite the difficulties, she accepted her husband’s advanced illness and saw caring for him as a privilege. PD interfered with their life but sharing simpler activities, such as talking together about their grandchildren, helped to strengthen their mutuality. Mary’s spirituality focused on going to church, which offered a respite from her husband.

Many indicated that church is about both connection to others and having a transcendent relationship with God. Most expressed sadness at being unable to attend religious services and be with their community, or share spiritual experiences with their spouse. Larry and Jim brought rituals into their home for shared meaningful observances:

*“I talk to her in the morning for the morning prayer... I say ‘it’s you, me, and Jesus.” (Larry)*

*“I go [to church] every Sunday... I bring her communion (Jim)*

They were each able to find a way to create a shared religious experience that could bring spiritual fulfillment to both; for these couples, this helped to bolster mutuality.

### **6.1.7 Love**

Love can be fragile and possibly lost when life situations become challenging; illness can be the cause. Most participants thought hard about how to describe their love for their PD partner. Teasing out the strands of love, responsibility, resentment, isolation, and pity resulted in heart-rending responses. Some participants articulated feeling pity mixed with love for their spouse, while others questioned whether they love their partner any longer; others thought out loud:

*“Oh that is a big question because it is a love very pinched with sadness and pity. And I can say whenever I feel sorry for myself I kind of say ‘if this is so hard for me, think about how much harder it is for him’. And so it kind of recalibrates my feelings for him.” (Natalie)*

Natalie resented losing once exciting and stimulating activities, but admitted that wondering how hard PD is for him, imagining herself in his position, made her realise that she did still feel love for him.

Some considered their love through compassion or spirituality. Jim found meaning in his deep faith and connection to others, expressing love for his wife in this context:

*“We are both satisfied...once you try the other way (spiritual), you see you have something different. You have energy in your mind” (Jim)*

Larry’s love for his wife tugged at his heartstrings. He felt sorry for her and for himself at the same time, reflecting on the loss they both experienced. His love for his wife was no longer one of passion but of wellbeing. Although PD had changed her dramatically, he loved her deeply, who had given him so much, and therefore deserved to be loved by him for this. Many participants, notwithstanding their

frustration, echoed this feeling. Others were able to think beyond the current challenges and reflect on the long-term love that sustained them as a couple:

*“...I would say the word is enduring... love is wanting the best for the other person. It’s not about what you can get from it; it’s about what you are together.”(Susan)*

Despite the blurring of feelings, most participants expressed love for their partner that endured. Mary denied feeling affection but ensuring that her husband is always well cared for is the extent of her ‘love’ for him. She expressed commitment only out of duty as his wife; her anger hindered her ability to recognise this as love. Sam, on the other hand, said his wife “filled” his life.

The four existentials highlight the key aspects of mutuality in the marital relationship in advanced PD when one partner is the caregiver. Although they have been presented independently, the four are interdependent and overlap. PD affects all aspects of life, and the lifestyle that couples had once been accustomed to becomes altered. Challenges abound for the participants in this study, and whether they are most challenged by changes in shared space, changes over time, the physical effects of caregiving on their own body, or varying emotional feelings toward their partner with PD, they demonstrated devotion and commitment even while struggling with conflicting emotions toward their PD spouse. Some participants openly shared their resentment and frustration. Nevertheless, when asked about how they would describe the love they felt toward their partner, responses highlighted the reality that love is vulnerable to change but runs deep. Their love may be altered, but despite unexpected changes, their love is for the most part, in Susan’s words, enduring.

## 7 Discussion

Mutuality entails the quality of the relationship that partners share and their care for each other (Tanji et al., 2008). Data about the caregiving spouses' lived experience of mutuality in advanced PD were analysed using the four existentials of spatiality, temporality, corporeality, and relationality. Results showed all four existentials contributing to mutuality. Participants described multiple effects of their partner's PD on their mutuality within the framework of these existentials. The existentials are not mutually exclusive, but overlap, making this approach applicable to studying lived experience.

This study of lived experience shows how caregiving spouses face complex challenges to mutuality in advanced PD: 1) participants expressed a perceived *loss of identity* as the couple they and their partner had once been; 2) many grappled with mixed feelings toward their ill spouse as they struggled with *ambiguous loss* (Boss, 1999); 3) *finding meaning* in their changed mutuality with their spouse was a challenge for many, and 4) *gender differences* were noted in some areas. Each is discussed in relation to mutuality in this chapter.

### 7.1 *Loss of identity as a couple*

#### 7.1.1 PD as a 'couple disease'

The use of the existentials in analysing this data provided insight into the confusion around advanced PD as a caregiving spouse. Since PD does "affect everything", the existentials address four broad areas of lived experience. Whereas most PD studies focus on the patient or the couple, my study focused on the caregiving spouse in relation to the PD partner; whereas other studies ask spouses how they see their

partner, my study concentrated on how they feel toward their ill partner and their mutuality experience specifically. Markus (1977) conducted research on self-identity or self-schemata that he describes as cognitive generalisations influenced by personal social experiences that each person considers about himself/herself that guide and process information related to oneself. The self-schemata organise information into a knowledge structure that helps the individual make choices about personal behavior. People also possess relational schemas resulting from interpersonal interactions (Markus and Kunda, 1986). Acitelli et al. (2002) propose that couple identity is a broader self-schema in which being part of a couple becomes part of an individual's identity and self- concept. Couple identity involves seeing the relationship as a single entity rather than two individuals; that entity becomes a part of oneself (Acitelli et al., 1999). The couple becomes a part of a person's self-concept and identity.

Hodgson et al. (2004) claim PD is a 'couple disease' as both partners feel the chronic impact, compared to a disease with one ill partner and the other watching a quick decline and death. In chronic illness with a long trajectory such as PD, sadness is common when one partner becomes a caregiving spouse because changes in everyday life affect the unique identity they once had as a dyad. This is especially prevalent when cognitive changes occur, and is apparent in published studies of Alzheimer's disease; some studies compare relationships in Alzheimer's and PD couples (Shim et al., 2011, Williamson et al., 2008, Tanji et al., 2008). Results show that when mutuality was high before dementia or increased PD severity, caregivers experienced less sadness, but increasing cognitive impairment in the ill partner influences mutuality as shared memories diminish, interaction lessens, and

behavioural changes occur (Williamson et al., 2008). However, my study results indicate that even when mutuality was reported as high prior to PD, couple identity suffered and caregivers expressed profound sadness. My study focused on advanced illness with older participants who had long marriages, creating an even greater loss of shared experiences and their distinctiveness as a couple after a lifetime together; the extreme changes were accompanied by melancholy, possibly attributed to their long history and previous depth of mutuality in addition to PD itself. For these couples, PD as a 'couple disease' was real and affected them each in their own way. Contrary to some studies that have considered the current couple relationship, I asked participants how being a caregiving spouse has changed them as individuals. Responses included negative self-regard and sadness for many; others found strength in spirituality and religion; some acknowledged their role as secondary to that of their partner and how invisible they feel the way society treats them. Many spoke about feeling bad about how they spoke to their PD partner at times due to their frustration and lack of support. These responses indicate a strong need for spousal support in advanced PD.

van Manen says individuals come to know each other and themselves through relationality of significant mutual contributions and interactions (van Manen, 1990). However due to their partner's illness, many of my participants struggled with their identity both as a couple and as individuals. Carter et al. (2012) write that declining mutuality is characterised by the loss of crucial components of relationality: communication, friendship, intimacy, support, and connection. The cessation of joint activities among my participants demonstrated that when any of these components are missing, the couple identity is fundamentally changed.



Many participants in my study expressed feeling less shared involvement than before, even if their partner participated in some activities. This left them wondering if they were still a couple and undermined the relationality through which they experienced their world: how others see them and how they see themselves (van Manen, 1990). van Manen proposes it is through relationality, a strong component of mutuality, that humans find their sense of purpose, their connection to others, and what makes their life meaningful together. When advanced PD threatens mutuality between partners, they experience a loosening of the ties that created their identity as a couple. This loosening of ties contributes to the gradual loss of communication, friendship, intimacy, support, and connection (Carter et al., 2012).

Roger and Medved (2010) who studied communication and living with PD, suggested the disease itself becomes part of the couple's identity (Roger and Medved, 2010). This was evident in my study; most participants stated they no longer engaged in previously enjoyed activities even individually due to lack of time for self-care, and this lack of personal attention contributed to resentment. In spite of the changes, maintaining strong mutuality was vital for many who wanted to be with their partner, to do things together, and to have their partner at home rather than in long term residential care. Seven of the twelve participants explicitly said they still chose being together, while five participants articulated feeling obligated to care for their ill spouse. Thus the reality that PD is a couple disease implied they journey together even if they were unhappy about it. Williams and Keady (2008) reported life history re-construction is important for couples in maintaining the closeness needed to maintain mutuality and couple identity. This includes moments and milestones experienced together, even difficult ones; events in shared life history can maintain a

relationship that has strong reciprocity that helps maintain that shared history even if some sadness is involved. Many of my participants spoke of past significant events as a couple that had strengthened their mutuality and connectedness (Williams and Keady, 2008). Such results were reported as well by Martin (2016) but some of her participants also said that despite their commitment to facing challenges of PD, there was uncertainty about the future of their marriage (Martin, 2016). My study introduced a new approach as I asked participants to reflect on their relationship in the current absence of such events.

### **7.1.2 Changes bring disappointment to the relationship**

As illness advances and requires more caregiving, disappointment occurs regarding changes in the marital relationship (Carter et al., 2012, Williamson et al., 2008, Davis et al., 2011, Carter et al., 2010, Martin, 2016). Williamson et al. (2008) reported caregivers feeling they had lost the closeness and affection they previously felt toward their partner especially when speech diminishes. Lack of meaningful communication was identified as contributing to the change in mutuality participants experienced. My participants also spoke of this as a loss; for one participant, a daily disappointment was not hearing his wife's voice, saying this was the hardest loss to bear; this has not been reported by others in the literature. For my participants who had been together many years, the multiple losses represented a fading of the partnership that had characterised them as the unique couple they had been. Such slipping away of their joint identity contributed to decline in mutuality for many participants.

For those whose partner had a psychosis with PD, this was another challenge that affected their interactions. Carter et al.'s (2012) study on pre-death grief in PD caregivers indicated statistically significant higher levels of heartfelt sadness ( $p < 0.001$ ) and worry and isolation ( $p < 0.01$ ) in caregivers when the PD partner showed severe changes in cognitive function, indicating anxiety around losing connection and characteristics as a couple.

My participants spoke of the loss of their spouse as an equal partner in their relationship. Many had shared ventures in business, spiritual life, hobbies, and politics, all of which had contributed to their identity as a couple. Some participants said this changed for them when caregiving became part of their duty as a spouse and their lives centred on the needs of their PD partner. This was also reported by McLaughlin et al. (2010) whose participants said caring was part of their duty as a spouse despite their own difficulties, which contributed to their feelings of helplessness, stress, and resentment although their study focused more on caregivers' discontent with the medical system and burden of taking on new roles whereas my study examined the impact of PD on the emotional quality of their relationship.

Caregiving spouses are attuned to observing changes in their PD partner, but they can be surprised by changes in themselves. Some of my participants barely recognized themselves due to the emotional effect of modifications in their lifestyle. Several were impatient with their partner, and this was echoed by Carnett Martin (2015) by a participant who said he became negative and impatient with his wife due to caregiving stress; this led to a vicious circle of stress and impatience leading to a

decline in mutuality as time together became unappealing (Carnett Martin, 2015).

Not only do some report seeing their spouse as a stranger, but they lose sight of themselves in the marital relationship. It no longer resembles how they once related and presented themselves together, further affecting their identity as a couple.

### **7.1.3 Communication with the PD partner and with others**

Carter et al. (2010) reported young spouses experienced lower levels of mutuality than older spouses even in early PD that requires less care (Carter et al., 2010). Davis et al. (2011) showed participants were saddened by the loss of their intimate connection as a couple, not experiencing verbal communication together, not being recognised by the PD partner, inability to travel, tension due to mood swings, and criticism by the PD spouse. They felt distanced without the ability to communicate and share feelings through discussion together about these tensions.

Hodgson et al. (2004) wrote that communication and mutuality are enhanced when partners use a relational approach to PD rather than focusing on individual effects.

Skerrett (2003) in her therapeutic work with couples facing illness stresses the mutuality of storytelling by both partners; healthy partners often believe they do not have a story to tell about the illness and its impact. These authors emphasise the importance of a relational approach, however their work was in early illness (Skerrett, 2003, Hodgson et al., 2004). My participants who felt close to their PD spouse also preferred making joint decisions, but found this was not always possible in advanced illness and several found themselves bossing their spouse, screaming at them, or behaving like a “sergeant major”. Continually watching over them resulted in an unbalanced relationship and affected mutuality due to the PD-induced power

imbalance in a previously equal partnership. My study results thus exemplify the effect of advanced illness on the importance of a relational approach which often is no longer possible.

Carnett Martin's (2015) study reported the sadness caregiving partners feel when their ill spouse can no longer communicate and they do all the talking themselves. Similarly, several participants in my study felt distant from their partner and wondered how life had become so lonely. This loneliness contributed to decreased mutuality for a number of my participants who said it seemed like a different life from when they had felt a connection with their partner and questioned what happened to the couple they had once been. In my study, I asked specific questions about how their relationship, as opposed to lifestyle alone, had changed for the participants from the time before PD became advanced. Many of my participants spoke of how they had conducted business with their spouse who was robbed of their savvy approach to business; others indicated their pride in their spouse who had won awards, run companies, and engaged in politics. Such stories spoke of their relationship as partnership that was lost to them. This topic has not been reported in other studies about PD caregivers.

Another type of communication loss occurs with social isolation which is common in caregiving for a partner with a chronic illness (Hodgson et al., 2004, Carnett Martin, 2015, Eriksson and Svedlund, 2006, Birgersson and Edberg, 2004, Martin, 2016). Couples lose their circle of friends, and social isolation may contribute to resentment by the caregiving spouse toward the ill partner with resultant decrease in mutuality (Habermann, 2004, Birgersson and Edberg, 2004, McLaughlin et al., 2010, Carnett

Martin, 2015). Moreover, their relationship becomes centred on PD; several participants in my study enjoyed time with their spouse only when the illness was not the focus. While outsiders inquire about the ill partner, there is frequently little support for the caregiving spouse (Birgersson and Edberg, 2004, Habermann, 2000). My findings show that cognitive and emotional changes in the PD partner contribute to the caregivers' loss of self as social engagement declines over time, leaving them isolated from their partner and others. The loss of shared experiences can fuel loss of self concerning what was once important and meaningful to oneself and each other, contributing to the loss of couple identity with resultant mutuality decline. A component of shared activities not evident in other studies but one that I investigated was the experience of fun. Having fun together is an important component of the marital relationship that my participants unanimously said was missing in their lives. The only participant who responded positively said that talking about their grandchildren was fun. All my participants spoke wistfully about their lack of fun as a couple due to advanced PD.

#### **7.1.4 Undesired new roles**

Many participants shared roles in the past that contributed to functioning as a couple for household, work, and social activities. Caregivers often assume new roles, and several of my participants resented their lack of preparedness for their spouse's extreme dependence on them. McLaughlin et al. (2010) reported caregiving spouses having to assume care for the spouse and the family, be the sole breadwinner, and coordinate all household matters; as a younger cohort, most tried to be stoic and take it all on. However my participants with an average age of 75, found handling everything to be very challenging; some were angry with the attention their spouse

required and felt unable to achieve everything independently. This, along with the inability to “fix” the physical condition of the spouse and the responsibility for new tasks, can be a threat to couple identity.

Caregiving spouses spoke of experiencing mood changes while watching their partner decline, mourning many losses including their earlier role as an equal, and the quality of their marital relationship (Hodgson et al., 2004). The inability to work, assuming all responsibilities, and the need to remain healthy because of caregiving responsibility created stress and loss of identity (Carnett Martin, 2015). Most participants in my study retired earlier than expected to care for their PD partner. These added responsibilities often led to exhaustion and resentment, contributing to decline in mutuality.

As an older cohort, many of my participants expressed the physical toll of caregiving; a common theme was their own physical limitations as they were aging. Caregiving depleted their strength and stamina, and a common concern was how much longer they could care for their spouse. Their physical exhaustion and sadness affected the mutuality they experienced as their identity as a couple dyad changed from how it used to be. Many told me they felt like a nurse or a parent to their PD spouse. Several participants in Martin’s (2016) study also described their changed role as that of a parent and some said the relationship shifted from a romantic one to a roommate type of relationship that was disappointing (Martin, 2016).

#### **7.1.5 Lost lifestyle changes affect couple identity**

My participants indicated that enjoyable shared experiences and lifestyle interests had helped partners solidify their identity as a couple and typically had an element of

fun prior to the illness. However, for most, fun was barely experienced as a couple in their current reality. Their experiences showed that mutuality was affected by relationship quality changes ensuing from decreased participation of the PD partner in previous mutually enjoyed activities. Lyons et al. (2009) reported that high levels of mutuality at the start of their longitudinal study were associated with low levels of strain, but this was not a guaranteed protection from relationship stress as PD progressed. Hodgson et al. (2004) and Martin (2016) reported a positive impact of PD for some couples as it deepened commitment and brought them closer; however only one of my participants expressed this. This discrepancy may be because none of Hodgson's (2004) and Martin's (2016) participants had partners with stages 4 or 5 PD.

Carnett Martin (2015) reported spouses experienced sadness in losing shared enjoyed activities. Habermann's (2000) participants also expressed this as a loss in addition to seeing themselves differently as a couple, especially when social invitations by friends dwindled (Habermann, 2000). My participants spoke of this a great deal, especially having to socialise only in their own home; for some this created a social imbalance as a couple because going out was difficult. The mean age of caregivers in Habermann's study was 51 years of age, representing a younger age group, with no spouses categorised higher than stage 3 PD. This differs from my study with a mean age of 75 years and all PD spouses having stage 4 or 5 PD. Shared socialising with friends was challenging and affected mutuality; fun had decreased and the couple identity changed from that of a shared relationship to one of a nurse and patient. In addition, increased age and advanced illness exacerbated this difficulty even more.



Apparent across many studies is the expressed disappointment about the inability to travel together. Carnett Martin (2015) reported one spouse saying, "I've lost my dreams," because travel was impossible due to PD. The average stage of disease in her study was 2.5; despite the difference in stage of illness, the results show the deep effect this has even in earlier illness. Disappointment about the inability to travel was highlighted by all my participants, with emphasis on how the complicated logistics of PD care has affected their identity as a couple who had once had dreams of travelling together in their retirement years. Advanced illness together with older age made this dream impossible.

Most participants in my study felt restricted to their home due to difficulties in going out with their PD spouse. This was evident in studies about earlier PD (Habermann, 2000, Carter et al., 1998, Tanji et al., 2008, Eriksson and Svedlund, 2006), but was more universally experienced in my study of advanced illness. This is emphasised by Carter's et al. (1998) statistically significant finding that negative lifestyle changes ( $p < 0.05$ ) and decreased mutuality ( $p < 0.05$ ) are experienced by caregiving partners as PD progresses; they attribute this association to caregiving tasks tripling as disease advances (Carter et al., 1998). My results suggest that lack of stimulation from minimal changes of scenery and interaction with others plus increased caregiving tasks influence mutuality in PD couples as life becomes routine and dull.

