

UNDERSTANDING CAREGIVERS' DECISION PROCESS WHEN CHOOSING
TO INSTITUTIONALIZE A RELATIVE WITH PARKINSON'S DISEASE

By

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To my husband, John

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Abstract of Dissertation Presented to the Graduate School
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Parkinson's disease is a degenerative neurological disease that affects millions. Treatment priorities focus on delaying its progression and resulting disability and helping persons with Parkinson's disease (PWP) continue to live at home as long as possible. This often requires long-term assistance by family caregivers. The purpose of the study was to better understand how family caregivers make the decision to institutionalize a relative with Parkinson's disease and which factors influence this decision. The study also sought to discover what caregivers needed to help them better manage the care of PWP at home. Twenty interviews were conducted with caregivers in this grounded theory study. Interview questions focused on the nature of caregiving experiences and caregiving decision making. Data were coded and analyzed using dimensional analysis.

A conceptual model of caregiving was developed from the data which illustrated that an increase in the magnitude of caregiving load in relation to the increasing severity of the illness over time results in increasing strain which is a risk factor of institutionalization. The combined components of this model influenced how and when a decision was made about institutionalization. Thus, it was important to understand the

process in order to better understand how this decision was made. The findings identified factors, such as a risk of safety to caregivers and PWPs, falls with severe injury, the inability to manage a change in health status, and depleted support, to influence institutionalization. Findings also identified a multifaceted support network helped caregivers better manage care of PWPs at home.

Implications from this research can lead to better communication between health care providers and caregivers, formalized caregiver assessments, improved care coordination with anticipatory guidance and family centered interventions that delay premature institutionalization of PWPs. Furthermore, the model developed from this research can support existing models or inform the development of future models that reflect the experiences of those caring for persons with other chronic conditions. The findings from this research are a crucial addition to the body of health care literature since there are no existing studies that explore the process of long term care placement for PWPs.

CHAPTER 1 INTRODUCTION

Background

Parkinson's disease (PD) is a degenerative neurological disease that affects 1.5 million people in the U.S., with 60,000 new cases diagnosed each year (National Parkinson Foundation, 2007). The actual number of these cases is probably much higher because initial symptoms often go unnoticed and physicians are not mandated to report new cases. PD affects men and women alike; however, it has a higher lifetime risk in men (2%) compared to women (1.3%) (Liebson et al., 2006). The average onset is 60 years old, with only 15% of cases affecting people who are under 50 years old (Shagam, 2008). Thus, this condition is more common in older adults which are a group that is expected to be 20% of the population in the United States in 2030. Moreover, this group is expected to increase to 88.5 million in 2050; more than doubling from 38.7 million in 2008 (Bernstein & Edwards, 2008).

The Face of Parkinson's Disease

No one knows the exact etiology of PD but researchers believe that a combination of genetics and exposure to environmental toxins such as pesticides, illicit drugs and infectious agents may be the cause of the majority of cases (Shagam, 2008). The effects of this illness can be debilitating, especially as dopamine, which is a central nervous system (CNS) neurotransmitter that controls motion and balance, diminishes in the body (Ozuna, 2000). PD brings a degeneration of the dopaminergic nigrostriatal pathway, which has neurons in the substantia nigra that project to areas of the basal ganglia in the brain. Damage or loss of the dopamine producing cells in the substantia nigra leads to dopamine depletion in the basal ganglia (Boss, 2002; Ozuna, 2000; Ganong, 2005).

In general, dopamine concentration diminishes with age; however, there is an acceleration of this loss in persons with PD (PWP). The onset of PD symptoms usually occurs where there is a 60 to 80% loss of dopamine producing cells in the substantia nigra (Ganong, 2005). The onset is often insidious, beginning with slight tremors or twitches. As Michael J. Fox remarked,

It (pinkie finger) was trembling, twitching, auto-animated. How long this had been going on, I wasn't exactly sure. But now that I noticed it, I was surprised to discover I couldn't stop it. Unbeknownst to me, things had been deteriorating long before the morning of the pinkie rebellion. But by declaring its dysfunction in such an arresting fashion, my brain now had my mind's full attention (Fox, 2002, p. 3-4).

The tremor associated with PD is a resting tremor because it occurs when the limb or body part is not moving. These tremors may be worsened by stress. Another sign of the disease is rigidity and this often affects the muscles in the arms and legs (Ozuna, 2000; Lieberman, 2003). This rigidity or stiffness can cause muscle soreness due to sustained muscle contraction even when the person is at rest. Usually this stiffness affects the same side of the body as the tremor; yet, in time there is often bilateral involvement.

The third classic symptom of PD is bradykinesia, or slowness of movement, which is a result of alterations in the basal ganglia and related structures in the extrapyramidal portion of the central nervous system (CNS). These autonomic spontaneous movements, such as blinking of the eye, swinging the arms while walking, swallowing of saliva, facial expressions, hand gesticulation, and other minor spontaneous movements are diminished in the PWP. In the later stages of the disease, PWPs develop a stooped posture, shuffling gait and a masked expressionless face. They also have an excess of saliva due to infrequent or inefficient swallowing which results in drooling, a condition

that is more common in men than in women (McNamara, 2009; Tuite, Thomas, Rueker & Fernandez, 2009). Eventually PWP's have difficulty initiating movement such as getting up out of a chair (freezing) or completing a movement such as the failure to blink their eyes (Ozuna, 2000). In time, complications such as difficulty swallowing and possible aspiration pneumonia occur along with urinary tract infections and skin ulcerations.

Nonmotor symptoms are also common in PD, and they are infrequently recognized or treated poorly in clinical practice (Weintraub, Comella, & Horn, 2008). For example, depression is common among these individuals, and it may be situational or endogenous which is related to the chemical imbalance of PD (Lieberman, 2003). Apathy (i.e. indifference, lack of motivation) is also a symptom of this chronic illness. Researchers have discovered that apathy may be a core feature of PD irrespective of depression (Dujardin et al., 2007).

It (apathy) is a characteristic of this disorder and likely a direct result of disease pathology. Thus, apathetic behavior is not under the PD patient's voluntary control and is not oppositional behavior or laziness, but a symptom of PD (Kirsch-Darrow, Fernandez, Marsiske, Okun, & Bowers, 2006, p.37).

PWP's often have other cognitive impairments as evidenced by difficulties with executive function, memory retrieval difficulties, problems with visuospatial abilities and attention deficits. This is often accompanied by hyposmia and anosmia (reduced ability to smell odors and a loss of smell) (Weintraub et al., 2008). Eventually PWP's can develop dementia and visual hallucinations (Mosimann & McKeith, 2003; Tuite et al., 2009). Moreover, each person's experience with PD is unique because clinical presentation and progression varies among persons, and these symptoms can go unrecognized for years (Weintraub et al., 2008). Families (i.e. informal caregivers) may

not always be aware of these complex symptoms especially the cognitive effects, and could be caught unaware when they occur. Therefore, it is critical to provide family centered care which focuses on the health and welfare of an entire family, and implements interventions that are needed for the whole family as well as each of its members (Shelton, Jeppesen, & Johnson, 1987). Thus a focus on family centered care for optimal disease management can foster the continuance of care for PWWs at home (Gage & Storey, 2004; Robison, Fortinsky, Kleppinger, Shugrue & Porter, 2009).

Family Caregiving

In the United States there are more than 44 million informal family caregivers (CGs) providing help to persons who have limitations with activities of daily living which include PWWs. The importance of these CGs must be acknowledged especially since the value of their care is greater than \$350 billion annually (Administration on Aging, 2008; Levine, 2008). Unfortunately, the challenges of caregiving have increased over the years due to persons living longer with disabling chronic conditions. Although the effectiveness of medical care has increased, the burden of more intense care giving has shifted toward unpaid care providers such as family CGs (O'Brien & Elias, 2004).

In general, family CGs are usually spouses, adult children, and other relatives. They are 63 years old on average and usually assume the major care responsibilities but may or may not live with the care recipient (CR). If a spouse is unavailable to provide care, another family member, often a daughter or daughter-in-law, may assume the CG role (Administration on Aging, 2008; National Alliance for Caregiving, 2004). Stephens and colleagues (2001) found that 95% of adult daughter CGs had many roles in their lives; however, the biggest role stressor was caring for an older adult parent.

Pinquart and Sorensen (2003) identified CGs to have significantly higher rates of depression and stress than those who are not CGs. Not surprisingly, those who care for PWPs experience similar degrees of psychosocial burden as those caring for persons with stroke and dementia (Thommessen et al., 2002).

Caregiving can bring a major change in anyone's lifestyle. CGs often need to be available 24 hours a day, being always watchful, organized and needing to be knowledgeable about the CR's illness. They also need to be patient and compassionate toward the CR's changing condition. The inner strength and determination to balance these many responsibilities can be very daunting (Parkinson's Disease Caregiver Information, 2010). An example of caring for someone with PD is described in the following quote.

For the caregiver, Parkinson's is more than a list of symptoms and drug side effects. It is being vigilant at all times for the sounds of distress- a weak voice calling for help, the sound of a person falling, coughing or choking, something being dropped. It is washing every item of clothing worn by the person with Parkinson's after each day to prevent skin rashes from abnormally oily skin and excessive sweating (Waite, 2000, p. 184).

These responsibilities of caring for persons with chronic illness like PD are all encompassing. Unfortunately, family CGs often do not receive the guidance and support to carry out their responsibilities in an effective manner (Scott, 2006). Existing formalized support services, which aim to relieve the emotional, physical and financial hardship of informal caregiving, vary from state to state, and many are poorly funded (Administration on Aging, 2009; Florida Department of Elder Affairs, 2007; Florida Council on Aging, 2008; O'Shaughnessy, 2008). Thus, when CGs can no longer manage care of their relative at home, they make other caregiving decisions such as

moving their loved ones to long term care (LTC) facilities (i.e. assisted living or nursing home environments).

Decision Making and Institutional Placement Factors

Caregivers' decisions to move a relative to a LTC facility can involve many factors. For example, CGs often experience a myriad of emotions during this decision process. They may have guilt when they make this decision for fear of being judged by others or because of a former promise they made to their loved ones to never put them in a nursing home (Rappoport & Lowenstein, 2007). Other emotions may include grief over losing the person as he or she once was or over the new found physical separation of that person. CGs can become stressed and anxiety ridden about making even more complex decisions during placement and angry that their options are so limited (Answers4families, 2007).

The concern for the PWP's safety is another factor to consider when making LTC placement decisions. For example, fear of falls, incontinence and excessive nighttime activity may also play a role in these decisions (Hope, Keene, Gelding, Fairburn & Jacoby, 1998). Not surprisingly spousal CGs tend to delay institutionalization, and may need help in the decision-making process (Cohen et al., 1993). Moreover, the interventions that improve the quality of CG well being can also delay institutionalization according to Mittelman and colleagues (2006).

During the decision process, care giving families must take the financial cost of facility placement into consideration which, for many, may be anxiety producing. Some may have long term care insurance while others do not. By 2030, many older adults will not have enough assets to cover basic expenses or any costs related to a nursing home residence or services from a home health provider (VanDerhei & Copeland, 2003).

Consequently, learning about the reasons people are placed in nursing homes or LTC facilities, and how families come to those decisions, can help people make informed decisions based on the needs of the individual and CG (DeLuca, 2008). Thus, the experiences and caregiving decisions for PWP is a research area that needs to be addressed.

Statement of the Problem

Parkinson's disease is a complex chronic disease and the care of many PWPs is managed at home by family CGs. These informal CGs are vulnerable and often overlooked in professional settings. They experience poorer health and higher mortality rates than non-caregivers (Giunta, Parrish & Adams, 2002; Scott, 2006). Without support, they can become strained especially when the caregiving experience becomes overwhelming. This can lead to a negative impact on the family unit if they have difficulty managing the caregiving role. Although the goal of caring for PWPs is to have them remain home as long as possible, there may come a time when family members must make difficult decisions about whether and when to institutionalize the PWP. Guilt about placing a family member in a facility and concerns about end-of-life care are common reactions as the illness progresses (Rappoport & Lowenstein, 2007).

There are numerous studies on the factors that play a role in institutionalizing persons with chronic illness. Most of these studies are quantitative and focus on illnesses such as dementia (Dorenlot, Harboun, Bige, Henrard, & Ankri, 2005; Hope et al., 1998; Yaffe et al., 2002). Although the number of these types of studies has increased, there is scant amount of research available that addresses the day to day decision processes of CGs caring for those with chronic illnesses such as PD.

Qualitative studies can provide this type of rich description of detail that can enhance quantitative studies as well as provide new insights on caregiving and health care decision making. Moreover, the outcome of such a study can provide a stronger understanding of CG needs and perceptions which can facilitate the development of tailored interventions for PD management through community resources, education, and CG support. Supporting CGs especially to mitigate strain and adapt to the effect of disability on role functioning in the family will fill a needed research gap and can help CGs prevent premature institutionalization of the PWP. Thus the following study was the next step in understanding the complexities of caregiving for PWPs.

Purpose of the Study

The purpose of the study is to better understand how family CGs make the decision to institutionalize a relative with PD. The researcher examined how informal (family) CGs, (spouses and adult children) conceptualized their experiences in light of their individual situations. The aims were to explore how families made LTC placement decisions and the factors that led to LTC placement. This study also explored the needs of CGs to help them better manage the care of a relative with PD at home. These issues were investigated qualitatively by allowing these family CGs to tell their stories about their lives, their families, and their environments as they interact through the process of caregiving and decision making regarding the future of their family member.

The following research questions guided this study of CGs of PWPs.

1. How do family caregivers make the decision to institutionalize a relative with PD?
2. What factors influence this decision making process?
3. What do caregivers need to help them better manage the care of a relative with PD at home?

Methodology: Grounded Theory

The methodology used in this study was grounded theory (GT) which is a qualitative theory generating research method stemming from the sociological worldview of symbolic interactionism (SI) (Glaser & Strauss, 1967). GT is an appropriate methodology for studying complex phenomena that have not been well researched such as the decision to institutionalize a relative with PD. A study using this methodology may provide insight into CGs' perspectives which will help health care providers determine the manner in which to maintain home placements.

Secondly, GT can be used to compare different perspectives or lenses through which a social phenomenon is viewed. Also, this method, which is based on the premises of SI, allows the researcher to create theory to explain interaction in a world of complex social phenomena (Bowers, 1988; Strauss, 1987). The substantive theory produced in this study speaks specifically to the CG population from which it was derived. Finally, there is good methodological congruence because the research problem, the study's purpose, research questions, data and analysis techniques fit well with this method (Richards & Morse, 2007; Strauss & Corbin, 1998).

GT is a unique method because the research process is iterative and begins with the discovery of a research problem followed by data collection, analysis, idea generation, theoretical sampling, and inductive theory development which occur simultaneously throughout the study (Bowers, 1988; Charmaz, 2006). In this study, data were collected through in person interviews with CGs and some family members with PD. Open ended questions and subsequent probes were used to gain deeper insight into CGs' personal thoughts, behaviors, relationships and experiences. This thick, rich, and detailed description of the phenomenon of caregiving formed the bedrock of

qualitative reporting and provided a twofold advantage by contributing to understanding the phenomenon and encouraging interpretation of meaning and significance (Denzin & Lincoln, 2005; Patton, 2002;). The small sample size, which reduces generalizability, increases the depth of understanding of the people and situations studied (Patton, 2002). The data were analyzed using constant comparative dimensional analysis of transcribed interviews.

Thus, GT is not used to test existing theories; however, the data collected using this methodology provides a richly contextual and meaningful description of caregiver decision making experiences and may lend support to the existing qualitative decision making theories or begin building new theory. A more in depth discussion of all aspects of this research methodology including its sociological foundation (symbolic interactionism) are detailed in Chapter 3.

Limitations

A challenge in GT research is recognizing that researchers may bring assumptions to the analysis. It is important to prevent these assumptions from becoming a part of the interpretive reasoning of the conceptual framework. This challenge is addressed in Chapter 3 with full disclosure of the researcher's assumptions and statement of preconceptions. This challenge is also addressed through the rigor of standard systematic analytical processes (Strauss, 1987; Schatzman, 1991). Transcribed interview data were analyzed by a team of researchers well versed in GT methods, and participants were asked to verify their interviews (i.e. member checking). Data were also checked and rechecked throughout the study (i.e. member checking), searching for negative instances that contradict previous observations and interpretations. The audit

trail also consists of analytic and methodological memos to enhance confirmability of findings. Processes to promote scientific integrity are further addressed in Chapter 3.

Summary

Parkinson's disease (PD) is a degenerative neurological disease that affects 1.5 million people in the U.S., with 60,000 new cases diagnosed each year. Research reveals that there are significant numbers of family CGs providing care at home for relatives with chronic illness including PD. The goal of treatment in caring for someone with a chronic illness is to delay the progression of the disease and its resulting disability, and to help persons continue to live in the community as long as possible. As the disease progresses, family CGs are often forced to make difficult decisions about whether and when to institutionalize the PWP. Research provides us with predictors of institutional placement; however, there is scant evidence about how families made these life altering decisions.

The knowledge from this study will help health care professionals understand the (a) factors involved in LTC placement decision making and (b) needs of family CGs in order for them to better manage the care of a relative with PD at home. More thoroughly understanding families' experiences in caring for their relatives with PD will fill a needed research gap and lead to implementing interventions that may prevent premature institutionalization of the PWP. Additionally, the results from the study can lead toward new policies of integrated care across disciplines which are critical to meet the needs and improve outcomes for families caring for PWPs at home.

A comprehensive review of literature follows in Chapter 2 that emphasizes caregiving and decision making processes and it also provided the rationale supporting the argument to conduct research in this area, It is important to note that during the

course of this inquiry, the researcher returned to the existing literature and continuously reviewed it during this research process which is part of the iterative nature of GT research methodology.

CHAPTER 2 REVIEW OF LITERATURE

In order to understand how family caregivers (CGs) of persons with Parkinson's disease (PWP) make decisions about long term care (LTC) facility placement, we need to understand the impact of caregiving for a person with a progressive chronic disease over time. This chapter contains a review of the literature which focuses on the impact of long term caregiving on family CGs and decision making related to LTC placement. Moreover, the chapter contains a review of the network of support systems that CGs need to help them care for their relatives with PD at home. These areas are explored in more detail in the following sections.

Informal (Family) Caregiving

There are more than 44 million informal CGs in the United States providing help to persons who have limitations with activities of daily living (Administration on Aging, 2008). In many cases, there is considerable stress when one is caring for aging loved ones with cognitive and physical disabilities. Often both CGs and persons receiving the care are aging adults. Moreover, CGs have significantly higher rates of depression and stress than those who are not CGs (Martinez-Martin, et al., 2008; Pinquart & Sorensen, 2003).

Caregiver Stress and Burden

The prolonged consequences of physical and emotional CG burden among informal CGs have been recognized in the literature (Pinquart & Sorensen, 2006; Robinson, Adkisson, & Weinrich, 2001; Roth, Perkins, Wadley, Temple, & Haley, 2009; Rubin & White-Means, 2009; Wrester, Enstrand & Granerus, 2007). An interesting finding by Roth and colleagues (2009) suggested that the negative effects of caregiving

are mainly linked to psychological or mental health problems in those CGs ($N = 43,099$) who also experienced high caregiver strain. Studies using qualitative methods revealed that CGs exhibit general fear, worry, and various intensities of anxiety when caring for PWP's and individuals recovering from a stroke (Davey, Wiles, Ashburn & Murphy, 2004; Hodgson, Garcia & Tyndall, 2004; Subgranon & Lund, 2000).

Effect of cognitive impairment on caregivers

A number of studies identify the impacts on CGs when their loved ones with a chronic disease have cognitive impairment (Coehlo, Hooker & Bowman, 2007; Robinson, Atkinson & Weinrich, 2001; Michon, Weber, Rudhard-Thomazic, & Giannakopoulos, 2005; Thommessen et al., 2002). For example, Thommessen and colleagues (2002) found that informal spousal CGs taking care of cognitively impaired elders ($N = 186$) with mild dementia, stroke or PD experience similar degrees of psychosocial burden.

In another study, Robinson, Atkinson and Weinrich (2001) measured relationships between different types of problematic behavior and the total impact on caregiving. The researchers used a non-experimental, correlational design using cross sectional data. This prospective study had a convenience sample ($N = 30$) of individuals (mainly female spouses) caring for family members with Alzheimer's disease (AD) and related dementia. Results revealed that female CGs had a greater reaction to disruptive behaviors than male CGs even though both genders of CGs had similar frequencies of these types of behaviors. In another study providing care for persons with dementia also had a huge stressful impact on family CGs because of the need to manage disruptive behavior. For example, one CG stated her husband tried to kill her because he thought

she was a robber. Thus, she sought nursing home placement for him (Coehlo et al., 2007).

The role of family functioning can contribute caregiver stress according to Mitrani and colleagues (2006) in a study of various caregivers: spouses = 124 (69%), daughters = 44 (24%) and other relatives = 13 (7%) who managed the care of persons with cognitive impairment. Family functioning was expressed by various patterns of family interaction patterns. These patterns included a) enmeshment-cohesion – defined as highly permeable boundaries between family members which permit a high level of closeness even bordering on intrusion between family members, b) disengagement – defined as highly rigid boundaries between family members that precludes family closeness, and c) identified patient hood – which is defined as the extent of negativity in the forms of comments and attitude that the family exhibits toward the patient (i.e. care recipient) These subcategories were summed and the total score of all categories reflected the overall assessment of family functioning. The researchers discovered that family functioning partially mediates the relationship between caregiver stress and caregiver distress in families caring for persons with dementia (Mitrani, Feaster, McCabe, Czaja, & Szapocznik, 2005; Mitrani et al., 2006).

Caregiver stress was also explored in narratives to illustrate the story of a daughter caring for her mother with dementia. The findings revealed that she had an overwhelming caregiving experience especially since she did not know how to handle situations or make appropriate choices for her mother. An example of her frustration was noted in the following quote, “You really are in a jungle and you don’t know if you

should go forward or backward to the left or to the right” (Goldsteen, Oeseburg, Verkerk, Verhey, & Widdershoven, 2007, p. 4).

Sleep disturbances

Sleep disturbances have also been found to contribute to caregiver burden (Secker & Brown, 2005; Schur, Whitlatch & Clark, 2005). CGs from three groups of patients (stroke, Parkinson’s and dementia) experienced sleep disturbances. (Thommessen et al., 2002). Tsukasaki and colleagues (2006) discovered similar findings in a study of female CGs ($N = 35$) who had sleep disturbances which may have impacted other health symptoms such as chronic fatigue and new onset hypertension (Tsukasaki et al., 2006).

Family members in the Thai culture caring for persons recovering from stroke experienced similar symptoms. Results revealed that culture, tradition and religion played major roles in the commitment to providing care for family members. Caregiving was a way to repay past deeds, and community support was essential to maintaining caregiving at home. However, some of the CGs in this study experienced tiredness, sleeplessness, stress, anger, short temper and discouragement (Subgranon & Lund, 2000).

Effects of uncertainty in chronic illness on family caregivers

Chronic illness can cause distress for the person with the illness and the family. Studies on dimensions of illness uncertainty (i.e. ambiguity, unpredictability of symptoms) identified that higher levels of patients’ uncertainty of illness had an inverse effect on partner supportiveness (Reich, Johnson, Zautra, & Davis, 2006; Reich, Olmsted, & van Puymbroeck, 2006). Michon and colleagues (2005) also noted that the unpredictability of behavior in dementia can also cause distress for CGs and Sanders-

Dewey, Mullins and Chaney (2001) identified that illness uncertainty in PD were associated with caregiver distress.

Positive Aspects of Caregiving

The positive aspects of caregiving were noted in some studies (Cohen, Colantonio, & Vernich, 2002; Habermann, 2000; Habermann & Davis, 2005) and the general themes of the positive aspects of caregiving were categorized in the following headings:

- Companionship
- Sense of being fulfilled
- Rewarding
- Sense of duty and obligation
- Enjoyment
- Knowing that the person is getting good care
- It helps the family

Cohen and colleagues (2002) also noted that having satisfaction in caring is an approach families use to manage caring for the PWP. A study of family CGs ($N = 290$) in Finland also showed similar results, and those results specifically suggested that CGs are content when they can help their relative feel more comfortable, and this activity makes them (the CGs) feel needed and wanted (Kuuppelomaki, Sasaki, Yamada, Asakawa, & Shimanouchi, 2004). Thus, interventions can be targeted more appropriately when clinicians understand the negative and positive aspects of caregiving,

Caregiving Styles and Communication

The way CGs communicate with the person with the chronic illness, how they provide care and the roles they play are all a function of informal (family) caregiving. In 1956 Szasz and Hollender developed three caregiver styles (active-passive, guidance-cooperation, mutual participation) to describe doctor-patient relationships (Szasz &

Hollender, 1956). Edwards and Chapman, (2004a) applied these styles to informal CG and care recipient (CR) relationships. They also developed The Model for Health Promoting Communication in family caregiving dyads (Edwards & Chapman, 2004b) which reflects the processes associated with each of the three caregiving styles. Accordingly, in their study, these processes defined how decisions are made, who is responsible for those decisions and who holds power in the relationship. Therefore, according to Edwards and Chapman, (2004a), communication and relationship outcomes are based on one of those three designated styles.

Edwards and Noller (1998) utilized a theory driven study to assess CG dyad communication on CR quality of life. The results revealed that the patronizing tone of the CG was correlated with low levels of life satisfaction among CRs. This type of communication toward the older adult can reinforce certain stereotypes of aging and may reinforce that functionalistic sick role persona indefinitely (Edwards & Chapman, 2004a). The findings revealed that clear communication and an understanding of the three designated caregiving styles can lead to positive outcomes and healthy role expectations in the relationship of the CG and CR dyad.

Caregiving Roles

It is not surprising that CGs experience conflict and stress arising from the demand to balance caregiving with all their other roles (i.e.: mother, father, husband, adult child and worker). This can add stress to caregiving (Amirkhanyan & Wolf, 2006; England & Tripp-Reimer, 2003). Filial CGs (i.e. adult children) may experience crisis points when caring for family members. CGs ($N = 92$) identified stressors that were related to their caregiving roles. They included strain among siblings (i.e. not enough help for parent care), parental behavior problems including cognitive impairment, and marital strain

(lack of understanding, and worry about resource allocation) (England & Tripp-Reimer, 2003).

Symbolic interactionism and social learning theory was supported in another study ($N = 43$) which sought to explain how adult children and grandchildren became CGs to their older adult relatives (Piercy & Chapman, 2001). Findings identified religious beliefs, family rules and expectations were important values in caring for older adults. When CGs acted as role models they helped their own children learn to be CGs (Piercy & Chapman, 2001).

An interesting ethnographic narrative defined male spouses' (married over 50 years) accounts of their caregiving roles. Black and colleagues (2008) noted that men ($N = 4$) viewed caregiving as a labor intensive task that needs to be completed. The way they acted in their caregiving tasks was similar to the way they acted in their previous careers. In other words, caregiving became a concrete symbol of who they were (i.e. husbands and workers). Women did not perceive the CG role in this manner and had more difficulty than males when balancing the caregiving role with other family responsibilities. Many of the CGs stated they felt exhausted and overwhelmed with their roles. Their physical symptoms included depression, irritability, headaches, anxiety and exhaustion in a study of caregiving spouses (Hodgson, Garcia, & Tyndall, 2004).

Caring for Persons with Parkinson's Disease

Caregiver burden has been studied in PD families as briefly mentioned earlier. Studies found that caregiver health (i.e. depression), marital satisfaction, perceived social support, illness uncertainty, and emotional attitude are associated with distress and burden in caring for PWPs. (Cifu et al., 2006; D'Amelio et al., 2009; Edwards & Scheetz, 2002; Lyons, Stewart, Archbold, & Carter, 2009; Sanders-Dewey et al., 2001;

Tanji et al., 2008). For example, a study ($N = 41$ couples) showed that the ability to perform ADLs and perceived social support accounted for 44.3 % of the variance of perceived caregiver burden reflected by a multiple regression analysis. Marital satisfaction and psychological well-being were also significant variables when bivariate analysis was performed. This study reinforced how PD affects both the CR and CG. Practitioners were urged to help educate families and assist them in necessary lifestyle adjustments as the disease progresses (Edwards & Scheetz, 2002).

Yates and colleagues (1999) developed a model based on combining the stress-process model (1990) and an appraisal model (1989) which was later adapted by Chappell and Reid (2002) and was used in a PD study ($N = 136$) focusing on CGs' quality of life and burden (as cited in Goldsworthy & Knowles, 2008). One of the findings revealed that an increase in the PWP's functional dependency contributed to CG burden and lower CG quality of life. Additionally, as functional dependency increased the frequency of CG breaks decreased and this also negatively impacted burden and quality of life for the CG.

Overall, the Chappell and Reid model provided a good fit for the data; however, the small sample size for structural equation modeling made generalizing the findings difficult for this quantitative study (Goldsworthy & Knowles, 2008). Consequently, it was deduced that breaks for CGs would be important interventions that could improve well being when caring for PWPs with high functional dependency.

