

The Experience of Care-giving for a Person with Parkinson's Disease

A DISSERTATION
SUBMITTED TO THE FACULTY OF THE GRADUATE SCHOOL
OF THE UNIVERSITY OF MINNESOTA
BY

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IN PARTIAL FULFILLMENT OF THE REQUIREMENTS
FOR THE DEGREE OF
DOCTOR OF PHILOSOPHY

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May 2010

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Acknowledgements

With the support, direction, guidance and love from family, friends, colleagues, and my doctoral committee, I was able to complete this dissertation. The road was bumpy to be sure, especially with my diagnosis of breast cancer in 2005. I am thankful for the encouragement I received that helped me persevere at times when I felt I could not go on.

First, I would like to thank all the caregivers who so graciously volunteered to participate in my study. They opened their homes and hearts so that I might better understand their daily care-giving experience. They touched my life in a powerful way, and I appreciate their commitment to caring. They exposed the pleasures and struggles of the care-giving experience for all to see.

Second, words of gratitude need to be extended to my advisor, Dr. Shari Peterson and to the other members of my doctoral committee: Dr. James Brown, Dr. James Carey and Dr. Rosemarie Park. Dr. Peterson started this journey with me in 2003 and has been a steadfast mentor every step of the way. I would also like to say a special thank you to Dr. Sharon Gibson who mentored from a far.

Lastly, my family was there to push and pull me along with hugs and kisses, chocolate, Dr. Pepper and licorice. Thank you to my parents, Darwin and Fredericka Schuur who have always supported me in my life as a child and as an adult through times of joy and despair. My three wonderful sons, Benjamin, Andrew and Patrick and my husband, Steven Bogard have truly been my hope and foundation; thank you for your laughter, patience and enduring love. Thank you all for getting me to my goal.

Dedication

Fitting for such a thesis, I dedicate this dissertation to all those caregivers in the world who with their loving hearts, minds, and hands have committed to providing vigilant hours of support. The journey they take is not always easy and their acknowledgments are often few and far between. With advances in medicine and changes in technology, demographics, and family systems, the need for compassionate formal and informal caregivers will remain an integral part of societal structure. By understanding their experiences, the human race can glimpse its own humanness. May we learn from their stories and experiences so that their wisdom and tacit knowledge can be used to guide new generations of caregivers.

Abstract

As the population continues to become more aged and at risk for chronic illness, there will be a growing need for caregivers. Caregivers to persons with Parkinson's disease (PD) face the challenge of providing care over many years due to the chronic progressive nature of this neurological disorder. The purpose of this study was to understand and discover the multi-dimensional cognitive, affective and psychomotor capabilities and attributes of informal care-giving for individuals with PD. The research question was: What is the meaning of the caring experience from the perspective of the informal caregiver in the day-to-day interactions with the person with PD? This phenomenological investigation looks into the lives of 13 caregivers who perceived that they were in a caring relationship with a person diagnosed with Parkinson's disease. Caregivers participated in two in-depth, open ended interview sessions that were audio-taped and then transcribed verbatim for analysis. Three themes emerged from the analysis: (a) Care-giving is an unplanned journey; (b) I am living with the disease too; and (c) My relationship with the person I care for and others is changing. Subthemes for each were described. The findings suggested implications for clinical practice and future research. First, caregivers should be provided formal guidance and educational opportunities from health care providers over the course of the disease process. Second, caregivers and persons with PD should be viewed from a holistic perspective to ensure optimal care for the person with PD and support for the caregiver. Third, a multidisciplinary collaborative team approach should be used to facilitate communication across disciplines with the management of PD. Fourth, caregivers should be provided opportunity and connections with support groups. Fifth, caregiver health and wellness should be optimized over the course of the disease process to keep the caregiver-care recipient relationship intact and strong. Sixth, caregiver vigilance and concern for safety should be fostered and evaluated. Seventh, caregiver stressors and protective factors should be identified and appropriate interventions instigated.

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Chapter 1

Introduction

Caring for a family member or significant other with Parkinson's disease (PD) is a unique human experience. The caregiver or care-partner should be viewed as an important and valuable person on the health care team (Glenn, 2007; Bello-Haas, 2002). Spousal caregivers to persons with PD are often older, since PD is typically diagnosed between ages 55-60 (Cameron & Monroe, 2007; Dauer & Przedborski, 2003). Considering the increase in the aged population (Dilworth-Anderson, Williams, & Gibson, 2002), the need for informal caregivers in the lives of individuals diagnosed with PD will likely escalate (Parkinson's disease: hope through research, 2001).

PD as a chronic progressive incurable neurological disorder can cause cognitive and motor impairments impacting quality of life (QOL) for both patient and caregiver (Berry & Murphy, 1995; Den Oudsten, Van Heck, & De Vries, 2007; Levine & Murray, 2004). The caregiver is often put into a situation of learning and synthesizing information about this complex neurological disorder from numerous sources including formal health care providers, other caregivers, resource books, patient education materials, internet resources, television and radio.

Informal care-giving for the individual with PD is a multi-dimensional phenomenon often embedded into the function of the family unit with increased demands for physical, cognitive, psycho-social, emotional, and economic support placed on its members (Brod, Mendelsohn & Roberts, 1998; Glenn, 2007; Whetten-Goldstein, Sloan, Kulas, Cutson, & Schenkman, 1997). This care-giving is influenced by demographic changes, culture, context, policy, and actions of society, communities,

health care institutions, and families (Biegel & Blum, 1990; Gordon, Benner, & Noddings, 1996). Care-giving or care-partnering for persons with PD has been given more attention as the public gains more access to information and resources through the media and internet as well as support associations, foundations, organizations and networks like National Family Caregivers Association, Michael J. Fox Foundation, American Parkinson Disease Association and Parkinson's Action Network (PAN) respectively. The influence of national organizations, like these, have given caregivers to persons with PD a growing voice through advocating on care-giving issues at a federal level (Legislative Impact, 2009).

As increasingly more people are diagnosed in older age with chronic neurological disorders like PD (Cousins, Davies, Turnbull, & Playfer, 2002; Davis, Ehrhart, Trzcinski, Kille, & Mount, 2003), caregivers must learn to understand and deal with both motor and non-motor dysfunction as they care for a person with PD. Motor dysfunction typically includes slowed movement, tremor, postural instability and rigidity (e.g. muscle stiffness). Non-motor dysfunction could include loss of memory and slowed thought processing. Additional information specific to the pathophysiology and clinical presentation of PD can be found in Appendix A. Considering the research attention in PD (e.g. falls, balance disturbances, medications, surgery) (Bloem, Hausdorff, Visser, & Giladi, 2004; Grimbergen, Munneke, & Bloem, 2004; Koller, Glatt, Vetere-Overfield, & Hassanein, 1989; Playfer, 2001), caregivers are put in situations in which they must make sense of the current research and medical recommendations often interpreting information from formal care providers like neurologists, physiatrists, nurses, physical and occupational therapists, dieticians,

pharmacists and social workers. Because of the progressive chronic nature of PD, the care-giving responsibilities typically increase as the disease progresses for the person with PD. Dealing with a person with PD who progressively loses his or her balance and chronically falls because of slowed and poorly coordinated movement is one such example.

Caregivers must manage the actual fall from a physical perspective (e.g. assist person up from the floor and care for injuries), as well as the emotional aspect (e.g. worry and anxiety that person with PD will fall again). Increased fall risk in the elderly and specifically in PD has warranted investigation (Bloem, van Vugt, & Beckley, 2001). Roberts (2003) described the complexity of falls in her article titled, "Falls: What a Tangled Web." Thus, demands for vigilance and physical assistance are added to the multi-dimensional roles of the caregiver or care-partner. Besides dealing with the profound physical effects on movement when caring for a person with PD, caregivers are often unprepared for the mental and behavioral changes that impact the thoughts and judgment of the person with PD (Medical News Today, 2008). Unfortunately, the caregiver may experience, feelings such as anxiety, isolation, frustration, guilt, fears for the future and unexpected and often unwanted change which can lead to stress and physical deterioration of the caregiver (Hamburger, n.d.). Considering these general issues, a more detailed problem statement is presented.

Statement of Problem

There are two intertwined problems impacting care-giving for individuals with PD. First, there is a *cultural divide* which exists between families, health professionals (formal caregivers), and policy makers (Levine & Murray, 2004). According to Levine

and Murray, “Families and professionals have different assumptions, values, attitudes and behaviors—in other words, they have different cultures” (p. 6). Levine provided a view on this problem:

Indeed, the policy culture seems to view care-giving for impaired family members as a responsibility that families not only must but ought to cope with, with minimal, if any, public support. As long as the policy culture’s basic presumption is that family responsibility is open ended and unlimited, policy is likely to regard support for caregivers as an unwise rather than a prudent investment.

(p. 111)

Gordon, Benner, and Noddings (1996, p. xiv) further elaborated on assumptions, noting that caring is often equated with “*doing for him or her*” versus “*being with another human being.*” They suggested that in American culture, it may be far harder to *be with* and to demonstrate compassion for people (suffer with) than to *do for them*. Schulz, et al. (2007) suggested that research and intervention efforts have emphasized caregiver skills training (doing for him or her) versus emphasis on the affective domain of patient suffering and caregiver compassion. Certainly dissonance (Calne, et al., 2003; Levine & Murray, 2004) can occur between informal caregivers and health care professionals as spoken and unspoken expectations of care-giving emerge throughout the course of caring for an individual with a progressive chronic illness like PD.

The second problem takes shape in that health care professionals lack understanding of the experiences, values, and assumptions of informal caregivers, and

thus limits or prevents provision of important support for informal caregivers (Cutson, Zhu, Whetten, & Schenkman, 2004; Whetten-Goldstein, Sloan, Kulus, Cutson, & Schenkman, 1997). Unfortunately, this lack of understanding may negatively impact the delivery of important health care services which could enhance caregivers' problem-solving capabilities, care skills, self-health skills, and resource acquisition skills (Habermann, & Davis, 2006; Kurylo, Elliott, & Shewchuk, 2001).

Western health care has targeted services to the "individual" versus the family, often leaving family members ill prepared to take on the challenge of care-giving (Gordon, Benner, & Noddings, 1996; Levine & Murray, 2004), especially for a family member who is at risk of falling because of motor and/or cognitive impairments (Davey, Wiles, Ashburn, & Murphy, 2004). As clearly articulated by Benner (2005) of the present day "medico-centric cure approach":

Managing a chronic illness does not fit well into a cure-oriented medical system. Those with chronic or terminal illnesses do not fit the cultural paradigm for scientific and technical cure. Caring for the incurable lacks public space, language, and understanding in its own terms. p. 65

Therefore, an important integrated problem statement emerges: Within the American cure-oriented health care system, the often paramount contribution of informal caregivers to the lives of individuals with PD is inadequately understood and thus hampers health care professionals in providing sufficient and appropriate support and education which could ultimately enhance quality of life for persons with PD and their

informal caregivers. With this problem statement in mind, the following holistic, culturally and contextually bound research purpose and question was proposed.

Purpose of the Study and Research Question

The purpose of this study is to understand and discover the multi-dimensional cognitive, affective and psychomotor capabilities and attributes of informal care-giving for individuals with PD. Gordon, Benner and Noddings (1996, p. xiv) noted that “caregivers learn from each other, from those they care for, from embodied intelligence, and from their own reflections and experience.” This embodied intelligence may also be referred to as tacit knowledge which is “taken-for-granted understanding (Wrubel, Richards, Folkman, & Acree, 2001) based from practice and experience and captured through shared stories or interviews (Ontario’s Health Care Information Exchange, 2009). As individuals live with the progressive debilitating symptoms of PD and move through early, middle and late stages (Bello-Haas, 2002), so too must their caregivers experience life changes in relationships, roles, and plans.

“Care-giving is extensive as well as intensive work” (Gordon, Benner, & Noddings, 1996, p. xiv), so exploration of just how informal caregivers navigate and manage change deserves attention. Both rewarding and challenging experiences (Cohen, Colantonio, & Vernich, 2002; Glenn, 2007) occur for caregivers and are worth explicating. Further, this study aims to provide a thick rich description of both positive and negative perceived experiences of the informal caregiver using an interpretative paradigm. According to Gioia and Pitre (1990), an interpretative paradigm can generate

descriptions, insights, and explanations of events so that the system of interpretations and meaning, and the structuring and organizing processes are revealed.

The research question is: What is the meaning of the caring experience from the perspective of the informal caregiver in the day-to-day interactions with the person with PD? In terms of the literature and similar research questions, Creswell (1998) and Moustakas (1994) recommended developing phenomenological questions that explore the possible structural meanings of the experience embedded in context and within time. In addition, the research question stays true to the methodological research paradigm of phenomenology in which *what is it like* (van Manen, 1997) is at the heart of the research question.

Need/Justification for Study

The need for this study is timely and pertinent considering the growing aged population and the increasing rise in progressive neurological disorders like PD, that result in physical, cognitive and behavioral changes, which eventually lead to increased demand for formal and informal care-giving. These trends ultimately impact health care dollars and services (Carroll, Slattum, & Cox, 2005; CDC, 2008; Gillespie, et al., 2007). The need for the study is based off of three main areas: the complex challenges of care-giving for a person with PD, enhancing support of holistic care-giving theory and supplementing care-giving qualitative research.

First, the complexities of care-giving for individuals with PD, have necessitated the need for evidence-based medical and therapeutic practice interventions (Glaros, 2003; Habermann & Davis, 2006; Sackett, Rosenberg, Gray, Haynes, & Richardson,

1996). Unfortunately, there is no “best” practice or universally accepted approach to providing support for informal caregivers or to managing patients with progressive neurological disorders like PD (Deane, Jones, Playford, Ben-Schlomo, & Clarke, 2001; Dowding, Shenton, & Salek, 2006; Pressley, et al., 2003). Furthermore, research on the burdensome aspects of care-giving may be peripherally embedded within studies but not be the focal point of the study with the primary emphasis in the study being how interventions impact the client with PD (Trend, Kaye, Gage, Owen & Wade, 2002; Wade, et al., 2003).

Second, there is need to enhance care-giving practice through understanding, supporting and enhancing holistic theory. The use of nontheoretical approaches in care-giving research has existed, as well as reported flaws in methodology (Amirkhanyan and Wolf, 2003; Bell and Richard, 2000; Biegel & Blum, 1990; Deane, Jones, Playford, Ben-Schlomo, & Clarke, 2001). For example, published care-giving studies have lacked reference to a foundational care-giving theory or conceptual framework, clear operational definitions or in the case of quantitative studies, lacked controls and used convenience sampling with small numbers (Deane, et al.). Cousins and colleagues (2002) noted that despite nearly 40 years of care-giving research, there was just a recent move to provide holistic explanatory models of informal care-giving. The need for a holistic model or approach to assessing informal caregivers, measuring caregiver outcomes and strategizing interventions for caregivers has been discussed in the literature (Cousins, Davies, Turnbull, & Playfer, 2002).

Furthermore in the development of a holistic perspective, recently Talley and Crews (2007) proposed a triadic model of care-giving (professional caregiver, family

caregiver, care recipient). This triadic model can be described as a middle-range theory. According to Hinshaw et al. (1999),

The decisive advantage of middle-range theories is that the three different philosophical approaches [positivistic, interpretative and critical] each can be used to develop the same descriptors for a common theory. Thus, the strengths of all three approaches can be exploited in the development of the middle-range theory. (p. 9)

In addition, from a holistic caregiver education and adult learner perspective, the literature was nascent and further research seems warranted. For example, the application of adult learning theory like Yang's (2003) holistic theory of knowledge has not been researched related to adult caregiver education. He suggested three knowledge facets and their dynamic relationships in his holistic theory: explicit knowledge (objective, one truth, cognitive/thinking), implicit knowledge (multiple and subjective realities, tacit, behavior/action), and emancipatory knowledge (affective, emotion). Yang stated, "The facets of knowledge are different aspects of the way in which we know the physical, social, emotional, and spiritual world" (p. 108).

The affective perspective of care-giving has also been further addressed by Bell and Richard (2000). They argued that the "dyadic emotion of caring" be at the heart of the care-giving phenomenon and "serves as autonomous motivation to see that the needs of a specific dependent are met" (p. 69). Furthermore, the need to address the phenomenon more holistically was introduced by Brod, Mendelsohn, & Robert, (1998). They suggested that researchers and clinicians have too narrow a focus on medical symptomatology without giving sufficient recognition to the multi-dimensional nature

of the caregiver's and patient's experience. Jensen (2007) stated there is desperate need for investigations like a phenomenological approach to gain insight and understanding of the meanings embedded in rehabilitation. Benner (2005) also recommended the need for emphasis on "attentive care" practice and research.

Wrubel and colleagues (2001, p. 175) in their study of informal care-giving, concluded: "Better understanding of caregivers' tacit definitions can facilitate and enhance effective support and interventions for caregivers." Informing the care-giving research world from a holistic perspective could add breadth and depth to our knowledge of the phenomenon of care-giving. Viewing care-giving from a more holistic vantage point may let researchers and practitioners focus on families, groups, communities, cultures and institutions with collaboration in mind.

Thirdly, in terms of the need to supplement qualitative research, at present, research addressing the experiences of informal caregivers remains scant and primarily directed toward spouses at specific stages of the disease process (Davey, Wiles, Ashburn, & Murphy, 2004; Habermann, 1996, 1999, 2000.) In a recent study by Davey et al. (2004), they used semi-structured interviews with informal caregivers to understand the impact of falling in PD on the informal caregiver. The Davey study explored only the views and experience of the informal caregivers of repeat fallers with PD. All caregivers were marital partners; adult children, other family members, significant others or friends were not interviewed. Their study did not address the broad experience of care-giving and was not linked to care-giving theory. They concluded that caregivers felt unprepared for their role and expressed a need for more support and advice. Additional research of the care-giving experience could potentially help to fill

gaps related to caregiver education and training needs, as well as address the support needs of caregivers.

Considering the need for further research, the following phenomenological study aims to add depth and breadth to understanding the informal care-giving experience by recruiting not only spouses but adult children or other relatives or friends who are caring for individuals with PD at all stages of the disease process. The results of this study may further inform theories of care-giving through relating the thematic findings to care-giving theory in the literature. This is valuable as care-giving theory can provide an organized framework to conceptualize the roles and interactions of both the informal and formal caregivers. Theory, practice and research inform each other, so another implication of the study may include informing health care providers of potential adult education and therapeutic intervention strategies that could enhance their clinical practice and interactions with informal caregivers to persons with PD.

Definitions Related to Care-giving

The terms “caregivers” and “care-partner” have recently been used interchangeably in the literature (Whitlatch, Judge, Zarit, & Femia, 2006), yet, the more widely used term, “caregiver” may conjure the notion of one-sided *giving* versus the notion of *reciprocity* (giving and receiving) which could be attributed to the term “care-partner”. The distinction was not always clear in the literature. Understanding the various operational definitions related to care-giving was necessary. The nature and extent of informal care-giving could be considered variable and diverse. Perceptions of the level or act of care-giving may be different for each person in the caring

relationship. In a literature review of informal caregivers, Goodhead and McDonald (2007) stated the following in their executive summary:

Care-giving is routine and ongoing. It arises out of a relationship with the recipient in response to the need for support which is greater than normally expected due to impairment in functioning. Because lower levels of care-giving merge into normal relationship reciprocity, and because it is outside any formal agreements, it is relatively invisible. (p. 4)

In terms of care-giving, both informal and formal caregivers are involved with providing persons with PD the assistance and services they need to function within all levels of society. Wielinski and colleagues (2004) reported that persons with PD with motor dysfunction often require health care services from a variety of formal caregivers/providers (e.g. physicians, nurses, physical therapists, occupational therapists, speech therapist, pharmacists, home health aides, and hospice volunteers). These services occurred in a variety of contexts including hospitals, outpatient clinics, homes, residential/nursing home settings, and adult daycare. Formal and informal caregivers have provided affective, behavioral, physical and cognitive commitments to a person with PD. According to Lyons (2003), the role of each has been considered unique in a collaborative health care team which has assumed the patient to be a key member. The following terms have been arranged alphabetically for ease of location.

Care-giving- Pearlin and colleagues described care-giving as an affective and behavioral commitment to a person, and therefore, refers to whoever looks after a sick

person because of an affective tie regardless of his/her family relationship (as cited in Ferrario, Zotti, Ippoliti, & Zotti, 2003).

Caregiver/Care-partner-“A caregiver can be broadly defined as anyone who provides care” (Canadian Hospice Palliative Care Association, 2006).

Formal care-giving- Formal caregivers (providers) are paid health professionals and support workers or volunteers associated with a service system, as members of an organization they are accountable to defined norms of conduct and practice (Canadian Hospice Palliative Care Association, 2006).

Family-“a system or unit of persons-in-relations, with strong social bonds, with commitment and attachment, whose central purpose is to create, maintain, promote the social, mental, physical, and emotional development of each and all its members” (Taylor, 2001, p. 7)

Family care-giving skills-Mezey defined family care-giving skills as the ability to engage effectively and smoothly in nine core care-giving processes: (a) monitoring, in other words, keeping an overall vigilance over the care, (b) interpreting –making sense of what is observed, (c) making decisions-choosing a course of action as necessary, (d) taking action-carrying out care-giving instructions, (e) providing hands-on care like medical and nursing procedures which address both safety and comfort aspects, (f) making adjustments-finding the right strategy as the situation requires, (g) accessing resources-ensuring the care recipient has their needs met, (h) working with the care recipient showing sensitivity and respect, and (i) negotiating the health system (as cited in Goodhead & McDonald, 2007).

Informal care-giving- “Informal caregivers are caregivers who are not financially compensated for their services. Vitaliano and colleagues (2003) stated that informal caregivers were usually relatives or friends who provide assistance to persons who are having difficulties with daily activities, because of physical, cognitive, or emotional impairments.

Parkinson’s Disease (PD) has been described as a chronic, progressive disease of the nervous system characterized by the cardinal features of rigidity, bradykinesia, tremor and postural instability (O’Sullivan & Schmitz, 2007, p. 853).

Patient Education- Bartlett (1985) defined patient education, the process of educating individuals receiving health care, as “a planned learning experience using a combination of methods such as teaching, counseling and behavior modification techniques which influence patients’ knowledge and health behavior” (as cited in Rindflesch, p. 193).

Quality of Life (QoL) has been a difficult construct to define. Calne, et al. (2003, p. 115) proposed it as a general construct: “to maximize satisfaction by living life to its fullest and functioning to the optimum of one’s capability in all stages of life.”

Tacit Knowledge has been defined as the knowledge that is acquired through everyday experience but has an implicit, unarticulated quality and occurs spontaneously in the day-to-day care of patients and guides practice (Jensen, 2007). The term professional craft knowledge has also been used.

My Research Assumptions and Worldview

In this section, I have articulated my own fundamental views and assumptions on using a phenomenological research paradigm based on my understanding of the

literature. In addition, I addressed my assumptions on care-giving. Articulation of preconceptions has been recommended in qualitative research. As described by Husserl and used by others, a researcher using a phenomenological paradigm must practice bracketing, in other words, setting aside preconceived experiences, understandings, beliefs, biases, assumptions, presuppositions, and theories so as to best understand the experiences of participants in the study (Creswell, 1998; Gearing, 2004; van Manen, 1997; Wotrlich, von Koch, & Tham, 2007). I have further elucidated bracketing in chapter three (Phenomenological Research Methodology). I specifically explored and recorded my ontological and epistemological assumptions (worldview), as well as my assumptions about inter-subjectivity and care-giving prior to data collection and analysis.

Ontologically (what is being), I asked myself what are the assumptions I am willing to make about the nature of reality. In other words, how I believe and understand things in the world. In my mind, the notion of one single objective reality in human science research does not exist but rather multiple constructed realities do. Even when quantitative (positivistic) research assumes a single objective reality and attempts to establish strict study controls, the researcher and the participants will always be historically and contextually bounded. I believe that when a researcher does either qualitative or quantitative research, the researcher will bring life experiences and bias to the study and the interpretations of the study. Even random clinical control trials are conducted within a certain point in time and in a specific location which may impact the results (e.g. medical, social, economic, and political forces). The need for transparency to understand potential biases and/or prejudices in both qualitative and quantitative

research is essential, and I made a cognizant effort to address my biases prior to and throughout this study.

In my attempt to be transparent, I addressed my epistemological assumptions, or in other words, how do I know or come to know something (what it means to know). For me, it would seem that knowledge about caring is socially constructed from the experiences of the researcher and the participants and based off their values, beliefs, and culture (dependent investigator-subject relationship versus an independent object-researcher relationship). Unfortunately, most of my training as a physical therapist has been reinforced through the “biomedical pole” that “draws from an empirical-analytic paradigm as the clinician interprets physical signs, symptoms and conditions in an objective manner” (Jensen, 2007, p. 789). Prior to graduate school, my exposure to the lived experience pole of research was superficial to say the least, so this phenomenological study is a new approach for me as a researcher. For my research problem and question, my preference was to find knowledge through “reflective lifeworld research” (Dahlberg, Drew, & Nyström, 2001) and researching lived experience (van Manen, 1997).

I considered the notion of inter-subjectivity. In my study, I felt it important to inform the participants of my background as a physical therapist, an educator of physical therapy students and my assumptions regarding caring for persons with chronic progressive illness. Dahlberg and colleagues (2001) described this as inter-subjective openness. As phenomenology is a human science in which the researcher and the participant enter into an open research situation in order to better understand a lived experience. She further stated, “In a scientific approach the claim of openness demands

from the researcher an awareness of what happens in an inter-subjective encounter, so that the unequal relationship is formed in favor of the informant” (p. 113).

Inter-subjectivity has been described by Dahlberg (2001) as a primordial quality of the human world, in other words, to be human in the world means being-with others. I recognized and considered that defining the inter-subjectivity between researcher and participant in qualitative research best aligned with the paradigm shift espoused by King, Henderson and Stein (1999) which considered relationships in research. They stated, “Focusing on the relationships involved in all human subject research serves not only as a means of addressing the characteristics of research that give rise to particular ethical concerns, but also as means of beginning to structure meaningful analysis and successful solutions (King, et al., p. 11-12). I recognized the importance of creating an empathetic open relationship with phenomenological research. Finlay (2005) referred to this as reflexive embodied empathy.

My assumptions regarding care-giving have been established over twenty-five years as a physical therapist. I have worked with many patients and their families who are managing life with PD. I have educated patients and their families in regards to gait training and exercise, encouraged them to purchase adaptive equipment to aid in walking and made suggestions for environmental modifications to enhance safety, all with a mixture of success. My practice has emphasized the patient centered model versus a family centered model with caregiver education certainly important, but potentially marginalized depending on available treatment time and patient goals, as well as caregiver availability during interventions, interest and follow-through. As a physical therapist, I am trained to analyze movement dysfunction in patients;

unfortunately, this can be problematic if my “therapy blinders” prevent me from recognizing care-giving issues (e.g. loss of memory) that are impacting the person with PD and their informal caregiver. I have felt less prepared to address the needs of the informal caregiver; yet, I believe physical therapists should take the responsibility to recognize the needs of the informal caregiver and to know when to refer patients with PD and their caregivers to other qualified health care professionals (e.g. psychologists, social workers, dieticians, occupational therapists).

Over the past ten years, my exposure and involvement with persons with PD and their caregivers, through a local Parkinson’s disease support group, have made me more aware of the importance to address the caregiver’s needs, as well as the patient’s needs. For example, when I hear of patients who chronically fall or are at risk of falling at home or in the community, as a physical therapist, I feel the need and/or obligation to better understand why this is happening and perhaps propose strategies for education and prevention. My bias becomes clear in that I feel there must be better ways to help patients and their caregivers as they manage the physical, cognitive, emotional, spiritual and economic changes that occur in their lives over the years as they deal with PD.

Cohen and colleagues (2000) described, “The meaning that patients attribute to their experiences help create the needs they have and how these needs can best be met” (p. 4). For me, an important role of the physical therapist should be identification of these needs and development of intervention and educational strategies to address these needs. I feel strongly that caregivers need to be empowered with resource information, strategies and tools to be successful. Caring has been identified as an important value for professional physical therapy behavior and good patient care (Greenfield, 2006,

2008). I believe physical therapists need to challenge themselves to be consumers of both qualitative and quantitative research related to care-giving. In the field of physical therapy, Greenfield (2006, 2008) and Wottrich and colleagues (2007) recently have used phenomenological methods to better understand the meaning of caring. In my mind, I feel that more lived experience research related to care-giving would be beneficial to both formal and informal caregivers and a means for informal caregivers to have a voice.

Limitations

There were limitations to my research study. First, this study has restricted the scope of caregivers by operationally defining informal caregivers as individuals who reside with the person with PD, therefore other family members, friends or relatives not physically living with the person with PD were not sampled. This limited the recruitment of adult children who lived in close proximity to their parents and provided some perceived level of care-giving.

Second, as this is not a positivistic or quantitative study, the notion of generalizability was not applied. The intent of the study was not to generalize. Grbich (1999, p. 66) has stated, "Generalizability involves the usefulness of one set of findings in explaining other similar situations." Instead, qualitative researchers have used the term "projectability" (as cited in Grbich, 1999, p. 66) suggesting that data can potentially be applied to similar persons in similar situations. In this study, the participants and context were confined to recruitment from and interviewing in a specific Midwest region which was primarily rural with some urban communities dispersed within the area. Participants that volunteered were all Caucasian and thus not

racially diverse. This limited the projectability and transferability of the findings.

Lastly, this study did not include interviewing the person with PD which limited the findings to the interpretation of the experiences of caregivers only.

Overview of the Study

Chapter One, Introduction, discusses the general background of the study, the statement of the underlying problem, the purpose of the study, the research question, elaboration on the need or justification for the study, definitions related to care-giving, my research assumptions and world views, and study limitations.

Chapter Two, Review of the Literature, explores the literature on the meaning of care-giving; foundational theories about care-giving in general; implications of an aging population for caregivers; positive and negative attributes of care-giving; and implications for caregiver education and support. A summary of the literature is provided.

Chapter Three, Phenomenological Research Methodology, reviews the phenomenology framework, procedures, and methodological rigor employed during the study.

Chapter Four, The Experience of Care-giving for a person with PD, describes the phenomenological analysis of the text of the interviews. This chapter identifies themes or essences that emerge from the analysis and reflect the meaning of the care-giving experience for a person who cares for a person with PD on a day-to-day basis.

Chapter Five, Discussion, explores the findings of the study and integrates the contributions of this study with prior research and theory of the care-giving experience,

particularly as it relates to PD. Implications for both clinical practice and future research are offered. Lastly, this chapter includes my final reflection.

Chapter 2

Review of the Literature

Care-giving for a person with PD is a complex phenomenon. The purpose of this study is to understand and discover the multi-dimensional cognitive, affective and psychomotor capabilities and attributes of informal care-giving for individuals with PD. Therefore, the following research question was formulated: What is the meaning of the caring experience from the perspective of the informal caregiver in the day-to-day interactions with the person with PD? In order to provide a foundation for this research question, the literature was reviewed in the following five areas: (a) Meaning of Care-giving; (b) Foundational Theories about Care-giving in General; (c) Implications of an Aging Population for Caregivers; (d) Positive and Negative Attributes of Care-giving; and (e) Implications for Caregiver Education and Support.

The literature on the first area, meaning of care-giving, was broken down into three categories: etymological perspective; informal and formal caregivers; and history of care-giving and philosophical issues. The second area reviewed, foundational theories about care-giving in general, was broken down into two categories: concern for non-theoretical based research in care-giving and care-giving theories from the health professions. The third area reviewed, implications of an aging population for caregivers, was broken down into four categories: life expectancy, prevalence of informal care-giving, economic impact of care-giving, and economic impact specific to caregivers to persons with PD. The fourth area reviewed, positive and negative attributes of care-giving, was not broken down into additional categories. And the fifth area reviewed, implications of caregiver education and support, was broken down into

two categories: caregiver and patient education and support in general; and educating the caregiver in their role to prevent falls. In addition, a summary of each specific area was provided after each area was reviewed. An overall literature review summary was provided at the end of this chapter. The review method was modeled from recommendations for doing literature reviews by Baker (2000), Cooper (1982), Merriam (1998), and Torracco (2005).

Meaning of Care-giving

The literature on the meaning of care-giving was divided into three categories: etymological perspective; informal and formal caregivers; and history of care-giving; and philosophical issues. Care-giving has evolved through time and societal change. The language of care-giving has been imbedded in human interactions and transformed over time with social, health, political and economic pressures.

Keeping in mind the definitions presented earlier, in general, a caregiver can be broadly defined as anyone who provides care” (Canadian Hospice Palliative Care Association, 2006). Pearlin and colleagues described care-giving as an affective and behavioral commitment to a person, and therefore, refers to whoever looks after a sick person because of an affective tie regardless of his/her family relationship (as cited in Ferrario, Zotti, Ippoliti, & Zotti, 2003). According to Bridges (1995), care-giving is based on a reverence for life and the belief that human beings have the innate right to function to their highest level of mental and physical capacity with the major mission to promote independence by maintaining the person’s most functional state—physically, intellectually, emotionally and spiritually. Further understanding of care-giving can be deemed from etymological analysis.

Etymological Perspective

First, the etymological perspective was explored as recommended by van Manen (1997). He described the purpose of phenomenological reflection as an attempt to grasp the meaning of something and further described the use of etymological reflection as a way to draw us closer to “the construction of a way of life: a willingness to live the language of our lives more deeply” (p. 59). Caring can be understood etymologically. The word care comes from *caru, cearu* which means “sorrow, anxiety, or grief”. The verb *carian, cearian* means to feel concern or interest (Online Etymology Dictionary, 2001). van Manen (1997) argued that the word *caring* was overused by social work, medical, legal, educational and counseling professionals and that there was a disconnect between the original meaning and the services provided. He suggested “the term *care* possesses the dual meaning of worries, trouble, anxiety, lament on the one side, and charitableness, love, attentiveness and benefice on the other side” (van Manen, 1997, p. 58). In addition, caregivers can be spouses. Etymologically, spouse comes from *spondere* which means to “bind oneself, promise solemnly (Online Etymology Dictionary, 2001). The notion of commitment has been imbedded in this definition.

In terms of the verb *give*, which had 20 different definitions in the Webster’s New World College Dictionary (2002), the word comes from the Old English word *giefen* and the Scandinavian word *giva* meaning to make a gift or present. The nuanced meanings of the word *give* have added to the complexity of interpreting the care-giving phenomenon (e.g. to give or impart pleasure versus to perform a physical act of giving a

hug). When the term *care* and *giver* are combined, caregiver means a person who takes care of someone requiring close attention (Webster's New World College Dictionary).

Interestingly, some have argued that most of what is known about caring can be found in a thesaurus—as an extensive chain of semantic associations which are overlapping, branching, radiating and converging (Paley, 2001). Words like empathy, concern, loving, compassion, givingness, friendliness, sympathy, understanding, patience, sensitivity, kindness, interest, intimacy, cheerfulness, strength, tenderness, vulnerability are examples that were found in the literature. In his exposition on the caring knowledge, he stated that knowledge of caring is outdated, preparadigmatic, and not multi-paradigmatic. Paley suggested that the problem is a consequence of what nursing takes to be knowledge of caring. He concluded the following about the interpretative nature of care-giving research:

It is a knowledge of 'things said', a chain of association and resemblance which is constantly extended, constantly repeated.

It represents an endless project, whose monotony is matched only by its uselessness. It is the domain of an 'elusive concept, which is destined to remain elusive—permanently and irretrievably. (p. 196).

His argument and conclusion have painted a somewhat hopeless picture of understanding the phenomenon of caring, yet researchers in search of knowledge to better humankind have continued to pose questions about the meaning of caring and care-giving.