Hope for the future as well as the emotional toll becomes worrisome for caregivers especially if they experience a nurse/patient relationship, which was unexpected for their later years (Carnett Martin, 2015, Hodgson et al., 2004). Tanji et al. (2008) reported the most significant predictors of decline in mutuality were caregiver strain

followed by gait impairment and incontinence of the PD partner, affirming that outings are difficult. These restrictions limit the extent to which outings reflect the shared pleasures that helped to establish their couple identity, which becomes diminished due to PD; many of my participants said their outings are not only difficult but minimal due to advanced illness. Participants voiced disappointment that PD interfered with lifestyle and retirement, but age itself did not imply a lessening of mutuality for my participants; in fact for some, aging together strengthened their bond.

Despite a sense of obligation, most wanted to be with their PD spouse. A similar finding reported by Lyons et al. (2007) indicated that mutuality did not decline significantly over their 20 month study period; the majority of decline had already occurred prior to the study. This was also true for some of my participants whose spouse had had advanced PD for many years; their long relationships did not change much as they had grown old together and felt dedicated to caring for each other (Lyons et al., 2007). Rather than age, fluctuations in health affected mutuality in both our studies. Similarly, Carter et al. (2012) and Turney and Kushner (2017) reported caregivers experienced higher levels of sadness and isolation when their partner had health fluctuations, severe cognitive changes, and depression (Carter et al., 2012, Turney and Kushner, 2017). Extreme changes in health contributed to the expressed identity as a couple no longer having the same meaning since they could no longer engage in shared activities to the same extent, if at all.

### **7.1.6 Loss of physical expression of love**

Loss of intimacy can elicit feelings of abandonment for a caregiving spouse who feels a lack of acknowledgment or appreciation from the PD partner (Habermann, 2000), affecting identity as a couple who had been sexual partners. Bronner (2014) describes sexual dysfunction as a PD issue related to relationship satisfaction. When sexual expression and intimacy are diminished in PD couples, this may be perceived as rejection of love that was once physically expressed, profoundly affecting mutuality and creating loneliness. In studies of couples interviewed together, some partners of PD patients spoke of the loss of feeling attractive to their spouse whereas PD patients indicated more satisfaction (Bronner et al., 2014). The average ages were 50 and 64, respectively. Most participants in my study were older and accepted minimal physical intimacy, but expressed sadness about it. The BBC aired an interview with Sue, a caregiving spouse to her husband with advanced PD (Woman's Hour, BBC, 2017). The loss of their sexual relationship was painful for her. She wanted to feel desired, but he told her she was "useful". She said that she no longer "fancied" him and how profound a loss this was for her as she reflected on the tension between her need to feel desired and her lack of sexual attraction to her husband.

The subject of intimacy is sensitive; yet given the opportunity, my participants spoke openly, realising the effect of decreased intimacy on their couple identity and felt mutuality. My study, focusing on relationships and feelings toward their partner, encouraged participants to share their mutuality experiences related to sexuality and intimacy. None still had sexual intercourse, but some engaged in kissing and hugging each other. Although some wives did not miss the sexual relationship, they

expressed wistfulness likely related to the link of sexual relations to their changed emotional connection with their spouse.

In addition to the topic of physical intimacy, I explicitly asked participants to describe the love they felt for their partner at the time of the interview. Some other studies research the effect of PD on physical sexuality but this question not seen in other studies was related to their relationship on an emotional level. Participants spoke honestly with some saying they felt an obligation to care for their spouse and one no longer having affectionate feelings, but most said they still felt deep love and wanted to be with their spouse despite struggling with the daily caregiving experience.

#### **7.1.7 The need for empathic understanding**

Being heard by health professionals helps caregiving spouses feel acknowledged and validated, strengthening the couple's shared experience of advanced PD. My study findings reflect those of Bergerrson and Edberg (2004) who report caregiving spouses feeling neglected in their Swedish study. Many of my participants commented on the lack of attention at medical appointments, feeling invisible other than answering questions for their spouse, thereby losing their couple identity and their individual identity. Medical appointments generally focus on the clinical symptoms of PD, minimising emotional and social wellbeing. Furthermore, most participants were unfamiliar with other people in similar situations and felt alone. Bergerrson and Edberg (2004) reported partners experiencing strong community support from libraries, pharmacies and city councils, literature, awareness for the general public, and connections with other PD couples which my participants did not have in their Canadian experience.

Mutuality is at risk as well when little opportunity exists for the caregiving partner to vent or share with others; as a result, caregivers' time is spent with their ill spouse or on their own, sometimes grudgingly. Mutuality is at risk of decline when the caregiver feels invisible, wondering about his/her role in the relationship and feeling confused about self-identity. A caregiving wife in my study said caregivers are "taken for granted by physicians". Nevertheless, the caregiving partner who devotedly cares for the PD spouse is overlooked, contributing to the vulnerability of their identity as a couple. As Hodgson et al. (2004) elucidate, this can contribute to loss of mutuality.

Parallel findings were reported in recent research by Karlstedt et al. (2017) who explored mutuality perceived by PD couples and its relationship with motor and non-motor symptoms, caregiver burden and health-related quality of life. Using the Mutuality Scale, patients significantly ( $p=.014$ ) rated the reciprocity component higher than their partners did. They report the strongest predictors of caregiver burden were the mutuality rating of the caregiving partner ( $p <.001$ ) and caregivers' perception of their partner's cognitive decline ( $p=.05$ ). Non-motor symptoms such as patients' decreased cognitive functioning and dependence contributed more to mutuality than did motor symptoms (Karlstedt et al., 2017). The mean PD stage was 2 indicating such experiences even in early illness.

In other research, Karlstedt et al. (2018) stated that the effects of non-motor symptoms on health related quality of life was mediated by patients' mutuality. Due to many and various non-motor symptoms, PD couples experience difficulties in aspects of mutuality such as fewer shared enjoyable activities, challenges in agreement about coping with PD, and intimacy and love. They report a less direct

influence of motor symptoms: although motor symptoms can be limiting, increasing severity in motor symptoms alone did not affect health-related quality of life as much as the combination of motor symptoms and mutuality did (Karlstedt et al., 2018).

This section on loss of couple identity has shown the all-encompassing effect of PD on mutuality between spouses in my study. Advanced PD influenced the degree to which couples communicated verbally with each other, socialised together, and shared life activities that once bonded them and contributed to their identity as a dyad. PD slowly diminishes common interests, mutual care and interest in each other, and fun together. Most participants said caring for their spouse with advanced PD changed their life, their shared identity, and their mutuality.

## **7.2 *Ambiguous Loss***

### **7.2.1 Defining the concept: Boss and Doka**

Boss (2010) outlines two types of ambiguous loss: 1) a person is physically absent and it is unknown whether he/she is alive or dead; 2) a person is present but psychologically absent such as individuals with Alzheimer's or advanced PD (Boss, 1999). Confusion is experienced when a loved one, in this study the caregiving spouse, feels something resembling grief yet their spouse is alive; there is physical presence with psychological absence (Boss, 2010). Boss stresses this is psychological loss due to numerous losses from the illness and not knowing what will disappear next (Boss, 2010). However, Boss' definition of psychological loss does not go far enough to completely describe the loss of mutuality experienced in advanced PD; this is illustrated by Doka (2002).

Doka writes about psychosocial death in which the psychological essence, individual personality, or self is perceived as dead despite the individual being alive (Doka, 2002). This concept better describes individuals with advanced PD who are not “psychologically absent” but whose personality or essence is lost. Some individuals with advanced PD can communicate and participate in activities albeit to a lesser extent; the main loss is that the person’s personality has changed dramatically. While Boss (2010) says they are psychologically absent, according to Doka (2002), the essence of who they used to be is gone, which is very different. Several of my participants said their PD partner’s cognitive level had not changed as much as their personality. Doka’s concept reflects the loss of mutuality experienced by some caregiving spouses who witnessed the slipping away of the partner they had known for many years and with whom they had shared significant times.

### **7.2.2 Confusion in ambiguous loss**

Many participants in my study found it challenging to cope with their spouse whose persona had changed and was sometimes barely responsive. Many shared their pride in their spouse’s earlier accomplishments, but acknowledged that now their essence was almost absent. For Doka, this illustrates psychosocial loss on a continuum of reversibility to irreversibility (Doka, 2002). Loved ones watching this continuum experience feelings of loss with each change in the PD partner. As the progression approaches irreversibility, increased ambiguity ensues for the caregiver who provides more caregiving as dependence increases and verbal interaction is diminished. The combination of both Boss’ (2009) and Doka’s (2002) models demonstrates the lived experience shared by participants in my study. Psychosocial death and ambiguous

loss work synergistically, creating a decline in perceived mutuality; sadness, isolation, and resentment increase as PD progresses with resultant hopelessness.

Caregivers feel profound loss watching their partner's mental, physical, social, and relational skills slip away (Doka, 2002). Boss' (1999) research showed that rather than specific symptoms, the degree to which family members viewed their loved one as "present" or "absent" determined the degree of depression they experienced.

Similarly, my participants mourned both their partner's decline in physical integrity and the loss of stimulating experiences they once mutually engaged in. The person who had debated political matters or who was the president of his own company or someone who had received a prestigious award in literature was now barely able to speak clearly or concentrate; this elevated sadness for their caregiving spouses who watched their partners' essence recede, and with this came a decline in mutuality.

### **7.2.3 The effect on mutuality**

Mutuality is at risk when physical and emotional changes limit the extent to which life is shared and enjoyed. Some of my participants spoke of still enjoying spending time together, but no longer having the same shared excitement they used to have; this resulted in ambiguity when they wanted to be with their spouse yet dreaded the boredom. However, mutuality entails both positive and negative caregiver relationship strategies. Negotiation, compromise, appreciating the PD partner's limitations, empathy, and compassion comprise positive strategies while negative strategies include criticizing, ignoring, confronting, and minimizing communication (Kramer, 1993). Some of my participants tried teaching their spouse skills such as using the computer but were unsuccessful, reinforcing their sadness that *"no one is*



*there*” (Barbara). Well-intended hopeful initiatives that began as positive strategies sometimes resulted in negative outcomes. These unsuccessful results increase feelings of ambiguous loss, potentially contributing to decrease in mutuality.

Since PD does not have a short linear progression, participants did not often see changes in their partner who may have some “good” days as in more acute illnesses when they move a bit more easily, speak more clearly, or are more lucid. Such days, when they do occur, can offer caregivers a glimmer of hope for improvement. Yet as symptoms worsen, perhaps even the next day, caregivers find themselves challenged emotionally, dealing with unpredictability and the emotional upheaval that ambiguous loss entails.

#### **7.2.4 Struggling to understand**

Ambiguous loss in chronic illness can be long-term. With relentless illness progression, caregivers in my study experienced a mix of emotions toward their spouse while confronting daily unpredictability. This issue has been mentioned in the earlier section on loss of couple identity; however, the matter of labile and confusing emotions transcends boundaries. Such emotional changes bring confusion as caregivers try to make sense of their situation.

With the long term nature of PD, the caregiving spouse experiences a difficult combination of deep sadness, and resentment, sometimes resulting in a “love/hate relationship” with their partner (Turney and Kushner, 2017). Carnett Martin (2015) reported caregiving spouses saying they felt angry, impatient and “emotionally distant” from their partner with personality changes. This differs from acute terminal illness with a short trajectory in which time is precious and caregivers often value as

much time as possible together (Hodgson et al., 2004). Chronic physical changes in PD are exacerbated by interpersonal difficulties imposed by the illness, the likelihood of anticipatory grief, which is the grief that occurs in anticipation of the death (Rando, 1984), caregiver health challenges, and poor sleep (Carnett Martin, 2015).

Some of my participants told themselves their partner is not “difficult” but rather changed because of PD in order to maintain the affection and mutuality they previously had, but others felt resentful. Carnett Martin (2015) reported similar findings; lack of patience was a theme in both our studies, with caregiving spouses often expressing guilt about this. Impatience contributes to increased confusion as the caregiver becomes frustrated with an individual who cannot cooperate due to PD; while understanding this intellectually, it can be emotionally overwhelming. Moreover, positive and negative emotions concerning their partner contribute to felt ambivalence (Boss, 1999). Boss explains that not coping with negative emotions concerning the ill partner’s degenerative illness risks judgment by others because of socially expected roles of being understanding and flexible toward an ill person. The caregiving spouse struggling to make sense of the situation may feel conflicted and pulled in opposite directions (Boss, 1999).

### **7.2.5 Ambiguous loss and chronic sorrow**

Boss (2010) refers to ambiguous loss as a relational disorder, and as in other studies, my participants expressed feelings of sorrow for themselves and their partner (Lindgren, 1996, Birgersson and Edberg, 2004, Martin, 2016, Williamson et al., 2008). Chronic sorrow is described as “a continuous grief that occurs in a cyclical pattern of resurgent feelings of sorrow interspersed with periods of calmer emotions”

(Lindgren, 1996, p. 352). The resurgent grief feelings differ from those following a death; rather than lessening over time, their intensity can increase and persist, becoming stronger over years (Lindgren, 1996). Lindgren's (1996) seminal study of chronic sorrow in PD showed that many caregiving spouses experienced chronic sorrow triggered by physical events such as falls by their partner or psychosocial disappointments. Not all of my participants experienced chronic sorrow; however, they all indicated an element of sadness as part of the caregiving experience. This may be related to the long trajectory of PD and some participants had adapted easier than others to the caregiving role by the time it had become advanced. Lindgren (1996) reported sorrow related to decreased social activity and altered retirement plans but did not address mutuality, whereas my study focused on mutuality and showed sorrow related to relationship changes as well (Lindgren, 1996).

Williamson et al.'s (2008) study of caregiving wives with a husband with psychosis due to PD highlighted the sorrow they felt throughout the PD trajectory; each new symptom represented another component of the disease snatching away more of the person they once knew. Similarly, Carnett Martin (2015) reported caregiving partners experiencing sorrow about what their PD partner must endure. My participants in watching the cruelty of advanced PD, reiterated this empathy and shared disappointment on the one hand, yet felt resentment on the other, as they watched their partner struggle. Their own mixed feelings toward their spouse contributed to the ambiguous loss they experienced.

Ambiguous loss is traumatic due to lack of supports for such grieving (Boss, 1999). In this study, the individual with advanced PD had not died, but the caregiving spouse

grieved the many losses from PD such as decreased communication, social isolation, and loss of identity as a couple. Ambiguity arises for someone who feels the emotions of grief but is confused by them because death has not happened. Moreover, Doka (2002) explains such grief is poorly understood by others who do not sanction this experience as 'grief'.

### **7.2.6 A combined model**

In this section, the combination of Boss' (1999) theory of ambiguous loss and Doka's (2002) theory concerning psychosocial death provides a new perspective of the lived experience of a caregiving spouse in advanced PD and its impact on mutuality. My findings show that when couples have high mutuality prior to advanced illness and are able to share the PD experience together as a couple, caregiving spouses report mutuality that is stable despite imposed lifestyle changes, enabling the caregiving spouse to find meaning and coping strategies. This is illustrated in Figure 4 (Appendix L). When resentment and isolation occur, a greater chance exists for a decrease in mutuality with resultant hopelessness for the caregiving spouse as illustrated by Figure 5 also in Appendix L.

## **7.3 Finding Meaning**

### **7.3.1 Viktor Frankl**

Viktor Frankl (1959), known for his work in logotherapy, or meaning making, wrote in his classic work *Man's Search for Meaning*:

*"We must never forget that we may also find meaning in life even when confronted with a hopeless situation, when facing a fate that cannot be changed. For what then matters is to bear witness to the uniquely human potential at its best, which is to transform a personal tragedy into a triumph, to turn one's predicament into a human achievement."*(Frankl, 1959 p. 135)

Frankl addressed fundamental understandings of stress and its impact, which contributed to our understanding of the mechanisms of suffering. He argued that an individual need not be devoid of stress, but rather requires an understanding of what meaning can be ascribed to a stressful situation (Frankl, 1959).

### **7.3.2 Finding meaning in ambiguous loss**

People experiencing ambiguous loss while caring for a spouse with a degenerative illness can feel confusion and multiple emotions in an unchangeable situation; daily challenges and ambiguous loss must be channeled into the arduous task of finding meaning within the confusion. Boss stresses the importance of mastering one's internal self when the external environment cannot be mastered (Boss, 2010). For caregiving spouses, this involves finding what is fulfilling and creating opportunities to engage in meaningful activities; finding and accepting the "new normal" is the goal. However, the new normal is often not aligned with earlier dreams. Although couples expect to encounter the ups and downs of life together, illness brings challenges to their mutuality and connectedness. Not everyone has the wherewithal to recreate their lives intellectually, financially, socially, and personally when their partner is ill; some people do not have the internal resources to find fulfillment in caring for their ill spouse.

The extent to which a caregiving spouse adapts to the new normal can affect mutuality. This was seen in my participants who lamented the loss of the meaningful active life and relationship they used to experience with their spouse. Some accepted their lifestyle changes and found ways to adapt, such as going to exercise classes or meeting friends when the PD partner was at a day program, using visiting nursing

care time to run errands, or sitting in the park to reflect. Adaptation, however, is not equivalent to acceptance of the new normal as desirable or to finding meaning in the challenges of PD to their relationship. Others resented what had become the new normal for them as a couple and experienced a decline in mutuality as they no longer enjoyed their relationship or the context in which they lived, struggling to find meaning.

### **7.3.3 Thankfulness**

Almost all my participants were thankful for spirituality as a significant component in their spousal relationship, whether or not they could attend religious services together or share aspects of their life together that held meaning for both. Hodgson et al. (2004) reported thankfulness as an important strategy mentioned by all their study participants. Although thankfulness was interpreted differently by each participant, they all articulated being thankful for an aspect of their lives concerning PD such as slow progression, community supports, and gratitude that their partner's diagnosis was not a worse illness. One of their participants said the PD diagnosis strengthened their relationship because they had to accept the illness as permanent and actually brought them closer in their adjustment to it (Hodgson et al., 2004). However, only two of their ten PD patients were classified at stage 4 and none at stage 5, so participants were caregivers in early illness compared to my study with participants caring for spouses with advanced illness. According to Hodgson et al. (2004), thankfulness and recognition of a deeper relationship are likely to be more tangible in earlier stages of illness. Only one of my participants indicated a stronger relationship with her spouse, but did not specify whether this was a function of her caregiving or the length of their marriage.

Mavandadi et al. (2014) reported that when spouses of PD patients found benefits in caregiving, greater mutuality was experienced contributing to better emotional wellbeing, which in turn had a positive effect on marital quality and new meaning in their relationship (Mavandadi et al., 2014). My study results did not demonstrate this; many expressed caring deeply for their partner, but nobody spoke of positive responses to caregiving, reflecting more on exhaustion and less on a sense of accomplishment. This may be related to their own advanced age, physical limitations, and number of years of caregiving.