In another study, the perspectives of Parkinson's caregiving on the impact of daily living were explored (Wressle, Engstrand & Granerus, 2007). The authors developed a conceptual framework based on aggravating factors (ex; fatigue, functional deficits), and

facilitating factors (ex: access to health care, coping strategies) toward consequences in daily living (ex: habit changes, worries, role changes). The following sections illustrate studies addressing specific PD symptomology effects on CGs.

Rigidity and Falls

Falls are one of the biggest worries in middle to late stage PD and symptoms such as bradykinesia, postural instability and gait disturbances put the patient at a fall risk (Calne & Kumar, 2003; Hauser, 2006). Davey and colleagues (2004) explored the experiences of CGs ($N = 14$) of individuals with PD who have fallen repeatedly. Eleven of the fourteen CGs in this study were married females of PD partners. The age range of the participants was between 44-79 years. It was noted that informal CGs of PWDs have significant demands on their physical, psychological and social well being. The six themes that were identified from the semi- structured interviews were: causes and consequences of falls, managing falls, information about falls, impact on CGs, the general impact of PD and managing the impact of PD. One CG shared what a fall impact meant to her.

I got him back on the bed and settled him all down and then when I went into my own bed, I shook. I shook; my heart was like this (hitting her chest) and I was shaking, you know. While I was seeing to him I was alright but once I got back into bed I was shaking (Davey et al., 2004, p. 1364).

Rigidity and postural instability are symptoms of the effects of PD, and dyskinesia can be a side effect of PD medications. This quote reflects a CG's account of the causes of falls.

He'll call me when he freezes – you see he freezes going between two doors sometimes – something to do with Parkinson's. He gets there and he can't speak and he can't move and he's gripping this, this frame. . . . There's always that constant worry that if he breaks a bone then he can't take his anti-Parkinson's medication for 6 weeks while the bone mends because he so terribly dyskinetic (Davey et al., 2004, p. 1362-1363).

The majority of the CGs in this study were frightened about their spouses falling. They experienced a significant level of anxiety, worry and fear as a result of previous falls. Other emotions included shock, anger and frustration (Davey et al., 2004). Cifu and colleagues (2006) also report that falls are a factor in burden and also added that PWP's decreased ability to perform activities of daily living (ADLs) and CGs interrupted sleep patterns were associated with greater CG burden.

Neuropsychiatric Symptoms

The neuropsychiatric symptoms (recurrent depression, apathy, anxiety, and hallucinations) of PWP's can also be exhausting for CGs since these symptoms may intensify during the course of the disease, and those who have advanced PD with dementia experience this symptomology at a more intense level (Ehrt & Aarsland, 2005; Aarsland et al., 2007). Apathy, due to a disturbance in the frontal-subcortical circuits of the brain caused by reduced dopaminergic afferents, is highly prevalent in PWP's and can lead to decreased quality of life and CG burden (Aarsland et al., 2007; Dujardin et al., 2007; Ferreri, Agbokou & Gauthier, 2006). Understandably, CG burden increases as symptoms of PD worsen, particularly with these mental health problems as well as increased incidence of falls and confusion (Schrag, Hovris, Morley, Quinn, & Jahanshahi, 2006).

In a more recent phenomenological study ($N = 10$), one CG reflected on being puzzled by behavior changes since she was not aware that psychotic symptoms could occur from medication side effects. She stated, "if you haven't come across it before it's a shock to you too. Because in the beginning you don't know if they're going mad do you" (Williamson, Simpson & Murray, 2008, p. 586). The four themes that emerged during the analysis revealed that there was a lot of uncertainty in caring for the PWP

which was coupled by the person having a changing identity (i.e. not being his usual self). Other themes noted that the CGs learned to adapt to the PD symptoms over time and they used social comparison as a coping strategy (i.e. “We’re not so bad compared to them”, p. 585). In order to reinforce credibility in this study the researchers kept a diary of their own assumptions and beliefs during data collection and analysis (Williamson et al., 2008).

An interesting study comparing the needs of CGs of persons with Alzheimer’s disease (AD) and PD was conducted. Each group had 20 CGs and the responses to questions on the Caregiver Assistance Measure (CAM) were in 75% agreement between the two groups. This indicates the two groups may have common needs. Several similar responses addressed self care needs for both groups. The AD group had concerns about knowledge and skill needs such as how to dress the person with AD whereas those caring for PWP were more concerned with another area of knowledge skill which was to make sure the PWP was getting correct and timely medications (Habermann & Davis, 2005).

Effects on the Relationship

Studies showing the impact of PD on relationships among spousal CGs was well noted in the literature; however there was scant evidence of PD studies on the effects on adult child/parent relationships (Habermann, 2000; Lyons et al., 2009; Hodgson et al., 2004) Anxiety and fears of the future were felt by informal CGs in Hodgson and colleagues’ study (2004) of the lived experiences of the couple relationships of PWPs and their CGs (i.e. significant others). The following themes were created from the interviews of the ten couples: (a) relationship and disease history, (b) impact on the couple relationship, (c) impact on self and others, (d) connecting with resources and (e)

strategies for survival. The authors noted that studies addressing relationship issues and chronic disease management may promote feelings of anger and guilt within the dyad. "Conversations often become strained as caregiving partners carefully craft dialogue to avoid the reality of the illness" (Hodgson et al., 2004, p. 102). The themes that originated from this qualitative study emphasized the need for couples to maintain open communication with each other, have a positive attitude, develop trust and offer reassurance to one another. It was also important to not "take over for the person" with the illness and to allow for self empowerment (Hodgson et al., 2004, p. 112).

An interesting finding in Habermann's study (2000) revealed that spouses (8 women, 3 men) were supportive of one another and encouraged their partner with PD to stay active and involved. The spouses who did not have PD did not describe themselves as CGs and some resented that label. They saw themselves as being supportive to the other person. The most significant challenge in the spousal relationship was for CGs to watch their loved ones become frustrated and struggle with the illness as they renegotiated their lives (Habermann, 2000).

Mutuality in the relationship was another important factor on caregiving spousal dyads. Mutuality denotes relationship quality, interaction, reciprocity, and shared loved and values. A study of spouses ($N = 255$) of PWP's over a ten year period revealed that pessimism and low mutuality played a role in caregiver strain. High mutuality (especially for women) and optimism was a buffer in protecting CGs from role strain (Lyons et al., 2009).

Caregiver Health

Caring for PWP's is stressful. A ten year longitudinal study using multilevel modeling revealed that CGs' attitude of pessimism with depressive symptoms early in

caregiving was considered a predictor for poor CG health (Lyons, Stewart, Archbold, Carter, & Perrin, 2004). CG attitude is a particular concern because as the disease progresses to its late stages the symptoms can become quite debilitating (Lyons et al., 2009). Late stage problems include dementia, impaired communication, postural instability, and dyskinesia related to side effects of medication (Lyons et al., 2004).

Depression among CGs of PWP's exists as revealed in several studies (Carter et al., 1998; Fernandez, Tabamo, David & Friedman, 2001; Martinez-Martin et al., 2008). Fernandez's study ($N = 45$ spousal pairs) found that the length of time the spouse had PD was a strong predictor of symptoms of depression among their caregivers. Another finding noted that patients' sleep disturbance (insomnia, fragmentation) also contributed to spousal depression (Fernandez et al., 2001) and CG burden (Cifu et al., 2006). However, the patient's incontinence and hallucinations had no effect on caregiver depression. A larger sample size may have identified other factors. Martinez-Martin's study ($N = 289$ pairs) conducted in Spain with spousal and filial CGs also revealed that CGs' depression, anxiety and worsening health status were greater than those symptoms in the general population. These affective disorders influenced burden and the dyads' quality of life (Martinez-Martin et al., 2008).

Health Care Decision Making

Review of Health Care Decision Making Studies

Health care decision making has been researched in many areas which include decisions about daily caregiving, decisions about long term care and the choice whether or not to withhold life support (Hansen, Archbold, & Stewart, 2004; Krull, 2000; Pratt, Jones-Aust, & Pennington, 1993). For example, a symbolic interaction (SI) perspective was used in Krull's (2000) study on the CGs' career as it leads up to nursing home

placement of patients with and without Alzheimer's disease. A three phase caregiver career model was identified which depicted how CGs (a) realized family members needed care, (b) assumed the CG role, and (c) actually made nursing home placement decisions for family members.

Definition of self, meaning, context and process were woven through the three phases and results revealed that CGs' sense of self, their definition of quality care and the meaning they place on a nursing home (NH) were important factors for NH placement. They concluded that these factors were just as important as CG burden and care recipient health (Krull, 2000). Thus, decision making affects all facets of life which includes the choice to put a relative in a NH. This decision is understandably difficult for many families because it can produce a life altering change and may not alleviate the CG's stress (Whitlatch, 2008).

In another study researchers discovered that role strain evolved over time among family members before, during and after the decision process to withdraw or withhold life support for their older adult relatives (Hansen et al., 2004). Role strain in this study was defined as the difficulty CGs felt when making these decisions. Seventeen family CGs were interviewed about their decision making experiences during this difficult time period, and the results noted that strain was a complex, dynamic and multidimensional phenomenon. It was further noted that there were two dimensions that described the ease of this decision process. These dimensions were feelings of being without discomfort and feelings of being content with their decisions. Unfortunately the study did not address how CGs came to these decisions rather the emphasis was on the resulting emotions.

The use of strategies was also a factor in daily caregiving decision making as illustrated in a study of mother / daughter relationships ($N = 64$ pairs). Results revealed that positive strategies such as asking persons with chronic illness what their opinions are and how they feel emotionally increased the level of intimacy in the dyad. There were many overt and covert types of strategies that were used to influence daily caring decisions such as ignoring the need for a decision on an issue, or withholding support if the CG disagreed with the decision. Overall most strategies were positive in this dyad; however, those who said decision making with the other person was difficult felt their partner would use negative strategies (Pratt et al., 1993).

Health Care Decision Making Frameworks

Conceptual frameworks and models exist in the literature pertaining to health care decision making during life transitions, and LTC placement; however the majority of these frameworks do not focus on PWP's and their CGs (Caron and Bowers 2003; Caron, Ducharme, & Griffith 2006; Davies, 2005; Meleis, Sawyer, Im, Messias & Schumacher, 2000).

Meleis' middle range nursing theory focuses on the process of life transitions that individuals make when encountering changes in health and illness. Meleis believed that this concept was an important area in nursing theory because people undergoing transitions tend to be more vulnerable due to the need to change behaviors and which can alter the definition of self in a new social context (Meleis et al., 2000). This theory has three domains which are (a) the nature of transitions, (b) transition conditions and (c) patterns of response (Davies, 2005; Meleis et al., 2000). Transitions may be situational, developmental or based on health/illness events (Meleis, 2007). For example, the effects of change during mature adulthood may include gerontological

problems related to identity, chronic illness and retirement. The theory guides nursing clinical decision making by understanding that people go through transitions to accept life changes such as moving from a state of wellness to chronic illness, and making decisions to institutionalize a loved one (Meleis, 2007).

Davies' (2005) study ($N = 48$) used Meleis' theory as a framework for researching relatives (mainly adult children and spouses) experience of nursing home entry. Results from interviews revealed that the identified phases and themes in the study supported the domains of the theory. For example, there were multiple patterns of transitions within the first domain (nature of transitions) as indicated by CGs having to address changes in their own health status as well as the change in the relationship with the family member causing a series of stressors that were not all related to the transition of institutionalization (Davies, 2005). However, the interactions between formal and informal CGs were not adequately represented by the model in this study (Davies, 2005). The pathology of the older adults was unknown except that one category was mentally infirm.

Caron and Bowers (2003) developed a caregiving theory that explained some of the decisions and caregiving phases that play a role in complex decision making processes related to caring for persons with dementia. They posited that informal caregiving is a complex fluid process affected by the caregiver – care recipient relationship. It is essential for health care practitioners to understand this process in order to develop interventions that effectively meet the needs of informal CGs in the community.

In another grounded theory study, Caron, Ducharme, and Griffith (2006) focused on CGs and decisions involving institutional placement of their relatives with dementia. Findings were used to develop a model of the decision-making process. CGs' perceptions of their ability to provide care and evaluations of their relatives' ability to make care decisions were two central components of this model. A third component addressed the evolving influence of contextual factors and interactions with health care professionals. Findings from both studies revealed complexities of the decision making process that CGs used when meeting the needs of family members, Caron and colleagues' model portrays an evolving, fluid decision making process that weaves in human relationships and changes over time.

Factors in Institutionalization

There are numerous studies on intent to institutionalize family members with chronic disease and the majority focus on caring for individuals with dementia (Andel, Hyler, & Slack, 2007; Coehlo et al., 2007; Hope et al., 1998). For example, multivariate analysis of data revealed that patient depression played a major role in the early placement of dementia patients ($N = 348$) living in the community (Dorenlot et al., 2005). Although this factor was an indicator in this study, another quantitative study ($N = 5788$) noted that patient and CG characteristics as well as the sociocultural context of patients and CGs were important considerations for nursing home (NH) placement. These characteristics included: (a) older age, (b) being married, (c) caregiving for >90 hours/week, (d) functional dependency, (e) depressive symptoms, and (f) a high burden score (Yaffe et al., 2002). Coehlo and colleagues (2007) also reinforced in previous findings that CG depressive symptoms were instrumental in NH placement .

Disruptive behavior is a factor of institutional placement (Coehlo et al., 2007; Hope et al., 1998). Being cared for by a female, excessive night time activity, difficulty walking, and incontinence also predicted institutionalization in persons with dementia living at home with a CG within one year of baseline; however, aggressive behavior was most prevalent four months before entering an institution. Advanced age, absence of potential CGs and decreased functional ability increased the risk of NH placement in the elderly, but those who also had dementia were at much higher risk of being institutionalized (Andel et al., 2007).

Quality of relationships among CGs and care recipients (CRs) were also considered risk factors in NH placement. Spruytte and colleagues (2001) utilized a logistic regression analysis to predict institutionalization of cognitively impaired elderly cared for by their relatives. Results revealed that a good current relationship between the CG and CR reduced the risk of NH placement; however, there was no connection found between premorbid relationship quality and institutionalization. Findings in this study confirmed that NH placement should be a process in which relational dynamics have an ongoing role (Spruytte, Audenhove & Lammertyn, 2001).

Another study of CGs ($N = 304$) analyzed the impact of the effects of family help on NH placement. This study was driven by the stress-process model (1990) for dementia caregiving (as cited in Gaugler et al., 2000). For example, the study measured care demands, role captivity (i.e. being trapped in the caregiving role) and family help which are variables in the model. The researchers found that CGs delayed institutionalizing their relative when they received specific help for their relatives' ADL dependencies and help in the form of overnight respite. They also found that CGs who

reported greater role captivity were more likely to place their relatives in an institution than those that did not have those feelings. There was no relationship in the amount of help and timing of placement (Gaugler et al., 2000).

The transition to a NH is a major life event, and that decision process for families is difficult. Buhr, Kuchibhatla and Clipp (2006) noted that it is paramount for families to consult with health care providers during this decision making process. They found that spousal CGs were more likely to note their own health to be a reason for institutionalizing their spouse. These couples tended to be older, have lower incomes, lower life satisfaction and high stress symptoms.

Interestingly, older adults' self expectations for NH placement were rationally reflected by their individual risk profiles and were associated with subsequent NH placement. The self report data did not include extensive health characteristics of the older adults; however it was noted that self rated health, incontinence, and low ADL levels were associated with NH placement (Akamigbo & Wolinsky, 2006).

This presents other concerns related to co-morbidity. Kitayama and colleagues (2007) noted that "Aging is an important factor for the development of dementia in PD. (Visual hallucinations) are a common symptom in (PD dementia) patients and may be one of the more notable symptoms for the development of dementia in PD" (p. 194). It is not unusual for PD psychosis to overwhelm CGs and warrant NH placement (Melamed, Friedberg, & Zoldan, 1999). In 1993, Goetz and Stebbins found that the presence of hallucinations/delusions was a statistically significant risk factor ($p < 0.0001$) for NH placement for PWP. Other studies, mainly quantitative in nature, have also posited that hallucinations are one of the most frequent predictors of NH placement in PWPs.

(Aarsland, Larsen, Tandber, & Laake, 2000; Goetz et al., 2001; Goetz & Stebbins, 1995). Noonan, Tennstedt and Rebelsky (1999) utilized qualitative data in a study of adult CGs regarding the option of placing their parents in a NH ($N = 11$). The participants were part of a large population based study of community dwelling older adults. Results from semi-structured interviews appeared to be nebulous because CGs had noted that they would consider placing their relative in a NH at a certain point in the future, but the meaning of that point was never identified from the CGs' perspective.

Johnson and colleagues (1994) analyzed interviews with older adults who were already in NHs ($N = 18$). Their goal was to study the older adults' perspective regarding the factors that influenced NH placement decisions. This was a descriptive study that focused on thematic analysis. A characteristic of rigor was noted as data were analyzed separately by each of the members on the research team. The four major themes that evolved from the interviews were (a) subjects' health problems, (b) inability of family members to provide care, (c) inability of older adults to provide self care, and (d) their fear of living alone (Johnson, Schwiebert, & Rosenmann, 1994).

Some participants said a "critical incident" (p. 273) such as a stroke prompted a relocation to a facility. Some older adults did not want to be a burden to their CGs (i.e. mostly spouses); especially if the spouses were in ill health themselves. Comments were made about others making the placement decision without the elders' input which was identified as an aspect of powerlessness in the decision process. One subject stated, "From the hospital, they brought me here. I didn't decide nothing about it. I didn't know where I was going" (p. 276). A common theme in all the interviews was a sense of resolve regarding the decision process outcome. "I'm just trying to tell myself now that

I've got to put up with it because I've got to live here the rest of my life. My furniture's all gone, my apartment's gone and neither one of my kids has got room for me. . . . I've got to stay here" (Johnson et al.,1994, p. 278).

Ryan and Scullion (2000) explored the experiences of family CGs regarding NH placement. Interviews of 10 CGs were analyzed and themes for NH placement emerged which included CGs' inability to cope and deteriorating health status of the family member. The authors noted that basic categories emerged from the data analysis and claimed to use grounded theory techniques to interpret the data and identify themes; however, there was no mention of coding, comparative analysis, or memoing to analyze/interpret the data. In referencing the typology of qualitative findings (Sandelowski & Barroso, 2003), this study appeared to be a thematic survey because data were not transformed to produce a grounded theory and there was no conceptual pattern of the data or a reframing of the phenomenon.

In summary, the above studies found the following factors to be instrumental in long term care placement of a person with disabilities.

Factors related to caregiving

- Caregiver health (declining)
- Inability to manage caregiving
- Overtaxed with care giving (> 90 hours a week)
- No support to care for person
- Relationship dynamics

Factors related to disease symptoms

- Symptoms of psychosis (hallucinations)
- Aggressive behavior
- Incontinence
- Low ADL ability
- Decreased functional ability

- Decreased mobility
- Increased falls

Support for Caregivers

There are many different avenues of support that caregivers need to manage their role of caring for persons with chronic illness (Eberstein, 2005; Linderholm & Friedrichsen, 2010; Kosloski & Montgomery, 1995; Pierce, Steiner, Havens, & Tormoehlen, 2008). These support structures are categorized into formal (professional support) and informal (assistance from unpaid sources such as family and friends).

Formal Support

Formal support is important for CGs from the professional community whether in a support group setting or at the clinic. Linderholm and Friedrichsen (2010) noted that CGs felt they needed to develop a relationship with health care providers during the care for a loved one in the terminal stages of illness. Without such a relationship in which they could talk about their role, CGs felt powerless and in a sense invisible. They desired “to be seen” by the health care professional (Linderholm & Friedrichsen, 2010, p. 28).

Support groups can provide a source of strength to CGs for persons with disabilities. In a study about the predictors of loneliness in CGs of PWPs, researchers found that persons attending support groups were not as lonely and had higher perceptions of support than those not attending support groups (Eberstein, 2005; McRae, Fazio, Hartsock, Kelley, Urbanski, & Russell, 2009). However, caution should be mentioned with support group attendance according to Tuite and colleagues (2008) who emphasize that support groups have their own dynamics and families may need to visit more than one group to find the best match for their needs. Some groups may be

self run and others may be sponsored by professional organizations and moderated by formal CGs such as nurses or social workers.

As illness progresses CGs may seek respite care to achieve the needed self care and strength to provide the necessary care for their relative with chronic illness.

Kosloski and Montgomery (1995) revealed that respite use was a potential intervention to delay or decrease the probability of LTC placement in the study of 541 caregiving dyads. The results of respite use remained constant even after controlling for the effects of 11 other variables which included other support services.

Informal Support

One of the main sources of support for CGs is the family unit. Family support is a natural interaction among families even when there is no illness. However, when there is illness and the support evolves to the form of “caregiving” then it becomes more intense because it goes beyond the bounds of usual care (Singer, Biegel, & Ethridge, 2009).

Other sources of support for CGs can be categorized into various areas. For example, many CGs feel spirituality is a great source of support during trying situations (Sanders, Ott, Kelber, & Noonan, 2008). In a qualitative descriptive study with stroke survivors, emails ($N = 230$), from a discussion group of CGs one year after caring for stroke survivors, were analyzed. The results emphasized the importance of spiritual support in areas such as being one with nature, being able to practice rituals, feeling the presence of a greater power and being with family and friends. The results of the interpretation emphasized that spirituality brings CGs that realm of hope that allows CGs to express themselves fully (Pierce et al., 2008).

This need to be acknowledged, even in the home setting, can be accomplished by the unconditional support of the family pet. Researchers found that animals help CGs cope with the effects of disease. They noted in a mixed methods study ($N = 201$) that high levels of grief are experienced by those caring for persons with Alzheimer's disease and related dementia. Support from pets was one of the themes found to help CGs. Specifically, pets served as companions to combat feelings of loneliness and isolation. CGs had a tendency to talk to their pets about their feelings and frustrations (Sanders et al., 2008).

Barriers to Support

Another study which centered on support for the caregiving family was a replication analysis of social support models and CG distress over four community based studies. The results revealed that behavior problems of persons with chronic illness and CG ill health led to distress. Moreover minimal emotional support is linked to high levels of distress. The authors in this study acknowledged this is a complex issue and that stressors are not always amenable to the influence of different types of social support. For example, if the person with an illness exhibits disruptive behavior, it may be difficult for the CG to leave for the evening with friends (informal supporters) for a period of respite (Miller et al., 2001). In another study, McRae and colleagues found that attending PD support groups can decrease CG loneliness ($N = 70$); however, those who work or have difficulty getting transportation may not have access to these types of supports. They noted that support group attendance was specifically beneficial for older adults who often felt a need to be with other CGs.

Summary

This literature review highlighted the impact of long term caregiving on family CGs and decision making related to LTC placement. The effects of caregiver burden and strain were highlighted in chronic illness. Moreover, in order to understand how CGs for PWPs make decisions about LTC facility placement, we need to understand the impact of caregiving for a person with a progressive chronic disease over time which was illustrated by various studies of experiences of spousal and filial CGs for PWPs.

An overview of decision making process literature was identified from studies focusing on, life transitions and caregiving decision making. Specific factors that influence institutionalization such as falls, hallucinations, and declining caregiver health were discussed. Finally, an overview of a support system to care for persons with chronic illness was also introduced in the literature review. The following is a brief synopsis of the specific issues raised in this chapter.

- There are more than 44 million informal CGs in the United States and many of them are aging adults with illnesses.
- The literature is replete with quantitative and qualitative studies specifically focusing on CG burden and stress.
- Decision process models in dementia care have been developed using grounded theory methods (Caron & Bowers, 2006; Caron et al., 2006); however, to date, no studies have focused on caregivers' decision process when choosing to institutionalize a relative with PD.
- There are several studies of LTC placement factors for persons with chronic illness such as Alzheimer's disease; however, literature specifically focusing on LTC placement factors for PWPs is dated (Aarsland, et al., 2000; Goetz et al., 2001; Goetz & Stebbins, 1995; Goetz & Stebbins, 1993).
- The support structure to assist caregivers is complex and incorporates support groups, spirituality, friends, family and pets. The professional community also has a role in this support structure for caregivers especially as patient centered care becomes more focused on family centered care.

Thus, this study was a necessary next step toward documenting evidence about caregiving experiences and CG decision making for CGs of PWPs. Caregivers are vulnerable and often overlooked in professional settings. A better understanding of their needs is essential especially in promoting increased support and integrated care to meet the needs and improve outcomes for families caring for PWPs at home. The following chapter explores GT research methodology used in this study.

CHAPTER 3 METHOD: A PROCESS OF INQUIRY

The purpose of this chapter is to provide direction for this study. This direction depicts the contextual development of this research and illustrates the process of analysis that led to the development of a conceptual framework that illustrates how caregivers make decisions to institutionalize a relative with Parkinson's disease (PD). The chapter is divided into three sections. Section one begins with a discussion of the sociological tradition of symbolic interactionism (SI) and the methodological processes of grounded theory (GT) which include the rationale of using this method for this inquiry. This is followed by my own assumptions and experiences as they relate to the context of this study. The second section of this chapter outlines the study's research plan that includes: a) a description of the sample and b) an account of the study's procedures, data collection and phases of analysis. Section III describes how scientific integrity was employed, and ways in which human subjects were protected.

Section I: Methodology within a Sociological Perspective

Symbolic Interactionism (SI)

The inspiration for the grounded theory research method evolved from symbolic interactionism (SI) which is not a philosophical doctrine but a sociological perspective in empirical social science. It is an approach designed to study human group life and conduct (Blumer, 1969). SI can be traced back to pragmatism, which is a post-Darwinian philosophy that saw the universe as a dynamic world and reality still in the making. This was a world where "The individual continuously adapts to his environment, changing his action to meet the exigencies of the situation and transforming the situation to satisfy his practical needs." (Shalin, 1986, p.11). Pragmatism views

knowledge as learned and remembered; but, its usefulness is dependent on one's ability to apply it (Charon, 2007; Shalin, 1986). It is a reaction to the rationalist / mechanistic philosopher view of a structured predetermined universe (Shalin, 1986).

The sociological world view of SI begins with the following three premises: (a) human beings act toward things on the basis of the meanings that those things have for them, (b) these meanings come from social interaction with one another, and (c) these meanings are defined and changed through an interpretive process that people use when they encounter different situations (Blumer, 1969). In addition to these premises, SI is also grounded in a number of basic "root images" or constructs which represent the way interactionists see human society and behavior. Figure 3-1 depicts and explains these important images which show that humans construct reality, society and themselves through their interactions (Blumer, 1969, p. 6; Charmaz, 2006).

Charon (2007) reinforces these concepts and states there are several assumptions of SI. Initially, the human being must be understood as a social person who exists through social interaction. Secondly, humans are "thinking beings". Characteristics of a "thinking being" include having the ability to interact among individuals and to interact within oneself (Charon, 2007, p.30). A second assumption states that humans define the situation they are in and do not sense their environment directly. In other words, even though the environment exists, the person's definition of the environment, which is created through social interaction and thinking, is what is important. Another assumption states that the cause of human action is reflected by what is currently occurring in the environment and not what has occurred in the past. Interactionists believe, "The past, therefore, does not cause what I do in the present;

instead, I use the past to define the present and to guide my action in the present” (Charon, 2007, p. 131). The last assumption states that humans are actively involved in their environment, and to an extent, they can control their actions based on thinking, defining the situation and interacting (Charon, 2007). Thus, “To understand human action, we must focus on social interaction, human thinking, definition of the situation, the present and the active nature of the human being” (Charon, 2007, p.30). Humans, then, act toward their environment and toward themselves. In their role as actors they all have a self. In other words, humans are subjects (actors) and objects (selves) (Charon, 2007).

The concept of the self is an important consideration for the symbolic interactionist. The self (the “me” and “I”) is a process or a stream of thought that evolves over time (James, 1968, p. 47). The self can only exist for the person if he or she takes on the role of the other, and then views objects as others do (Bowers, 1988; Mead, 1968). Behaviors can be viewed from the perspective of the self:

This perspective is formed through successive stages of role-taking and becomes a social object for our own thoughts. The self has a dynamic quality as well—it is the internalized conversation between the I and the Me. The Me is the social object, and the I is the seat of the impulses. When the self is able to role-take with generalized others, society can exist as well as an integrated self. Role-taking with generalized others also allows us to think in abstract terms (Allan, 2006, p. 118).

Thus, the “I” is more spontaneous and has been referred to as the pure ego whereas the “Me” is the part that allows people to control their actions, thinking and ability to make choices. This “Me” is the person’s created identity (Charon, 2007; James, 1968).

Blumer (1969) saw society as people engaged in living and in dynamic relationships between meaning and action which emphasized the focus of SI on the

active process through which people create meaning (Charmaz, 2006). Action can be seen as a constant continuous process, and each act is part of a large stream of action. This stream is complex with many features, dimensions and interwoven connections. Humans evaluate their actions, roles, goals and redefine their objects along a continuum. They make active decisions along this stream and are thus able to control the direction of their actions /decisions as they go through the life continuum. Figure 3-2 shows decision making along this stream of action.

