CAREGIVER PREPAREDNESS OVER A 10-YEAR PERIOD: A STUDY OF PARKINSON'S DISEASE SPOUSES

By

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ABSTRACT

Title: Caregiver Preparedness Over a 10-Year Period: A Study Of Parkinson’s disease Spouses

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Parkinson’s disease (PD), a chronic, progressive neurological disease, affects at least one million Americans. During the course of PD, family members, mainly spouses, provide most of the support and care in their homes. Providing care to a relative with PD has been associated with depression and poor quality of life. Research shows the important link between high levels of preparedness and low levels of role strain. The study was aimed at describing caregiver preparedness in spouse caregivers of persons with PD over time, and identifying the role of transition conditions and nature of PD caregiving factors in predicting preparedness over time. The secondary data analysis examined 251 caregivers over a 10-year period (baseline, Year 2, and Year 10). A Level 1 hierarchical linear model revealed that preparedness varied across spouses at baseline, but there was no significant change in caregiver preparedness over time and no significant variability around the average trajectory. Two hierarchical multiple regressions examined the transition conditions associated with preparedness at baseline and Time 3. At baseline, with minimal care needed, spouse caregivers’ well-being and relationship quality with the patient with PD (mutuality) were significantly associated with preparedness, while at Time 3, when more care and assistance were required, care-related factors (predictability, the number of direct care activities, and help received from relatives) were significantly associated with preparedness. Findings suggest that early on in the caregiving trajectory, clinicians should detect and initiate couple-based interventions in cases of low mutuality to help build and maintain stronger relationships. Over the course of caregiving, practical information on how couples and spouse caregivers can handle an increasingly less predictable care situation should be provided so that PD couples can adapt to, and live with, the disease as a team.

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CHAPTER 1

Introduction

Family caregiving is highly needed by much of society, with an estimated 80% of persons who have a chronic illness, including Parkinson's disease (PD), staying at home (National Family Caregiver Association, 2009). Their family members, mainly their spouses, provide most of the care. Due to the new information, skills, and behaviors required of spouse caregivers, it involves a role transition (Ziemba, 2002). The term "spouse caregiver(s)" is used broadly to refer to a committed partner, who provides care to his/her spouse who has PD in their home. The spouse caregiver is viewed as an extension of the common spousal role (Habermann, 2000). However, many spouses have no formal training and feel inadequately prepared and overwhelmed by the caregiving experience (Giarelli, McCorkle, & Monturo, 2003; Hudson, Aranda, & Hayman-White, 2005) as they struggle to adjust to the tasks and duties that make-up the caregiving role (D'Amelio et al., 2009; Davis, Gilliss, Deshefy-Longhi, Chestnutt, & Molloy, 2011; Habermann, 2000; Roger & Medved, 2010).

Caregiver preparedness, a feeling of being prepared to provide in-home care to a relative (Archbold, Stewart, Greenlick, & Harvath, 1990), is key to obtaining the most favorable outcomes related to the caregiving experience (Linendoll, 2008; Taylor, 2010). Hence, it is viewed as a process indicator of a healthy transition into a spouse caregiver role. This definition of the term "caregiver preparedness" is used throughout the study. Previous studies in older adult and cancer caregiving have demonstrated that caregivers who had low levels of preparedness had higher levels of negative caregiving outcomes, including role strain (Archbold et al., 1990), caregiving difficulties, negative well-being

(Scherbring, 2002; Schumacher, Stewart, & Archbold, 2007), and perceived symptom distress (Linendoll, 2008). However, little is known about this important relationship in PD caregiving. Given its positive effect on caregiving outcomes in other contexts, whether and how caregiver preparedness changes over time is a matter of concern. More importantly, enabling nurses to identify early-warning signs for long term negative outcomes of caregiving on spouse caregivers due to a low level of caregiver preparedness is worthy of study, especially in spouse PD caregiving (Carter et al., 1998).

In spite of ample knowledge about the protective effect of this important caregiving factor, whether and how caregiver preparedness changes over time in spousal PD caregiving remains unclear (Carter et al., 1998) for at least four possible reasons. First, the vast majority of existing caregiver preparedness research has been cross-sectional in design, severely limiting the ability to determine whether caregiver preparedness changes or remains stable over time (Linendoll, 2008). Caregiving, including PD caregiving, is an ongoing process that accommodates changes in the care situation (Giarelli et al., 2003; Pearlin & Aneshensel, 1994). Thus, there is a potential for change over time in many aspects of the caregiving situation, including caregiver preparedness (Schumacher, Stewart, & Archbold, 1998). Therefore, it is essential that caregiver preparedness be examined over time.