#### **7.3.4 Striving for normalisation**

Williamson et al., (2008) reported caregivers compared their situation to those of other PD couples. Seeing others who were “worse off” provided relief that their partner had less severe PD. Such comparisons were helpful, despite seeing what more advanced illness looked like and what the future might hold. A few of my participants mentioned that seeing other patients who appeared to have worse PD symptoms than their spouse was helpful, but this was not universally articulated. Despite the attempts documented above and the adoption of a ‘new normal’, participants in my study struggled to find meaning that was helpful in coping with their partner’s PD and with decreased mutuality in their relationship; accepting the situation was evident in most cases as opposed to finding meaning.

Finding hope and meaning is highly individual as each person strives to identify what hope means. Hope in advanced PD will not be for a cure, but hope for an easier day. While many of my participants said that PD had ruined their lives, some did speak about finding hope and meaning even in their difficult situation. Some described

their spouse as childlike feeling distressed about this as they tried to maintain an adult relationship, but struggled to do so because they believed they must protect their vulnerable spouse. Most tried keeping rituals and religious holidays such as Christmas and birthdays as significant times for celebration so the PD partner could feel included; this often helped the caregiving spouse in their attempt to achieve normalcy. While ensuring such important times were still celebrated, it was bittersweet for them; although it was meaningful to see their spouse enjoy these times, it was painful watching the changes in their partner and their decreased participation in these events. Celebrating these days did not bring universal fulfillment and meaning to all the participants who attempted it.

Eriksson and Svedlund (2006) reported caregiving spouses strove to preserve their previous lifestyle to achieve normalisation with their PD partner but struggled to have shared leisure time as well as time together with friends to restore balance within the context of advanced illness. This was echoed by most of my participants who found it difficult to establish a balance between enjoyable times together and time with others. My study in advanced PD indicates that cognitive changes in advanced PD requires increased creativity to assist the individual to recognise what might have been “normal” in the past but also points to the need for the caregiving spouse to maintain some normalisation.

Optimism is associated with high mutuality (Lyons et al., 2009). Findings in the longitudinal study by Lyons et al. (2009) showed that optimism, pessimism, mutuality, and spouse gender are predictors of strain in caregiving spouses. The process of finding meaning in a stressful situation is difficult. Participants in my study



who were able to find some meaning in caregiving or in their changed relationship with their PD partner were those who demonstrated higher mutuality such as strong marital quality, more optimism, and more time enjoyed spent together despite limitations, although this was vulnerable to variations in the daily experience with their PD partner.

### **7.3.5 Acceptance**

Accepting one's situation does not necessarily imply finding meaning. Many of my participants accepted the difficulty of their situation as unchangeable and worsening; they recognized their degree of acceptance and adaptation to the situation affected the mutuality they felt with their spouse. Frankl emphasised suffering stops being suffering when a meaning is attributed to it (Frankl, 1959); however this does not always mean acceptance. He argued that having a life project to fulfill and having someone to love and be loved by in return are crucial to the discovery of meaning (Storli et al., 2008, Frankl, 1959). Finding meaning did not come easily, if at all, for most of my participants. Some participants' acceptance was aided by their enduring love toward their spouse; others felt loyal in their promise to commit themselves to each other in good times and bad. Mutuality for them was caught up in a cycle of illness, limitations, resentment, and suffering.

### **7.3.6 An ongoing struggle**

For some people, finding meaning in a difficult situation results in personal growth and deeper insights (Mavandadi et al., 2014). Although an optimistic outlook is helpful, Grinyer (2006) emphasises that how caregivers feel and how they seem to others are not necessarily aligned; this discrepancy can contribute to emotional strain and isolation associated with caregiving. Some of my participants

acknowledged their difficulties but also said they had no choice. They bravely appeared to take their situation in stride; as a result they said others saw them as managing well. Those who find meaning in caregiving offer great support to their PD partner in the mutuality they experience. Cancer research shows similar results in caregivers of loved ones (Kim et al., 2007). Turney and Kushner (2017) hold that the good support some of their participants had did not negate their feelings of exhaustion, loneliness, and stress (Turney and Kushner, 2017). My research indicates this was difficult for participants who were older and worn out from years of caregiving for their spouse with advanced PD; mutuality for some had declined quite drastically.

## **7.4 Gender Differences**

### **7.4.1 Gender in caregiving**

Participation in health research has been associated with women more than with men (Lokk, 2009, McLaughlin et al., 2011, Habermann, 2000, Davis et al., 2011, Carter et al., 1998, Tanji et al., 2008, McRae et al., 2009, Goy et al., 2008). I attempted to have as equal a gender balance as possible to study differences and similarities in women's and men's lived experience of mutuality as a caregiving spouse to a partner with advanced PD. Lyons et al. (2009) reported caregiving wives who experienced low mutuality had increased strain versus those with high mutuality with their spouse (Lyons et al., 2009). In my study, proportionately more wives than husbands spoke of both their resentment and the relational challenges they faced with their PD spouse.

Historically, caregiving has been regarded as a woman's role rather than men's and exerts a greater influence on identity for women (Navaie-Waliser et al., 2002, Hagedoorn et al., 2001, Carnett Martin, 2015). Research suggests men have easier adaptation to caregiving and less psychological distress in the role of caregivers (Hagedoorn et al., 2001). This was evident in my findings as wives expressed more frustration concerning fatigue from caregiving. Research indicates female caregivers spend 50% more time providing personal care such as bathing, whereas male caregivers focus on finances and making healthcare arrangements (Roche and Palmer, 2009). This was not observed in my study, perhaps because all the PD spouses had advanced illness and required a great deal of physical care.

Wives typically express more concern about marriage quality especially when living with chronic illness (Berg and Upchurch, 2007). Mott et al. (2005) reported women are at higher risk than men for loneliness, anger, frustration, and emotional stress (Mott et al., 2005). This was evident in my study as well; women expressed the expectation that they must care for their spouse while husbands were lovingly striving to provide the best possible support and to "give back" for the years their wife cared for their family. Grinyer (2006) reported differences between mother and father caregivers of young adults with cancer: whereas mothers were willing to deal with emotions and discuss fears, the fathers' contributions were more practical, such as organising transportation and researching treatment (Grinyer, 2006).

Lyons et al. (2009) reported higher baseline mutuality as protective; caregiving husbands had slower increases in strain than caregiving wives. Low mutuality was negatively associated with tension for wives but not for husbands; wives with low

levels of mutuality experienced significantly increased strain compared to wives with high mutuality, suggesting increased risk of burnout and resentment when the marital relationship is weak. In my study however, both genders expressed sadness about their spouse's changes and their decline in mutuality. Resentment was articulated more strongly by the wives; husbands expressed more sadness. The caregiving wives articulated more disappointment concerning lifestyle changes than the caregiving husbands. The husbands demonstrated acceptance of unmet plans and exhibited a greater tendency to share meaningful events in their relationship; the caregiving wives on the other hand, focused on the present and how their relationship had changed. This observation suggests that given societal expectations for their generation, husbands had been the breadwinners and exempt from the caring role. In contrast, the wives would have been at home caring for children, their husband, and possibly elderly relatives. The dashing of their dream for relaxation, travel, and freedom from caregiving may have been more devastating after a lifetime of caregiving.

#### **7.4.2 Emotional responses**

Bergs (2002) reported caregiving wives voicing sadness over loss of intimacy, closeness, and attachment to their husband. They experienced mixed emotions as they struggled with not feeling as close as before, yet felt deep fondness for their spouse and missed the person they once knew (Bergs, 2002). Many female participants in my study expressed mixed feelings as they described their love for their spouse. Several said they felt sorry for him, some said they missed the "old" person they once enjoyed, and others said their love was still very deep despite the

difficulties; they expressed more profound losses than the male participants.

However, the five caregiving husbands all reported feeling close to their wives.

Four wives emphatically said they no longer enjoyed spending time with their husband because of PD, but all five men spoke about sitting with their wife to watch television, talk, or simply be together. This was in contrast to the wives who spoke about everything they had to “do”; few sat with their spouse as their male counterparts did. All the husbands spoke of the deep love they felt for their wife and feeling attracted to them despite PD; none indicated feeling abandoned or unappreciated, sentiments expressed by some wives. This may be a reflection of the societal expectation for women to nurture and care for family members, whereas husbands taking on a caregiving role may receive admiration and praise because they are not expected to do so.

#### **7.4.3 Gender differences in logistics**

Navaie-Waliser et al. (2002) reported wives had a harder time balancing caregiving with other demands; they provided more complex care and experienced poorer emotional health than caregiving male counterparts. This was observed in my participants as well. Since the husbands came to the caregiving role at a later age, they were not as worn out with caregiving. The women in Navaie-Waliser et al.’s (2002) study reported religious activities as a support more than the husbands did. In contrast, my study showed no gender difference; religious participation was mentioned by eleven of the twelve participants in my study. The one participant who did not mention this was a caregiving wife.

Navaie-Waliser et al. (2002) found wives were less likely to seek resources for caregiving assistance and when they did, it was at a later stage in caregiving. I observed this as well: all five caregiving husbands had assistance from children or individuals they hired to provide them with time outside the home for themselves or for errands. Of the caregiving wives, one hired an occasional helper and one received help from her children at weekends. Most felt obligated to do everything themselves, using the minimal time when the visiting nurse was present for errands. One husband said they were “not swimming in money,” but having a cleaning lady was beneficial. The wives tended to say they had always been expected to do everything and could not change. This contributed to resentment, anger, and disappointment felt toward their PD husband. Because the husband caregivers more readily accepted help, they went out more frequently than the caregiving wives and reported less social isolation and higher mutuality with their wives.

All the husbands spoke of the depth of meaning of their relationship and acceptance of caregiving despite the difficult times. Mutuality did not suffer as much from their perspective as for caregiving wives. Having more breaks, albeit short ones, in the caregiving may have helped them to cope. Whereas Navaie-Waliser (2002) showed women were more likely to assume more complex tasks, this was not seen in my study. Among my participants, the caregiving husbands provided the same level of care as the caregiving wives did, although they did draw more on paid assistance (Navaie-Waliser et al., 2002).

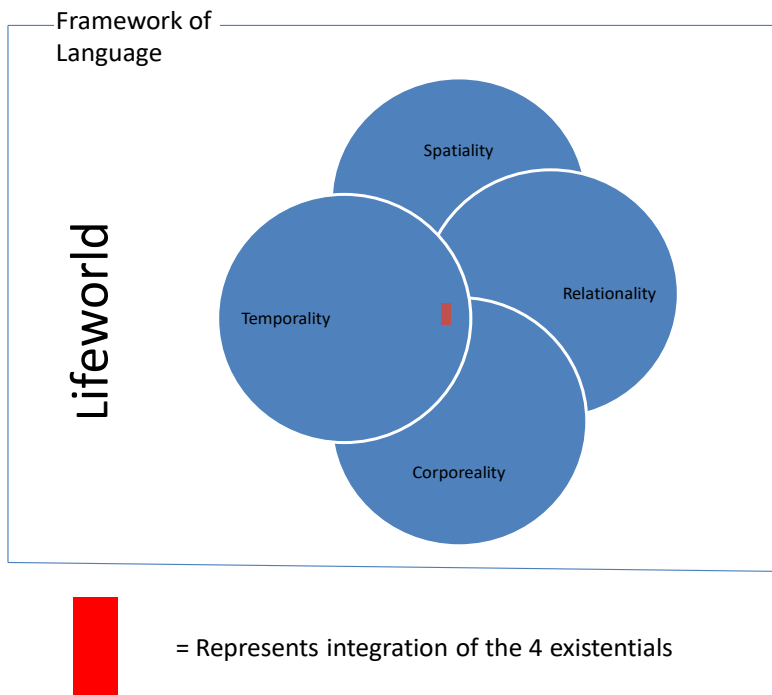
Although some differences were observed between the genders in my study, it was less than expected given the literature findings. Some of the gender differences may

be attributed to generational sociological trends – that women traditionally maintained the home, were caregivers to children and/or elderly relatives, and accepted (or appreciated) a decline in their sexual relationship. Caregiving husbands comprised almost half of my study sample. To my surprise, all who were approached agreed to participate; I had assumed men would be reticent to participate in a qualitative study and be forthcoming about their feelings. More research is needed in the caregiving experience for husbands in advanced PD.

### ***7.5 A Changed Understanding of Mutuality***

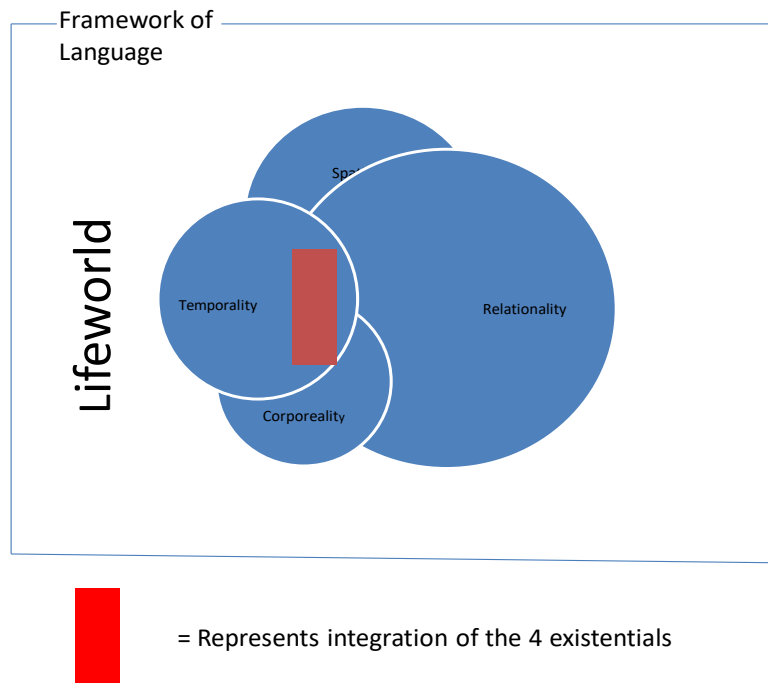
My initial understanding of the lived experience of mutuality as analysed through the existentials was that it would be one of an equal contribution of the four lifeworld existentials. However, I now see varying contributions from each existential to the overall lived experience of mutuality. These two models are exemplified in Figures 5 and 6.

Figure 5 shows my earlier assumption while the representation in Figure 6 demonstrates what I have learned; relationality influences mutuality the most, and strongly overlaps with spatiality as couples spend much time together, often in stressful environments. Temporality overlaps less and corporeality the least. This is not to be assumed that the three existentials of spatiality, temporality, and corporeality are less important, but that relationality is the one that contributes most to the mutuality experience. In both figures, it is in the central section where the existentials are integrated that mutuality reveals itself as the lived experience:



**Figure 5. Model reflecting my earlier understanding of mutuality from the integration of existentials**





**Figure 6. Model reflecting my changed understanding of mutuality from the integration of existentials**

### ***7.6 Reflection on Mutuality***

The concept of mutuality has been applied in this thesis to study the marital relationship in advanced PD. For couples living with illness (and advanced illness in particular) the illness has the potential of challenging the marital relationship. In researching the impact of illness on mutuality, caution must be taken when an assumption is made based on early research about mutuality that proposes high mutuality permits caregivers to cope with difficult caregiving challenges (Archbold et al., 1990, Lyons et al., 2009). However research findings as outlined in the literature review chapter as well as in my own research show that other variables can influence mutuality over time as illness progresses.

In advanced PD in which caregiving is demanding and exhausting and the PD partner has limited communication, physical function and sometimes cognitive and personality changes, mutuality is vulnerable to decline and poor relationship outcomes.

Most of the studies included in the literature review chapter show when health professionals observe low mutuality in their patients, they ideally want to assist in restoring and maintaining relationship quality as before to help provide meaningful quality of life and interactions within the context of the illness. Community interventions can assist in this endeavor. However, it must be recognised that as much as health professionals hope to improve relationships for couples struggling with decreasing mutuality due to PD, situations may exist in which the caregiving spouse or the care receiver decides the relationship is no longer desirable. It is therefore important to accurately assess the level of mutuality in the relationship and to provide assistance, support, and resources for those who want to improve mutuality as well as for those who decline. Health professionals must recognise that in some situations, encouraging the couple to continue living in a caregiving situation and attempting to improve mutuality may not be the perfect solution. This was demonstrated by my participant Mary who reported minimal time with her partner when she does not have to provide care and resentment toward him; she would accept an alternate solution if she knew her husband would receive appropriate and dignified care. A new and necessary goal for health professionals therefore is recognising when encouraging couples to remain together may not be the ideal solution.

### **7.7 Contribution to Knowledge**

This thesis presents empirical research conducted on mutuality in solely advanced Parkinson's disease from the perspective of the caregiving spouse. Although other studies have examined mutuality in PD, this is the first that focuses on advanced illness only. The utilisation of van Manen's approach using the existentials to analyse data to gain insight into the lived experience of caregivers of partners with advanced PD provides a unique methodology; this has not been seen in PD research.

Furthermore, this thesis draws together the theories of Boss, Doka, and Frankl as applied to mutuality in the participants' lived experience; this offers broad insight beyond coping with the illness itself. Some important findings in this research and not reported in studies with analogous groups are reported here.

Whereas most other studies concentrate on current mutuality, my study asked participants to reflect on changes in their relationship since PD became advanced. Previous research reports that relationships often change losing the experience of equal partners; several of my participants spoke as well about the loss of "partnership" for those who had worked together with their spouse in a shared business, thereby losing not only lifestyle but business insight as well. Most of my participants spoke of wanting to be with their partner despite the difficulties and changes in mutuality.

Results from my study with its focus on mutuality, highlights the implications of changes in lifestyle for my participants. This important perspective differs from other studies concentrating on burden of care, preparedness, symptoms, and caregiving tasks. Notwithstanding the illness itself and the caregiving required, many participants

spoke of the drastic changes as a couple as their previous known lifestyle has come to an end.

Some of my participants indicated the PD partner has become like a child. Hodgson et al. (2004) reports a participant saying that although she dresses her husband as she would dress a child, then he functions on his own. Several of my participants explicitly said that their PD partner has become like a child and as a result, they treat him/her as such for everything.

An important area this study focused on was fun which has not been seen in other studies with the specific question asking how they have fun with their PD partner. As many have difficulty experiencing fun, this is an important area to be considered in intervention programs for advanced PD.

Murray (1995) reported that individuals with MS who continue friendships and community interests maintain a rewarding life. However, my study indicates that as the PD partner's symptoms worsen and increased apathy and disinterest in others occurs, shared friendships and socialising diminish considerably, contributing to social isolation and resentment. My participants reported a decrease in social interactions as a couple as well as individually despite friendships and community interests.

Participants in my study were cognisant of the importance of taking care of themselves. O'Brien (1992) reported poor health behaviours and self-neglect among caregivers of people with MS and attributed this to multiple stressors including caring for young children, working, and caregiving (O'Brien, 1992). This was not evident in my study: while some participants spoke about their own health issues,

despite the sadness most reported, they did indicate that it was important for them to take of themselves so that they could continue to be the caregiver for their spouse and they were committed to ensuring their own good health.