Interactionists believe that meaning is constructed and shared meanings are reflected in symbols. Human interaction depends on the ability to access shared symbols which include both verbal and nonverbal gestures that designate objects in the social world. People are able to interact in a predictable or meaningful way when a symbol is shared by the other members of the social group, and it is possible to redefine social structure but it would require a change in the way others see symbols (Bowers, 1988). From a theoretical perspective, SI emphasizes the actions of the person rather than the social system, and therefore analysis begins from the individual and rises through social groups and organizations (Bowers, 1988). Additionally, the roles people play are a consequence of the interactive process between the social context and the self (Bowers, 1988).

Research influenced by SI such as grounded theory (GT) is qualitative and data is often gathered by observing people in real situations (Charon, 2007). Research is concerned with discovering the realities of subjects and the nature of the objects in their world. It also focuses on how subjects define and experience the world. Observing participants is a powerful way to collect data from an SI perspective because it helps

recover "the meaning that social reality has for those participating in its production" (Shalin, 1986, p. 19). SI informs GT because its research method examines these processes of human action based on SI's premises which leads to theory development (Glaser & Strauss, 1967; Lutz, 2000). SI helps the grounded theorist to see the "complexity and variability of phenomenon and of human action" and that actors (persons) take an active role in responding to situations (Corbin & Strauss, 1998, p. 9). Therefore, GT has its origins in SI because it takes "the perspective that reality is negotiated between people, always changing, and constantly evolving" (Richards & Morse, 2007, p 59).

Grounded Theory

Grounded theory (GT) is a qualitative research method with a focus on developing theories or conceptual frameworks through an iterative approach to data collection and analysis. Therefore, the term "grounded theory" is utilized in theory development grounded in empirical data (Bowers, 1988, p. 43; Charmaz, 2006). Richards and Morse (2007) reinforce this assumption by noting that researchers can construct theory grounded in data through detailed exploration with theoretical sensitivity. In other words, theory is developed through the "intimate relationship with the data" (Strauss, 1987, p. 6).

GT is an interpretive method that focuses on understanding the meaning of phenomena as they are perceived and experienced by the subjects being researched. In order to capture the complexity of phenomena, researchers themselves must become the instruments of data collection (Glaser & Strauss, 1967; Strauss, 1987). As data are gathered, new theoretical concepts are identified. During the theory building process concepts, which are abstract representations of objects, actions or events, are

discovered. Eventually these concepts are grouped into categories (Corbin & Strauss, 1998). “Discovering and describing the characteristics (dimensions) of the objects (categories), and identifying the salient objects (core categories) in the object world are the first steps in a grounded theory analysis” (Bowers, 1988, p 47). A core category is a strong theme that is woven through the data, and researchers do not hesitate to describe how it emerges (Richards & Morse, 2007, p. 62).

Grounded Theory Research Process Overview

GT differs from traditional research methods in some important ways. The GT research process is iterative and begins with the discovery of a research problem followed by data collection, analysis, idea generation, theoretical sampling, and inductive theory development which occur simultaneously throughout the study (Bowers, 1988; Charmaz, 2006). This type of research is dynamic because “the phases of literature review, question/hypothesis generation, and data collection and analysis occur simultaneously rather than as a sequence of distinct phases” (Bowers, 1988, p. 45). Data analysis extends through the writing and rewriting phases of the study which leads to discoveries of ideas and development of a theoretical framework grounded in the data (Charmaz, 2006). The GT process ends with an overall reflection on all the steps of this process, and with an assessment on the present and future impacts of the grounded theory research (Charmaz, 2006). From an evaluative standpoint, Sandelowski (2004) believes that the transferability (generalizability) of theory in GT occurs when it is applied to other situations outside of the ones to which they were identified.

Sampling

Initial sampling of subjects in qualitative research provides a point of departure that results from establishing a sampling criteria before research begins. Theoretical sampling is a type of purposeful sampling specific to GT sampling that is often used to refine the properties of existing categories subsequent to initial sampling. It enhances conceptual and theoretical development, and maintains a focused analysis (Charmaz, 2006). Initially the researcher has already identified categories of data, and theoretical sampling enhances precision and structure that helps the researcher predict where to find data “to fill gaps and to saturate categories” (Charmaz, 2006, p. 103). For example, this type of sampling can be used to interview previous subjects and ask additional questions or explore areas with them that had not been previously covered. This new analysis could be based on recent data and memoing resulting from interviews of other participants. When gathering new data no longer sparks new insight, and does not reveal new ideas in the core categories, then the categories have achieved saturation (Charmaz, 2006).

Analytic Techniques

Coding is considered the foundation of analysis, and it shapes the frame from which researchers build analysis. Different types of coding are used depending on researchers’ goals and perceptions of data analysis. During the initial coding process data are opened and read closely. These initial codes are provisional so that the researcher can be open to other analytic possibilities and thus create and alter codes that fit the data. Data are coded as action words which prevent the researcher from making theoretical and conceptual conclusions before all the data are analyzed (Charmaz, 2006; Richards & Morse, 2007). In vivo codes help preserve the participants’

own meanings of their views/actions. This may be useful in a study that seeks to understand what is going on in the lives of these CGs (Charmaz, 2006).

Focused coding synthesizes and explains larger segments of data. Focused coding is important because it leads the researcher to make decisions about which previous codes could be used analytically to thoroughly categorize the data. These focused codes appear to be at a higher level of coding because they are more conceptual, directed and selective than the line by line codes (Charmaz, 2006). Eventually, axial coding is implemented. This type of coding focuses more around a concept and it “relates categories to subcategories, specifies the properties and dimensions of a category and reassembles the data” that was previously fractured during the initial open coding process (Charmaz, 2006, p. 60; Richards & Morse, 2007; Strauss & Corbin, 1998).

During the data analysis process constant comparative methods are used (Charmaz, 2006; Glaser & Strauss, 1967). The process of analysis is essential in order to determine similarities and differences of each level of analysis. In this study, statements and situations upon which caregivers reflected were compared to other interview statements and situations. As new themes were developed, I went back to review that earlier data to see if what I found in later interviews existed in the earlier interview data. By constantly comparing data among codes, categories and interviews the researcher is able to make analytic distinctions which enhance inductive theory generation and ascertains that categories are conceptually clear and well represented through the data (Charmaz, 2006). Even though constant comparative analysis is a key

feature of GT, Schatzman (1991) believed it should be delayed until more dimensions were identified in the data (Bowers, 2007).

These dimensions would be identified through the process of dimensional analysis which is a naturalistic comparative analytic strategy based on the coding procedures set forth by Strauss (1987) and Strauss and Corbin (1998) and designed for use with text or narrative data in a grounded theory study (Schatzman, 1991). In this type of analysis, codes take on the form of dimensions which are attributes of a constructible reality. "In dimensionalizing, the analyst seeks only to identify experiences that answer the methodological question and perspective: What 'all' is going on here?" (Schatzman, 1991, p. 330)

Memos, Diagrams and Field Notes

Memo writing embraces the form of informal analytic notes; however, this process is an essential bridge between collecting data and composing a working draft of a research manuscript. This process triggers an analysis of the data and codes throughout the research process. It also helps researchers synthesize abstract ideas and develop new insights about the study and participants. Memoing can enhance productivity and expedite analytic work (Charmaz, 2006). Strauss and Corbin (1998) believe that memos take on various forms such as theoretical or operational. Sorting memos that have strong existing categories further empowers the development of theory. Specifically, sorting helps to integrate categories and directs the researcher toward more abstract categorical comparisons. Diagrams are visual representations of concepts discovered in the data. In other words, they are visual memos. Both of these depictions evolve and grow in complexity as the research progresses (Strauss & Corbin, 1998).

Montgomery and Bailey (2007) explain that field notes are also used in GT research and require observational sensitivity. These notes are a source of data that represent facts from observations whereas memos define deconstruction and reconstruction of the data. "Field notes serve a fundamental role in showing the field while memos abstract meaning from the field" (Montgomery & Bailey, 2007, p. 78). Key features of GT are further described in Table 3-1.

Different forms of GT have evolved. Objectivist GT and Constructivist GT are on two separate ends of a spectrum. They do however share certain assumptions such as maintaining the iterative, comparative emergent and open-ended approach in the research process (Charmaz, 2007). Objectivist GT arises from positivism and the expert observer, who discovers the data, remains neutral. Constructivist GT assumes multiple realities and multiple perspectives. These constructivist grounded theorists, such as Charmaz (2009) acknowledge the relativity of the data and seek to explain how their interactions have influenced the analysis. Charmaz (2009) comments,

Data are not separate from either the viewer or the viewed. Instead they are mutually constructed through interaction. Granted the grounded theorist renders these data but they arise in situations under particular conditions and therefore affect the resulting analysis. Thus constructivist grounded theorist sees the representation of data- and by extension, the analysis - as problematic, relativistic, situational and partial (Charmaz, 2009, p. 138).

The constructivist approach is a contemporary revision of Glaser and Strauss' (1967) classic grounded theory (Charmaz, 2007). In this study a constructivist GT approach was used. I, the researcher, achieved an interpretive understanding of caregivers' experiences with decision process to institutionalize a family member with PD. A substantive theory was sought that has credibility, resonance and usefulness (Charmaz, 2009).

Strengths and Weaknesses of Grounded Theory

GT is a highly demanding method that seeks methodological congruence in research initiatives (Richards & Morse, 2007). It is unfortunate that some researchers do not understand the nature of GT and often misrepresent the method (Richards & Morse, 2007). Furthermore, inexperienced researchers may have difficulty determining when categories are saturated and thus become mired in the data (Creswell, 2007). Another challenge in GT research is recognizing that researchers may bring assumptions to the analysis. It is important to prevent these assumptions from becoming a part of the interpretive reasoning of the conceptual framework. The goal is to maintain marginality which is having the ability to see the caregivers' world from the inside while keep the distance that is essential to raise analytical questions (Bowers, 1988). This challenge is addressed through the rigor of standard systematic analytical processes (Guba & Lincoln, 1989; Strauss, 1987; Schatzman, 1991). During the research process GT theorists may become extensively immersed in the research world, develop blurred boundaries and may not be able to differentiate their world with the participants' world. It is important to overcome this by doing constant comparative analysis which is comparing subjects' data with data in the literature (Bowers, 1988; Lutz, 2000). Also, it is essential to compose memos especially to sort out preconceived assumptions regarding the phenomenon of interest. It is also essential to seek feedback on findings from data analysis groups composed of experts in the field of qualitative research.

Grounded theory's strength is its versatility. The constructivist view of GT lends itself well to the topic of the process of decision making to institutionalize a relative with PD because it is more flexible than objectivist GT, and can take the researcher "deep in

to the phenomena without isolating it from its social location” (Charmaz, 2007, p. 24). GT sees data and analysis as created from shared experience and therefore sees resulting theory as an interpretation. Going deep into the phenomenon allows researchers to see how participants’ experiences may be embedded in relationships. This method was ideal to analyze this topic because it led researchers to grasp at the root of caregiving issues (Charmaz, 2007).

The GT method is compatible with studying a complex phenomenon such as the decision to institutionalize a relative with PD. GT, in this study, provided insight into caregivers’ perspectives which can aid in maintaining home placements. Finally, this study is methodologically congruent because the research problem, the study’s purpose, research questions, data and analysis techniques fit well with the chosen GT method (Richards & Morse, 2007; Strauss & Corbin, 1998).

Researcher’s Assumptions

As the researcher, I come to this study with set assumptions about caring for a family member with a long term illness. Personally, I have lived the experience of being a caregiver since my mother was diagnosed with Alzheimer’s disease over 20 years ago. The deleterious effects of providing 24 hour care with no respite were a common occurrence in our home. My father, who was the primary caregiver, experienced many different emotions and had symptoms of exhaustion, burden and severe stress which he would not acknowledge. The feelings of constant worry from fears of her wandering at night or falling in the house, and the stress from being overwhelmed were never far from my mind. Watching my mother lose her memory was especially devastating. I remember coming home one day after being away for a period of time, and she looked at me and asked, “Who are you?” Even as my mother’s condition worsened my father

would not entertain any thoughts of placing her in a long term care (LTC) facility. Watching his health be affected by this experience was difficult. He refused hospice care and any other types of respite.

I experienced a lot of guilt because I began to think about LTC placement for her, yet he was vehemently opposed to placement and promised her it would never be a consideration even though his exhaustion level was mounting as these caregiving tasks became too much for him. Therefore, in order to address this potential bias, I have analyzed and processed my assumptions have strived towards marginality by reflecting personal thoughts/bias thoughts through journaling/memoing before and during the study, and by working jointly with a multidisciplinary research group (Bowers, 1988).

Section II: Research Plan

Sample

The sample for this study included men and women who were alert and oriented, and had been the primary family caregiver (CG) for a person with Parkinson's disease (PWP) and it included persons with Parkinson's disease (PWPs). These CGs had the option of having the PWP be present and participate in the interview. After initial purposeful sampling was completed, theoretical sampling was used to obtain data that helped to explicate the emerging explanatory model (Charmaz, 2006; Glaser & Strauss, 1967). For example, during the course of sampling, there was a scant amount of male CGs and their experiences were slightly different from those of female CGs. Thus, a concerted effort was made to find additional male CGs.

The sample size for this study was determined once core themes (categories) were identified and data saturation occurred (Richards & Morse, 2007). In order to achieve saturation, interview structure, content and participant homogeneity were

considered (Guest, Bunce, & Johnson, 2006). Typically, 20 to 30 interviews are required to reach saturation in a grounded theory study (Creswell, 1998).

In this study saturation was achieved with 23 participants who consisted of 17 CGs and 3 caregiver/PWP dyads for a total of 20 interviews. These 3 dyads included filial and spousal CGs. Even though there were 23 interview participants, 37 individuals were enrolled in the study because information about PWPs not interviewed during single CG interviews was obtained with permission which discussed in more detail in the procedure section.

Fifty-two families were contacted for this study. Thirteen phone numbers were either incorrect or out of service. Nineteen potential participants either declined or stated they were inappropriate. The following is a list of these responses.

- PWP had only paid CGs
- PWP did not have a CG due to mild stage of illness
- CG was too ill
- Person on data base list did not have PD
- CG too busy or stressed with caregiving
- CG agreed but cancelled due to sudden illness

The majority of those who participated in the study never had relatives in a LTC facility. Therefore those CGs were asked to respond to LTC placement questions hypothetically.

Procedure

I recruited study participants from the University of Florida Movement Disorders Center (UFMDC) data base and targeted those participants who resided in suburban and rural areas of North and Northwest Florida. Eligible participants were approached at PD support group meetings or were contacted by phone from the provided data base list. All contacts whether in person or by phone followed research protocols especially

stating that participants were only eligible if their family member with PD received care from the UFMDC.

After approaching eligible participants, I (a) explained the study, (b) asked if they were interested in participating in the study, (c) asked if they would like more information about the study, and (d) ascertained that their family member with PD was a patient at the UFMDC. Eligible participants were also given a copy of a flyer (see Appendix A) inviting them to participate in the study. The flyers were distributed at Parkinson's support groups in north Florida. Participants were recruited using purposeful, snowball, and theoretical sampling in North and West Florida counties. Purposeful sampling was initially used to select participants based on characteristics fitting the inclusion criteria and willingness to reflect on their caregiving experiences (Richards & Morse, 2007).

Data were collected through individual interviews with primary family CGs of PWP. These CGs had the option of having the PWP be present and participate in the interview. Interviews lasted 1 to 2 hours, and were digitally recorded and transcribed verbatim by a professional transcriptionist. Digital audio recordings were downloaded to a secure password protected computer server with a secure firewall as soon as possible after the interview. The recordings were then erased from the recorder. The audio files were password protected and were deleted after data analysis was completed. All files were secured on encrypted electronic media. Subjects were allowed to be interviewed a maximum of two times, and were allowed to participate in the study for a maximum of 7 months.

Before beginning the recorded interview, demographics were collected such as age, education level of the participants. The initial interview questions were open-ended and loosely structured to allow CG participants latitude to describe the experiences of caring for someone with PD and factors they found challenging in helping the person manage the disability. Follow-up questions and probes were used to gain more in-depth insight into their decision making process regarding institutionalizing their family member with PD. These questions allowed for discovery regarding how participants perceive these phenomena without imposing the researchers' ideas or categories (see Interview Guide in Appendix B). If at any time participants became uncomfortable (i.e. experienced psychological distress) during the study, I offered them a list of community resources to call upon and encouraged them to contact their health care provider.

Two forms of informed consent were obtained. One type was for the CGs and one for the PWPs in the event they were also interviewed during a CG interview. Subjects were asked to consent in an inpatient or clinic setting (e.g. the patient's room or a private area in the facility or in another location convenient to the participant such as the patient's home etc). Also, the Institutional Review Board (IRB) of the University of Florida (UF) granted a Waiver of the Health Insurance Portability and Accountability Act (HIPAA) Authorization in order to allow me to obtain and use data on PWPs who were not present for the interviews. Information on the PWPs was accessed through the UF Movement Disorders Center data base. My major professor, Dr. Barbara Lutz, oversaw the safety of the subjects and reviewed the analyzed data.

Transcribed data were entered into NVivo 8.0 qualitative data management software. Every effort was made to maintain the confidentiality of study records as

outlined IRB protocol. A numeric code was assigned to each participant, and only the researcher and her major professor had knowledge of the names of the participants. If more than one individual from a family participated, information was not exchanged among family members unless they agreed to be interviewed together. Any scientific data or medical information that resulted from the study may be presented and published so the information can be useful to others, but no data or information will be presented that would identify a particular participant. All contact information, the consent form, the numeric code key, and the transcript of the interview were kept in a secured locked office. Copies of the consent form, contact information, and transcribed interviews were kept by the researcher in a locked office and locked file cabinet. The numeric code key was destroyed at the conclusion of the study.

Data Analysis

I listened to the audio recordings and clarified any noted discrepancies in the transcribed documents. Initially only 2 to 3 interviews were completed which were then analyzed. I began by analyzing each of the interviews line by line, remaining open to exploring different theoretical possibilities in the data. I felt it was important to explore the dimensions (categories) of caregiving experiences throughout the disease trajectory because they helped to expand my understanding of the phenomenon of caregiving and decision making across the illness trajectory (Bowers & Schatzman, 2009). Learning the participants' caregiving experiences from diagnosis to their current state of caring was essential during the interviews. Telling their stories:

- provided insight into their decision making processes
- fostered trust between us during the interview process.
- helped me understand their overall experience

This interaction between the caregiver and the interviewer fostered a sense of trust so that they could openly discuss the sensitive topic of long term care facility placement. Memos were written and /or diagrammed based on what was seen in the data. Moreover, rhetorical questions were asked of the data.

One of the codes that emerged was how caregivers managed the illness of the PWP. Many of the caregivers were organized as they provided the many aspects of caregiving. Yet there was also a lack of self care and a stream of emotion that varied for caregivers. After further exploring this code, I realized the way they managed the illness was a strategy however, I saw that complex dimensions of caregiving were being identified which led to further detailed analysis. Appendix C shows a sample of a memo about illness management. It is important to note that memos are not meant to be “polished” work but rather a way to track the researcher’s thought processes in GT research (Lutz, 2000).

Although relationship dynamics were not the main focus of this study, it was interesting to hear the different perspectives of interviewees when they talked about the PWP. Figure 3-3 is a rudimentary pictorial depiction of interview comparisons and a speculation about caregiving decisions (such as LTC placement) being influenced by the dynamics of the CG and the PWP’s relationship.

Other early categories were coded around the concept of “planning” which later emerged as a strategy in caregiving. Throughout the analysis process consistencies and inconsistencies within the data were noted. For example, some CGs considered themselves as planners (long and/or short term), while others did not describe themselves as planners as referenced by this CG, “I’ve never been one to plan, just

take it, we've been taking it a day at the time. That's the way we cope a lot of times. Deal with what's happening today and tomorrow, we'll worry about tomorrow" (CG 3)¹. Emerging strategies like these were analyzed in order to understand meanings. In addition to uncovering categories through coding and memoing, field notes were essential since I was able to record facial expressions and general impressions of interviews which were incorporated into the data analysis. Diagrams were also helpful in data interpretation. The diagram in Figure 3-4 was created with the assistance of an interdisciplinary qualitative data analysis group to help me remain focused on the research questions while incorporating the "planning" strategy caregivers used to manage the illness.

The data was analyzed using dimensional analysis (DA) which was completed by hand and with NVivo 8 data management software. During DA the stories of the participants were broken down into parts. These parts identified the many different dimensions (attributes or subcategories) that made up the experience of caregiving and decision making. The most important attributes that related to the research focus were identified through clustering, memo writing, coding and discussions with the data analysis group. Also through this analysis, the most relevant conditions that influenced caregiving and decision making as well as the consequences that resulted from caregiving were identified. This type of analysis allowed me to see the implicit and explicit dimensions of concepts. It was a useful tool to illustrate the complexity of a phenomenon like caregivers' experiences and decision making processes. This analysis also helped to compare multiple perspectives within and across texts surrounding the

¹ All interview data in this study is de-identified; therefore, all quotes from study participants are labeled by either a CG for caregiver or PWP for Person with Parkinson's disease. Also, the number following those acronyms designates the number assigned to that participant in the study.

phenomenon. For example, I looked at factors in the decision process for institutionalization. As I compared the data I realized that all caregivers needed validation from others before they made this decision. Then upon further analysis, this validation came mainly from authority figures (health care providers, legal system) when it was a crisis event whereas when it was a culmination of events occurring over time that led to this decision, the validation came from other family members.

Table 3-2 shows how DA was used in this study. For instance, it provides definitions of DA concepts and then applies those concepts to the areas of my study (i.e. dimensions or subcategories of caregiving).

Throughout the research process NVivo 8.0 data management software was utilized more extensively as codes were identified. Initially I categorized all codes as free nodes and as coding clusters were identified and coding became more selective and axial, I then utilized the software's tree node function. The codes in the tree nodes were restructured several times during the iterative nature of the analysis. Figure 3-5 is an example of the coding scheme used in the analysis.

Developing the Conceptual Framework

The final phase of the data analysis was to develop a conceptual framework that illustrated the impact of PD caregiving and LTC placement decisions. This phase took approximately six months of diagramming, writing, revising, renaming and reviewing culminating in the final version described in Chapter 4. Figure 3-6 was the initial attempt at diagramming a model which showed the impact of PD on caregivers' lives. Upon further analysis of the data I realized that it was difficult to delineate disease stages as shown in the model and subsequently after feedback from the qualitative data analysis group, I revised the model.

After more intensive analysis and additional interviews the model took a different form as it began to represent some core categories and a disease trajectory framework showing the impact of caregiving as the illness progresses (see Figure 3-7). Several of the concepts in this second model were still unclear and disconnected. Therefore, additional analysis, more data collection and feedback from the data analysis group produced several more iterations of the caregiving model. Upon extensive analysis and feedback from interview participants the conceptual framework for this study was completed. It is depicted and described in Chapter 4.

During the later phase of model development, two important dimensions in caregiving which were named caregiver “doing” and caregiver “being” were identified. These terms were theoretical constructs borrowed from occupational therapy literature (Lyons, Orozovic, Davis & Newman, 2002; Wilcock, 1999, p. 1). I selected them because the data in my study revealed that caregiving was categorized into (a) what caregivers did and (b) what it meant to be a caregiver during the caregiving process. Upon further exploration of the data, the categories were renamed to instrumental caregiving and interactive caregiving which more clearly defines this process from the perspectives of the study participants. These core categories are described in Chapter 4.

In summary, the analysis was completed in several phases because the process of DA is iterative (i.e. non-linear and fluid, the different phases of the process often overlap or occur simultaneously) (Lutz, 2000, p. 142). Data collection and analysis took place simultaneously and was tracked through theoretical and substantive memos. Methodological memos, such as the advantages and disadvantages the sample

recruitment methods used, were completed throughout the data analysis process in order to remain grounded in the research methodology. Moreover, I went back to the literature and completed more reviews during the analysis. The different phases are outlined in Table 3-3.

Section III: Scientific Integrity and Protective Assurances

Evaluation Criteria

Scholars vary in their determination of criteria for scientific rigor/integrity in qualitative research (Charmaz, 2006). Rigor in this study was applied based on Guba and Lincoln's (1989) established criteria for qualitative research. The term trustworthiness is used in place of rigor, and it includes several evaluative criteria (Guba & Lincoln, 1989).

Credibility parallels with internal validity and establishes that research results are believable from participants' perspectives. Strategies to establish this included prolonged engagement which is the investment of sufficient time to learn the "culture" of the environment. Another strategy was to build trust which, I believe, was accomplished through the extensive interview process and frequent attendance at support group meetings. Another strategy was peer debriefing, which is a formal or informal discussion with peers to help clarify aspects of the research that may otherwise remain implicit in the researcher's mind. An example of this strategy was working jointly with a qualitative data analysis group that included professors and graduate students with backgrounds in nursing, anthropology, rehabilitation science and public health. An additional strategy was member checking which is formal or informal checking of data with participants, such as at the end of an interview or during informal meetings (Guba & Lincoln, 1989). This was done during interviews by asking for clarifications and by asking for feedback

after summarizing their thoughts. Also, on two occasions, I met with a small group of participants to present some initial findings. On one of those meetings I had them review a draft of the GT model of this study. They indicated that caregiver “strain” rather than caregiver burden was more appropriate since it was not as harsh as the word “burden”.

Transferability parallels external validity/generalizability and refers to the degree that results may be applied to other settings. I achieved this by thoroughly exploring the context of caregiving for PWP. Other researchers who wish to transfer this to other contexts will need to make their own judgments about the sensibility of the transfer.

Confirmability refers to the degree to which research results can be confirmed by others and thus parallels objectivity in the quantitative realm of research. Because of potential bias due to previous experiences with caregiving, data audit trails were used and data were checked and rechecked thoroughly throughout the study, searching for negative instances that contradicted previous observations and interpretations. Confirmability was further enhanced by the use of the aforementioned multi-disciplinary data analysis research group consisting of qualitative methodologists including grounded theorists. The group assisted me on numerous occasions with data analysis and interpretation. Member checking was also achieved through informal meetings with groups of participants to review initial findings and the drafts of the conceptual framework.

Protection of Human Subjects

This study was conducted following approval by the UF IRB Participants were given an explanation both verbally and in writing that their participation was strictly voluntary and that no identifiable data would be released or used in reports and

publications. Furthermore, the dissertation funding agency, The Rehabilitation Nurses Foundation, received reports of this research but had no access to any raw identifiable data. All informed consents were fully explained to participants and they were told there was no penalty if they decided to leave the study before its completion. All members of the research team have completed the HIPAA compliant training and all raw data was secured per IRB procedures and protocols previously outlined.

This study involved minimal risk. Study participants were told they might experience psychological distress or discomfort in answering some questions. They were told they were free to answer only those questions they were comfortable with and that the interview could be stopped at any time for any reason without penalty. In the event participants experienced discomfort, a list of community health services was offered to help meet their needs.

The possible benefits from participating in this research for the participants included learning about the issues that were important to them related to experiences of caring for someone with PD: The participants were told that the study could provide information that may lead to improved training for doctors, nurses and other health care workers to help PWPs and their families

Summary

This chapter highlighted the complexity of the methodological process to be used in this study. Specifically, it explored grounded theory (GT) inclusive of its sociological underpinnings, data collection and analytic processes. The rationale for using this type of research methodology in studying this complex social phenomenon was explained. The researcher's assumptions (i.e. bias statements) were expressed and a goal to achieve marginality in this research was noted. The sampling method and study

procedures in this study were outlined noting specific safeguards of data management.

The importance of scientific integrity was emphasized in GT research and the manner in which it will be accomplished was discussed. The following chapter illustrates the final version of the conceptual model and addresses the research questions within this framework.