Informal and Formal Caregivers

Second, in the literature there was referral to the terminology of informal and formal caregivers. Informal caregivers have provided support in various contexts and situations; typically this has been in the home setting. The concept of long term care has been used referring to: (1) informal care, (2) formal home and community based care (including home health), and (3) institutional care (i.e. nursing home and residential care homes) (Davey & Patsios, 1999). “Informal caregivers are caregivers who are not financially compensated for their services. According to Vitaliano and colleagues (2003, p. 946), “They are usually relatives or friends who provide assistance to persons who are having difficulties with daily activities, because of physical, cognitive, or emotional impairments” (Vitaliano, Scanlon, & Zhang, 2003, p. 946). Informal caregivers may reside with the person or reside elsewhere and come into the home to provide care as needed.

Pinquart & Sörensen (2005) in a meta-analysis of family care-giving found within the studies they examined that 38% of caregivers were spouses and 46% were adult children. As family members have provided the greatest percent of care-giving, a definition of family is useful. “The family is a system or unit of persons-in-relations, with strong social bonds, with commitment and attachment, whose central purpose is to create, maintain, and promote the social, mental, physical, and emotional development of each and all of its members” (Taylor, 2001, p. 7). Adult children often were described as managing care-giving for a parent, as well as working and raising their own families.

Unfortunately, over the past several decades in research on family caregivers, the use of many different definitions of care-giving has made comparison of surveys and studies problematic (Levine & Murray, 2004). For example, many surveys have used very specific legal and tax code terms (i.e. family) or used specific measures of activities of daily living (ADLs) or instrumental activities of daily living (IADLs), but then did not document caregiver's advocacy efforts or vigilance. Variations perhaps have stemmed from the concept of culture. Levine and Murray (2004) suggested that families, health care professionals, and health policy makers and administrators have distinctive cultures. They proposed that culture "goes beyond ethnicity, religion, or language; it encompasses a shared understanding of a way of life which encompasses principles, values, attitudes, and behaviors based on membership in a group, whether that is family, professional discipline, institution, or agency" (Levine & Murray, p. 1). Addressing the many dimensions of care-giving from various cultural lenses has added to the difficulty in developing consensus around care-giving practice and theory.

For caregivers, both positive and negative aspects of care-giving have been reported. In order to understand the detrimental dimensions, researchers have investigated caregiver burden and strain. Burden has been defined as "the extent to which caregivers perceive that their health, social life, and financial status are adversely affected because of their caregiving" (Edwards & Ruettiger, 2002).

In contrast to informal caregivers, formal caregivers (providers) have been described as paid health professionals and support workers or volunteers associated with a service system, as members of an organization they are accountable to defined norms of conduct and practice (Canadian Hospice Palliative Care Association, 2006).

In health care, the formal caregiver (provider) has had the dual responsibility of meeting the needs of the patient/client, as well as addressing the needs of the informal caregiver. Greenfield and colleagues (2008) described the professional (formal caregivers) caring behaviors to be:

(a) understanding an individual's perspective; (b) being an advocate for a patient's or client's needs; empowering patients or clients to achieve the highest level of function possible and to exercise self-determination in their care; and embracing the emotional and psychological aspects of patient and client care. (p. 1155)

Care-giving in History and Philosophical Issues

Third, review of care-giving in history and philosophical issues have provided a better understanding of the meaning of care-giving. Care-giving as an act and state of being has evolved and been transformed through out human history, in essence it is a phenomenon which has perpetuated humankind. Physical care, social care, and emotional care have been woven together in care-giving relationships.

Unfortunately, looking back through history, a darker side of care-giving behavior has been recorded, especially for individuals with disabilities and chronic illness. Practices like infanticide by the Greeks and Romans, marginalization or banishment during the medieval ages, institutionalization from the 6th century to the 20th century, and Social Darwinism with its connections with eugenics in the late 19th

century have shown the evolving contextual milieu for informal and formal care-giving for persons with disabilities and illness (Winzer, 1993).

In the 1800s and early 1900s, care for aged persons and persons with disabilities occurred primarily in the home as nursing homes and residential care were not a part of the historical context. Care was typically of short duration because of mortality associated with limited medical knowledge and interventions, sanitation issues, disease control, and infection control. Historically, women have typically filled the role of caregiver for children and aging parents. “Adult daughters have traditionally served as primary caregivers for frail unmarried adults, but the levels of care they provided in the past may interfere with their growing work responsibilities” (Johnson, & Lo Sasso, 2006, p. 195).

According to Winzer (1993), in the 21st century, both persons with disabilities and their caregivers have come from isolation to integration, yet a challenge has remained. As the baby boom generation nears retirement and old age, concerns about how the United States will meet the long-term care needs of its growing elderly population have intensified (Spillman, & Pezzin, 2000). The ability for the family to provide care has changed with the following trends altering the needs of older persons and their caregivers: increased life expectancy with concomitant increased risk of disability, smaller family size, increasing childlessness, increased labor force participation among women, high rates of divorce and cohabitation, and shorter acute care hospital stays (Davey, & Patisios, 1999; Johnson, & Wiener, 2006). These trends have influenced philosophical issues of justice in care-giving.

Understanding justice in care-giving has challenged ethical and moral assumptions. Private and public morality issues on care-giving have been found throughout recorded history. Supposedly Aristotle stated, “There can be no injustice toward things that are one’s own...” (as cited in Jecker, 2002). Practically, the question becomes: Can spouses or adult children say no to care-giving for their family member? Justice and equity in family care-giving have been questioned and analyzed, especially by feminist scholars. Jecker (2002) compared the voice of justice with the voice of care through the work of Gilligan, a feminist scholar:

The voice of justice prevails mostly among boys and men. It dominates among those who were traditionally granted opportunities to act in the ‘public sphere.’ By contrast, in the private sphere the voice of care, rather than justice, is said to prevail...The voice of care is expressed primarily by girls and women. Caring is called a ‘feminine ethic’ because it is associated with the ‘private sphere’ of home and hearth, traditionally considered a woman’s domain. (p. 120)

Jecker (2002) argued that historically women have been deprived of opportunities for careers and education because of care-giving roles. Issues of justice and equity within families have emerged as decisions are made regarding who will provide the care-giving role for adult family members with illness or disability. She suggested that “under a veil of ignorance,” policies that empower women and men to make free choices about care-giving could decrease the social construction of gender-based inequities in care-giving (Jecker, p. 124). As adult children assume care-giving roles for their aged parents, Jecker has argued that justice establishes a requirement of fair

equality of opportunity within families, and adult children have the moral freedom to choose to accept or reject parent care-giving. With this said, care-giving may move from a previously private family sphere to the public sphere as adult children choose not to be involved with care-giving for their aging parents. This becomes complicated when both parents are aged and one parent may also have a progressive neurological disorder like PD.

With shorter hospital stays, making explicit formal and informal care-giving roles must be addressed in a collaborative way with families. Ethical issues become entwined with culture, policy and service delivery systems. Donelan, et al. (2002), suggested social policy challenges were: providing a wide range of support activities, formal training (especially related to administering medications), providing better access to paid assistance, provision of information, and public awareness of the value of care-giving. Health care providers like physical therapists, have needed to reexamine their assumptions about and expectations of who will care for the person with illness or disability following hospitalization.

Historically, physical therapists (PT) as formal care providers and educators entered the health care scene in the early 1900s (Murphy, 1995). Today, physical therapists are trained at a doctoral level to be formal health care providers and educators. As a licensed and ethically governed profession, physical therapy has evolved into a profession dealing with current health care policy and reimbursement directives that impact informal caregivers.

From a current physical therapy profession perspective, informal caregivers have been considered extrinsic factors in the milieu of patient/client care (Cott, et al.,

1995). According to Cott and colleagues (1995), physical, social, psychological and environmental factors have affected the movement continuum throughout the life span for both the caregiver and the person with illness or disability. The PT as a formal or professional caregiver would fit within the triadic model of care-giving described by Talley and Crews (2007). The physical therapy profession has evolved in the areas of collaborative management of chronic illness (Von Korff, Gruman, Schaefer, Curry, & Wagner, 1997), as well as patient/client and caregiver education (Rindflesch, 2009; Sluijs, 1991). In patient and caregiver education, the PT has had a role in explicit, implicit and emancipatory facets of knowledge production as described by practice expectations from the normative model of physical therapist professional education (American Physical Therapy Association, 2004).

Summary: Meaning of Care-giving

To better understand the meaning of care-giving, the literature was reviewed in three categories: etymological perspective, informal and formal caregivers, and the historical and philosophical issues of care-giving. Care-giving was described as a complex phenomenon embedded in relationships with others, language, time, culture and context. In terms of the etymological perspective, it has been argued that care possesses a duality of meaning with one side being worry, anxiety, lament and the other side being charitableness and love.

Care-giving was described as physical, emotional, psycho-social and spiritual support which could be provided by both informal and formal caregivers. The support provided by caregivers has evolved over the history of mankind and intimately linked to the family unit. Care-giving has changed in society and has been impacted by

technological advances and changes in the family unit. Issues of justice in family care-giving have emerged and have created controversy. Philosophical issues in regard to care-giving were discussed with questions posed like: who will be responsible for care-giving and how will care-giving be handled especially as care-giving responsibilities become shared between the private domain of the family and the public domain of health care.

Foundational Theories about Care-giving in General

The literature review on foundational theories about care-giving in general was divided into the following two areas: concern for non-theoretical based research in care-giving and care-giving theories from the health professions. This section was included in the literature review so that the later discussion of the findings could be informed by past theories on care-giving. Numerous care-giving conceptual frameworks were used, yet there was no consensus on use of any one model.

According to Swanson and Holton (2005) theory is pivotal, interacting with practice, development of interventions and research (Theory-Research-Development-Practice Cycle). Unfortunately, there was inconsistent reference to care-giving theory in the research literature as noted by a number of authors. (Cousins, Davies, Turnbull, & Playfer, 2002; Vitaliano, Scanlon, & Zhang, 2003; Whetten-Goldstein, Sloan, Kulas, Cutson, Schenkman, 1997). Yet, literature on caring theory was most abundant in the health profession literature, especially in the field of nursing.

Concern for Non-theoretical Based Research in Care-giving

Dilworth-Anderson, Williams, & Gibson (2002) completed a review of care-giving literature published from 1980 to 2000. Their study's purpose was to "synthesize what is known about care-giving among diverse groups and to identify gaps in knowledge to guide future research on care-giving" (Dilworth-Anderson et al., p. 237). Upon review of 59 articles, they concluded that care-giving experiences and outcomes varied across racial and ethnic groups; however, the use of non-theoretical approaches, non-probability samples, and inconsistent measures among studies had limited understanding of care-giving among diverse population" (Dilworth-Anderson et al., p. 237). Furthermore, Vitaliano, Scanlon, and Zhang (2003), argued that a theoretical model was needed that related caregiver stressors to illness.

In an earlier critical review of the psychological impact of care-giving on the caregiver, Raveis, Siegel and Sudit concluded, "While the evidence concerning the emotional impact of care-giving to a physically, mentally, or cognitively impaired individual has been accumulating, much of the research suffers from serious conceptual or methodological problems" (as cited in Biegel & Blum, 1990, p. 54). A decade later, Bell and Richard (2000) recommended the need for research related to theorizing. "Bridges across multiple theoretical perspectives may serve to further enrich our understanding of the care-giving system" (Bell & Richard, 2000, p, 90). Amirkhanyan and Wolf (2003) further noted that the theoretical frameworks developed to understand caregiver stress 'have not fully informed empirical research on the consequences of informal care-giving" (p. 817). In addition empirical research has looked at the negative consequences such as caregiver depression, poor perceived health and

increased risk of mortality versus positive psychological factors. Kramer stressed the need to enhance theory in this area (as cited in Cohen, Colantano, & Vernich, 2002),

Many disciplines have been affected by issues related to caregiving (e.g. caregiver education and training). These professions have created theoretical frameworks that can be applied to caregiving including: physical therapy (Greenfield, 2006), rehabilitation medicine (Nieuwboer, et al., 2001), nursing (Leininger, 2001; Watson, 1979), social work (Kurylo, Elliott, & Shewchuk, 2001), psychology (Bell & Richard, 2000), family relations (Fontes, 1998; Piercy, 1998), human resources (Shoptaugh, Phelps, & Visio, 2004), and adult education (Yang, 2003). Yet, the development of caregiver theory has been confounded by the western notion of health care which has addressed the primary needs of the patient, often independent of the needs of the family and informal caregiver. Hinshaw, Feetham and Shaver (1999) stated,

From a perspective of theory development, there is an overriding emphasis on the “individual” health rather than “public” or “population-based health” in nursing science. Although inroads are being made as we develop science related to community health, family health, and effective delivery models and systems, to date this progress is scant. (p. xv)

Care-giving Theories from the Health Professions

Scant theory related to informal care-giving has been published in physical therapy related literature. Although, Greenfield (2006, 2008) addressed physical

therapists as formal caregivers in his studies on the meaning of caring. Informal caregivers were not interviewed in his studies. In terms of general physical therapy theory, Mueller and Maluf (2002) and Cott, et al., (1995) described persons in society and their interaction with the environment as factors influencing physical stress and movement. Caregivers were described as external factors which could impact physical stress and movement. More specific to PD, Morris (2000, 2006) provided conceptual models for physical therapists working with caregivers and persons with PD. According to Glanz, Rimer, and Lewis (2002), there has been interest in cultural care and diversity issues in the PT literature, but the exploration of theories has been typically outside of the field of PT. In contrast, there has been a plethora of care-giving theory based research published outside of physical therapy primarily from the nursing field for over 50 years (Leininger, 2001).

Twelve theories (models and conceptual frameworks) for caregiving were reviewed. First, Leininger began explaining the phenomena of care and culture in the mid 1950's within the nursing literature. She developed the Theory of Culture Care Diversity and Universality and created the Sunrise Model to illustrate dimensions and relationships. "The central purpose of the theory was to discover, document, interpret, and explain the predicted and multiple factors influencing and explaining care from a cultural holistic perspective" (Leininger, 1997, p. 36). The theory operationally defined seventeen core concepts (i.e. care, culture, health, culturally congruent nursing care) and articulated thirteen assumptive premises of the theory. Her cultural care worldview considered technological factors, religious and philosophical factors, kinship and social factors, cultural values and lifeways, political and legal factors, economic factors and

educational factors. Leininger (1997, 2001) and other researchers (Carr, 1998) linked the theory to an ethnonursing research method. Leininger clearly provided criteria for the ethnonursing method including credibility, confirmability, meaning-in-context, recurrent patterning, saturation and transferability. Although this is a grand theory, embedded into nursing research and practice, it could have application to the field of physical therapy and the education of adult caregivers and patients. Crossing disciplinary boundaries for theory use may be advantageous.

Disciplinary borrowing certainly has the potential to shed new light on caregiving for persons who fall especially looking at the construct of vigilance. Carr (1998) used a holistic ethnographic method (inductive process) to explore the phenomenon of vigilance. She framed her study using Leininger's theory of cultural care diversity and universality. Vigilance was defined as "the close, protective involvement of families caring for hospitalized relatives" (Carr, p. 74). The research question was "What are the meanings, patterns and day-day experience of vigilance for family members with hospitalized relatives?" (Carr, p. 74). There were five categories of meaning derived from the data: commitment to care, emotional upheaval, dynamic nexus, transition, and resilience. The author provided description of the data analysis process which was informative and helpful, especially if future researchers attempted to replicate the study. Each theme/category had a participant quote to help illustrate the interpretation. In terms of limitation, two acute care, neurological units were used as the site for data collection so the contextual sampling was narrow. Findings potentially could be used to guide formal caregivers' decisions and actions related to informal caregiver vigilance. Studying the meaning of caregiver vigilance may be a fruitful research area especially

related to caring for persons who fall. Both informal and formal caregiver vigilance has potential to reduce falling and subsequent injury in persons with PD. Vigilance has been presented as a cognizant effort at watchfulness, the physical act of modifying the environment to make it safer (i.e. installing grab bars, using emergency life lines, using appropriate adaptive equipment) or providing the necessary emotional support when fear of falling exists.

Second, Watson's theory of human caring was reviewed. It has evolved since the 1970s and reflected the influences of consciousness theory, noetic sciences, quantum physics, transpersonal psychology, Jungian psychology, and feminist theories (Falk Rafael, 2000; Watson, 1979). Watson's theory stressed the lived experience of both client and nurse (Falk Rafael, 2000). Watson's theory acknowledged multiple ways of knowing, including empirical, aesthetic, ethical, and personal knowing (Falk Rafael). At the heart of this theory, Watson (1979) proposed ten primary carative factors:

- (a) the formation of a human-altruistic system of values, (b) the instillation of faith-hope, (c) the cultivation of sensitivity to one's self and to others, (d) the development of a helping-trust relationship, (e) the promotion and acceptance of the expression of positive and negative feelings, (f) the systematic use of the scientific problem-solving method, (g) the promotion of interpersonal teaching-learning, (h) the provision for a supportive, protective, and (or) corrective mental, physical, socio-cultural, and spiritual environment, (i) assistance with the gratification of

human needs, and (j) the allowance for existential-phenomenological forces. (pp. 9-10)

As physical therapists interact with caregivers and persons with PD who fall, this theory could be used to inform practice (both assessment and intervention) as well as research.

Third, Orem's Self-Care Deficit Nursing Theory (SCDNT) (Hartweg, 1991) was reviewed. It has evolved over the past 50 years and considered both the individual and the family. Orem's theory has clearly articulated propositions and presuppositions reflecting the complexity of human relationships and systems. Research related to the theory has been from both an interpretative (i.e. grounded theory, descriptive) and positivistic (i.e. correlational and experimental) (Taylor, Geden, Isaramalai, & Wongvatunyu, 2000) perspective. This theory represented three interrelated theories (Theory of Self-Care Deficit, Theory of Self-Care and Theory of Nursing System). Taylor (2001) further suggested the SCDNT addressed persons who have limitations in providing for themselves the amount and quality of required self-care providing for further consideration of the family. According to Taylor (2001), "Self-care is learned within the family" (p. 7). In addition, self care and dependent care was performed "purposively" or with purpose in response to a known need (Hartweg, 1991, p. 12). The "deficit" term was used to describe and explain the relationship between abilities of individuals to care for themselves and the self-care needs or demands of the individual, their children, or the adults for whom they care (Hartweg, 1991). As physical therapy has addressed specific self care and dependent care behaviors like exercise, ambulation, transfers, fall risk modification activities, and activities of daily living, Orem's theory has application both for practice and research.

Fourth, Newman's theory of health as praxis (Yamashita, 1999) was reviewed. This theory looked at health and illness as a single unitary process. Newman viewed health as a whole with disease within the whole, presenting itself as an evolving (temporal characteristic) pattern of person-environment interaction. "Newman referred to this pattern of the whole as expanding consciousness" which is characterized by a choice point, an illumination, pattern recognition and results in transformation at a higher level of organization (Yamashita, 1999, p. 73). Yamashita studied the concept of caregiver burden which has negative connotations, through serial interviewing participants over one year and found their evolving understanding and acceptance of their relative's mental illness. This theory could be meaningful to physical therapists since they often work with caregivers who are caring for a family member with progressive decline in physical and cognitive functioning as in PD. This theory captured the temporal nature of family care-giving with progressive disease processes and suggested the positive capabilities of families to adapt, grow and change.

Fifth, the Roy Adaptation Model (RAM) was reviewed. Tsai (2003) presented this middle-range theory of caregiver stress from an empirical study of the context of caregiving for the chronically ill. Caregiver stress was the major construct addressed in the article. RAM evolved since the 1970's and its scientific assumptions were based off general systems theory (final model includes four constructs: input, control process, effectors and output). Four assumptions of the caregiver stress theory were described and a major conceptual-theoretical structure was illustrated. The author described possible relationships and possible causal paths among three types of stimuli (focal, contextual and residual) and the coping mechanism. Suggestions on how to statistically

handle an interaction term were made by the author. The author used past research and the theory of caregiver stress to make appropriately directed hypotheses.

Sixth, a theoretical model of stress and health/illness by Vitaliano and colleagues (2003) was reviewed. This model was based from a meta-analysis of literature on caregiver physical health characteristics. This study looked at 23 studies to compare the physical health of caregivers with demographically similar non-caregivers. The health categories were stress hormones, neurotransmitters and, immunologic, cardiovascular and metabolic functioning. They stressed the need to develop a unified theoretical model to use for research on caregiver health. The authors developed the theoretical model of stress and health/illness (exposure to stress and vulnerability and resources; psychological distress and health habits; physiological responses; illness; mortality). The authors primarily focused on building theory direct toward the physical aspects of care-giving.

Seventh, a care-giving model by Pinquart and Sörensen (2005) was reviewed. Their model used a meta-analysis of 116 empirical studies related to ethnic differences in caregiver background variables, objective stressors, filial obligation beliefs, psychological and social resources, coping processes and psychological and physical health. Their model of ethnic differences included race/ethnicity, other background variables, resources and cultural norms, care receiver health and functioning, amount of care provided, care burden and gain, psychological and physical health outcomes. It was implied that care-giving interventions should be designed specific to the needs of various cultural groups of family caregivers.

Eighth, a model specific to PD by Edwards and Ruettiger (2002) was reviewed. They proposed a model of which included the care-giving family member and the person with PD in terms of variables thought to influence the management of the condition. This was a correlation path analysis study which investigated couple's marital quality, caregiver's perceived burden, PD individual's perceived support and internal locus of control and PD individual's management of chronic conditions. They found "for those who reported moderate to severe burden, an increase in caregiver perceived burden was associated with a significant decrease in the patients' management of the disease" (Edwards & Ruettiger, 2002, p. 184). Middle range theory such as this can inform physical therapists for research and practice. An example given by the authors was that recommending to the caregiver to take the person with PD to a weekly exercise group may be seen as another burden.

Ninth, the Economic, Social, Psychological and Educational Requirement Table (ESPERT) was reviewed. Ferrario and colleagues (2003) proposed a model for assessing caregiving related problems and needs which were based on findings of international research into care-giving. As a European model, the ESPERT was driven by health care legislation that acknowledged the important role played by caregivers and their social and economic value. The model was used in unison with the Family Strain Questionnaire. The authors attempted to address the difficulty of improving the quality of health and social welfare services, while simultaneously reducing their costs (Ferrario et al., 2003).

Tenth, a critical caring hybrid middle range theory by Falk-Rafael (2005) was reviewed. She proposed the theory based off of on nursing science and critical feminist

theories. She transformed seven of Watson's carative health-promoting processes (described earlier) into a critical caring theory for public health nursing. The social justice agenda and empowered caring was at the core of this critical caring theory. Critical social theories, public health nursing and primary health care have addressed the inequalities in health to be politically, socially and economically unacceptable. Falk-Rafael described clients as care partners and the concept of caregiver advocacy. Determining the appropriate balance of formal and informal care-giving support and health education built on the active participation of teacher-learners in a "respectful, collaborative, and dialogical approach" (Falk-Rafael, p. 45) was presented.

Eleventh, the crisis theory by Wooley's (1990) was reviewed. Family caregivers must deal with stressful and/or crisis situations. Caplan (as cited in Woolley, 1990) defined a crisis as occurring:

when a person faces an obstacle to important life goals, that is, for a time, insurmountable through the utilization of customary methods of problem-solving. A period of disorganization ensues, a period of upset, during which many different abortive attempts at solutions are made. (p. 1403)

Woolley suggested that with change and crisis, disequilibrium and loss of homeostasis existed for caregivers potentially leading to physiological and psychological ill-health. This theory suggested empowering families through a tripartite framework including improving cognitive understanding of the event (like a fall with resulting life-

threatening injury), providing appropriate situational support, and establishing effective coping techniques.

Twelfth, Talley and Crews (2007) recently proposed a simplistic triadic model of care-giving from a public health perspective. This model assumed a team approach with team members being: the care recipient, family caregiver and professional caregiver. Factors which influenced this relationship were described: (a) health care systems, (b) insurance industry, (c) society, (d) internet access, (e) consumer choice, (f) aging demographics, (g) scientific discoveries, (h) advocacy/membership organizations, (i) global disease burden, (j) political forces, and (k) media portrayals.

Considering the plethora of caring and care-giving theories, Cousins and colleagues (2002, p. 389) have argued that “Despite nearly 40 years of care-giving research, it is only relatively recently that there has been a move toward drawing upon individual pieces of research in order to provide holistic, explanatory models of informal care-giving.” Braithwaite further asserted “that it is the lack of consensus on the conceptualization and operationalization of caregiver distress that is responsible for the absence of a basic theoretical model of the care-giving experience, and application of research findings” (as cited in Cousins, Davies, Turnbull, & Playfer, 2002).

A holistic perspective in research was advocated in the field of physical therapy. Shephard and colleagues (1993, p. 88) suggested that both philosophical perspectives, positivism and phenomenology, be used to pose research questions so as “To capture the variety of dimensions that embody the essence of physical therapy practice...” Furthermore, Lincoln eloquently stated, “The danger lies in granting sacerdotal status to

one set of methods over another, one paradigm over another, a single theoretical lens, rather than multiple fruitful lenses (Swanson & Holton, 2005, p. 231).

Since the Renaissance, there has been discourse between advocates of the philosophy of nature (reality of the physical sciences) and advocates of the philosophy of the mind (the nature of the human experience) resulting in what some have suggested as “competing worldviews” (Hinshaw et al., 1999). The post-positivist (objectivist, empirical-analytic) approach, the interpretative (humanistic or naturalistic) approach and the critical (emancipatory) approach have emerged as three distinct foundations for caregiving research. Gioia and Pitre (1990) suggested a multi-paradigm approach to theory construction and believe that theory building should be viewed “...not as a search for truth, but as more of a search for comprehensiveness stemming from different worldviews” (p. 587). In review of the literature, care-giving theories have emerged from positivistic, interpretative and emancipatory paradigms.

Summary: Foundational Theories about Care-giving in General

In the literature, there have been complaints that care-giving research has been non-theoretical which may be related to the fact that there was no consensus on the conceptualization and measurement of care-giving or use of a universal theory of care-giving. Care-giving research studies have not consistently and explicitly stressed underlying theory in their introductory review of the literature sections, although there have been numerous published theories on caring and care-giving which could be utilized to inform the research. Theories were found in the literature from various disciplines including nursing, physical therapy, psychology, sociology and medicine,

although the most developed and older theories were from nursing literature. In general, there has been recent recommendation that theory building, research and practice need to inform each other.

The theories reviewed have been developed and modified using various research paradigms including interpretative (qualitative), positivistic (quantitative) or critical (emancipatory) methodology. With these various worldviews, recently researchers stated the need for the development of a holistic theory of care-giving. Researchers have argued that despite nearly a half century of care-giving research, there has been only a recent move to provide holistic, explanatory models of informal care-giving. Although there was not one unified accepted care-giving theory, the common concern for caregivers' physical, psychosocial and emotional well being was often described with terminology like strain, burden, stress, distress, psychological well-being, depression, health, and cost of care. These dimensions were then linked to demographic and economic trends of our aging population which was explored in the next area: implications to an aging population

Implications of an Aging Population for Caregivers

The American population has had a growing number of older citizens with increasing demands for and on caregivers. Exploring the need for caregivers now and in the future was addressed. To better understand the societal trends, the following four categories were reviewed: life expectancy; prevalence of informal caregivers; economic impact of care-giving in general; and economic impact specific to caregivers to persons with PD.

Care-giving research has been structured within a contextual orientation. Researchers have investigated the changing demographics in relation to care-giving in order to better understand changing cultural and economic issues. Predicting future needs for an aging society seemed to be at the heart of much of the care-giving research.

Life Expectancy and Demographics

Life expectancy (the average number of years a person can expect to live) has increased dramatically in the past century. “In 1930, life expectancy at birth in the United States was 58 for men and 62 for women. By 2001, the average U.S. life expectancy was 74 for men and 80 for women.” (National Institute on Aging, 2006, p.1). The U.S. Census Bureau projects that one in every nine baby boomers (80 million people born between 1946 and 1964) will survive into their late 90s, and that one in 26 (3 million) will reach 100 (National Institute on Aging, 2006, p. 2). Tuljapurkar’s life expectancy forecasting model projected life expectancy in the U.S. to rise to 86 by 2075 and to 88 by the end of the century (as cited in National Institute on Aging, p. 3).

Factors influencing this trend included: reduction in infant and child mortality, improved nutrition, improved living standards, changes in health behavior and improved medical care (e.g. control of infectiousness diseases and chronic diseases like heart disease and stroke). In industrialized nations, the demographic changes of an aging population represented a transnational phenomenon forcing long term care needs and policy to the front ranks of policy agenda (Davey, & Patsios, 1999; Gray, & Hughes, 2005; Johnson, Toohey, & Wiener, 2007; Wallhagen, & Yamamoto-Mitani, 2006). Tuljapurka and colleagues (2000) showed that mortality in the major

industrialized countries declined exponentially and at a constant rate from 1950 to 1994 (as cited in National Institute on Aging, 2006). Research on the projections of life expectancy has been deemed increasingly important in order to determine the future size of the elderly population. The National Institute on Aging (p. 1) suggested that this understanding was key to the “informed planning for the allocation of public and private resources.” Providing health care and meeting care-giving needs for an aging population has become a primary societal and political concern.

The population has been aging and with that aging has come the concomitant increase in morbidity (condition of being unhealthy or diseased) associated with increasing numbers of people living with progressive neurological disorders like PD and Alzheimer’s disease. To better understand morbidity, researchers have actively attempted to differentiate between active and disabled life expectancy. Active life expectancy has been defined as the projected amount of remaining time free of disability in activities of daily living (ADLs) and disabled life expectancy is defined as the projected amount of remaining time disabled in ADL’s (Gill, Allore, Hardy, Holford, & Han, 2005). Policy makers have used this information to forecast the functional health of older persons and to plan accordingly. With increased disabled life expectancy, there would likely be the concomitant need for caregiver assistance with ADL’s (e.g. bathing, dressing, eating, toileting, grooming).

According to the U.S. Bureau of the Census, “with the continued population aging, those older than 65 are projected to increase to 20% of the total U.S. population by the year 2050” (as cited in Dilworth-Anderson, Williams, & Gibson, 2002, p. 237). Between 2000 and 2050, the size of the population age 85 and older will increase from

4.3 million to 20.9 million (Johnson, & Weiner, 2006). In addition, Dilworth and colleagues reported, “the percentage of racial and ethnic minority elders will increase at a much higher rate than of non-hispanic white elders over the next 50 years” (p. 237). Van Den Eeden and colleagues (2003) reported that this becomes important as chronic disease can vary by race and ethnicity. Unfortunately, racism and health inequity among Americans has existed. Shavers & Shavers (2006, p. 286) in an extensive review of the literature, concluded that “racial/ethnic disparities in health care are the result of a combination of social factors that influence exposure to risk factors, health behavior, and access to and receipt of appropriate care.”

In addition, with an aging population comes projected increases in the elderly dependency ratio (the ratio of the population aged 65 and over to the population aged 15 to 64 stated as a percentage) (Hollman, Mulder, & Kallan, 2000). Globally, the burden of care will be placed on a shrinking younger population. By 2050, the elderly dependency ratio is expected to rapidly increase in many parts of the world including Europe, North America, Oceania, Latin America and Caribbean, Africa and Asia (U.S. Government Accountability Office, 2004). It has been suggested that the demographic and economic forces associated with population aging has and will challenge health and social services leaders and policy-makers in the coming decades (The Atlas of Canada, 2004). In terms of health, some of the implications of an aging population have been summarized (The Atlas of Canada, p. 1):

- (a) increases in diseases and disabilities associated with aging and therefore the need to provide relevant care, especially in terms of chronic physical and mental health problems,
- (b) changes in the skill sets of our health care providers (physicians, nurses, etc.) that will be required to respond to the needs of the elderly,
- (c) shifts in the delivery of formal health care services, particularly increased long-term care,
- (d) and an increase in the number of informal caregivers (unpaid family and friends) of the elderly in community settings and the need to provide supports for those caregivers

Prevalence of Informal Caregiving

According to Arno, Levine and Memmott (1999), from national data sets, there were 24.0 to 27.6 million caregivers providing 22-26 billion hours of care-giving per year nationwide. In terms of care recipients, Johnson (2007) reported that about 10 million Americans ages 65 and older, representing about 29 percent of the older population, needed help with basic personal activities or household chores and errands. According to Donelan and colleagues (2002), “each year 23 percent of Americans provide unpaid assistance to ill, disabled, or elderly persons” (p. 222). Johnson and Wiener (2006) reported unpaid care assistance is primarily given by a spouse or daughter with women accounting for about two-thirds of all unpaid caregivers.

In another national survey of 1002 caregivers, both the heterogeneity of the caregivers and the complexity of their experiences were described (Levine & Murray, 2004). In terms of gender, the national survey reported by Levine and Murray found 53.7 percent of caregivers were female and 46.3 percent were male. In addition, Levine & Murray reported, caregivers were younger (86.6 percent between 18 and 64 years), and employed (52.6 percent). In addition, the majority provided episodic care ranging from a few hours a week to 59 hours a week. Constant care was considered to equal sixty or hours or more per week of care. In terms of the care recipients, most were female (65.3 percent) and two-thirds were older than sixty-four. Although many studies identified single primary caregivers, Piercy (1998) found that family caregiving was a shared responsibility among several family members.

Hospitalization impacted caregiving and the types of tasks expected from the caregivers with 54.6 percent of the care recipients having been hospitalized within a year of the survey (Levine & Murray, 2004). Tasks performed by the caregivers included activities of daily living (ADLs), instrumental activities of daily living (IADLs), shopping, managing incontinence, feeding, administering medication, wound care, helping with medical equipment, and transportation.

In another report, AARP Public Policy Institute (Pandya, 2005), the National Alliance for Caregiving (NAC) and AARP estimated that 21 % of the U.S population provided unpaid care to friends and family age 18 and older which translates into 44.4 million caregivers. In addition, they reported the following: (a) the typical caregiver is a 46 year old female with some college experience who provided more than 20 hours of care each week to her mother, (b) nearly 39 % of caregivers were male, (c) most

caregivers lived in close proximity to the person for whom they provided care with 25 % living in the same household, (d) 79 % of care recipients were 50 years and older with the average age of this group being 75, (e) most recipients were female, (f) more than half of care recipients lived in their own homes, and (g) nearly 60% of caregivers were employed.

Unfortunately, the distinctions between caregiver and recipient have not been always clear cut as some older caregivers may prefer to see themselves as primarily a spouse or partner rather than caregiver (Goodhead & McDonald, 2007). For example, in a study by Habermann (2000), spousal caregivers did not describe themselves as caregivers, and in some cases, reacted negatively to this idea. Family members and friends have provided care and support without perceiving or recognizing they are caregiving. Furthermore, in the elderly population, it has not been always possible to clearly differentiate caregiver and recipient, as in some households the roles are blurred with both members of the pair giving and receiving care (Argyle, 2001).

Economic Impact of Care-giving In General

As the population ages, with accompanying increases in dependency, the determination of the economic value of both formal and informal care-giving has become increasingly relevant. On May 16, 2007, principal research associate Richard W. Johnson testified before the Joint Economic Committee of the United States Congress regarding the financial challenges confronting family caregivers (Johnson, 2007). Data was provided from the 2002 Health and Retirement Study conducted by the National Institute on Aging. Johnson reported that the assistance of unpaid helpers to the frail elderly was worth about \$51.2 billion dollars. This conservative figure, limited

to the frail elderly, was contrasted with a more staggering figure. Arno provided an estimate of \$257 billion for the economic value of informal care-giving in the United States (as cited in Levine & Murray, 2004). Arno and colleagues (1999) stated, “Because ‘informal’ care-giving lies outside the market economy and is socially and politically invisible, its economic value is not generally acknowledged” (p. 182).