My participants spoke a great deal about the monotony of the days that offered little stimulation with a partner who was very limited in ability to move. They lamented about their desire to do activities, go out, or even play board games as Ann said. Most felt stuck at home and Barbara mentioned feeling she is in prison. This varies considerably from information derived from caregivers of people with Alzheimer's who have reported never having a typical day because the person with AD feels different and behaves differently from one day to the next and some demonstrate such variability even during the same day (Daniels et al., 2007, Wuest et al., 1994). Furthermore, staying involved in daily activities and having social activities with others have been reported to be important and doable for couples living with AD as the affected partner does not have the physical limitations that PD imposes. (Bielsten et al., 2018). This is something my participants could only dream of.

While the topic of sexuality has been researched and published, less exists about intimacy and how caregiving spouses describe the love they feel for their partner with advanced PD. In describing the love they feel, many participants mentioned feeling sorry for their spouse and feeling pity for them in addition to admiration, devotion, adoration, and companionship. One said she had no feelings of love any longer. With the exception of this participant, the majority of responses are contrary to reports of divorce rates being higher in Huntington's Disease and Multiple Sclerosis (Rothing et al., 2015, Banaszkiwicz et al., 2012). The participants in this

study were partners in relationships that were long and involved, many shared life experiences without the added stresses of raising children, genetic inheritance, and the need to stop working. These findings are important for health professionals working with couples living with advanced illness and in proposals for therapeutic interventions.

Medical visits for PD patients focus primarily on motor and physical symptoms of PD, with less attention paid to the important psychosocial components of their life that are affected by PD such as relational satisfaction and well-being and spiritual and emotional well-being of both patient and family. Paradoxically, the individual who cares most for the patient often gets overlooked or dismissed; resentment is a common response to this and was shared by most of my participants even though they were grateful for the medical care their spouse received. This study supports Wright's (2005) argument, promoting the need for further research concerning the marital relationship in illness. Wright (2005) stresses the need for health professionals to recognise the "marital subsystem" that becomes vulnerable in the context of illness (Wright, 2005 p. 344).

This research concentrated specifically on mutuality in advanced PD but issues that were uncovered by participants' lived experiences may be applicable to couples living with other chronic illnesses which have long term and degenerative trajectories, such as Alzheimer's disease, Multiple Sclerosis, Huntington's, and cardiac illness. The findings may be relevant to couples living at home together where one is the caregiving spouse in other medical conditions as well.

## **7.8 Summary**

The lived experience of mutuality in the caregiving experience of advanced PD is complex; professionals caring for these couples require an in-depth understanding of their reality. In this study, challenges to mutuality for caregiving spouses identified in the study results were analysed according to van Manen's (1990) framework of the temporality, spatiality, corporeality, and relationality existentials. In addition, the concepts of ambiguous loss (Boss, 1999, Doka, 2002) and finding meaning (Frankl, 1959) were applied to my study findings for a unique insight. Observations of gender differences between caregiving spouses are important; gender differences have been shown to contribute to some extent to the degree of mutuality felt by some participants. Loss of identity, ambiguous loss, and the quest to find meaning are challenges for caregiving spouses in advanced PD. This study offered a distinctive approach with the use of the existentials as a framework for analysis. Participants were asked sensitive questions not found in other studies. It is evident that in addition to care for the PD partner, a holistic approach to support for the caregiving spouse is imperative in order to maintain ideal mutuality.

The Conclusion chapter briefly reviews the study findings of mutuality experiences in advanced PD from the perspective of caregiving spouses. Individuals with advanced PD do not live in a vacuum; the illness affects family members, especially the caregiving spouse. The next chapter includes limitations and contributions of this study. The application of my study results to professional practice is presented as professional healthcare teams require a holistic understanding of the effects of PD. Moreover, it is necessary for health care teams to understand the degree to which PD affects the marital relationship in order to provide care and support to both the

patient and the caregiving spouse, who as a partner in this debilitating “couple disease”, requires recognition and acknowledgement.



## 8 Conclusion

My research explored the lived experience of mutuality in advanced Parkinson's Disease and has been analysed through the framework of the existentials of spatiality, temporality, corporeality, and relationality. This framework provided a holistic structure that explored many aspects of mutuality from the perspective of the caregiving spouse. Moreover, it offered a unique approach to understanding the words introduced in the first chapter spoken by the caregiving husband of a PD patient: "Parkinson's affects everything". What I understood prior to my research as a "love-hate relationship" in couples is exposed as both multifaceted and multilayered as they live daily with a disease that is unrelenting and degenerative.

I learned from participants in my study that PD does indeed affect every aspect of the marital relationship as a result of the many challenges accompanying advanced PD. My study participants not only validated findings in the early PD literature of the many losses that occur but also demonstrated the intensity and increased depth of despair and feelings of isolation that accompany and amplify losses in advanced PD. The symptoms of advanced illness exacerbate the frustrations and emotional changes experienced by some caregiving spouses over time. While many of my participants demonstrated acceptance of the losses and changes in their marital relationship due to advanced PD, they did struggle with the juxtaposition of deep care and love for their ill spouse and resentment that life had become something other than what they had imagined and hoped for as a couple.

This study, with its use of hermeneutic phenomenology, laid the groundwork for meaningful in-depth analysis of the participants' lived experience of mutuality by use

of the hermeneutic circle through my movement back and forth between the parts and the whole to gain insight into the day to day experience of being a caregiving spouse in advanced PD. The step by step process of interpretation provided a rich interplay of the stories offered by participants and my own understanding of advanced PD. This was a validation of van Manen's belief that the researcher's own pre-understanding of the research topic provides insight and contributes to the analysis.

The writings of Boss (1999), Doka (2002), and Frankl (1959) allowed me to move forward in my own understanding of mutuality in advanced PD in order to more fully appreciate how decline in mutuality between marital partners influences ambiguous loss, psychosocial death, couple identity, and challenges in finding meaning. While I had originally believed mutuality to be based on personal interactions, the four existentials illustrated that mutuality within the marital relationship incorporates space, time, and body as well.

### ***8.1 Implications for Practice***

An important finding from my participants was that psychosocial aspects of living with PD are at best a secondary consideration during clinic appointments and may be overlooked entirely. The caregiving spouse can provide important information about physical symptoms, but also needs to be included in the psychosocial aspect of living with PD. Moreover, as an important partner in the experience of living with PD, it is crucial for healthcare professionals to be cognisant of the exhaustion and frustrations caregiving partners experience on a regular basis and the implications this can have for the PD patient.

Palliative care's holistic approach must address psychosocial components of health delivery in chronic illnesses that entail a long and degenerative trajectory such as PD. PD partners often struggle to handle the disease together because they don't know how to do so on a relational level (Hodgson et al., 2004). Health care professionals providing care to PD patients play a key role in this respect and need to be aware of the challenges of caregiving in PD; they need to treat PD patients and their spouse as a unit and recognize the caregiving spouse as both a partner in care and someone who is deserving of attention from the care team. A multidisciplinary team approach can assist such couples to address their multiple challenges. This research demonstrates that community services are needed that will offer opportunities for couples living with advanced PD to have quality time that does not focus solely on physical symptoms of PD but can enhance and maintain the quality of the marital relationship through fun, enjoyable shared activities, and social diversion. Increase in mutuality in chronic illness has the potential to provide couples with improved relationship quality contributing to enhanced well-being.

Palliative care clinicians, among others, play an important role in paving the way for couples living with advanced illness to receive holistic services. Fins (2006) writes that palliative care's goal of enhancing and providing optimal quality of life to patients and their families provides a new model of care: palliative medicine expands the traditional boundaries of the physician/patient relationship by addressing the psychosocial and spiritual needs of both the patient and their family in addition to the management of physical symptoms (Fins, 2006). Lanoix (2009) warns that family members, including a caregiving spouse, can become invisible when the partner

suffers from a chronic illness such as PD, making them vulnerable as illness advances (Lanoix, 2009).

Palliative care principles are relevant and necessary in chronic illness and cancer as couples can live together for many years with a condition that changes what had attracted them to each other. Through physical treatment, as well as psychosocial, emotional, and spiritual support to patients and their families, palliative care reduces suffering; early provision of all aspects of palliative care in PD as an adjunct to conventional treatment throughout the illness' trajectory is ideal in meeting the many needs of PD patients and their families (Ng, 2017). Despite this, PD palliative care has been slow in developing according to research in the UK (Walker et al., 2014, Fox et al., 2017). Miyasaki and Kluger (2015) stress the value of their interdisciplinary team's palliative approach for PD patients that includes spiritual care and caregiver inclusion, addressing caregiver burnout and relational issues as a focus of care (Miyasaki and Kluger, 2015). When couples receive explanations about ambiguous loss as a response to living with profound changes, they can better understand their own experience and have the opportunity to be heard. Results of this study indicate the enormity of the emotional effect of advanced chronic illness.

It is evident that I have learned a great deal from my own research. Spouses of PD patients in my clinical work have told me recently that they are impressed with the depth of my understanding of their challenges, understanding that I have come to through this research. When I have explained ambiguous loss relating to their relationship with their spouse, they have indicated how relevant this is to their own lived experience. My plan following completion of this thesis is to apply for advanced

PD program funding that will provide a joint opportunity for patients and their spouses to improve mutuality and provide fun for them together. Rather than a program in which everyone will do the same thing, intake would incorporate their unique interests as a couple with plans to provide programs they can look forward to attending together. This would not be a respite initiative but rather one that would bring partners together in their shared interests.

## **8.2 Limitations**

This study has contributed new knowledge and has important implications for practice; nevertheless, there are some limitations. My research was conducted with participants from one hospital alone, and in one country, thereby limiting comparisons to other centres. As a non-longitudinal study, this research does not study changes in mutuality as PD progressed even further over time. In this thesis, I have described mutuality in the lived experience of caregiving spouses but do not include the lived experience of other family caregivers such as children, parents, or siblings. Their experience may have similarities and differences and are thus important areas for future research. My research was conducted with couples living together in their home and did not include situations in which the PD partner is living in a nursing home; results cannot be applied to those couples who live apart. This study was intended to research the perspective of caregiving spouses and does not include that of the PD partner. Participants were recruited as a small scale purposive sample and not a random sample from the general population of advanced PD caregiving spouses; as such, results are not generalisable to all caregiving spouses in advanced PD.

### ***8.3 Suggestions for Future Research***

My research concentrated on mutuality from the perspective of the caregiving spouse. This was intentional in its design in order to give voice to the caregiver as research in this area is limited. My research has presented important insights into the lived experience of caregiving spouses in advanced illness and future work in this important area is needed. Longitudinal qualitative research of mutuality in PD couples is necessary to observe the impact of both the illness itself and the evaluation of PD programs in order to observe how mutuality changes within the context of advancing illness and which interventions can best support these couples. This research could be adapted and studied in different cultures and languages that will help clinicians to understand the cultural and spiritual aspects of caring for one another in difficult times when illness occurs, whether gender differences are evident, and how caregivers behave in relationships with healthcare teams. Continued utilisation of the lifeworld existentials of spatiality, temporality, corporeality, and relationality as a framework outlined by van Manen for the analysis of lived experience has the potential to provide further insight into mutuality changes in terminal illness.

Participants in this study had all been married to their spouse for longer than twenty-five years. Research conducted in couples married for a shorter period of time may indicate different results. Since PD typically affects older adults, and my research has been on those with a long marriage history, couples living with advanced PD and shorter relationships will be an important area to investigate. Future research in mutuality in advanced illness including both partners would require recruitment of PD couples in which the PD partner could participate at the necessary depth of

involvement and was not the aim of this research. While some individuals with PD can still communicate, many with advanced PD cannot engage in a research interview of this depth.

#### ***8.4 My Learning and Final Words***

I am deeply aware of how much I have learned from my own research. This study contributes to closing the gap created by the dearth of empirical research with caregiving spouses (Hempel et al., 2008). When I began the study, I had assumed that I would hear somewhat guarded statements from participants, who would be careful about the information they provided due to the sensitive nature of the subject. I was both surprised and delighted to receive very deep emotional responses with a profound depth of trust extended toward me. My own understanding of the lived experience of caregiving and mutuality in advanced PD has deepened by having immersed myself in the data; the application of hermeneutic phenomenology provided the opportunity to uncover the essence of the lived experiences of mutuality of my participants. This has been so powerful that I have found myself able to understand and support caregivers I work with professionally on a more profound level.

Caregivers in particular need to be acknowledged, heard, and honoured for the work they do to provide meaning to themselves and their spouse with advanced PD; their connection as a couple is important on emotional and spiritual levels that enable the continuation of the attachment they had experienced in earlier and healthier years. The responsibility of caregiving to a spouse with advanced PD is heavy, and at a time in their lives when they too are aging, caregivers are in need of support and

opportunities to experience mutuality with their spouse as they had once dreamed it would be in their later years. Palliative care, according to Dame Cicely Saunders (Saunders, 1964), is about living and quality in living. Caregiving spouses living with and caring for their partner with advanced PD are worthy of our assistance in ensuring the philosophy espoused by Saunders enhances mutuality within the context of life threatening and debilitating illness.



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## Appendices

### *Appendix A. Hoehn and Yahr Scale for Parkinson's Disease (Hoehn & Yahr, 1967)*

Stage	Description
1	Unilateral involvement only usually with minimal or no functional disability
2	Bilateral or midline involvement without impairment of balance
3	Bilateral disease: mild to moderate disability with impaired postural reflexes; physically independent
4	Severely disabling disease; still able to walk or stand unassisted
5	Confinement to bed or wheelchair unless aided

## ***Appendix B. Mutuality Scale (Archbold, 1990; Kao, 2011)***

A 5 point Likert scale ranging from *not at all* to *a great deal*:

How often do:

1. The two of you see eye to eye?
2. Feel physically close to him/her
3. Enjoy sharing past experiences with him/her?
4. Does he/she express feelings of appreciation for you and the things you do?
5. Feel emotionally close to him/her?
6. Does he/she help you?
7. Like to sit and talk to him/her?
8. Feel love for him/her?
9. The two of you talk about common family values?
10. Does he/she comfort you?
11. The two of you laugh together?
12. You confide in him/her?
13. Does he /she give you emotional support?
14. Enjoy spending time together?
15. Does he/she express feelings of warmth toward you?

## **Appendix C. Literature Search 2018**

Ovid MEDLINE(R) <1946 to February Week 3 2018>

Search history sorted by search number ascending

<b>#</b>	<b>Searches</b>	<b>Results</b>	<b>Type</b>
1	[Parkinson's Disease and related disorders]	0	Advanced
2	exp Parkinsonian Disorders/	69748	Advanced
3	Movement Disorders/	14978	Advanced
4	exp Multiple System Atrophy/	3107	Advanced
5	Supranuclear Palsy, Progressive/	2178	Advanced
6	parkinson*.mp.	97689	Advanced
7	ramsay hunt.mp.	472	Advanced
8	(Lewy Body adj2 disease?).mp.	3477	Advanced
9	(Lewy Body adj2 dementia?).mp.	722	Advanced
10	(movement adj2 disorder?).mp.	24035	Advanced
11	(Multiple System adj2 atroph*).mp.	3310	Advanced
12	(Multisystem adj2 Atroph*).mp.	157	Advanced
13	(Multisystemic adj2 Atroph*).mp.	17	Advanced
14	(Progressive adj2 Supranuclear adj2 Palsy).mp.	3392	Advanced
15	(Progressive adj2 Supranuclear adj2 Palsies).mp.	0	Advanced
16	(Progressive adj2 Supranuclear adj2 Ophthalmoplegia?).mp.	17	Advanced
17	Steele-Richardson-Olszewski.mp.	99	Advanced
18	Richardson? Syndrome.mp.	76	Advanced
19	or/2-18	121499	Advanced
20	[Mutuality]	0	Advanced
21	Interpersonal Relations/	64742	Advanced
22	mutual*.mp.	43991	Advanced
23	(Interpersonal adj2 Relation*).mp.	67815	Advanced
24	(Inter-personal adj2 Relation*).mp.	48	Advanced
25	Interaction?.mp.	1047926	Advanced
26	intimate.mp.	15850	Advanced
27	intimacy.mp.	2897	Advanced
28	Communicat*.mp.	311748	Advanced
29	conflict?.mp.	66384	Advanced

30	Family Conflict/	1574	Advanced
31	Forgiveness/	222	Advanced
32	forgive*.mp.	877	Advanced
33	Trust/	7848	Advanced
34	trust*.mp.	36395	Advanced
35	support*.mp.	8633308	Advanced
36	(quality adj3 relationship*).mp.	5361	Advanced
37	(relationship* adj3 satisf*).mp.	3051	Advanced
38	well-being.mp.	49445	Advanced
39	wellbeing.mp.	8225	Advanced
40	Cooperative Behavior/	39258	Advanced
41	collaborat*.mp.	100467	Advanced
42	cooperat*.mp.	182343	Advanced
43	co-operat*.mp.	9391	Advanced
44	dialogu*.mp.	10666	Advanced
45	exp Emotional Intelligence/	76471	Advanced
46	emotion*.mp.	158856	Advanced
47	empath*.mp.	21206	Advanced
48	caring.mp.	31137	Advanced
49	compassion*.mp.	6738	Advanced
50	bonding.mp.	81669	Advanced
51	exp Emotions/	209215	Advanced
52	love.mp.	7851	Advanced
53	fear?.mp.	62782	Advanced
54	anger?.mp.	14109	Advanced
55	angry.mp.	3390	Advanced
56	anxiet*.mp.	177207	Advanced
57	anxious*.mp.	12988	Advanced
58	frustration?.mp.	7411	Advanced
59	guilt*.mp.	9714	Advanced
60	shame.mp.	4078	Advanced
61	hostil*.mp.	12543	Advanced
62	regret*.mp.	2880	Advanced
63	reciprocity.mp.	3148	Advanced
64	sharing.tw.	39293	Advanced

65	intersubjectiv*.mp.	836	Advanced
66	inter-subjectiv*.mp.	96	Advanced
67	boundedness.mp.	210	Advanced
68	bondedness.mp.	9	Advanced
69	responsiveness.mp.	86510	Advanced
70	attune*.mp.	1209	Advanced
71	exp Stress, Psychological/ px.fs.	113181	Advanced
72	px.fs.	917673	Advanced
73	exp Adaptation, Psychological/ adapt*.mp.	115907	Advanced
74	adapt*.mp.	523140	Advanced
75	psychologic*.mp.	409204	Advanced
76	psychosocial*.mp.	71838	Advanced
77	psycho-social*.mp.	3163	Advanced
78	experience*.mp.	794681	Advanced
79	coping.mp.	39340	Advanced
80	cope.mp.	23825	Advanced
81	"Quality of Life"/ (quality adj2 life).mp.	157638	Advanced
82	(quality adj2 life).mp.	243839	Advanced
83	QoL.mp.	25246	Advanced
84	burden*.mp.	155530	Advanced
85	stress??.mp.	721656	Advanced
86	strain*.mp.	851474	Advanced
87	or/21-86	11218916	Advanced
88	19 and 87	69571	Advanced
89	[Spouses or Caregiving Partners]	0	Advanced
90	Spouses/ Marriage/ Sexual Partners/ spous*.mp.	8674	Advanced
91	Marriage/ Sexual Partners/ spous*.mp.	22211	Advanced
92	Sexual Partners/ spous*.mp.	13992	Advanced
93	spous*.mp.	26907	Advanced
94	wife*.mp.	5247	Advanced
95	wives.mp.	4415	Advanced
96	husband*.mp.	30787	Advanced
97	marriage.mp.	30163	Advanced
98	marital.mp.	30447	Advanced
99	partner?.mp.	106559	Advanced