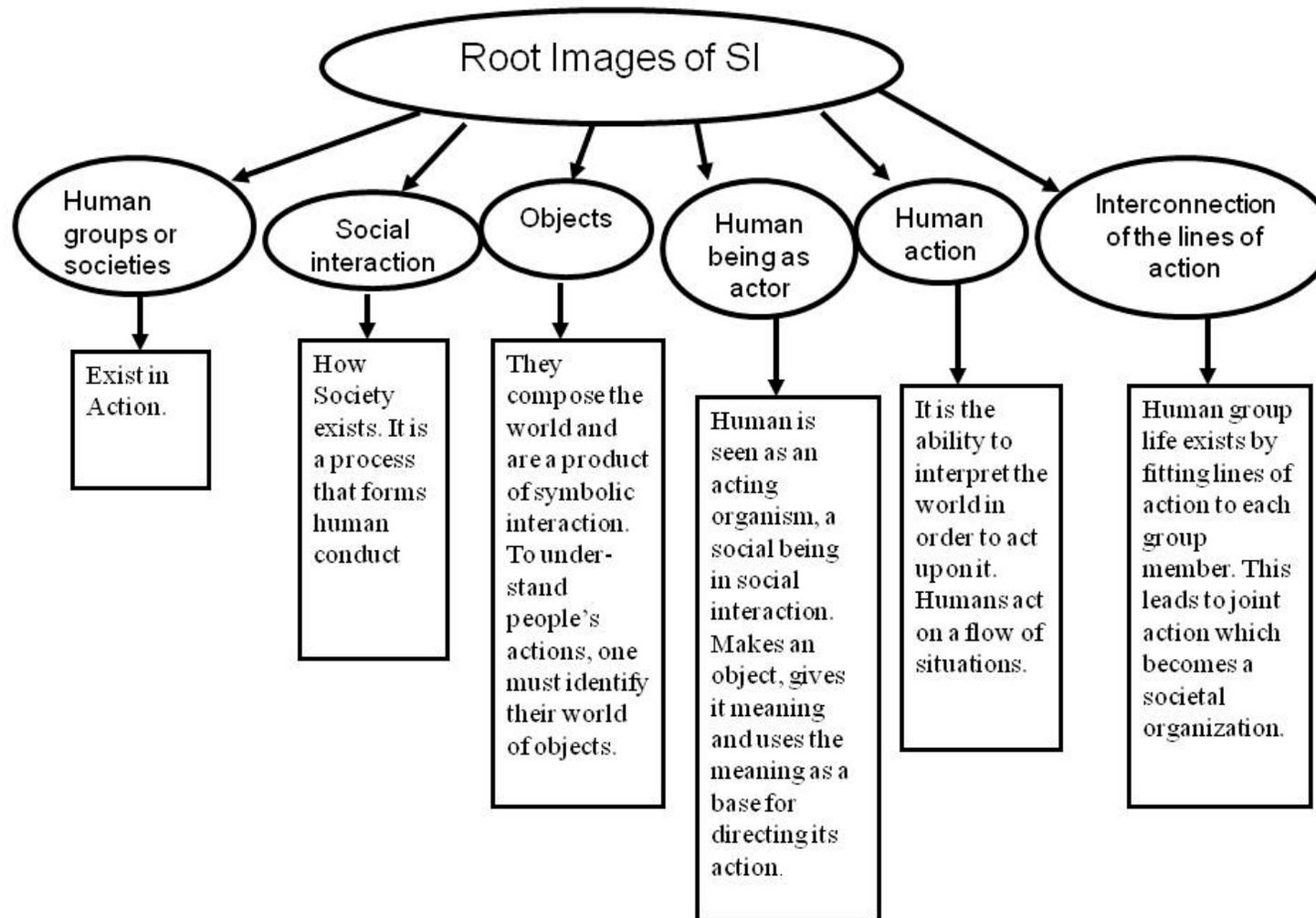


Figure 3-1. Root images of symbolic interactionism (SI)

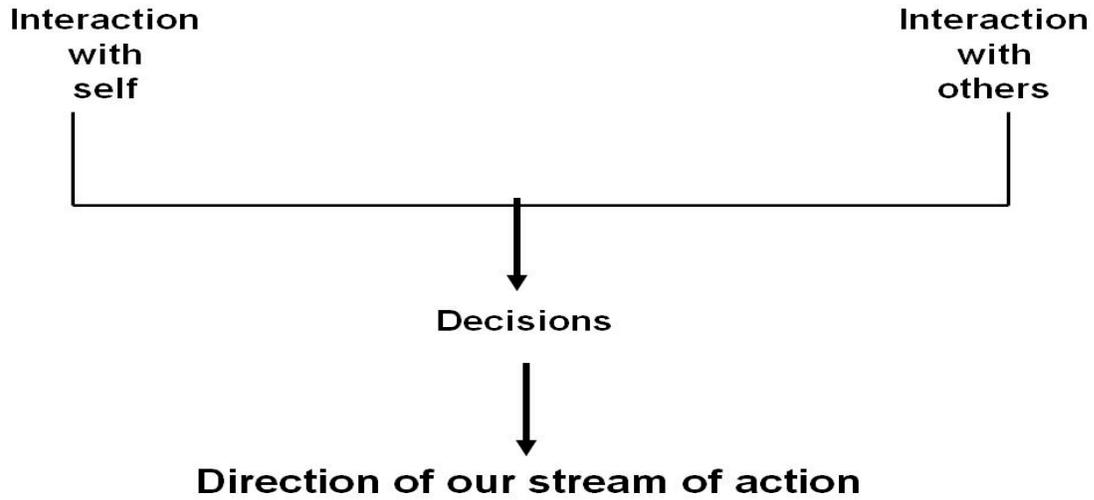


Figure 3-2. Illustrating human action (Charon, SYMBOLIC INTERACTIONISM: AN INTRODUCTION, AN INTERPRETATION, Fig. 9.2 p. 119 "Illustrating Human Action", © 2007. Reprinted by permission of Pearson Education, Inc.)

Table 3-1. Key components of grounded theory

Key Components	Description
Initial literature review	Research discovers gaps in knowledge
Marginality	The ability to see the subject's world from the inside while keeping a distance in order to develop analytical questions
Data involvement	Simultaneous involvement in data collection and analysis. Data collection / analysis are ongoing and fluid. Researcher = instrument. Advance theory development during each step of data collection and analysis.
Coding and Categories	Categories and core categories – initial steps in analysis Open coding, initially, focused coding, conceptual coding. Developing subcategories and comparisons. Diagramming and clustering. Construct codes from data, not from deduced hypothesis.
Theoretical Sampling	Sampling of groups based on emerging theory. Use to build theory not for representativeness in a population. Saturation occurs when no new themes are identified in the data.
Constant Comparative Method	Making comparisons during each stage of analysis. This analytic method generates abstract concepts/theory by comparing data with data and with categories.
Dimensional Analysis	A naturalistic comparative analytic strategy based on coding procedures. Data collection and analysis take place simultaneously and will be tracked through theoretical and substantive memos. Need to delay comparative analysis until a many dimensions are identified in the data.
Memo writing	Done to elaborate categories, define relationships and identify gaps. Captures the researchers' thoughts. A crucial activity – it prompts the researcher to analyze data early In the research process. Many types of memos including theoretical, operational, and methodological depending on phase of research
Literature Review (ongoing)	Review ongoing done during and after the independent analysis.

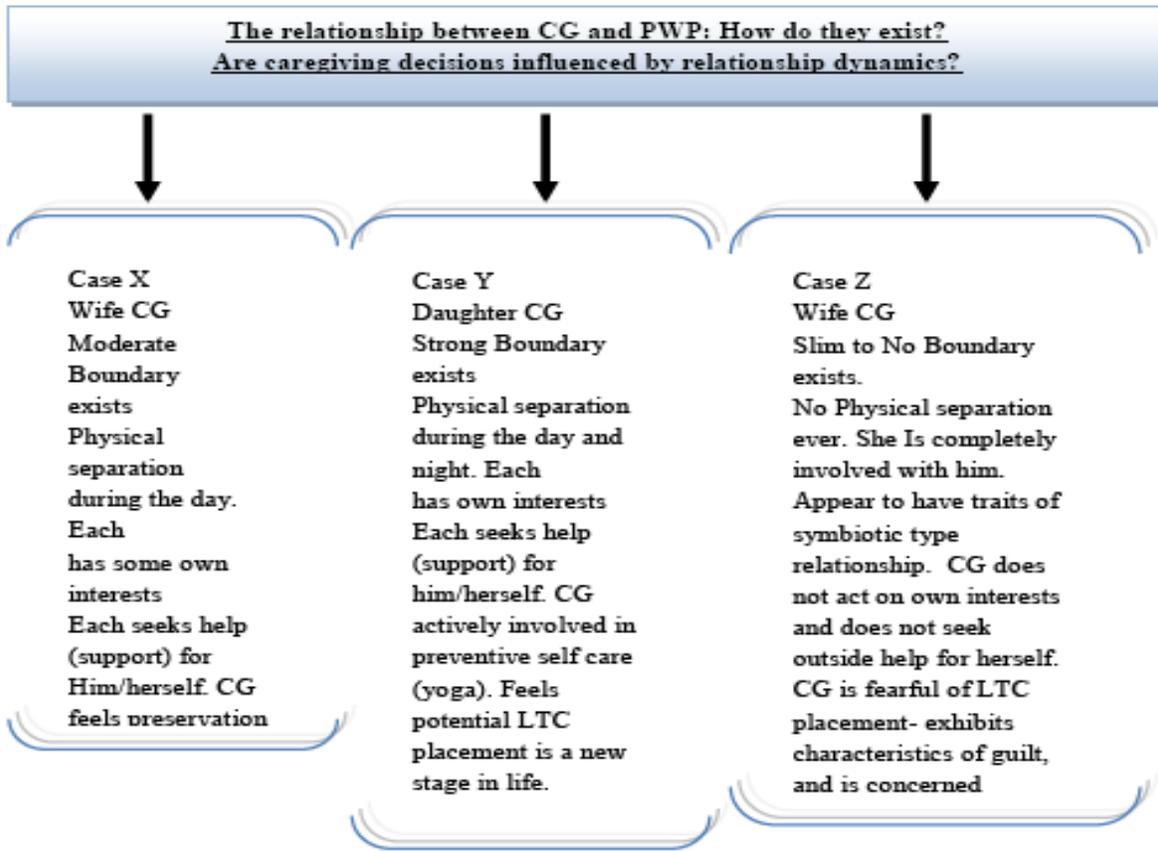


Figure 3-3. Relationships and decisions

How has the disease changed their lives?
Scope of PD – its impact \longleftrightarrow Interpret this out
of the data

Going back to the RQ1.

1. How they view their problems?
2. Viewed as a “big deal”
3. Breaking it down --- PLANNING allows for this
4. Outcome of this control

Dealing with Problems

1. emotional aspects (Planning allows for control – empowerment empowering the self. Knowing what is going to happen tomorrow, provides some consistency provides predictability, may reduce fear
2. cognitive aspects – keeps them from dealing with the emotional. Big Push for knowledge seeking
3. behavioral \longleftrightarrow (Action) – planning many trips around the country with RV Before person with PD can no longer do it. Planning to stop trips

Are coping strategies working for coping?
Is there damage being done? There is a cost to this.

Stages of Planners exist - also a continuum
Planning is a symptom, a strategy

Reasons for Planning

- to take control
- lives are in chaos

Planning

Rationale role as a Caregiver

- to justify time and effort
- to make it meaningful

What happens when the person (CR) is no longer there?
What happens if something happens to the CG?
Are the planners the ones that survive?
Is there a gender difference?

Figure 3-4. Diagram on the impact of PD

Table 3-2. Applying dimensional analysis (DA) to the PD study

Steps	Description	Application
Goal of DA	To achieve a framework that explains what is going on in the phenomenon of interest	
1	Designate the social object. What you are talking about (i.e. Categories)	Parkinson's disease caregiving Categories: Instrumental and Interactive caregiving
2	From whose perspective?	From the caregivers' perspective.
3	Look at the Attributes or Dimensions or Subcategories Components. Subcomponents Properties	Example: Subcategories: Relational Domain Components: Evolving Roles Subcomponents: Teacher Properties Type of Teacher
4	Look at these in Context	Example: Within the context of particular family relationships, generational beliefs.
5	Under what Conditions?	Conditions: Demographics (advancing age, existing co-morbidities, gender), and life circumstances
6	Describe the Action/Process (i.e. what are people doing –their strategies)	Strategies: planning, seeking knowledge, taking care of self, making caregiving decisions, adjusting the environment
7	With Consequences What are the outcomes? Can be multitudinous.	Caregiver exhaustion vs caregiver self preservation (satisfaction). LTC placement

Tree Nodes

Name	Description
Category of Interactive Caregiving	Emotions and Relationships, Roles
Emotional Realm	emotions experienced by the caregiver
Anger	
Denial	
Depression	
Empathy	
Feeling abandoned	
Forgiveness	
Grief and loss	
Guilt	
Hope	
Satisfaction	
Relational Realm	relationship and role dynamics
Changing relationship	role reversals, change in dynamics
Evolving Roles	
What is a caregiver	How they see the caregiving role
Who is the caregiver	How participants see themselves
Supercaregiver	Think they can do it all

Figure 3-5. Example of NVivo tree node hierarchy

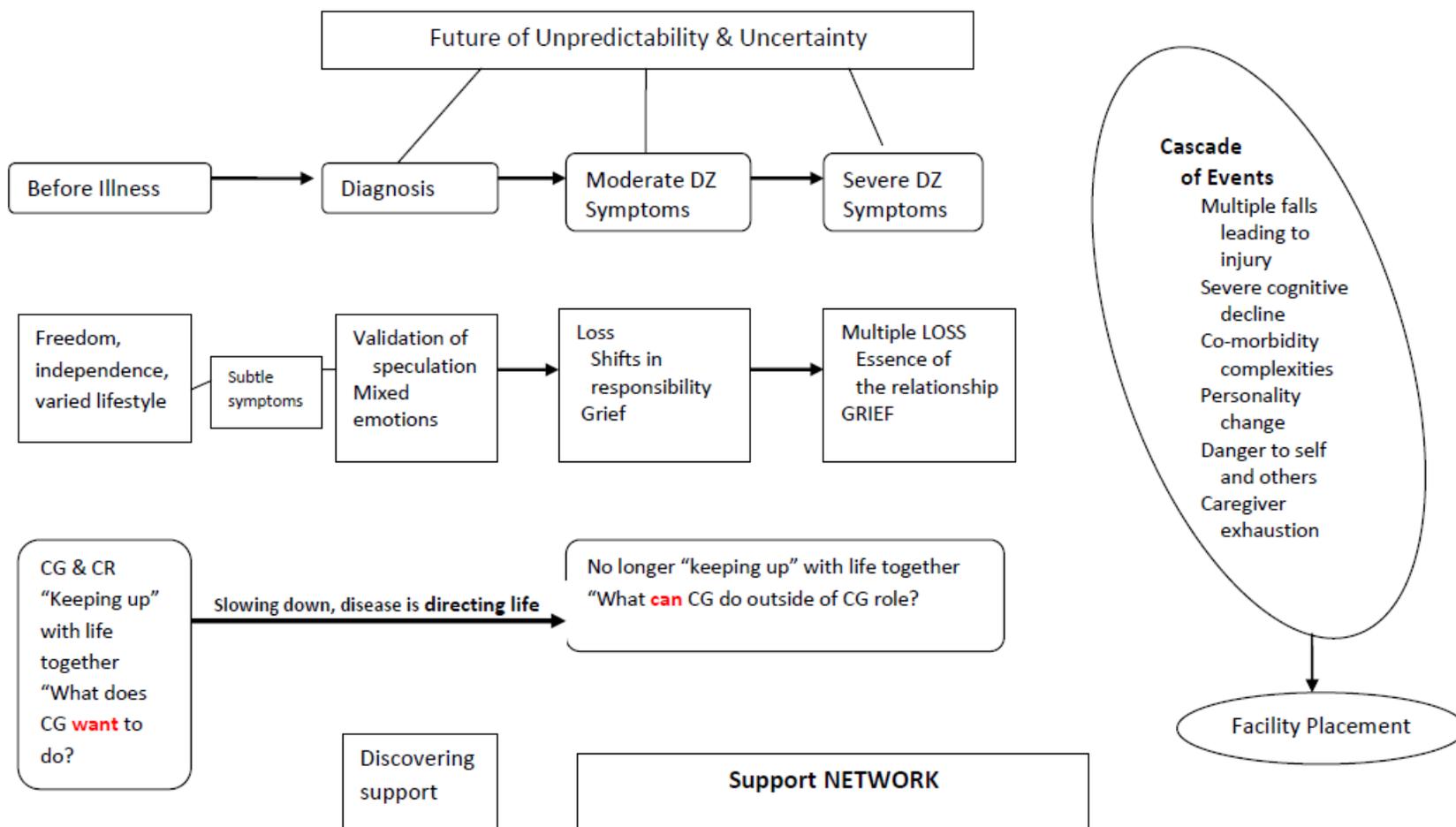


Figure 3-6. Impact of Parkinson's disease on caregivers' lives

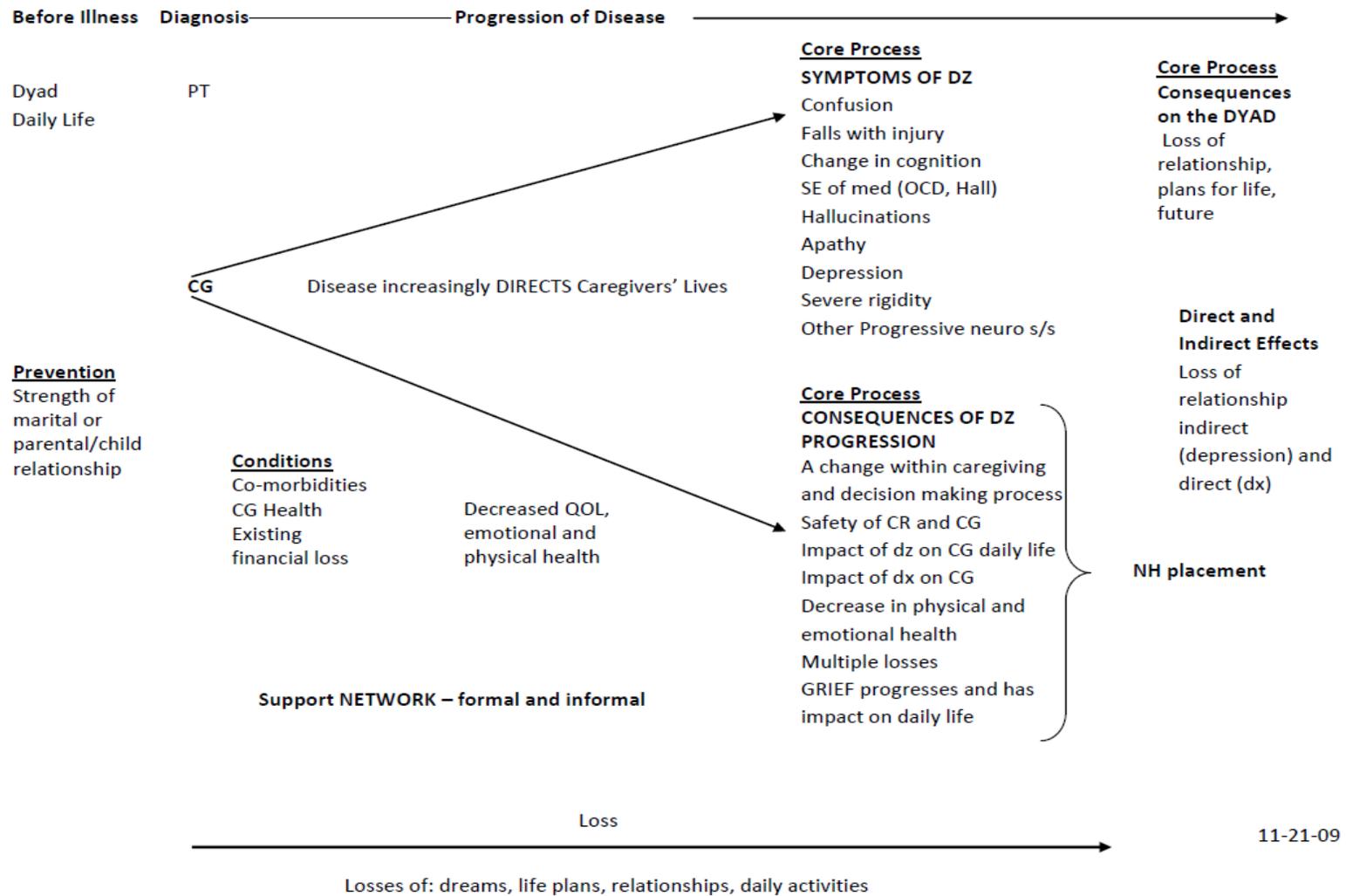


Figure 3-7. The impact of caregiving as the illness progresses

Table 3-3. Synopsis of phases of analysis

Phases	Description
Phase I	Initiate interviews and identify multiple dimensions of the caregiving decision making process. Develop rudimentary illustrations of the dimensions of decision making. Develop individual diagrams for major concepts (categories). Utilize various types of coding. Write field notes, methodological and theoretical memos to track thinking. Meet regularly with data analysis group. Begin using NVivo software in conjunction with hand coding and analysis of interviews.
Phase II	Additional data analysis and comparisons of conceptual models of caregiver decision making to institutionalize chronically ill relatives in the literature. Comparisons help determine where to focus continually analysis in the interviews and looked for missing theoretical links in the literature. Continue with memos and coding and dimensional and comparative analysis.
Phase III	Return to the analysis in phase I and initiate the development of an overall conceptual framework that illustrates how caregivers make decisions to institutionalize a family member with PD or lend support to an existing qualitative decision making theory. Continue with memos describing components of the framework and how they were related.

CHAPTER 4 FINDINGS

The purpose of this study was to better understand how family caregivers (CGs) make the decision to institutionalize a relative with Parkinson's disease (PD). The aims were to explore how families made or would make long term care (LTC) placement decisions and the factors that led to long term care placement. This study also identified the needs of CGs to help them better manage the care of a relative with PD at home.

This chapter explains the findings of the CG interview data in the context of the model developed from this grounded theory (GT) study. This chapter is divided into three sections. The first section describes the participants in the study. The second section provides a description of the conceptual model which incorporates a discussion of the research questions. The third section illustrates case examples within the framework of the model.

Section I: Description of the Sample

Demographic Data

The sample that was interviewed consisted of 17 spousal CGs and 3 adult daughter CGs from north and northwest Florida. Three of the 20 interviews were with both the CG and the PWP. Thus, 23 persons participated in the interviews. It is important to note that there were a total of 37 people enrolled in the study (20 CGs and 17 PWPs) because information about the PWPs were collected even though they were not present for the interviews. Three of the 20 CGs had deceased spouses who had PD (male = 2 and female = 1) before the study began.

Seventeen CGs were female which is not unusual since the prevalence of PD is mainly in the male population (Liebson et al., 2006). The spousal CGs ($n = 17$) were

between 60 and 81 years of age and the adult daughter CGs were between 30 and 52 years of age. The age ranges of the PWP (n = 17, including those not present for the interviews) were 54 to 80 years old and approximately 70% of the PWP were over 65 years old. All persons were White non Hispanic and their education levels ranged from high school to graduate degrees. The majority of the families were retirees and household yearly income was greater than \$30,000 for all participants.

The length of time since diagnosis of PD ranged from 3 to 23 years and the Modified Hoehn & Yahr immobility scores ranged from 2 to 5 on a scale of 1 to 5 with 5 indicating severe immobility (Goetz et al., 2004). It was interesting to note that the length of time since diagnosis and the immobility scores were not related. For example, one PWP was diagnosed for 10 years with an immobility score of 5 while another person had a diagnosis of 12 years with a score of 2.5. Thus, the PWP were at various points in their illness ranging from being fully cognizant with mild physical symptoms (i.e. tremors, changes in gait) to moderate disability with symptoms of dementia. The persons in this latter group were the majority of the PWP / CG dyads in this study. For some, their disability included the necessity of having assistive devices such as wheelchairs, walkers and canes. Table 4-1 is a more detailed description of the demographics in this study.

Two of the 20 CGs currently had their family member with PD in a LTC facility and a third CG's spouse had returned home from being in a LTC facility. Therefore, the interviews with the other CGs, whose relatives were in various stages of the illness, focused on how they would make the decision and what factors would be involved in this decision if they chose to institutionalize the PWP.

Participants' Perceptions

Although this study was about CGs, some of the persons interviewed did not consider themselves CGs because caregiving, to them, was more direct hands on care which was not currently a part of their lives. Others considered themselves CGs from the day they were married since the act of caring was part of the marriage. When people marry, they become CGs whether for their husbands or for their children as reflected in this quote from a CG.

I don't know that my life, to me my life is always been caregiving. Always. I had, that's kind of just me. I have 2 children, 2 adult children, so I was a caregiver to them. I was a school teacher; I was very much a caregiver to my students, more than a teacher. I really care about taking care of people. And if someone's in the grocery store, and they look like they're having trouble, I'll just smile at them and instantly there's a conversation going on (CG 5).

Some defined the role of a CG such as, "To me a caregiver is more like a nurse or something like that, and I really am not there maybe, because I feel like right now, I mean, he can pretty much take care of himself" (CG 19). Thus, the subjects had their own perspectives of caregiving. For the purposes of this study those who were not PWPs were called CGs.

The Faces of the Caregivers

The CGs in this study were all very committed to assuring that their loved ones received the best possible care. They were at various stages of the caregiver journey. Some were just beginning and did not have major adjustments in their lifestyles since the PWP had minor symptoms. Yet, future changes to the PWPs' abilities and what that meant for their families, loomed in CGs' thoughts. These CGs were hoping for a cure or some discovery that would delay the progression of PD. They openly talked about their spouses' involvement in clinical trials, and their energy and hope were contagious. They

perceived PD as something to beat and conquer. Some of these CGs were still able to work full time because their loved ones were still independent enough to care for their basic needs.

Those CGs whose husbands had deep brain stimulation (DBS) surgery were also filled with hope. The surgeries brought much symptom relief for some. It seemed to give them another chance at walking without as much rigidity. This brought some relief to CGs because it was so difficult to watch their spouses struggle with their symptoms. Other CGs were heavily in the middle of the caregiving journey and had good days and bad days caring for their loved ones with a chronic debilitating illness. A good day was the relief that all the medications, which often were given every two hours throughout the day, were taken on time and worked to reduce the symptoms of PD as well as managed to not produce any side effects. A good day was also when the CG was still standing after cooking meals, changing a soiled bed numerous times and making sure any others in the home were cared for including the pets. It was the simple things that made the day good such as just being able to rest or watch TV with their loved ones and just holding hands, hoping the tremors in the persons' hands might subside.

In one family a bad day occurred when the CG's husband with PD had increasing swallowing difficulty which meant that she had difficulty administering his medications and hence needed to contact the physician. These numerous medications were administered every few hours throughout the day. She also had to monitor his diabetes. A bad day occurred when his dementia worsened and he had delusions which scared her. In the same home lived the CG's mother with Alzheimer's disease and another family member with developmental disabilities. It was easy for this CG to become

overwhelmed yet, she tried to maintain a positive tone. I remember her saying how shocked she was when she found out that PD could have a dementia component. This person gave so much of herself every day to this family, and also quit the activities she used to enjoy. She no longer attended church or sang in the choir. She no longer went for walks. Dinner outings were limited to cafeteria style restaurants because it was easier for her to select her husband's food and bring it to him on a tray since he was in a wheelchair. She cut up all his food and always made sure all his needs were met before she attended to her own.

Many CGs tried to remain positive amid being overwhelmed. They often tried to maintain a sense of humor as one CG remarked about the chronic falls that she and her husband have due to his PD and her chronic illness. "It's like Fibber McGee or what is that, three stooges, trying to get up, and I mean we're just a comedy of errors around here" (CG 12). Unfortunately, there was also a lot of stress in the family. Her husband with PD was in a wheelchair, and during the interview, the couple heard that their home was sold. They were so thrilled and relieved because now they could leave Florida and move near family in another state. They yearned for that support from family because the CG remarked that one can only rely on friends for support to a certain degree.

I also interviewed three adult daughters who were CGs, and each had her own story. They all worked full time and had families of their own. Fortunately, they lived in the same town as their loved ones with PD. I could tell they really loved their parents. For example the first daughter CG changed her work schedule to meet the needs of her dad, a widower, who lives alone. She took the lead among the three siblings to care for him. She also worried about her sister who had cancer. The CG missed her mom for

many reasons especially for not being around to make her dad a warm pot of homemade soup on a cold day. Then there was the second daughter CG, who worked two jobs and was ready to be at her mother's side at a moment's notice. She may have had a guarded façade, but later said when her mamma cries, so does she. Then there was the third daughter CG who said she could fix everything and later realized the situation with her mother's illness was out of her control. This daughter made great sacrifices for her mom with PD. The family moved to a bigger home to accommodate her mom, and the CG changed jobs and had home health support. After several years, this CG placed her mother in a nursing home after a fall which injured both of them.

Many of the CGs, whether they were spouses or daughters, sacrificed their own needs such as taking time to do things to take care of themselves such as hobbies or simply taking a "break", in order to be with the PWP. It almost seemed like the CGs and the PWPs identities blended together without either of them realizing it. It was especially difficult when one CG told me that she had to practically think for her husband now. Many CGs feared having to do the household finances and retirement planning, especially if their husbands previously had that responsibility; however, others were more self sufficient and were able to manage. It seemed like one group of CGs had well defined boundaries of how much and what they could/would do while others did not.

As we spoke about the topic of loss, the sadness on many of the CGs' faces was apparent. They experienced loss in many ways as the PWPs' condition progressed. I could see the sadness in their eyes as they reminisced about the past and how the persons they once knew were physically and mentally changing. They loved to show me pictures of former times showing me their hopes and dreams in photos. Yet many of

them never gave up hope, trying to understand the process, hoping for a cure, trying to be so in control of the home front that they could face anything.

Some CGs had different grief. I had the privilege of interviewing those CGs who had completed that journey because their loved ones had passed away before this study began. They remembered their loved ones and were able to reflect on caregiving. One of these CGs called me the very next day after our interview and said to not forget to address grief in this research. She said, "I don't think people realize all the grieving they're doing as they're going along" (CG 18). Some of the ones who lost their loved ones are now reaching out to others and are giving back to the ones who helped them either by being active in the PD movement or helping other CGs.