Millions of adults in the U.S. provided care to disabled or aging relatives which has saved the health care system billions of dollars per year (Cutson, Zhu, Whetten & Schenkman, 2004). Estimating the projected number of informal and formal caregivers needed for the next century and the economic impact of this care has been a daunting task. According to Arno and colleagues (1999), the economic value of informal care-giving has moved from “the micro level, where individual caregivers attempt to cope with stresses and responsibilities of care-giving, to the macro level of health care system, which must find more effective ways to support family caregivers” (p. 182).

Economic Impact Specific to Caregivers to Persons with PD

Hidden behind the statistics were substantial burdens for patients, their families, and society in terms of increased health resource use, poorer quality of life, caregiver burden, caregiver stress, disrupted family relationships, decreases in social and leisure activities, deteriorating emotional well-being, and direct and indirect costs of illness (Amirkhanyan, & Wolf, 2003; Rubenstein, DeLeo, & Chrischilles, 2001). Care-giving for persons with PD has been reported in the literature. Because of the progressive and chronic nature of PD (Van Den Eeden, 2003), care-giving has been routinely required

with advancing PD. It has been deemed important to understand the implications of this disease for caregivers (Cutson, Zhu, Whetten, & Schenkman, 2004).

Considering the large number of persons with PD, there has been a concomitant need for informal caregivers. Demographically, PD affects 6.3 million people worldwide (Medical News Today, 2008). PD may be described as early onset (less than 40 years) or late onset (greater than 40 years) (O'Sullivan & Schmitz, 2007). Van Den Eeden found the incidence of PD increased over the age of 60 years and is greater in men (19.0 per 100,000, 95% CI) than women (9.9 per 100,000, 95 % CI). According to Dauer and Przedborski (2003), the mean age of onset is 55, and the incidence increases markedly with age, from 20/100,000 overall to 120/100,000 at age 70. According to the NINDS, the disease has subtle symptoms (e.g. bradykinesia, resting tremor, rigidity, and postural instability) that develop gradually as early as 40 years of age with the average age of onset being 60 years of age. In addition, incidence of PD varied by race/ethnicity with greater incidence among Hispanics followed by non-Hispanic Whites, then Asians then Blacks. In 95% of the cases, there is no known genetic linkage (Dauer & Przedborski).

Specific to the United States, The National Institute of Neurological Disorders and Stroke (NINDS) stated that about 50,000 Americans are diagnosed with Parkinson's Disease each year, with more than half a million Americans affected at any one time (*Parkinson's disease: hope through research*, 2001). NINDS estimated the total cost to the nation to exceed \$5.6 billion annually. Scheife and colleagues (2000) reported, "PD markedly reduces health-related quality of life (HRQL) and places an economic burden on society of up to \$25 billion per year" (p. 953).

Whetten-Goldstein and colleagues (1997), in a cross sectional descriptive study of 109 persons with PD and their caregivers concluded that the direct costs of the disease reflect a small portion of the burden and the hidden costs were in the form of lost wages, informal care and changing roles. These spouses provided a mean of 22 hours per week of caregiving. In a later study by Parrish, Guinta, & Adams (2003), PD caregivers reported providing an average of 96 hours of care per week to their care recipients. In this study, the typical PD care recipient was a 76-year old married man living with his caregiver wife.

Adding to the economic burden has been the health care issue of falls with subsequent injury occurring in the elderly and in persons with PD. According to Stevens and colleagues, in 2000, the total cost of all fall injuries for people 65 and older exceeded \$19 billion (as cited in CDC's Cost of Falls Among Older Adults, 2008). Unfortunately, "the total economic burden is significantly higher because this estimate does not include direct nonmedical, intangible, and indirect costs (Carroll, et al., p. 307). Care-giving was considered a hidden cost. Englander reported by 2020, the annual direct and indirect cost of fall injuries was expected to reach \$54.9 billion dollars (adjusted to 2007 dollars) (as cited in CDC). Rizzo found the average health care cost of a fall injury was \$19,440 (including hospital, nursing home, emergency room, and home health, but not doctor services) (as cited in CDC)

Summary: Implications of an Aging Population for Care-giving

The United States population is becoming more diverse and older. Accurately projecting the life expectancy of the American population remains a challenge, as well

as controversial with the life expectancy ceiling unclear. Similarly, allocating resources for a more aged population will require planning and conscientious policy making. As the population ages, there is greater likelihood of people developing chronic diseases like Parkinson's disease which is diagnosed in later life.

Chronic diseases can alter active life expectancy. With physiological, physical, cognitive, emotional and psycho-social changes, persons with PD will likely require assistance from health care providers and informal caregivers with resulting increases in health care expenditures. And finally, there were identified hidden costs to care-giving.

Positive and Negative Attributes of Care-giving

The fourth area reviewed was related to the positive and negative attributes to care-giving. Commitment to care-giving can make a profound impact on the life of a caregiver. The care-giving experience has been described in terms of enriching positive attributes and burdensome negative attributes. Care-giving has impacted physical health, mental health, employment, financial security, family relations, social connectedness, life's opportunities, and plans for the future (Goodhead & McDonald, 2007).

Although the negative aspects of care-giving have had center stage, Canadian researchers argued that there are positive aspects of care-giving which need to be identified in order to gain a better comprehension of the complete care-giving experience (Cohen, & Colantonio, Vernich, 2002). In terms of enriching attributes, Patterson reported the following positive aspects: keeping the person out of residential care, being satisfied at a doing a good job, undertaking care-giving as an act of love,

and the opportunity to move out of the paid work force (as cited by Goodhead & McDonald). In addition, Argyle (2001) noted that many caregivers identified a significant decline in the quality of their lives after the care recipient had died including reduced income, boredom, isolation and sense of loss of both the person and the care-giving role.

In further exploration of the negative attributes, caregiver distress has been identified as a potential factor leading to institutionalization of the care recipient especially if the caregiver's health breaks down. Cousins and colleagues (2002) described various concepts of care-giving distress, including caregiver strain, burden, stress, distress, psychological well-being, depression, health and cost of care. Cousin et al. summarized that there is a lack of consensus in the conceptualization and measurement of care-giving outcomes, and this may be responsible for the lack of progress in identifying distressed caregivers and following from that, targeting resources to effectively ameliorate distress. They further suggested that the many different perspectives may be hindering the development of a unified and methodological approach to understanding the impact of care-giving. They argued that the research has focused on accounting for all demographic differences like studies that differentiate between spouse and non-spouse care-giving, between female and male care-giving, between older and younger groups of caregivers, between the different styles according to ethnicity, between resident and non-resident care-giving, and between the different role demands according to the disease, and even stage of disease.

In a Canadian longitudinal study of stress, Armstrong-Ester and colleagues studied 330 informal caregivers of the elderly over a 30 month period and identified

predictors of caregiver stress (in order of importance) including (a) caregiver financial difficulty, (b) lower age of caregiver, (c) care recipient being a spouse, (d) providing more hours of care-giving per day, (e) greater mental disability in the recipient, (f) higher levels of cognitive decline in the recipient, (g) receiving more respite care (as cited in Goodhead & McDonald, 2007). These variables only accounted for 20 percent of the variability in caregiver stress. This suggested there may be other factors contributing to stress.

In terms of caregiver related research in PD, according to Pasetti and colleagues (2003), only a little more than 1% of the published papers concerning Parkinson's disease refer to care-giving-related problems (e.g. health or emotional well being). In terms of the quantitatively designed caregiver studies, various scales to investigate caregiver stress and burden, including the physical, emotional, and economic burden were used (Berry & Murphy, 1995; Caap-Ahlgren & Dehlin, 2002; Edwards & Ruettiger, 2002; Pinguart, & Sörensen, 2005; Sörensen, Pinguart, & Duberstein, 2002). In a comprehensive meta-analysis, Vitaliano and colleagues (2003) reviewed 23 studies, using matched control studies to compare the health of caregivers of persons with dementia (seen in later stages of PD). They found a nine percent greater risk of health problems in caregivers and a 23 percent higher rate of stress hormones than for non-caregivers. In addition, they found caregivers had poorer antibody production, a higher incidence of sleep problems, less adequate diets, and more sedentary behavior. Because patients with PD do experience cognitive decline in later stages of the disease process, these results were considered pertinent.

Specific to PD, Carter et al. (1998) used a cross sectional questionnaire design with 380 (spouse) caregivers to persons with PD at various stages (modified Hoehn and Yahr Parkinson's Disease Severity Scale; six definitive stages 1, 2, 2.5, 3, 4, and 5). In this scale, the higher the stage number, the greater motor involvement. Three categories of variables were used: caregiver role strain (10 items), caregiver situation (four items), and caregiver characteristics (4 items). They found a strong association between advancing stages of disease and increasing role strain (worry, tension, frustration due to communication problems, direct care, role conflict, mismatched expectations, economic burden, lack of resources, manipulation, global). Negative changes in lifestyle plus decreases in predictability in caregivers' lives increased significantly in late stage-disease. Depression (an item in the caregiver characteristics category) was significantly higher in caregivers by stage 4/5. The authors suggested that by defining the types and amounts of strain by stage of disease could be helpful in designing formal intervention trials to provide more effective help for spouse caregivers.

Similarly researchers have attempted to measure psychological caregiver distress with instruments like the Caregiver Distress Scale (CDS) which includes five subscales-relationship distress, emotional burden, care-receiver demands, social impact and personal cost (Cousins, Davies, Turnbull, & Player, 2002). Their longitudinal study of 80 PD caregivers concluded that the scale was quick to administer and reliable. Further psychometrics testing of the instrument was recommended especially to determine the scale's ability to monitor progress of interventions.

In 2003, Calne et al. used the Parkinson's Impact Scale (PIMS) in a cross sectional design to measure quality of life in 135 caregivers of persons with PD. The

PIMS has 10 items (self positive, self negative, family relationships, community relationships, work, travel, leisure, financial security, sexuality). Participants rate the impact Parkinson's disease has had on their lives (0=no change, 1 slight, 2=moderate, 3 moderately severe, 4= severe). "The caregivers rated the negative impact of PD most highly in three areas. They were, in order of priority, sexuality, travel, and leisure. "Safety and community relationships were least important." (Calne, et al., 2003, p. 120). The authors recommended the PIMS as a reliable tool to determine caregiver burden clinically and in research trials. The above studies showed the complexity in determining the impact of care-giving. Studies varied from cross sectional to longitudinal. Considering the chronic dynamic nature of caring for person with PD both types of studies have provided valuable information.

In terms of qualitative research, Habermann and Davis (2006) stated there was limited qualitative data about caregiving in chronic illness like PD. In terms of qualitative research, there are a few studies specifically exploring the lived experience of PD in the literature (Davis, Ehrhart, Trzcinski, Kille, & Mount, 2003; Habermann, 1996, 1999, 2000; Hobdell, 1996; Lindgren, 1996; Whitney, 2004). Habermann (2000) explored the experience of living with a partner who has PD in middle life (age range of 44-58 years). She described the most significant challenge to spouses as watching their partner struggle, being frustrated, and renegotiating their own lives. Habermann identified the spouses' most frequently used coping strategies as maintaining their lives, encouraging their partner to stay active and involved, and seeing the challenges they experienced as secondary.

Although caregivers were not the focus of the study by Davis and colleagues (2003), the implications for caregivers were implicit. According to Davis and colleagues, the intent of their study “was to provide the health care community with new information that could lead to better global care of persons with PD (p. 44). They identified three emergent themes in their qualitative study of experiences for individuals living with PD: the variability of experiences among people living with PD, the variability in compensatory and coping strategies used by participants and the inadequacy of the health care system for addressing the variable needs of the PD population. The scant published qualitative interpretative research on care-giving to persons with PD pointed to the need for further research.

Summary of the Literature on Positive and Negative Attributes of Care-giving

Both positive and negative attributes of care-giving have been identified. These attributes have impacted physical, cognitive, emotional, social and financial aspects of a caregiver’s life. Positive aspects reported in the literature have included: keeping the person out of residential care, being satisfied at a doing a good job, undertaking care-giving as an act of love, the opportunity to move out of the paid work force in order to provide care-giving. If the care recipient dies, caregivers have reported reduced income, boredom, isolation and sense of loss of both the person and the care-giving role.

Although both positive and negative attributes of care-giving have been reported, the negative aspects like caregiver burden and strain were more pervasive in the literature. In terms of caregiver burden and strain, quantitative approaches have addressed various tools (e.g. scales, inventories, questionnaires) which have been shown

to be reliable to assess the impact of care-giving so that specific caregiver interventions can be formulated and outcomes measured. In addition, qualitative approaches have explored the lived experience of care-giving spouses especially in the early stages of the disease process and have identified challenges including: watching their partner struggle, being frustrated, and renegotiating their own lives. In general, the studies recommended further care-giving research.

Implications of Caregiver Education and Support

The fifth and final area reviewed, implications of caregiver education and support, was broken down into the following two categories: (a) caregiver and patient education and support in general, and (b) educating the caregiver in their role to prevent falls. Barker, Grant and Hodnicki (1998) stated that learning about PD can help patients and their caregivers understand the disease and give them a sense of control over their illness and lives. As caregivers have become involved with more health care decisions, they have learned about care-giving and disease specific information through their day-to-day experiences, through self-directed efforts, through formal caregiver training, and through peer support.

Both the person with PD and the caregiver have been the focus related to education which has addressed disease specific issues (Oertel, & Ellgring, 1995). Yet, there has been growing awareness for the need for both informal (family) and formal (professional) education of caregivers. According to the American Association for Caregiver Education (n.d, p. 1), “health care providers and agencies have been remiss in

developing the education and training programs that are necessary to teach caregivers how to care for themselves and their loved ones.”

Caregiver and Patient Education and Support in General

In reviewing the literature on caregiver education and learning, the information was often intermingled with general information on patient education and patient centered care. Often patient centered care activities by health care providers have assumed support of the family (Davidson, et al. 2007). Interestingly, in the 40's, Richardson argued for research to understand the family unit, and for the development of intervention techniques which focus on the family as a unit as opposed to focusing on individuals in isolation (as cited in Woolley, 1990). Patient and family centered care has evolved over the past 35-40 years (Johnson, 2007). Johnson (2000) described the core principles of family centered care which evolved from the belief that the family has the greatest influence over an individual's health and well-being, and that because of this influence, families must be supported in their roles as caregivers. Davidson and colleagues (2007), in an extensive review of over 300 related studies on family support and a consensus task force process, recommended the need for further research and endorsed practice guidelines for support of the family like shared decision-making, consistency in communications, culturally appropriate care, and spiritual support.

As a physical therapist, I purposely explored the physical therapy literature related to patient and caregiver education. Recently, Rindfleisch (2009) described the continued lack of physical therapy related patient education literature. The literature available has been directed toward patient centered versus caregiver or family centered.

For example, Sluijs (1991) tested application of a checklist to assess patient education in physical therapy practice. Caregiver education was not explicitly listed, although the provision of supportive care with handicaps and personal distress was identified.

Fortunately, there has been renewed interest in the exchange of both tacit and explicit knowledge among educators, researchers, policymakers and caregivers (Bruyère Continuing Care, 2009; Wrubel, Richards, Folkman, & Acree, 2001).

As health care providers have attempted to educate caregivers and patients with PD, the literature showed some use of the underlying foundational tenets of adult education (Dreeben, 2010; Lieb, 1991; Materna, 2007). Recently, Dreeben (2010) has applied the following concepts to caregiver and patient/client education:

- (a) informing the learner why the information is important to learn, (b) showing the learner how to self direct through the information, (c) relating the topic to the learner's experience, (d) taking into consideration the fact that people will not learn until they are ready and motivated to learn, and (e) the teacher helps the learner overcome behaviors, beliefs, and inhibitions about the learning process (p. 228).

In addition, Dreeben recommended incorporating critical elements of adult teaching and learning into caregiver and patient education like learner motivation, feedback and reinforcement of learning, retention of information and transference of knowledge, self efficacy, managing change and assessment of learning style.

Patient and caregiver education programs to complement medical treatment of PD have been aimed at improving knowledge and skills related to self-monitoring, health promotion, stress management, depression, anxiety, social competence and social support (Lyons, 2003; Macht, et al., 2007). Reid (2003) listed five implications of patient education for practice:

- (a) Patient education is vital when trying to help patients come to terms with their diagnosis;
- (b) It must be tailored to each individual;
- (c) It empowers patients to make informed decisions about their care and long-term management;
- (d) Dedicated multi-disciplinary PD clinics provide patient education as one of their important functions;
- and (e) Patient education improves quality of life for PD patients and their carers, from time of diagnosis onward.

Over 20 years earlier, Mazzuca's (1982) meta-analysis of patient education research suggested that knowledge of the disease alone was not enough to cause changes in health behaviors. This notion of behavior changes among patients and family caregivers have been further addressed in the trans-theoretical model or stages of change (Burbank, & Riebe, 2002). Although a burgeoning approach, researchers have begun to focus attention on enhancing caregivers' problem solving capabilities, care skills, self-health skills, and resource acquisition skills (Habermann, & Davis, 2006; Kurylo et al.). Behavioral changes for patients and caregivers have also been considered in self-management models.

McComb and Tickle-Degnen, (2005) suggested developing the construct of social support in PD. Lyons (2003) advocated a self-management (SM) training program to assist persons with chronic illness like PD to gain skills and confidence to promote their own health and well-being. Where as patient education programs were typically designed to provide disease specific information to participants, self-management emphasizes social learning techniques and behavioral changes, in addition to disease specific education. Lyons suggested that in such a SM model, persons with PD ideally would be independent and autonomous in negotiating daily function, but in reality, the effectiveness of SM will depend on inclusion of family members and caregivers in collaboration with the health care team.

SM training programs emphasized development of problem solving skills and were based off Bandura's social cognitive theory (Bandura, 1997). Lyons (2003) offered six guidelines: (a) teach systematic observation, (b) set measurable goals that are explicitly communicated, (c) evaluate behavior realistically and use incentives, (d) allow practice of skills and tasks, (e) target self-efficacy, and (f) use a group format for modeling and persuasion. Self efficacy increased as a person developed belief in his own ability to solve problems. Both the person with PD and the caregiver both had perceived self efficacy which influenced their actions and interactions. As the person with PD and the caregiver moved along the pathway of this chronic disease through the diagnosis period, into the maintenance phase, to the complex phase and then into the palliative final stage (MacMahon, 2004), perceived self efficacy would likely change as the health care aims and outcomes changed.

A number of studies have addressed the need for multidisciplinary approaches to patient and caregiver education (Carne, et al., 2005; Holloway, 2006; Monnin, et al., 2003; Shimbo, et al., 2004; Sitzia, Haddrell, & Rice-Oxley, 1998; Trend, Kaye, Gage, Owen, & Wade, 2002; Wade, et al., 2003). In an UK study, Trend and colleagues (2002) studied the short-term effectiveness of intensive multidisciplinary rehabilitation for people with PD and their caregivers. When instigated, caregiver interventions have been found to be effective, especially psychoeducational and psychotherapeutic interventions (Kurylo, Elliott, Shewchuk, 2001; Habermann & Davis, 2006; Secker & Brown, 2006; Sörensen, Pinguart, & Duberstein, 2002). Caregiver education and interventions have been tried. Results of a preliminary, randomized controlled trial (N=34) of cognitive behavioral therapy (CBT) for caregivers of patients with PD supported value in this type of psychological management approach (Secker & Brown). Each module (eight total) targeted a specific stressor and/or trained a new adaptive coping method. Similarly, Donelan et al., (2002) noted, "Support and instruction could lighten caregivers' burdens and help to ensure high quality care at home."

Oertel and Ellgring (1995) developed medical education material for persons with PD and their caregivers. They used analogies and illustrations like describing the neuronal damage seen in PD like a TV broadcasting system and the effects of the medication used by the brain as a sink with one tap and two outlets. This paper was descriptive and not designed into a controlled study.

A common development has occurred in the U.S. and some European countries in the past 20 to 30 years with the development of organizations (e.g. American Association for Caregiver Education, Family Caregiver Alliance, Institute for Caregiver

Education, National Parkinson Foundation) providing for research, educational pamphlets, newsletters, web sites, referrals, and support group information to patients and their families (Fischer, 1999; Heijman, 1995). These foundations, associations and organizations have accumulated and disseminated information on the physical, social and psychological effects of PD. For example, Sutter and colleagues (2006) reported on “The Wellness Course for Person’s with Parkinson’s disease and their caregivers” (p. 19). This course was developed as a partnership with the American Parkinson Disease Association, Washington University School of Medicine and the Lutheran Charities Foundation. The course applied “health and wellness concepts and an empowerment-based, participatory-learning approach to encourage persons with PD and their caregivers to share information, problem-solve challenges, and build confidence” (Sutter, Curdt, & Neufeld, 2006, p. 20).

Even though patient and caregiver education has been an evolving phenomenon, Schulz and colleagues (2007) argued that current health and social service policy focused on family care-giving interventions have emphasized care provisions (e.g. home alteration and caregiver skills training) versus the affective dimensions of patient suffering and caregiver compassion. They further suggested that cognitive reframing methods could be useful to minimize caregiver distress by enabling caregivers to come to terms with the limits of their ability to control suffering. Patient suffering was described as having three components—physical, emotional and existential or spiritual (Schulz, et al). Addressing these various facets have added to the complexity of providing caregiver education and meeting the caregiver’s needs. This was further highlighted in the literature on the caregiver’s role in fall prevention.

Educating the Caregiver in their Role to Prevent Falls

According to Dennison and colleagues (2007), for the patient with PD and the caregiver, the progressive nature of the disease process can be manifested over many years with increasing risk of falling for the person with PD. When a person with PD falls, it impacts not only that individual but others too, like a stone dropped into water producing far-reaching ripples. According to Davey and colleagues (2004), falls increased morbidity as well as mortality, which strongly impacted quality of life for the patient and the care-giving spouse.

Falls have lead to fracture, other injuries and fear of falling which then lead to immobilization, all a part of the vicious circle of postural instability and falls seen in PD (Bloem, van Vugt, & Beckley, 2001). Literature supported that caregivers experience tension and worry as the individual with PD progresses through the disease (Carter, Stewart, & Archbold, 1998; Pearlin, Mullan, & Semple, 1990; Secker & Brown, 2005). Davey and colleagues (2004, p. 1360) concluded that caregivers in their study “felt unprepared for their role and expressed a need for more support and advise especially about managing falls.” Unfortunately, many informal caregivers must learn to understand how to deal with falls without sufficient skills and resources to do so. As Levine & Murray (2004, p. xxii) stated, “family caregivers are poorly prepared to take on their daunting frequently medicalized tasks and that they have significantly unmet needs”.

In the situation of dealing with a spouse who falls, the care-giving spouse would need to make multiple decisions including doing nothing, seeking medical advice,

modifying the home to prevent falls, purchasing adaptive equipment, moving to an assistive-living situation or moving his/her spouse to a nursing home environment (O'Sullivan & Schmitz, 2007). The care-giving spouse has been dependent on the health care system (e.g. physical therapists) to provide direction and support as he/she coped and learned to deal with the progressive nature of PD (Bello-Haas, 2002). Formal caregivers (e.g. rehabilitation specialists like physical therapists) have provided services in clinics and hospital settings remote from the home environment where falls are likely to occur. Lack of evaluation of the home environment by rehabilitation specialists has potentially resulted in inadequate detection of both human and environmental risk factors for safe mobility (Wottrich, von Koch, & Tham, 2007), for example the caregiver and patient lacked understanding of proper transfer techniques/skills or how medication cycles affected exercise.

Bloem and colleagues (2003, p. 1023) have remained encouraging, stating, "Clinicians should not automatically assume therapeutic nihilism, because several strategies might reduce falls and injuries in PD." Newly developed patient and caregiver education programming for PD have generated both national and international promise for reducing falls and empowering both patient and caregiver (Habermann & Davis, 2006; Lyons, 2003; Macht, et al., 2007; Secker & Brown, 2004). Habermann and Davis recommended using tip sheets to PD caregivers as part of the educational and skill-building process. Tip sheets that were used included managing: falls, stress, drooling, freezing, nutrition, blue moods. In addition, fall prevention resources for the elderly were abundant on the internet (Center for Disease Control, 2009).

Considering the number of people with PD who are at risk for falling, it was important and relevant to understand just what the meaning of this falling experience was from the perspective of the caregiver in unique contextual situations. Exposure to education on fall prevention by health care providers could impact the lived experience of the care giving spouse who must deal with and cope with his/her spouse's postural instability and/or falls. Active learning of fall prevention strategies could be an important function for the care-giving spouse. Cutson and colleagues (2004) suggested that an important aspect of physical therapy may include working with the spouse on a variety of perspectives including:

- (a) assist spouses to better understand the disorder and their role in assisting the individual with PD, (b) recognize potential strains when involving the spouse in the patient's plan of care; (c) recommend services that can alleviate the burden of care on the spouse; (d) assist the spouse to find appropriate wellness programs and preventive avenues of care that will enhance his or her ability to remain able to provide the care for the partner with PD; (e) when appropriate, assist the couple to realistically evaluate the benefits and barrier of remaining in an independent living situation. (pp. 122-123)

Physical therapists have had the responsibility to educate both caregivers and persons with PD as part of a team approach to care and disease management (APTA, 2004; Morris, 2000, 2006).

Summary: Implications of Caregiver Education and Support

There is growing support of the benefits of both patient and caregiver education. Unfortunately, when looking at the patient education literature, it was variable in terms of who is being studied. Some studies included only patients with PD, others looked at both patient and caregivers, and others only the caregiver. If only the patient with PD was educated in the study, often it was unclear of the involvement and participation of the caregiver.

Fortunately, recent studies have focused attention on enhancing caregivers' problem solving capabilities, care skills, self-health skills, and resource acquisition skills as well promoting self management. A collaborative multidisciplinary team approach (including the patient, caregiver, health care professionals, local support groups and layperson organizations) appeared a viable strategy to positively impact health behaviors and promote positive adaptive lifestyle changes. Lastly, in the patient and caregiver educational studies reviewed, most did not directly refer to adult education theory, principles or concepts. Although, there has been some recent attempt in the physical therapy literature to integrate adult learning concepts into patient and caregiver education, as well as integrating concepts on negotiating behavioral change and readiness to change.

There has been interest in caregiver education in the area of fall prevention and management. Multi-component psycho-educational skill training intervention have been tried with PD and have been shown to be feasible. Further random clinical trials have been recommended.

Literature Review Summary

In review of the literature, there was substantial growing interest in better understanding the role of informal caregivers. Opportunities for new research questions, practice and policy related to caregivers were found. Care-giving was addressed from a general perspective, as well as from the specific perspective of the caregiver to a person with PD. Five key areas reviewed in the literature on care-giving included: meaning of care-giving; foundational theories about care-giving in general; implications of an aging population for caregivers; positive and negative attributes of care-giving; and implications of caregiver education and support.

First, the meaning of care-giving was reviewed from an etymological perspective, through exploration of the different terminology related to informal caregivers and formal caregiver and through historical views of care-giving and philosophical issues related to care-giving. There was no universally accepted definition of care-giving, yet the notion of care-giving being dependent on culture and context was evident. The meaning of care-giving has been intimately linked to the family in the literature. Historically, care-giving primarily occurred within the family unit. With technological advances and social changes, care-giving has become part of the public sphere. Both formal and informal caregivers have identified roles although these have not always been clearly defined. Philosophical issues of justice have complicated the situation in defining who should be responsible for care-giving.

Second, general foundational theories in care-giving were explored. There was no universally accepted care-giving theory or conceptual model that has been used. Recently, researchers have called for the development and use of a holistic care-giving

model which can be used to guide practice and research. Care-giving related theories were found in multiple disciplines including physical therapy, nursing, medicine, sociology, psychology and education. The nursing literature had many care-giving theories including Leininger's theory of culture care diversity and universality Sunrise Model., Watson's theory of human caring, Orem's self care deficit theory, Newman's theory of health praxis, and Roy's adaptation model. The theories were typically associated with specific research paradigms including interpretative, post-positivistic and critical. From an adult education perspective, Yang's holistic theory of knowledge and adult learning provided a bridge for the paradigms in identifying three knowledge facets (explicit knowledge, implicit knowledge and emancipatory knowledge). Importantly, health care legislation has driven the development of theory (e.g. The Economic, Social, Psychological and Educational Requirement Table (ESPERT) which recognized the social and economic value of caregivers.

Third, implications of an aging population for caregivers were addressed through review of the literature on life expectancy, demographic trends, prevalence of informal care-giving, economic impact of care-giving and implications specific to caregivers to persons with PD. Life expectancy in the United States has continued to rise with projected life expectancy into the late 80's by the end of this century. Along with older people comes increased dependency and risk for acquiring chronic illnesses (e.g. progressive neurological disorders like PD and Alzheimer's disease.) Progressive neurological disorders progress through stages which often require informal care-giving. Care-giving for the elderly with chronic disease has had a significant economic impact which has required consideration by multiple stakeholders including

policymakers, health care institutions, health care providers, caregivers and care recipients.

Fourth, research studies on the positive and negative attributes of care-giving were reviewed. Physical, cognitive, emotional, social and financial changes may affect the caregiver's quality of life. Both negative and positive aspects of informal care-giving could be found in the literature, but the negative physical, psycho-social, and emotional dimensions were reported more abundantly than the positive aspects. Negative aspects included constructs like worry, anxiety, depression, physical strain or burden, and loss of support systems. Positive aspects included constructs like being satisfied doing a good job as a caregiver and care-giving as an act of love. The literature had a greater abundance of quantitative studies versus qualitative studies related to care-giving for persons with PD. Quality of life measures have been used to objectify caregivers' life satisfaction. Physical strain and burden scales are also used to quantify the negative impact of care-giving.

Fifth, implications of caregiver education and support were identified from the literature. Caregivers to persons with PD have had to learn about disease symptoms, pharmacological management, nutritional management, surgical management and rehabilitative services. Caregivers have been required to learn facts, skills, and deal with the affective aspects of care-giving (e.g. patient suffering), although the emphasis on teaching skills (e.g. transferring a patient) has been reported in the literature. Some patient and caregiver education programs have been tried to encourage self management and self-efficacy. In the specific area of fall prevention, specific caregiver education research on managing falls in the elderly and persons with PD indicated the multi-

dimensional impact of care-giving (e.g. physical, social, mental, emotional and financial aspects). Although nascent, patient and caregiver education related to fall prevention has shown promise.

A considerable body of literature was found on caring and care-giving, especially as it relates to our aging society. Yet, there was scant literature which shared the voices of the caregivers to persons with PD. As PD is a chronic disease, it has been shown to impact not only the person with disease but also the family and specifically caregivers over the course of the disease process. Because of the complexity of care-giving in light of the changing demographics, economic impact, health care delivery, social supports, technological advances and intervention strategies, there has been ongoing interest in and need for care-giving research from both qualitative and quantitative perspectives. My inquiry into the day-to-day experiences of care-giving for the person with PD will seek to uncover, describe and interpret the underlying themes or essences of the experience. By understanding the nature of the phenomenon, health care professionals (formal caregivers) can be informed of the meaning of the experience through the voices of actual caregivers.

Chapter 3

Phenomenological Research Methodology

The purpose of this study is to understand and discover the multi-dimensional cognitive, affective and psychomotor capabilities and attributes of informal care-giving for individuals with PD. Therefore, the following research question was formulated: What is the meaning of the caring experience from the perspective of the informal caregiver in the day-to-day interactions with the person with PD? In order to understand this unique phenomenon of caring, a descriptive phenomenological method was incorporated in the study design (Giorgi & Giorgi, 2003; van Manen, 1997, Wojnar & Swanson, 2007; Wottrich von Koch, & Tham, 2007).

This chapter was divided into three sections: (a) Phenomenology Framework, (b) Procedures, and (c) Methodological Rigor. The first section, phenomenology framework, was broken down into the following three subheadings: philosophical and historical foundations; inter-subjectivity, bracketing and context; and phenomenological definitions. The second section, procedures, was broken down into the following four subheadings: participants and setting; participant profiles; data collection procedure and interview method; and data (text) management and thematic analysis. The third area, methodological rigor had no subheadings.

Phenomenology Framework

Creswell has described both qualitative and quantitative paradigms to human and social science (Creswell, 1998). Phenomenology was categorized as a qualitative approach along with ethnography, case studies, and grounded theory. In order to understand the phenomenology framework used in this study, the following three

sections were presented: philosophical and historical foundations; inter-subjectivity, bracketing and context; and phenomenological definitions.

Phenomenology has had a long philosophical history. Over the last hundred years phenomenology as emerged as an interpretative approach to understanding the world and “describing how the world is constituted and experienced through conscious acts” (van Manen, 1997, p. 184). Researching lived experience within a human science perspective (e.g. in education, health care, psychology) often has been equated with phenomenology. In his description of phenomenology van Manen stated, phenomenology does not produce empirical or theoretical observations or accounts, but instead, offers accounts of experienced space, time, body and human relation as we live them.

Philosophical and Historical Foundations

As historical background, phenomenology research was built on a foundation based on phenomenological philosophy described by Wilhelm Dilthey, and later developed by Edmund Husserl in the late 1800s and early 1900s (Caelli, 2001; Gearing, 2004). Phenomenology was developed and articulated notably by Husserl in his publication *Logical Investigations* which later influenced scholars like Heidegger, Merleau-Ponty and Satre (Giorgi & Giorgi, 2003). Phenomenology has developed both as a philosophical movement, as well as a method to do interpretative qualitative research. Hadjistavropoulos and Smythe (2001) stated that “qualitative research seeks to understand and articulate the meanings of people’s experiences rather than formulate general laws of behavior” (p. 163). From an interpretative perspective, the goal of research was described as a way to understand new insights (*verstehen*) through the

individual meaning of events or experiences within different contexts (Gioia & Pitre, 1990, Hinshaw et al., 1999, Swanson & Holton, 2005).

Although the American phenomenological movement started in the early half of the 1900s with Snygg and Combs within the field of psychology (Giorgi & Giorgi, 2003), there has been increased interest in and need for utilization of phenomenology in health care research (Balls, 2009; Jensen, 2007). Recently, phenomenology as a form of qualitative research in the rehabilitative fields of physical therapy, occupational therapy, nursing, and physical medicine and rehabilitation has contributed to the evidence-based practice paradigm currently being utilized in these inter-related professions (Hammell & Carpenter, 2004; Hammell, Carpenter, & Dyck, 2002). Domholdt (2005), a physical therapist, described the assumptions of the interpretative paradigm (she used the term qualitative) to be: (a) reality has multiple constructions, (b) there is a dependent relationship between subject and participant, (c) there is limited generalizability of findings which are situation specific, (d) the intent is not to establish cause and effect relationships, and (e) value bound.

Phenomenology has been used to explore and describe lived perceptual experiences or phenomena. Husserl has been credited with the phrase *zu den sachen*, “meaning to the things themselves” (Gearing, 2004). Gearing elucidated this phrase, from a phenomenological vantage point: “Essentially, to know is to see, and to see is to look beyond constructions, preconceptions, and assumptions (natural attitude) to the essences of the experience being investigated” (p. 1430). Further explication of phenomenological research has been undertaken by scholars like Martin Heidegger, Hans-Georg Gadamer, Amedeo Giorgi, Barbro Giorgio, Max van Manen, and Karin

Dahlberg (Cohen, Kahn, & Steeves, 2000; Creswell, 1998; Dahlberg, Drew, & Nystrom, 2001; Giorgi & Giorgi, 2003; van Manen, 1997). Heidegger, a student of Husserl, introduced the concept *dasein* (the human way of being in the world), the hermeneutic (interpretative) circle of understanding and the notion that social, political, and cultural context was of central concern to understanding the meaning of the human experience (Wojnar & Swanson, 2007). Wojnar and Swanson stated, “The goal of hermeneutic [interpretative] inquiry is to identify the participant’s meanings from the blend of the researcher’s understanding of the phenomenon, participant-generated information, and data obtained from other relevant sources” (p. 175).