100 common-law.mp.	748	Advanced
101 commonlaw.mp.	3	Advanced
102 Caregivers/	29141	Advanced
103 caregiver*.mp.	52224	Advanced
104 care-giver*.mp.	2076	Advanced
105 carer*.mp.	9997	Advanced
106 couple.mp.	22787	Advanced
107 couples.mp.	30150	Advanced
108 or/90-107	288562	Advanced
109 [PD AND Mutuality AND spouse/caregiver]	0	Advanced
110 88 and 108	1481	Advanced
111 limit 110 to english language	1364	Advanced
112 animals/ not (animals/ and humans/)	4393833	Advanced
113 111 not 112	1325	Advanced
114 limit 113 to ed="20160401-20180228"	216	Advanced
115 remove duplicates from 114	213	Advanced

Ovid MEDLINE(R) Epub Ahead of Print and In-Process & Other Non-Indexed Citations

Search history sorted by search number ascending

# Searches	Results	Type
1 parkinson*.mp.	12648	Advanced
2 ramsay hunt.mp.	63	Advanced
3 (Lewy Body adj2 disease?).mp.	147	Advanced
4 (Lewy Body adj2 dementia?).mp.	143	Advanced
5 (movement adj2 disorder?).mp.	2248	Advanced
6 (Multiple System adj2 atroph*).mp.	379	Advanced
7 (Multisystem adj2 Atroph*).mp.	16	Advanced
8 (Multisystemic adj2 Atroph*).mp.	1	Advanced
9 (Progressive adj2 Supranuclear adj2 Palsy).mp.	381	Advanced
10 (Progressive adj2 Supranuclear adj2 Palsies).mp.	0	Advanced
11 (Progressive adj2 Supranuclear adj2 Ophthalmoplegia?).mp.	0	Advanced
12 Steele-Richardson-Olszewski.mp.	7	Advanced
13 Richardson? Syndrome.mp.	20	Advanced
14 mutual*.mp.	10211	Advanced



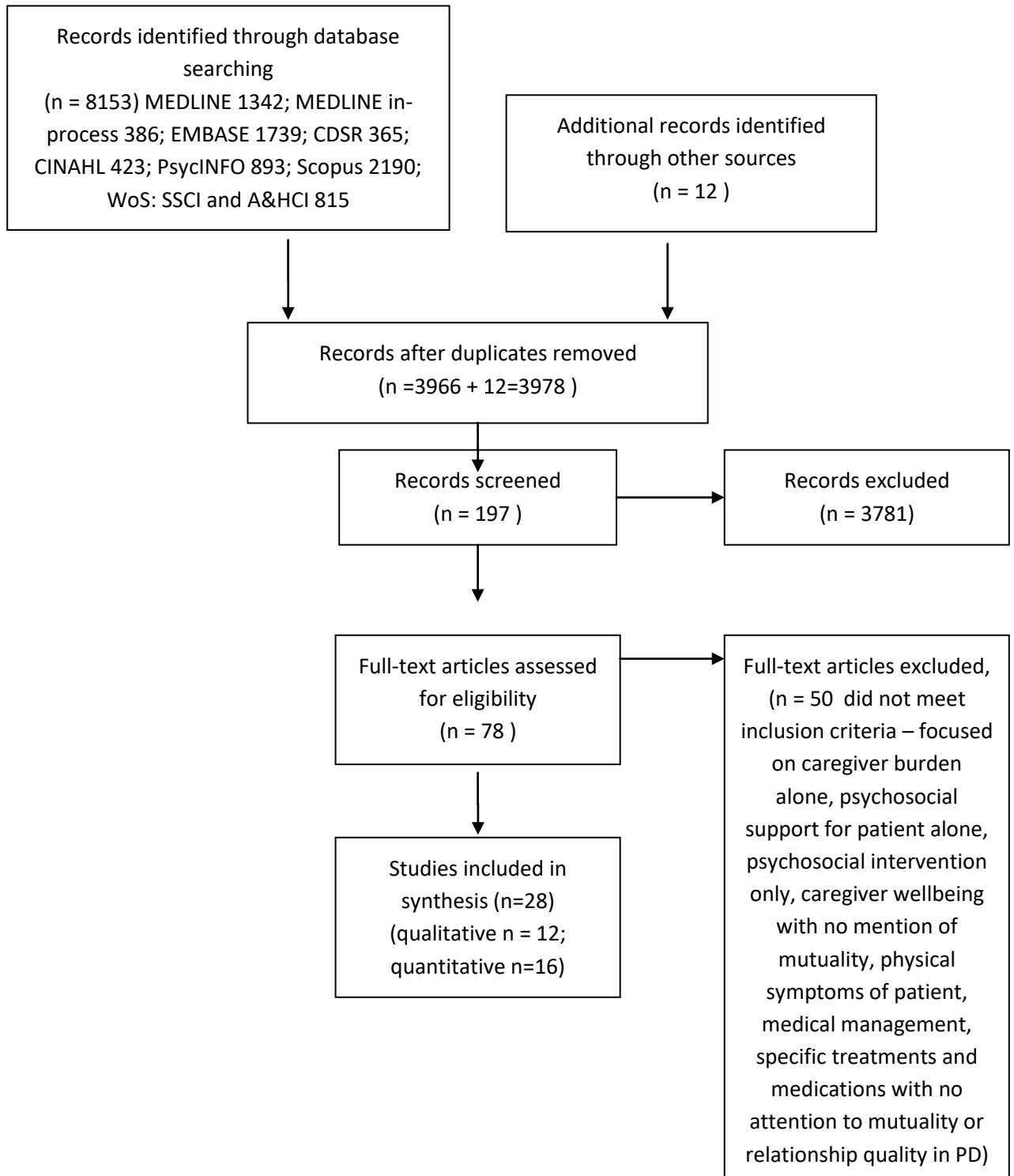
15 (Interpersonal adj2 Relation*).mp.	806	Advanced
16 (Inter-personal adj2 Relation*).mp.	14	Advanced
17 Interaction?.mp.	189504	Advanced
18 intimate.mp.	3314	Advanced
19 intimacy.mp.	486	Advanced
20 Communicat*.mp.	42738	Advanced
21 conflict?.mp.	8940	Advanced
forgive*.mp.		
22	188	Advanced
23 trust*.mp.	6617	Advanced
24 support*.mp.	288389	Advanced
25 (quality adj3 relationship*).mp.	1153	Advanced
26 (relationship* adj3 satisf*).mp.	581	Advanced
27 well-being.mp.	10283	Advanced
28 wellbeing.mp.	2597	Advanced
29 collaborat*.mp.	18661	Advanced
30 cooperat*.mp.	15233	Advanced
31 co-operat*.mp.	935	Advanced
32 dialogu*.mp.	1695	Advanced
33 emotion*.mp.	25098	Advanced
34 empath*.mp.	2323	Advanced
35 caring.mp.	4073	Advanced
36 compassion*.mp.	1328	Advanced
37 bonding.mp.	26800	Advanced
38 love.mp.	1118	Advanced
39 fear?.mp.	8095	Advanced
40 anger?.mp.	1786	Advanced
41 angry.mp.	632	Advanced
42 anxiet*.mp.	22746	Advanced
43 anxious*.mp.	1756	Advanced
44 frustration?.mp.	2065	Advanced
45 guilt*.mp.	1046	Advanced
46 shame.mp.	652	Advanced
47 hostil*.mp.	1496	Advanced

48 regret*.mp.	969	Advanced
49 reciprocity.mp.	1024	Advanced
50 sharing.tw.	9209	Advanced
51 intersubjectiv*.mp.	172	Advanced
52 inter-subjectiv*.mp.	14	Advanced
53 boundedness.mp.	196	Advanced
54 bondedness.mp.	0	Advanced
55 responsiveness.mp.	6543	Advanced
56 attune*.mp.	263	Advanced
57 adapt*.mp.	68586	Advanced
58 psycholog ic*.mp.	26500	Advanced
59 psychosocial*.mp.	10832	Advanced
60 psycho-social*.mp.	511	Advanced
61 experience*.mp.	116558	Advanced
62 coping.mp.	6402	Advanced
63 cope.mp.	4720	Advanced
64 (quality adj2 life).mp.	37259	Advanced
65 QoL.mp.	4997	Advanced
66 burden*.mp.	28488	Advanced
67 stress??.mp.	96531	Advanced
68 strain*.mp.	69904	Advanced
69 spous*.mp.	1890	Advanced
70 wife*.mp.	500	Advanced
71 wives.mp.	483	Advanced
72 husband*.mp.	1731	Advanced
73 marriage.mp.	2132	Advanced
74 marital.mp.	3636	Advanced
75 partner?.mp.	15615	Advanced
76 common-law.mp.	56	Advanced
77 commonlaw.mp.	0	Advanced
78 caregiver*.mp.	8856	Advanced
79 care-giver*.mp.	306	Advanced
80 carer*.mp.	2102	Advanced
81 couple.mp.	5811	Advanced

82 couples.mp.	4989	Advanced
83 or/1-13	14359	Advanced
84 or/14-68	881940	Advanced
85 or/69-82	41615	Advanced
86 83 and 84 and 85	240	Advanced

## Appendix D. PRISMA Flow Diagram

### PRISMA Flow Diagram



## Appendix E. Data Extraction Table (n=28)

Table 5. Data Extraction Table

### Quantitative Studies

Author, year, country, score, Purpose	Population/sample	Research Design, Outcome measure/scale	Results	Critique
<p>Bronner et al., 2014</p> <p>Israel</p> <p>Score 32</p> <p>To assess quality of sexual life (QoSL) of PD patients and their partners</p>	<p>89 PD patients (n=66 men, 23 women) and 69 partners (52 women, 17 men)</p>	<p>Consecutive PD patients and their partners from Sheba Medical Centre completed 5 item Quality of Sexual Life questionnaire, SF-12 to measure physical and mental health, illness severity, Hoehn &amp; Yahr staging, presence of depression, and demographics</p> <p>Relationship quality, intimate communication, desire, and sexual satisfaction</p>	<p>Male patients had higher sexual desire and fewer rejections than female patients but female patients had higher sexual satisfaction. Couples generally reported good sexual satisfaction. For partners who had lower QoSL, predictors could be difficulty in coping with PD of their partner and loss of companionship as illness progresses and caregiving demands are heavier. The physical and mental health (SF-12) scores of partners were below average</p>	<p>The authors state they had a low response rate but they do not provide the number of patients and/or partners approached; frequencies of Hoehn &amp; Yahr scores are not provided other than a median score of 2 indicating that most had early illness but the numbers of patients at advanced PD stages are not known; scores of SF-12 for physical and mental health are provided for partners only with scores for patients lacking. These omissions do not provide a clear picture of the study sample.</p>

<p>Brown et al., 1990</p> <p>UK</p> <p>Score 28</p> <p>To study perceived sexual function in PD patients and their partners</p>	<p>Couples attending a weekend meeting for PD patients and their partners organised by the Parkinson's Disease Society of the UK (n=33 couples)</p> <p>Male patients had more advanced illness</p>	<p>Convenience sampling for one-time completion of questionnaires</p> <p>Relationship quality, intimate communication, desire, and sexual satisfaction</p>	<p>More male than female patients dissatisfied with their sexual relationship; 9% of male spouses dissatisfied compared to 58% of wives; more male patients had sexual problems than female patients; more female spouses than male spouses had sexual problems; infrequency of sexual behaviour high in all but male spouses; male patients and their partners had greatest marital dissatisfaction; anxiety score similar among patients but higher in female spouses than male spouses. Motor symptoms, infrequency, non-communication, non-sensuality, and avoidance contributed to sexual dysfunction</p>	<p>Younger sample size according to mean of 49.6 years but range is not provided; duration of PD is provided but not stages; disability is self-rated according to ability in activities of daily living; recruitment of participants at a weekend meeting implies earlier stage of illness and less caregiving burden, thereby limiting generaliseability across PD stages</p>
<p>Carter et al., 1998</p> <p>United States</p> <p>Score 34</p> <p>Caregiving experiences of spouses of PD patients and whether their experiences differed by Hoehn &amp;</p>	<p>Caregiving spouses (n=380)</p> <p>There were no significant demographic differences across PD stages</p>	<p>Cross sectional; mailed questionnaire across 23 sites of the Parkinson Study Group, a 30-centre RCT (DATATOP) in early stage PD with focus on caregiver role strain, caregiver situation, and caregiver characteristics</p> <p>Mailed version of the Family Caregiving Inventory (FCI) to study caregiver role strain; the caregiving situation; characteristics of the caregiver</p>	<p>Strain frustration, and depression increased significantly by stages 4/5; number of caregiving activities increased significantly at stages 4/5 with more lifestyle changes and decline in predictability; mutuality declined by stage 2 and was significantly lower at all stages</p>	<p>Cross-sectional design was limiting; longitudinal would give more information; sample selected from RCT did not represent general population as eligibility criteria required no dementia or depression; more female than male subjects</p>

Yahr stage of disease				
Carter et al., 2012 (Pre-death grief) United States  Score 32  Predictors for pre-death grief in caregivers of persons with PD	Caregivers to persons with PD (n=74, male 72%, female 28%) who attended a PD family symposium  Average length of time since PD diagnosis 6.8 years. Grief was indicated in 17%.	Cross-sectional descriptive study  t-tests and regression analyses performed  1) Marwit and Meuser Caregiver Grief Inventory (MM-CGI) 3 subscales: Personal sacrifice and burden; Heartfelt sadness and longing; Worry and Felt Isolation 2) One open-ended question: "what would you say is the biggest barrier you have faced as a caregiver?"	Grief in caregivers higher in those whose partners had more advanced disease & severe symptoms; non-motor symptoms have greater impact on grief than motor symptoms. Important predictors of grief for caregivers: loss of personal freedom and their lives as they once knew them; loss of dreams loss of partner they had known; minimal understanding by others	Anonymous; no clinical assessment other than comments from participants; unequal number of male/female; recruitment from a family symposium does not likely provide an accurate reflection of PD patients
Carter et al., 2010 United States  Score 32  Caregiver strain in young versus older PD caregivers of partners with early	Spouses recruited from the Parkinson's Spouse's Project clinical trial, year 5: young=40-55 years of age (n=37); older aged 70+(n=28)	Cross-sectional study with participants recruited from the clinical trial  Variables studied: Role strain - worry, lack of personal resources, global strain  Mutuality-Archbold Mutuality Scale, rewards of meaning, and preparedness	Young spouses showed significantly higher role strain from lack of personal resources (p<.05), lower mutuality (p<.05), and lower rewards of meaning (p<.01). Young spouses have competing role demands and difficulty finding rewards in caregiving; lower mutuality in younger spouses is concerning because mutuality decreases as the disease progresses. Important to provide age-specific supports as younger spouses will live with caregiving for PD for a long period along with other competing demands vs. older	Small sample size; first study that examined age of caregiver so no comparison studies; included early PD stages only and not more advanced illness; spouses 56-69 years of age were not included; longitudinal study would show more effects on spouse

stage PD; influence of mutuality		t-tests, chi-square, regression analyses	caregivers	
Goy, 2008 United States  Score 27  Caregiver burden and unmet needs, experiences, and challenges, sense of preparation, and benefit of support services of caregivers of PD at end of life	Caregivers of PD decedents (n=47) after the death of their PD relative with PD  Mean age was 68 years.	In-person survey with caregivers recruited from Oregon Movement Disorders Clinic, VA, and a PD support group; t-tests, Mann-Whitney U, and correlations  Center for Epidemiological Studies Depression Scale (CES-D); FAM-CARE scale (satisfaction with medical care); questions about caregivers' preparedness; need for specific services; anxiety	One third of participants were unprepared to cope with emergencies, many physical patient needs, and overall stress of caregiving; physical needs were most stressful; poor family preparation for death of patient; cost of physical burden with maintaining patient at home; need for better communication with health providers	Sample drawn from just two hospital systems in one city; exploratory only and needs replications with more generalisable sample; no clinical assessment of patient; respondents more likely to be enrolled in hospice than most; majority were female respondents recruited from VA; many analyses; retrospective study that relied on memory
Lokk, 2009 Sweden  Score 27  Impact of PD and its caregiving time-course by the	A random sample of caregivers from the PD Association (n=404)-62% women, 32% men; 98% were spouses.	Cross-sectional telephone survey of caregivers selected by random sample  Questions generated from existing scales and the literature; use of Likert scale and dichotomous response questions; analysis done by logistic regression, ANOVA, or Kruskal-Wallis for groups of	Participants reported difficulty performing leisure and self-care activities; relationships impaired with friends & relatives; some still working; 57% reported no affirmation of their situation by others; increase in impairment in relationships as caregiving duration increased; professional home help resulted in no increased effect on social activity opportunities; limitations increased as duration of caregiving increased. PD has strong social impact on caregivers; equality and mutuality changes as disease	Telephone interviews without disease assessment; caregiving duration may not reflect disease state; not all PD patients are members of the PD Association in Sweden so these results may not be completely representative



partner from the caregiver perspective - focus on social factors and relationships; use of home support		caregiving duration by years (0-4), 5-10, >11 years	progresses; family balance gets disrupted by PD	
Lyons, 2009 United States  Score 35  Optimism, pessimism, mutuality, and spouse gender and the interaction of mutuality and gender in predicting role strain in PD spouses	Spouses of PD study subjects from a large clinical drug trial (n=255)	Longitudinal study with mailed questionnaire to caregivers over a 10 year period with data points at baseline, Year 2, and Year 10  Life Orientation Test (LOT) to measure optimism and pessimism; questions to measure role strain; Archbold's Mutuality scale  Bivariate and multivariate analyses	The spouse caring for a partner with PD demonstrated being at risk of increased role strain; female spouse gender predicted higher role strain with faster increases in role strain; high mutuality and optimism at baseline are protective against increased role strain at Year 10; strained relationships are more problematic for female than male caregivers	Advantages: long study period to examine changes in strain; focus on PD; results could help MDs plan ahead with patients and spouses  Limitations: only 3 data collection points; mailed questionnaire; large gap in time from Year 2 – 10; many lost to follow-up over 10 years
Lyons, 2007 United States	Family care dyads (n=103)	Longitudinal study over 20-month period with data collection at 5 month intervals; sample was drawn from the	Older adults demonstrated higher mutuality scores than their family caregivers; improvements in health associated with increase in mutuality and worsening health	Secondary data was used; only older frail adults and caregivers were included; younger relationships