Second, there is a dearth of research determining what the factors are that may predict caregiver preparedness over time. A great number of cross-sectional studies have examined the association of caregiver preparedness with other caregiving-related factors. However, it has primarily been examined as a predictor of caregiving outcomes in general and not as an outcome in its own right or, in other words, not as the condition being predicted (Samartkit, 2008; Schumacher et al., 2007). Little is known about the factors affecting or predicting caregiver preparedness over time (Ziemba, 2002). Fortunately for caregivers, high levels of long-term negative outcomes of caregiving on caregivers due to a low level of caregiver preparedness may be preventable if we can identify early-warning signs, and then modify them through proactive interventions.

Third, only a few of the prior caregiver preparedness research projects have been conducted longitudinally and the few longitudinal studies that exist have demonstrated inconsistent findings (Giarelli et al., 2003; Scherbring, 2002). This shortcoming could be explained by several factors, including a small sample size, a short study time period, and only traditional statistical approaches being applied in the studies' designs (Giarelli et al., 2003; Scherbring, 2002). As discussed later, this study addresses these limitations. Lastly, no existing longitudinal caregiver preparedness research was found in the context of PD spouse caregiving, which is unique in its nature and differs from other care situations (National Parkinson Foundation, 2011). Unique characteristics of PD include functional fluctuations and unpredictable and uncontrollable symptoms and progression, even when proper treatments and medications are well-administered (Carter, Stewart, & Archbold, 2008), which could have a tremendous effect on the persons with PD and their spouse caregivers (Habermann, 2000). Thus, it is crucial that a study examining whether and how caregiver preparedness changes over time be conducted in this vulnerable group.

Problem Statement and Significance

Parkinson's Disease and Spouse Caregiving

Approximately 50,000 to 60,000 new cases of PD are diagnosed each year, adding to the at least one million people who currently have PD in the United States

(National Parkinson Foundation, 2011). PD is a chronic, progressive neurological disease with limited therapeutic options in its advanced stages, no known cure (Fernandez, Tabamo, David, & Friedman, 2001), and little predictability in its progression (Carter et al., 1998). As an age-related disease, the incidence of PD is more common in older adults (Van Den Eeden et al., 2003). With its trajectory of progressive motor and non-motor dysfunction, a person with PD generally endures physical impairment which results in an increasing loss of their independence. As the disease progresses the patient becomes more dependent on others to meet their needs (Carter et al., 1998). Their family members, primarily their aged spouses, provide most of their in-home care (Carter et al., 1998; Davis et al., 2011; Habermann, 1996). The link between providing care to a relative with PD and poor quality of life, caregiver strain, and depression is well-documented (Berry & Murphy, 1995; Fernandez et al., 2001; Martinez-Martin et al., 2008; Martínez-Martín et al., 2005; Peters, Fitzpatrick, Doll, Playford, & Jenkinson, 2011).

PD caregiving is a prolonged and ongoing process, not a one-moment type situation. Given the slow, progressive trajectory of PD, without specific-time range estimates for reaching the next stage of the disease, caregivers may not know how, or when, to prepare for the next stage during the course of caregiving. These unique characteristics of PD can lead to the likelihood of unpredictability and a failure in preparing for managing ongoing, daily changes (Carter et al., 1998). Because of this the spouses may not only have to gradually adjust to a new role, but restructure their existing family roles to adapt to any changes that may occur (Bogard, 2010). The likelihood of subsequent life disruptions after taking on a spousal caregiver role for a person with PD is greatly increased (Burton, Zdaniuk, Schulz, Jackson, & Hirsch, 2003). Thus, transitions in PD caregiving could move the caregivers, particularly spouse caregivers, in the direction of greater vulnerability and risk instead of health, which could lead to experiencing an unhealthy transition.

Healthy Transition in Spousal PD Caregiving and Caregiver Preparedness

A healthy transition is defined as a greater feeling of being prepared during the transitional process and the perception of health and well-being toward the caregiver's adaptation to the new challenges which the caregivers must meet. Healthy transition, when it is experienced, is thought to lead to better caregiving outcomes including increases in the sense of connectedness, commitment, willingness to stay in the caregiver role (Meleis, Sawyer, Im, Hilfinger Messias, & Schumacher, 2000), and in keeping the afflicted person at home rather than placing her/him in a care facility (Chesla, Martinson, & Muwaswes, 1994). In the literature on aging, being less-prepared comes with disruptions in the normative timeline and results in decreased effectiveness of care (Linendoll, 2008) and an increased risk of compromised health in caregivers (Archbold et al., 1990). Decline in the caregiver's health is a vital factor predicting the discontinuation of caregiving in their home (Arai, Sugiura, Washio, Miura, & Kudo, 2001; Okamoto, Hasebe, & Harasawa, 2007) and early placement in a care facility (Abendroth, 2010; Gaugler, Kane, Kane, Clay, & Newcomer, 2003).

Caregiver preparedness can be viewed as one of the vital determinants of the transition process into, and the continuation of, healthy caregiving (Ducharme et al., 2011; Schumacher et al., 1998). The protective effect of preparedness against the negative outcomes of caregiving has been well-established in various family caregiving situations (Archbold et al., 1990; Samartkit, 2008; Schumacher et al., 2007; Shyu et al., 2010). On the other hand, we do not know how caregiver preparedness changes over time.