Polkinghorne (2003) stated that “meaning is a personal act which individuals ascribe to their selves and actions, to the actions of others, and to the happenings and events that affect their lives” (p. 14). Furthermore, Cohen (2000) suggested that an underlying assumption of this world-view was that the mind and body (i.e., consciousness and physical existence) are not separate, and thus there was intentionality or an “in the world” experience of consciousness, in other words, an attending to something in the world. In addition, Polkinghorne (2003) suggested in his review of the validation of qualitative knowledge claims, that “in the hermeneutic (interpretative) approach, validity is established through the use of argument” (p. 16). According to Polkinghorne (2003), in order to show this argument, a researcher must draw upon the hermeneutic circle taking individual passages from text (i.e., transcribed interviews and/or written lived experience descriptions) and relate them to the researcher’s unfolding text as a whole.

In my study, understanding of the care-giving experience unfolded through the conceptual use of a hermeneutic circle, the movement back and forth between the understanding of the whole text (transcribed interviews) and understanding of the parts in an iterative process. The outcome of this process yielded meaning units, structures of meaning or themes that reflected the experience of care-giving for a person with PD. van Manen (1997, p. 78) stated, “the meaning or essence of a phenomenon is multi-dimensional and multi-layered.”

Inter-subjectivity, Bracketing and Context

Inter-subjectivity has been a foundational concept in phenomenological epistemology. Because inter-subjectivity has a primordial quality of the human world (Dahlberg, Drew, & Nystrom, 2001), the interaction and relationship of the researcher and the interviewee become essential elements of the phenomenological research. Dahlberg (2001) wrote,

Lifeworld theory and phenomenology is about human beings, about humans in the world. When we refer to the human world as the lifeworld, we are implying that as humans we are already in a world context, a world of tradition, a world of history, as well as a world of other humans. (p.63)

In light of this concept of inter-subjectivity, the interview process was grounded in the assumption that there are multiple realities which emerge through a participatory interaction between the researcher and the subject. According to Dahlberg and colleagues (2001), the researcher must engage in openness to the phenomenon and this openness supports objectivity in phenomenological research. As the researcher, I

entered this study with my own reality with biases and assumptions about care-giving and PD. My assumptions were articulated earlier in chapter one. Schutz asserted that the first step in Husserl's phenomenological reduction was the elimination of all preconceived notions (as cited in Koch, 1995). Husserl used phrases like "refraining from judgment" and "suspension of belief" to explain this step of phenomenological reduction (Koch, p. 829). Bracketing was the term Husserl coined to this aspect of the inquiry (Koch).

Gearing (2004) described bracketing as fundamental term in phenomenology and provided a typology for bracketing in research. Gearing stated the importance of qualitative researchers to explicitly state their ontological and epistemological positions early in the research, and then later the researcher should reintegrate bracketed data into the discussion of the phenomenon. Similarly, Fontes (1998) reinforced this ethical notion that "it is important for researchers to question their own assumptions and state them openly" (p. 55). Finally, Koch (1995, p. 829) stated, "Husserlian phenomenology, through the process of bracketing, defend the validity or objectivity of interpretation against the self-interest of the researcher. Thus, I made my assumptions explicit early in the research process (see chapter one), as well as during data collection through use of field notes for reflection following each interview.

Finally, considering care-giving occurred within a context, I reviewed van Manen's recommendations. He suggested that in a phenomenological study, a description of the experiential situation or context needs to be transparent. van Manen (1997) noted there was contextual complexity in human science research in that studied phenomenon can be drastically different in the home, the community, the hospital, the

classroom or the workplace. During the data collection process, I had the opportunity to interview some of the participants in their own homes. According to van Manen (1997), well defined experiential situations have been advocated (e.g. interviewing in specific contexts and observing participants in designated contexts so that the researcher uses field notes to write experiential anecdotes).

Phenomenological Definitions

Specific phenomenological terminology was found in the literature (Giorgi & Giorgi, 2003; Moustakas, 1994; Ruona, 2005, van Manen, 1997.) According to Creswell (1998), authors of qualitative texts constructed a language distinct from traditional research language in order to emphasize the qualitative paradigm. Some useful phenomenological terminology as described by Moustakas (1994) have been defined below.

Epoche or bracketing-This is the first step in “phenomenological reduction,” the process of data analysis in which the researcher sets aside, as far as is humanly possible, all preconceived experiences to best understand the experiences of participants in the study (Moustakas, 1994).

Essential, invariant structure (or essence)-This is the goal of the phenomenologist, to reduce the textual (what) and structural (how) meanings of experiences to a brief description that typifies the experience of all of the participants in a study. All individuals experience it: hence, it is invariant and it is a reduction to the “essentials” of the experiences (Moustakas in 1994). Instead of the term essence, Ruona (2005) used the concept of sensing themes.

Lived experience-This term emphasizes in phenomenological studies the importance of individual experiences of people as conscious human being (Moustakas, 1994).

Phenomenon-This is the central concept being examined by the phenomenologist. It is the concept being experienced by subjects in a study, psychological concepts such as grief, anger, or love.

Phenomenological study-This type of study describes the meaning of experiences of a phenomenon (or topic or concept) for several individuals. In this study, the researcher reduces the experiences to a central meaning or the “essence” of the experience (Moustakas, 1994).

Phenomenology- The word phenomenology was derived from the Greek work phenomenon which means that which shows itself or to bring to light, or in other words, “phenomenon signifies that which shows itself in itself, the manifest” (Heidegger, 1962, p. 51).

Procedures

In the literature, Creswell (1998) recommended use of the term procedures versus the term methods when describing qualitative research such as phenomenology. The procedures section was divided into the following subsections: (a) participants and setting, (b) participant profiles, (c) data collection procedures and interviews, (d) data (text) management and theme analysis. Using the procedure below, I described the meaning of the care-giving experience for persons with PD. Phenomenological research methods used in health care research similar to the ones presented in this study

were found in the literature and were helpful examples (Greenfield, 2006; Greenfield, Anderson, Cox & Tanner, 2008, Wottrich, von Koch, & Tham, 2007).

This study was approved by the Mayo Clinic and the University of Minnesota Institutional Review Boards. From a risk perspective, Mayo Clinic and the University of Minnesota IRB review committees determined that the study constituted minimal risk research, and therefore was eligible for expedited review in accordance with 45 CFR 46.110 item 7 (Appendices B and C). In the development of the research protocol including the written consent form, a risk-benefit analysis was used (e.g. exploration of principles of beneficence and non-maleficence). This had been described in the literature by Sales and Folkman (2000). In my study, a number of possible benefits were identified. First, illuminating the lived experience of the caregiver should help enlighten patients, family members, and health care providers as this disease process impacts an ever increasing number of people an aging western society. Second, potential strategies should facilitate/empower care givers in their daily challenge of providing quality care for the patient with PD, ultimately allowing them to maintain their own physical, emotional, and cognitive health. Third, formal health care providers who educate persons with PD, their families and caregivers should benefit from an in-depth study of the meaning of care-giving experiences (e.g. dealing with an individual with PD who has motor control and cognitive impairments) with possible modification of their educational interventions and tacit knowledge. For example, through a better understanding of the nature of falls from the caregiver's perspective, there may be a possibility of reducing the risk of falls for those persons with PD and impact quality of life for both the person with PD and the informal caregiver. This has the potential of

further impacting society and affecting decreased health care costs associated with injuries related to falls. Fourth, the study should add to the scientific knowledge related to care-giving theory and practice, as well as viable caregiver educational strategies.

Some possible risks for the participants were identified. These included: inconvenience in terms of time commitment, they could have remembered some unpleasant memory, and the meaning of the participant's experience could be inaccurately interpreted (using a member check via a second session was used to minimize this threat). Lastly, the risk that the participant and/or a third party could potentially be identified in verbatim narratives (use of exact words for thick description) found in publicly accessible documents such as the researcher's dissertation or published article. In order to minimize this risk and protect anonymity for the participant and third parties, the researcher coded the data, used pseudonyms (fictitious name), altered names of places and demographic characteristics of both the participant and third parties. Benefits and risks were included in the consent form (see Appendix D).

Participants and Setting

The goal of this study regarding participant selection was to identify individuals who could provide rich lived experience information on the nature of caring for a person with PD. The number of participants was identified based off recommendations described in the literature on phenomenological research. My study used purposive criterion sampling as described by Creswell (1998); Gall, Gall, & Borg (2003); and Mertens (1998). According to Creswell, criterion sampling worked well when all individuals studied represent people who have experienced the phenomenon. In

addition from the literature, Creswell suggested that 10 participants were a reasonable size for a phenomenological study with in-depth interviews.

Thirteen informal caregivers, who cared for individuals with PD in various stages of the disease, volunteered to participate and met inclusionary criteria. These stages have been described as early, middle or late stage by Bello-Haas (2002). Criteria for inclusion for informal caregivers included the following: (a) the interviewee was living with and caring for his/her spouse, partner or relative with PD, (b) the person with PD has motor, cognitive, psychosocial or emotional needs requiring care-giving as identified or perceived by the caregiver, (c) the informal caregiver could provide this information by report, and (d) the informal caregiver was available to meet with the researcher for two different interview sessions. Multiple caregivers within a family unit were eligible to participate. Spouses, non-spouses (e.g. friends) and other relatives (e.g. adult children) were recruited. The inclusionary criteria stipulated that the caregiver needed to reside with the person with PD. In the study, 12 spouses and 1 friend agreed to the interviews, all these participants resided with the person with PD. Adult children who perceived to be providing some care-giving but did not reside with the person with PD were excluded.

The participants were recruited from the mid-west region of states from both rural and urban areas. The recruitment advertisement (flyer) was approved by the Mayo Clinic department of Communications in conjunction with the University of Minnesota and Mayo Clinic Institutional Review Boards (Appendix E). All recruitment efforts and materials followed both the University of Minnesota's and the Mayo Clinic College of Medicine's Institutional Review Boards (IRB) guidelines. Participants were recruited

in various ways including: Mayo Clinic Classified section (under “Volunteers Sought”), flyers posted in local senior living facilities, and flyers distributed to local and state PD support groups (e.g. American PD Foundation caregiver support banquet). I had contact with the local PD support group within the community, so I made a verbal announcement at a monthly meeting regarding the research opportunity, and I provided the advertisement to inform individuals who would potentially be willing to participate.

Interested participants initiated the first contact by calling or emailing me. A telephone script was used to provide interested participants information regarding the study (Appendix F). If the individual was interested in participating, I then followed up by sending a contact letter (Appendix G) which provided the date, time and place of the first meeting, as well as a copy of the study’s IRB approved consent form for review (Appendix D). Potential participants were encouraged to discuss enrollment in the study with family, friends, clergy, other professionals for guidance if necessary.

In terms of the study location or setting, the interviews were conducted in a quiet private location mutually acceptable for the participant and the researcher. This included the participant’s place of residence. Some participants preferred a location other than their place of residence. Location was documented. Four individuals were interviewed in a location other than their residence (e.g. room in a local medical facility or a room in the high-rise complex). Free parking vouchers were provided as necessary.

Nine individuals were interviewed within the home environment. I was able to take field notes of their residential environments. According to van Manen (1997), a naturalistic environment allowed the researcher to also gather field notes on the contextual or experiential situation (van Manen, 1997). Since care-giving occurred in

the home, I followed the recommendations of van Manen. My study thus provided information on the contextual experience for the caregiver who had to oversee mobility and function of the person with PD in a variety of home environmental places (e.g. bathroom, stairs).

Participant Profiles

The thirteen participants in this study were all residing with and providing care for a person with Parkinson's disease at the time of the interviews (see Table 1). The participants were not receiving payment for care-giving to their spouse, family member or friend. Eleven females and two males participated in the study. The participants' age ranged from 47-79 years of age.

Table 1. Participant Profiles

Caregiver # and Pseudonym*	Gender F=female M=Male	Age	# of years or months perceived to be care-giving	Care-giving relationship	Employment Status
C1 Ann	F	79 years	2 years	Spouse	Retired
C2 Betty	F	66 years	8 years	Spouse	Retired
C3 Clara	F	74 years	2 years	Spouse	Retired
C4 Alan	M	69 years	1.5 years	Spouse	Retired
C5 Diane	F	56 years	2.5 years	Spouse	Full time employment
C6 Ellen	F	47 years	5 years	Spouse	Full time employment (using FMLA [†])
C7 Francine	F	57 years	20 years	Spouse	Full time employment
C8 Gayle	F	70 years	2 years	Spouse	Retired
C9 Heidi	F	73 years	0.5 years	Spouse	Retired
C10 Iris	F	64 years	2 years	Spouse	Retired
C11 Ben	M	52 years	16 years	Friend	Unemployed
C12 Jane	F	70 years	3 years	Spouse	Retired
C13 Kathy	F	75 years	13 years	Spouse	Retired

*Pseudonyms were used to ensure confidentiality of responses; [†]Family Medical Leave Act

The years that the caregivers perceived they were providing care ranged from 0.5 years to 20 years. All participants were spouses except one caregiver who stated he was a friend. Nine participants reported they were retired, three were employed full time and one was unemployed. Nine of the participants lived in their own homes and four lived in senior residential high-rise/complexes. All participants completed two interview sessions except one caregiver (C11-Ben) who was lost to follow-up.

Data Collection Procedure and Interview Method

The objective of the first meeting was to review the purpose of the study, describe the balance of risks and potential benefits of the investigation, complete the informed consent process and complete a face to face audio-taped interview. I adhered to the consent process described by Sales and Folkman (2000) and included three elements: information, comprehension and voluntariness. This study also incorporated the notion of process consent as described by Mundall (as cited in Hadjistravropoulos & Smythe, 2001) which suggested “that consent to participate in qualitative research should be an ongoing, mutually negotiated process between researcher and participant rather than merely the one-time signing of a consent form” (p. 164). To ensure process consent, participants were informed that they could terminate their involvement in the study at anytime. In addition, participants were provided on the consent form my office phone number, my dissertation advisor’s office phone number, and the Mayo Clinic’s and the University of Minnesota’s IRBs phone numbers, if they had questions or concerns prior, during and after involvement in the study (see Consent form in Appendix D).

Upon reviewing the consent form with the potential participants, they were asked if they had any questions and asked to verbalize their understanding and comprehension of the components of the form (what it meant to them). All participants provided voluntary autonomous informed consent. Upon signing the consent form (Appendix D), each participant received a signed consent form to take with them for their review and later reference. In addition, I retained a signed consent form for the study's records. I also completed and retained a contact summary sheet (Appendix H) after any participant contact (face to face, over phone or email).

In terms of confidentiality concerns, these were addressed for participants and third parties on the consent form and explained during the consent process. Considering the research design of interviewing the caregiver of a person with PD, the issue that the interview and the subsequent narrative text could be linked to third parties (i.e., the individual with PD, family members, friends, health care professionals) was a potential risk. Hadjistavropoulos and Smythe (2001) in their discussion of elements of risk in qualitative research suggested that participants be made aware that their comments regarding third parties may have ethical and legal implications. They further suggested that researchers include assurances of confidentiality of third parties who are mentioned in narratives within the informed consent process. Disguising identity of participants and third parties was noted on the informed consent and included use of pseudonyms, altering names of places and demographic characteristics. These assurances were reviewed with the participants at the first meeting when the consent form was reviewed (Appendix D).

Participant confidentiality and privacy was also reviewed during the consent process. I have retained the research data (narrative transcriptions) in a secured location. All records of this study will be kept private and stored in a locked cabinet and electronically password protected for at least five years after the results have been published. This will allow for scientific review if necessary, enhancing the study's commitment to the moral principle of fidelity and scientific integrity as described by Sales and Folkman (2000). Lastly, participants were offered remuneration of \$30 for their effort and participation. They were provided written information on remuneration in the initial advertisement (Appendix E) and in the consent form, as well as verbal information during the informed consent process.

After obtaining autonomous written consent, an in-depth interview conducted in private with each of the informal caregivers of persons with PD was completed. Interview length was considered and recommendation from the literature followed. Sieber (1992, p. 80) described "mere inconvenience, such as boredom, frustration, and taking up time that the subject might more profitably spend otherwise" can be a risk in a study and should be reviewed during the consent process." With this in mind, the consent form for my study stated that the interviews would be approximately one hour. The actual interviews ranged from 45 minutes to 1 ½ hours. The interviews were tape-recorded for later verbatim transcription and text analysis.

A conversational interviewing style was used to gather information from the caregivers about their day-to-day care-giving experience. The open ended interview format allowed for flexibility and exploratory probing. This style has been described in the literature (Merriam, 1998; Polkinghorne, 1989). The general opened questions about

the participant's caring experiences provided an atmosphere which minimized my control over the interview and therefore allowed the participants to more freely speak of their experiences.

A written note card with the same questions typed on it was given to the participant to read at the same time the question was asked orally so that the participant could refer to it at any time during the interview session. The following questions were asked of the informal caregivers: What is it like to care for a person with PD? Can you tell me about a specific caring event or situation which occurred? An audit trail was ensured by using the following data collection forms: Contact Summary Sheet (Appendix H); Interview Protocol Form (Appendix I), Field Notes Form (Appendix J) and Coding and Data Collection Template (Appendix K).

A second interview was designed into this study for member checking. The literature addressed member checks as an action toward the moral principle of fidelity to science as a strategy to enhance internal validity. Merriam (1998) defined this as "taking data and tentative interpretations back to the people from whom they were derived and asking them if the results are plausible" (p. 204). Caelli (2001) suggested bringing back to the participant derived narratives from transcripts so as to clarify and validate the data from the interview transcripts. In addition the moral principle of trust may be enhanced as a working relationship is further established between researcher and participant.

In my study, an effort to allow feedback from the participants (member checking) occurred at the second interview session. The session was scheduled with each participant 1-4 months after the first interview and upon completion of the first

interview transcription. At the second session, I provided the participants with a written and verbal narrative summary of the major points from the first interview. At this time, participants were given the opportunity to add to, modify or clarify their care-giving experiences. All the participants added additional comments at the second interview, except one participant who was unavailable for the second interview and thus was lost to follow-up (changed address and did not leaving forwarding address). These second interviews were also transcribed for analysis. Lastly, caregivers were offered and provided a list of health care providers and phone numbers in the local area for them to use as a future resource (Appendix L).

Data (Text) Management and Thematic Analysis

Data management followed the guidelines on analyzing qualitative data described primarily by Ruona (2005). She has provided a systematic word processing approach. Additional data management and analysis recommendations by Giorgi and Giorgi (2003), Moustakas (1994), Barritt, Beekman, Bleeker and Mulderij (1983), and Wottrich, von Koch, and Tham (2007) were also considered. The interview transcriptions and field notes were converted to electronic form using word-processing software. Microsoft Word was used for creating the transcribed documents and tables. Use of Word tables allowed for simple word processing functionalities like organizing, coding, sorting and retrieving data which enhanced analytic capacity and rigor of data analysis. Four stages of qualitative data analysis as described by Ruona (2005) were employed in my study.

The first stage included transcription of audio-taped interviews and field notes/reflections. During transcription, speakers in the text were coded in such a way

(letters and numbers) to ensure anonymity (e.g. C1 was the first caregiver to be interviewed; RC1 was researcher with first caregiver). Following transcription of the audiotapes, the text was read for completeness and errors requiring minor editing (e.g. spelling). A printed and electronic filing system was established. Participant privacy was followed according to IRB guidelines and specified in the consent form.

The second stage included familiarization with data or horizontalization, a term used by Moustakas (1994). In my study, familiarization included listening to audiotapes in their entirety, reading all transcriptions in their entirety, re-listening or re-reading notes and reflection, actively engaging in data by asking questions and identifying interesting and variant data. Exploration of the text began with reading it to get the sense of the whole as expressed by the participant.

The third stage included coding or assigning meaning units. Giorgi and Giorgi (2003, p. 253) used the term “meaning units” to describe using language to describe invariant psychological meanings. In this stage, I segmented sentences and paragraphs for both data simplification (e.g. assigning meaning units) and data complication (e.g. creation of new questions). To do this, each caregiver’s transcribed interview was converted to table format in order to more easily segment sentences and paragraphs into meaning units. The coding form in Appendix K allowed for compilation of meaning units from each interview. Meaning units were identified by first analyzing the language used by the informant/participant then meaning units were generated using discipline specific language to capture the important elements of the experience as described by Barritt, Beekman, Bleeker and Mulderij (1983). In this stage, the first caregiver interview which was converted to table format began the hermeneutic circle

(dynamic evolving recursive process of coding and recoding by going back to the data upon each successive interview reviewed). This is also referred to as an iterative process. During text analysis, I practiced the dynamic nature of revisiting the text from the whole to the parts with openness to new perspectives as described by Habermann (2000).

After the first caregiver was interviewed and preliminary meaning units were established, I generated a preliminary list of discipline specific codes (themes) inductively from the data. During this process, I followed Ruona's (2005) recommendations for coding which included making sure that codes were reflective of the purpose, exhaustive, mutually exclusive, sensitizing, and conceptually congruent. During the data collection, I actively reflected using field notes and by writing in the margins of the transcripts (notes/memos). This allowed me to be cognizant of my own thoughts and biases that emerged during the interview process and analysis.

In addition, once I transcribed the initial interview session and identified meaning units for that caregiver's interview, I brought those meaning units back to the participant for his/her feedback at a second interview. Wottrich, von Koch, & Tham (2007) described this as single case analysis synthesized into a "situated structure of meaning" and taken back to the participants for member checking. The caregivers were provided these meaning units in written form. I reviewed these bulleted meaning units one by one at the second interview. Participants had the opportunity to reflect on these care-giving meaning units, to modify as they felt necessary. The second interview was audio-taped for transcription and thematic analysis as well. Stages one through three

were completed for each participant interviewed and reflected the participant's unique care-giving experience.

In the final stage four, merging and working with all of the generated meaning units from all interviews occurred. Each caregiver's table was then merged into one table containing the meaning units for all caregivers. This allowed me to do cross case analysis through exploration of linkages and patterns that run across participants.

Wottrich, von Koch, and Tham (2007) referred to this as a general structure of meaning whereas van Manen (1997) referred to this process as thematic analysis.

Van Manen (1997) described the purpose of phenomenological reflection as trying to grasp the essential meaning of something through analysis of text and crafting that text. When getting at the essence (essential meaning), he referred to 'that what makes a thing what it is and without which it would not be what it is' (Van Manen, p. 177). Furthermore he stated, "Reflecting on lived experience then becomes reflectively analyzing the structural or thematic aspects of the experiences." (Van Manen, p. 78). He suggested that the process of interpreting the lived experience was not rule bound but rather insightful invention, discovery or disclosure. In this process, he proposed "three approaches toward uncovering or isolating thematic aspects of a phenomenon in some text: (a) the wholistic or sententious approach, (b) the selective or highlighting approach, and (c) the detailed or line-by-line approach" (pp. 92-93).

In terms of my study, I used all three approaches; however, the later two were predominantly used in search of the themes to describe the phenomenon/experience of care-giving. The themes that emerged from my study were described in terminology consistent with the phenomenological four existentials described by van Manen (1997):

lived space, lived body, live time and lived human relation. Lived space (spatiality) was defined as “the existential theme that refers us to the world or landscape in which human beings move and find themselves at home” (van Manen, p. 102). Lived body (corporeality) referred “to the phenomenological fact that we are always bodily in the world” (van Manen, p. 103). Lived time (temporality) was described as our subjective sense of time past, present and future. Lived other (relationality) was described as “the lived relation we maintain with others in the interpersonal space that we share with them” (van Manen, p. 104). In writing the phenomenological findings, all themes could be linked to specific verbatim text (specific participant quotations) which provided for a thick rich description of the lived care-giving experience. Through this process I identified three essential themes of the experience of caring for a person with PD. Subthemes also emerged. The following chapter provides description of these themes and subthemes.

Methodological Rigor

In the process of research, errors can occur and jeopardize the outcomes and usefulness of the results and thus compromise truthfulness. I reviewed the criterion for establishing methodological rigor for an interpretative study. So in keeping with an interpretative paradigm as described by Gall, Gall and Borg (2003), the criteria of usefulness, contextual completeness, researcher positioning, reporting style, triangulation, member checking, outlier analysis, long term observation, and coding check were adhered to in this inquiry. These criteria reflect the concept of interpretative “validity” which “refers to judgments about the credibility of an interpretative researcher’s knowledge claims” (Gall, et al., p. 462), or in other words trustworthiness.

Gall and colleagues have stated that credibility is present when there is recognition of truth in the findings by the participants and experts in the field. This credibility was ensured in my study by tape recording interviews for verbatim transcription, maintaining process notes through out the study, and conferring with participants as well as with experts in the field.

Methodological rigor was established throughout my study with adherence to the criteria described by Gall, Gall and Borg (2003). In this paragraph, the criterion and how I applied the criterion to my study can be conceptualized. First, the criterion of usefulness is that readers of the findings are enlightened or empowered. In my study, the participants were offered the final study results upon completion and publication of the research. All but one participant was interested in reading the final study. Second, the criterion of contextual completeness, was addressed in my study as I took careful reflective field notes that recorded and described contextual features like physical setting, environment, temporal/history (see Appendix J). Third, the criteria of researcher positioning was addressed by providing my sensitivities, views, assumptions, biases of the phenomenon and then setting them aside (bracketing or epoche) in order to gain a better understanding of the experiences of the participants. Written reflection following interviews also helped to bracket my biases. Fourth, the criterion of reporting style was enhanced in my study by reconstructing the participants' phenomenological reality by using verbatim quotes from participants. Fifth, the criterion of triangulation was enhanced in my study by using multiple data sources including multiple participants, field notes and returning to the literature upon completion of data analysis. Sixth, the criterion of member checking occurred at the second interview session which

allowed participants to review their own narratives for accuracy and completeness. This interview was audio-taped for analysis too. Seventh, the criterion of outlier analysis was enhanced as participants recruited in my study could have diverse care-giving experiences (e.g. interviewing a caregiver of an individual who fell and sustained a major injury or fatality). Eighth, the criterion of long term observation was enhanced in my study by scheduling a minimum of two interviews for each participant over a 1-5 month period. Finally, the criterion of coding check was enhanced by keeping a detailed meticulous audit trail throughout the study (see Appendices G, H, I, J, K for the documentation templates). An accurate audit trail was used to improve dependability of the study

Rather than using the term reliability, my study addressed Lincoln and Guba's concepts of "dependability" or "consistency" of the results obtained from the data (as cited in Merriam,1998). In other words, "rather than demanding that outsiders get the same results, a researcher wishes outsiders to concur that given the data collected, the results make sense—they are consistent and dependable" (Merriam, 1998, p. 206). In order to establish that the findings in my study were dependable and plausible, guidelines from Gall, Gall and Borg (2003) were used. These guidelines recommended retention of study documentation including: (a) source and method of recording raw data, (b) data reduction and analysis products, (c) data reconstruction and synthesis products, (d) process notes, and (e) my assumptions and pre-conceptions.

In summary, interpretative inquiry views reliability and validity with a different lens, yet with comparable rigor. The goals for validity in this phenomenological study were twofold. The first goal was to achieve "thoroughness in reasoning" also referred to

as “coherence criterion” which should make it “possible to follow the researcher’s reasoning all through the study (as cited in Dahlberg, Drew, & Nystrom, 2001, p. 231). The concept of “rigor” was also used and was referred to as “the researcher’s attempt to use as tight a research design as possible (Grbich, 1999). Secondly, in my study, the aim to achieve rigor included a detailed ethically designed research protocol.

Chapter 4

The Experience of Care-giving for a Person with PD

“It is a very difficult situation. It is a life changing experience.”

--*Jane, caregiver*

This study yielded thick rich narrative findings which were based off the following research question, “What is the meaning of the caring experience from the perspective of the informal caregiver in the day-to-day interactions with the person with PD?” The purpose of this study was to understand and discover the multi-dimensional cognitive, affective and psychomotor capabilities and attributes of informal care-giving for individuals with PD. The themes of the experience of care-giving for a person with PD were derived from the text of interviews with 13 caregivers who stated they perceived that they were in some way in a care-giving role within their spousal or friendship relationship.

The care-giving or care-partnering relationships were all spouses except one caregiver who was a close friend to the person with PD. Both genders were interviewed with the majority being women (11 women, 2 men). All caregivers were Caucasian. The persons with PD that were being cared for by the caregivers had a range of motor dysfunction from still being ambulatory to requiring a wheelchair. In addition, caregivers reported the person with PD having minimal to marked problems with memory, orientation, and judgment. All caregivers reported concern for the person with PD falling. From caregiver report, all care recipients had experienced fall episodes except for one, although the caregiver for this person with PD had noticed gait problems

like shuffling and slowed movement. All caregivers discussed their roles in managing medications for the person with PD. In terms of transportation and getting out of the house and into the community, all caregivers except for one had taken on the responsibility of being the driver or transporter in their relationship.

Three caregivers (Ellen, Francine and Ben) had spouses or a friend diagnosed with early onset PD which occurred before 55 years of age; Ellen was also caring for her young son. Eleven caregivers had adult children who did not reside with them. Ben had no children and the only friend providing care-giving. Iris had an unmarried adult daughter who was employed and residing with her parents but not a primary caregiver. One caregiver (Kathy) also reported being newly diagnosed with PD. All caregivers resided with the person with PD which was a key inclusionary criterion. The themes that emerged were reflective of care-giving for a person with PD in an independent living context versus in a skilled nursing environment (e.g. nursing home). The experience of care-giving for a person with PD affected many facets of the caregivers' lives. Three essential themes emerged which reflected these facets and the meaning of care-giving for a person with PD. Table 2 identifies the three themes and related subthemes. Theme 1 described care-giving as an unplanned journey which required the caregiver to deal with the past, present and future, as well as negotiate challenges, changes and resources along the way. Theme 2 reflected how caregivers perceived living with the disease too and how the PD disease impacted the caregivers' own health and well-being. Lastly, theme 3 recognized the relational aspect of the care-giving experience. The three main themes will be elucidated with specific quotes from the interviewees then the sub-themes will be presented with supportive quotes to

illustrate richness and depth. Finally, a phenomenological cohesive description of care-giving for a person with PD will be given.

Table 2 Essential Themes and Subthemes

Essential Themes	Subthemes
Care-giving is an unplanned journey.	A new path with occasional signs along the way
	A balancing act
	Navigating my way through
I am living with this disease too.	Moving out of the healthy box
	I have to take care of myself!
	Knowing when to let things go
My relationship with the person I care for and others is changing.	Staying connected to others
	Sharing the responsibilities with others
	Experiencing changes in intimacy
	Accepting the emerging personality of the person I care for

Theme 1: Care-giving is an Unplanned Journey

“...it certainly is a journey.”

–Iris, caregiver

“It’s a kind of experience that turns your world upside down...”

–Jane, caregiver

In describing their experience of care-giving for a person with PD, participants expressed that they felt care-giving had been like an unplanned and unpredictable experience or journey. A journey they had not self selected. As Jane stated, “We don’t always choose our challenges. You know, they just come to us.” Iris in her attempt to further explain the journey stated, “...again part of this little journey that you are kind of trying to understand all this and cope with it or absorb it or figure out, you know (pause), how to deal with it as a caregiver. It is just a different dimension.” Another caregiver, Ellen tearfully described how PD had disrupted their plans in life, to both be

able to work, raise a family and have a lake home. She said, “It is not what I expected. It’s (pause), this is not what I had expected...I had this dream...” The unknown quality of the journey was expressed by another caregiver {Alan}; he said it was “...not knowing what we are dealing with down the road.” One caregiver, who worried about her spouse’s depression and difficulty accepting the diagnosis, used this analogy, “I think it is going to be a rollercoaster...” {Diane}. A labored journey was described by Iris, who was dealing with her spouse’s urinary incontinence after he fell and broke his hip, “...I thought the last thing I want to do is really get down. It’s not good for me. It’s not good for him. It’s not good for anybody so I just kind of plod along”.

Caregivers voiced their feelings of being unprepared for and uncertain of the future. This was evident in Heidi’s statement, “So this is all very new to me.” And from Clara who said, “...you don’t know what the future holds with it.” For Iris, when they received the initial diagnosis of PD, she had been unprepared even though her husband had previous medical problems requiring care-giving. She stated, “But this, this one kind of hit me for a loop.” For her it was a big unknown, “I was absolutely petrified. I did not know what in the world was going on.” Yet, in addressing her unknown future care-giving role, Iris used a “We’ll see” mantra with friends and family, unsure of what laid ahead. In looking forward, Alan, another caregiver, commented that the PD “has not made real radical changes. We recognize that they come down the road.” For him the journey was hard to anticipate, “It is going to be a long long learning experience” {Alan}. In addition, he stated, “I don’t think you really know the questions that you would ask relative to this [in regard to care-giving in PD]” {Alan}.

Care-giving for a person with PD had taken the caregivers down different unknown paths, sometimes difficult, where they had to learn, make choices, sacrifices, navigate through and find help and/or resources. Some caregivers felt it important to live in the present. Jane commented on the importance of taking time to “step back into life”. As they struggled to live in the present, caregivers were dealing with trying to predict the future as the disease progressed as reflected in Heidi’s statement, “...I have talked to other people and it gets worse so it is more anticipation with down the road...” To further explicate this essential theme the following three subthemes provide thick description: (a) A new path with occasional signs along the way; (b) A balancing act, and (c) Navigating my way through.

A New Path with Occasional Signs along the Way

During the care-giving journey, caregivers had a sense of a new path or being in a new place in life. This was expressed by Francine, “Parkinson’s [disease] makes us live differently.” Ellen, as a healthcare professional, had experience providing services to families at health care conferences, but because of her spouse who was diagnosed with early onset PD, she herself was experiencing care-giving firsthand. “I was now on the other side of the fence” {Ellen}. Her spouse had been only 35 years old when he was diagnosed and now 14 years later she shared, “We have been through a lot to get where we are at today.” Her care-giving experience included trying to maintain her own career, caring for a young son, dealing with her husband losing his career and being placed on social security disability because of the PD, as well as providing support when her spouse had a deep brain stimulator implanted to manage the PD.

Iris, who was eighteen years younger than her spouse, struggled with the dual role of being spouse versus caregiver and what road to take. Iris's young single adult daughter lived with them and had discussed this with Iris. According to Iris, her daughter was concerned that Iris may move away from being a spouse to a caretaker [she did not use the term caregiver]. She described it as moving down a continuum and feared:

...you then kind of lose your emotion with it...it's a job. It's a duty. I need to do this which I think a lot of people go down that road. I think I find myself going down that road because you don't get the feedback you need. You don't get the love necessarily back. {Iris}

On a journey, there are usually signs along the way providing information. Unfortunately, some caregivers early in the disease process were as Francine stated, "...oblivious to what was to come." Even though caregivers did not know what to expect in the future, they had a sense of being on guard, looking for the signs that the disease was progressing. For example, a caregiver had a spouse diagnosed with PD for approximately nine years who came down with pneumonia, and he also lost bowel and bladder continence during this acute illness. Betty recognized her spouse's possible future functional decline.