<p>Score 34</p> <p>Mutuality in older adults and their family caregivers. Research questions: 1) do older adults and family caregivers have similar patterns of change in their mutuality? 2) are changes in physical health and depression associated with changes in mutuality? 3) are there cross-care-partner effects of physical health and mutuality?</p>		<p>control group of a larger nursing study of frail elderly recruited from referrals to home health care in low socioeconomic status households</p> <p>Measures: Mutuality using the Mutuality Scale; Physical health SF-36; Depression – Centre for Epidemiological Studies-Depression Scale</p>	<p>with decline in mutuality; higher depression was associated with lower mutuality; mutuality declined faster for care receivers than the caregivers; mutuality declined when physical health declined for both dyad members; enduring depression was a predictor for lower mutuality; <u>changes</u> in physical health predicted decline in mutuality; Unexpected finding – family caregiver mutuality did not decline significantly throughout the study – authors speculate that the major share of decline had already happened</p>	<p>would be a good comparator</p>
<p>Mavandadi et al., 2014</p> <p>United States</p> <p>Score 35</p>	<p>Veteran patient/spouse dyads with PD (n=25) from Philadelphia VA Medical Center</p>	<p>Each partner provided data for sociodemographic variables, physical &amp; mental wellbeing, relationship functioning, caregiver burden and Benefit Finding Scale</p> <p>Perceived benefits of having</p>	<p>Greater perceived benefits from having PD or living with a partner with PD was associated with higher marital quality for both partners. Benefit finding has a direct impact on marital quality in PD. Marital quality negatively correlated with spouses' anxiety</p>	<p>Early to medium stage of PD (mean H&amp;Y score 2.5); small sample size; cross-sectional design could not prove causality</p>

<p>Association between marital quality and benefit finding in PD patients and their partners</p>		<p>PD or being a partner to a person with PD (eg experience spiritual and personal growth, empathy, reprioritizing life goals)</p>		
<p>McRae et al., 2009 United States  Score 36  Predictors of loneliness in PD caregivers. 2 aims:  1)whether characteristics of patients or caregivers are more predictive of loneliness in caregivers 2) whether attending caregiver support groups indicates a difference in loneliness</p>	<p>Caregivers currently living with person with PD (n=70)</p>	<p>Mailed survey, 39% response rate (n=70), 74% female, 67 spouses  UCLA Loneliness Scale; Social Provisions Scale; Self-Efficacy Scale; questions related to caregiver and patient characteristics; modified Hoehn &amp; Yahr for caregivers; t-tests; regression analyses</p>	<p>Caregivers in this study reported higher levels of loneliness than all comparison groups except Alzheimer caregivers; caregiver variables were more predictive of loneliness than patient characteristics but better health, higher education and greater self-efficacy offered protection against loneliness; those who attended a support group were less lonely and received more support</p>	<p>Mailed survey to a local group only; generaliseability is questionable due to variations in respondents; no clinical assessment of patient; no subjective quality of life exploration</p>

<p>Morley et al., 2012</p> <p>UK</p> <p>Score 29</p> <p>Assessment of factors influencing quality of life (QoL) of carers of people with PD</p>	<p>PD patients and their carers recruited from Parkinson's UK, as well as an advertisement in the Parkinson's UK Research Opportunity website</p> <p>(n=283)</p> <p>61% response rate</p>	<p>Mailed questionnaire and a reminder letter four weeks after the questionnaire was mailed</p> <p>PDQ-Carer (29 item instrument with 4 domains- social and personal activities, anxiety and depression, self-care, and stress); PDQ-39 for patients for assessment of QoL in PD</p>	<p>Mobility and cognitive impairment in the PD patient, older age of the carer, and length of time in caregiving influenced QoL. Female caregivers and those with personal health issues reported lower quality of life; clinical management of PD focuses on symptoms and information rather than on support for caregivers</p>	<p>Bias selection as participants were self-referred from a national association of which they were members and from its website, not representative of a general PD population who may not be members; despite good response rate, one time data collection only is less ideal</p>
<p>Morrow et al., 2015</p> <p>United States</p> <p>Score 25</p> <p>To study whether PD patient-spouse co-reporting shows same health related quality of life (HRQoL) as patient ratings alone, and to assess whether mutuality of the marital relationship</p>	<p>Consecutive PD patient-spouse pairs (n=59) seen at University of Maryland Parkinson disease and Movement Disorder Centre.</p>	<p>Patient and spouse completed measures for themselves except for SF-12 – spouse completed it from his/her point of view for patient. Both completed SF-12 together agreeing on one response</p> <p>Measures: mutuality with Mutuality Scale; cognitive function with MoCA; mental and physical HRQoL with SF-12; medical status for patient only with Cumulative Illness Rating Scale</p>	<p>Spouses who had higher mutuality had greater agreement with patient's mental HRQoL and with the co-report but not for physical HRQoL (patient ratings were higher). Assessment of mental HRQoL may be affected by level of intimacy</p>	<p>This study looked at reporting differences, not the content of what was reported itself; quite complicated design</p>

is a factor of co-reported ratings				
Ricciardi et al., 2015 Italy  Score 29  Relationship quality and satisfaction in couples in which one partner has PD	PD patients and their partners (n=15 each) recruited from a workshop series at a conference	Validated instruments to evaluate quality of relationship, alexithymia, empathy, depression, and anxiety  Impact of alexithymia (inability to identify and describe one's emotions), empathy, depression, and anxiety on relationship quality and satisfaction in PD couples	Patients were significantly less satisfied with their marital relationship than their partners (p=0.03), more depressed (p=.003), and anxious (p=.015). Alexithymia and marital relationship quality were negatively correlated for patients; alexithymia influences loneliness and intimacy which are related to lower marital quality	Small sample size; pre-illness relationship was not studied for comparison; patients were recruited while attending a conference thereby including patients with less severe PD
Shim et al, 2011 United States  Score 32  To study factors that affect mutuality in the carers of people with progressive, neurodegenerative diseases over 12 months and changes over time	Caregivers of people with PD and Alzheimer's (AD) – n=187 dyads (102 AD and 85 PD); data from 91 carer-care recipient dyads in the control group who completed baseline, 6 month, and 12 month data completion	Secondary analysis of longitudinal data of RCT of control group  (multilevel design)  Mutuality scale (Archbold); Lawton Instrumental Activities of Daily Living Scale (IADL) – cognitive, motor, and decision making ability; Center for Epidemiologic Studies Depression Scale – depressive symptoms for carers	Lower mutuality was significantly associated with lower functional ability of the patient, less caregiving experience by the carer, more symptoms of depression in the carer, female caregiver; longer caregiving had significantly higher mutuality	Limitations due to being secondary to a larger RCT with use of data already limited to the parent study; longer period of study may have revealed more findings; longitudinal design is very good

for caregivers				
Tanji , et al. 2008 United States  Score 32  Association of mutuality in the marital relationship in PD, mental health, quality of life, and PD symptoms	PD spouse-patient pairs (n=96)	Cross-section – spouses completed mutuality scale & caregiver burden scales; both completed comorbidity, mental health, and quality of life scales; UPDRS for patients  Mutuality scale; caregiver Strain Index; brief symptom inventory; cumulative illness rating scale; SF12-v2; UPDRS	Less severe PD, less caregiver stress, and less depression for both partners were associated with increased mutuality; urinary incontinence, gait difficulties, balance problems, poor mental health and advanced disease associated with lower mutuality	Convenience sample of early PD H&Y stages 2-3 only; dyskinesia, tremor, incontinence, inability to go out much may not be seen as influencing mutuality due to focus on early PD when these symptoms are not as evident as in more advanced illness
<b>Qualitative Studies</b>				
Birgersson & Edberg, 2004 Sweden  Score 33  PD patients and the experiences of support for their	Persons with PD and their partners (n=6 couples); PD duration ranged from 14-24 years.	Content analysis; open-ended interviews with couples  Experience of support received and its effect on relationship	More support is available for PD patients than for their partners. Differing transition experiences in couples as disease progresses; pattern of transition influences type of support needed	Very small sample; all couples were married between 35 and 50 years – no comparison was possible to couples married for shorter times.

partners				
Carnett Martin, 2015, United States  Score 35  Psychosocial challenges of partners of people with PD	Partners of persons with PD (n=23, 15 women, 8 men)	In-depth semi-structured individual interviews with partners of persons with PD  Psychosocial changes both related and unrelated to caregiving	Many changes and losses for partners; minimal communication; unable to “rescue” frustration, resentment, impatience; housebound; unpredictability; fear for the future; helplessness, resentment, isolation,	Participants may not have revealed negative feelings due to feeling guilty about expressing them; sociodemographic variables were not considered for their impact on challenges of partners of PD patients; only 6 patients had advanced PD
Davis et al. 2011 United States  Score 35  The quality of caregiving relationships (mutuality) in caregiving spouses to persons with Alzheimer’s disease (AD) or Parkinson’s disease (PD) who said they have stressful caregiving	Caregivers recruited from a large clinical trial ASSIST caring for patients with early to mid-stage disease (n=187 – 102 AD; 85 PD)	Cross-sectional with use of quantitative measures and interviews  Comparison of AD and PD; comparison of groups for quantitative measures reported elsewhere (Shim, 2011 seen above)	40/130 said their relationship with the patient was the major source of their caregiving distress. Loss of the known relationship, tension, and care decision conflicts, declining mutuality were the main themes. Loss and grief were expressed more by PD carers than AD carers	No measurement of the quality of the relationship prior to the illness diagnosis A single interview cannot measure changes over time with a progressive condition that a longitudinal study could offer. Study recruited caregivers of patients with early to mid-stage illness only

relationships				
Eriksson & Svedlund, 2006 Sweden  Score 33  Middle-aged spouse's narratives about life with a chronically ill partner	Women living with chronically ill partners (n=4)	Phenomenological hermeneutic approach  Use of method of interpretation by Ricoeur (1976)  3 Steps:  1) Naïve reading  2)Structural analysis  3)Comprehensive understanding	1)Feeling of limitation 2) everyday life struggle 3)Striving for normalisation (preserving one's previous lifestyle; trying to restore balance;). Intimacy and mutual commitment are missing; feeling of abandonment; partner is a stranger	Very small sample size; only female partners studied; middle-aged women only not younger or elderly; no mention of what the chronic illnesses are
Haahr et al, 2012 Denmark  Score 36  The lived experience of being a spouse to a partner with advanced PD before and during the first year of DBS (Deep Brain	Spouses of partners with advanced PD and having DBS (n=10); 3 men, 6 women; 9 completed all 4 interviews	Longitudinal interview study with hermeneutic phenomenological approach influenced by methodology of van Manen  Methodology of van Manen utilised. Thematic analysis	Theme of solidarity emerged – shared responsibility and concern.  Before DBS: many losses – companionship, intimacy, social life, having a restricted life, After DBS: a sense of freedom but also things were not as before	All were Danish so same cultural background; big age range (41-76) so differing views on partnership may have emerged due to generational differences. Examined components of mutuality without explicitly calling it mutuality



Stimulation)				
Habermann, 2000 United States  Score 32  The illness experience of PD from the perspective of the spouse to identify their challenges and coping strategies	Middle aged spouses of persons with PD (n=8) – 5 wives, 3 husbands	Participants were identified from a larger study exploring PD in patients; semi-structured interviews conducted  Three interrelated interpretive strategies – thematic analysis, analysis of exemplars, and paradigm cases were done simultaneously	1)Challenges- watching spouse struggle; many losses of shared activities; changes in sexual relationships; 2)Coping strategies – 3 approaches: maintaining their own life; considering their own challenges as secondary; encouraging partner to stay active	Focus on being spouse of PD person not caregiver situation so not comparable to some other studies; small sample size; stage 2 or 3 so caregiving not needed as much; very homogeneous sample re: ethnicity, education, and SES; mean age of spouses was young at 51 years
Hodgson et al., 2004 United States  Score 32  The impact of PD on the couple relationship	Couples living with PD (n=10); purposive sampling from a PD support group  6 PD patients at stage 3, 2 each stages 2 and 4	Phenomenological qualitative approach; interviews with couples together;  Main question “what impact has PD had on your couple relationship?”	5 themes: relationship and disease history; impact on couple relationship; impact on self and others; resources; strategies for survival. Female caregivers had harder time coping with balancing needs; desire by couple to hide symptoms especially speech problems; PD causes strain on relationship; many losses that must be mourned; spiritual advisors needed; conflict with advancing illness; hope and thankfulness important to recognize; couples want to talk to professionals and see need to talk to each other	Participants recruited from a support group reflect those who can access resources and have less advanced illness; couples interviewed together may not allow for safety to each partner to speak about negative feelings

Hudson et al., 2006 Australia  Score 33  Palliative care needs of persons with PD and caregivers in Australia	8 patients with PD; 21 family caregivers (n=5 husbands, 14 wives, 2 children); 6 professionals 35 interviews in total; recruitment by advertising	Cross-sectional study with semi-structured interviews after self-referral from a state newsletter from PD association in 3 states  Use of different data sources was used to enhance dependability of findings	5 Themes: Emotional impact of PD and mutuality; difficulty staying connected; financial burden; managing physical challenges; finding help when disease is advanced. Recognition of many losses and the grieving of those losses physical, financial, social, emotional	Small sample size; questionable generaliseability as different groups were interviewed
Martin, 2016 United States  Score 35  How PD affects a couple's relationship	n=44 comprised of 21 dyads and 2 partners of PD patients whose PD partner did not participate	Cross-sectional study; participants recruited from flyers at support groups and advertisements in local newspapers and university newsletter; referrals from other participants (snowballing); for couples each member of the dyad was interviewed separately  Comparative techniques from grounded theory	Issues in the relationship resulted from: 1) changes in closeness between partners; 2) changes in roles in the relationship; 3) changes experienced in sexual intimacy; 5) financial stress; 6) fewer shared activities; 7) uncertainty about the future of their relationship  Many participants indicated no change in their relationship or feeling closer	Of the persons with PD, only 4 had advanced PD at Hoehn and Yahr stage 4 with none at stage 5. Only one partner cared for a spouse with advanced illness who could not participate. Therefore, this study was conducted on experience with early (n=11) to moderate (n=5) illness. Sample was well informed and connected due to self-referral from attending support groups and reading newspapers and university newsletter.  The majority of participants who lived with early PD may account for the response that they did not experience a change in their

				relationship; knowing that their partner was being interviewed may have influenced their response as well
McLaughlin, et al., 2010 UK  Score 33  The effects of caregiving experience for PD on spouses	Caregiving spouses (n=26); most older than 55 years of age	Cross-sectional study of interviews using convenience sampling  Content analysis	1) Increasing reliance on carer as disease progressed; inadequate medical monitoring; 2) big change in life routine, health issues and anxiety 3) loss of income. Big impact of caregiving on partners	Limited generaliseability ; convenience sampling; all lived in areas where community support is available even though some were not aware of them
Turney & Kushner, 2017, New Zealand  Score 32  1) To explore the experience of caring for a partner with PD; 2) to identify areas of needed support; 3) To inform health professionals about	Women over the age of 65; n=5; women were caring for their husband at home	Purposive method of convenience and snowball sampling  Semi-structured interviews; personal reflections in a diary by participants	1) Participants were very committed to caring for their PD husband and many emotions experienced due to being unprepared for the amount of work required and for the changes in their relationships and future plans. Some felt a love-hate relationship; 2) Good support was essential with most feeling the community and health professionals provided this; 3) There were limits to the amount of caring they could provide. It was very difficult to care for a spouse with PD at home and making the decision for residential care was difficult and painful  Despite reporting good support, stress, guilt, fatigue, and loneliness were reported by all	Very small sample size with no mention of the stage of PD of the husbands. One can only assume the three husbands in residential care had advanced PD but this is not explicit; participants were caregiving wives only – the perspective and experience of caregiving husbands is important but missing; lack of diversity in ethnicity and culture

the perceptions of caregiving spouses			participants	
Williamson et al., 2008 UK  Score 33  Experiences and coping strategies of caregiving spouses living with PD partners who have psychotic symptoms	Female caregiving partners of people with PD and psychotic symptoms (n=10)	Interpretative phenomenological study with purposive sampling in Lancaster, UK recruited from Movement Disorder clinic  Lazarus & Folkman framework for coping	Four themes contribute to strain on relationship: uncertainty and the desire for understanding; adapting to symptoms as disease progressed; the role of psychosis in changing identities; and comparing one's situation to others as a strategy to cope	Small sample size; no male caregivers were participants; not much emphasis on social support or mutuality; concentrated only on PD patients with psychosis

**Appendix F. Critical Appraisal Scale by Hawker et. al (2002)**

<b>1. Abstract and Title: Did they provide a clear description of the study?</b>		
<b>Score</b>	<b>Rating</b>	<b>Description</b>
4	Good	Structured abstract with full information and clear title
3	Fair	Abstract with most of the information
2	Poor	Inadequate abstract
1	Very Poor	No abstract
<b>2. Introduction and aims: Was there a good background and clear statement of the aims of the research?</b>		
4	Good	Full but concise background to discussion/study containing up-to-date literature review and highlighting gaps in knowledge; clear statement of aim AND objectives including research questions
3	Fair	Some background and literature review; research questions outlined
2	Poor	Some background but no aims/objectives/questions, OR aims/objectives but inadequate background
1	Very Poor	No background or literature review
<b>3. Method and data: Is the method appropriate and clearly explained?</b>		
4	Good	Method is appropriate and clearly explained (eg, questionnaires included); clear details of the data collection and recording
3	Fair	Method appropriate, description could be better; data described
2	Poor	Questionable whether data is appropriate; little description of data

1	Very Poor	No mention of method, AND/OR method inappropriate, AND/OR no details of data
<b>4. Sampling: Was the sampling strategy appropriate to address the aims?</b>		
4	Good	Details (age/gender/race/context) of who was studied and how they were recruited; why this group was recruited; the sample size was justified for the study; response rates shown and explained
3	Fair	Sample size justified; most information given, but some missing
2	Poor	Sampling mentioned but few descriptive details
1	Very Poor	No details of sample
<b>5. Data analysis: Was the description of the data analysis sufficiently rigorous?</b>		
4	Good	Clear description of how analysis was done; qualitative studies: Description of how themes derived/respondent validation or triangulation; quantitative studies: Reasons for tests selected hypothesis driven/numbers add up/statistical significance discussed
3	Fair	Qualitative: Descriptive discussion of analysis; Quantitative
2	Poor	Minimal details about analysis
1	Very Poor	No discussion of analysis
<b>6. Ethics and bias: Have ethical issues been addressed, and what has necessary ethical approval gained? Has the relationship between researchers and participants been adequately considered?</b>		
4	Good	Ethics: Where necessary issues of confidentiality, sensitivity, and consent were addressed; Bias: Researcher was reflexive and/or aware of own bias
3	Fair	Lip service was paid to above (i.e., these issues were acknowledged)