Previous studies have shown that several intrapersonal characteristics of both the spouse caregiver and patient, interpersonal characteristics, and environmental conditions could affect caregiver preparedness over time during the transition process (Archbold et al., 1995; Carter, Lyons, Stewart, Archbold, & Scobee, 2010; Carter et al., 1998; Cummings, Long, Peterson-Hazan, & Harrison, 1998; Hudson et al., 2005; Kneeshaw, Considine, & Jennings, 1999; Rusinak & Murphy, 1995; Samartkit, 2008; Schumacher et al., 2007; Shyu et al., 2010; Silver, Wellman, Galindo-Ciocon, & Johnson, 2004; Ziemba, 2002). These prior findings have suggested that we could prevent or alleviate negative outcomes during the caregiving transition process if we could identify the factors that are most closely correlated and then modify them through targeted interventions designed to increase preparedness among caregivers. However, one important factor remains unknown, does caregiver preparedness change over time (Linendoll, 2008). Although a few studies examining caregiver preparedness over time were found in the context of cancer caregiving, the findings were consistent across the studies (Giarelli et al., 2003; Scherbring, 2002). But, this question has yet to be answered across other caregiving situations, including in the PD caregiving context.

What has been found in the PD caregiving context is that neither the stage of the disease nor the spouse caregiver’s age-group makes a difference in the perception of preparedness when examined cross-sectionally (Carter et al., 2010; Carter et al., 1998). Additionally, whether and how caregiver preparedness changes over time in the PD spousal caregiving situation remains unknown. It is important to understand the stability or change in preparedness that might exist (Schumacher et al., 1998).

Specific Aims

To fill in these gaps in literature, this study examined caregiver preparedness in spouse caregivers caring for a spouse with PD in their home over a 10-year period in order to determine whether preparedness changes over time and to identify the role of factors in predicting any change that occurred through the lens of transitions theory. The primary aims of this study were to:

1. Describe caregiver preparedness in PD spouse caregivers over a 10-year period.
2. Identify the factors that predict caregiver preparedness over time.

Significance to Nursing

The long-term goal of this study is to facilitate healthy transition over the period of caregiving so spouses can continue to care for the person with PD in their home as long as they wish. It is believed that caregiver preparedness plays a vital role in accomplishing this goal. Importantly, given the existence of only a few research studies examining whether and how, it changes over time, there is insufficient information to effectively design spouse-based interventions targeting unprepared spouse caregivers over time. Effective interventions increasing caregiver preparedness do exist, but they are skill-based (Elliott & Berry, 2009; Elliott, Brossart, Berry, & Fine, 2008; Hudson et al., 2008; Leutz et al., 2002) and not purposefully targeted at caregivers who are at risk for long-term negative caregiving outcomes as a result of low levels of caregiver preparedness. Additionally, these interventions were conducted in caregivers of patients with cancer, traumatic brain injury, or spinal cord injury, not in the PD caregiving context. More importantly, they were not primarily targeted at spouse caregivers, except for the work of Giarelli, McCorkle, and Monturo (2003). Addressing the factors that could identify caregivers who are likely to be better-prepared over time has not been previously examined.

Knowing the factors that predict caregiver preparedness over time would allow nurses and other clinicians to identify the group of caregivers who may be vulnerable for long-term negative outcomes of caregiving. In addition, this knowledge would benefit the family caregiving community in terms of understanding what would be worth the investment and effort with regard to devising and implementing spouse-based interventions targeting those spouse caregivers providing care to a patient with PD at home. The findings of this study may help guide future research to new directions.

The current study addressed these limitations by using an advanced statistical approach, multilevel modeling, to capture change in preparedness and variability around that change. The study is innovative because it is the first study to specifically examine changes in caregiver preparedness in spouse caregivers of PD across North America over a 10-year period using an advanced statistical approach.

CHAPTER 2

Review of the Literature

This chapter presents the theoretical framework of the study, the conceptual model for the study, and an overview of the literature on transition into a caregiver role in individuals caring for a spouse with Parkinson's disease (PD). A critical review of prior research on caregiver preparedness over time is also presented followed by a summary and discussion addressing gaps in the literature.