I realized OK this is the future you know, this is what it would [pause], might be like if he was unable to move and he wouldn't be able to control his bladder and you know [pause] you know that's kind of scary because right now you know we are far from that point. {Betty}

Another caregiver, Francine, was alert to signs along the way too. She stated,

For me the hard part has been seeing the changes. On one hand, you don't notice them because you do it everyday, but on the other hand, you see everything every time. So it has kind of been mixed, like I can remember the first time he was sitting at the table and his head was cocked and it is like, "Pick

up your head, you know your head is at an angle.” And just knowing different body things that started to happen. I thought that was a tough one... {Francine}

Francine also commented that often when her adult children came home for a visit, they would see changes that she had overlooked because she saw her spouse everyday. She shared, “The hard part is I, in protecting the kids and that’s probably why I’ll be sad because they are really good [tearful], but they are all gone, so when they come home they see drastic changes” {Francine}.

For yet another caregiver {Ellen}, the disease brought a marker or turning point, that was a life alternating change to her and her spouse. PD had impacted her spouse’s sleeping patterns so they slept in separate rooms. She stated, “We are no longer sleeping together. That is just not happening. I grieve that trust me....okay just another piece, selling my bed.” For Iris, at times the disease related problems like her spouse’s bowel dysfunction was demanding and a sign of the disease progression. Iris responded, “Yeah consuming. And now it’s (pause), it’s I suppose this is another progression.” A sign along the way for Kathy was shared in her description of a day spent trying to paint the outside of their cabin. Her spouse had trouble with coordination and balance; he unfortunately fell, spilling paint all over. She was thankful he was not injured, yet it was more than that as she stated, “Well it was funny, I mean we had to laugh because it was so ridiculous, paint all around and that, but in another sense, I felt all right there’s something else.” On a more serious note, Betty’s spouse had a serious farm accident requiring extended hospitalization as a result of under-dosing of PD medication. She commented, “That was another kind of wake up call” {Betty}.

In terms of another sign a long the way, caregivers voiced concern that the person with PD had decreasing ability to take the initiative to complete activities, make social connections, or to exercise. This loss of initiation forced greater responsibility on the caregiver. For example, Jane described having lots of PD resources like books and video media on PD, as well as exercise pamphlets, but she felt reading them and making her spouse complete them occurred because she took the initiative to do it. In her words, “We have the resources, but I am the one who has to initiate it, not only initiate it, not only suggest it, but make sure it is done” {Jane} Ellen had similar concerns and described her spouse’s lack of initiation and obsession for doing puzzles. She stated, “He’s lost his initiation to complete a task....He is obsessed with doing suduko puzzles and computer games....That initiation piece to do other things, he’s losing. I mean it’s a lot of prodding.” Francine also described this loss of initiation, “It is just amazing what he has made [spouse creates clocks], but like I say he’s always had something going on and now that is less, less of that.” Another caregiver commented,

That is one of the things about Parkinson’s it takes away that initiative. He’ll never call his cousins. I always say, “He was your best buddy and why don’t you call him?” Never will call. The only way we have those engagements I guess is if I invite people in. It is so difficult. {Kathy}

Lastly, with the diagnosis of PD and the physical signs observed along the way, caregivers and persons with PD ended up having to take a different path in life then the one they had anticipated or hoped for. In the caregivers, they described how travel was more difficult and the leisure activities they both enjoyed had to be stopped or modified. Alan described it in this way,

We had kind of a mental list of the thing we liked to do....I noticed that she gets tired quickly and going through the hassle of some of those

major airports, I don't even like them myself, why should she. So things like that sort. So we're going to have to look at that and if we want to continue to do those and how do we schedule them in the near term rather than the future. {Alan}

Another caregiver described how they had reduced their travel experiences since the PD diagnosis, and they felt more comfortable staying close to their medical institution. She voiced her faith in their medical institution and commented, "You know we feel more secure with the American medical system" {Gayle}. Besides reduction in travel, caregivers reported a reduction in participating in leisure activities like going golfing, to the movies, or to the theater. Even driving trips were described as problematic, if the person with PD did not remember to bring his or her medication. Ellen described her experience when her spouse did not bring his medications on a road trip,

We literally had to go to the drug store to call in some meds so that he could make it to the funeral...He literally could barely make it through the food line because he was so frozen...So, I now carry a set of pills with me for him all the time. Or we also have some in our glove box in our car now ever since that incident. {Ellen}

Caregiver showed being alert to the signs of change and decline of motor, cognitive, social and emotional function on their journey.

A Balancing Act

For caregivers, balance in life meant making choices and sacrifices which cut across many life dimensions including structuring their day, as well as living, financial, and career decisions. Structuring their day often required making choices about how much time was required to accomplish what needed to be done or what additional support from others was needed. Trying to find a balance often was at the heart of their choices. Iris described it in this way, "I guess everybody finds their own equilibrium or

their own whatever works because so much of it depends on the response to the person who needs the care also.” At the time of the interview with Iris, her spouse was recovering from a hip fracture following a fall. Iris stated, “It is early on in this process, but the balance I haven’t quite figured out yet”. The importance of equilibrium in planning and making daily choices was also evident from Alan who likened it to:

...it just is kind of like a balancing act. I recognize that this is what we got to do and it is just now how do we plan it, how do we schedule it, how do we trade off things in that sense....Driving Miss Daisy is what we call it and it’s just recognizing that there are things that mean a lot to both of us and we will make sure we still do those. I think we have to plan our day and our week a little differently so we are not running all over the place, but that is just going to take up too much time if we are running. But if we do it in such a way that we, you know, schedule things together then I think it will be easier for both of us.
{Alan}

Finding this balance was not always easy for the caregivers as described by Ann, “I get tired of programming time...How much time will he sleep and can I really make it to the store and shop and back and have him still asleep.” She described a specific situation when she went to the store and left her sleeping spouse alone,

He sleeps a lot because of the drugs and sometimes if he is really sleeping hard I feel I can get out to the store. If I can get there and back in like 45 minutes, but then coming back I’m freezing in the car hurrying, please don’t let me have an accident, I have to get back. It’s all this mental stuff which I think is the hardest.
{Ann}

Establishing balance was found in caregivers choosing to have set routines often tailored around the medication regime of their care recipient.

Betty was dealing with her spouse’s memory loss and found following a daily routine to be helpful. Often people with PD take their medication (Sinemet) at least ½-1 hour prior to eating, so with this in mind, in the mornings Betty and her spouse had a

specific daily routine prior to breakfast which included bathing, dressing and feeding their animals. If her spouse wanted to divert from the routine, she convinced him by saying, “Oh, let’s do it like we usually do it and try to follow the routine.” Betty felt, “Usually the routine is good.”

For Iris, who was also dealing with her spouse’s declining memory function, routine was important, “The memory or the confusion is much more prevalent later in the day or...if the routine changes in anyway.” A major concern for Iris was establishing a routine with getting up in the morning and bedtime. The bedrooms were on the second floor and her spouse was not independent with stair-climbing following numerous falls. Iris commented,

It’s a very big routine to get to bed and get up and we’re kind of trying to see what the best regiment and routine for that is. He absolutely needs help with stairs. I mean he can not negotiate, do stairs at all by himself. {Iris}.

In terms of living situations, caregivers had to make choices about staying in their own homes, modifying their homes, moving to apartments or townhomes, senior living facilities or assisted living facilities. For some caregivers, locating near a medical center for PD care was very important. Many of these decisions revolved around the caregivers’ concern that if something happened to them, the persons with PD they cared for would not be able to manage living alone. Ann described their recent living environment change from their home to a senior living high-rise complex with available assistive living and skilled nursing facilities:

I think that is another worry I have. What if I got sick? He could not live alone anymore. There isn’t a possibility of that anymore that is why we came to [name of building/facility where they live]. I fought it for months and months and months. I thought we could go to a town house, I knew we would need to

leave our house because it is two stories. And I knew that, but I thought we could go to a townhouse, and he kept saying that some day I will be in a nursing home and you will be up at 5:00 in the morning and come and sit at the nursing home all day long and if we were in a place like [name of building/facility in which they live] then I would be in assisted care. At least we would be in the same building and that changed my mind a little bit but not completely until I thought if I dropped over dead tomorrow he wouldn't know what to do about our finances or where things are and I thought that was a decision then that we should come here. That solidified it for me. So at least we are here. {Ann}

Heidi described her spouse's inability to live alone from this perspective, "I have already said to the kids, because they probably won't be aware of it, that if something happens to me, dad probably shouldn't live alone. If for no other reason, that if he fell down, you know, so that is to me the biggest worry." Heidi, Ann, Alan, Gayle, and Kathy had all moved from independent living in their own homes to either a townhome or a senior living complex. Gayle described their move to a high-rise complex and how they were lucky to get a ground level apartment. She felt "this has been a real real blessing" {Gayle}. The other caregivers who remained in their own homes had all made modifications to their homes in some way (e.g. chair lift, grab bars, bed rail, hospital bed, widening doors for a wheelchair, removal of throw rugs, heavy carpet for cushion if a fall occurred). Betty and Clara cared for spouses who had been farmers. Both couples remained on their farms, but in the case of Betty their decision was to simplify their rural living by selling all the farm animals and equipment. For Clara and her spouse, they had family members in close proximity to take over major farm activities. Betty was concerned with her spouse's unhappiness if they moved off the farm they had owned for 25 years. She stated, "We are going to stay here and try to simplify things. We sold the horses. We'll probably try to find someone to plow snow

this winter and those have been our plans.” In regards to moving out of their home Jane stated,

Yeah I have contemplated it. And we are trying to do everything we can to stay in our house because I frankly don't see that any facility besides a rubber room [spouse falls a lot and had many fall related injuries] would be any better as long as everything is on one level and everything is reachable, I don't see that there is any improvement in any other kind of facility; however, I have made application on one of the retirement places here in town, that is kind of a back up system so that's a possibility if it comes to that. {Jane}

Caregivers in their own homes weighed the pros and cons of moving. The uncertainty of their ability to stay in their own homes was obvious and was reflected in concern for their care recipient. For Iris, “I have thought about it. I guess I would like to have him be here as long as possible.”

In the balancing act, learning to manage finances for some of the women caregivers was a new role. Prior to her husband's diagnosis with PD, Ann was not very involved with managing the finances. She stated,

Lots of things would fall apart if somebody weren't strong. It is surprising to me that I am the strong one now. And it just seems out of order; absolutely, completely because he was so strong. I tell other young couples be more aware of your financial status, all of these things, because I am paying a heavy, heavy price to get my head in order to do these things, but it is coming. {Ann}

Betty was another caregiver who had left the role of investing to her spouse but with his PD diagnosis this changed. Betty described how her spouse realized he should not handle the money affairs alone, so early in the disease process she became more involved with communications with their financial advisor. Considering her spouse's progress memory loss and anxiety regarding their financial situation, Betty shared, “I have tried to learn more about it.” To alleviate some of her spouse's anxiety, she had tried to use repetition a lot during the meetings with their advisor, so her spouse could

remember and understand changes. Jane was also not involved with the family financial affairs. She described her search for a bookkeeper and financial consultant to help her with the investments and the checkbook. About the process, Jane described, "...I went down the usual route, well how do I find someone who is going to help me with this and help me follow what's been going on and what are regular routines..." She eventually received a recommendation from a friend about a helpful bookkeeper.

For Ellen financial concerns were strongly articulated. These concerns included dealing with her spouse's gambling and interest in pornography which started after his diagnosis with PD, paying for his possible nursing home placement with progression of the disease, as well as saving for her own retirement and her young son's education. Her concern was evident in her statement, "I will tell you this, this past summer I was ready to throw in the towel [in regards to her marriage] because his disease has just gotten so bad." At one point Ellen stated that she had lost her job and her husband was transitioning to social security disability, "...we had no funds at the time and I was in a state of panic." Ellen sought legal and financial assistance from an attorney; but from her perspective, "He didn't give me advice, when I look back in hindsight, he didn't give me anything. I am still lost in this maze of don't know what to do." Caregivers were experiencing making financial decisions and attempting to select the best route to follow.

Lastly, caregivers discussed their thoughts on balancing care-giving and their careers or retirement plans. Of the 13 caregivers interviewed, only three were still employed, another one was unemployed but was considering seeking employment outside the home, and nine caregivers were retired. The employed caregivers were all

younger and two had spouses diagnosed with early onset PD. Ellen had the additional charge of caring for her young son who was born after her spouse's early onset PD diagnosis. Her spouse was one of the early recipients of the deep brain stimulator surgery for PD. With her spouse's many medical appointments and hospitalizations, she often had to be away from work. Unfortunately, she did not receive support from her employer and was put on probation. In regard to her employer, Ellen stated, "This is the worst place then, if you can take, you don't have any caring feeling for the caregiver at all." She eventually sought employment elsewhere. During a period of unemployment, her spouse was applying for social security disability which "...was turned down three times" {Ellen}. She described the specific experience:

Finally, the last time, there was an attorney with his [referring to spouse] employer who said lay your pills on the table, and he [her spouse] did and that is how he got his, he got social security even though it was pretty bad. {Ellen}

At the time this was all happening, they wanted to have a family. They eventually did have one child, but this was a difficult situation for her as she explained:

I knew I had to grieve the fact that I was only going to have one child. Financially I couldn't do more than that. And that was hard for me knowing that with this disease, financially I wouldn't be able to do it. That was hard [tearful]. {Ellen}

At the time of the interview, Ellen was employed in a federal government position and under a union. She described going through great lengths to work with her supervisor and human relations to get some time away for care-giving and her responsibilities at home. Her frustration was evident in this passage:

Here I am trying to work extra hours just so I could get off that I ended up going to the union and I talked to the union. I said, you know, here I am trying to work extra hours so I can get home because I have all these things. I even went to personnel at one time too. Let me tell you. Let me back track and say, I am

overwhelmed. My husband has Parkinson's, I don't know what to do, and personnel said to me, "Oh you can work part-time," and they handed me a part-time form. And mind you, I work in the federal government, okay. So the federal government should know what the benefits are. It wasn't until I went to the union representative. The union rep said to me, did you know there is a Family Leave Act."

Finally Ellen was able to arrange for unpaid time away through the Family Medical Leave Act (FMLA) for care-giving. She stated, "I now have paved the way for another co-worker to use FMLA" {Ellen}. Ellen remained troubled about the financial piece as her employer wanted her to do overtime. She described a career choice she made:

We have overtime on Saturday, I say no, and I do not feel guilty about it, because I just can't take on one more thing. Even though my employer wants me to work overtime, and they want me to work Saturdays, and they want me to do this. I have learned that I have got to say no, because I will kill myself if I continue on that.

For the other two caregivers who were employed, the physical demands for care-giving were less articulated. Caregivers experienced caring as a balancing act which required choices and sacrifices along the way. Balancing life's choices were not always easy.

Navigating my way through

Learning more about PD, as well as finding help and resources, was described by the caregivers. Learning, in many cases, was self-directed and often occurred in a trial and error or problem-solving manner. In plotting their course to understanding how to live with PD, a caregiver described how she and her spouse were managing his PD, besides his medication regime, they learned that it was important to consider environmental and contextual factors. In Jane's words, "...it seems to me that, that's you know, that's the holistic approach. That's the large picture approach....you look at the environment as well as the disease."

For Ann, it was learning about her capabilities. She described it as "...gradually catching onto what I thought was lacking, some things become better" {Ann}.

Caregivers used books, the internet, television and health care professionals to gain information about disease. For example, Francine's spouse had been diagnosed with early onset PD shortly after they had been married, so she had been a care-partner for approximately 20 years. In regards to seeking out information, Francine stated "when he was first diagnosed one of the ways that we did it was we were reading like crazy. Reading, everything we could get our hands on and going to workshops, stuff like that, conferences." Similarly Diane stated, "I go on the internet, and then I read about it, and I think that is a very important thing for the person who is taking care of a Parkinson patient to read as much as you can." There was a caregiver at the other end of the continuum. Clara was not as interested in finding out about the PD and care-giving. From her perspective, "Well I don't know if I have really pushed it either because I just, I guess you might say, I'm not a medical person, far from it, and I just kind of take things where they are, and I'm not looking to what's going to be."

Unfortunately, for Jane, the experience of negotiating care-giving resources was met with some difficulty and frustration.

I think that it's really important for those who have to experience this to have as much help as they can. I think there are lots of resources for help but they aren't pulled together. They're very piece meal and you have to stumble on them and follow the path on to the other and one to the other, kind of making your way on your own without anyone guiding you on the path. {Jane}

Having dealt with her spouse being hospitalized for PD, Jane further described how they were given the same list of basic resources for the elderly from multiple health care providers without any annotations or detailed information. In her words, "...you kind

of pick your way through...” in regards to the search of resources that best fit their needs. Jane recommended, “There is need for a handbook or workbook rather than a list of information...” Jane further reinforced her concern about the coordination of resources when describing the experience they had trying to make home modifications (e.g. grab bars, chair lift). Jane’s spouse was unable to ascend and descend stairs. They were given no information on how to get a home assessment from the health care professionals who followed her spouse. Jane and her spouse searched on their own and she stated, “...it would have been helpful at the start so that we don’t have to stumble through all this on our own...I didn’t know what options were available...It was a lot of research. Scrambling to see what is the best solution for this...” She felt they had no guidance as to what the best options might be. Jane further described her search for care-giving and PD resources in this way, “They are not pulled together. They are scattered and they reside in various individuals who may or may not be talking to other individuals [referring to members on the health care team].” For Jane and her spouse, their own searching and discovery was what lead them to finding appropriate adaptive equipment (e.g. gait belt, beeping pill boxes) and home modifications (e.g. blocks to build height of bed). From learning vantage point, Jane further elaborated,

You know, here is an idea, I just finished taking four classes on basic computers. Now what would happen if you had a class for caregivers which would just be the simple steps but would be an introduction to all of the things that are available and that you can keep in mind. I think that would be really helpful. {Jane}

Alan and Iris had similar experiences. Alan was upset with the diagnosis process for his wife. He stated it was “...really frustrating in the sense that it seemed

like the doctors were not talking to each other.” Iris shared, “There is not a coordinated effort.” She was referring to the psychiatrist, neurologist, internist, urologist and psychologist they had seen with her spouse’s diagnosis with PD. She further commented, “I was the one who had to piece these things together and if somebody wanted something from somebody I had to do it or whatever. But I think that is the nature of the way medicine is today.” Although on a more positive note, Iris stated, “There are so many resources that I haven’t even tapped into.” After her spouse’s fall and hip fracture, she had used the block nurse program and had received grant funding for caregiver respite which allowed her to experience time away from care-giving.

In navigating through the resources and seeking help from medical professions, a male caregiver had this recommendation:

I think the best thing you can do is ask questions and listen. And as far as asking questions, you are going to be your own advocate no matter what, so it is like any aspect of health care. You got to ask the questions or you are not going to learn anything, and I think that is why we are where we are now is we did [ask questions]. We were not satisfied with what we were hearing, and we pursued it ourselves. {Alan}

Alan and his spouse with PD eventually changed medical centers because the center they started with provided little focus on the care-partner. They were not given information on community resources like the local PD support group. They had selected to drive over 80 miles to a medical center which specialized in PD. Alan felt the care-partner needed “more support in terms of knowing what the disease is and how to cope with it.” For another caregiver, she defined herself as a care-partner. This was described as she shared her frustration when interacting with her spouse’s physician (neurologist):

...he sees that this just is a medication management thing. I do not think he is listening to me, and I think the doctors need to listen to the care-partners because we are the ones, we can tell you how it really is.
{Ellen}

In terms of finding resources from the media, Michael J. Fox and his book about his life with PD was discussed by some caregivers. As some caregivers described the person with PD they cared for, they would compare his/her spouse or friend with Michael J. Fox. For example, Kathy compared her spouse's late onset PD with Michael J. Fox's early onset PD, noting her spouse's heavy dosing of leva-dopa and lack of dyskinesia. For Alan, he had been surprised and shocked with his spouse's diagnosis with PD. He had thought of Michael J. Fox.

I had heard of Parkinson's Disease and what we had just been through with the situation with Michael Fox and all the things that were going on there, and you know it was kind of a surprise, that is what we are going to be dealing with the rest of our lives. {Alan}

Similarly for Diane, within a week of her husband's PD diagnosis, she started paying closer attention to how her spouse was moving, "I paid attention and I knew it. Because I just knew it, it looked like Michael J. Fox." According to Diane, her spouse had been in denial and would not accept the diagnosis. Michael J. Fox as a celebrity living with PD had indirectly impacted these caregivers.

As caregivers learned more about PD from various sources, their navigation took them to new places like active involvement in fundraising for PD and advocating for PD. Francine shared how she and her spouse had become more politically active in regards to health care policy that could impact persons with PD. They had become active in the Parkinson Action Network, "We have gone there [referring to Washington

D.C.], two or three times already, where we lobby for Parkinson's research and for bills. We talk to our legislators. It's phenomenal. We are surrounded with Parkinson's" {Francine}. And Ellen described running a marathon, "I was raising money for Parkinson's if you can believe it."

Lastly, in the process of navigating through and finding help and/or resources, caregivers commented on their contact with a local PD support group from a caregiver perspective. Clara described their attendance at a support group meeting which allowed her the opportunity to compare her situation to those of other caregivers. "When we go into groups with the caregivers, there is such a range of what the caregivers have to do for the patient" {Clara}. Alan described how their participation in a support had helped them learn more about care-giving for a person with PD, as compared to the care-giving information provided to them by their doctors at their local medical center.

I think the participation in the support group has helped a little bit along that line [in regards to caregiver education]. I don't think that I well, I don't think from a caregiver point of view we got anything really from [name of medical center] or the doctors in that particular sense, other than a diagnosis, and we talked well what are some of the things we expect to see and is it something we should worry about other members of the family. We got answers to those but say from a caregiver's point of view, what should I anticipate and what should I plan, no! {Alan}

He shared how he views the support group as a resource and as an opportunity for interactions with other caregivers in the future. "That's information for both of us but it is really picking up support for her, and I will probably get more involved with that as I see the need for it myself" {Alan}.

For Ellen, she had sought out a support group when her spouse had been diagnosed with PD when he was about 35 years of age. She had been frustrated

because there was not a local support group for persons with early onset PD and their families. She was able to connect with another couple at a PD conference who were looking for a similar support group. They eventually started one on their own which met in their homes. The support group's numbers grew and eventually they required a larger facility for their meetings. Participants were under 60 years of age. She described the importance of caregivers coming together to share, "We do a check in and then everybody talks and after the check-in, the people with PD they talk [separate into groups] and then caregivers talk" {Ellen}.

Francine described their support group as a "good network of people." She further described how she had attended her first PD conference and had to excuse herself because she had been overwhelmed with what she had been seeing and hearing about PD. "I had to go into the bathroom because I was seeing what I was going to be seeing in the future. And you don't know that until you go there. Nobody tells you what you are going to see" {Francine}. Because of this experience, Francine has tried to share with others who were new to their support group, "...when people have come to our support group, you kind of give them a little heads up, you know just to be prepared for a lot of different things" {Francine}.

Finally, support groups were generally viewed by caregivers in a positive light. Eight of the thirteen caregivers had attended PD support group meetings at the time of the interviews. Interestingly, Diane was one who had never attended a PD support group and seemed unsure if it could benefit her. She stated, "I don't think a support group of other people would help me you know, I don't know" {Diane}. Another of the five who had not attended a support group meeting specifically commented that they

were not provided information about the local support group from the medical community. Jane stated, “And here again nobody has really suggested that to me in my wanderings, it’s something that I have discovered.” For those who had experienced this resource, support groups were described to provide caregivers the opportunity to share stories, find commonalities, validate their own experiences and see others as role models. Gayle described another caregiver from their support group who had cared for her spouse at home as he progressed into the advanced stage of PD, “...what she had to contend with at the end you know that was really tough and she never complained, a remarkable gal. People like that are good examples” {Gayle}. Kathy (who is both a caregiver and a person with PD) recommended that getting out and talking with other caregivers was helpful. “I think visiting with other people is very energizing...exchanging views and be forced to answer questions. It is all good for your brain” {Kathy}.

Summary: Care-giving is an Unplanned Journey

Participants expressed that care-giving has been similar to taking an unplanned journey. They experienced lack of knowledge about the disease and skills necessary for care-giving. They did not know what to expect down the road as the disease progressed, yet they remained alert to signs of change in cognitive and physical function along the way. These caregivers experienced having to fulfill new roles which they may not have planned for including household chores, managing finances, driving, and investments.

For three of the participants who were caregivers for persons with early onset PD, the journey had been prolonged impacting both the caregiver's and the care recipient's careers. The majority of the participants interviewed were retired and caring for a person who was also retired. Those caregivers who were retired viewed it as a positive attribute that helped reduced the burden of caring.

Caregivers described the experience as a balancing act. In other words, trying to provide only the necessary care yet allowing the person with PD to do as much as they could physically, cognitively, and socially. The balancing act became more complex for caregivers if they were still employed and also caring for a child. To maintain balance, caregivers made sacrifices and choices in their daily schedules to accommodate the needs of the person with PD. This often meant scaling back on community involvement like volunteerism, church going or running errands.

Lastly, in finding their way, caregivers learned to seek out help and resources from the internet, specialty PD clinics, and support groups. Unfortunately, caregivers described being frustrated with the help they received from health care professionals along the way. They described that there were resources, but they were often poorly coordinated. As one caregiver illustrated, "They're very piece meal and you have to stumble on them and follow the path one to the other and one to the other, kind of making your way on your own without anyone guiding you on the path" {Jane}.

Theme 2- I am Living with this Disease too

“No it is our disease, we are all living it.”

–*Francine, caregiver*

“I am trying to not let it run our life which is easier said then done. But, anyway we try.”

–*Francine, caregiver*

Caregivers were often saddened watching the changes that would happen to the person with PD. Caregivers watched for and recognized the physical, social and cognitive changes in the person with PD and often felt that they too were living with the disease. The demands for physical care were described by caregivers, yet the emotional demands (e.g. worry) were described as well. Care-giving went beyond providing physical assistance (e.g. taking over driving, helping with dressing and managing medications) to spill over into the caregivers’ mental processing (e.g. vigilance and attentiveness to safety, guilt, fears).

Caregivers felt part of the disease experience. The disease was a force that the caregiver and person with PD were up against together. For some of the caregivers, a collaborative team effort between caregiver and the person with PD was described, and if not present, there was evidence of tension between the caregiver and the person with PD. Three subthemes emerged that provide further depth to this essential theme: (a) Moving out of the healthy box, (b) I have to take care of myself, and (c) Knowing when to let things go.

Caregivers described feeling part of the PD experience. The following caregiver statement described this connection:

I don’t know if I will be with [name of her spouse] five years from now.
I don’t know if I will reach a breaking point and I just can’t do this. I

daydream sometimes about what it would be like not to have him around...I don't know but it is a difficult disease and I think sometimes I've got the disease as much as he does because I have to, you know, I am living it too. {Ellen}

This notion of living the disease too and contending with it now and in the future can be heard in Francine's statement, "I feel you just work around the Parkinson's. It has its own power Parkinson's, but it hasn't gotten us too much yet." PD had impacted Francine, evident in this statement, "I am losing my control. I'd like to think a little bit more, have a little bit more power over them [referring to changes in their lives because of PD]".

Moving Out of the Healthy Box

Caregivers were managing the physical and cognitive changes of the person with PD. In caregivers, this created anxiety, fatigue and stress with added responsibility as described by Kathy, "...everything falls on my shoulders...It is just all my responsibility, from paying the bills to driving the car." Caregivers felt it was hard watching the person they cared for have to give activities up and transition out of the healthy box with the disease progression. All were concerned with the issue of safety and their role in keeping the person with PD moving. Vigilance in the prevention of falls and accidents was overarching for all caregivers. Caregivers' awareness and management of medications for the persons with PD was woven with vigilance. Caregivers experienced the struggle to keep the person with PD exercising.

Physical and cognitive changes in the person with PD were often interrelated and often linked by the caregivers. The complexity of the physical and cognitive

changes was described by one caregiver in this way. Jane's spouse started to have some visual problems and she attempted to learn more about the problem, she explained:

You are in a healthy box. You are not looking for these things. And then when you move into the other box, where you are living a life that you are trying to reduce the impairments on every level, you don't know where to look for resources...It goes on and on. There practically isn't a function that you don't have to be aware of. {Jane}

Similarly, Kathy, who was caring for a spouse with PD as well as her own PD, described the transition out of the healthy box in the following way,

"And we have now moved to the classification of old shut ins...I've crossed the line from being young and efficient and able to being old and a shut in. And I guess I should be happy but I [laughter], it is hard you know when you have always been active to go from one category to the next." {Kathy}

In terms of the physical and cognitive changes due to PD, one caregiver stated, "And the physical problems with someone with PD, they're easy to see, but people don't understand the mental part of it because of my worry and concern, and I feel so bad for him" {Ann}. She was very concerned about how her spouse had to give up driving, singing, lecturing, golfing and swimming. Ann added, "It is hard for me mentally to look at him and think about the things he has given up. And that, that is very hard." In terms of cognitive changes in the person with PD, some caregivers found loss of memory as an added problem. For Betty, the added component of her spouse having PD with Lewy body dementia had required greater vigilance.

But since this dementia has come into the picture. I feel like being there almost all the time, at least keeping a pretty close eye on what [spouse's name] is doing and such. It is very important for his own safety, so it's become kind of all consuming, the care-giving has. {Betty}

Ann had also experienced her spouse's changing thought processing and tendency to wander off. She shared one of her care-giving experiences:

He did wander away a couple times which was difficult and um so then I had him go to the grocery store and do errands with me, and he asked once if this was his punishment for going away...then he asked if I did not trust him anymore. And I said, "No I don't right now and we'll have to earn that trust back, but I can't leave you alone if I can't be sure that you are going to stay."
{Ann}

Ann also explained her concern and anxiety when she had to run errands and would leave her spouse alone for a short while: "... I write him a note...where I am going, when I will be home, and at the end in big block letters, "PLEASE DO NOT LEAVE."

Ann's concern for her spouse's safety was further reinforced in this statement:

"Mentally it is hard. I think you have to be alert all the time because he falls. And I try to avoid situations where he might do that." Unfortunately her spouse's falling could not always be prevented and was an ongoing worry.

We were going from the 3rd floor to the 4th floor here in [name of senior living facility]. We hadn't had a lot of exercise, so my big fine idea was to walk up the stairs instead of going in the elevator. And we came to a landing, and I was going up and somehow he swiveled his foot and fell. And he fell face forward and you could hear the thump, thump, thump all the way down. He is also on Coumadin so anything that would affect his blood if he got cut or a head injury is terribly dangerous. And he had the mental stamina to keep his head up so his shoulders were very sore in the front of him but his head was saved. That I think that was the worst fall he had here. I was just beyond him so I tried to rush to him and it's like a scene from a nightmare where you're trying to go somewhere fast and you can't, you can't so he lay in a heap on the floor, and I rushed up to the landing and called for help, and there were two maintenance people that came and some nurses walking down the hall and they came so he was all right. Nothing nothing physically happened but I would relive that in dreams night after night after night and hearing the clunk, clunk, clunk as he went down the stairs face first...so that was a haunting haunting memory.

Ann shared another incident when she and her spouse got separated in an elevator and she got off without him. She described not locating him until many hours later back at

the coffee shop in their senior living facility. Her ongoing vigilance was further described in this passage:

And I guess that is another tiring part to me is that I feel I have to be with him any time we leave the apartment... the other day I left him for a few minutes to get the mail. I can do that easily but it is always being with him. And I think sometime he gets tired of my hovering and one day he wanted to go for a walk and I said, "Ok, where should we go? He said, "I think I'll just go myself." So he did, and I came down after ,and I was going to sit on a bench out there, but I kept looking to see where he was going, couldn't see him so I got out on the street to see if I could see him then he walked around [name of park near their building], and I kept getting out of the chair and looking to see if I really could see him, and when he came back he said, "You followed me, didn't you?"[laughing]. I wasn't very good at that and I apologized for that, but I think he gets tired of somebody always looking after him too. I think his job in the [name of his profession], he was very independent and I think it must be hard on him to always have somebody who thinks they have to be with him. I would think that would be hard. {Ann}

Unfortunately, her concern for her spouse's safety caused her anxiety which at times was very disconcerting to her. She shared this situation,

And he sleeps a lot because of the drugs and sometimes if he is really sleeping hard I feel I can get out to the store if I can get there and back in like 45 minute, but then coming back I'm freezing in the car hurrying, please don't let me have an accident I have got to get back. It's it's all this mental stuff which I think is the very hardest. {Ann}

For Betty, her vigilance for her spouse's safety (e.g. he had episodes of hallucinations, wandering off and a serious farm accident) led to her family making home adaptations and activity modifications. She stated,

...I kind of keep an eye on it [her spouse's activity] because once in awhile he will get into something that is really dangerous like starting up the chain saw and I am afraid with that and so I try to go out and see what he is doing and make sure he's safe. {Betty}

She was concerned about her spouse getting up in the middle of the night when she was sleeping so they installed a motion detector. Betty described not leaving her spouse

home alone but rather bringing him along on errands or finding another activity where others could monitor his safety and well being.

All the caregivers had some concern or comment regarding the person with PD falling or being at risk of falling. During the caregivers' daily lives, they experienced along with the person with PD aspects of disease like watching freezing of gait, shuffling gait, trying to get the person with PD back up after a fall, exploring alert systems like Lifeline or cell phones, exploring gait aides like walkers and/or use of sensory cues and helping after an injurious fall. For example, Iris cared for her spouse following his fall and resultant hip fracture requiring a hip replacement, Ben cared for his friend following his fall and resultant spinal cord injury, and Jane cared for her spouse who had a rib fracture, lacerations and chronic back pain due to frequent falls.

Iris's spouse had experienced problems with low blood pressure (postural hypotension) which led to him falling on the stairs and in the kitchen. He had been medicated for the low blood pressure, so she felt he could be left alone for a short while. Iris and her daughter were out doing errands when the fall occurred. Iris's spouse was found with a severe head laceration and a broken hip. She described that her previous medical experiences with her spouse had helped and prepared her for the situation; "It wasn't frightening to me necessarily. It was (pause), I need to help him. I want to help him. We need to do this then we'll see." Later, in the hospital, he fell again while trying to get out of his wheelchair. He was unattended at the time and ended up dislocating the new total hip replacement. During his rehabilitation stay, Iris worried about bringing him home and not knowing what to do especially if his blood pressure was not stable. "I was really at that point thinking I can't deal with this and it was just

too much going on here” {Iris}. This caregiver seemed to explore and reflect on the limits of her ability to care for her spouse.

Ben shared his poignant experience of his friend with early onset PD who had a serious fall due to the PD resulting in quadriplegia. Prior to the fall, Ben’s friend had difficulty managing his medications and would have severe dyskinesia (involuntary movement). He shared how he had to come to his friend’s apartment to help him at all hours. Ben stated how his friend could no longer live alone and required care-giving,

He [friend with PD] was getting to the point where that [living alone] was not a viable option so we didn’t know it at the time, but he was over medicating which is not unusual for Parkinson’s patients, and so we would find him in this awful state...extreme dyskinesias, I mean he’d be flying all over the place just because he’d over medicated.

Ben and his wife eventually cared for their long time friend (high school friends) in their home, dealing with both the PD and the spinal cord injury.

Further vigilance for safety during walking was described. Jane described her challenge managing her spouse’s frequent falling and his use of a gait aid. “I think the falling that is associated with Parkinson’s disease is very challenging and getting the person involved to use a walker on a regular basis to get that to be habit” {Jane}. Her spouse was inconsistently using his walker around the house which she was concerned about:

There are many instances when he will fall if he just turns around. If the walker was right there by his side he could grab on to it. Just yesterday he was getting something out of the refrigerator and he fell. {Jane}

Jane found her spouse’s falling experiences to be “frightening and emotionally draining.” She explained how she used a trial and error strategy to figure out how to get her spouse up after a fall. She stated she had no training in how to use a gait/safety belt

or assistance in selecting a walker and teaching her spouse how to use a walker. From Jane's experience she recommended,

I think just instruction on walkers. Just a session on walkers and there ability to help you, I think that is the single most important aide we have and basically we have had four or five doctors say you must use that walker but really with no instruction. {Jane}

There was a range of concern and need to address gait problems and falling amongst the caregivers interviewed, as not all persons with PD that were being cared for required assistive devices like walkers.