In summary, the profile of the CGs in this study consisted mainly of female spouses caring for their husbands with PD. The other CGs included daughters and husbands. All the families were from north and northwest Florida. The average age of the CGs was 64 whereas the average age of the PWP's was 69. All persons were White non Hispanic with varied education levels and had moderate income levels. Yet amid all this demographic information, they were real people who had a story to tell. A heartfelt story of their experiences, the good days and the bad days of caring for their loved ones with PD. The following section introduces the conceptual model developed from the perspectives of the participants in this grounded theory (GT) study.

Section II: Substantive Model Grounded in the Data

The conceptual model, which was created from the data, addresses the research questions by illustrating how CGs make decisions along the course of the illness (PD trajectory). In order to understand this complex decision making process and the

supports that are needed to better manage the care of the PWP at home, I will describe the model and explain how the following research questions are woven into the model.

1. How do family caregivers make the decision to institutionalize a relative with PD?
2. What factors influence this decision making process?
3. What do caregivers need to help them better manage the care of a relative with PD at home?

I have included two versions of the model. Figure 4-1 is a basic form of the model; Figure 4-2 includes an expanded level of detail. In Figure 4-1 the vertical line illustrates caregiving load which increases over time. Caregiving load is the combination of doing the specific tasks of caregiving (i.e. Instrumental) and the emotional / relational domains of caregiving (i.e. Interactive). The Disease Trajectory is depicted by the horizontal line which illustrates increasing severity of PD symptoms over time. Caregiver strain is the diagonal line indicating the intersection where the disease trajectory and the caregiver load results in strain. The basic premise of this model is that as the volume of caregiving load increases in relation to the increasing severity of the illness over time, caregiver strain also increases. The following is a more detailed narrative of the Disease Trajectory, Caregiving Load, and Caregiver Strain components of the model.

Disease Trajectory

During the interviews the CGs described their caregiving experiences from the perspective of first hearing about the illness (diagnosis) to the present. This time span was termed the disease trajectory and it was based on Strauss and colleagues' research on dying patients (1991). In this study however, it was not possible to label specific phases in the disease trajectory, as depicted in Strauss' model (1991). There was no consensus among the participants regarding phases of mild, moderate and

severe illness stages because each case was very individualized. Regardless, a trajectory framework is applicable because it is built around the idea that PD is a chronic illness that progressively worsens over time (1991). Even though the horizontal line on the model is straight, in actuality, the course of a chronic illness like PD is dynamic with ebbs and flows. This means that PWDs have good and bad days, and these days are unpredictable in nature even when interventions are done appropriately. In addition to the unpredictability of the symptoms, CGs identified that the type of symptom progression was also unique as noted by this CG.

You can take your medications just exactly right, consistently; you will have 2 days that are terrible, 3 that are good, 1 that is terrible, 2 that are good. There is no consistency with Parkinson's. Our friends will tell you, you can go to 8 out of 10 of them. They'll tell you what I just told you; doesn't matter. It's (symptom progression) not predictable. And with my husband it may have been even more difficult because of the dementia (CG 15).

While, the uncertainty and uniqueness of the disease progression and its symptoms were common in PD; CGs also identified symptoms that were similar in their loved ones. These included micrographia (i.e. small handwriting), voice changes, cognitive deficits, tremors, and balance problems. However, these symptoms were not associated with a specific time frame, especially since disease intervention treatments were different for each family in this study. Regardless, as the disease progressed over time, caregiving load increased and the probability of caregiver strain became a reality. The following sections explore the Caregiving Load located on the vertical arm of the model.

Caregiving Load

The analyses from this study identified two conceptually distinct categories of caregiving which are labeled Instrumental and Interactive Caregiving. The combination

of these two categories is called Caregiving Load. Although they are conceptually distinct the two categories of caregiving (instrumental and interactive) possess some overlapping elements such as the emotions resulting from the role reversal as the CG provides physical care for the PWP. Caregiving Load forms the other arm of the model.

Instrumental caregiving is observable actions and/or mental activities of the caregiver, such as making decisions on the behalf of the PWP for long term care (LTC) placement. Interactive caregiving is the shifting of relationship characteristics during the act of caregiving as well as the thoughts and emotions that are felt by the CG during this process. Instrumental and interactive caregiving are explored further in the following sections and are illustrated in Figure 4-3.

Instrumental caregiving

The term instrumental caregiving was borrowed from Bowers' (1987) grounded theory study which generated a theory on intergenerational caregiving. Instrumental caregiving is the most basic aspect of providing care, and is often the direct hands on approach used in helping a person with activities of daily living (ADLs) such as bathing, eating, and dressing. Bowers (1987) defined instrumental caregiving as doing, providing and giving care, i.e. direct caregiving. The data in this study revealed two subcategories of instrumental caregiving, direct care and indirect care (see Figure 4-2).

Direct care. Direct care consists of numerous components seen in Figure 4-3. The amount of physical care each CG needed to provide depended on the severity of illness; however, physically monitoring medications was a common task for many CGs especially since PWPs often had cognitive deficits and the amount and frequency of medications can be overwhelming for anyone as noted in this quote from a CG.

Every 2 hours he was taking medication and I tried, I couldn't understand why he couldn't do that, we had watches, we had charts, I would tell him whatever. I could figure out, why can't you do this? You know they start out good in the morning, by after lunch it's like, it's difficult. It's extremely difficult. So unless you sit with a watch, a glass of water and a bottle of pills, it's just almost impossible, especially if you can still walk, drive, you know do anything (CG 5).

As the PWP's cognitive ability began to diminish, CGs were often obliged to help them with executive functions such as computer operations and to encourage them when they became frustrated. Being sensitive to the PWP's needs to maintain their independence as their abilities were diminishing was an important psychological aspect of caregiving as reflected by this quote from a CG.

He didn't want me to give him his medications. That was a big thing with him. And I finally, by working, working, working, every way I could think of that would not make him feel inferior or something, so I started making, I got a chart, that you wouldn't believe, a medicine chart, right next to my stove, and right under the board, and then I write, so he wouldn't feel uncomfortable or feel out of sorts (CG 8).

Often it was difficult to provide this direct care especially as hands on caregiving shifted into the type of care a nursing assistant would provide as revealed in this quote from a CG.

I don't know how many pads I had on the bed, and an adult diaper with padding in it. Of course he was aware that I was doing all this for him. He never said anything, but I know it must have been very difficult for him to have me have to do those things for him (CG 18).

In addition to providing this direct care, the CGs were also involved with an indirect type of care for the PWP.

Indirect care. Indirect care was care given on behalf of the PWP. For example, as driving became difficult for the PWP, many CGs provided transportation to local and out of town health care providers. Also, when necessary, CGs began to take a more active role in interacting with health care providers. Another example of indirect care occurred

when CGs made care decisions on behalf of the PWP including LTC placement when appropriate as noted in this quote.

And the great shift came about where I was the decision maker, and he wasn't able to make those decisions any more or if he made the decisions, they really weren't all that great. So I became the one in charge (CG 18).

Indirect caregiving also focused on responsibilities that were necessary to run the home, such as managing day to day finances, household maintenance and yard work. These were activities previously done by the PWPs and now done by the CG because the PWP was no longer able to do the activity. In this situation the CGs either did these extra duties themselves or hired someone as this CG states.

Yes, and we've just been really hard workers. I mean everything that we've done, we've done basically ourselves and that's the hard thing right now is calling on people, even calling, having someone to come rake your roof off it's a bad situation now (CG 4).

Without some type of support, this extra caregiving responsibility often resulted in mixed emotions and difficulties in the relationship which is addressed in the following section.

Interactive caregiving

The second category identified in the data was interactive caregiving. This category has two sub-categories (domains), the relational domain and emotional domain. The relational domain consists of two components: roles and relationships. The role component refers to the different and shifting roles in the caregiving experience. The relationship component refers to the way the CG / PWP dyad relate to each other throughout the disease trajectory. There may be pre-existing relationship dynamics; however, this discussion emphasizes changing relationship characteristics since diagnosis.

Relational domain. Caregivers of PWP's assume multiple new roles as the disease progresses. These roles included being a coach/cheerleader, teacher, informal counselor, head of household, driver/navigator and supervisor. For example, being a coach to help encourage the PWP to do activities, and being a supervisor to oversee the safety of PWP's with unsteady gait in the home. Some CGs may not consciously realize they are taking on these new roles and corresponding responsibilities. Table 4-2 depicts these roles within the larger caregiving role component and explores their meaning and how they were acquired.

In addition to these changing roles, CGs experienced shifts in their relationship with the PWP's as the illness progressed. This was described by spousal CGs as a shift from a partnership to more of a parent/child relationship. The shift was especially visible when the PWP's' cognition was affected as noted by this CG: "She and I were in love for ever, and as things changed, that love changed. You know it wasn't so much, at least for me, like man and wife. It was more like, maybe father, daughter" (CG 10). Other caregivers had similar experiences that are reflected in this quote.

It's more like, I think the mother, like you're taking care of him, covering him at night, making sure he's warm, that type thing. It's more of that relationship rather than just an equal relationship as a husband and wife situation. Because we have to do that, so then that's the role that a mother would take, I guess, you know, dressing him, making sure, make sure he eats properly (CG 20).

For adult children this shift was more of a role reversal where the adult child became like a parent and the PWP became the child, as this quote illustrates.

It was just a bizarre feeling, because I (adult daughter CG) was shopping with my mother (PWP) and my son and having to tell them the same thing. No __ (son) you don't need that. No mom, if __ (son) can't have it, you can't have it. You know that kind of thing. I can remember when I finally realized that we couldn't take her with us to do things any more. . . she's my mom

and I love her and I'd do anything in the world for her, and it's funny to think that there are days when I feel like the mom now (CG 14).

As CGs reflected on these shifts, it was clear how strongly the changes affected them. Many acknowledged a profound sense of loss of the previous relationships they had with their family member with PD as they recounted their stories. Grief, which was a response to loss, was a thread that was woven throughout all the interviews as the PWP's illness progressively worsened. These emotions and others and their link to the relational domain are explored in the following section.

Emotional domain. The emotional domain was defined by the many positive and negative thoughts, beliefs and emotions that are experienced by caregivers as a result of interactions with PWP's as well as from the effects of instrumental caregiving. In this study one of the main emotions people identified was grief resulting from existing or impending loss. This emotion was succinctly expressed by one CG upon hearing her husband had Parkinson's disease. She said, "Allow for grieving. It is in a sense a death and you feel that" (CG 5).

Caregivers expressed loss of their previously imagined past and future lives. Emotions connected to this loss were expressed in many of these interviews. This CG noted, "You don't have the 15 to 20 years of just laying back and enjoying life, so then, you're bitter, you're um, you just have to work it through and take it like life's a change, so this is a change" (CG 4). The following CG expressed this loss as he grieved throughout his wife's illness.

Well it costs us both what your American dream is as far as retirement, the travel, that she and I were going to do, being with my friends, doing my hunting trips, my fishing trips out of state, I was not able to do. Being with my grand kids in an environment other than a sick environment (CG 10).

Many accepted changes to their daily routines and the loss of time to do the leisure activities they previously enjoyed because their priority was now taking care of the needs of the PWP. Caregivers began to sense a loss of who their loved one used to be, such as the person with more energy, the person who did things faster, the person who showed an outward expression of a smile. As this CG notes, “He liked to do things outside. He liked to camp. He liked to do day hikes and back packing. And he can’t do that. It hurts (sounding tearful). Because I know he was such an active person” (CG 16).

Not only was there a loss of these physical characteristics but there was a sense of profound loss due to the person’s diminished cognitive ability such as the inability to maintain a checkbook when the person had previously been brilliant with numbers. Many CGs were incredulous when they talked about the changes from the person of the past to the person of the present. Not being able to do relatively simple tasks due to diminished cognitive ability was heartbreaking to many of the CGs and these feelings were exacerbated by fears of the future especially if they were not already involved in retirement and financial planning. Another type of loss was a change in the dynamics of the marital relationship.

The loss and grief for CGs was profound especially when they began to sense the terminal loss of the personal connection the couple had in their relationship. One caregiver specifically talked about the loss of this relationship by referencing the movie “Australia” when the Aborigine boy, Nullah, said “I sing you to me”, and Lady Sarah Ashley responded, “And I will hear you, my darling!” (Internet Movie Data Base, 2010) This CG was a gifted singer and she said she could no longer sing her husband back to her. With tears in her eyes she said he was not the man she once knew. The

spontaneity and humor were gone, and she wanted so much to sing him back to her but it was not possible for him to come back to her anymore (CG 17). This other CG also sensed the loss in the relationship she and her husband once had as reflected in the following quote.

I used to depend on him more as being, you know, when I would go to pieces or whatever, emotionally, he would be my rock. He would be the one who could comfort me, and console me, but I don't get that anymore; very seldom. I miss that (CG 3).

Although grief and loss were the main emotions expressed by caregivers, they also identified other emotions during their caregiving experience. These emotions included bitterness, anger, and sadness toward the person, toward the illness or even toward God. At times CGs felt abandoned and strained by the physical and emotional load of caregiving as reflected in this quote.

It was a horrible emotion (feeling abandoned). You would be, and you know you never knew when it was going to come on. I would be sitting there and all of a sudden, you know, my God, I've got to wash dishes, it's time to cook dinner, I've got clothes to fold, I've got to go strip the bed and remake it, because of an accident. And tomorrow is just going to be the same thing, and the next day (CG 10).

Feelings of guilt were also experienced by CGs throughout the caregiving process, and for some these feelings lingered after LTC placement as noted by this caregiver.

I made the decision that I think all the time about whether I made the right decision. Even now after 4 years, I just, I think that, I hope I made the right decision and so forth. So there is guilt. I have guilt, I feel guilt all the time. Well I need to go over and see him, and again, I go over, during that period of time, I go over everything in my mind and I need to reassure myself that I've done the best, made the best decisions for his care (CG 6).

It is important to note that while CGs felt strained by the day to day responsibilities, they also experienced a sense of satisfaction in helping the PWP as reflected in this quote.

It was also being pleased with myself, for being able to do this. It was, I was very happy to do these things for my husband. I tried to make his life as enjoyable as possible. That wasn't drudgery, but that was rewarding. So, I think just when you know that you have gone the extra mile to do something for someone, that that gives you a good feeling. There was drudgery, I mean you know, washing the sheets every morning and running to the emergency room (CG 18)

Many emotions were woven through the disease trajectory and were not necessarily triggered by any specific event. However, the accumulation of the events leading to caregiver exhaustion and even LTC placement for some, often exacerbated these emotions. This caregiving experience along the PD trajectory is extremely complex and filled with numerous types of interactions and activities that impact caregiving and caregiving decisions. The intersection of Caregiving Load along the PD trajectory is called Caregiver Strain which is explored in the following narrative.

Caregiver Strain

The Caregiver Strain diagonal line on the model (Figure 4-1) slopes upward from the intersection of the caregiving load and the disease trajectory. As both the volume of the caregiving load increases and the symptoms of the illness worsen over time, caregiver strain also increases. The type and magnitude of caregiving load that lead to strain varied among CGs.

Caregiver strain was the most appropriate construct representing the experiences of the participants in the study especially since strain represents physical emotional, social and/or financial burden in the process of giving care to another (Carpenito-Moyet, 2008). Initially, the term was labeled "burden" in the preliminary model. However, when this model was presented to caregivers during informal meetings (member checks) they felt the term "strain" more accurately described the construct. They thought strain was less negative and harsh compared to the word burden even though the words are often

used interchangeably in the literature (England, 2000). The defining characteristics of caregiver strain include having insufficient time or energy to provide care, apprehension and worry about the person's care. Feelings of anger and resentment also occur, especially if there is no available support or respite (Carpenito-Moyet, 2008). The following CG illustrates these how a typical day leads to strain in caring for a PWP.

The whole day was surrounded by medication, by therapy, by exercising, by naps, by we can't eat protein for breakfast because of what it does with the medicine, by we have to have lunch by a certain time. Yeah. . . if she takes the medicine at 8, then we can schedule a doctor's appointment for 9, because the tremors will be over, and we can be dressed. If we can get back by 11, then we can take medicine at home. So, that half hour or so that she's going to be trembling so badly, she's here and she's comfortable. Then we can have lunch, and then if we want to go out, we have this window of time (CG 14).

Therefore, strain is often a result of unrelenting care secondary to an unpredictable illness course such as PD. This unrelenting care increases over time as the PWP becomes more disabled and needs frequent medical care. As strain increases, the risk for long-term care placement also increases. The results of the analyses also identified (a) the conditions that increase and decrease caregiver strain, (b) strategies that decrease caregiver strain and, (c) specific triggers that lead to LTC placement. These are shown on the expanded version of the model (Figure 4-2).

Conditions that Influence Caregiver Strain

There are several conditions that can either increase or decrease caregiver strain.

These include:

- Informal and formal support
- Sense of self preservation
- Pre PD life circumstances
- Imposing life events

Informal and formal support

A major finding of this study is the importance of support for the CG/PWP family unit. Families mentioned various forms of support that were important to their overall well being especially in reducing strain and to help them better manage the care of the PWP at home which was the focus of one of the research questions.

The support network. A strong support network, individualized for each family, was crucial for the family structure to survive as a caregiving unit and reduce the risk caregiver strain which in turn reduces the risk of LTC placement. This multifaceted support network is an umbrella term that includes multiple informal and formal types of support. The analysis of the data showed that the network of support had many facets that were intertwined. For example, friends provided the needed empathy that some families were unable to provide whereas professional caregivers provided specific services such as nursing care and rehabilitation counseling. Families as well as friends were present even late in the night during a crisis while organizations like Hospice reinforced that home presence with professional and compassionate support.

There was also a type of indirect support that benefitted CGs. For example, if others, such as friends, emotionally supported the PWP, then that support reinforced the care and support provided by the primary CG. For example, a spousal CG indicated that the support her husband receives from his church group reduces the amount of support she needs to provide since it comes from others. All these interwoven types of assistance were essential in a multifaceted support system. This was explained by the following CG.

Well you probably need all those (informal and formal supports), you need it for different, nobody understands a job except your coworkers. Nobody understands a marriage except people that have probably witnessed or

been. When I go to a friend that knows him or that's how my husband is, and that kind of gives you that strength (CG 19).

Table 4-3 illustrates the various types of CG support in the network. This table provides a list of types of support with examples. This following discussion explores the facets of caregiver support which helped families better manage the care of PWP's at home.

Family support structure. The family structure is considered an informal source of stability and played a pivotal role in helping to care for relatives with PD. Specifically, children and step-children of CGs and PWP's living in the vicinity offered assistance with various needs such as helping with home maintenance or providing respite for the CG. In one family the adult sons attend Rotary Club meetings with their father so that their mother can have time to herself. In another example, a daughter visits her father to talk about poetry which provides emotional support for the couple and helps keep her father's mind active. Often support was very strong in families who did not live near one another. For example, interactions among siblings who cared for their parent with PD were identified to include all facets of support as seen in this quote.

My brother and I are only 20 months apart, and next to my husband, he's my best friend in the entire world and there is not anything that we've gone through with my mom (with PD) that we have not gone through together, that we've not shared the decisions, that we've not shared the research, that we've not walked that path together (CG 14).

Several CGs over the course of data collection made decisions to move closer to family in order to reduce the family's worries and to be physically present for emotional support. "We're just a very close family and the kids are going to worry, one way or the other. So why aren't we just there?" (CG 12) However, there were families who were more reserved in their interactions. Some family members were unable or chose not to

provide emotional support but were present for any physical needs, such as home repair or transportation for the CG and the PWP were needed.

This type of physical presence was very important to families because those family members were also available at short notice whenever the need arose as reflected by this quote, “When he’s (caregiver’s brother) out this way, he swings by to check on mom and get him a Coke or whatever, so I don’t see him a whole lot, but I can call him and he’s there for me, whenever, for whatever” (CG 9).

Both physical and emotional types of support were seen among the participants; however, some CG / PWP dyads did not want to burden other family members, especially their children, with their needs. This type of stoicism was more prevalent with older CGs as this person states, “I don’t complain about feeling lonely to them” (CG 6). However, family support is important in caregiving situations, especially if serious caregiving decisions need to be made. Thus, not wanting to ask for help or even feeling uncomfortable to ask for help from others can have negative outcomes for families.

Friends as informal support. Friends were also a strong source of support for CGs. Whether they assisted with meal preparation or provided empathy, they were available. At times though, CGs felt supporters could not truly understand what they were going through unless they had similar experiences as noted in this quote from a CG.

Nobody sees my husband’s full condition. Nobody. Nobody sees it. The children don’t see it. Somebody just needs to stay with him a week or maybe 24 hours. I think they’d be shocked that he’s lost so much of his abilities (CG 4).

In this study some support from friends was lost as the illness worsened. CGs speculated that it might have been due to friends either feeling helpless if the PWP

would fall or feeling uncomfortable about the effects of the illness (i.e. obsessive compulsive mannerisms). The waning of support affected CGs because they felt abandoned especially if their friends were an integral part of their lives. Several families also yearned to have friends who would not focus on the illness. They wanted to enjoy other areas of life without having to think about the disease as this CG stated.

I have a lot of younger friends. I have one group my age and they're sort of there somewhere, and then I have a lot of younger friends. We go to the beach and we go for the weekend and we go partying if we want to, we go out and act silly, you know we just do. And they're always saying I'm the one that gets them in trouble instead of them getting me in trouble (CG 20).

Spiritual support. In addition to the family and friend support structure, many CGs found solace in a strong spiritual foundation as this CG said.

God is my main source of strength. I couldn't make it without Him. I probably don't take the time to pray as much as I should, maybe things would be easier if I spent more time praying, but there's just not a lot of extra time (tearful sounding). Usually it's after I go to bed at night, is when I pray, because then everybody else is taken care of. Of course during the day, I do a lot of little short prayers for help (CG 3).

In many of the interviews, faith in God was very powerful and this faith spanned across the illness trajectory. Anger and bitterness toward God did exist among some CGs though these feelings seemed to subside with time. It was apparent that CGs needed a source of strength to carry them through difficult periods because they had no control over the effects of the illness. Thus, "God" as a source of strength gave some comfort. Several participants said that a lack of faith and a support network would create total chaos and disarray in their lives. It would also be "A deep dark hole with no way out, a pit" (CG 14).

The community of providers and support groups. Professional caregivers and other types of formal professional or paid services were a strong source of assistance

for CGs. Several CGs thought health care providers should inquire about the CGs' health and well being during routine visits for the PWP. CGs needed to feel validated by professional caregivers as well as have their own needs addressed to help minimize strain from caregiving. One person felt her provider could not provide optimal care due to not being able to coordinate family care. She said, "And even doctors, primary care, they treat him, they treat me. I'm not so sure they really even know we're a couple" (CG 19).

There were mixed feelings about the advantage of PD support groups. Some CGs and PWPs were uncomfortable with the dynamics of the support groups they attended because everyone was at different stages of PD and the dyad felt unable to relate to them. They also perceived that many of the programs at support groups were redundant and not helpful. Thus, the dynamics of support groups did not always fit the CG / PWP dyad's needs as reflected in this quote.

And so we went to one of the support group meetings, and he saw people shuffle in and he saw people in wheelchairs and people who were in a frozen state, and it alarmed him more than it helped him, so we didn't go back to any more of those support group meeting (CG 7).

Others thought these groups were helpful, especially if participants had an opportunity to talk among themselves or break into separate CG and PWPs groups. Also, groups that formed around specific needs such as ones solely focusing on CGs of PD relatives were popular. One CG support group was referred to as a sisterhood which denoted a safe environment in which sharing and empathy were valued. She referenced a "sisterhood" because there were no men in that support group. This type of support system was unassuming yet always present when needed.

A unique PD couples group was formed among some of the CGs. It was originated by families whose spouses with PD were at similar stages of disease progression. They met once a month to discuss advances in disease treatments, validate each other's concerns and then socialize. This tailored group was a strong source of support for those five couples as this CG explained.

So we get together, and this is like a little support group thing that we do. . . we're all in the same boat on this thing. I've developed a rapport with these people to an extent and so it's a social event for me and it's a support thing for her (CG 13).

Mental health counseling was another means of assistance which was beneficial to CGs' well being and the continued ability to care for the PWP at home. Participants openly discussed symptoms of depression during their interviews and many felt these symptoms existed in the CG and PWP population. Thus, counseling and medication, as a form of support, were interventions that addressed that need according to the CGs. CGs also stated that their counselors encouraged them to find time to care for themselves as stated by this CG.

I finally had to starting doing that, taking time for myself and doing something just for me. And it took me a year to do that without feeling guilty. My counselor said, I want you to make a list of all the things that you would enjoy doing, just for you (CG 7).

Respite care. Respite was noted as a highly important source of support for the CGs in this study as reflected by the following CG.

I've tried it (respite) before and my attitude changed during that time. Actually I felt more rested and I felt like I could cope better. When I could just go do something by myself without having to worry about getting the wheel chair out of the trunk and get him in and out of the car (CG 3).

Unfortunately, this CG would currently greatly benefit from this type of respite care but has not utilized it.

Other CGs in the study often needed a person to stay with the PWP while they did errands. Some did not feel comfortable leaving the person alone due to being a fall risk. Unfortunately, these short moments away from home were not always enough for the CGs. It was more of an opportunity to run errands without fear or worry about PWP's safety. CGs needed respite care which was not always available. This CG explained his perspective of respite care.

At least, the very least, 4 or 5 hours (time away) where you do not have, ideally, 8 to 16 hours. And 24 hours would be ideal, just to give you a little R&R (rest and relaxation) and sometimes you have to go away for several days. If you don't, you'll become so ill that you won't be able to do what either mentally and physically, but you won't be able to take care of the person (CG 10).

Even though it was important for the CGs to disengage from the caregiving environment, several did not do this. The result of not caring for self was well stated by this CG.

I see caregivers that themselves need to be cared for. Maybe they have stress, maybe they have depression, maybe they have whatever, but they almost need a caregiver themselves, they're not in a condition to be a good caregiver (CG 5).

CGs were often aware of support agencies and organizations that could provide in home assistance; however, there were situations when the PWP did not want others coming into the home because of the cost or because they did not want strangers in the home. Those reactions placed added stress on CGs especially those who were in great need of respite.

Pets as support. Sometimes though, those CGs as well as others in the study, had pets, such as dogs and cats, which provided a unique source of comfort in the home. Pets were present in the homes of almost all the families in this study. Pets provided comfort to relieve stress for CGs and PWP's. Some persons admitted that they

treated their animals like their children and it was evident during the interviews that their pets were a source of happiness and emotional support for the families as reflected in this quote.

I have been replaced by a 4 legged fuzzy little kitty cat. But they're just like babies to us and he loves them and I love them. But it brings tears to his eyes, when he sees how gentle they are and if he doesn't feel well, he'll go in and lie down with them (CG 7).

Another CG felt very attached to his dog who remained closely by his side throughout the entire interview. It was very apparent that the couple in this interview adored their dog. The wife with PD stated, "She (the dog) loves her grandpa (the CG)" (PWP 11). Pets and the other types of support described above helped CGs and their families and were essential components to help maintain caregiving in the home.

Consequently, support provided knowledge, comfort, companionship, professional and custodial care and it helped CGs maintain an independent life outside of the CG role. These CGs did utilize various aspects of a support network including guidance from health care providers and noted that a lessened support network would have greatly increased strain and precipitated LTC placement of their loved one.

Caregivers' sense of self preservation

Another condition that moderated strain was the CGs' sense of self preservation. CGs typically had a strong commitment to their spouse or parent with PD and LTC facility placement was not often considered, especially by CGs who were raised to believe that care should begin and end in the home. However, some CGs became so involved with the PWP that they neglected their own basic needs. Two types of CG characteristics that impacted caregiving decisions were revealed in the data. These were (a) degree of self preservation (i.e. promoting self care) and (b) a lack of self care,

which were depicted in Figure 4-2 under conditions that decrease and heighten caregiver strain. Those CGs who exhibited a sense of self preservation were compassionate in their care for the PWP; however, they also realized that it was important to make time for their own needs. One of the CGs used an analogy to emphasize this point.

You have to nourish yourself. And take time for yourself so you can give to others. If you have a pitcher of water and you pour that pitcher of water, for everybody in your family, over and over and over, and you don't save any for yourself, you run dry. You have nothing left to give. You're burned out, you're parched and then you're frustrated and you're angry. You've given to everybody else and nobody's giving a hill of beans about you, or given anything back to you. And they keep taking and they keep taking. So you have to save some back for yourself in order to give to somebody else (CG 7).

It was interesting, yet not surprising, that many CGs spoke about the need to care for the self or have a sense of self preservation but could not do it for one reason or another. Some CGs had difficulty separating themselves emotionally and physically from the PWP. Their lives were so connected with that person that there was no time for the needs of the CG. The following quotes from CGs are examples of the difficulty to separate from the PWP.

It did help me to be able to get away. That did help, yes, but I still, I guess I've always been a nurturer and I still, that was my main priority was, that was my priority to take care of him and make sure he was safe (CG 6).

I've had a lot of years of painting and it's just, I know it helps me as far as my well being and contentment within myself. It helps me to paint. But if it's going to take getting me stressed out to get out here and paint, while I'm worried about him, I'll just set this aside and make sure he's taken care of (CG 8).

Sometimes this need to find time for self care was difficult because some CGs felt they needed to be in full control of caregiving. The following CG urged others to be realistic about their caregiving abilities as noted in this quote.