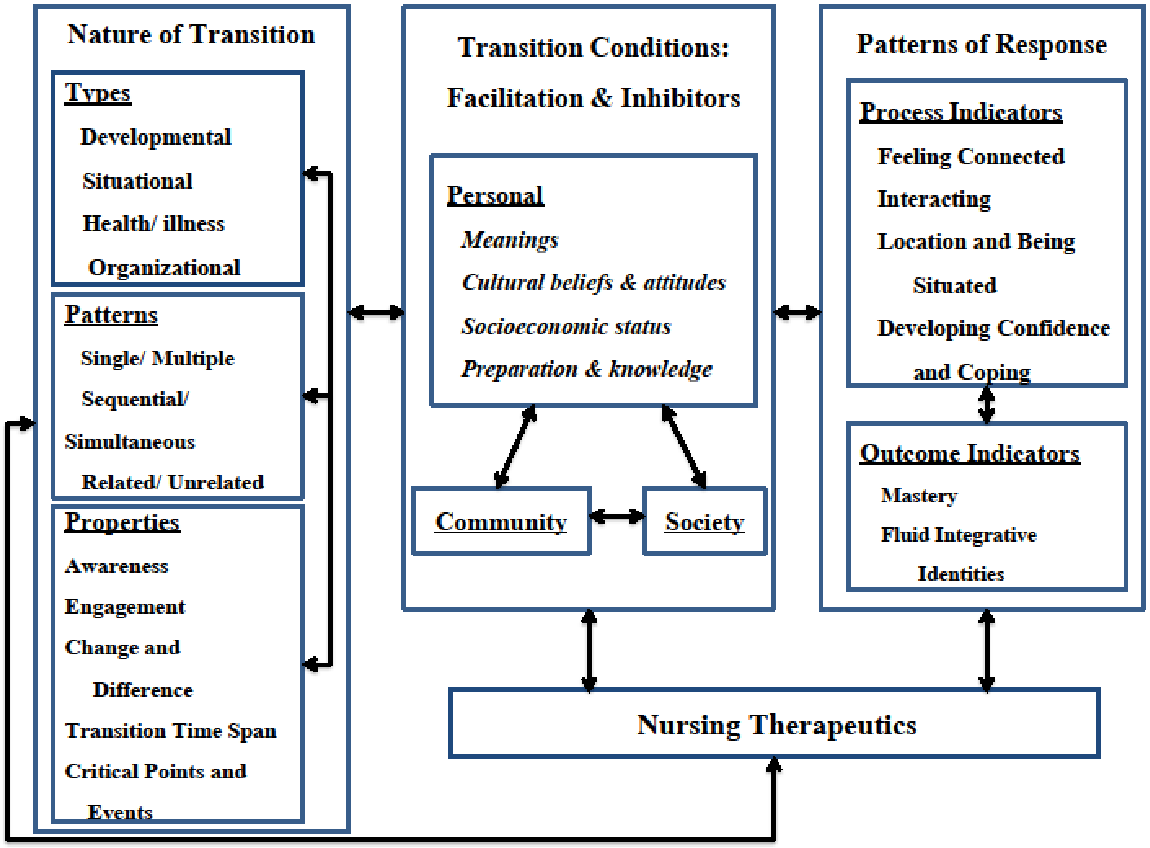
Theoretical Framework

The central focus of this study was to describe caregiver preparedness among spouses of persons with PD over a 10-year period and to identify the factors that may predict caregiver preparedness over time. Caregiver preparedness is viewed as a process indicator of a healthy transition into a spouse caregiver role. To attain these research goals, a framework that could account for variations in caregiver preparedness over time and uncover the factors that are likely to have an influence on it is needed. Therefore, nursing transitions theory served as the theoretical framework for this study.

Transitions Theory

Transitions theory, a middle range nursing theory, was developed by Meleis and her colleagues in 2000 to help describe and understand how an individual experiences the multiple transitions they experience during a life time. They have focused on transition as a core concept of nursing. Transition is conceptualized as "both a *result of*, and *result in,* changes in lives, health, relationships, and environments" (Meleis et al, 2000; *p.*13). The theory addresses the four major components of a transition including the nature of transitions, transition conditions, patterns of response, and nursing therapeutics (Meleis et al, 2000; See Figure 1).

Figure 1. Transitions: a Middle-Range Theory (Meleis et al., 2000)



Transitions stem from a variety of life events including situational, developmental, and social or cultural changes. For instance, a transition into spouse caregiving is precipitated by a health decline, illness progression, or an increased dependence of one spouse. Transition is seen as an ongoing process that people encounter when they face changes in their lives that often create disruptions in their routines and roles. Concomitantly, that could make people vulnerable to risks that might affect their health and well-being (Meleis et al., 2000). Maintaining a healthy direction through a transition and achieving positive outcomes are desirable. Meleis and her colleagues suggest that personal, community, and society resources can either facilitate or inhibit healthy transitions or the achievement of positive outcomes of transitions.

On the personal level, meaning, cultural beliefs, and attitudes towards the change are critical. Moreover, socioeconomic status, preparation, and knowledge are also important personal conditions that may impact how people respond to a transition. Being prepared for the complex nature of transition may increase the likelihood of experiencing the positive outcomes of a transition. Community conditions such as the availability of resources, which may vary from area to area, can influence a given transition. For example, in the case of a transition due to illness, a patient who lives in a rural area may experience his transition from hospital to home differently from those who live in an urban area with respect to the availability of needed health care services. Societal conditions, such as gender inequity and societal expectation, can also affect transitions. In some societies, women, especially daughters-in-law, are expected to provide care for their live-in parents-in-law regardless of their wishes.