Caregivers/care-partners to person who were in the early stages of PD were living with safety concerns as well. For example, Diane was a care-partner to a recently diagnosed person with PD who also had depression and denied having PD, as well as the early motor signs of a shuffling gait and slowed reaction time. She was specifically concerned with his decision to continue driving, car racing and home maintenance activities like getting up on the roof. Diane described her situation:

He bought a corvette two years ago which he wanted before he was diagnosed, and now he has changed this \$75,000 car into a race car, and he is driving it at 140 mph which is kind of crazy with what he's got, but you know I have done all I can to discourage it, but I can't do anymore (long pause). {Diane}

For Francine, her spouse's postural instability is a daily concern which required them to modify there home with plans for his future use of a wheelchair. She stated, "He falls all the time, all the time. Yes or tripping. We just ripped up the carpet here so we could get the floor because the carpet made it a little more difficult too and we widened a door" {Francine}. Besides home modification, caregivers considered use of cell phones and medical alert systems to help with ensuring safety for the person with PD.

Gayle was particularly concerned with her spouse falling especially when she was away or at night time.

Well I was working and one day I came home and you know he seemed fine, no problem and then a little later I looked at the wall and I thought, it was much darker and I looked at that and I said, “[Spouse’s name] what happened?” Well his chair had fallen backward and by the grace of God he was able to catch it but that really really concerned me because if the had fallen down here between the table and chair leg, the chair and the table leg, I don’t know how he would have gotten up. So that is when we decided to get [name of alert system]. {Gayle}

Similarly, Kathy had considered having her spouse use an alert system, but she felt he would resist using it even though he fell frequently with minor injuries like bruises and lacerations. She, like other caregivers, had to physically help the person with PD get up off the floor. They actually installed extra thick carpet and padding throughout their residence to cushion his falls. Kathy further recalled her spouse falling in the shower and the difficulty she had getting him up when he was wet and slippery, “We worked at it but I did get him up. That was the most scary time.” Because of her spouse’s increased risk of falling, they seldom went out unless accompanied by one of their adult children. “We don’t go out anymore unless one of my sons is along and then they are stronger, and they are able to get him right up if he falls” {Kathy}.

Particularly interesting, this caregiver noted that with her spouse’s increase in falling, “I can tolerate it more” {Kathy}. She described getting use to his falling.

Well this has come on gradual, and I have gotten use to it. At first, every time he fell and I heard the bang I would just (pause), my heart would just jump...I never realized how accustomed I was to it until our, we have cleaning person come in once a month and she is just a young girl. And I happened to be gone, I guess to the fitness center and [spouse’s name] fell trying to get into a chair and she was petrified. She didn’t know what to do and you know I remember that feeling when he first started to fall, but it was just renewed, the feeling, hearing her. She didn’t know what to do. {Kathy}

Likewise, Jane commented on the inevitableness of her spouse falling and her acceptance of this part of the disease progression for her spouse.

I have come to and I think it may be a perception that I think is really important, there will be falls. That's what this is about. There's no way to prevent all falls and when my son was here, he was watching him like a hawk and my brother-in-law when he comes would watch him every single minute and even then they fall. So to come to the acceptance and not feel that you have to be vigilant every single minute, it's part of the disease. There will be falls that you can't prevent. You do as much as you can...All of the things you can put into place, still doesn't prevent what is going to happen. You just do the best you can. Otherwise you are going to drive yourself crazy. {Jane}

Similarly another caregiver who experienced her spouse having freezing and falling episodes stated, "I think I have gotten kind of used to it. I think that is where some of the anxiety has gone....I think it really is getting accustomed to it" {Heidi}. She went on further and described acceptance of her spouse's deteriorating function in this way: "Maybe you get used to things, I don't know. You know, and I am very much a realist. So, you know, this is the way it is, it is not going to change" {Heidi}. Yet Heidi still experienced ongoing anxiety related to leaving her spouse alone because of his freezing and falling episodes. She described, "I feel a low level anxiety all of the time" {Heidi}. She shared a recent experience in which she had left him alone in their apartment and upon returning had buzzed to be let in, "He didn't answer right away, right away the anxiety kicks in and I wonder if he has fallen" {Heidi}. She feared that he would fall and need to move to a nursing home with resulting decrease quality of life.

Now if he fell outside and hit his head and killed himself, I'll betcha it wouldn't take me more than 15 minutes to say thank you God because, what I don't want him to do is fall and be injured, break a hip or whatever and lay in a nursing home. {Heidi}

In further regard to quality of life concerns, caregivers addressed the management of PD medication for the person with PD and how this management impacted their daily lives. The timely dosing impacted eating, communication, driving, walking, dressing and exercise. There was a range in terms of caregivers' participation with preparation and administration of medications to persons with PD. For a few caregivers, they took a more marginal role with medications, yet they remained concerned with patient compliance and dosing. They recognized and anticipated greater involvement with medications as the disease progresses. For instance, Francine has not been involved with her spouse's medications but has realized the tasks around the home our dependent on getting done relative to when her spouse's medications are working. She described doing household chores like this:

“He needs rest right now because the pill hasn't kicked in. So then your clock, you know when I am ready to go, he is not necessarily ready to go, but that's a little learning piece for us, how to make it work”
{Francine}.

At the other end of the spectrum, caregivers had a more active role with medications.

Ann's spouse was dependent on her assistance for medication as evident here:

The first thing I do in the morning is to set out his pills. I usually do his pills one month at a time with those long pill boxes. And then for the day, he's got a small one divided into four parts and I make sure that all of the pills are there, so breakfast, lunch, dinner and evening. An then so that is really the first thing I do in the morning, and it is not time consuming, but he will forget that he has to take the pills so that is another thing that you have to be aware of all the time. Has he taken the pills, have I given them. He wouldn't take them by himself, wouldn't think this is lunch time I have to take pills and the trouble with this is that some of his [pills] have to be taken an hour before he eats, so if we are going to eat at one, an hour before. If we are invited out, and if we have to eat at a certain time that changes that. So that is a constant thing and sometimes we forget. And that is hard. That's hard. {Ann}

Ellen was particularly concerned with her spouse's compliance in self administration of medications and regulation of his medications with his deep brain stimulator. Her spouse had been driving alone and sustained a serious accident which resulted in her spouse temporarily giving up his license. At the time, his dyskinesia was poorly controlled. She described her predicament in this way:

He told his neurologist, I don't think I should drive anymore, so his license was taken away. Mind you, I work fulltime, I have an eleven year old kid who is in scouts and everything else, and I am not only working fulltime, but I am driving [spouse's name] all over the place, and I am driving my son so it was insane, ok losing his license for me the care partner was crazy. {Ellen}

At the time of the last interview, Ellen's spouse had been allowed to return to driving although she feared for her son's safety as a passenger when her spouse was driving. She stated, "I am going to talk to the neurologist and say I am not sure that [spouse's name] takes the seriousness of taking his medications. As you know, everything relies on medication" {Ellen}. These experiences showed how caregivers were more vigilant and involved with safety as the person with PD progressed and transitions out of the healthy box.

I have to take care of myself!

Caregivers shared their need to monitor their own well-being. Caregivers seemed aware of the importance of their own physical, mental, emotional and spiritual health and tried to schedule time for themselves into their daily lives, but it was not always easy especially if it meant leaving the person with PD alone at home. Caregivers taking care of their own health included exercise, outings into the

community, positive thinking, staying in the present, spirituality and maintaining a sense of humor. Maintaining the energy to care-give was associated with caregivers participating in planned exercise like walking, yoga, martial arts, meditation, aquatics, stretching, strengthening, hydro-massage, breathing exercises, recreational activities as well as just simply getting outside. Exercise was performed at an individual caregiver level and as dyads (caregiver and person with PD).

Caregivers associated their well being with their ability to help maintain the well being of the person with PD. Caregivers addressed their own exercise needs as well as the exercise needs of the person with PD. Three caregivers perceived that their spouses' vigorous level of exercise prior to being diagnosed with PD was of great benefit. This was captured in the statement by Jane as she shared her viewpoint on current exercise research in PD,

My husband is making the point that he used to be a runner and his course of Parkinson's is probably more or less, what should we say, that he's less damaged than a lot of parkinsonian people with the same time from of Parkinson's because he probably had all of this other, you know, background that helped him.

Likewise Heidi equated that her spouse had stayed unimpaired from the PD for so many years because of his pre-diagnosis fitness level, "And he is using a walker now. He is an old athlete..." {Heidi}. As a couple, Francine and her spouse with PD were involved with vigorous exercise, from her standpoint, "We did a lot of strenuous activity and he did it all. He works out a couple times a week which is good because I think it has actually helped make his Parkinson's go slower, progress slower" {Francine}. She noted that he was functioning well although he did routinely lose his balance and fall. They attempted to find

exercise activities they could still do together such as cycling, yet she made time prior to work most mornings to go to the gym to exercise without her spouse.

Exercising with the person with PD was both beneficial and limiting for the caregiver. For Gayle, exercising together meant spending time together going walking and to a local health club. She shared, “I think you know that [referring to walking] gets your heart pumping and gets you going and you feel better. I know I feel better after we do that” {Gayle}. She also recommended, “I like to have him get out and get a little fresh air every day if possible...” {Gayle}. From a different perspective, Jane described the added responsibility of supervising her spouse’s exercise program which made her feel like now she was her spouse’s therapist. She stated, “Yes, so then I become the physical therapist (long pause)” {Jane}. She also tried to get in her own exercise but found it hard to fit in the daily schedule, “I haven’t gotten that [exercise] into my schedule now. So walking the dog is you know that’s an hour a day at least. And so that’s about the best I can do right now” {Jane}.

Maintaining health and wellness contributed to the caregivers feeling they would be able to keep care-giving in the future. They worried about not being present to provide care-giving if their own health was compromised, or they died before the person with PD. This perspective was revealed by Alan,

I think (pause) the biggest worry I have is not from the diagnosis of her having Parkinson’s. I think we can deal with that, it will change what we’re anticipating but what happens if I come down with something...There is a long term thing there that I don’t know what to deal with and what happens if something happens to me in that interim then what do we do? So yeah it is kind of a nagging worry in the back of my mind. {Alan}

Although Alan recognized the importance of his own health and wellness, taking the time to get regular exercise was compromised with the demands of care-giving. With loss of his own physical stamina, he recognized his own need to exercise, “Having felt that some of the things I used to do, age is one thing, but at the same time losing physical tone, I said, Ok let’s get back on that program” {Alan}. For he and his wife, the walking exercise program they did together had to be modified from outside on nature trails to indoors, especially in the winter months when ice and snow increased their risk of falling.

Other caregivers also tried to explain their attempts at taking care of their own physical, mental, and spiritual needs. Caregivers taking care of their own well-being was not always an easy task. Caregivers commented on being tired. The day-to-day energy demands of care-giving were described by Ann.

This has lots to do with me I guess. I am always doing, rather energetic and loved what I was doing no matter what. I was a happy homemaker and all and now there are some days when I am so tired at night that I can hardly wait for the day to end. And that is a strange feeling for me to have. To be done with this day and let it end. I don’t like that feeling and it doesn’t happen all the time and I think that tiredness gets from one thing maybe being cooped up in a small apartment. That is hard for me because I love to me outside.

Ellen shared her thoughts in this way, “I think that I look at it like I need to focus on me and I need to focus on what is right for me and taking care of myself, if I am going to take care of him.” She maintained her physical health through running and training in the martial arts and commented “So those are some of the things I try to focus in on my self, because I’ve the true belief that no one can take care of yourself but yourself {Ellen}. Similarly, Francine also still employed, struggled to find time for

herself and she described it in this way, “And I mean I go to work and I am there at seven and I got home tonight at what 5-5:30 p.m., so it is a long day and so just to know that I am (pause), I don’t get my down time so to speak. I need my sit down time.”

This notion of the caregiver having down time from the demands of care-giving was reiterated by yet another caregiver,

I think you have to bring a certain passionate involvement to what you do and feel that you have done your best. I think it is really important to get away and to plan on time when you take charge of your own life and have a break on a regular basis, not a periodic once every month or two basis to keep your perspective intact. I think that is really important because otherwise your life gets absorbed. {Jane}

Time away from the demands of care-giving was significant for Ann as well. She described life in their apartment, and her need to get away to be alone,

I try to find different ways to get out of the apartment. We have a very small apartment. We had signed up for two bedrooms and a really small one bedroom apartment became available and we were told that maybe it would be to our advantage at this time to move in then. It has 690 square feet so it is very small and when I feel antsy and he likes to watch a lot, news programs, so if I know he is going to be there watching it, and if I feel I am going to cry or just feel so antsy I’ll start walking the halls or go down to the library for 15 minutes. Anything to get out of there, just for a while. Then I think that’s important and I don’t, I don’t, I don’t want to cry with him [pause participant became tearful]. This is awful now. I have the reason to go unload the laundry. I drop the laundry and come home. I tell him, maybe I am going to sit just to make sure the laundry is doing well which is a bare face lie [chuckling], because I know it will be all right. But it just gives me a chance to be alone. And I do not know if that is a natural reaction or what? Or it is just me?

Iris who was caring for a spouse eighteen years her senior, wanted to keep active with her own fitness and volunteerism but when her husband fell and broke his hip this changed. She shared,

I love to play tennis. It is my outlet. I love it. So I was still able to do that...but I have now been struggling with taking care of myself and wanting to keep doing what I am doing because I think it is good for me, but you have the additional piece of care-giving so it's (pause), you think something has to give here, something's got to. And I haven't found that balance at all. {Iris}

For Iris it was about staying positive, "I have a pretty good attitude about the whole thing." She described controlling her attitude, "I am trying really hard not to get exasperated. so there's (pause), I can't believe I am saying this, there is more of an acceptance of all this on my part." Yet, Iris struggled with adding more care-giving responsibilities like attending support group and caregiver meetings, "That is the one thing I haven't done because I think if I did do that maybe I'd have to give up some of this other stuff that I do for myself. But I think as time goes on it will be more important." Iris had other family members stay with her spouse which allowed her to get away from care-giving, "I'm still being able to do some of the things I can do because if I couldn't I would be worthless to everybody." She linked her well-being to her support system.

It's like I am feeling that I am stronger than I thought I was. But if I didn't have the support I'd fall apart. It is only because there is the support system, I mean it's just that I know I can call on people. {Iris}

Similarly Jane felt a caregiver should call on others when in need.

Ask for help when you need it and try and stay as positive as you can because things go better when you are positive and that is easier said than done, but I think trying to work each day rather than looking you know at the past or the future is probably as good as any. Staying in the present as much as you can. {Jane}

Other caregivers described the importance of staying in the present. Francine shared her experience, "I kind of feel lucky too, my ex-marriage [husband] was an alcoholic so I did Al-Anon. So we're pretty, both pretty good about staying in the

present because that is one of the huge issues I think for Parkinson's." Ellen reiterated the notion of living in the present,

I know where this is going. I know that it is only getting worse, but I know that he is a very loving person, he has forgiven, he has apologized for this past. For me, I try to take it one day at a time. {Ellen}

And for Clara, "I just kind of take things where they are and I'm not looking to what's going to be." Similarly, Heidi articulated this about living in the present, "I believe all you got is right here and right now."

In addition to staying in touch with the present, maintaining a positive attitude while being a caregiver was significant. Keeping the caregiver's spirits up was described as simply as developing a mantra, going to lunch or meeting a friend. Jane described the challenge of taking time away from care-giving in this light,

To look forward to and to kind of refresh yourself, to step back into life, the life of others. The life, you know, of other people because you become isolated into a box of your own parameters, and there tends to be a dividing line between what you are able to do and what other people are able to do, and it can be isolating. And sometimes you would choose that it is just too much trouble to step out of that after awhile. So (pause), but when you do that it is refreshing. You can come back with a renewed kind of energy. {Jane}

For this caregiver, avoidance of negative thinking was reinforced with use of mantras which could act as a cue or key to switch her into getting back into the right frame of mind (e.g. in times of frustration or anxiety). Jane stated, "Like it might be 'forgiveness' or it might be 'patience' or it might be something like that that immediately switches you from one state of mind to another."

In the process of self management of their own health and wellness, caregivers had recognized their own limitations. Ann stated, "I think the hardest thing for me is

that I have believed that physically I am strong I think, and I thought that I was mentally strong, and I have found that I am not.” Another caregiver addressed these limitations and eloquently stated,

Our role is just to do the best we can knowing that we will not always meet the mark or not always be our best selves in every situation. You just keep struggling and just carrying on and do the best you can and accept what you have to accept and make the best of it. {Jane }

In the process of exploration of their abilities and limitations, caregiver well being was linked to spirituality. As Betty described, “And there is, I don’t know, my faith as well. You know, I think there is something in the Bible that says we will not, you know, be given more than we can handle, so, that helps a lot.” For Francine who attended church regularly, “...my higher power has gotten me through. He is everything. That is when I cry.... and I got my angels up there with Mom and Dad, so therefore I know I can do anything. So it is okay.” Her belief in being cared for by a higher power was clearly important, “I always feel like I am taken care of so therefore I can take care of him. So that kind of works” {Francine}. For Iris who has not attended church on a regular basis, it meant re-examining her faith and seeing other family members use prayer in the home. She described it as a “... a kind of a calmness.”

Maintaining a sense of humor was also described by caregivers. Kathy linked humor with spirituality, “Keep your sense of humor that is important...I heard a quote, I think I like it, ‘Laughter is the hand of god upon a troubled world.’ “For Ben, in the position of care-giving for a long time friend, the experience was described as extremely difficult at times yet rewarding and enjoyable. He stated, “It can be good times and fun and laughs and all of what life offers to people...” {Ben}. Jane found

taking care of herself and maintaining a positive attitude meant finding activities they could both enjoy, as well as finding ways to keep laughing (e.g. humorous books, books on tape and movies). She described watching lighthearted television programs,

...not the usual litany on the TV or radio of the woes of the world which you don't need to compound what you are already dealing with, so I think finding things that are cheerful and fun...It's a challenge but I think that is what you have to do. {Jane}

In these illustrations, caregivers shared the importance of taking care of the self and taking breaks away from care-giving to nurture the self. Humor and spirituality were additional important factors described that were used to help maintain the caregiver's health and well-being.

Knowing when to Let Things Go

This subtheme described caregivers dealing with a spectrum of mixed feelings (e.g. guilt, frustration, impatience, worry, or satisfaction, gratefulness), developing strategies for coping with these feelings and knowing when to let things go. Caregivers described how they had learned to accept the changes that they were experiencing because of the PD. The need to "let things go" was described as a coping strategies.

Jane explained dealing with her feelings and her coping strategy,

...maybe even looking at this as a you know, your well (pause), your life lesson, this is you are in school, you're in life school. What are you suppose to learn from this? And I think it is easier said than done but you know we're trying to learn compassion, to let go, to not get frustrated by small things, to accept things that you can't change, accept things that are valuable.

For Jane, care-giving was not just an innate ability but a learning process. The process required not only learning motor skills but also emotional skills like compassion.

Caregivers experienced feelings of hope, gratefulness and thankfulness. Ellen described her experience,

I learned very quickly (long pause) that I have to be grateful for the small things that I do have. I am grateful for my son that I do have. I am grateful for the time that I do have with [spouse's name] now. {Ellen}

Caregivers expressed making decisions that they were grateful they had made. Kathy shared this story about moving to a senior living complex after her husband had been diagnosed with PD,

We used to trim the tree together. Well that's impossible. Everything is, and I am so grateful that we are here because you know I can't complain when I think about how hard my mother worked, you know, and I've got everything right at my fingertips—laundry, and it is just a wonderful place to be you know and there is community too. We have good neighbors that said you are not alone. People are here. I hear people out in the hall and I can go out and talk to them and it is, it's really, I mean, so much to be grateful for. {Kathy}

Caregivers conveyed feeling of hope for the future with stem cell research. For Kathy who was both a caregiver for her spouse with PD and a person with PD, her hope was in research:

...that's my only hope, the stem cell research and I would like to be a candidate, you know, if my Parkinson's gets worse. I asked my neurologist, and I said, "Do you foresee doing stem cell?" Oh," he says, "we're doing it already, but he says, "only with rats" (laughing). I said, "I don't qualify." (laughing). So anyway. But there is hope. {Kathy}

For this caregiver hope was important. "If you lose hope, boy life could be miserable, yeah" {Kathy}. Thankfulness for being retired so they had time for care-giving was reported. Betty stated. "I am lucky to be able to be retired..." Her spouse with PD had an associated sleep disturbance so they were up a lot at night by being retired they could get a nap after lunch.

Not all feelings described by the caregivers were as positive in nature. Feeling like guilt, frustration, impatience, and worry were also described. Ellen worried about her spouse's ability to safely drive a vehicle especially after he sustained a motor vehicle accident. Even though he had a deep brain stimulator implanted and medications, he still suffered from severe dyskinesia. She was especially concerned when he would be driving their young son to activities. She stated, "I can't tell you the concern I had; I had to let it go." She further described it as using the Al-Anon principle, "I have to let it go. If he gets in a car accident and kills himself then that is what happens. I have to let it go. I can't constantly worry" {Ellen}. Having sought professional help, Ellen shared, "...I have learned through therapy to let go". She was also frustrated with his lack of initiation when home all day while she worked outside the home. Ellen described his obsession for Suduko puzzles and computer games as a way to keep his mind off the PD. "At first, I used to be really angry about it, but now I have realized it is just the disease. It is not him (pause), that's his way of coping" {Ellen}.

Ann shared her feelings of guilt when she had to leave her spouse alone to run errands or do volunteer activities,

But if I am going to go and be so nervous I'm not going to do a good job there [referring to her volunteer work] so that is what...what to do with that? We do have some friends from our church who said that they would come and sit with him but they were mainly women. One would have to bring a two year old child with her as nice as that would be I didn't think that would possibly work out. So there will probably be answers that I can do, but I always have a guilty conscience then when I leave. That's hard because I think he has taken care of me for 58 years and here I am thinking I need two hours by myself and it doesn't seem fair, so that is a hard thing to reckon with [pause] for me anyway. {Ann}

Even though Ann's adult children encouraged her to get out more she reiterated her feelings of guilt.

I miss (pauses) I guess being with other people more. I lie the social thing I use to do and I love this volunteer work. And I enjoyed being a participant in a bible study and I miss things like that. And my kids say, well you can do all of that but I don't know, I don't know what to do about my guilty conscience. That 's hard to figure that out that I can leave him. {Ann}

The pervasiveness of Ann's feelings of guilt appeared often within her narrative. She described, "It's funny how that guilt goes through...here's guilt again." For Ann, her family supported and encouraged that she get out into the community (e.g. volunteer work, bible study), "And my kids say, well you can do all of that but I don't know, I don't know what to do about my guilty conscience [soft laugh]. That's hard to figure that out, that I really can leave him." Ann felt she was learning about her own capabilities of care-giving and in the process reflected on "Am I doing the right thing?" Caregivers had a wide range of feelings they experienced and coping strategies. Caregivers showed the ability to reflect and recognize their limits to being a caregiver, part of that was shown in their knowing when to let go, in other words, recognizing that they could not control all aspects of the PD.

Summary: I am Living with this Disease too

For all the caregivers, they interacted on a daily basis with a person with PD. PD profoundly impacted their lives in a way that these caregivers felt like they too were living with the disease. One of the thirteen caregiver in this study was diagnosed with PD too, although years after her spouse. This caregiver thus was truly living with PD as well as caring for a person with PD. Caregivers experienced watching the person with

PD struggle with motor and cognitive function including falling, decreased communication, diminished judgment, and lack of initiative. This was perceived as transitioning out of the healthy box into a new dimension.

Living with a person with a chronic progressive neurologic disorder meant caregivers were vigilant and attentive to the safety and well being of the person with PD. Unfortunately this vigilance could become a stressor, leading to anxiety and worry. Caregivers recognized they needed to take care of themselves; otherwise they would be unable to continue providing care to the person with PD. They suggested strategies like getting away (e.g. breaks from care-giving), yet this was not always possible. Lastly, caregivers described their feelings of guilt, anger, frustration and worry. They provided strategies for coping and letting go.

Theme 3: My Relationship with the Person I Care for and Others is Changing

When it is someone you love it makes it a lot easier.
–Gayle, caregiver

“I recognize that this is what we got to do!”
–Alan, caregiver

Relational aspects of care-giving were described. Caregivers shared experiences about maintaining their relationship with the person with PD as well as family, friends and other support persons (e.g. clergy, health care providers). In regard to the dyadic relationship (caregiver-person with PD), some caregivers preferred to use the term care-partner versus caregiver. Relational aspects included problems with communication which led to feeling of loneliness and isolation. The need for outside support systems

for the primary caregiver was revealed. For caregivers who were spouses to persons with PD, concerns for intimacy were expressed.

Subthemes revealed the complexity of the human care-giving experience. All caregivers dwelt with the person with PD and therefore allowed for togetherness and closeness. Four subthemes emerged which further revealed the care-giving experience: (a) Staying connected to others, (b) Sharing the responsibilities of care-giving with others, (c) Experiencing changes in intimacy, and (d) Accepting of the emerging personality of person I care for.

Staying Connected to Others

“The isolation is devastating.”

–*Iris, caregiver*

Caregivers commented on how the person with PD had lost his/her ability to interaction in conversation with the caregiver and others. Changes in the ability to communicate both verbally and nonverbally impacted their relationship as well as relationships with others. In addition, caregivers noted how decreased oral-motor control during eating made meal time difficult especially as a social event. Similarly, decreased ability of the person with PD to cognitively process conversation led to declining ability to socialize and isolation. Both the communication problems described by caregivers and their resultant social isolation fell along a continuum with caregivers actively trying to keep the person with PD socially active, as well as themselves.

The important connectedness of conversation was described by caregivers. In addition, caregivers described the effort it took to maintain conversation. Other factors were also described which impacted the caregiver’s sense of connectedness. Loneliness

was described even in the presence of the person with PD. For example, Ann's spouse slept a lot due to his medications. She stated,

Here is a huge one, because he has pills, like the other day, he slept until 5 in the morning. Then he had breakfast and he slept all morning. He slept all afternoon and he wanted to go to bed at 7 o'clock and I felt (pause), I have done this before, I felt really lonesome, a lonesome feeling. Here he was physically but nothing else, and that made me lonesome. I was surprised that that hit me, that I was so lonesome. I know people who have lost their spouses and lonesomeness is a big thing for them, and I do not want to tell them that I am lonesome because they would say, well he is there, when he is there physically. So, that is another guilt one. Why would I feel lonesome when he is still with me? Very guilty. {Ann}

Loneliness was Kathy's main frustration. Her spouse's advancing PD affected his speech, making conversation and socializing problematic. She felt she had modified her own behavior because of his decline.

He was always very sociable; in fact I was the shy one in the family. I've had to compensate for that and because when we have guest over he hardly says anything and when I ask him why, he says, "Well it's so hard to process the conversation." And when he thinks of something he could respond with they'd have gone on to another area and that's frustrating for him, but it makes it lonely, makes it lonely for me. Even the two of us, we can sit at the breakfast table and maybe not say a word. {Kathy}

Kathy felt loneliness in her relationship with her spouse and missed the "give and take" which had occurred with conversations in the past. She cherished having had many "really good years" with her spouse prior to the PD. Her isolation extended to other relationships,

Yes, we would go to films, go to movies, and our social life is totally (pause), you know, getting together with friends, it is just almost negligible because people just don't understand, you know, unless they've had a disease or something. It is real hard and I understand how they feel... {Kathy}

Furthermore, as caregivers dealt with changes in communication in social contexts, one caregiver described filling in the words for the person with PD who was unable to complete his or her sentence. For Ann the experience was fatiguing, evident in this description:

Well that is another thing that makes me tired, because I am saying “Pardon me, what did you say?” So many times during the day and then I I think I can’t do that anymore and I just kind of block things out which is the worst thing I can do. So then I ask him to talk louder and he says “I can’t because it seems like I am yelling to you.” But conversation is harder, when you can’t hear somebody. So that is (pause)...that is a change. And once he loses a word, sometimes he loses a whole thought well then he feels bad and kind of ...the conversation has kind of ended then. That is another hard thing.

Ann further reflected on how she would try to help and fill in for her spouse during conversation. She seemed to struggle with the appropriateness of her action as expressed in this statement:

Sometimes I think I should not be doing that or should I? I don’t know. I don’t want to embarrass him especially when we are out and he is looking for words but then sometimes he will look at me and I know somehow his face is, he needs help. So then I will I will fill in for him. I think there is a fine line when do you help and when do you not and sometimes I don’t know where that fine line is. {Ann}

Similarly, Clara grappled with how to manage changes in her spouse’s communication. She used various strategies if it seemed like her spouse had a delay in processing communication. She would go over it a couple of times to make sure he understood what was going on in their conversation. In other cases, she became frustrated with their communication,

Oh, you know there are times that you are human, you get frustrated...Sometimes I will just go on to the next thing instead of

waiting which I don't know is right or wrong thing to do, but that is what I do. {Clara}

Besides management of speech and communication problems, caregivers described how socialization was impacted as the person with PD lost oral-motor control and the ability to eat. Ann described this experience:

And meal time is hard. His table manners have deteriorated so I don't feel comfortable inviting people to eat with us. Some people I know it bothers. And then there are others...you find out who your really close friends because you feel some are walking away from the whole situation maybe not their fault they don't know what to do with him. But it is not a pleasant sight sometimes. But good good friends say what's the difference we know him and we love him as he is. But that meal time is hard.

Keeping socially active was linked with having family and friend who could provide meaningful closeness and connectedness. Ann described this aspect:

We have very good friends. An interesting part of this whole thing, we have been with a lot of groups of friends some of whom now are very cordial and good but they don't know what to do with [husband's name]. One of the doctors asked, once if we had good friends that would stick by him. Then there are other people that are dear friends and they are just as good to him now as they were. That is an enormous help for me and our children. {Ann}

Caregivers had the need to seek out others to share their feelings and emotions.

Ann described her experience:

I have a niece in town with her family and we are extremely close to them, their kids think that we're [pause], that they just have an extra grandma and grandpa so we are with them a lot. And she is my lifeline often times. She is a person if she calls quite often if we have not been together, and she can tell by my voice, I don't realize it sometimes so sometimes I do my utmost that I put on a different voice, but she sees through that, and I can cry with her, and I can feel bad, and I can feel mad at the situation or I could be free with her. I have one friend like that too. You need somebody that you can just scream with or something. {Ann}

Caregivers recognized the risk of being isolated as the demands of care-giving increased and as the person with PD became less able to communicate. They showed the ability and the desire to stay connect with other family members and the community yet found this not always easy.

Sharing the Responsibilities with Others

All caregivers voiced their need for support from others like family, friends and clergy. Caregivers shared their experience of learning to let others help them along their journey. Betty recalled, "...through some of these scary things [e.g. serious farm accident] that have happened I think we're finally learning to accept help, and we have a person coming from the elder care network."

Caregivers described the importance of getting support from both adult children and other adults. Francine reported, "I have siblings here and I think that has been one of our luckiest things, we have an incredible support system....nobody is afraid of it..." Iris expressed having family or church member assistance in this way, "If it was just the two of us. It would be very different." With others coming in to help she felt, "It is just a breath of fresh air." For Iris having assistance to avoid feeling alone was necessary and in her words, "...absolutely key". Iris was the only caregiver interviewed who had an adult child who resided with them. As a caregiver, Iris was concerned about the demands placed on her adult daughter's who was employed as well as assisting her mother with care-giving. Iris appreciated that light heartedness which her daughter brought to the care-giving and living situation.

Although support and assistance from others was recommended by caregivers, that assistance was not always easily coordinated or available. Jane had described the importance of asking for help and support from family and friends but stated, “It’s hard to plug someone into all the things that need to be done”. Through trial and error, Jane found that employing formal care-providers was helpful; for example, she hired an older gentleman who was a peer or companion to her spouse with PD. Jane recommended getting support and getting away on a regular basis by either hiring respite care or relying on family members to allow this to happen. She emphasized teaching others to care,

...that also lets them feel as if their helping and their participating, and it can lead to I think closer relationships and when you go through something together I think that is a good thing. I know our grandchildren brought him [her spouse with PD] a card and made it themselves, and you know, it teaches them about caring and about caring for someone, being cognizant of their situation and being, participating in trying to be helpful so all of that can be positive because everybody is going to have help someone some point or another. {Jane}

For Ellen, finding support had been a struggle and maintaining friendships with others. She felt her family, friends, and work colleagues did not understand the complexity of her care-giving. Ellen stated, “Even my own family doesn’t understand.” Through it all, Ellen explained, “I have learned to cherish the people who understand, who are there for us, not necessarily family.” She reported receiving support from a neighbor who was a minister, a person outside of the family.

Not only did caregivers address sharing the responsibilities of care-giving with family and friends, but the use of formal paid caregivers was addressed. Ann shared her hesitancy in leaving her spouse for short time periods in the charge of professionals on

the skilled nursing floor within the high rise senior living complex which was their place of residence. She described her difficulty with relinquishing care to others and developing a trusting relationship with the formal paid professionals.

My first thought is, “I should have never have left him [pause] anywhere”. And our friends are concerned about that but [researcher’s name] I have to get out and do some things on my own. And I said, “no I can’t it cost money to leave him here”. He said, “We’ll pay for anything”. And I know money isn’t it, isn’t really the problem so I tried the 4th floor again [assisted care floor in building] the trouble is it is the nursing home set up. And there are people there that are sleeping and making sounds like a nursing home and that is their life. Well then they set him in front of the TV set with cartoons on it and that was not good. And they said they would change that as soon as one woman leaves, they would change it to another channel. And then after this episode where he walked away, they were panicky because they were in charge of him. And they said they should have put on a bracelet, an ankle guard that told them as soon as he got to a door that that he was up. {Ann}

Caregivers shared the importance of accepting help from family, friends and formal caregivers and sharing the responsibility of caring, even though at times it was difficult to orchestrate. At the heart of these relations was the concept of trust.

Experiencing Changes in Intimacy

“What do they call it? An oxymoron, alone together.”
 –Kathy, caregiver

Caregivers who were spouses to persons with PD described what it was like to lose intimacy and their sexual relationship. All caregivers were providing care for spouses, except one caregiver. Ben was caring for a male friend with PD. Both he and his wife were in a care-giving relationship with the friend with PD. Besides the PD, caregivers associated that changes in intimacy and sexual function with their spouses may be related to aging, medications and other co-morbidities like arthritis. Caregivers shared both celebration of maintenance of intimacy, as well as grieving the loss of

intimacy. As Kathy described above, that residing physically with a person did not necessarily equate to being together. For her togetherness seemed to represent the feeling of being close to another person both emotionally and physically. This togetherness was compromised because of the PD.

For Francine who would provide her spouse assistance with dressing (e.g. buttoning shirts, tying ties), this physical act provided her the opportunity to be close to her spouse. She stated, "...it just gave me another chance to get closer you know, to hugs that kind of thing, so I think we have been lucky in that regard" {Francine}. Likewise Ellen reported the importance of hugs from yet another perspective. She and her spouse had discovered that using hugs could lessen her spouse's freezing episodes.