I'm telling you to take time for yourself, because you can't handle it and as a caregiver you want to be able to handle everything, and be able to do everything by yourself, and sometimes you just need to be reminded that you're not by yourself (CG 14).

Having a lack of self preservation subsequently put CGs at risk for exhaustion and an inability to manage unexpected events which can result in LTC placement. Thus, people who had a strong sense of self preservation and valued the need for self care can prevent or moderate an increase in caregiver strain.

Not surprisingly, CGs whose spouses or parents with PD were still relatively independent, had a stronger ability to maintain their physical and mental health during the caregiving experience. These CGs were also very organized and used support when needed. Another group of CGs who were able to have time to focus on their own needs were those whose loved ones with PD did not live with them in the same household. This condition and several others, such as a strong support network were things that helped to decrease caregiver strain and lessen the risk of LTC placement (see Figure 4-2).

Depending on the relationship between the CG and the PWP, the emotional turmoil of the placement decision process yielded feelings of guilt, betrayal, abandonment and a general sense of defeat (i.e. not having the fortitude of being able to care for the PWP at home). These strong emotions impeded the decision making process and delayed placement even if it jeopardized the CG's own health. In the following example, the feelings of guilt still existed, but the CG (adult daughter) realized that self preservation for her family needed to be a priority in the LTC decision process.

It was, and still is, something, a decision that I, (CG), agonize over every day. Every time I go there, I leave in tears, because it breaks my heart. But I also know that my first obligation is to my husband, and to my boys. And

to myself and because of that, she's (PWP) 3 minutes from me, I see her every day (CG 14).

Pre Parkinson's disease life circumstances

There were several pre PD life circumstances that were part of the caregiving context and were conditions that impacted caregiver strain. For example some of these circumstances were generational beliefs, pre-existing relationship dynamics and positive or negative attitudes (see Figure 4-2).

The participants in this study were from different generations. They were either from the WW II era often called the silent generation or the Baby Boomer generation which lived through the civil rights era and the Vietnam War. Their different views, based on shared generational events, impacted the CGs' perspectives on caregiving as shown by the following quotes. In the first example an older person caring for her spouse comments about the capabilities of future CGs implying that they will have caregiver strain because they are not prepared for life.

I came from a generation that was different than today's generation. And I think as caregivers change, I just pray that they have the strength to do it (caregiving) because a lot of them don't have the resources that we have. You know when you look back at the men that fought, WWI, WWII and look at the film clips of what they went through and you think, I don't think today's people can do that. So I think, is a concern to me that generations that are coming up haven't been prepared very well for life, and life going to keep right on ticking (CG 5).

In the following example, an adult daughter makes an observation about LTC placement decisions by stating how today's generation accepts LTC placement and having that pre planned option could subsequently decrease stress for the next generation of CGs (i.e. her children).

I think with my dad's generation, they didn't put their parents in different types of homes. Our generation, we understand, like I know for my girls, I want to have that set up. I think my dad, we always had my grandparents at

home. They never went anywhere because the family always took care of everything, but back then, not everybody was working either the way that we are today in our society (CG 2).

Thus, CGs attitudes and opinions were impacted by the events of their generational time period.

CGs' general attitudes about life were also an existing life circumstance. Their outlook, whether it was the "glass half full or half empty" philosophy, played a role in how they managed their caregiving experiences which included how they managed strain. For example one CG noted,

My glass is generally always half full or full, I had to work really hard to get to that point in my life, I was always a pessimist. And it's only been in the last 15 years and 4 years of intensive counseling that's made me realize that my cup is half full. And regardless of what I'm handed, I still feel that my life is so much richer and so much happier because of my husband. He has helped me show my kids what I always wanted the ideal marriage to be like. And I've watched them take that into their relationships, too. And that just means everything to me (CG 7).

Also, it was assumed that the families in this study had their own relationship dynamics before the illness began. Pre-illness relationship dynamics and attitudes affected the way CGs managed their responsibilities and risk for strain along the course of the illness. One person talked about these relationships in the following quote.

I'm beginning to see that if people will have taken care of their ill person, they become stressed themselves and things that maybe were in a marriage way back or things they tried to put back and they get tired enough from taking care of them, they pop out. And when that pops out, that caregiving, I think changes. Now I'm lucky in 2 ways. We don't have a whole lot of bad history. I mean we have normal marriage things, you know, well why didn't you do this or why didn't you do that, but we don't have any serious flaws. And again, my faith is to forgive and try to forget and go on. So I think we don't have that, I constantly try to make ___ (husband) feel like he's loved and cared for (CG 5).

I did not see any differences in relationship dynamics or caregiving responsibilities between males and female CGs. One CG made an interesting reference to gender

identification and cultural expectations of caregiving when she noted, “the caregiver is always the woman. The woman’s position is always the secondary one. That’s the way our society is” (CG 1). That comment indicated that from her perspective caregiving is part of a woman’s role. Thus, women should not complain to anyone when they become strained from caregiving as noted by this CG.

And I think, too, even learning to ask for help, because sometimes I’ve been so frustrated, not necessarily with him (PWP), but everything that’s on the plate, plus him. I need something, please, but as a woman, you’re hesitant to say that, and there again, to men doctors, that’s whose my primary care, because they think, you know, you’re a woman, you know men are supposed to do this, and you’re just belly aching. I don’t know (CG 19).

Being uncomfortable to ask for help because of these perspectives can put the CG at risk for increased strain.

Many of the CGs and PWPs were older adults and their physical health was an existing factor in this study. In some cases CGs had physical injuries as a result of caregiving or developed new illnesses or had exacerbations of existing illnesses during the caregiving period. Many of the PWPs had co-morbidities in addition to PD. Some of the co-morbidities were chronic while others had been various acute injuries. Table 4-4 lists the health conditions of the PWPs and CGs.

Imposing life events

Another condition that affected caregiver strain is imposing life events. Several CGs were worried about not being able to care for the PWP in the event of something unexpected happening to the CG. This worry, especially if it worsens, can lead to caregiver strain. An example of this concern is revealed in this quote. “My biggest, if there’s a fear, would be that something would happen to me first, and I wouldn’t be there to help him through everything” (CG 7) which is similar to this CG’s concern. “And

then I worry about my health (emphatic tone). I mean I really do. I mean sometimes I feel like I can have a heart attack in a minute” (CG 4). Thus the fear of an imposing life event such as sudden illness was real among these CGs. If a sudden event, like a very severe illness, did affect a CG, the strain would be so severe that it could not be moderated by any condition that would decrease strain. In this example, the imposing life event condition could only increase strain (i.e. only be one sided).

Another concern or imposing life event was a change in family finances due to lost retirement as reflected by this quote. “And with the stock market, of course, being what it has, we’re having to be a little more careful because what we had set aside, we lost a lot (CG 16). Other financial concerns were directly related to the cost of caregiving and LTC placement decisions especially since the cost of LTC placement is prohibitive for many. This CG emphasized that the strain stemming from the financial cost of caregiving is great.

I think when people hear Parkinson’s they think Michael J. Fox, they think Janet Reno, they think Pope John Paul, Mohammed Ali. The difference between those people and the reality of most Americans is that they have plenty of money to have the best care (including long term facility care) and all the help in the world that they need, and 99 percent of Americans don’t have that (CG 14).

Thus if CGs have difficulty managing events such as the unexpected loss of health or imposing financial difficulty, then their risk of caregiver strain increases and in some cases cannot be moderated.

Strategies that Decrease Caregiver Strain

The strategies CGs use to successfully balance the many elements of caregiving can reduce strain and subsequently reduce the risk of LTC placement decisions. The CGs in this study engaged in multiple strategies to minimize primary caregiver strain

and the untoward effects of caregiving. They were also used to better manage the changing roles and responsibilities the CGs had to assume. The following is a description of each of the strategies which are also illustrated on Figure 4-2 by the box linked to a green arrow “pushing down” on the strain line to signify that the strategies decrease strain.

Planning

The strategy of planning, which includes organizing and preparing, was pivotal in caring for PWP's because of the complexities of the disease process. Long range plans included verifying that the family's affairs were in order. Day to day planning, which focused on the illness, became a priority as the disease progressed. The strategy of planning became so focused that it revolved around short term or day to day planning, such as preparing meals. This type of planning took precedence over long range plans because of this intense daily caregiving. For example, the day often revolved around medication schedules which had their own challenges due to (a) the high frequency of dosing and (b) the PWP's diminished ability to self medicate. Therefore, the CGs needed to assure that the days were planned well.

The following CG kept her days planned with many mnemonic devices to help the PWP.

Right now, actually I've taken over his medications, administering his medications totally. And so the night before, I make sure that I have all the medications lined up. I have an erase board right in my kitchen that I put up only after he started having a problem remembering what day it was. I write the name of the day, write it out and then I write only things up there that are absolutely essential that we're going to do. Like doctor's appointments and things like that because I found out that if I start putting too much up there, it gets him really confused and makes him worry (CG 8).

CGs would eventually alter job schedules and give up or alter activities that they once had the freedom to do because of the responsibilities of caring for the PWP. This need for organization and planning was even reflected in long range plans by this CG.

You need to start a filing system and maybe your folders are empty for awhile, but you need to make some. You need to make social security, you need to make retirement plan, you need to make will folders. You just have to start easy, but don't stop, keep at it. Get those files going, get a long-term health care file going, social security, disability insurance, supplemental health (CG 5).

When another CG was asked what it would be like if she were not organized or did not have short and long range plans, she emphatically responded, "I would be in a panic. I would be in a panic. Head over heels wondering about the next day, and how we would be spending our later lives" (CG 7).

Another strategy similar to planning was organizing. The need to be organized, which included good multitasking and planning skills, was reflected by the majority of the CGs. Those who felt they were not organized commented that they needed to become more so as the PWPs' illness progressed. They also felt a need to have strategies in place to help them maintain a sense of normalcy in their caregiving lives since the course of PD is so unpredictable. Thus, the activity and satisfaction from planning can help prepare CGs for changes in the person's condition. Although planning was a good strategy to reduce strain, caregiver strain still existed at times due to unexpected situations especially when CGs were not physically present with the PWP as described in this quote.

So when you get a phone call at 2 o'clock in the morning because dad is seeing Indians in the house or he feels like someone's breaking in, then you do have a concern about that, because we don't want anyone to be afraid in their own home. And of course, as the drugs get altered, then it will stop doing the hallucinations, but still, it's little things like that or if they're going to fall (CG 2).

In addition to planning (and preparing, organizing), the data revealed other types of strategies CGs used to help them manage their lives and responsibilities.

Seeking knowledge

The strategy of seeking knowledge was common among the CGs in this study. Many of them assertively sought to learn as much as they could about the illness to harness a semblance of control over that feeling of uncertainty about managing the care of the PWP as the disease progressed. The unpredictability of day to day symptom inconsistencies due to the effects of different new medications, adjustments to post Deep Brain Stimulation (DBS) surgery and other physiologic changes were an ongoing concern. Thus, the strategies of seeking knowledge about the illness, as well as being organized, were an attempt to manage the unpredictability of the disease progression.

The strategy of seeking knowledge is also related to learning about temporary LTC placement options so that the CG may have respite. The following CG would have benefitted from that knowledge as she talked about her husband and potential nursing home placement.

But when you think about things like that, that's almost like an impulse thing. Then I get the thought, now what if, on an impulse like that and I'm mad, I go ahead and make the arrangements and he's in there and then I regret it. Then what (nervous laughter)? How do you undo it (nervous laughter)? My thinking is, it wouldn't be undoable at that point (CG 3).

The consequences of the belief of the irreversibility of LTC placement would prevent the CG from using placement for short term respite or cause the CG to delay institutionalization if it is needed for the well being of the CG/PWP dyad.

Adjusting to the environment

Another strategy that was important to these CGs was making adjustments to their home environment in order to prevent falls which can lead to injuries. People with PD

can be fragile because of balance problems and severe rigidity. This fragility was figuratively described by this CG when she said, “Here you have people who fall down like a leaf” (CG 1). Making the home environment open and free from clutter reduces the fall risk and possibly reduces the risk of LTC placement in the event of a severe injury. One family moved from their existing home to accommodate the PWP as revealed in the following quote.

We sold the house that we were living in because it was 2 story. All the bedrooms were upstairs. There was no way that she could have navigated it. We bought a home and moved her into it with us, and she lived with us for probably almost 3 years. It (the move) was completely because of her. And we bought a bigger house that allowed for her to have her own nook (CG 14).

While these were the most common strategies discussed, CGs also mentioned additional approaches to care, such as seeking support by reaching out to family and other sources previously mentioned and caring for self by making the time to focus on their own needs. These caregiving strategies were essential to minimize the consequence of strain and exhaustion to the CG and family. Maintaining good strategies could also help care for the PWP at home whereas the absence of these strategies could be a step toward more strain resulting in the ultimate consequence of LTC placement. Thus, these CG strategies and CG characteristics can impact the LTC decision making process. The following section explores the factors that influence the LTC placement decision which was the focus of another research question. These placement factors (i.e. specific triggers) are also reflected in Figure 4-2 by a box linked to a red arrow pointing to the LTC placement point of entry line.

Factors that Influence the LTC Placement Decision

Several factors that influence LTC placement were identified. However, the type of caregiver strain and the triggers that led to LTC placement varied among the CGs.

Three of the 20 CGs moved their loved ones with PD to a LTC facility. One of the three PWP's returned home after several months. This LTC decision process for these families was a journey, and the decision was part of the CGs' focus that occurred over a period of time.

Specific factors that actually led to placement

The factors that caused placement for these families were:

- Risk of safety to caregiver and/or PWP
- Falls with severe injury
- Inability to manage a change in health status
- Depleted informal and formal support

Regardless of the reasons for placement, all three CGs agreed that there were ongoing stressors from caregiving that kept worsening and finally there was a pivotal event that caused them to make the determination of LTC placement. For two of the three CGs the decision was made during a crisis (falls with injury, depleted support and hallucinations causing a risk of safety to the CG and PWP). For the third person the pivotal event was the realization that she could no longer provide care for her husband at home due to the inability to manage his worsening health status. Thus, the event is what shifted the picture of caregiving from LTC placement not being an option to now being the only option.

Interestingly, all the CGs needed validation from other family members, health care providers or the legal system in order to place their loved one in a LTC facility. The CGs who needed validation from the professional community were addressing a crisis

event associated with their loved one with PD whereas in the other case there was no specific crisis event and the validation came from family. For example, this exhausted CG stated, “My children and I felt that he needed to be someplace where he could have care (round the clock care), which is where he is now (CG 6).

Risk of safety to caregiver and/or PWP. One serious factor was the fear that the PWPs would hurt themselves others because of symptoms of hallucinations. This fear was very real and this CG indicated that her husband with PD was experiencing delusions and hallucinations for a period of time and subsequently began causing potential harm to her and well as to him. At one point his delusions were so severe that he followed her on the highway and tried to force her off the road. She shared that he was Baker acted (i.e. hospitalized involuntarily for mental health evaluation and treatment) for 3 ½ weeks and stated, “The Judge told him that he needed to go to an assisted living facility for a while, to get things straightened out” (CG 17).

Subsequently this PWP was able to return home after a period of time; however the CG was open to having him return to the LTC facility if it became necessary. Other CGs who did not have their loved one in a LTC facility were also concerned about visual hallucinations as was noted by this CG as she shared a conversation with her husband with PD.

He was very agitated and he said, Do you see that cat there, do you see that cat? And I thought he was kidding, but I saw he was aggravated so I said no, no honey, I don't see a cat or a cap, and he said, cat, CAT. He was very angry. . . . He said, I see them and they're all over this room. And I really got upset and I thought, well the thing to do is just be calm about this and maybe try to be lighthearted about it (CG 8).

There were other CGs whose loved ones with PD experienced visual hallucinations and were concerned about what they would do if these symptoms worsened.

Falls with severe injury. Interestingly, the act of falling alone, especially if there were no severe injuries, was not a trigger which caused facility placement. Many of the PWP's with more advanced symptoms had numerous falls, some with injuries; however, placement was not even considered unless the injury from the fall was severe. The data revealed that falling was a way of life for PWP's and CGs managed the aftermath. They did not minimize any incident, it was just accepted that this occurs with Parkinson's disease even as one CG noted,

And one night I came home about 9:30, he's sitting on the stool in the kitchen, blood caked all over his face, and he had a beard, blood caked in his beard, all over his clothes, and he lost his glasses. And so well, because of the hour, we took him to the emergency room, he got all cleaned up and stitched up, he didn't want to go, he didn't think that it was necessary for him to go (CG 18).

Another CG whose mother with PD lived with the family and had previously fallen, felt she had no other choice but to place her mother in a long term care facility when both of them were injured as she explains in the following comment.

I fell catching her because I know you know when Parkinson's patients fall, its dead weight. And I caught her going into the tub. And hurt my back and at that point, our family doctor said, you're done (CG 14).

A third example of a serious injury that was exacerbated by other events, led to LTC for this family member.

When he fell in the bathroom, hit his head, and I had to call the emergency squad, and they, he did have some bleeding in his head, they called a neurologist in and just in case he would have to go in and do surgery. And so it was after that situation and he went into rehab and did exercises and he started having, well I thought they were mini strokes, but it turned out to be seizures as a result of the head injury. So it just, it kept going on and on

over the summer. And that's when I finally decided, with my children's help, to put him in a long term care facility (CG 6).

Inability to manage a change in health status. The inability to manage exacerbations of an illness in addition to the PD was also a trigger in LTC placement as reflected in this quote.

It was not just the Parkinson's. It really mainly was the intestinal problems, the reason. Well it was, and because I didn't feel I could handle, or handle the intestinal thing. And also the Parkinson's, with it's really being the other problem he has that made me realize that I couldn't any more (CG 6).

In that specific situation, there were numerous triggers that led to placement and the PWP's gastrointestinal health condition played a pivotal role in the CG becoming exhausted and unable to manage his care.

Depleted informal and formal support. Another strong factor that would cause LTC placement according to CGs is a lack of support from other informal CGs and formal CGs. Many of the CGs in this study had family who lived nearby and openly communicated the PWPs' health status and needs with them. CGs explained that without that support from various sources, the decision to institutionalize would be hastened. The following example from a CG relates how family support can become splintered when there is intense caregiving for the PWP.

I think my husband finally got to a point where he said, I know you love your mom and I know you'd do anything in the world for her, but hello, what about me? And before we got to a point where he said it's me or her, my brother and I just talked about it and just decided, this is (LTC placement) what we had to do for all of us, to be able to survive and have a life (CG 14).

Considerations for potential placement

The other families who currently did not have their loved one in a LTC facility, were asked if they had considered LTC placement and, if they did, what factors would

influence the decisions to place the PWP in a LTC facility. These CGs responded with similar reasons for placement as the CGs who actually moved their relatives to LTC facilities. However, these reasons for placement may change as the CGs move through the caregiving / PD trajectory. Yet, most believed that LTC placement would always be the option of last resort.

Some CGs also explored the LTC placement option with their extended families and many of those families said they would help take care of their loved ones by providing some form of support to help the PWP remain at home longer. However, these comments were individualized because in some families (as discussed earlier), CGs did not want to involve their adult children in caregiving or caregiving decisions because they felt that their adult children needed to focus on their own lives.

One of the reasons CGs indicated LTC placement might be a consideration was changes and outcomes in the PWP's mental state. This was especially relevant for participants who reported that their loved ones had cognitive changes which caused changes in personality and shifts in the relationship. When this occurred CGs thought about LTC placement. The following quote reflects these thoughts.

Then there's times when he just, he's just not himself. And those are the times that it scares me and I think (sighs), one of the main reasons I guess I have thought about putting him in a nursing home is because we'd always been so close and I feel like I can't live without him kind of thing (tearful). But there's times when he acts like that, I get scared, and I almost hate him because it's not him. It's like, he's not the one I fell in love with when his personality changes like that. And then I'm ready to send him off, you know (CG 3).

Unfortunately, several families in the study did not realize that there is a delayed capacity to process information for the PWP, and they also did not realize that dementia

can occur with PD. This lack of knowledge can cause added caregiver strain because when it happens it feels like another illness diagnosed in addition to .PD.

Another example related to LTC placement consideration related to the inability to manage a change in health status occurred when an adult child felt it would be wise to have her father move to an assisted living facility before his condition worsened. Since he lived alone, she felt an assisted living environment would prevent loneliness. Thus, she reframed his disability and illustrated a positive outlook in the event LTC placement became a reality for him. She described her conversation with her father in the following quote.

And I tell my dad all the time, everybody has a new chapter in their life, and it's how you're going to write the chapter. You know this part of your life is over, but it doesn't mean it's ended, it just means that we're starting something new again (CG 2).

Moreover, encouraging a parent to move to an assisted living facility before symptoms worsen can take the strain off adult children of eventually needing to make LTC placement decisions in possible situations when filial CGs can no longer manage the change in their parents' health status. Yet, it is often difficult to enter into that type of conversation with a parent because of the uneasiness of that shift (role reversal) in the relationship. Although this was stated by only one adult daughter CG, other CGs, especially spouses, made general comments about the importance of future caregiving options.

Some stated that their number one option would be to eventually move with their spouses to tiered retirement facilities and be cared for incrementally as either person's conditions' worsened. This was a popular option; however, it was not feasible for everyone because of the financial cost. Furthermore, some families had purchased LTC

insurance which also provides for care in the home, as an alternative or delay to LTC placement. Unfortunately, some others had wished they bought insurance before the PWP was diagnosed because many LTC policies will not cover PWPs.

Reasons for non placement

Three of the 20 CGs had deceased spouses who had PD. These CGs did not choose LTC placement for their loved ones. Their decisions to keep the PWPs at home were mainly a result of having strong formal and informal support networks, accessibility to resources and good CG health. Other reasons included generational beliefs to remain at home and a dislike of LTC facilities due to perceived low quality of care. Some CGs felt very negative about LTC facilities especially nursing homes and felt LTC placement equated to abandonment as this CG noted. "I'll be here, I'm not shipping her off nowhere, or like some people put it, dumping, I'm not going to go dump her in no home or nothing' like that, she'll be right here" (CG 9).

In summary, it was difficult to understand the LTC placement decision making process with families who spoke hypothetically. This was because the actual placement decisions occurred as a result of an accumulation of expected and unexpected events for families who already had relatives in LTC facilities. This decision process should be further evaluated in future studies with a larger sample of those who have placed their family members in a LTC setting. Regardless, in this study there was a rich variety of caregiving situations that provided insights into the complexities of caregiving.

Section III: Case Examples within the Model

The complexity of caregiving is shown in Figure 4-4 which depicts the caregiving model with four CG / PWP dyad cases in different caregiving situations. Each case has its own unique set of conditions which show the effects of caregiver strain illustrated by

four different diagonal lines which represent caregiver strain. For instance, a very low caregiver strain angle (line D) represents low strain because there is strong support since the CG is able to care for the PWP and to adjust well to negative life events. In this line, the PWP never enters a LTC facility. Whereas in the other lines, (A, B, C), the PWPs did enter at different points in time. These other lines represent caregiver strain resulting from various degrees of support and caregiving abilities as described in the legend at the bottom of the diagram. The wider the angle of caregiver strain, the earlier LTC placement occurs.

An example of line “D’ in the study was a case in which a CG was surrounded by family who lived in the area and friends who were helping her take time out for herself when caregiving started causing strain. They also had pets in the home which were a good source of support for her and the PWP. She had a good relationship with health care providers and always claimed to be self sufficient with a positive outlook on life. As her husband’s condition worsened she was able to continue to care for him which included all activities of daily living. He had some cognitive deficits which still allowed him to communicate. In this situation, he remained at home until he died.

An example of line A in the study was a situation in which the CG was neglecting her own health needs and was not doing anything recreational for herself. She was caring for a person with advanced PD and there were others living in the home with disabilities. The PWP had decreased cognitive function and had a history of some aggressive behavior. There were some family members in town but they were not highly supportive. The CG no longer attended church because of the difficulty of traveling with her husband. Her health care providers were concerned for her welfare and have

encouraged her to make short and long term plans for her husband's care which she really had no time to do. The risk of LTC placement for this person with PD was very high and any additional negative life events or other types of stressors, such as sudden CG illness, could easily trigger LTC placement.

It is important to understand that it was difficult to specifically define (measure) the different placement factors in these cases. These are characteristics of cases that occurred in the study and not representative of a mathematical model depicting numerical values on an x and y axis. However these generalities showed a good description of the influences of caregiver strain on caregiving decision making processes and LTC placement factors.

Summary

A conceptual model of caregiving was developed from the perspectives of the CGs in this study. The basic premise of this model is that as the volume of caregiving load increases in relation to the increasing severity of the illness over time, caregiver strain also increases. In this model, the conditions, strategies, triggers, caregiving load, disease trajectory and caregiver strain, when taken together, influenced how and when a decision is made about institutionalization. So, it was important to understand the process in order to better understand how this decision was made.

This understanding of the process addressed the first research question. The factors or triggers that influenced the decision making process addressed the second research question. The data identified that a strong multifaceted support network helped CGs better manage the care of their relative with PD at home. This finding was the focus of the third research question. Moreover the importance of these support structures (informal and formal types) were illustrated throughout the model. They were

seen as a condition that positively or negatively affected strain, and a strategy (seeking support) that reduced strain. A depleted support network was also a trigger that led to LTC placement. Therefore, the research questions were an integral part of the conceptual model that illustrated the decision making process. The findings helped us better understand the complexities of caregiving and CGs' needs. Chapter 5 explores the implications of these findings and compares the model to others in the literature.

Table 4-1. Demographic characteristics of the sample

	All Subjects (n=40)*	Caregivers (n=20)	PWPs (n=20)**
Age (years)			
Mean (SD)	66 (10.1)	64 (11.4)	69 (8.3)
Gender			
Female	22 (55%)	17 (85%)	5 (25%)
Race			
White	40 (100%)	20 (100%)	20 (100%)
Education			
High School ⁺	16 (40%)	9 (45%)	7 (35%)
College (2 & 4 yr)	16 (40%)	7 (35%)	9 (45%)
Graduate School	8 (20%)	4 (20%)	4 (20%)
Household income			
>30,000	3 (15%)		
>40,000	17 (85%)		
Characteristics Specific to PWPs			
Mean Disability Score ⁺⁺	3 (on a scale of 1-5)		
Years with PD			
Mean (SD)	11 (5.9)		
DBS (Yes)	3 (15%)		
Currently in LTC facility	2 (10%)		
Previously in LTC facility	1 (5%)		
Characteristics Specific to Caregivers			
Spousal	17 (85%)		
Filial (adult daughters)	3 (15%)		
Work status			
Full time	5 (25%)		
Retired	15 (75%)		
Marital Status			
Married	15 (75%)		
Divorced	2 (10%)		
Widow/widower	3 (15%)		
Characteristics of Interviews			
Total	20		
Caregiver alone =	17 (85%)		
Caregiver/PWP dyad =	3 (CG wife/PWP, CG husband/PWP, CG daughter/mother with PD)		
* Subjects included caregivers (n = 20) and PWPs (n = 20). A total of 37 persons were officially enrolled in the study as three of the PWPs were deceased.			
** Includes deceased and those not present during the interviews. Those persons who were not present during the interviews were still enrolled in the study since information about those persons was shared during interviews.			
+ Includes high school and technical school			
++ Modified Hoehn & Yahr Scale (1-5 range)			

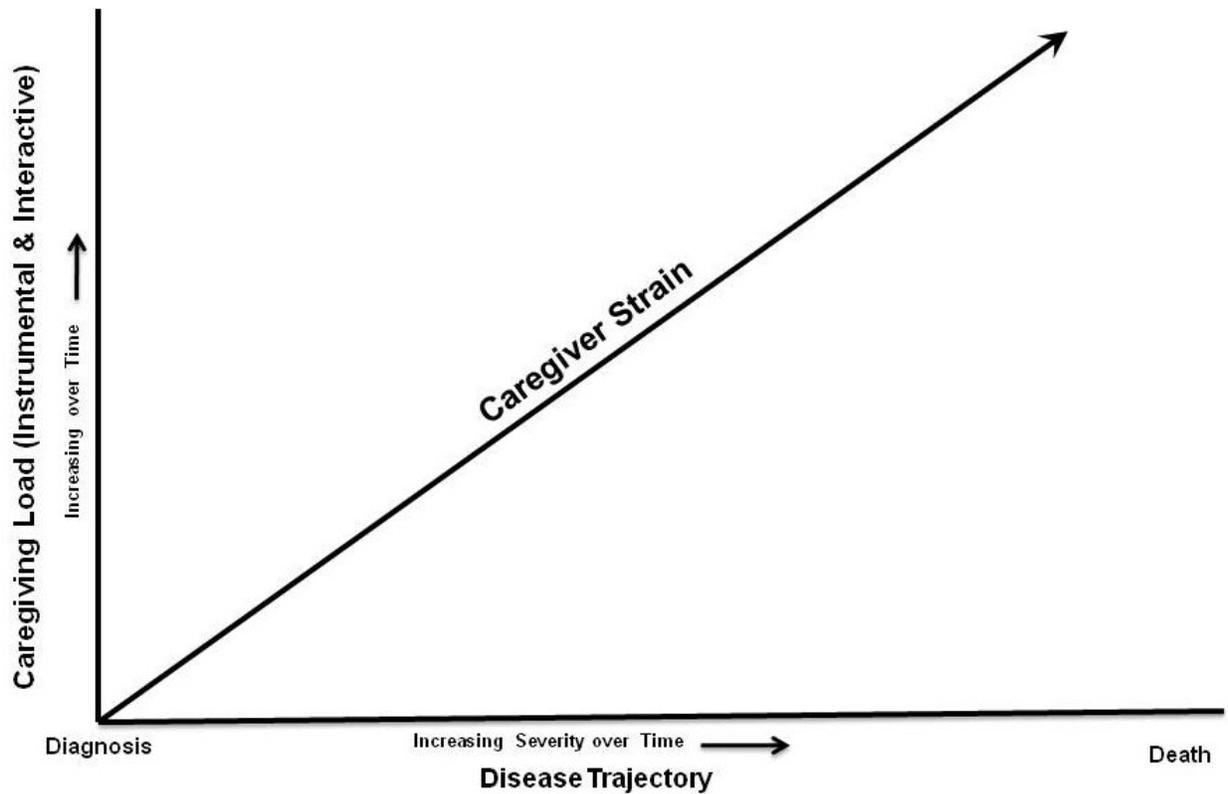


Figure 4-1. Basic model of caregiving model along the PD trajectory. The vertical line illustrates Instrumental and Interactive Caregiving that increase over time whereas the horizontal illustrates the Disease Trajectory that shows the increasing severity of PD over time. The third component of the model is Caregiver Strain which is represented by the diagonal line that slopes upward from the intersection of the caregiving and the disease trajectory line. As the volume of the caregiving load increases in relation to the increasing severity of the illness over time, caregiver strain also increases.