Meleis and team argue that process and outcome indicators (termed patterns of response) are measures of a healthy transition (Meleis et al., 2000). Process indicators, including feeling connected, interacting, being situated, coping, and developing confidence are signs of a successful transition and health during the transition. Increases in confidence could be shaped by the sense of being prepared to deal with the transition. On the other hand, the outcome indicators of healthy transition can be seen when people have developed the skills over the transition process to prepare for subsequent changes and have successfully restructured their identities to meet those changes. Finally, Meleis and her colleagues incorporate nursing therapeutics into the theory and point out that fostering a healthy transition is a focus of nursing practice. The transitions theory guides nurses in identifying the characteristics of healthy transitions, as well as their facilitators and inhibitors.

Implications of Transitions Theory for PD Spousal Caregiving Transition

Transitions theory focuses on the health and well-being of those who experience changes, making this nursing theory markedly distinguishable from transition concepts from other disciplines. The theory illustrates the fluidity of the transition's components and that each component influences and is influenced by the others. Furthermore, because of the close relationship of family members and how their experiences are interrelated, Meleis and her colleagues suggest that interaction between a caregiver and a care receiver is a vital aspect of family caregiving (Meleis et al., 2000). This means that the experiences of a transition into a caregiving situation which is experienced by one spouse cannot be understood in isolation from those of the other spouse (Schumacher, 1996). A failure to do so could result in an unhealthy caregiving transition that may have negative impacts on their health and well-being. These important characteristics of transitions theory resonate within the complex nature of transition in the caregiving process.

PD is a progressive disease, and spouses provide most of the care during a chronic illness. Transitions in PD spousal caregiving can be viewed as a result of the decline in the health, or illness progression, of one spouse resulting in the other spouse taking on a caregiver role. This would be considered a situational transition. Transitioning into this role requires spouses to commit to their caregiving responsibilities over the length of their caregiver career. Being prepared for the complex nature of spousal caregiving transitions at the beginning can help set caregivers well on their way to a healthy transition and accomplishing positive outcomes.

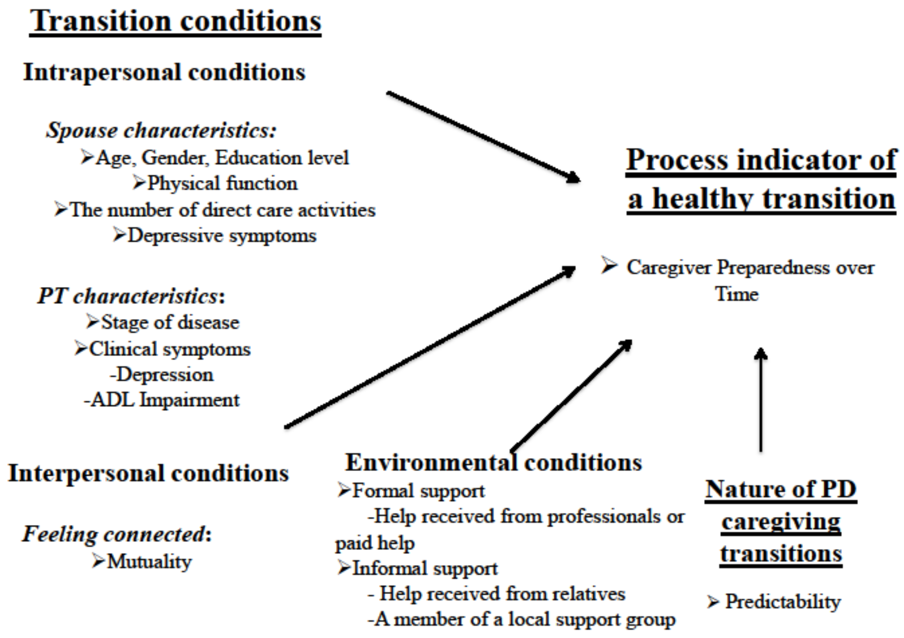
Hence, feelings of being prepared can be viewed as a process indicator of a healthy transition in spousal caregiving. Being prepared for caregiving is characterized by the spouse’s beliefs and abilities to obtain new knowledge and skills to adapt to the new situation of PD caregiving and its subsequent events during the course of PD. These can be found when an individual caring for a spouse with PD is able to create a new perception of who they are, what to do, and how to handle their PD caregiving situation so they can reflect and develop increasing confidence in coping with the new situation (Meleis et al., 2000).