One thing [spouse's name] does a lot, which is kind of weird from a physical therapy standpoint, if he is not moving, he'll say, "Can I have a hug? Ellen can I have a hug?" And I don't know if it is an emotional thing or what but I have to give, and really anywhere, like we'll be in a store and he'll say, "Can you give me a hug?" And he wants a hug. So it is something he says to me all the time which is kind of strange, but that is what helps. {Ellen}

Although Ellen had these moments of physical contact with her spouse, their intimacy had been disrupted with the progression of her spouse's PD. For Ellen it meant, selling their king size bed as her husband slept in a different room. She shared, "This is crazy. We are no longer sleeping together. That is just not happening. I grieve that trust me" {Ellen}. Another caregiver described losing the physical intimacy, "The sex is long gone" {Iris}. Besides the loss of their physical relationship, Iris commented on how hard it was when her spouse lost the ability to have discussions and conversations. Gayle described how the PD, diabetes, and cancer had impacted her spouse's sexual function. She stated "sex wise there is just not much there" and "that is just something

that I accept you know” {Gayle}. Yet she missed the intimacy, “I wish sometimes he’d put his arm around me more you know. Just cuddle me or something like that. I just think it’s hard...so that has been an adjustment, but you know at my age that is not all bad either” {Gayle}.

For Heidi who had known her spouse since she was 16 and married when she was 18, the care-giving experience was integrally linked with her long term commitment and years of intimacy with her spouse. She shared these perceptions on marriage and care-giving.

Frankly, if the marriage is bad I don’t know how you could be a caregiver. You know if you haven’t been too crazy about your husband for 40 years but you have stuck it out, you know, for the kids or whatever, I don’t know how you can go through caring for them. You know, I think that would be very difficult. {Heidi}

For this caregiver, having had an intimate relationship with her spouse for many years, the changes to their relationship were significant like not sleeping in the same bed because of spouse’s dyskinesia, as well as joint pain which they both experienced. She further shared,

We have had a very active sex life and that changes more than you know. I don’t think enough has been written on the subject because I think we [in regards to older adults] have the same libidos that we had in our 40s, but you know, you’ve got aches and pains and so of course that too makes you depressed. I think particularly men, you know. So that has been a major, major issue. Wanting to have more sex and it’s just more difficult. {Heidi}

Jane also described sleeping in a different room so she could get uninterrupted sleep. For Jane although this had impacted their intimacy, she stated it had “...helped tremendously so I could get a good night sleep.”

All caregiver had maintained intact marriages except Ben who was divorced. According to Ben, the demands of care-giving for their friend with PD contributed to the development of relationship problems with his ex-wife who was also a primary caregiver to the person with PD. He described this triadic care-giving relationship at the transition point when his friend with PD had such declining function that he could no longer live alone.

But it just didn't make sense at that point, we were providing so much care that it didn't make sense for us to go from our home to his especially during the night when he was having problems, in the winter time and whatever, so then we started looking for a house that would accommodate him, so we all could live together. {Ben}

Eventually the situation led to marital discord. He stated, "The strain of me working full time and a lot of overtime and more and more care for [friend's name] and just no time really to have a relationship, the marriage didn't last and we ended up divorced" {Ben}. From his perspective care-giving was "...more than one person can handle...we both had no idea what we were getting involved in..." {Ben}. A change in intimacy was a common perception for caregivers.

Accepting of the Emerging Personality of the person I care for.

Caregivers contended with the evolving personalities of the persons they cared for. The personality of the person with PD impacted their ability to care. Caregivers reported various personality features that they observed. For some the changes were seen as helpful and positive, whereas for others, the changes were perceived as more problematic. As the person with PD changed (e.g. personality, motor function, cognitive function), caregivers tried to define their own roles and who they were in their relationships. For example, Francine stated, "I like care-partner better than caregiver it

seems like it is a two way street. I think care-partner is probably a stronger, stronger one.” Gayle’s statement,

I like to call it a helpmate. You know, he [referring to spouse with PD] has called me caregiver different times, but I just say [spouse’s name] “I don’t like that title.” I will be your helpmate, you know if I have problems then he helps me and if he has a problem I help him. {Gayle}

With the progression of PD, both the caregiver and care recipient have their own unique personalities and perceptions of care-giving (e.g. when is care-giving needed, what is needed, who is responsible, where does it happen and why is it necessary). Caregivers reported their experiences with this aspect of the phenomenon.

From a more positive perspective, Kathy described her spouse as easy to live with and a contented person. She stated,

He has never complained, never complained about his illness or been angry. He just accepts it and is grateful for the life he has had and that makes it easy because I know I have friends who have to deal with a different attitude. {Kathy}

Francine had a comparable experience, “I think we’re lucky because the person that has Parkinson’s disease in our house is really good and easy with it.” Similarly, Ann described being thankful for her spouse’s emerging personality in this way:

What I am thankful for is that he has turned into a calm sweet gentle person and people have not expected that out of him. They thought he would get more feisty, belligerent when I would have to dress him. Belligerent when he couldn’t do the things that he has wanted to do, but he has turned absolutely opposite so that I’ll tell you, that is a gift from God that he is like that. {Ann}

In Ann’s relationship, she had recognized the importance of accepting her spouse’s emerging personality as demonstrated in this statement, “...at this stage of life you can’t love the person as he was, but you need to love him as he is right now.”

The personality changes observed by caregivers were not always perceived as being helpful. For Ellen, she had to inform her family of her spouse's personality changes. Her spouse's family thought her husband would ask for family help if he need it, but Ellen countered with, "No, he won't. He's got Parkinson's. He's not going to do it. He is not going to reach out and cognitively he is not doing it...He is not the same person." Ellen had become aware of the non motor aspects that could impact her spouse with PD like obsessive-compulsive disorders and pathological gambling. Over the course of her spouse's disease, Ellen stated she tried to help family and friends understand her spouse's personality changes. She felt these were related to the disease process itself and intervention strategies like medications and her spouse's deep brain stimulator.

Caregivers like Diane dealt with the care recipient's personality changes as well as attitudinal changes. Even though her spouse was in the early stages of PD, Diane pondered her spouse's personality changes which impacted them both. She shared her concern about her spouse's denial,

Ok, well first of all, my husband does not have it very severely at this time. What I am really dealing with is his emotional problems with it. Right now he is in denial, for the second time...So he doesn't have a real good attitude about things and that's the difficult part, and I think, if you want to do the best at this you kind of have to have a good attitude or try to anyway. And denial at this point is not good. {Diane}

In addition to her spouse's denial, Diane experienced his depression.

Well I can say this, he was depressed before I thought he was depressed. I thought that was what was wrong with him before he was diagnosed. So I guess with this situation it's the depressions at this point that I am probably concerned about. He hasn't been depressed lately because he feels he doesn't have it, the disease I should say...I worry about what he would do to himself a few times. {Diane}

As a caregiver Diane was unsure of what she should do about her spouse's depression as expressed here:

I don't even know if I am doing this all correctly because I question when he gets very depressed, and if you know that it is real depression should you seek help? I don't know what to do about that. I guess I question that part. If I am doing that correctly, but then it seems like he gets over it you know. If it were continuous I would get help definitely.
{Diane}

In further reflection, Diane compared her own personality with that of her spouse.

"He's just a very impulsive individual, and he is a very 'A' type personality." She later went on to say, "I am the easy going one. He is not. He is very impatient, very impulsive individual...He has a very difficult personality to cope with this disease in my opinion.

At the other end of the continuum, Ben was care-giving for a friend with PD who was in the later stages of PD. With the disease progression, Ben felt he no longer understood his friend's personality or wishes, especially related to his friend's health care directives. Having known the friend since high school, Ben knew his friend had a strong will to live, but unfortunately uncertainty replaced this understanding as his friend lost his ability to communicate.

I don't want him to die but I (pause) his quality of life has continued to go down hill, and he is not able to communicate. He lost his vocal capability quite some time ago and when he first lost his vocal capability he was communicating with a Dynavox. He still had use of arms and over time his arms had become so constricted that he had no use of his arms anymore, and so he lost his ability to communicate with the Dynavox and then it was nods of the head and blinks of his eye or raise an eyebrow or whatever and that lasted awhile, and now it is to the point where there is almost no communication what so ever. Occasionally when he is real passionate about something or you know upset or concerned or whatever he can manage to respond but um, so that makes

it a lot harder, and so even though we have known for years and years that he has had this strong will to live we don't know this for sure if that continues to be. We don't know that he hasn't [pause], but um I know personally if I were at the point he is at I probably wouldn't want to continue myself, but as a caregiver and the affect it has had on me it is hard to continue... {Ben}

As the PD progressed, caregivers experienced the changing and emerging personality of the person with PD. Caregivers lived with both pleasant and more deviant personalities (e.g. person with PD in denial or having impulse control disorders). And, in the case of caregiver Ben, in essence his friend's personality was lost with the progression of the disease.

Summary: My Relationship with the Person I Care for and Others is Changing

Care-giving for a person with PD requires a commitment to another. It requires a relationship. These relationships can be spousal, filial or friendship. In this study, filial relationships were not studied as there were no adult children who met the inclusionary criteria of residing with the parent with PD. Each caregiver brought to his or her relationship some history of being cared for and providing to others. Taking caring history and the contextual world into account, care-giving was a function of deploying cognitive, affective and behavioral responses for and with the care recipient. Other family members, friends, and health care professionals enter the picture to form a triadic relationship.

For caregivers in this study, they described dealing with isolation and loneliness, as well as their attempts at staying connected with others especially as the disease had progressed. Caregivers described the consuming nature of care-giving and their

strategies to share responsibilities with other family members, friends and volunteers.

For those financially able, paying for formal care-giving assistance was described as an option especially allowing them to have time away from care-giving (e.g. respite). In their spousal dyads, caregivers discussed loss of intimacy often associated with getting separate beds because of sleep disturbances seen in persons with PD. Caregivers shared how they had opportunities to maintain physical intimacy like helping with dressing, providing hugs during freezing episodes.

Lastly caregivers shared how they dealt with the emerging personality of the person with PD. Most caregivers described being grateful and thankful that the person they cared for was so easy going. Unfortunately, caregivers were also confronting emerging cognitive impairments (e.g. memory loss, slowed thought processing), communication problems (e.g. hypomimia, quiet monotone speech), and impulsive control disorders (e.g. gambling, compulsions, obsessions) which impact personality.

Phenomenological Cohesive Description

As is common in phenomenological studies, I used the thematic findings to develop a cohesive description of the combined experiences. Other authors have referred to this as an exhaustive description (Hodgson, Garcia, & Tyndall, 2004) or a composite description (Moustakas, 1994). According to Polkinghorne (1989), the reader should come away with the feeling that “I understand better what it is like for someone to experience that” (p. 46). In regards to my study, the description attempts to provide the reader with the sense of what it might be like to walk in the caregiver’s shoes.

This composite description is intended to provide the reader with the meanings and essences of the experience, representing the group as a whole. Themes and subthemes have been synthesized into a cohesive description about care-giving for a person with PD so that the reader can better grasp the care-giving experience.

The informal caregiver or care partner (e.g. family member or friend) and the person with PD have a history together, a story to be told. A history bound in their own experiences of being cared for and caring for others. The dyad shares a space, the environment of care-giving. The dyad does not live in a vacuum but rather is integrally linked to others in their world. Their life flow together becomes interrupted by an unexpected force, PD. The impact of the disease is felt and lived through by both. With the diagnosis, an unplanned journey begins which requires a new set of guidebooks, a new commitment, and a re-exploration of plans, hopes and dreams. The journey is typically not short but extends many years into the future, a future which is unclear. There are new paths to follow and roles to learn especially considering the chronic nature of the disease which impacts the physical, cognitive, emotional, social and spiritual well being of the dyad. The care partner may notice subtle signs or markers along the way that indicate a change in function, behavior, and/or thinking for the person with PD. Moving out of the healthy box creates new challenges and may require coping strategies like living in the present, hope, optimism, thankfulness and gratefulness. It becomes a balancing act for the care partner as greater care-giving demands (e.g. managing medications, preventing falls, assisting with activities of daily living) arise. As the care partner experiences his or her limits and capabilities, choices and sacrifices are often made along the journey like moving to a safer more simplified living environment or retiring early. Care partners must discover and navigate through new resources which may include health care providers, PD organizations, support groups, technology and written material. This navigation may not be always be over smooth waters as care partners encounter barriers along the way like inadequacies in caregiver education and coordination of services. Although not always easy, the care-partner learns to take care of his or her bio-psychosocial needs so as to maintain the ability to provide care including getting support from others, taking breaks away from care-giving, getting proper rest, exercise and nutrition. As PD progresses, care partners find it harder to stay connected to the person with PD especially with changes in communication ability, personality and intimacy. Sharing care-giving responsibilities with others and finding needed support is a life line for

care partners. Relationships with others will expand and contract as new points in the journey dictate.

Chapter 5

Discussion

“The act of care-giving can encompass meeting a variety of needs for the patient including financial, emotional, legal, social, and physical support.”

–Bolean, 2009

“I myself have been with my husband for only 6 years now and he is a Parkinson’s patient. When I first met him and he explained a little about the disease to me, I had no idea what I was in for.”

–Sager, 2009

As a physical therapist, my work with patients with PD and their caregivers perked my interest in obtaining a fuller understanding and meaning of the care-giving experience. My curiosity led me to the formulation of the research question, “What is the meaning of the caring experience from the perspective of the informal caregiver in the day-to-day interactions with the person with PD?” To garner this meaning, I conducted in-depth interviews with thirteen caregivers who lived with and perceived themselves to be in a care-giving relationship with a person with PD.

The type of interview selected was an open ended conversational interview which used the same open ended question for each participant thus allowing the participants freedom to choose how to answer the question. Through analysis of the transcribed and coded interviews, three themes of the experience of care-giving for a person with PD were identified. In addition, subthemes were described for each theme to further elucidate the day-to-day experience of care-giving. These themes will be discussed in relation to the literature.

First, the linkages of my themes and subthemes to the literature will be presented. Second, the implications of findings for clinical practice will be summarized. Third, recommendations for future research will be proposed. Fourth, I will share my personal reflection.

Linkage of Themes and Subthemes to the Literature

The experience of care-giving for a person with PD was meaningfully shared by each caregiver who volunteered to participate in the study. They shared their thoughts, feelings, emotions and actions as caregivers. Through careful and critical analysis, their descriptions of the experience, the physical, psycho-social, emotional, and spiritual domains, were revealed.

This section will be divided into three subsections allowing for discussion of the specific findings from my study. The three themes and their subthemes will be discussed relative to the literature. The three themes which emerged from the analysis are: (a) Care-giving is an unplanned journey, (b) I am living with this disease too, and (c) My relationship with the person I care for and others is changing.

Care-giving is an Unplanned Journey

In addition, to this main theme, three subthemes emerged: a new path occasional signs along the way, a balancing act, and navigating my way through. What is a journey? Webster's New World Dictionary (2002, p. 773) defines journey as "any course or passage from one stage or experience to another." In my study, caregivers addressed different points in time and different contexts along the way. From a temporal perspective also referred to as lived time (van Manen, 1997), participants shared care-giving experiences that had occurred in their lives prior to the person with

PD being diagnosed with PD, at the time of the PD diagnosis and after the diagnosis of PD. From a contextual perspective also referred to as lived space (van Manen), caregivers described the unplanned events, places, people and resources they encountered on their journey. In other words, caregivers provided historical information and contextual information about the emergence of the PD and the paths they encountered. Heijman (1995, p. 277) also described living with PD as “the beginning of a long journey into the unknown, a journey which begins with hope, passing through periods of elation and frustration and finally ending in acceptance and resignation.”

Hodgkins, Garcia, and Tyndall (2004) described a similar theme in their qualitative study of 10 couples living with PD; their thematic cluster was called relationship and disease history. My study further revealed the added aspect of caregivers being watchful for signs along the way, or in other words, signs of deteriorating function in the person with PD like loss of initiative, changes in leisure and travel activities and subtle movement problems (subtheme: a new path with occasional signs along the way).

In addition, caregivers described another subtheme as a balancing act which required choices and sacrifices along the way. This concept of a balancing act has been described elsewhere in the literature on caregivers managing terminal illness in the home (Proot, et al., 2003). In their grounded theory study, Proot and colleagues described the vulnerability of family caregivers in terminal palliative care at home as a balance between burden and capacity. They used a figure to represent the vulnerability balance with one side of the scale showing vulnerability decreasing factors (e.g.

continuing activities, keeping control) and the other side showing vulnerability increasing factors (e.g. restricted activity, insecurity).

In my study, the balancing act was described by caregivers specifically as establishing routines, considering career changes (e.g. retirement, FMLA), making changes to their living situation and retirement plans, and learning about the financial impact of PD. The concern for finances articulated by the caregivers in my study is consistent with the financial challenges confronting family caregivers reported by Johnson (2007), although he reported primarily on the burden of caring for frail elderly in general (persons with PD may fall into the frail elderly category but not always). Finally, in regards to the balancing act subtheme, caregivers articulated that they wanted to find equilibrium in their daily lives like in taken for granted activities like being able to drive and run errands. With the progression of the PD, caregivers described their need to restructure daily life.

Caregivers also described navigating and finding help and/or resources along their journey. Resources were described as human (e.g. health care professionals, support groups) and nonhuman (i.e. books, home exercise pamphlets). In their journey, caregivers described learning in multiple ways: self directed reading and activities, attending conferences on PD, through support groups, from attending appointments and therapy sessions with the care recipient, from the internet, from organizations, from advocacy groups, and through the media. They described care-giving as an ongoing learning process requiring trial and error and problem solving.

This subtheme supports a similar thematic cluster reported by Hodgson and colleagues (2004); they referred to it as: connecting with resources. These researchers

found that caregivers had both positive and negative experiences related to the availability of knowledgeable and compassionate medical providers, service providers, transportation, and support groups. Proot et al. (2003) also found lack of information-related support a vulnerability risk factor. Comparably, my study found caregivers had both negative and positive experiences including some caregivers who were frustrated with the coordination and communication within the health care system. Specific to early on PD, Hodgson, et al., described a more fragmented path to receiving their final diagnosis. In my study, the disjointed medical intervention was reported by a range of participants from those caring for a person with early onset PD to those caring for a person of later stage onset. For example, a caregiver specifically felt that doctors needed to listen to the caregiver as well as the person with PD.

In the process of locating resources, finding their way and stumbling along, one caregiver specifically recommended taking a holistic approach to managing the PD. This is consistent with recommendations for a holistic caring and learning theories found in the literature (Hodgson, Garcia & Tyndall, 2004; Cousins, Davies, Turnbull & Playfer, 2002; Leininger, 2001; Watson, 1979; Yang, 2003). In my study, caregivers discussed trying to meet a variety of needs for the person with PD like financial, emotional, legal, social and physical support. In providing this holistic approach, the literature suggests a multidisciplinary approach (Boelen, 2009; Iansek, 1999; Hodgson, Garcia, & Tyndall, 2004; Ward & Robertson, 2004).

Considering the complexity of managing PD, Ward and Robertson (2004) stated that a multidisciplinary team implies:

joint or shared assessment and negotiation of goals with patient/client and family; shared methods of monitoring progress, an identified key worker (either health or social services professional), a joint resource for informing and educating patient/client and family, shared strategies to prevent future complications and a joint training programme. (p. 235)

Although a multidisciplinary approach is recommended, the caregivers in my study still felt that there needed to be the pulling together of services and development of instructional material for caregivers, suggesting that this recommendation found in the literature may not be adequately utilized in practice. Oertel and Ellgring (1995) argued for the development of educational materials for patients with Parkinson's disease and their care partners. They recommended taking problems found in PD and developing analogies that are understandable to the client and care partner. Along this line, a caregiver in my study specifically described the need for the development of a handbook or workbook for caregivers.

Particularly, resounding was the caregivers describing their self-directed use of technology (i.e. internet) and media to provide them resource information. In addition, caregivers described making connections to PD by learning about celebrities with PD (e.g. Michael J. Fox). This finding supports the triadic model of care-giving proposed by Talley and Crews (2007) that described the factors influencing the care recipient, the family caregiver and the professional caregiver team. These factors included: health care systems, insurance industry, society, internet access, consumer choice, aging demographics, scientific discoveries, advocacy/membership organizations, global disease burden, political forces and media portrayals.

Support groups as a resource was identified by the caregivers in my study even though caregivers used support groups in varied ways. Caregiver reported that they

learned more about care-giving and received more support for care-giving from the support group members as compared to that received by formal health care providers. Specific studies on the use of support groups by caregivers to persons with PD were not found in the literature, although the resource impact of national foundations for PD, like National Parkinson Foundation (NPF), was described (Heijman, 1995). According to myparkinson.org, the NPF has over 1000 active support groups exist throughout the U.S. and Canada (“Parkinson’s disease support groups,” n.d.). Interestingly in my study, a caregiver shared her frustrating experience of trying to find a support group for persons with early onset PD. This finding would be consistent with information provided by myparkinson.org which described that there is a tremendous need for support groups for those with Young Onset Parkinson's Disease.

Finally in regard to resource navigation and information seeking activities, caregivers in my study described behaviors and attempts at self management that were in line with adult learner principles (Dreeben, 2010; Lieb, 1991; Lyons, 2003). Caregivers described learning experiences that were self directed, required a foundation of life experiences, goal and relevancy oriented as well as practical. Caregivers were reflective and evaluated the outcomes of their care-giving actions and behaviors as they were learning to be better caregivers. Reflective thinking was evident in Jane’s statement, “...your life lesson, this is you’re in school, you’re in life school, what are you suppose to learn from this?”

I am Living with this Disease too

In addition, to this main theme, three subthemes emerged: moving out of the healthy box; I have to take care of myself; and knowing when to let things go.

Caregivers shared their experiences of moving out of the healthy box with the person with PD as physical, cognitive, emotional and social changes occurred. They shared how they felt they lived with PD too and how it impacted their daily lives in some way. Anderson (1999) discussed this concept of transition from healthy to sick and described that health is more than mere absence from disease but it is also a way to behave in relation to life, self and medical condition. He further suggested that the notion of a healthy PD patient is not necessarily a contradiction if the patient and their families can be encouraged to view organic disease as a learning opportunity.

For caregivers in my study, the cognitive and physical were described as challenging. They related that the safety and well-being of the person with PD was a concern for them, sometimes leading them to worry and become anxious. All caregivers in my study described some experience with the person with PD falling or being at risk for falling. They voiced concern that the persons with PD did not consistently use a walking aide like a walker and that overtime they had become accustomed to the person with PD falling. Caregivers felt ill prepared to handle getting the person with PD up off the floor after a fall and freezing episodes. Caregivers described managing falls through trial and error. Home modification, medication changes, procuring adaptive equipment, use of medical alert systems and vigilance were described strategies to keep the person with PD safe. For example, one caregiver described that she had to learn on her own that a safety or gait belt could be used to assist getting her spouse up off the floor.

The significance of educating the caregiver in their role to prevent the person with PD from falling and sustaining injury emerged through this subtheme (moving out

of the healthy box). The descriptions provided by the caregivers regarding their involvement with safety and fall prevention are consistent with the literature (Bloem, Munneke, Carpenter, & Allum, 2003; Davey, Wiles, Ashburn, & Murphy, 2004; Habermann & Davis, 2006; Cutson, Zhu, Whetten, & Schenkman, 2004). Davey and colleagues (2004) reported caregivers being injured when trying to help the person with PD up off the floor. In addition, they stated that the majority of caregivers in their study were frightened about their spouse falling as well as having received little information about falls. As PD progresses, increased frequency of falling occurs then in later stages falls decrease because the person with PD loses his ability to ambulate and becomes wheelchair dependent (Bloem, van Vugt, and Beckley, 2001).

Unique to my study, caregivers described becoming accustomed to the care recipient falling on a daily basis and seeing the care recipient inconsistently using walking aides. This may have been related to the person with PD being on versus off with his or her medication cycle. Questions like these come to mind: Were caregivers letting down their guard? Were they slackening their attentiveness? Were they accepting that falls are just a part of PD and nothing can be done to prevent them? Falls that occur on a daily basis should be considered pathologic and require intervention. Considering this finding, caregiver and patient education related to falls would seem worthwhile. In addition, recommendation for physical therapy assessment and intervention (Morris, 2000, 2006) could be made.

The subtheme, I have to take care of myself, represents a lived body experience as described by van Manen (1997). Caregivers described how they recognized the importance of their own physical, mental, social and spiritual health and wellness. If

they were not healthy then how could they provide care to the person with PD.

Negative aspects of care-giving emerged like being tired. Caregivers described how they tried to exercise, take breaks from care-giving, use positive thinking, stay in the present, address their spiritual needs, and maintain a sense of humor.

Previous studies (Cousins, Davies, Turnbull, & Player, 2002; Goodhead & McDonald, 2007, Goldworthy & Knowles, 2008) have explored caregiver stress and predictors of that stress. “PD caregivers have been found to have increased depression scores, poor social lives, and generally low quality-of life scores” (Goldsworthy & Knowles, p. 372). Goldsworthy and Knowles reported primary stressors like functional cognitive impairment, dependency of the care recipient, behavioral problems of the care recipient, and hours of care-giving. They also described protective factors like social support social support, self esteem, and quality of the caregiver-care recipient relationship. My study does support that caregivers do experience stressful situations, and that caregivers also have the ability to find ways to take care of the self like through finding time away from care-giving, exercise and eating right. Yet, caregivers in my study did describe the difficulties in being able to step away from care-giving for short periods. Similarly, Habermann (2000) found spouses of persons with PD to use three strategies for dealing with challenges they faced: maintaining their own life, seeing the challenges they experienced as secondary, and encouraging their partner to stay active.

Caregivers in my study tried taking care of the self through use of positive thinking, humor and spirituality. These strategies are consistent with research on the importance of positive thinking (Scheier, & Carver, 1993), humor (Parrish & Quinn, 1999; Bethea, Travis, & Pecchioni, 2000; Buffum & Brod, 1998; Pasquali, 1991) and

spirituality (Chang, Noonan, Tennstedt, 1998). Similarly, Hodgson and colleagues (2004) described two thematic clusters, the first being the impact on self and others, and the second being strategies for survival with maintaining a sense of humor one of these strategies. In addition, getting breaks away from caring was deemed important by caregivers in my study. This would be consistent with the finding of Goldsworthy and Knowles (2008) who reported that “protective factors such as the quality of the caregiver-recipient relationship, the frequency of breaks, and perceived social support can help to ameliorate the adverse effects of care-giving” (p. 376).

Finally, the subtheme, knowing when to let things go, was described by caregivers as a way to deal with feelings. Caregivers in my study described a spectrum of feelings like worry and guilt to thankfulness, hope and gratefulness. In situations, that they felt were beyond their control, they described having to let things go to help maintain their own health. In addition, caregivers used acceptance in situations. Similarly, Hodgson and colleagues (2004) described the importance of thankfulness, acceptance, hope and optimism under their thematic cluster called strategies for survival. In addition, Watson’s holistic theory of human caring described faith-hope as a caring factor (Watson, 1979).

My Relationship with the Person I Care for and Others is Changing

In addition, to this main theme, three subthemes emerged: staying connected to others, sharing the responsibilities with others, experiencing changes in intimacy and accepting the emerging personality of the person I care for. From a relationship perspective, also referred to as lived human relation or lived relationality (van Manen, 1997), caregivers described their connections with the person with PD as well as others.

Considering the relational nature of care-giving, participants selected to use alternative words for caregiver including: care partner, helpmate, and caretaker.

Caregivers experienced difficulty in communication with the person with PD and changes in intimacy which resulted in loneliness. They described the importance of staying connected to others and allowing others to share in the care-giving responsibilities. Unfortunately, one caregiver thought other relatives (not in residence) just did not understand how the PD was impacting their family's lives. Sharing the responsibilities with either unpaid or paid helpers was described as an option for respite, but coordinating the effort was not always viewed as an easy task. Caregivers felt they needed to have a trusting relationship with others who shared in care-giving. Interestingly, caregivers discussed teaching others to care, like the next generation of caregivers (e.g. grandchildren).

The three subthemes (staying connected to others, sharing responsibilities with others and accepting the emerging personality of the person I care for) were similar to those found by Hodgson and colleagues (2004) who interviewed the caregiver and the person with PD together. Although, they identified two thematic clusters: impact on the couple relationship and impact on self and others. The subtheme on intimacy brought out in my study was not addressed specifically in the Hodgson study. In my study, caregivers discussed the interaction of motor dysfunction (freezing/motor blocks) and sleep disturbances for the person with PD on their intimacy, sexuality and other interrelated activities.

In my study, caregivers described how care recipient's sleep disturbances impacted them emotionally, physically and socially. Caregivers in my study described

loss of sleep and fatigue while managing the care recipient's sleep disturbances (e.g. insomnia, day time sleepiness, movement disorders when sleeping or moving in or out of the bed, nocturia, medications and sleep apnea). They discussed how the sleep problems impacted their relationship with their spouse (e.g. getting different beds, sleeping in different rooms, sexual activity, day time sleepiness impaired driving and communication). For example, one caregiver's spouse would fall asleep while driving which led to her doing the driving and medication changes for her spouse. This added to his functional dependency on her.

My findings were consistent with the literature related to sleep and sexual function issues for persons with PD and their caregivers. From a physical standpoint, the literature reported that persons with PD have sleep issues (Adler & Thorpy, 2005), and caregivers are at greater of health problems because of the higher incidence of sleep problems (Vitaliano, Zhang, & Scanlon, 2003). According to Adler and Thorpy, nocturnal sleep disturbances occur in 60% to 98% of patients. They recommended that persons with PD be interviewed in the presence of a relative or caregiver so as to get a clearer estimation of the sleep issues. Pal and colleagues (2004) reported that caregivers of persons with PD had significant sleep disturbances, which was likely to be secondary to night time care of their spouse with PD. They concluded that sleep and mood disturbance adversely affected the quality of life of spousal caregivers. As well as having sleep disturbances, caregivers and persons with PD can have sexual dysfunction (Brown, Jahanshahi, Quinn, & Marsden, 1990; Moore, et al., 2002) impacting quality of life. Brown and colleagues reported in their study that the most

effected were the couples in which the patient was male. The caregivers in my study who reported concerns for sexuality were all female and caring for a male with PD.

The subtheme, accepting the emerging personality of the person I care for, warrants further discussion. Caregivers had both positive and negative experience with the emerging personality from seeing the person with PD as easy going to confronting the person with PD who is in denial. Mendelsohn, Dakof, and Skaff (1995) argued that the PD accelerated and intensified personality changes normally expected later in life. Further complicating matters, caregivers in my study reported problems with pathologic gambling and impulsive control disorders in persons with PD. Interestingly, three caregivers in my study revealed their experience of dealing with a care recipient who had pathologic gambling and/or impulsive control disorders (ICD). These problems have been reported in the literature (Ardouin, et al., 2006; Dodd, et al., 2005; Gschwandtner, Aston, Renaud, & Fuhr, 2001; Voon, et al., 2007; Weintraub, et al., 2006). According to Voon and colleagues, “patients with PD having a younger age at PD onset, higher novelty seeking traits, and a personal history of alcohol use disorders may have a greater risk for pathologic gambling with dopamine agonists” (p. 212). One caregiver in particular described similar features in her spouse and the situation was placing pressure on their marital relations. None of the caregivers in my study expressed that they had or had not discussed the gambling and/or ICD with their primary health care professional. Perhaps this added stressor may not be reported as frequently because of the social stigma that caregiver and the person with PD may fear.

Implications of Findings

Phenomenological research is derived from first person reports of life experiences (Moustakas, 1994). This approach allowed the voices of caregivers to be heard and descriptions of their experiences recorded with the intent to extract the meaning of the care-giving phenomenon. The current study looked broadly at care-giving for persons with PD across the various stages of the disease.

The implications of the study are really multifaceted addressing the physical, cognitive, emotional, social, and spiritual aspects. Care-giving is not a static process but rather a dynamic and evolving process as the disease progresses. Caregivers in my study recognized that they did not know what was in store for them in the future, often unsure of what was around the bend. As this is, in essence, a journey, caregivers had to traverse foreign territory as they learned about the disease and its impact on daily living. This was evident in their narratives. Seven relevant implications will be discussed.

First, considering the chronic nature of PD and changes that occur with the disease progression, caregivers should be provided formal guidance and educational opportunities from health care providers over the course of the disease process. As caregivers and persons with PD in my study did not know what to predict in the future or in other words, what lay down the road, ongoing follow-up for the person with PD and their caregiver would be recommended. As the disease progresses, caregivers reported have to explore home modifications, respite care, a change of living environment, and receive training in exercise and adaptive equipment to keep the person with PD mobile. Scheduled follow-ups could promote keeping caregivers

prepared for their roles. This would be consistent with best practice (Deane, Ellis-Hill, Dekker, Davies, & Clarke, 2003).

Second, caregivers and persons with PD should be viewed from a holistic perspective to ensure optimal care for the person with PD and support for the caregiver. Caregivers openly shared how they managed the physical, cognitive, emotional, social and spiritual aspects of care-giving and one caregiver specifically recommended a holistic approach. Considering adult learning occurs on three levels: cognitive, psychomotor and affective (Yang, 2003), health care professionals need to address these when interacting within a health professional-caregiver-care recipient triad (Talley & Crews, 2007).

Third, a multidisciplinary collaborative team approach should be used to facilitate communication across disciplines with the management of PD. Caregivers in this study recommended a more collaborative coordinated approach. Evidence supports this approach. Caregivers and persons with PD should be encouraged to find health care professionals that practice empathetic active listening. Caregivers in this study noted the importance of having a physician who understood both the needs and concerns of the person with PD, as well as the caregiver. The person with PD, the informal and formal caregivers need to develop trust within the triadic relationship as described by Talley and Crew (2007).

Four, caregivers should be provided opportunity and connections with support groups. Caregivers in this study discussed the importance of support groups in their lives. Health care professionals need to be cognizant of local support group in the area so they can refer caregivers and persons with PD. Health care professionals need to ask

the right questions to find out if caregivers are aware of support groups, local resources and national support organizations. For caregivers to persons with early onset PD, their support needs may be different (e.g. still employed and in childrearing) and should be considered. The need for early onset PD support groups has been reported in the literature. One caregiver in this study shared her frustration when initially looking for an early onset support group. She and her spouse eventually started a support group on their own with another couple.

Fifth, caregiver health and wellness should be optimized over the course of the disease process to keep the caregiver-care recipient relationship intact and strong. This should include respite or breaks from care-giving and promotion of quality sleep, nutrition and exercise. Health care professionals need to be alert to signs of depression in caregivers. Again asking the right health and wellness questions and referral to appropriate care could be considered best practice.

Sixth, caregiver vigilance and concern for safety (e.g. prevention of falls) should be fostered and evaluated. Provision of resources and necessary adaptive and assistive equipment/devices are necessary for the caregiver to optimally provide a safe environment for the person with PD. Training caregivers in how to assist the person with PD to get up from a fall should be standard practice. If this is not possible, caregivers and persons with PD need to know alternative strategies (e.g. use of an emergency response system, carry a cell phone). Caregivers should have strategies that they can articulate and be proficient with. Caregivers can not be vigilant 24 hours a day and seven days a week, so respite care needs to be recommended and options discussed. Caregivers in my study reported that they had become accustomed to the person with

PD falling on a daily basis and the person with PD inconsistently using a walking aid.

Falling episodes on a daily basis are pathologic and should be discussed with proper health care professionals like a physical therapist or occupational therapist. Health care professionals need to carefully investigate falling episodes from both the perspective of the person with PD and the caregiver and discuss strategies to prevent serious injury and even death.