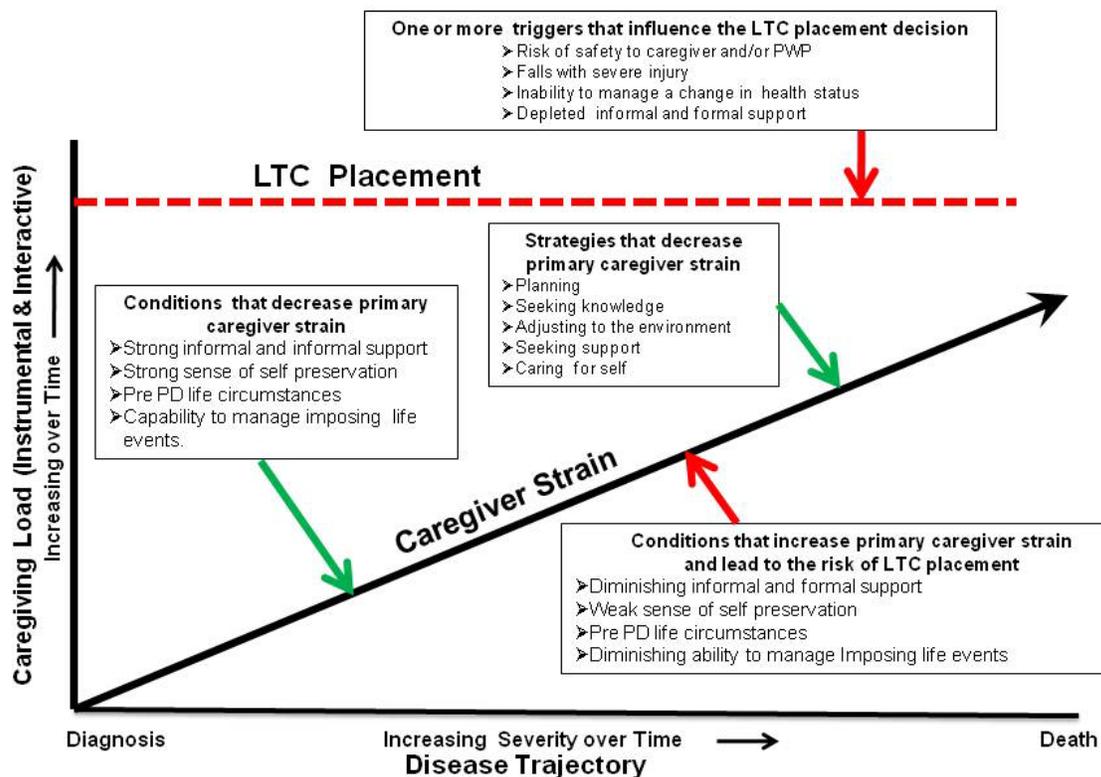


Figure 4-2. Expanded model of caregiving along the PD trajectory. As the magnitude of the caregiving increases (vertical line), caregiver strain also increases (diagonal line), and this situation occurs as the symptoms of the illness worsen over time along the disease trajectory (horizontal line). This framework depicts the factors that increase and decrease caregiver strain. These factors and strategies are encased in several boxes connected to red or green arrows. The arrows symbolized a pushing motion to increase (red arrow) or decrease (green arrow) caregiver strain. The red dotted line is the decision point at which the PWP's enter long term care (LTC). The box with the arrow pointed down toward the dotted long term care (LTC) placement line represents triggers that lead to the LTC placement decision.

Table 4-2. Examples of caregiver roles

Caregiver Roles	Resulting from
Coach/Cheerleader	<p>Needing to help the person become involved in activities which include physical exercise. May be difficult due to an apparent lack of motivation accompanied by symptoms of depression and apathy.</p> <p>How well, he does really depends on the care taker and whether the care taker insists on, alright let's go out and lets you know, take a walk, let's go out, let's go walk in the mall. Let's go do tai chi, you know. The care taker at some point, has to take on that responsibility cause the Parkinson person will sit and do nothing (CG 1)</p>
Teacher	Reinforcing and assisting with exercises from physical therapy, or helping to take steps when coordination and walking is difficult
Informal Counselor	Managing anxiety and anxiety attacks when it becomes out of control. "And so I have felt that my role has been that I have to try to keep him buoyed up and I have to constantly look for the positive in him" (CG 7)
Head of household	Taking on more house hold responsibilities including executive functions such as financial management and decisions of home repair when originally coordinated by the other spouse.
Driver and navigator	Becoming the main driver in the house hold or helping to navigate while the person with PD is driving
Supervisor	Being watchful so the person doesn't get hurt around the house as coordination decreases and confusion increases.

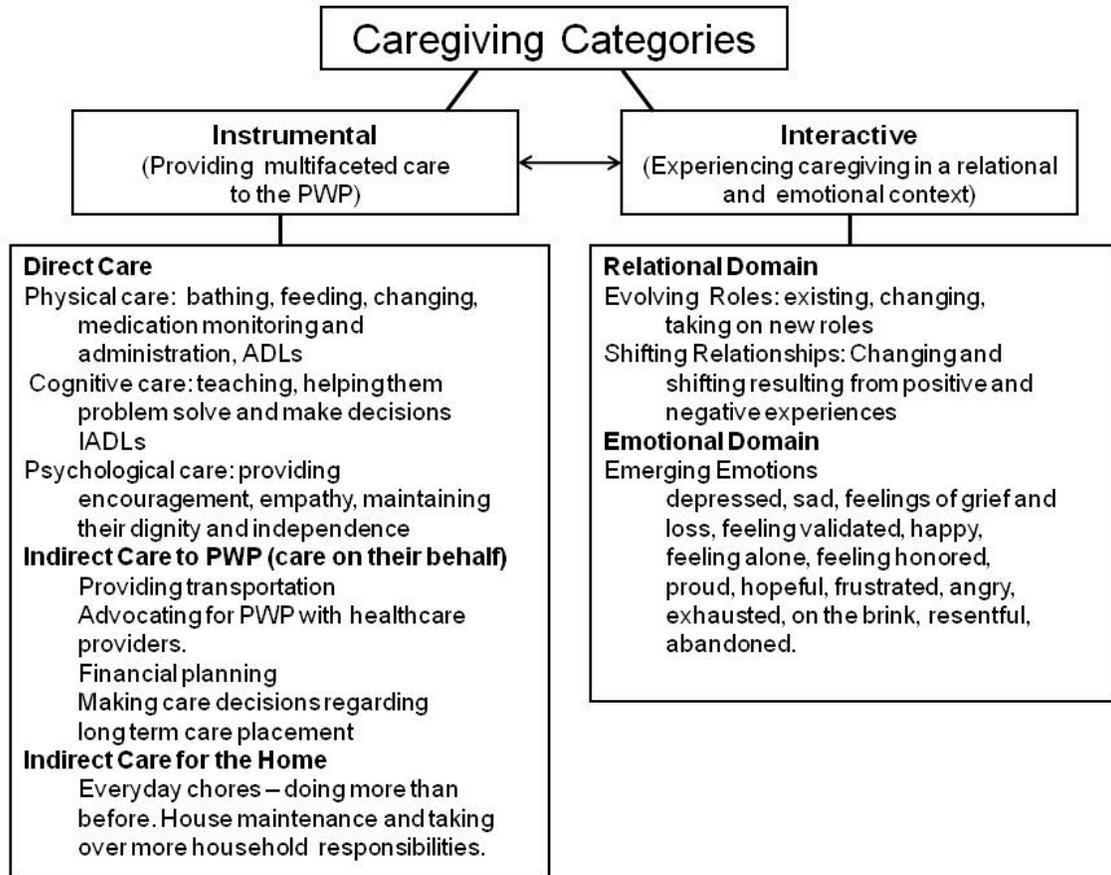


Figure 4-3. Two main categories of caregiving

Table 4-3. Caregiver support network

Support structure (Branches of the Network)	Examples	Areas of support
Family	Family support includes immediate and distant relatives. Includes step families.	Emotional Cognitive Physical
Friends	Could be immediate friends or long distance. To provide direct support pertaining to illness and to provide social support not related to the illness	Emotional Cognitive Physical
Spiritual Support	Prayer groups, church support	Emotional Physical – providing meals in time of need
Professional support	Doctors, nurses, therapists, counselors, physical therapists, hospice, elder care services, government agencies to help attain benefits, Elder law attorneys to help with estate planning, home health agencies custodial care, maid, gardener	Emotional Cognitive - education Physical – hands on medical care, assistance with ADLs, IADLs, handy man service
Financial stability	Long term care insurance, health insurance, wills, health care surrogate	Cognitive
Support Groups	Regular PD support groups and those specifically for caregivers	Emotional (like a sisterhood)
Respite	Extended respite through professional agencies. Provides a break for the caregiver. Helps to enhance self care by providing time for self care activities (Tai Chi, Gym, hobbies, other entities)	Emotional
Pets as Support	Dogs, Cats - Comfort to family unit	Emotional
Internet	Internet support – person to person support via the internet. Information seeking: Health Care Websites and National Organizations, groups	Emotional Cognitive

Table 4-4. Health conditions of caregivers and persons with PD

	Co-morbidities
Caregivers	Chronic obstructive pulmonary disease (COPD), asthma, sleep apnea, restless leg syndrome, overweight, diabetes, fibromyalgia, history of breast cancer, Sjogren's syndrome, arthrosclerosis, rheumatoid arthritis, osteoarthritis, history of myocardial infarction, shingles
Persons with Parkinson's Disease	History of prostate cancer, history of colon cancer, multiple systems atrophy, lupus, atrial fibrillation, myocardial infarction, ischemic bowel, degenerative bone disease, history of symptoms of dementia (PD related), Reynaud's syndrome, fibromyalgia, lupus, myasthenia gravis

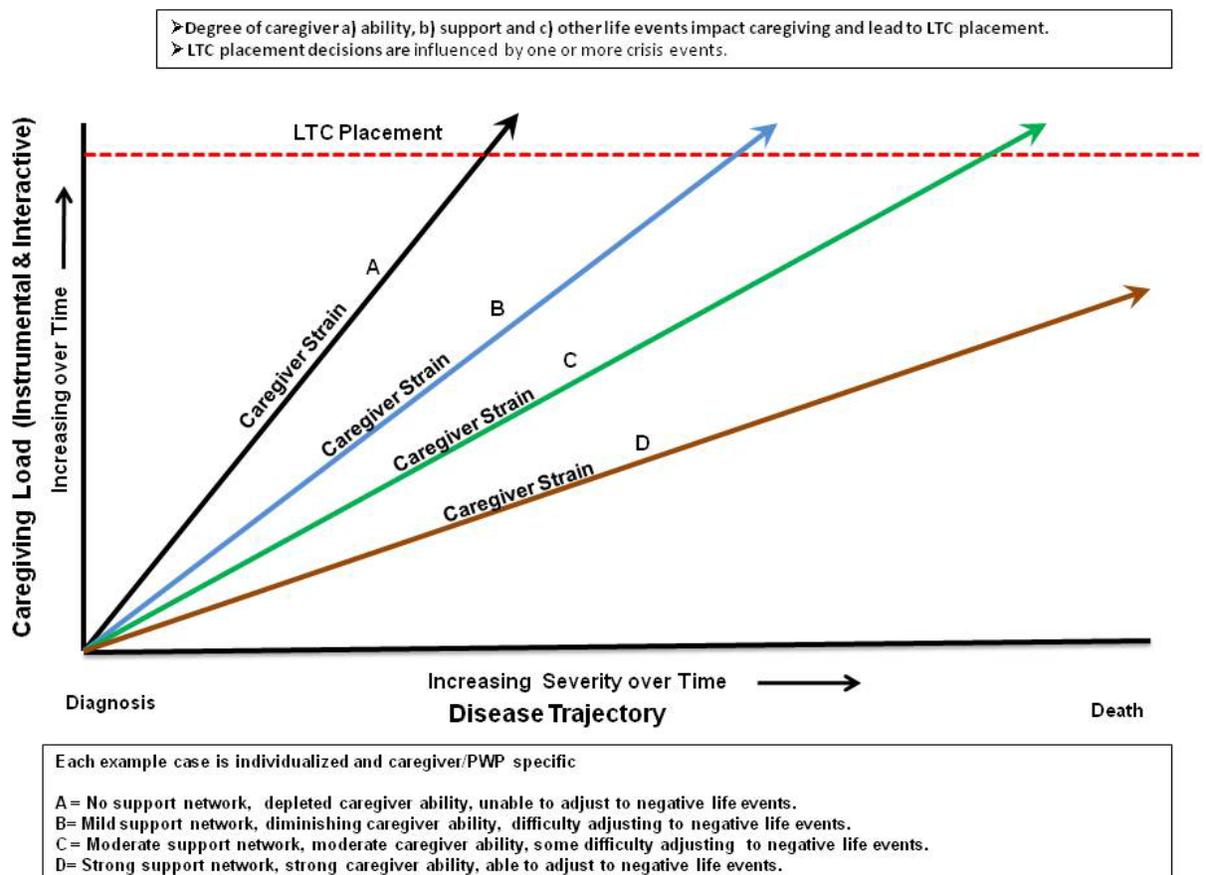


Figure 4-4. Specific cases of caregiving reflected on the caregiving model. This figure shows four cases that depict caregiver / PWP dyads in different caregiving situations. The four cases are illustrated by four different diagonal lines which represent caregiver strain. It is important to understand that it is difficult to specifically define (measure) these cases. These are generalities of cases that occurred in the study and not representative of a mathematical model depicting numerical values on the x and y axis.

CHAPTER 5 DISCUSSION AND CONCLUSIONS

The purpose of the study was to better understand how family caregivers (CGs) make the decision to institutionalize a relative with Parkinson's disease (PD) and which factors influence this decision. The study also sought to discover what CGs needed to help them better manage the care of a person with Parkinson's disease (PWP) at home. This chapter includes a discussion of the findings and a comparison of the model created from this study to another model in the literature. Implications for professional practice are explored followed by limitations and directions for future research.

Major Findings

The primary intent of this research was to explore CGs' long term care decision making and the factors that helped them manage the care of their relatives with PD at home. During the course of the study I discovered the importance of listening to the CGs' full stories of their caregiving experiences from the point of diagnosis to the present. Not only did this foster trust but it helped me to see the full experience of caregiving from their perspectives. Analyzing and interpreting this experience crystallized my understanding of the complexities of caregiving and brought to light the intricacies of long term care (LTC) decision making and family support needs for PWPs.

Learning about the LTC decision making process was a crucial addition to the body of health care literature since there are no existing studies that explore this process with those caring for PWPs. Moreover, understanding the factors that influence LTC placement for PWPs can help us to better understand how and when to intervene to help CGs and PWPs manage PD at home and prevent premature institutionalization. Finally, studies of LTC placement factors specifically for PWPs are dated (Aarsland,

Larsen, Tandberg, & Laake, 2000; Goetz et al., 2001; Goetz & Stebbins, 1995; Goetz & Stebbins, 1993). With the changes in health care funding policies and treatments for PD that extend survivorship, additional studies are needed.

The Decision Making Process

A conceptual model of caregiving was developed from the perspectives of the CGs in this study (see Figure 4-2). The combined components identified in this model influenced how and when a decision was made about institutionalization. So, it was important to understand this fluid process, as illustrated in the model, in order to better understand how this LTC placement decision was made.

The findings identified two conceptually distinct and complex categories of caregiving. Instrumental caregiving, formerly called hands on caregiving, was illustrated through observable actions, behaviors or mental activities, such as making decisions on behalf of the person with PD. Interactive caregiving revealed a relational and an emotional domain that illustrated the evolving roles, relationships and emotions in the caregiving experience. When taken together these two categories are called caregiving load. This load was impacted by the severity of the illness that was depicted as a disease trajectory. The trajectory implies an unfolding chronic illness course that affects the caregiving family in all aspects of life (Corbin & Strauss, 1991; Robinson, Bevil, Arcangelo, Reifsnnyder, Rothman, & Smeltzer, 1993).

CGs' experiences showed that as the magnitude of caregiving load increased in relation to the increasing severity of the illness over time, caregiver strain also increased. Originally, I labeled this concept caregiver burden because of the increasing severity of CG stressors over time; however, when I discussed my preliminary findings with CGs they felt strain was a more appropriate term because they did not think of

caregiving as burdensome. This is interesting to note because the literature either denotes strain as being more severe than burden, or uses the terms burden and strain interchangeably (England, 2000).

Some situations and life circumstances such as existing co-morbidities and advancing age for both the CG and the PWP had an unavoidable impact on caregiving. These situations and other conditions such as a diminishing support system and a weak sense of self preservation put CGs at risk for increased strain. Moreover, the literature revealed that sleep disturbances increased caregiver strain/burden; however, this was not specifically mentioned by the CGs in my study (Secker & Brown, 2005; Schur, Whitlatch & Clark, 2005).

The conditions that lessened strain were (a) a strong support system such as family, friends, and health care practitioners, (b) a strong sense of self preservation (self care), (c) the capability to manage imposing life events such as a loss of finances, and (d) pre PD life circumstances, such as having a positive attitude. Moreover, employing strategies such as seeking knowledge about PD and long term planning reduced strain and lessened the risk of LTC placement. It was not surprising to see the variety of strategies the CGs used to maintain their caregiving and home responsibilities because caregiving for someone with PD is a complex process. For some, being very well organized was essential just to get through the day. Some CGs were also able to make long range plans and have well-developed skills to manage the caregiving experience; however, that was not the case for all the CGs in this study. For some CGs there was a point in time when LTC placement was the only option.

Long Term Care Placement Factors

Several factors that influence LTC placement were identified. However, the type of caregiver strain and the triggers that led to LTC placement varied among the CGs.

Three CGs moved their relative with PD to a LTC facility. This decision process was a journey of increasing caregiver strain over a period of time. The journey ended with a pivotal event that caused placement.

The factors that caused placement identified from the data in my study were:

- Risk of safety to caregiver and/or PWP
- Falls with severe injury
- Inability to manage a change in health status
- Depleted informal and formal support

Regardless of the reasons for placement, all three CGs agreed that there were ongoing stressors from caregiving that kept worsening and finally there was a pivotal event that caused them to make the determination of LTC placement. For two of the three CGs the decision was made during a crisis (falls with injury, depleted support and hallucinations causing a risk of safety to the CG and PWP). For the third person the pivotal event was the realization that she could no longer provide care for her husband with PD at home due to the inability to manage his worsening health status. Thus, the pivotal event is what shifted the picture of caregiving from LTC placement not being an option to now being the only option.

The other CGs who did not have their loved ones in LTC identified several factors that would cause placement; however, the LTC placement decision making process for these CGs was difficult to explore and analyze because they were anticipating rather than reflecting on actual decisions. Yet these families identified the same factors to place a PWP in LTC as those made by the other three families.

Davey and colleagues (2004) concluded that repeated falls had a deleterious impact on the family. In my study, falls were a worry but they were also considered a “normal” part of the illness. The consequences of falls (unless they resulted in severe injury) seemed to be taken in stride as reflected in these quotes from CGs. “He did fall the other day out at the garage, coming out of the laundry room door into the garage. A little fall, but he was fine and he got up” (CG 2). “There are times when he’ll fall, 5, 6 times a day, then there’s times when he won’t fall for 3 weeks” (CG 5). The following quote illustrates how falling is also common for the CG.

If he falls, and he’s not, quote, injured, we have a little system of how we get to each other. Well, see, I fall a good bit, too, because I had the shingles. . . I lost total hearing in this ear, and it’s left me with a walking and balance problem (CG 12).

The literature addressed many factors that were influential in institutional placement that included hallucinations/delusions, dementia related behaviors, not enough support, excessive night time activity, and the quality of the relationship between the person needing placement and the family (Andel, Hyler, & Slack, 2007; Buhr, Kuchibhatia & Clipp, 2006; Goetz & Stebbins, 1993; Kao & Stuifbergen, 1999). The factors that were specific to actual LTC placement in my study were an inability to manage a change in PWP’s health status, injury from falls, hallucinations/delusions and depleted support. Hope and colleagues (1998) also noted that incontinence and immobility were also factors in LTC placement; however, those conditions were not influencing factors in my study.

Support Systems

During the interview process CGs spoke extensively about the multifaceted support system or a support network (terms the participants used) that was essential to

better manage the care of a relative with PD at home. This support existed in the form of assistance from family, friends, informal support groups and the professional community. For example, the following CG commented on these areas, “I got family support on both sides, so I mean his side and my side, and so that helps, neighbors, and the neighbors having to go to church, they’re just good people” (CG 19).

The assistance from friends and family allowed a few CGs to have short periods of respite which resulted in their improved health; however, others chose to not take time for themselves. For one family it was difficult because of PWP had disruptive behavior which made it difficult to have others in the home while the CG was away. Barriers to support like this were supported in the literature (Miller et al., 2001). In my study, the CGs benefitted from short periods of time away but some were often nervous because they kept worrying about their loved ones at home. These short periods of time, whether for running errands or for seeing a movie, were considered a “break” by many CGs. Yet several still needed a true respite experience in which they could leave for a longer period of time knowing that the PWP was in good care. A formalized respite service in the form of temporary care at some designated assisted living facilities was mentioned to CGs and many did not know this type of opportunity existed. Some did not understand what the word “respite” meant.

Support was so important for some families that they felt it was important to be geographically near relatives who could ultimately help them better manage the care of the PWP at home. In two cases, CG/PWP dyads who participated in this study have since moved away from Florida to be nearer to their relatives who can help them manage the day to day care of the PWP. The importance of spiritual support was

another main finding. Several CGs emphasized how their spirituality was a strong source of comfort for them. It was a theme woven through numerous interviews and strongly supported by research (Pierce, Steiner, Havens, & Tormoehlen, 2008; Sanders, Ott, Kelber, & Noonan, 2008).

Ultimately, the multifaceted support focused on the whole family and not just the PWP. These findings were not surprising. However, what was surprising was the variety of types of support that each family used to maintain their caregiving abilities. For example, many relied on their families who lived nearby, and when they were not available there were friends as well as a church community. In one situation, the PWP's former sorority sisters from college were a source of support for the family as they brought food on several occasions during her illness. Even family pets were ever present as comfort to CGs.

Caregivers (CGs) valued the need for support such as guidance from health care providers. Many CGs were satisfied with the type of care they received from health care providers especially those CGs who considered themselves self-sufficient. However, those who had a moderate amount of strain, such as having other health issues, working full time, and taking care of others in the family, did not feel that professional support from their primary health care provider was present. Some CGs felt that primary care providers rarely asked about them or their needs which erased any hope for feelings of validation of their caregiving experiences or referrals for professional assistance. Care was splintered and not integrated into the family unit which ultimately frustrated CGs because they felt it was difficult to foster trust in a health care environment that had a narrow focus.

Support from specialists (i.e. neurologists) had mixed results. The determining factor of good professional support for the CG was physician bedside manner and the quality of auxiliary support from physician assistants or nurse practitioners in the specialty practice. Unfortunately, that was not always the case according to the following CG who commented about her health care provider.

Yeah, he (physician) says, delusions and paranoia are real common with Parkinson's disease he says. When he said that, without looking up (while writing notes), I was caught off guard as could be because like I said, I guess I missed that part when I was reading on the Internet and I was dumbfounded (CG 17).

Moreover, the finding that this CG was not knowledgeable about disease symptoms was not unusual especially since the literature referenced that CGs had difficulties when they did not realize that PWP's could have hallucinations as a symptom of PD (Williamson, Simpson & Murray, 2008). Thus, many CGs in my study not only needed more of a connection with their health care provider but would have benefitted from a more supportive means of learning about the disease process.

There were numerous types of informal and formal support families sought to meet their needs and some CGs in this study had a greater support network than others in order to better care for the PWP at home. The findings from this study which illustrate the various types of CG support adds to existing literature on caregiving in PD especially in areas of spiritual support. Most of the CGs believed in a higher being and included prayer as a source of strength and perseverance in their caregiving tasks. Moreover, many families had some type of pet such as a dog or cat that they considered an integral component in supporting them especially during difficult days. In some interviews, the pets were present with the participants and I could see the emotional connection which is reinforced in other literature (Sanders et al., 2008). There

is little research on the importance of extended family support (i.e. relatives outside of the CG/PWP dyad) in the literature; yet in this study, family support was crucial to the viability of the dyad. Interestingly, since the beginning of this study, some of the CG/PWP dyads have already left Florida to be nearer to family.

Caregiver strain is highly complex and this study has shown that caregivers need a network of support to combat those areas of strain. One intervention that health care providers must reinforce is formal respite care which can be a major source of support for CGs of PWP and can sustain CGs in preventing their loved one from being prematurely institutionalized. This finding was supported in the literature (Kosloski & Montgomery, 1995; Garces, Carretero, Rodenas, & Aleman, 2010). In addition to the caregiving model that illustrates CG support structures in this study, there are other models in the literature that reinforce support and LTC placement decision making specifically focusing on CGs of persons with Alzheimer's disease (Caron & Bowers, 2003; Caron, Ducharme, & Griffith, 2006). The following section compares my model with another caregiving model that is specific to the LTC institutionalization decision process in the literature.

Comparing the Caregiving Model to the Literature

The model of caregiving (Figure 4-2) that was developed in this study was compared to Caron, Ducharme, and Griffith's model (2006) of the decision-making process to institutionalize a relative with dementia (see Figure 5-1). The three main dimensions of their model are: "(a) contextual factors related to the care situation, (b) the decision making process, and (c) the decision itself" (Caron et al., 2006, p. 199). The contextual factors which change over time include formal and informal support available for CGs, the precipitating events that cause outside assistance for the CG and

the physical environment in which the person with dementia lives. The researchers contended that a combination of these contextual factors led to LTC placement considerations over time. A feedback loop in the model illustrates this decision making process that continues in a feedback mode for those still caring for their family members at home.

Although there was no feedback loop in my model, there was the same consideration that the decision process occurs over time. My approach showed how caregiving load along the disease trajectory affects strain, and that increased strain can put families at risk for placing their relative in LTC. Specifically, in my model, as the volume of caregiving load increases in relation to the increasing severity of the illness over time, caregiver strain also increases. Caron and colleagues (2006) defined the contextual factors that led to placement. I defined specific conditions that influenced placement and also conducted an in-depth analysis of the meaning of caregiving from the perspectives of the CGs in the study. Additionally, unlike Caron's model, mine used the concept of strain as pivotal to LTC placement. It also showed (a) specific conditions that decrease and increase strain, (b) strategies that moderate strain and (c) factors that trigger LTC placement.

Another feature found in Caron and colleagues' model was how the physical environment can precipitate a trigger to cause institutionalization. In other words, falls resulting in hospitalizations can lead to LTC placement. In my study, recurrent falls that led to injury to either the PWP or the CG were also factors that influenced LTC placement. Moreover both studies emphasized the importance of formal and informal support related to care. Caron and colleagues' model (2006) was based on CGs who

had already placed their loved ones in long term care whereas the CGs in my study had only a few relatives in long term care. This was a limitation which is addressed in a later section. Regardless, the model developed from this study was an important contribution to research on informal CGs because it sheds a spotlight on the PD population of CG decision processes and it can lend support to existing decision making models.

Moreover, my research can be used to inform the development of future models that reflect the experiences of those who are caring for persons with other chronic conditions

Implications for Practice

The development of the caregiving model from the findings in my study identified many implications for professional practice that are pivotal to meeting the needs of these vulnerable CGs of PWP. There are implications for training of providers which include training to improve communication with caregivers. The literature revealed that caregivers complain about poor communication with health care providers which led to a lack of understanding about their medical advice (AARP Public Policy Institute, 2009). This study of CGs of PWPs urges the importance of training to enhance communication because sometimes health care providers are so focused on the patient that they ignore the needs of the CGs who are critical to decision-making regarding nursing home placement for PWPs.