Factors that may impact caregiver preparedness are transition conditions including spouse and patient characteristics, the spouse’s beliefs and attitudes toward caring for a spouse with PD, and receiving help and support from their formal and informal networks and community. In addition to transition conditions, the nature of PD caregiving can be an important factor affecting caregiver preparedness. A major characteristic of PD is that its progression and symptoms are unlikely to be predictable or controllable, so that PD patients and their spouses live in a state of uncertainty. This lack of predictability in PD’s progression may affect the spouse caregiver’s feelings of being prepared due to an inability to predict changes in the caregiving situation, make a plan, and follow through with it. The potential for being able to understand how caregiver preparedness changes over time in relation to these factors further justifies the need for this study.

The Conceptual Model

The purpose of this dissertation study is to describe whether and how caregiver preparedness changes over time. The conceptual model was adapted from, and organized around, the major components of the transitions theory of Meleis and her colleagues (2000, See Figure 2). A feeling of being prepared (termed caregiver preparedness) is viewed as a process indicator of transition in spousal caregiving. To attain the goal of identifying spousal caregivers at risk for unhealthy transitions early in the caregiving trajectory, baseline transition conditions and the nature of PD caregiving factors were selected. The selection of potential predictors was theory-based and made by focusing on the factors that are relevant to spousal PD caregiving, while retaining the emphasis on caregiver preparedness over time. The relationship between the potential baseline predictors and caregiver preparedness over time is displayed in Figure 2.

Figure 2. Conceptual Framework.



To provide a better understanding of this phenomenon, the following section presents an overview of the literature related to transitioning into the spouse caregiver role of a person with PD, including background in PD caregiving and spousal PD caregiving. Finally, a critical review of prior research on caregiver preparedness over time, transition conditions, and the nature of caregiving are discussed with regard to how they may predict caregiver preparedness over time, followed by a synthesis and discussion of the available literature.

The Literature Review

Parkinson's Disease and Caregiving

Parkinson's disease is a chronic, progressive neurological disease with limited therapeutic options in its advanced stages and with no known cure (Fernandez et al., 2001). In the United States (U.S.), based on the National Institute of Neurological Disorders and Stroke (NINDS, 2006), about 50,000 Americans are newly diagnosed with PD each year. Estimates of PD prevalence may not be precise but around 1.5 million Americans are believed to have PD (National Parkinson Foundation, 2011) in the U.S. The disease has subtle symptoms that develop gradually and the average age of onset is 60 years of age. Both prevalence and incidence rapidly increase among people who are in their 70s and 80s (Van Den Eeden et al., 2003).

Living with any chronic illness, including PD, can be daunting and PD can be profoundly frustrating as walking, talking, and even eating become more challenging and time-consuming (Habermann, 1996), particularly in the later stages of the disease when its symptoms are difficult to control or predict (Bogard, 2010). As PD progresses both formal and informal caregiving are commonly required (Bogard, 2010). However, only approximately 7% of persons with PD are admitted to a long-term care facility (Mitchell, Kiely, Kiel, & Lipsitz, 1996). When persons with PD lose their ability to navigate through their environment, communicate, and perform self-care tasks (Pretzer-Aboff, Galik, & Rersnick, 2009) they heavily rely on their family members for assistance in their home. Providing care to a relative with PD has been associated with depression and poor quality of life (Ali & Ward, 2011; Fernandez et al., 2001).

Symptoms of Parkinson’s disease: Progressive and unpredictable.

Even though a person with PD can struggle with both motor and non-motor symptoms, the prominent features indicating PD’s progression are four motor dysfunctions: tremor, rigidity, bradykinesia, and postural instability (Pretzer-Aboff et al., 2009). These symptoms can have a significant effect not only on the affected person’s ability to perform activities of daily living (ADLs), but also their ability to live independently (Pretzer-Aboff et al., 2009). Early motor symptoms are subtle and can go unnoticed. They may be mild at first, but gradually become more intense and debilitating. The rate of progression in PD varies from person to person and can take up to 20 years, or longer, to fully manifest. In some people, however, the disease progresses more rapidly (NINDS, 2006).

The non-motor symptoms are the result of neuropsychological dysfunction and may include mood disorders, cognitive dysfunction, complex behavioral disorders, sleep disorders, autonomic dysfunctions, sensory symptoms, and pain (Poewe, 2008). PD is commonly accompanied by depression (Aarsland et al., 2007), difficulty chewing and swallowing, urinary problems, constipation, and sexual dysfunction (Factor & Weiner, 2008) that can affect the patients’ physical functioning. In many instances these symptoms can be more distressing and debilitating for the person with PD and their caregivers than the motor symptoms (Carter, Stewart, Lyons, & Archbold, 2008; Pretzer-Aboff et al., 2009).