2	Poor	Brief mention of issues
1	Very Poor	No mention of issues
<b>7. Results: Is there a clear statement of the findings?</b>		
4	Good	Findings explicit, easy to understand, and in logical progression; tables, if present, are explained in text; results relate directly to aims; sufficient data are presented to support findings
3	Fair	Findings mentioned but more explanation could be given
2	Poor	Findings presented haphazardly, not explained, and no progress logically from results
1	Very Poor	Findings not mentioned or do not relate to aims
<b>8. Transferability or generalizability: Are the findings of this study transferable (generalizeable) to a wider population?</b>		
4	Good	Context and setting of the study is described sufficiently to allow comparison with other contexts and settings, plus high score in Question 4 (sampling)
3	Fair	Some context and setting described, but more need to replicate or compare the study with others, PLUS fair score or higher in Question 4
2	Poor	Minimal description of context/setting
1	Very Poor	No description of context/setting
<b>9. Implications and usefulness: How important are these findings to policy and practice?</b>		
4	Good	Contributes something new and/or different in terms of understanding/insight or perspective; suggests ideas for further research; suggests implications for policy and/or practice
3	Fair	Two of the above
2	Poor	Only one of the above

1	Very Poor	None of the above
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**Appendix G. Critical Quality Appraisal of Included Studies Utilizing Hawker et al. Approach (n=28)**

**Table 6. Critical quality appraisal of included studies utilising Hawker et al. approach (n=28)**

Author	Abstract & Title	Introduction & Aims	Method & Data	Sampling	Data Analysis	Ethics and Bias	Results	Transferability/ Generaliseability	Implications & Usefulness	Total Score
<b>Quantitative Studies</b>										
Bronner et al., 2014	4	3	4	4	4	3	4	4	2	<b>32</b>
Brown et al., 1990	3	4	4	4	4	0	4	3	2	<b>28</b>
Carter et al. 1998	4	4	4	4	4	2	4	4	4	<b>34</b>
Carter et al., 2010	4	4	3	4	4	2	4	3	4	<b>32</b>
Carter et al., 2012	4	4	4	3	4	1	4	4	4	<b>32</b>

Goy, 2008	3	3	3	2	4	3	4	2	3	<b>27</b>
Lokk, 2009	4	3	4	2	4	3	3	2	4	<b>27</b>
Lyons 2007	4	4	4	4	4	3	4	3	4	<b>34</b>
Lyons et al., 2009	4	4	4	4	4	3	4	4	4	<b>35</b>
Mavandadi et al, 2014	4	4	4	4	4	3	4	4	4	<b>35</b>
McRae et al., 2009	4	4	4	4	4	3	4	4	4	<b>36</b>
Morley et al., 2012	3	3	4	2	3	4	4	2	4	<b>29</b>
Morrow et al., 2015	4	3	4	3	2	2	4	3	2	<b>25</b>
Ricciardi et al., 2015	4	3	4	3	4	1	4	4	2	<b>29</b>
Shim et al. 2011	4	4	3	3	4	3	4	3	4	<b>32</b>

Tanji 2008	4	3	4	3	4	3	4	3	4	<b>32</b>
<b>Qualitative Studies</b>										
Author	Abstract & Title	Introduction & Aims	Method & Data	Sampling	Data Analysis	Ethics and Bias	Results	Generalizeability	Implications & Usefulness	Total Score
Birgersson & Edberg, 2004	3	4	4	3	4	3	4	4	4	<b>33</b>
Carnett Martin, 2015	4	4	4	4	4	3	4	4	4	<b>35</b>
Davis et al., 2011	4	4	4	4	4	3	4	4	4	<b>35</b>
Eriksson & Svedlund, 2006	4	3	4	3	4	4	4	4	4	<b>33</b>
Haahr et al., 2012	4	4	4	4	4	4	4	4	4	<b>36</b>
Habermann,	4	4	4	4	4	2	4	4	2	<b>32</b>

2000										
Hodgson et al., 2004	2	4	4	4	4	2	4	4	4	<b>32</b>
Hudson et al., 2006	4	3	4	3	4	3	4	4	4	<b>33</b>
McLaughlin et al., 2010	4	3	4	4	4	3	4	4	3	<b>33</b>
Martin, 2016	3	4	4	4	4	4	4	4	4	<b>35</b>
Turney & Kushner, 2017	4	3	4	2	4	3	4	4	4	<b>32</b>
Williamson et al., 2008	4	4	4	4	4	3	4	4	3	<b>33</b>

## Appendix H. Relationship of Variables in Quantitative Studies

**Table 7. Relationship of variables in quantitative studies**

	Mutuality scale	Care giving	SF-12/SF-36	Depression	Preparedness	Grief	Sexuality	Optimism and/or pessimism	Loneliness	Role strain	Quality of Life	Alexithymia	PD	Benefits of Illness	Carer
Tanji	√	√	√										√		
Shim	√	√		√									√		√
Carter 1998	√	√		√									√		√
Goy				√	√										
Lok															
Carter 2012						√									
Lyons	√			√				√		√					
McRae									√				√		√
Carter 2010	√				√					√					
Lyons	√		√	√											

2007															
Morrow	√		√								√				√
Mavandadi														√	
Ricciardi				√								√			
Bronner							√								
Morley											√				√
Brown				√			√						√		

***Appendix I. Analytic process showing the evolution from text into themes***

**1. Example of data provided by Barbara showing meaning from text**

Participant	Text	Meaning from Text
Barbara	<p>Then some places have inadequate parking spaces. There is only one or two token parking spaces and if they're already taken, now what? <u>Then you have to park way at the other end of the parking lot and then you have to shuffle this person...</u> so you finally say <u>'the heck with this; I'm going home, forget it.</u></p> <p>The last time we were at Tim Hortons <u>it was such a thrash to get in and out of that building and the same with the washroom. They have a little handicap sticker on the door. What a joke.</u></p> <p>There is a narrow door and then I have to go into the men's washroom because I have to assist him. No one has said anything but I'm kind of thinking that people think what's going on that this woman is going in the men's washroom... I'm thinking 'what are people thinking?'"</p>	<p>Going out is too difficult with somebody who cannot move</p> <p>Barriers in public places contribute to the difficulty of going out with somebody with advanced PD</p>

## 2. The evolution from text of each participant to Overarching Theme Using van Manen's Selective Approach

Text from each participant	Emerging Themes	Overarching Theme
<p>Elizabeth: <u>my son says 'let's go here, let's go there' but I m not going because I don't know when he (husband) is going to faint; when he is going to fall; I don't want to go.</u></p> <p>Barbara: <u>I sit and dream about wouldn't it be nice to go here or there. We had planned our retirement...we were going back to Hawaii...New Orleans. I wanted to do some other countries.</u></p> <p>Susan: <u>we very seldom have friends in.</u> we are in a bible study group together and they meet here in the winter which makes it easier for us.</p> <p>Barbara: <u>Then you have to park way at the other end of the parking lot and then you have to shuffle this person... so you finally say 'the heck with this; I'm going home, forget it.'</u> The last time we were at Tim Hortons <u>it was such a thrash to get in and out of that building and the same with the washroom. They have a little handicap sticker on the door. What a joke.</u></p> <p>Robert: <u>I take her down and we get an ice cream in the van</u></p> <p>Ann: <u>I can't physically get him out. The only place we go is to appointments and that is always a chore so I have get somebody to help me</u></p> <p>Sam: <u>Most is she goes to the hairdresser and</u></p>	<p>Going out is too difficult with somebody who cannot move;</p> <p>Barriers in public places contribute to the difficulty of going out with somebody with advanced PD; Going anywhere is so very challenging whether it is a simple local gathering with friends, travel to other cities or countries, or going out for lunch for a treat; Staying home seems to be easiest and safest; One wife is not comfortable going out without her husband so they do not go out; outings are minimal and for a short time only</p>	<p>Where can we go?</p>



<p><u>we come back</u></p> <p>Natalie: we do go for a walk every day; not very much.</p> <p>Mary: recently I haven't gone out with him but it's just so much-that was when we were taking the subway-<u>it's a lot of work</u></p> <p>Larry: <u>Nothing</u> – until a year or two ago, I would take her for a walk. She would be in the wheelchair</p> <p>Fatima: <u>I don't feel comfortable to leave him home alone and to go [myself]. To let him feel like this and he cannot move and that is why he is home. So that is not for me; I cannot do it.</u></p> <p>Jim: Yes, when she is okay we do that <u>but not too much.</u></p> <p>Craig:if you're out, she wants to get home to rest so you know our social activities have been restricted</p>		
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**Emerging themes by participants**

Barbara and Mary; going out with someone with PD requires planning and assistance due to the person's difficulty in walking and societal barriers

Elizabeth: going out is too difficult because he may fall and we will be away from home

Barbara: travel away from home is a dream that can no longer be fulfilled

Susan: our inability to go out has really limited our social life; friends have to come to us

Ann: even going to medical appointments is difficult and help is required

Robert, Sam, Natalie, Jim: outings are simple and for a short duration

Fatima: since PD partner cannot go out, she does not like to leave him behind so they do not go

Craig: PD partner cannot tolerate being out for long

Elizabeth: his physical condition is too precarious

**Overarching Theme: Where Can We Go?**

**Appendix J. Ethics Application Submitted to Lancaster University**



**Faculty of Health and Medicine Research Ethics Committee (FHMREC)**

**Lancaster University**

**Application for Ethical Approval for Research involving  
direct contact with human participants**

<p>1. Title of Project: Experiences of Mutuality in the Spousal Relationship in Advanced Parkinson's Disease from the Perspective of the Caregiving Partner</p> <p><i>This research is being conducted as part of my PhD studies at Lancaster University UK</i></p>
<p>2. If this is a student project, please indicate what type of project by ticking the relevant box:</p> <p><input type="checkbox"/> PG Diploma      <input type="checkbox"/> Masters dissertation      <input type="checkbox"/> MRes      <input type="checkbox"/> MSc      <input type="checkbox"/></p> <p>DClinPsy SRP</p> <p><input checked="" type="checkbox"/> PhD Thesis      <input checked="" type="checkbox"/> PhD Pall. Care/Pub. Hlth/Org. Hlth &amp; Well Being      <input type="checkbox"/> MD</p> <p><input type="checkbox"/> DClinPsy Thesis</p> <p><input type="checkbox"/> Special Study Module (3<sup>rd</sup> year medical student)</p>
<p>3. Type of study</p> <p><input checked="" type="checkbox"/> Involves direct involvement by human subjects</p> <p><input type="checkbox"/> Involves existing documents/data only. Contact the Chair of FHMREC before continuing.</p>

<b>Applicant information</b>
4. Name of applicant/researcher: Rena Arshinoff
5. Appointment/position held by applicant and Division within FHM
PhD Student
6. Contact information for applicant:

E-mail: rarshinoff@rogers.com/rena.arshinoff@lancs.ac.uk

Telephone: 1-416-733-7930

Address: 167 Lord Seaton Road

Toronto, Ontario M2P 1K8 CANADA

7. Project supervisor(s), if different from applicant:

Name(s): Dr. Anne Grinyer / Dr. Sara Morris

E-mail(s): [a.grinyer@lancaster.ac.uk](mailto:a.grinyer@lancaster.ac.uk) / s.m.morris@lancs.ac.uk

8. Appointment held by supervisor(s) and institution(s) where based (if applicable):-

Dr Anne Grinyer (80%)

Senior Lecturer, Lancaster University Department of Health Research

Director Masters Programmes

Division of Health Research,

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Lancaster LA1 4YG

University.Tel: 01524 592677

Dr Sara Morris (20%)

Senior Research Associate and Public Involvement Specialist

Faculty of Health and Medicine,

Division of Health Research,

Lancaster University,

Lancaster, LA1 4YG

Direct Tel: 01524 592656

9. Names and appointments of all members of the research team (including degree where applicable)

Rabbi Rena Arshinoff RN, BA, MHSc, MAHL

The Project

**NOTE:** In addition to completing this form you must submit a detailed research protocol and all supporting materials.

Please see the attached protocol

10. Summary of research protocol in lay terms (maximum length 150 words).

Parkinson's Disease is a neurodegenerative and prolonged progressive illness affecting the patient and family members especially the spouse who is frequently the main caregiver (Tanji, 2008; Martinez-Martin, 2008; O'Connor, 2008). The spousal relationship may change from one of loving and equal partners to that of caregiver and patient with associated feelings of frustration, disappointment, anger, and multiple losses for both parties (Carter, 1998; Archbold, 1990; Moore, 2002). While this has been observed anecdotally, there is paucity in the literature in relation to PD concerning this issue and the little that does exist is quantitative research. This qualitative study seeks to capture the lived experience from the perspective of the caregiving spouse. While work has been done on caregiver burden, this research study focuses on the spousal relationship, specifically mutuality. This study uses a phenomenological approach with semi-structured interviews recruited using purposive sampling from the Palliative Parkinson's clinic at Toronto Western Hospital

**References:**

Carter JH, Stewart BJ, Archbold PG, et. al. (1996). Living with a person who has Parkinson's Disease: the spouse's perspective by stage of disease. *Movement Disorders*. 13(1): 20-28.

Martinez-Martin P, Arroyo S, Rojo-Abuin JM, et. al. (2008). Burden, perceived health status, and mood among caregivers of Parkinson's Disease patients. *Movement Disorders*. 23 (12): 1673-1680.

Moore O, Gurevich T, Korczyn AD, et. al. (2002). Quality of sexual life in Parkinson's disease. *Parkinsonism and Related Disorders*. 8:243-246.

O'Connor EJ, McCabe MP. (2008). The impact of neurological illness on marital relationships. *Journal of Sex & Marital Therapy*. 34:114-132.

Tanji H, Anderson KE, Gruber-Baldini AL, et. al. (2008). Mutuality of the marital relationship in Parkinson's Disease. *Movement Disorders*. 23(13): 1843-1849.

11. Anticipated project dates

Start date: October 2014    End date: December 2015

12. Please describe the sample of participants to be studied (including number, age, gender):

It is expected at this time that 12-15 participants will be recruited in order to achieve data saturation. Parkinson's Disease tends to affect older individuals as a general rule but not always so it is anticipated that study subjects will be older than 50 years of age. Both men and women will be recruited.

13. How will participants be recruited and from where? Be as specific as possible.

Participants will be the caregiving spouse of Parkinson's patients who attend the Palliative Parkinson's clinic at Toronto Western Hospital, University Health Network, one of Canada's largest teaching and research hospitals. A third party, specifically, a clinic staff member can approach eligible candidates, providing information about the research study and inviting them to participate although the hospital prefers either the principal investigator or a staff member known to the patient to do so. An information letter will be provided.

14. What procedure is proposed for obtaining consent?

Either the researcher or a staff member of the clinic known to the patient will approach potential study subjects. Upon agreeing to participate, the name and contact information of the potential participant will be forwarded to the researcher. Informed consent will be obtained and questions answered by the researcher.

15. What discomfort (including psychological), inconvenience or danger could be caused by participation in the project? Please indicate plans to address these potential risks.

There are no medical risks associated with participating in this study. There can be physical discomfort if sitting for one hour is uncomfortable or emotional discomfort if some of the subject matter raised elicits tears, sadness, anger, or frustration. There may be questions that participants prefer not to answer. At any time, the study subject can request that the interview stop and this will be honoured. Emotional and spiritual support will be arranged for study subjects should they require and/or request this.

16. What potential risks may exist for the researcher(s)? Please indicate plans to address such risks (for example, details of a lone worker plan).

As the researcher is working alone on this study, support is required if interviews

will be done in the home of participants. Details will be given to a hospital clinic staff member as to the whereabouts of where the interview will be held and availability by phone.

It is possible that the researcher may be triggered emotionally by information provided by study subjects. Emotional and spiritual support will be planned in advance of the start of the study for this.

17. Whilst we do not generally expect direct benefits to participants as a result of this research, please state here any that result from completion of the study.

The researcher will use results learned from this study to identify areas of importance where future work will offer more support and resources for individuals dealing with such issues. It is hoped that a model of care will be developed to assist others and perhaps participants as well.

18. Details of any incentives/payments (including out-of-pocket expenses) made to participants:

Nil

19. Briefly describe your data collection and analysis methods, and the rationale for their use

After providing informed consent, the caregiving spouse will participate in a single semi-structured audio recorded interview either in the clinic following an appointment, at a separate appointment, or at the home, depending on preference and logistics. Broad open-ended questions formulated on studies and findings in the literature will be formulated, field-tested, and utilized with appropriate revisions made accordingly. The sample size is determined to be 12-15 participants for achieving data saturation.

#### Rationale

The qualitative approach offers the opportunity to participants to share their lived experience rather than responding to structured Likert scale questionnaires. Semi-structured interviews allow for in-depth sharing, reflection, and meaning as participants will share their experiences from their individual perspective (Bowling, 2009). Such interviews allow respondents to be heard and thus empowered by both telling their personal experience and contributing to salient research (Bowling, 2009). The semi-structured interview allows for the spouse's perspective to some general questions rather than responding to highly structured questions. This permits some flexibility as the emphasis can be on what the respondent considers to be significant (Bryman, 2012).

References:

Bowling, A. (2009). *Research methods in health*. Berkshire, UK: McGraw-Hill House.

Bryman, A. (2012). *Social research methods*. New York, NY: Oxford University Press.

20. Describe the involvement of users/service users in the design and conduct of your research. If you have not involved users/service users in developing your research protocol, please indicate this and provide a brief rationale/explanation.

Users/service users have not been involved as this is a small scale PhD study.

21. What plan is in place for the storage of data (electronic, digital, paper, etc.)? Please ensure that your plans comply with the Data Protection Act 1998.

A unique study identification number will be assigned to each participant and transcripts and tapes will be identified by this number alone. The only documents with a participant's name will be the informed consent form and a list mapping the name to the study number. These documents and transcripts will be stored in a locked cabinet in a locked office and transcribed interviews will be stored on the server of the hospital's computer system. The digital recorders will be kept separate from the documents to maintain the integrity of the confidentiality. Transcripts that have been coded by the researcher will be kept under lock and key. Data and recordings will be kept in these secure areas for 10 years and then destroyed.

22. Will audio or video recording take place?  no  audio  
 video

If yes, what arrangements have been made for audio/video data storage? At what point in the research will tapes/digital recordings/files be destroyed?

Transcribed interviews will be stored on the server of the hospital's computer system. The digital recorders will be kept separate from the documents to maintain the integrity of the confidentiality. They will be kept for 10 years (University Health Network requirements) and then destroyed.

23. What are the plans for dissemination of findings from the research?

Study results will be disseminated initially at a formal university dissertation at Lancaster University and subsequent presentations at Toronto Western Hospital, University Health Network, professional conferences and through publication in peer reviewed journals. Journals of interest for this thesis topic include *Movement Disorders*, *Journal of Pastoral Care and Counselling*, *Journal of Health Care Chaplaincy*, *Neurology*, *Journal of Neurological Sciences*, and many of the



Nursing journals. It is hoped that findings from this study will be of interest for chapters in books on Movement Disorders as well as living with chronic illness.

24. What particular ethical problems, not previously noted on this application, do you think there are in the proposed study? Are there any matters about which you wish to seek advice from the FHMREC?

#### Perceived Coercion

The researcher or clinic coordinator will approach the individual to participate. Because the researcher may be known to potential participants, it is important to minimize perceived coercion which may occur if the spouse does not want to disappoint the researcher. To minimize such bias, a recruitment letter, flyer, or verbal invitation will be provided and potential study subjects may take this information away with them to think about it if so desired. When desired participation is expressed, the clinic coordinator will inform the researcher who will contact the individual, introduce and conduct the informed consent process, and initiate the interview after obtaining consent. A statement indicating there is no conflict of interest must be provided. (Silverman, 2010). These actions will assist the potential participant to make a voluntary decision about participation. The informed consent process will follow the process required by both Lancaster University (UK) and University Health Network (Canada).