Another important implication is the need to do formalized caregiver assessments similar to the types of assessments currently being proposed for stroke caregivers (Lutz & Young, in press). As previously discussed the literature has revealed that health and well being of CGs is lower than for those in the general public. Thus, it is paramount to include the health of CGs in family centered care. The importance of caring for CGs of PWPs by doing caregiver assessments was supported in the literature as identified by

Martinez-Martin and colleagues (2005). They noticed that “Caregivers should be assessed in order to identify the characteristics of and factors associated with the strain that they are experiencing” (p. 463). The knowledge gleaned from these types of assessments can be targeted toward interventions to improve CG well being.

There are tools that evaluate caregivers / needs; however, they often assess CGs after they provide care for a period of time (Lutz & Young, in press). For example, the Caregiver Burden Inventory (Novak & Guest, 1989) has been used with CGs of PWP and Alzheimer’s disease (D’amelio et al., 2009; Raccichini, Castellini, Civerchia, Fioravanti, Scarpino, 2009). This study supports the implementation of a method of assessment that was developed by the Family Caregiver Alliance (2006). Their “Caregivers Count Too! Toolkit supports the gathering of information in a systematic manner in order to assess caregivers’ issues, such as current problems and existing support structure. This assessment can be done in any setting and it indicates the need for reassessment as needed when caregiving situations change (Family Caregivers’ Alliance, 2006). An assessment like this should be implemented for CGs of PWPs

The results of this study also indicate the importance of specific interventions focusing on CGs in order to help them better manage the care of the PWP at home. Essential interventions for CGs such as formal respite care have been supported in the literature to help prevent premature institutionalization of persons with chronic disease yet there have been no specific studies on these types of interventions for PWPs (Garces et al., 2010; Kosloski & Montgomery, 1995). The importance of support groups which are facilitated by health care providers were mixed in this study due to the fact that the dynamics of support groups do not always meet the needs of CGs/PWP dyads.

This finding was previously supported by Tuite and colleagues (2006) who recommended that caregivers take their time and speak with support group leaders to learn about the group before they select one.

My study also adds to the literature on the importance of anticipatory guidance for CGs which is mainly focused on CGs for the pediatric population and scantily introduced in the area of adult caregiving (Thobaben, 1999). All these types of strategies must be coordinated through better case management. As previously discussed health care delivery is often splintered and optimal case management with the use of professionals like Geriatric Care Managers or other types of case management services to improve the quality of family centered care (Cress, 2007). The following sections address these implications in more detail and include strategies to help CGs of PWP provide optimal care to PWPs while maintaining their health and well being.

Provider Training

Many CGs expressed a need to have a greater connection with their health care providers as revealed in this quote. "I think it would validate you, that you're sitting there and that you're somebody and that you've been going through this with the patient" (CG 20). This interaction is crucial for their well being in their role as CGs for PWPs. Several CGs said they received minimal attention, which must change for this population, or they will become the next generation of persons with disabilities.

Thus, providers need to understand the impact PD has on the CG as is illustrated in my model. They need strategies when working with CGs so they can feel validated and know that their needs are being met. An important basic strategy for providers is communicating better with CGs of PWPs. There were some providers who were highly praised by CGs in my study because they listened to the CGs' needs and hence

allowed them to feel valued. In other settings some CGs felt uncomfortable expressing their thoughts for various reasons which included the perception of being stigmatized as complainers because they were women. In one situation a CG was very frustrated because she was never given information that could help her husband with PD as reflected in the following quote.

Many years after, as a matter of fact, I asked the neurologist, I understand that people with Parkinson's do better if they can have some physical exercise, is there some place I can find out about where he can get more physical exercise, and he said well the Parkinson Center is on the 4th floor (CG 15).

She could not believe that all the time they never said anything to her. However, after this conversation they gave her many materials and information about resources. She said,

It was a God-send just to get manuals that had information in them, and then we come to find out that, ok, if you do this before you do this in the morning, it's a little easier for them or it's just sharing of information with people. It was huge, and not feeling like you were in it all by yourself. We struggle to do the right thing, the two of us, not knowing (CG 15).

In this situation there was a severe lack in communication; however, a bigger concern is the numbers of families that need assistance and do not ask. How are they helped? It is therefore crucial to share this type of research with providers and enforce the necessity of inservice training and team meetings to discuss ways to communicate with CGs using a family centered approach. This type of training can include strategies such as role playing with CGs in different scenarios involving the PWP.

Another strategy providers should employ is anticipatory guidance which will help CGs understand some of the impending changes of the disease process over time. Anticipatory guidance is the act of preparing the person with chronic disease or the CG for an anticipated developmental or situational crisis (Bulechek, Butcher, Dochterman,

2007). This term is often used in pediatrics and end of life care; however, here it is used specifically with CGs of PWP. Unfortunately, the literature is dated and scant on anticipatory guidance for CGs. For example, Thobaben (1999) identified anticipatory guidance to be a good strategy to be used by home health care teams for families going through the caregiving process. This study provides additional evidence to support this important need as identified by the perspectives of the CGs. This type of guidance is paramount because CGs are often stressed due to the unpredictable way PD progresses.

The findings from this study identified that the uncertainty of illness (i.e. ambiguity, unpredictability of symptoms) and its day to day effects resulted in worry and eventual strain among CGs. These effects of illness uncertainty were supported by literature which identified that the unpredictability of behavior in dementia and the uncertainty of illness in PD were associated with caregiver distress (Michon, Weber, Rudhard-Thomazic, & Giannakopoulos, 2005; Sanders-Dewey, Mullins and Chaney, 2001). Thus utilizing anticipatory guidance based on individual family unit needs can combat the force of illness uncertainty. Instituting these changes with in-service training for providers would positively impact the well being of CGs

Caregiver Assessments and Interventions

Caregiver / patient dyads are vulnerable and health care providers need to focus also on the health of the dyad even though the family CG is not the patient (Sherman, 2008). There are three crucial factors that are paramount to meeting the needs of CGs which in turn benefit the PWPs. These factors are detailed in the following sections.

Formalized caregiver assessments

The findings revealed that the existing structure in health care settings does not lend itself to any formalized caregiver assessment protocol. In order to assure the well being of the CGs they must be assessed because they are a vulnerable stressed population who are responsible for the needs of persons with progressive chronic disease. This assessment would be extremely beneficial to determine if CGs are experiencing strain and if there are any specific risk factors toward LTC placement for the PWP.

There were health care providers in the study who informally asked CGs about their well being and then made recommendations as noted by this caregiver.

Well the doctor told me that I needed to make short range and long range plans, which I thought well what does that mean? Short range means what to do with the current situation, how to deal with it, and long range would be when you get to the point where he really does need to be institutionalized. I guess the short range would be like respite or things that can help every now and then or just temporarily or whatever (CG 4).

This concern from the physician was well intentioned; however, it is unknown if there was any follow up on a subsequent visit. Thus, a formalized caregiver assessment would take the place of just cursory questioning of CGs' well being on each visit.

These assessments specifically focusing on CGs should occur in a health care setting/facility or in the home through an agency like home health or elder care services. Moreover, CGs stated that it was important to be able to speak privately with the health care provider, especially the physician, to discuss the condition of the PWP. Sometimes CGs thought the conversations the PWPs had with physicians were not always accurate because of the cognitive deficits of the PWP. The CG's frustration was reflected in the following quote from a CG.

They did that assessment on him (husband with PD) where they test him for a lot of things. . . . My husband said don't ask me anything because I don't remember anything. . . . Well the next day he said he still couldn't remember whether or not he gave it (a note from the wife) to the doctor. Well he didn't have it with him, so I said, the doctor must have gotten it, but then, I couldn't get any answers so I called the doctor's office, for one of his people to call me back, and they never called me back. And I thought, then I thought ok, you are really dumb, this is the privacy act, they can't, even though I'm the wife and the caregiver, they can't tell me anything. . . I don't know (CG 8).

In some cases if the CG was present with the PWP and interjected during the meeting with the health care provider because the PWP was misinforming the provider, that interjection would cause tension in the CG/PWP dyad after that visit. Thus, a private conversation with the provider should be part of the assessment.

The caregiver assessment could be completed by the nurse, social worker or rehabilitation counselor. The type of assessment should be in the form of one on one interviews and giving the CG opportunities to elaborate on any concerns. This type of assessment cannot be completed with existing instruments such as the caregiver strain index because it does not allow probing for additional information (Robinson, 1983). For example, when asking about their support system, some CGs say they do not want to bother their adult children. In this situation, interviewers would probe to determine what type of support these CGs rely on, if any.

The context of this assessment interview must ask about CGs' lives such as their ability to handle any current imposing life events such as financial strain, their own health, and their sense of self preservation (i.e. taking time out for them). It is important to note that these assessment components are directly linked to the conditions found in my model that increase caregiver strain and eventually lead to a greater risk of situations like LTC placement. I do not believe there are any specific instruments that

specifically address all the components of my model. Therefore, it is essential to develop such an instrument.

These assessments also need to be individualized to meet the needs of the caregiver's situation. For example, the results of the study revealed emotions of loss throughout the caregiving trajectory. Assessments and bereavement counseling are options that are needed for this group of caregivers. Several CGs in my study have been to counseling to address strain and life events that impacted caregiving or to address relationship issues with the PWP. Moreover, this caregiver assessment process is not a onetime event; it is fluid. It is mandatory to follow up on these assessments and make referrals and follow up on those referrals. Therefore, these formalized assessments are essential for CGs of PWPs and the type and frequency of these assessments should be based on individual needs because each CG/PWP dyad's situation related to life events, stressors and disease processes is unique.

Care coordination

Another factor that is important to meet the needs of the CG is to have care coordination that optimally links their needs to resources. Providers must identify what resources are available for CGs and then coordinate those services. Services are splintered in many health care settings as noted by this caregiver. "And even doctors, primary care, they treat him, they treat me. I'm not so sure they really even know we're a couple" (CG 19).

One of the goals in optimal care coordination is to prevent a crisis such as a tense situation in one family in which obsessive compulsive behaviors of the PWP were destroying the marital relationship. Difficulties with medication that caused those behaviors could have been anticipated and handled with care coordination that focused

on preventive measures such as support, counseling and frequent follow up after the new medications were started. In this case there were no preventive measures to help address a potential crisis. Help was given during the crisis but the coordination and the benefit of this help was questionable. The CG was very unsatisfied about how their situation was coordinated as reflected by this quote.

They called in a social worker, I don't know, I think he was more than a social worker, he ran down and gave me about 20 minutes. But that's all they've ever done, but we had a very, very big setback that I think they had to make sure that they covered all bases which is why they brought that person in (CG 4).

Good care coordination includes recognizing the gaps in services for the family unit (PWP and CG). Caregiver needs, for example, can be met by coordinating care for homemaker services to help CGs who may also have chronic illness, continue to be able to care for the needs of the PWP at home. Other needs that can be coordinated include transportation, medical equipment rental, spiritual support and volunteer sitter services and especially formal respite care. CGs are often unaware of these various services and are in need of guidance. Employing case management services or even geriatric care managers who can visit the home and be a liaison between the health care provider, community services and the CG/PWP dyad would be beneficial to a seamless approach to care (Cress, 2007).

Organizations like hospice provide excellent care coordination which is centered on a multidisciplinary team approach with services from physicians, nurses, social workers, chaplains, music therapists and other auxiliary support. Team meetings are held to discuss family care because for hospice, the patient is viewed as the family unit. Since hospice is only appropriate for end of life palliative care, there is a need for the

primary practitioner to have a greater sense of care coordination to include the CGs' needs so that health care in the family is not splintered.

Parkinson's disease is a very complex disorder and CGs need resources to help them manage care of the PWP. For example, health care practitioners are often overwhelmed with many responsibilities and the task of coordinating support group meetings may not be a high priority. It is essential for them to better coordinate existing support group meetings for CGs and be more instrumental in facilitating these meetings until CGs can take ownership of the group. Helping CGs become empowered to learn to seek support and to eventually develop multiple sources of support for themselves is crucial to the health and well being of the PWP/CG dyad. However, it is important to note that some support groups have existing dynamics that do not always meet the needs of CGs and their families. Tuite and colleagues (2006) indicate that families need to find the one that best suits their needs.

Family centered care and interventions

Family centered care is paramount for the well being of the CG/PWP dyad. Family centered care is primary health care that focuses on the health of an entire family, and implements interventions that are needed to maintain and improve the health of the whole family as well as each of its members (Shelton, Jeppesen, & Johnson, 1987). Some CGs in the study revealed that they were often given materials on how to reduce stress; however, just reading material did not help them. Receiving materials in an attempt to address the many needs of caregivers is not a sufficient means to help them especially if they are too overwhelmed, or cannot read, or do not have a moment to sit down to read. Therefore, it is important to institute family centered interventions based on formalized caregiver assessments.

One major finding in this study strongly supports the need for respite services to ease caregiver strain. Some CGs noted that they had “breaks” while running to the store while a friend, neighbor or relative would care for the PWP. It is questionable whether this was truly considered time off for the CG. The definition of respite is time off to focus on the needs of the CG which results in being more refreshed after a break in caregiving (Mueth, 2006). There are three types of formal respite services available to relieve caregiver stress. They are: home help, day center and residential or night time respite services (Garces et al., 2010). Many of the CGs in this study did not know that these formal services existed, and several had a crucial need for some type of respite opportunity.

I have found that formalized respite care is a valuable service for the CG. In a hospice setting, for example, family members may bring their loved one to a hospice facility for a small period of respite care. This service also exists in some long term care facilities. One staff person from a facility told me that they have short stay services; however due to the amount of paper work that is required the shortest stay is one week, and the cost, which is not covered by Medicare, is \$135 dollars per day. This is a valuable service for CGs; however, many families may not be able to access it since this type of respite care is private pay. Moreover, not all long term care facilities or day centers offer this service (J.F. Griffin, personal communication, March 24, 2010). Therefore, it is important to find other means of respite care if these specific options are cost prohibitive.

Respite services are crucial for the health and well being of CGs and studies have shown that intervention in the form of respite services reduces the burden of caregiving

and can delay moving their loved one to a LTC facility. This finding in this study is supported in the literature (Garces et al., 2010; Koslaski & Montgomery, 1995,). Thus, the importance of individualized care which includes family centered interventions are crucial for health care providers to integrate into holistic care.

Limitations

A challenge in grounded theory (GT) research is recognizing that researchers may bring assumptions to the analysis. In order to prevent this from becoming a part of the interpretive reasoning of the conceptual framework, I disclosed my assumptions and wrote memos addressing any preconceptions as well as had discussions with peers and my major professor. Another challenge to this method is the need for the researcher to remain neutral during the interviews. Interview questions are open-ended and initially loosely structured to allow caregiver participants latitude to describe the experiences of caring for someone with PD. Researchers using GT conduct follow-up questions and probes based on what the respondents said earlier in the interview. This is done to gain more in-depth insight into the participants' caregiving experiences and decision making. Because of the risk of not remaining neutral, this interview strategy reinforces the importance of analyzing this data in interdisciplinary research groups whose members generate a variety of perspectives. Members of these groups question possible researcher bias and hold the researcher accountable for the way data is conducted and analyzed. GT is "a unique and highly demanding method, with strong congruence" (Richards & Morse, 2007, p. 61). Thus, novice researchers like myself, needed mentorship and guidance in conducting this method.

Another limitation of this study was the choice of sampling strategy which only permitted data to be collected from the University of Florida Movement Disorder Center

(UFMDC) data base. The study protocol required that the family member with PD be enrolled in that data base. This limited access to other potential participants in the North Florida area. Moreover, the UFMDC data base, which was difficult to obtain, had information that was outdated since several of the phone numbers were no longer in service. Out of 52 attempts to recruit participants from the north and northwest Florida areas, 12 phone numbers (23%) were out of service.

A further limitation was that only a small number of CGs had family members in long term facilities. Therefore, the decision making questions focused more on how families would make that LTC placement decision. Saturation was achieved after 20 interviews; however, within that sample size, only 2 family members were currently in a LTC facility and a third was now home after having been in a facility. If the sampling strategy would have allowed for recruitment at LTC facilities there might have been more opportunities for a more appropriate sample of families. It is important to note that many of the participants' relatives with PD had advanced symptoms in this study; however, they were not at a point of potential LTC placement.

Another limitation was the lack of ethnic diversity in the interviews since all the participants were White. Only 7% ($n = 6$) of the individuals in the data base covering the north and northwest Florida region were ethnic minorities. Of that group, 50% ($n = 3$) had phone numbers that were out of service. It is important to note that the ethnic minority population of the entire data base of all PD patients ($n = 1290$) was 4 % ($n = 85$). Also, the literature reveals that it is truly unknown how extensively PD affects minorities; yet it is substantially more common in Caucasians (Willis, Evanoff, Lian, Criswell, & Racette, 2010).

Another limitation was related to disproportionate gender distribution in the study. Only 15% ($n = 3$) of the 20 CGs in this study were male (spousal CGs). There were several attempts to find male CGs; however, they were not accessible within the available database. Van Den Eeden and colleagues (2008) revealed that the incidence of PD has a 2:1 male / female ratio which can then possibly play a role in the lack of male CGs. Even though there were 5 females with PD enrolled in the study, two of them had adult daughter primary CGs. Moreover, this larger male population of PWPs was higher than females in the UFMDC data base (i.e. males = 63%, $n = 815$ out of the 1290 total).

When conducting GT research and using dimensional analysis the researcher has many possibilities and directions for the study. The extensive amount of interview data, (600 pages or 246,000 words), produced a substantial amount of information to manage. However, due to time constraints, grant requirements, and other restrictions, I needed to make choices regarding the leads to pursue and what needed to be left for future projects. Regardless, the results from this pivotal study can be instrumental in opportunities for future research initiatives that are highlighted in the following section.

Directions for Future Research

Parkinson's disease has been a focus in many areas of research, and the results of qualitative studies like this one can provide a more in-depth insight into phenomena such as caregiver strain in PD. There are numerous areas of different research designs that could be pursued from the outcomes of this study. One of the main recommendations for the next step of my research program would be to use the model to give us an idea of what specifically a caregiver assessment would include and then to develop a formalized caregiver assessment instrument based on the constructs in the

model. Other examples of directions for future research include, mixed methods design studies exploring the feasibility of a case management/care coordination intervention that would include an array of services similar to what is offered by hospice. It would be interesting to see if this type of model would be cost effective for this population by preventing unnecessary LTC placements and hospitalizations for PWP, and improving CG well-being.

Other future studies can provide a greater emphasis on male caregivers of PWP who were slightly underrepresented in this study. Current evidence shows that males and females view caregiving from different perspectives. It would be interesting to learn if that is the case with PD caregiving. Moreover, the results of these studies would alert health care providers to the different needs of this population. Another group that should be studied is minorities with PD since they were not represented in this study. Questions to consider in this research would be whether or not their caregiving experiences are similar or different from this current study. Other considerations would be whether their family dynamics and support systems are similar or different than one ones identified in my study. Another recommendation for future research would be a replication of this study with a larger percent of caregivers who have family members with PD in LTC facilities especially because many of the caregivers in my study had to make assumptions on placement decisions rather than reflecting on actual experiences. Moreover, this research could have an additional arm extending to a post institutionalization component focusing on how caregivers continue caring for the PWP post LTC placement. This current study included both spousal CGs and filial CGs which added to the complexity of this research since differences were found among each

group's dynamics such as whether or not CGs lived with the PWP. Studies using either spousal or filial CGs could focus more on the phenomenon at hand rather than injecting confounding factors into the caregiving process.

On a grander scale, other areas of future study could incorporate this research of CGs of PWPs in multiple chronic disease areas which could provide rich outcomes and be appealing to federal initiatives such as National Institutes of Health (NIH) funding on chronic disease management. Specifically, I could partner with others doing research on caregiving for persons with stroke and see if their intervention studies on caregiver assessments can apply to PWPs. Moreover, this type of initiative could be enhanced with studies incorporating multi center research venues. In other words, my own research of CGs of PWPs could be conducted in other areas of the country where large research centers are already doing caregiver research. This would be an important partnership with joint studies in other areas of chronic illness and could lead to an understanding of the similarities and differences in caregiving among those caring for persons with various illnesses. These findings could lead to crucial interventions for the vulnerable population of caregivers.

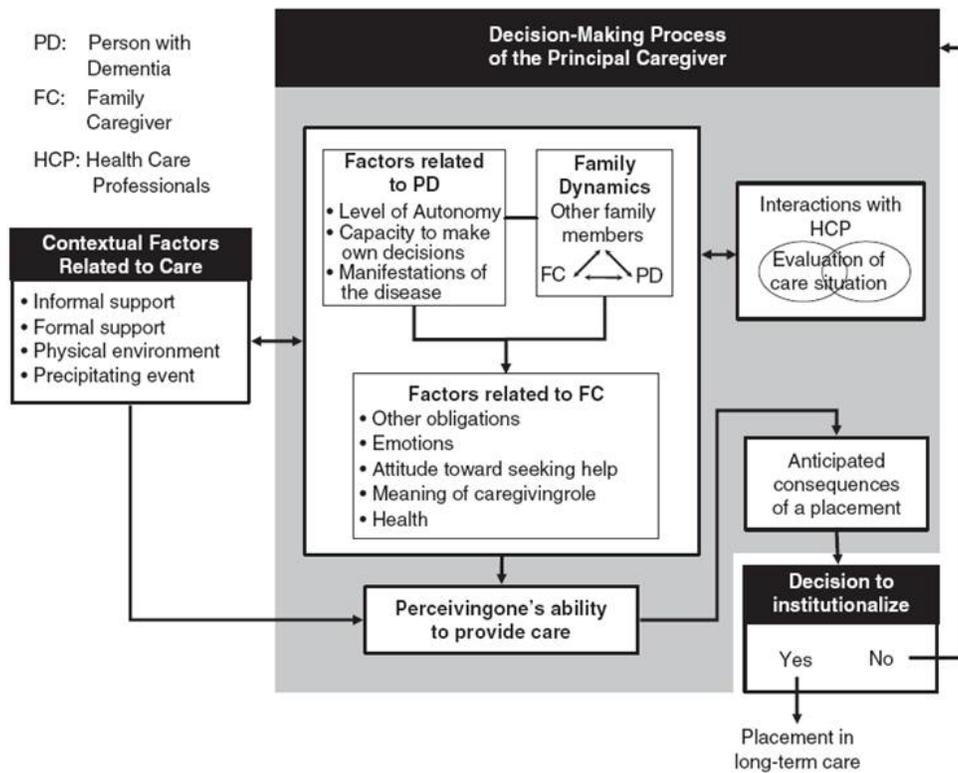
Summary

Caregivers are vulnerable and often overlooked in professional settings. The quality of their experiences can have a negative impact on the family unit if they have difficulty managing the caregiving role. A better understanding of their needs is essential especially in areas of increased support and respite. Additionally, guidance for health providers across disciplines is critical to meet the needs and improve outcomes for families caring for PWPs at home. These CGs are the threads that bind and keep the family together.

Conclusion

This study began with an identification of gaps in the literature with respect to the decision making process involved in institutionalizing a relative with Parkinson's disease. Studies that focus on the factors that predict institutionalization of PWP are dated. Research that emphasizes the caregiving decision processes and models that illustrated the process exist in dementia studies. To date, no studies have focused on caregivers' decision process when choosing to institutionalize a relative with Parkinson's disease. Furthermore, the use of the GT method in this research provided a richly contextual and meaningful description of caregiver experiences that can blend well and enhance other types of research.

This study identified the complexities of caregiving, decision making and the support structures needed to care for persons with PD at home. Implications from this research can lead to instituting formalized caregiver assessments, better care coordination and family centered interventions that delay premature LTC placement of PWPs. Furthermore, the model developed from this research can support existing models or inform the development of future models that reflect the experiences of those caring for persons with other chronic conditions. Thus, this study was a necessary step toward documenting evidence about caregiving experiences and health care decision processes of caregivers of persons with Parkinson's disease.



Caron, Ducharme & Griffith (2006) Emerging theoretical model explaining caregivers' decision to institutionalize an older relative with dementia

Figure 5-1. Decision to institutionalize model ("Deciding on institutionalization for a relative with dementia: The most difficult decision for caregivers" by Caron, C.D., Ducharme, F., & Griffith, J. Canadian Journal on Aging, Vol. 25, No. 2 (2006), pp. 193- 205 Copyright © 2006 Canadian Association on Gerontology. Reprinted with the permission of Cambridge University Press")

APPENDIX A
RECRUITMENT FLYER



Caring for a Family Member with Parkinson's Disease

An invitation for Family Caregivers

Our Research: The purpose of this study is to learn more about your experiences in caring for a family member with Parkinson's disease and to look at the process you go through when thinking about moving your family member to a nursing home for care.

How You Can Help: Your input is too important because it will help people in the health care field understand your care giving experiences, which in turn, will create better ways to provide care for you and your family.

For Further Information or to become a participant in the study

Please contact

Maryann Abendroth, MSN, RN at the University of Florida College of Nursing

Email: miabend7@ufl.edu

Phone: 850-445-3730 or 352-273-6350

IRB
APPROVED
ON 2/13/09 egd

APPENDIX B INTERVIEW GUIDE

This is an interview guide for the interviews with caregivers. The questions are designed to elicit elaborate responses from study participants about the meaning and experience of caring for someone with the disability, quality of life, and factors that influence the decision to institutionalize a relative with PD. Questions will be altered and revised depending on the context and tone of the interview.

1. Tell me a little bit about yourself.
2. Tell me about caring for [name of person with PD]
Probe: Describe a typical day.
3. How has caring for [name of person with PD] changed your life?
4. What helps you caring for [name]? What problems have you encountered? How do you handle them?
5. Could you describe the events that led up to the decision to think about moving (name) to a nursing home?
6. What contributed to this decision?
7. Tell me about your thoughts and feelings as you were deciding whether or not to place (name) in a nursing home.
8. Who has been the most helpful to you during this time? How has he/she been helpful?
9. What kinds of services/assistance would help you be able to better care for (name) at home?
10. What kinds of things (relationships, activities, etc.) are important to you?
11. What do you look forward to?
12. What kinds of things would you like to be able to do?
13. Do you think about your future? How do you see it?

APPENDIX C SAMPLE OF A MEMO

Illness Management

It was very interesting to see the lengths this couple went through to help the PWP remain at home. What I mean is that the devices and outside help they received. She had a wheelchair, a high quality walker. They bought a board so that she can communicate and a voice amplifier with a keyboard. This was helpful for when she could no longer speak. They also learned sign language. Unfortunately in some of the other interviews, caregivers did not actively seek such support. This caregiver did regret not calling in hospice sooner and I've seen in practice that people do not call in hospice until close to the end of their loved ones lives. It was also interesting to note that he didn't care what kind of damage she did to the house with her wheelchair. Her care and well being overrode everything. He sought support but it was mainly for her care. Did he provide support for himself? I mean a sort of strategy of self care? This caregiver considered himself a planner or organizer and this he says helped in illness management. "I would sit down and we would map out what had to be done in her care" line 414. "I would try to keep the calendar updated as to when somebody was going to come, when they weren't when her doctor's office visits were. I wrote out schedules for her medications, I organized her pills in her pill organizer and got these little red dots for one day and blue dots for the 2nd day and stuff like that." lines 414-420. He even planned her funeral and wrote her eulogy. I later asked him what would have happened if he wouldn't have organized her day and the future in this manner and he simply said there would have been chaos. "The house would have been in utter chaos, her health care would have suffered greatly, and meals wouldn't have been prepared in a timely fashion lines 464-466. I feel there were many reasons why the organization was necessary. Yes perhaps it was to bring a feeling of control, but also to bring about safe appropriate care for the person with PD. This is a very complex illness and even being off with medication administration, which is a complex endeavor in itself, can cause huge complications. The day to day organization from many facets is important to maintain a balance for the person living at home. It is understood that executive function is affected with PD, so a lot of the responsibility may fall on the caregiver to organize their lives. Even though this CG was organized and planned daily care I kept wondering how his own physical and mental health were faring without an extended break away from the PWP. He never mentioned himself until later in the interview when he expressed emotions of abandonment, anger and a sense of being overwhelmed.

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BIOGRAPHICAL SKETCH

Maryann Abendroth earned her BSN and MSN degrees from the College of Nursing at Florida State University. Her master's thesis focused on compassion fatigue risk among hospice nurses. She has been on faculty at Florida State University since 2005 and will continue in the role of Assistant Professor upon receiving a PhD in nursing sciences from the University of Florida. She also holds a BA in French literature from Emory University and has taught secondary school before becoming a nurse in 1997. Her professional background includes medical surgical, public health and hospice nursing as well as nursing education. Her research areas of interest are formal and informal caregiving, chronic illness, and gerontology. She also holds a graduate certificate in geriatric care management from the University of Florida. Maryann has been married to John Abendroth since 1985 and they have two adult children who have blessed their lives. Maryann and John have lived in Tallahassee, Florida since 1993.