When the motor symptoms are coupled with non-motor symptoms, the level of despair and frustration are exacerbated making it much more difficult for both the affected person and their caregivers to deal with them on a daily basis (Habermann, 1996; Habermann, 1999; Pretzer-Aboff et al., 2009). Furthermore, medications for PD can cause a number of complications including involuntary twitching or jerking movements of the arms or legs, hallucinations, sleepiness, and a drop in blood pressure when standing up (Factor & Weiner, 2008; Imke, Hutton, & Loftus, 2003) resulting in fluctuations in mobility that are poorly controlled (Carter et al., 1998). The person with PD may be able to perform an activity at one moment and, a few minutes later, be unable to perform the same function. The adjustments of persons with PD and their caregivers have to make in learning to deal with the *"On/Off"* fluctuations in PD symptoms, the back and forth between the periods of time with symptoms and periods of time without symptoms, can be overwhelming. Typically, a patient can experience the cycle between the *On* and *Off* periods three to four times every day, although everyone's experience is unique (Hardie, Lees, & Stern, 1984; Poewe, 2009). It should be noted that being diagnosed with PD proposes a future of living with uncertainty and unpredictability over a protracted period of time that can create a life of chaos in the PD caregiving experience (Abendroth, 2010).

The impact of PD caregiving.

The impact of providing care for a relative with PD at home on the individual, family, and community at large is hardly disputed (Davis et al., 2011; Gibson & Houser, 2007; Goldsworthy & Knowles, 2008). Family caregiving could help reduce the huge cost of health care associated with PD. While this impact can be viewed as beneficial for the health care system and public in general, it could be counted as a cost that is paid for by their family. Receiving low wages, un-reimbursed informal care, and changing roles and responsibilities as a result of caring for a relative with PD at home were reported as negative impacts of the caregiving experience (Whetten-Goldstein, Sloan, Kulas, Cutson, & Schenkman, 1997).

Without any doubt, the positive and negative impacts of PD caregiving on individual caregivers as a part of their caregiving experience have been well documented (Davis et al., 2011; Gibson & Houser, 2007; Goldsworthy & Knowles, 2008). However, investigation of the negative aspects of caregiving was more pervasive in the literature. Caregivers may experience caregiving positively, as enriching their lives, while its negative side can be burdensome. Positive experiences have been described as rewards of caregiving (Carter et al., 2010) and finding a provisional meaning of caregiving (Hooker, Manoogian-O'Dell, Monahan, Frazier, & Shifren, 2000; Konstam et al., 2003) as well as satisfaction and reward (Nolan, 2001). On the other hand, caregiving has been prominently linked to poor emotional, social, and physical health in caregivers (Pinquart & Sorensen, 2007; Schulz & Beach, 1999; Schulz & Sherwood, 2008), including that of PD caregivers (O'Reilly, Finnan, Allwright, Smith, & Ben-Shlomo, 1996). Caregivers of persons with PD may experience more negative outcomes from caregiving than other caregivers because of the inherent unpredictability of the progression and symptoms of PD.

Parkinson's disease and spousal caregiving.

Having symptoms diagnosed is a critical turning point for persons with PD and their spouses, as it marks the starting point of the transition from being a wife or husband to being a caregiver (Roger & Medved, 2010) or a partner in caregiving (Davis et al., 2011). Roger and Medved (2010) reported that being diagnosed with PD was a shock and anger producing moment; however, in some couples anger and shock do not appear to be a part of their experience. Variations in their previous caregiving and illness experiences could explain the differences in how couples respond to this serious, life changing event (Roger & Medved, 2010).

Although spousal caregiving is viewed as an extension of the common spousal role (Habermann, 2000), over many years it can pose a challenge due to the unpredictable, progressive nature of PD (Habermann, 2000) and the greatly increased likelihood of subsequent life disruptions (Burton et al., 2003). As a consequence it may create demands related to the changes in roles (Habermann, 1996), the sense of identity (Roger & Medved, 2010), the loss of shared meaning and reciprocity in the marital relationship (Hooker et al., 2000), and relational stress, including loss of the relationship and care decision conflicts within the relationship, due to a lack of skills to function as partners in PD management (Davis et al., 2011).

Spouses provide most of the support and care during the course of PD (Mitchell et al., 1996; Peters et al., 2011). PD caregiving can place spouse caregivers, who are usually aged themselves, at a greater risk for compromised health. Research with a control group has shown that spouse caregivers of persons with PD had worsened social conditions (i.e., having an outing only once a week, no holiday/vacation in last year), as well as psychological and physical problems, including having a greater number of chronic illness profiles than those whose spouses did not have PD (O'Reilly et al., 1996). The findings of O'Reilly et al. (1996) were partially supported by the study of Peters et al. (2010), wherein they found that the physical health of caregivers was comparable to that of general populations, while their mental health status was found to be substantially compromised in comparison (Peters et al., 2011). Caregiver distress was significantly associated with either a higher number of years as a caregiver, more hours spent per week on caregiving activities, or the patient's physical and mental health being more compromised (Peters et al., 2011). All of these significant relationships were expressed as small to moderate correlations and must be viewed with caution given such a large sample size (N=755).