#### Conducting Fieldwork

##### 1) Interview conducted with the spouse alone

The research conducted in this study focuses on the perspective of the spouse who does not have PD and is the primary caregiver. Movement disorders affect the immediate family as well as the patient. Several concerns arise if both parties are included: one interviewee may dominate, the patient may feel his/her opinion is not important, the focus of discussion may take an undesired shift losing sight of the research questions, and antagonisms between spouses may arise (Arksey, 1996). Soderberg focused on the perspective of the husband in order to obtain "an insider view" (Soderberg et. al., 2003). The discussion of difficult topics can be challenging and may be avoided in order to maintain the stability of that relationship (Morris, 2001). Moreover, data derived from a joint interview provides a picture that is a combined result of separate perspectives while an individual one provides data from a single person's lens (Seymour et. al, 1995). This study seeks the individual perspective.

Spiritual support assists individuals in finding meaning. Ohman and Soderberg propose that understanding meaning is essential in the development of assistance and interventions that can assist those who care for a close relative living with a progressive illness (Ohman & Soderberg, 2004). The objectives of this research are best met by

interviewing the spouse alone. If patients question why their spouse alone is included, information will be provided to them about the rationale for this study.

2) Location of the interview

This concerns the issue of privacy for the spouse who is being interviewed as well as the needs of the patient who is in the home at the time of the interview. Issues arising include the need for the patient to be in another room and excluded which carries possible feelings of feeling physically unsafe and excluded from the experience (Morris, 2001). The ideal location will be at the hospital before or following a clinic appointment if the patient can be left alone for one hour or if another person accompanies them for the visit to be present during the private interview; interviews conducted at the hospital can provide greater safety but may not be practical for the participants. An alternative for some will be conducting an interview while the patient is at a day program, if applicable. If these are not possible, and the choice is to participate in the interview at the home, a private room will be required. Once again, this will require some planning in order to be sure the patient is safe and the location ensures privacy.

3) Support for the participant and the researcher

Engaging in dialogue about the spousal relationship with an ill spouse may induce feelings of anxiety, sadness, anger, or impatience. Participants will be informed that they may end the interview at any time or change their mind about participating. At the same time, it is possible that the researcher may be emotionally triggered as well. Ensuring the availability of emotional and spiritual support will be arranged.

4) Safety of the researcher

In order to ensure safety of the researcher when interviews are conducted in homes, arrangements must be made for availability by phone of a team member of the Movement Disorders program while still maintaining confidentiality. It will be important for the researcher to be aware of the need to end the interview in the case of perceived risk (Ritchie & Lewis, 2003). Debriefing will be necessary in such cases.

References:

Arksey, H. (1996). Collecting data through joint interviews. *Social Research Update*. 15:1-7.

Ohman M & Soderberg S. (2004). The experiences of close relatives living with a person with serious chronic illness. *Qualitative Health Research*. 14: 396-410.

Morris SM. (2001). Joint and individual interviewing in the context of cancer. *Qualitative Health Research*. 11(4): 553-567.

Ritchie J & Lewis, J. (Eds) (2003). *Qualitative Research Practice*. London, UK: Sage Publications.

Soderberg S, Strand M, Haapala M, Lundman B. (2003). Living with a woman with fibromyalgia from the perspective of the husband. *Journal of Advanced Nursing*. 42(2): 143-150.

Signatures:                      Applicant: Rena Arshinoff

    Date: January 13, 2015

    Project Supervisor\* (if applicable):

.....

    Date:

.....

\*I have reviewed this application, and discussed it with the applicant. I confirm that the project methodology is appropriate. I am happy for this application to proceed to ethical review.

Appendices: Forms required by University Health Network (UHN) as submitted to UHN and FHMREC at Lancaster University

- Consent Form to Participate in a Research Study
- Data Collection/Case Report Form
- Letter/Telephone Script for Use by Third Party (if needed) for Introduction Information for Potential Study Participant
- Recruitment Materials
- Interview Guide
- Confidentiality Agreement for the Transcription of Qualitative Data

Data Collection/Case Report Form

Study Title: Experiences of Mutuality in the Spousal/Common Law Relationship in Advanced Parkinson's Disease from the Perspective of the Caregiving Partner

Study Participant Descriptive Data

Study ID Number	
Address	
Telephone Number	
Date of Birth	
Date Consent Signed	
Date of Completed Interview	

Letter/Telephone Script for Use by Third Party (if needed) for Introduction of Information for  
Potential Study Participant

Study Title: Experiences of Mutuality in the Spousal/Common Law Relationship in Advanced  
Parkinson's Disease from the Perspective of the Caregiving Partner

Date to be inserted here

Dear \_\_\_\_\_,

My name is \_\_\_\_\_. As you know, Toronto Western Hospital of University Health Network is a teaching hospital and a leader in Canada that conducts many research studies. I am contacting you to tell you of a research study that you might be eligible to participate in. This study is conducted by Rena Arshinoff, Spiritual Care Professional in our Movement Disorders program. This study is the research for her PhD. The purpose of this study is to understand how the spousal relationship changes in chronic illness course of Parkinson's Disease from the perspective of the caregiving spouse. The ultimate goal is to understand such changes throughout the illness and to study the spiritual and emotional feelings and needs associated with them. This will clarify the role of Spiritual Care in palliative care for couples facing long term chronic illnesses that are progressive.

Participation is voluntary and involves a single interview for approximately one hour to be done at a time and location convenient for you. If you are interested in participating, I will forward your name to Rena who will contact you. Rena will be able to respond to any specific questions you may have.

On behalf of Rena, thank you for your interest.

Best wishes,

\_\_\_\_\_

## Recruitment Materials

**Study Title: Experiences of Mutuality in the Spousal/Common Law Relationship in Advanced Parkinson's Disease from the Perspective of the Caregiving Partner**

Recruitment will be purposive sampling from among caregiving partners of the patients who attend the Palliative Parkinson's clinic at Toronto Western Hospital. No public recruitment will occur with no need for recruitment materials besides the Telephone Script to be used by the Third Party

Study Title: Experiences of Mutuality in the Spousal/Common Law Relationship in Advanced Parkinson's Disease from the Perspective of the Caregiving Partner

Confidentiality Agreement for the Transcription of Qualitative Data

Name of Study:	Experiences of Mutuality in the Spousal/Common Law Relationship in Advanced Parkinson’s Disease from the Perspective of the Caregiving Partner
Study PI:	Rena Arshinoff

In accordance with the Research Ethics Committee at Lancaster University (UREC), all participants in the above-named study are anonymised. Therefore any personal information or any of the data generated or secured through transcription will not be disclosed to any third party.

By signing this document, you are agreeing:

Not to pass on, divulge or discuss the contents of the audio material provided to you for transcription to any third parties

To ensure that material provided for transcription is held securely and can only be accessed via password on your local PC

To return transcribed material to the research team when completed and do so when agreed in password protected files

To destroy any audio and electronic files held by you and relevant to the above study at the earliest time possible after transcripts have been provided to the research team, or to return said audio files.

Your name (block capitals) \_\_\_\_\_

Your signature \_\_\_\_\_

Date \_\_\_\_\_

## ***Appendix K. Consent to Participate in a Research Study***

Study Title: Experiences of Mutuality in the Spousal/Common Law Relationship in Advanced Parkinson's Disease from the Perspective of the Caregiving Partner

Investigator: Rena Arshinoff

Contact Information: 416-603-5836

### **Introduction**

You are being asked to take part in a research study. Please read the information about the study presented in this form. The form includes details on study's risks and benefits that you should know before you decide if you would like to take part. You should take as much time as you need to make your decision. You should ask the investigator or study staff to explain anything that you do not understand and make sure that all of your questions have been answered before signing this consent form. Before you make your decision, feel free to talk about this study with anyone you wish including your friends, family, and family doctor. Participation in this study is voluntary.

### **Background/Purpose**

The purpose of this study is to understand how the spousal relationship changes in chronic illness during the course of Parkinson's Disease from the perspective of the caregiving partner. The ultimate goal is to understand such changes throughout the illness and to study the spiritual and emotional feelings and needs associated with them. This will also help to clarify the role of Spiritual Care in palliative care for couples facing long term chronic illnesses that are progressive. You are being asked to participate in this study as you are the caregiving partner of an individual with advanced Parkinson's Disease. Your contribution will assist in further development in the assistance provided to families dealing with Parkinson's Disease.

### **Study Design:**

This study consists of a single interview that will last approximately one hour during which you will be asked to respond to some questions.

### **Study Visits and Procedures:**

If you decide you would like to take part, you will be asked to sign a consent form after your questions have been answered and the study has been fully explained to you. You will be asked to participate in an interview that take approximately one hour at a time



and location that is convenient for you. The interview will be one that is gently guided and will entail questions about your experience as a caregiver to your partner who has advanced Parkinson's Disease. This interview will be audio recorded and the recording will be made into a written transcript that will be anonymous and confidential.

### **Risks**

There are no medical risks associated with participation in this study, but please be aware there is a chance that you may find the process either physically or emotionally tiring. If there are questions you would prefer not to answer or wish to stop at any point in during the interview, we will respect your wishes immediately. If you experience any distress following participation you are encouraged to inform the researcher and contact the resources provided at the end of this sheet.

### **Benefits:**

You may not receive direct benefit from being in this study. The data from this project will help to identify areas where resources and support can offer benefit to future families and to yourself.

### **Alternatives to Being in the Study**

You may choose to participate or not with no influence on the care of your partner.

### **Confidentiality:**

If you agree to join this study, the researcher will obtain your contact information and date of birth which is the only information needed for the study. The information that is collected for the study will be kept in a locked and secure area by the researcher for 10 years. Only people involved in the study will be allowed to look at your records.

Representatives of the University Health Network Research Ethics Board may look at the study records and at your personal information to check that the information collected for the study is correct and to make sure the study followed proper laws and guidelines. As this is a PhD study for Lancaster University, the data you provide may be seen by the researcher's thesis advisor from Lancaster University in England.

All information collected during this study including your personal information, will be kept confidential and will not be shared with anyone outside the study unless required by law. You will not be named in any reports, publications, or presentations that may come from this study.

If you decided to leave the study, the information about you that was collected before you left the study will still be used. No new information will be collected without your permission.

The interview will be audio recorded for transcription, but at no time will these recordings be made public. The recording will not have your name on it. Any information about you will have a study number and will not show your name or address, or any information that directly identifies you.

### **Voluntary Participation**

Your participation in this study is voluntary. You may decide not to be in this study, or to be in the study now and then change your mind later. You may refuse to answer any question you do not want to answer, or not answer an interview question by saying “pass”.

### **Withdrawal from the Study:**

You may leave the study at any time without affecting the care of your partner. We will give you new information that is learned during the study that might affect your decision to stay in the study.

### **Costs and Reimbursement:**

You will not to pay to participate in this study. You will not be reimbursed for your participation in this study.

### **Rights as a Participant**

If you are harmed as a direct result of taking part in this study, all necessary medical treatment will be made available to you at no cost.

By signing this form you do not give up any of your legal rights against the investigators, sponsor or involved institutions for compensation, nor does this form relieve the investigators, sponsor or involved institutions of their legal and professional responsibilities.

### **Conflict of Interest:**

Researchers have an interest in completing this study. Their interests should not influence your decision to participate in this study

### **Questions about the Study**

If you have any questions, concerns or would like to speak to the study team for any reason, please call Rena Arshinoff at 416-603-5659. You may also contact the investigator’s supervisor at Lancaster University in England at:

Supervisor: Dr. Anne Grinyer - [a.grinyer@lancaster.ac.uk](mailto:a.grinyer@lancaster.ac.uk)

If you have any questions about your rights as a research participant or have concerns about this study, call the Chair of the University Health Network Research Ethics Board (UHN REB) or the Research Ethics office number at 416-581-7849. The REB is a group of people who oversee the ethical conduct of research studies. The UHN REB is not part of the study team. Everything that you discuss will be kept confidential.

You will be given a signed copy of this consent form.

Consent:

This study has been explained to me and any questions I had have been answered.

I know that I may leave the study at any time. I agree to the use of my information as described in this form. I agree to take part in this study.

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

My signature means that I have explained the study to the participant named above. I have answered all questions.

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

## ***Appendix L. Interview Guide***

### **Study Title: Experiences of Mutuality in the Spousal/Common Law Relationship in Advanced Parkinson's Disease from the Perspective of the Caregiving Partner**

#### Introduction

"Hello, my name is Rena Arshinoff. Thank you for agreeing to participate in this study. You have signed the consent form for the study about the relationship of married/common law couples living with advanced Parkinson's Disease. We will have a one hour interview with some broad questions that you are asked to answer. I will be taping our conversation. Do you have any questions?"

When you are ready to begin, I will turn on the recorder.

We will start now." (Researcher turns on digital recorder)

Questions (interviews will be semi-structured but these probes will help to guide the conversation as needed)

You have told me that your spouse has had Parkinson's for \_\_\_\_ years.

1. Could you please tell me about your relationship with him/her since his/her diagnosis?

***Choice of probes if needed and appropriate:***

- *How much time do you spend together?*
- *What times of things do you do together?*
- *How often do you talk together, laugh together?*
- *How do you get along, generally?*
- *Does your relationship include fun times or is it primarily about his/her care?*
- *Can you tell me a story about this?*

2. Please compare your relationship now to how it was before the Parkinson's became advanced.

***Choice of probes if needed and appropriate:***

- *What is different now in your relationship?*
- *How often do you share past experiences together?*
- *How have you altered what you do together?*
- *How is this for you?*
- *Do you enjoy spending time with him/her?*

- *Can you tell me a story about this?*

3. What kinds of activities do you do together?

***Choice of probes if needed and appropriate:***

- *What has it been like for you to do the activities together that you used to do?*
- *How have these changed for you? How have these changed for your spouse?*
- *Do you enjoy his/her company?*
- *How do you have fun together?*
- *Can you tell me a story about this?*

4. How do you and your spouse experience intimacy now?

***Choice of probes if needed and appropriate:***

- *Do you hug, kiss, cuddle?*
- *Do you have sexual intercourse? Has that changed for you? If so, when?*
- *How can you find ways of having intimacy with your spouse now that the disease is advanced?*
- *Can you tell me a story about this?*

5. How would you describe your love for your spouse at this time?

***Choice of probes if needed and appropriate:***

- *Has this changed? If so, how? When did it change?*
- *How do you feel being married to someone with advanced Parkinson's?*
- *How do you take care of yourself?*
- *Can you tell me a story about this?*

6. How has being a caregiver to your spouse changed you?

***Choice of probes if needed and appropriate:***

- *What is spiritual in your life?*
- *Can you describe your purpose in life?*

### Interview Exit

“We are almost finished – is there anything more you would like to add?”

Is there anything you have said today that you would not want kept in the recording or transcribed?

You have said a lot today. How was it to do this interview?

Are you OK with finishing now?

Thank you so much for your interest and your contribution to understanding changes in the spousal relationship in advanced Parkinson’s Disease.”

Researcher turns off the recorder

*Appendix M. Figures 3 and 4*

Figure 3. Pattern of mutuality in the isolated experience by the caregiving spouse

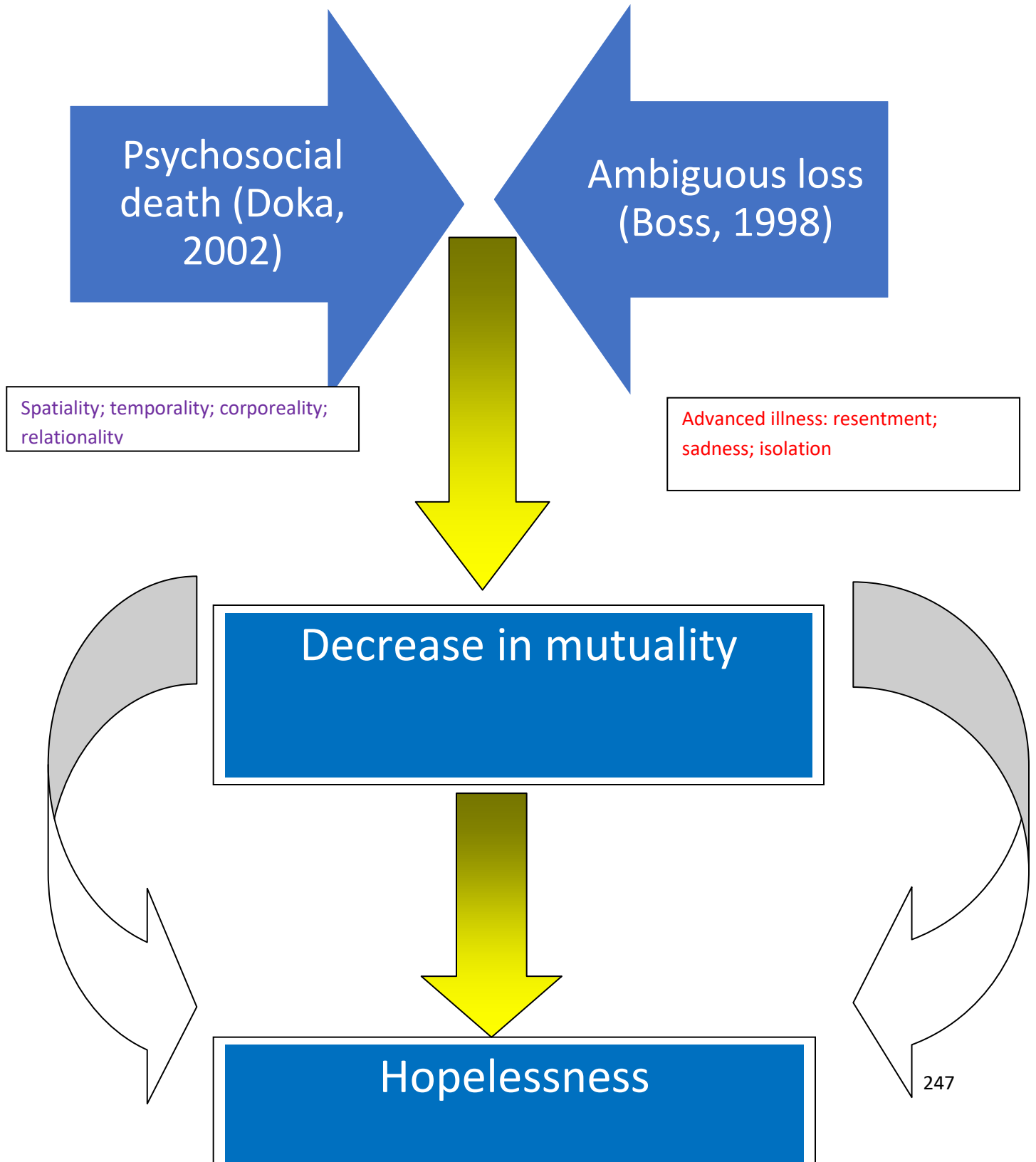


Figure 4. Pattern of mutuality in the shared illness experience