Seventh, caregivers and persons with PD are in relationships which can become potentially problematic as the PD progresses. Identification of stressors and protective factors (Goldsworthy & Knowles, 2008) could help persons with PD, caregivers and health care professionals with the balancing act seen in care-giving (Proot, et al., (2003). According to McRae, Sherry and Roper (1999), “stress is related to the family environment; therefore, the patient may be affected indirectly by the stress of the caregiver” (p. 72). With this in mind, the quality of life of both caregiver and the person with PD matters.

Recommendations for Future Research

As in all research, studies have their limitations. Being cognizant of the limitations in my study, I am able to make recommendations for future research in the area of care-giving. In interpretative qualitative research, the intent is not to generalize the results, but rather to take the findings and determine if they make sense given the data collected, context and timeframe. The goal is to learn if and how the particular experiences can be transferred to similar situations encountered later. My recommendations for future research are directed toward both enhancing the

transferability of the research findings and the ability to transfer these findings to a broader population.

First in regards to recruitment, my study recruited participants from only Midwestern States, I did not have a diverse participant group. The participants that volunteered for the study were all Caucasians. The majority of the caregivers were female. Although, I did not specifically ask about socioeconomic status, it appeared from the conversations that the caregivers were in the middle class or above. A future study would be helpful to target more socially and economically disadvantaged populations, as their experiences with care-giving could have some dissimilar features. Cultural, racial and ethnic differences may emphasize the family in a way not observed in my study. In terms of gender, I interviewed only two male caregivers which would be consistent with PD demographics (more men than women are diagnosed with PD). One male participant was care-giving for a spouse, and the other male participant was care-giving for a friend. Historically, most unpaid helpers or caregivers to the elderly are women. In a future study, targeting the specific experiences of male caregivers may add depth and breadth to the description.

Furthermore in terms of participant selection and recruitment, although my study did have inclusionary criteria which included family and friends, there was only one participant recruited who was not a spouse. It would be helpful to target caregivers who enter into care-giving relationships with a friend. The social, legal and economic impact of care-giving for a friend with a chronic illness may add further depth to understanding the experience. In addition, there were no adult children interviewed, although one spousal caregiver wanted me to interview her adult daughter to get her

perspective on care-giving. Unfortunately, the adult daughter did not volunteer to participate in my study.

In my study, the person with PD (care recipient) was not interviewed as was the case in the study by Hodgson, Garcia and Tyndall (2004). Their intent was to interview the couple unit so as to find out how couples view and manage the PD experience together. This certainly could be considered in a future study, although in my study four of the thirteen participants elected to be interviewed in a location other than their place of residence and preferred the care recipient not be present during the interviews. These caregivers may have felt it easier to more openly share their reflections on care-giving with the researcher if the care recipient was not in close proximity. In future studies, interviewing caregivers and persons with PD together and separate may provide a richer understanding of family dynamics in care-giving.

In addition, my study only recruited two participants who were care-giving for persons with early onset PD and one participant care-giving for a person in late stage PD. A future study targeting these specific groups may be worthwhile. In early onset PD, the care-giving period maybe potentially elongated, and in late stage PD, the physical demands of care-giving are likely to increase. In both situations, future research could enhance understanding of the dynamic nature of care-giving.

Second, I would like to recommend use of other research methods. Considering the thematic finding that care-giving is an unplanned journey occurring over time and in various contexts, research longitudinal in nature may be preferred. Bearing in mind the chronic nature of the PD, this could provide additional data on the caregivers' journeys over time versus at just one point in time as occurred in my study. For example,

caregivers felt ill prepared or lacked awareness of what was to come as the PD progressed. A longitudinal study addressing caregiver's life changes, coping strategies and educational needs may be prudent; although it would be time intensive and participant drop out would be a potential risk in such a design. Caregivers could be interviewed at set time points. A longitudinal approach has been recommended in the literature (Funk & Stajduhar, 2009). A possible study could be set up for caregivers to participate in an educational program at various stages of PD and then they are followed over time using either qualitative or quantitative methods or both.

A mixed method approach may also be of value in caregiver research. Funk and Stajduhar (2009, p. 865) suggested the following: "Observational research, with significant immersion in the field, combined with interviewing, might well be able to tell us more about how caregivers are coping than interviews alone." In addition, as the researcher spends more time in the field the potential for trusting relationships with participants can be established. They went on to suggest that interview and observation may be insufficient and that analytic strategies for data collection and analysis may allow for triangulation. A mixed method approach could permit triangulation of data allowing both the realities of experience to be recorded (positivist approach), as well as the meanings attributed to the experience (interpretative or constructivist approach) and thus provide a richer understanding of the phenomenon. Caregivers in my study shared their stories which included stressful and frustrating situations, as well as feelings of sadness and loneliness. Because of the nature of the design of my phenomenological study, I did not quantify specific caregiver stressors which could have been captured on a caregiver burden measurement instrument. Funk and Stajduhar noted that quantitative

measures alone may only provide “dichotomous assumptions about whether or not a caregiver is coping” (p. 865).

Lastly in terms of methods, a focus group method could be beneficial, allowing caregivers and persons with PD the opportunity to hear the experiences of others. Caregivers in my study discussed how they found involvement in their local support groups to be worthwhile and stimulating. A possible drawback to this design would be the turn taking aspect and ensuring that all participants had opportunity to share their experiences. Caregivers in my study reported the decreasing ability for the person with PD to communicate (e.g. slow and quiet) which would be an added challenge in a group interview.

Third, honing in on specific aspects of care-giving may be indicated. My study asked a broad open ended question about the experience of care-giving for a person with PD. Although touched upon in my study’s interviews, the areas of spirituality and sexuality in care-giving could be explored in more depth in a future study. Another aspect would be vigilance. In my study, caregivers were concerned and vigilant in respect to preventing the person with PD from falling. Considering the potential of death and serious morbidity associated with falls in the PD population, a future study specifically measuring caregiver participation in fall prevention which might include collecting data on how caregivers assist with transfers, getting the person up from the floor, getting the person with PD to adhere to exercise programs and be compliant with use of gait aids. Equally important would be investigating how physical therapists include the caregiver into patient education which could be done through a qualitative study using interview and clinical observation.

My Personal Reflection

I feel strong sense of gratitude to the caregivers who so willingly participated in my study. Their experiences touched my heart and certainly brought me closer to being a more competent empathetic person and physical therapist. The word *sisu* rings out the loudness to me after my research experience. It is a Finnish word that has been considered to lack proper translation in any language (“Sisu,” 2010, February 25; Strode, 1940). One of the caregivers in my study who was of Finnish ancestry used *sisu* in our interview sessions. In my mind, this word epitomizes what caregivers do on a daily basis. English translations for *sisu* include: strength of will, determination, perseverance, tenacity, resilience, acting rationally in the face of adversity and the ability to sustain an action against the odds (Stoller, 1996; “Sisu”). After completing my interviews and analyzing the narrative text, I believe that *sisu* is a part of the care-giving experience. Personally, I now wonder if I have the fortitude to provide the intense care-giving shown by the caregivers in my study. Their experiences have profoundly touched my heart, and I certainly continue to wonder how each participant is doing on their unplanned care-giving journeys.

I had no idea that when I met with these caregivers that I would be opening a floodgate of experiences and emotions for many of them. They all were so eager to tell me what it was like to care for a person with Parkinson’s disease with. I was particularly amazed at how open the participants were to me as a stranger. Lowes and Gill reported that there may be therapeutic benefits for caregivers in talking about their experiences (as cited in Funk & Stajduhar, 2009). This has also been referred to as an emotion-focused coping strategy. Funk and Stajduhar also reported that:

Interviews are believed to provide opportunity for and facilitate validation, introspection and growth, self-acknowledgement and self discovery, a sense of purpose, empowerment, healing, unburdening and catharsis, a sense of helping others, and a means to make sense of experiences through speaking about them and refining thoughts through the interview. (as cited in Funk & Stajduhar, 2009).

I hope the caregivers benefited in some way from telling their stories knowing that their contributions added to the knowledge about care-giving. In the future, my goal would be to take my results back to PD support groups to share these themes with other caregivers.

As an educator of physical therapists, I plan to further integrate my understanding of care-giving for persons with neurological disorders into my teaching materials and plans. I gained insight into the many facets of informal care-giving. The hardships, struggles, pleasures and dreams of these caregivers took shape for me. I realize how important their stories are for other caregivers and health care providers. As a health professional, I have been taught that the patient comes first in clinical care. Unfortunately, in western health care, the individual patient may be seen as the entity for care thus leaving the informal caregiver and family marginalized. Patient education may not necessarily mean caregiver education. It is my hope that others who read the experiences and stories will appreciate and gain increased awareness of the physical, mental, social, emotional and spiritual dimensions of care-giving within the context of PD. In addition, I would hope that health care providers would consider the themes which emerged from my study as they work with patients with PD and their families. By being more acutely aware of the daily lives of caregivers, hopefully health professionals, like physical therapists, can be better prepared to plan and implement

care and education that addresses not only the person with PD but the caregiver and family as well. I feel strongly that in order to better service our clients we need to be active listeners as well as participatory team players.

Taking time to consider theory also seems valuable for it can guide our actions and hypotheses. I would recommend that health care providers take a holistic approach to the care of persons with chronic illness. Persons with PD and their caregivers are adult learners who gain knowledge in multiple ways (e.g. implicit, explicit and emancipatory). As a physical therapist, I can teach a caregiver to do a basic transfer with the person with PD, basically a psychomotor task, but I can also empower them to nourish and care for their own health and wellness by recommending and helping the caregiver locate necessary resources like respite care.

Considering our aging population, the need for competent caregivers will likely escalate. Resources for caregivers need to be accessible and understandable. With the use of technology like the internet, caregivers have greater access to information and organizations that support PD and caregivers in general. Unfortunately, with the plethora of information that can be found, caregivers are put into the situation to sort through what is appropriate for their family's situation. I think health care professionals are in an excellent position to help persons with PD and their caregivers select appropriate interventions which are based off sound research. Selecting evidenced based interventions should help promote the quality of life for the person with PD and the caregiver. In my mind, there is benefit to providing ongoing patient and caregiver

follow-up over the duration of the disease, hopefully maximizing patient function and reducing caregiver burden and stress.

Living with a chronic illness and caring for a person with a chronic illness like PD was described as a journey. Does that journey need to be filled with unknown perils, wrong turns, frustration, and hardship? It takes more than just providing medication and surgical intervention to manage PD. Rehabilitation specialists, nurse educators, social workers, and family therapists need to be an integral part of the team. I feel health professionals are in a privileged position to provide support, education, and hope as persons with PD and their caregivers continue their journey with a chronic disease. In service to our communities, health care professionals can be participatory and available to local PD support groups and caregiver groups.

Lastly, by understanding the experiences of caregivers, I believe health care professionals can be better advocates and supporters of policies and legislation that could potentially strengthen families and caregivers. Strong health care policy and legislation is needed to support caregivers and care recipients in their homes through implementation of reimbursement for respite services, home modifications, adaptive equipment, and therapy services. Best practice guidelines for the education and training of both informal and formal caregivers of persons with PD should be established and embedded in curriculum. For health care provider professional programs (e.g. physical therapy, nursing, medicine), this would mean accrediting agencies should use clearly defined and recognized accreditation criteria which address the educational and training needs of both the person with PD, as well as the caregiver or care-partner.

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Appendix A

Pathophysiology of PD

It has been established that PD results primarily from the death of dopaminergic neurons in the substantia nigra of the midbrain (Dauer & Przedborski, 2003). The substantia nigra is one of a collection of interconnected gray matter (primarily cell bodies) nuclear masses deep within the brain (O'Sullivan & Schmitz, 2007). At present, there are PD dopaminergic medications (e.g. Sinemet or levodopa) that treat symptoms but can not arrest the neuronal degeneration, and unfortunately after several years of treatment, most patients develop involuntary movements, known as dyskinesias. In addition, with symptomatic therapy over time, approximately 50% of patients treated for more than two years develop disabling on-off phenomenon, in other words random fluctuations in motor performance (O'Sullivan & Schmitz, 2007). Both dyskinesias and the on-off phenomenon can contribute to postural and balance disturbance leading to falls. Evidence suggests that most falls occur when patients were in their best clinical condition (known as "on" state when medications are effective) possibly because they have regained their ability to move and function in their environments (Bloem, Hausdorff, Visser, & Giladi, 2004).

PD is diagnostically under the broader umbrella term referred to as Parkinsonian Syndromes which includes any disease that has striatal dopamine deficiency leading to tremor at rest, rigidity, slowness or absence of voluntary movement, postural instability and freezing (Dauer & Przedborski, 2003). Typically tremor is the chief complaint in the early stages of PD, but as the disease progresses, patients and caregiver report problems with balance and falls which are not alleviated with medication (Bloem,

Hausdorff, Visser, & Giladi, 2004). Bloem and colleagues suggest that gait and balance problems may occur because of lesions within non-dopaminergic nuclei since these problems are resistance to dopaminergic treatment.

PD is the second most common age-related neurodegenerative disease after Alzheimer's disease (Dauer & Przedborski, 2003). Within the last fifteen years researchers have learned more about the degenerative process through studies of neurotoxins (e.g. 1-methyl-4-phenyl-1,2,3,6-tetrahydropyridine better known as MPTP) and gene mutations (e.g. α -synuclein). As the disease progresses and pharmacological management become less effective, surgical management including ablative surgery, deep brain stimulation and neural transplantation become possible medical strategies (JAMA Patient Page, 2004).

In terms of clinical presentation, the stages of PD were described by Hoehn and Yahr (1967) and are widely used in clinical practice and research. In the management of PD, Morris (2006) recommends clinical decision making being based on research findings, the disease progression (stages), medication status, environmental conditions, individual factors and the goals of the patient and caregiver. She suggests using the World Health Organization's (WHO) International Classification of Functioning, Disability and Health (ICF). According to the WHO (2009) the ICF is a classification of health and health-related domains.

It acknowledges that every human being can experience a decrement in health and thereby experience some degree of disability. Disability is not something that only happens to a minority of humanity. The ICF thus

‘mainstreams’ the experience of disability and recognizes it as a universal human experience. By shifting the focus from cause to impact it places all health conditions on a equal footing allowing them to be compared using a common metric—the ruler of health and disability. Furthermore ICF takes in to account the social aspects of disability and does not see disability only as a ‘medical’ or ‘biological’ dysfunction. By including contextual factors, in which environmental factors are listed, ICF allows to record the impact of the environment on the person’s functioning.

The cardinal features or clinical hallmarks of PD include rigidity (heaviness or stiffness of their limbs), bradykinesia (slow or absent voluntary movement), tremor (involuntary oscillation of a body part) and postural instability (abnormalities in posture and balance) (Gelb, Oliver, & Gilman, 1999; Olanow, Watts, & Koller, 2001; O’Sullivan & Schmitz, 2007). Postural instability is associated with posture deficits like kyphosis or stooped posture (Bloem, Beckley, & van Dijk, 1999; Horak, Nutt, & Nashner, 1992) and gait disturbances (Schaafsma, et al., 2003) which may include falls, freezing episodes (motor blocks), turning en-bloc (a mass or whole), start hesitations, and festinating gait (progressive increase in gait speed with shortening of stride). Festination may be forward (anteropulsive) or backward (retropulsive). Motor control, motor planning, and motor learning are compromised in the disease process.

As patients lose motor function, develop rigidity or ligamentous strain, they may suffer from postural stress syndrome with associated pain and discomfort which can impact their fall risk. The psychological construct of fear of falling (FOF) has become entwined with fall risk factors (Adkins, Frank, & Jog 2003; Friedman, Munoz, West, Rubin, & Fried, 2002; Howland, et al., 1993; Legters, 2002; Maki, 1997; Zijlstra, et al., 2007). Patients also self-report physical and mental fatigue (Brown, Dittner, Findley, & Wessely, 2005). Loss of cognitive function which occurs in 20 to 40 percent of patient may present with dementia, visuospatial deficits, depression, dysphoric mood and bradyphrenia, in other words, a slowing of thought and information processing, (McKeith, 2002; O'Sullivan & Schmitz, 2007). Autonomic dysfunction (e.g. urinary bladder dysfunction) and cardiopulmonary dysfunction (e.g. low resting blood pressure also referred to as orthostatic hypotension and inadequate vascular response to exercise) contribute to falling risk factors in PD (Dennison et al., 2007). The importance of patient and caregiver education regarding these clinical features is recognized by physicians ("JAMA Patient page", 2004), other health care providers and layperson organizations like the National Parkinson Foundation (NPF), Parkinson's Disease Foundation (PDF) and the American Parkinson Disease Association (APDA) (Barker, Grant, & Hodnicki, 1998).

Appendix B

From: IRBe [irbe@mayo.edu]
Sent: Friday, May 16, 2008 9:36 AM
To: Bogard, Connie L.
Subject: A Protocol has been Approved by IRB

Principal Investigator Notification:

From: IRB
To: [Connie Bogard](#)
CC: Study Team Members that are marked as wishing to receive correspondence regarding the protocol/grant application
Re: Application # 08-002667
[08-002667](#)

Please Note: Effective immediately, communications for IRB decisions will be in a new format. This change is a result of recent standardization measures occurring in the IRB. If you have questions, please contact the IRB Service Center at (77) 64000.

Title: A Phenomenological Investigation: The Meaning of Caring in Parkinson's Disease from the Lifeworld Perspective of the Informal Caregiver

IRB#: 08-002667

Please note that all correspondence (modifications, continuing reviews, reportable events) related to this study/grant application must be submitted electronically in the IRBe system.

The following is an excerpt from the minutes of the Expedited Review B of the Mayo Clinic Institutional Review Boards meeting dated 5/13/2008:

The Committee reviewed and approves the above-referenced study. This approval is valid for exactly one year unless during the year the IRB determines that it is appropriate to halt or suspend the study earlier. The Committee notes that the human studies activities involve interviews with unpaid caregivers of individuals with Parkinson's Disease. A maximum of 20 healthy adults is approved for enrollment in this study at Mayo Clinic Rochester. The Committee notes that the subjects may or may not be Mayo Clinic patients. The contact letter and telephone script are approved as written. The consent form is approved with revisions. The IRB office will provide the final approved consent form on the IRBe workspace for this item. As protected health information is not being requested from participants, HIPAA authorization is not required for this protocol, in accordance with 45 CFR 160.103. The Committee reminds the investigator to contact the CTSA Service Center (formerly CPOR) at (77)5-7101 for communications review and approval prior to posting all advertisements for use in the study. The Committee notes \$30 remuneration will be provided to

participants who successfully complete study interventions, and determines that this is acceptable. The Committee notes approval is also being sought by the University of Minnesota IRB. The Committee notes approval from the PMR Research Committee, dated April 14, 2008. The Committee determines that this constitutes minimal risk research, and therefore is eligible for expedited review in accordance with 45 CFR 46.110 item 7. The Committee determines this research satisfies the requirements of 45 CFR 46.111.

[Pearson, Randall K. M.D., Chair](#)
[Elizabeth Dunn](#) , Specialist
Mayo Clinic Institutional Review Boards

Expedited Review B

Appendix C

From: irb@umn.edu
Sent: Thursday, May 22, 2008 3:37 PM
To: boga0036@umn.edu
Subject: final approval letter
05/22/2008

Connie L Bogard
9718 55th Ave N W
Oronoco, MN 55960

RE: "A Phenomenological Investigation-The Meaning of Caring in Parkinson's Disease from the Lifeworld Perspective of the Informal Caregiver"
IRB Code Number: 0803P28523

Dear Ms. Bogard

The Institutional Review Board (IRB) received your response to its stipulations. Since this information satisfies the federal criteria for approval at 45CFR46.111 and the requirements set by the IRB, final approval for the project is noted in our files. Upon receipt of this letter, you may begin your research.

IRB approval of this study includes the consent form dated May 13, 2008 and recruitment materials received May 19, 2008.

The IRB would like to stress that subjects who go through the consent process are considered enrolled participants and are counted toward the total number of subjects, even if they have no further participation in the study. Please keep this in mind when calculating the number of subjects you request. This study is currently approved for 20 subjects. If you desire an increase in the number of approved subjects, you will need to make a formal request to the IRB.

For your records and for grant certification purposes, the approval date for the referenced project is April 4, 2008 and the Assurance of Compliance number is FWA00000312 (Fairview Health Systems Research FWA00000325, Gillette Children's Specialty Healthcare FWA00004003). Research projects are subject to continuing review and renewal; approval will expire one year from that date. You will receive a report form two months before the expiration date. If you would like us to send

certification of approval to a funding agency, please tell us the name and address of your contact person at the agency.

As Principal Investigator of this project, you are required by federal regulations to inform the IRB of any proposed changes in your research that will affect human subjects. Changes should not be initiated until written IRB approval is received.

Unanticipated problems or serious unexpected adverse events should be reported to the IRB as they occur.

The IRB wishes you success with this research. If you have questions, please call the IRB office at 612-626-5654.

Sincerely,

Felicia Mroczkowski, CIP

Research Compliance Supervisor

FM/egk

CC: Shari Peterson

Appendix D



Name

Mayo Clinic IRB #08-002667 00 University of Minnesota IRB #0803P28523 Consent form approved April 6, 2009; This consent valid through April 5, 2010;

1. General Information About This Research Study

Study Title: A Phenomenological Investigation-The Meaning of Caring in Parkinson's Disease from the Lifeworld Perspective of the Informal Caregiver

Name of Principal Investigator on This Study: Connie L. Bogard, M.Ed., P.T. (Ph.D. Candidate at the University of Minnesota and a physical therapist at Mayo Clinic in Rochester Minnesota within the department of Physical Medicine & Rehabilitation)

A. Study Eligibility and Purpose

You are being asked to take part in this research study because you have experienced caring for a person with Parkinson's Disease (PD). You were selected as a possible participant because you responded to a local advertisement calling for volunteers and you have experience caring for a person who has been diagnosed with PD. You also reside with this person and provide unpaid caregiving.

The purpose of this study is to discover what it is like to provide caring and support for a family member or significant other with PD during the caregiver's day to day experiences and interactions with that individual.

As you read this form describing the study, ask any questions you have. Take your time to decide. Feel free to discuss the study with your family, friends, and healthcare provider before you decide. You may stop participating at any time during the study. You may decide not to participate. If so, none of your current benefits or normal health care will be affected in any way. When you feel comfortable that all your questions have been answered, and you wish to take part in this study, sign this form in order to begin your participation. Your signature means you have been told about the study and what the risks are. Your signature on this form also means that you want to take part in this study.

B. Number of Participants

The plan is to have 10 to 20 people take part in this study at Mayo Clinic.

2. What Will Happen To You While You Are In This Research Study? (Procedures)

If you agree to be in the study, you will be asked to participate in the following:

1) Once you have reviewed and signed the consent form at the first meeting/session (in a quiet location of your selection), the researcher will be asking you some interview questions about your caregiving experience. The interview will take approximately one hour and will be audiorecorded. The audio tapes will be transcribed by the researcher or a paid transcriptionist. An additional interview session will only be scheduled upon your request to the researcher.

2) The final (second) meeting will be a feedback session lasting approximately one hour. The researcher will share a narrative summary of your interview with you to get your input. This will allow you to receive and provide feedback on your individual interview. You will be able to share with the researcher if the findings make sense and are reasonable given the information you provided in your interview. The location of this meeting can be at your place of residence or if you wish, at an alternative agreed upon quiet location convenient for you and the researcher.

3. How Long Will You Be in This Research Study?

You will be in the study for approximately 3-4 months to complete two meetings with the researcher.

4. Why You Might Want To Take Part In This Research Study (Benefits of being in study)?

This study will not make your health better. It is for the benefit of research.

A benefit to participation is you might like to talk about your experiences.



By better understanding your experience of caring for a person with Parkinson's Disease you may recognize strategies that may enhance your caregiving knowledge, skills and attitudes.

5. What Are the Risks Of This Research Study?

The risks of this research study are minimal, which means that we do not believe that they will be any different than what you experience during your daily life.

Some questions you will be asked to answer in the study interview may make you feel uncomfortable, sad or bad. You may choose not to answer any questions that are uncomfortable to you.

Your experience will be re-interpreted by the researcher, this may cause you concern. In order to minimize this risk, a final (second) meeting will be scheduled to allow feedback between you and the researcher on the narrative summary from your interview which occurs at the first session.

There is the risk that you and third parties (your spouse, family members) will be identified in verbatim narratives (your own words) found in publicly accessible documents such as the researcher's dissertation or published article. In order to minimize this risk and protect anonymity for the participant and third parties, the researcher will use pseudonyms (fictitious name), alter names of places and demographic characteristics of both the participant and third parties.

6. What Other Choices Do You Have If You Don't Take Part In This Research Study?

This study is only being done to gather information. You may choose not to take part in this study.

7. Are There Reasons You Might Leave This Research Study Early?

Taking part in this research study is your decision. You may decide to stop at any time. You should tell the researcher if you decide to stop.



In addition, the researcher in conjunction with the University of Minnesota and Mayo may stop you from taking part in this study at any time:

- if it is in your best interest,
- if you do not follow the study rules,
- if the study is stopped.

8. Will You Need To Pay For Any Of The Tests And Procedures?

You will not need to pay for procedures which are done just for this research study. These procedures are:

-participating in two interview sessions with the researcher.

9. Will You Be Paid For Participating In This Research Study?

If you finish the study, you will receive \$30.00. This money is for the time you spend in this study. If you start the study but stop before finishing the study, you will receive part of this money.

10. What Happens If You Are Injured Or Ill Because You Were In This Research Study?

If you have side effects from taking part in this study, you need to report them to the researcher and your regular physician, and you will be treated as needed. Mayo will give medical services for treatment for any bad side effects from taking part in this study. Such services will be free if not covered by a health plan or insurance. No additional money will be offered.



11. What Are Your Rights If You Are In This Research Study?

Taking part in this research study will not change your rights and benefits. Taking part in this research study does not give you any special privileges. If you decide to not participate in this study, or stop in the middle of the study, no benefits are taken away from you. Specifically, you do not have to be in this research study to receive or continue to receive medical care from Mayo Clinic.

You will be told of important new findings or any changes in the study or procedures that may affect you or your willingness to continue in the study.

12. What About Your Privacy?

The records of this study will be kept private and stored in a locked cabinet, only the researcher will have access to the records. This research is intended to be published as the researcher's dissertation. In the researcher's dissertation, she will not include any information that will make it possible to identify a subject or another person. The researcher may receive help from a professional transcriptionist for transcribing of the interview. That person will be instructed to keep the information confidential and your name will be erased from the audiotape prior to transcription. As soon as the tape has been transcribed, the tape will be erased following completion of the study. The research data (transcribed narratives) and consent forms will be retained by the researcher for seven years after results have been published for her dissertation in order to address any ethical concern or scholarly review that may potentially arise following publication.

13. What Will Happen to Your Samples?

No biological samples will be collected as part of this research study.



14. Who Can Answer Your Questions?

The researcher conducting this interview is: [Connie L. Bogard, M.Ed., P.T.](#)

If you have questions later, you may contact the researcher at the following address:
Mayo Clinic, Mayo School Of Health Sciences, 200 First Street SW, Rochester, MN
55905. (507) 282-8488. Email-bogard.connie@mayo.edu

The researcher's advisor is: Shari L. Peterson, College of Education and Human
Development, University of Minnesota, 1954 Buford Ave. #420F VoTech Education
Building, St. Paul, MN 55126. Phone-612-624-4980. Email-peter007@umn.edu

If you have any questions or concerns regarding this study and would like to talk to
someone other than the researcher or her advisor, you are encouraged to contact the
University of Minnesota Institutional Review Board (IRB) and the Mayo Clinic IRB.
The IRBs review human research studies. They protect the rights and welfare of the
people taking part in those studies.

- Research Subjects' Advocate Line, University of Minnesota Medical Center, Fairview Riverside Campus, 2200 Riverside Avenue, Minneapolis, MN 55454; telephone (612) 625-1650.
- Mayo Clinic Institutional Review Board, 200 SW 1st Street, Rochester, MN 55905; IRB Administrator Marcia Andresen-Reid or Research Study Advocate Shari Brumm at telephone (507) 266-4000; toll free 866-273-4681.



15. Summary and Enrollment Signatures

You have been asked to take part in a research study, at Mayo Clinic. The information about this study has been provided to you to inform you about the nature of this IRB approved study.

- I have read the whole consent form, and all of my questions have been answered to my satisfaction.
- I know that joining the study is voluntary and I agree to join the study.
- I know enough about the purpose, methods, risks, and possible benefits of the study to decide that I want to join.
- I know that I can call the investigator and research staff at any time with any new questions or to tell them about side effects.
- I will be given a copy of this completed form.
- I may withdraw from the study at any time.

Please sign and date to show that you have read all of the above guidelines. Please do not sign unless you have read this entire consent form. If you do not want to sign, you don't have to, but if you don't you cannot participate in this research study.

(Date / Time)

(Printed Name of Participant)

(Signature of Participant)

(Date / Time)

(Printed Name of Individual Obtaining Consent)

(Signature of Individual Obtaining Consent)

Appendix E

Recruitment Advertisement

Mayo Clinic and the University of Minnesota are seeking men and women volunteers to participate in a research study on caring for a person with Parkinson's disease.

Participants need to be healthy adults who reside with and provide care for a person with Parkinson's disease. Participants should be informal caregivers including spouses, significant others, friends, and relatives who do not receive payment for care-giving.

Study enrollment involves participating in two scheduled meetings with the researcher, one to review the study and consent form, sign the consent form, and then complete an audio-taped interview lasting approximately one hour. The second meeting will be a feedback session to review a summary of your interview from the first session. Other eligibility criteria may apply. Remuneration will be offered to participants. For more information contact Connie Bogard, M.Ed., P.T. (Ph.D. candidate) at 507-284-8488 (work); email bogard.connie@mayo.edu

Locations to be utilized for posting advertisement or distribution of advertisement pending approval by Mayo Communications and Institutional Review Boards.

- *Mayo Clinic Classified "Volunteers Sought" section-available electronically and in hard copy*
- *"Volunteers Sought" posting distributed throughout Mayo Clinic campuses (typically near elevators).*
- *Posted at local senior citizens centers, senior high rises, libraries and churches*
- *Distributed to Rochester Parkinson's Support Group*

Appendix F

Telephone Script

(Response to be given to prospective participants by the researcher when they contact the researcher after reading advertisement).

“Thank you for your interest in this research study. As a physical therapist and instructor in the Mayo Program in Physical Therapy at the Mayo Clinic in Rochester, Minnesota, and as a graduate student at the University of Minnesota, I am interested in the phenomenon of caring. This research is being completed as part of my Ph.D. requirements. This study is designed to explore the experience of caring for a person with Parkinson's Disease. Caring for a person with Parkinson's disease is a unique experience. This study is recruiting participants who reside with and provide physical, psychosocial, emotional or economic support for a person with Parkinson's Disease. To participate, you must have no health problems which you feel would limit your ability to complete the interview sessions. If you agree to enroll in this study, you will be participating in two sessions. The first session will be to review the purpose of the study, review the consent form and to provide you with a brief overview of my background as a physical therapist and my interest in Parkinson's Disease and caregiving. Upon obtaining your written consent, we will proceed with an interview. I will be asking you some questions about caregiving. The interview will last approximately one hour and will be audiotaped. The final (second) meeting will be a feedback session for me to share a narrative summary of your interview and get your input. An additional interview session could be scheduled upon your request. If you would like to enroll in this study, we can arrange for the first meeting. The meeting can occur in your home or in a quiet agreed upon alternative location of your choice. I will

send you a letter confirming the date, time and location of the meeting. If you wish a few days to consider, I will call you back within one week. If you remain interested and would like to enroll, then the first meeting will be arranged as described previously. You can withdraw from the study at any time. Do you have any questions? If you have additional questions in the next week, please feel free to contact me (Connie Bogard) at my work number (507) 284-8488 and I will try to answer these for you. If you wish, I can review the consent form now or mail you a copy to read. Again if you decide to enroll, we will be reviewing the consent process at the first meeting. Your written consent will be necessary prior to beginning interviewing. You will receive a copy of the consent form for your files. Thank you for your interest in this study."

Appendix G

Contact Letter or Email for Application 08-002667

Date _____

Name _____

Address _____

Dear Interested Research Participant,

Thank you for your interest in participating in this study on caring for an individual with Parkinson's Disease. I wanted to send you this confirmation letter which would hopefully clarify any points that might have been unclear in our initial phone contact. Enrollment in the study will require reviewing and signing the consent form and participating in two meetings/sessions which will each be approximately one hour in length.

1. The first meeting will be to review the purpose of the study, provide information on the researcher's background in the area of Parkinson's Disease, review the consent form and sign the consent form. The location will be arranged in your home or a quiet location convenient for you. Upon signing the consent, you will then complete an interview related to the experience of caring for an individual with PD. The interview will take approximately one hour. An additional interview will be scheduled only upon your request.
2. The final (second) meeting will be a feedback session which will take 1 hour, again arranged in a quiet location convenient for you.

I will plan to be at the arranged meeting location at **[address]** on **[date and time]**. If for some reason between now and then you choose not to participate, you can

certainly call me and withdraw. My phone number at Mayo Clinic is **(507) 284-8488**. I have an answering machine at my work number so you can leave a message if I am away from the phone.

In addition, following the tape-recorded interview, the interview will be transcribed by the researcher or a trained transcriptionist and then analyzed for important themes. Your anonymity (no use of your name) will be protected throughout this project which will be part of my dissertation for graduate work at the University of Minnesota. This study will be published as my dissertation. This project has been approved by the University of Minnesota Institutional Review Board (IRB) and the Mayo Clinic College of Medicine IRB. If you would like a copy of my transcription of the interview please let me know.

Just as a reminder, the topic of my study is related to what it is like to care for an individual with Parkinson's Disease. If you could think of specific examples related to the person you care for and your caregiver education experience that you can share with me during the interview that would be fantastic. I am so looking forward to the opportunity to meet with you. Thank you again. If you have any questions, do not hesitate to call.

Sincerely yours,

Connie Bogard, M.Ed., P.T.
Assistant Professor Mayo Program in Physical Therapy
Mayo Clinic College of Medicine

Appendix I

Interview Protocol Form

Project: A Phenomenological Investigation-The Meaning of Caring in Parkinson's Disease from the Lifeworld Perspective Of the Informal Caregiver

- Briefly describe project Obtain and/or verify signed consent process
- Provide participant a copy of the signed consent form and retain the original.

Time Interview Began _____ Time Interview
Ended _____

Total Interview time _____

- Provide participant with note cards with questions written for them to read.

Questions

- 1) What is it like to care for a person with PD?
- 2) Can you tell me about a specific caring event or situation which occurred?
- 3) Record additional probes:

Provide participant with business card in case he/she would like to contact the researcher in the future. Thank participant and ensure him or her confidentiality of responses

- Attach this form to Contact Summary Sheet

Appendix J

Field Notes Data Form following interview in the home**(Adapted from Creswell, 1998)**

Descriptive Notes for IC#	Reflective Notes
Location of interview with the caregiver within home and location of person with PD, if present within the home at time of interview.	
Physical barriers to caregiving (lack of appropriate equipment and/or adaptive equipment)	
Sketch of home layout showing environmental barriers	
Aspects that facilitate caregiving (i.e., Lifeline, monitors, equipment, home on one level)	

Appendix L

Health Care Resources in Rochester Minnesota Area

Mayo Clinic, Rochester Minnesota (507) 284-2511

Mayo Clinic Department of Psychiatry and Psychology (507) 266-5100

Olmsted County Public Health Services (507)-328-7500

Olmsted Medical Center Main Clinic, Rochester Minnesota (507) 288-3443

Olmsted Medical Center Hospital, Rochester Minnesota (507) 529-6600