Moreover, as a result of caring, half of the spouse caregivers felt physically tired and that their health had suffered to some degree. One fourth felt that caregiving had made them physically ill, depressed, caused their relationship with other family members to suffer, and/or that their marriage deteriorated to some level. Interestingly, two-thirds felt that their social life had been negatively altered (Schrag, Hovris, Morley, Quinn, & Jahanshahi, 2006). The quality of life of spouse caregivers has been negatively associated with caregiver burden and depression, emphasizing the impact of PD caregiving on the spouses' overall health and well-being (O'Reilly et al., 1996; Peters et al., 2011; Thommessen et al., 2002).

Previous studies support the assumption that spouse caregivers are vulnerable to long-term negative outcomes of caring for a spouse with PD during the course of PD (Berry & Murphy, 1995; Hooker, Monahan, Shifren, & Hutchinson, 1992; O'Reilly et al., 1996; Peters et al., 2011). Most spouses have no formal training, feel inadequately prepared for escalating caregiving responsibilities (Linderholm & Friedrichsen, 2010), and also feel overwhelmed (Hudson et al., 2005). As a consequence this may affect the caregivers' abilities to adapt to and feel prepared for their spousal caregiving roles over a protracted period (Carter, Stewart, & Archbold, 2008). A spousal caregiver role transition is not a single event but rather a dynamic, evolving process (Burton et al., 2003) which occurs over time. It is influenced by factors that are not only related to the person with the diagnosis and/or the caregiver, as they are faced with their own personal changes including aging and employment status, but also with situational changes such as changes in family routines and responsibilities (Burton et al., 2003; Roger & Medved, 2010). These factors may play a role in determining how the spouses adapt to the duties associated with caregiving. Feeling unprepared for caregiving and poor adaptation over the course of PD caregiving can be viewed as an unhealthy and unsuccessful caregiving role transition process (Roger & Medved, 2010). More importantly, if they have experienced an adverse health outcome, caregivers may no longer be able to carry on the caregiver role physically which, in turn, could affect the quality of care provided to their afflicted spouse (Coeling, Biordi, & Theis, 2003). Additionally, it is foreseeable that when vulnerable caregivers reach their limits it may result in the unfortunate need to have the persons with PD transferred to a care facility instead of being cared for at home (Mittelman, Haley, Clay, & Roth, 2006).

In summary, transitioning into the spousal caregiver role is a complex process. Meleis et al. (2000) suggested that spouse caregivers respond to the transition differently depending on their PD caregiving situation and the associated transitional conditions that may facilitate or inhibit the transition. During the transition, the feeling of being prepared to take on the spouse caregiver role is key to obtaining the most favorable outcome of the transitional process, a healthy transition.

Caregiver Preparedness

Caregiver preparedness has been conceptualized in slightly different ways by different researchers. For the purpose of this study, it has been defined and measured based on the work of Archbold and colleagues (1990; 1992) and their Family Care Inventory *(FCI)* from the role theory perspective. Viewed as a role, caregiving is what caregivers have learned after entering into the role, not what they knew prior to entering it. The individual's willingness, commitment, perceptions of their knowledge, and ability to take on the overall role of a caregiver (Linendoll, 2008; Ziemba, 2002), rather than their actual ability to complete particular caregiving tasks, constitutes the feeling of being prepared for caregiving termed caregiving preparedness (Archbold et al., 1990). Conceptually, it is a domain-specific concept that is comprised of specifically relevant domains of caregiving provision (Archbold et al., 1990; Archbold, Stewart, Greenlick, & Harvath, 1992). Caregiver preparedness is seen as an ongoing process of skill refinement and attainment in relation to the changes in a given caregiving situation rather than as an achieved state of readiness for caregiving (Giarelli et al., 2003). If this holds true for spouse caregivers, caregiver preparedness is likely to vary across time over the period of caregiving and in some cases may never feel prepared.

The concept of caregiver preparedness holds a premise similar to those of the self-efficacy and mastery concepts, but there are some substantial differences (Archbold et al., 1992). Self-efficacy is a concept that was developed to explain how confident one feels to conduct a specific task, such as confidence in fall prevention (termed falls self-efficacy) or pain management (termed pain self-efficacy). Caregiver preparedness, on the other hand, is a concept which deals specifically with a general domain of caregiving, such as the physical or psychological domains. Likewise, caregiver preparedness is not defined as the actual ability to carry out any specific caregiving activity, whereas the mastery concept is directly related to the ability to perform specific caregiving activities (Schumacher et al., 1998).

The lack of preparedness is a precursor of negative outcomes of caregiving in caregivers. Previous research has demonstrated the important associations between a caregiver’s level of preparedness and levels of role strain, caregiving difficulty, and negative well-being. Caregivers who had high levels of preparedness reported lower levels of role strain (Archbold et al., 1990), experienced less difficulty in caregiving, and less negative well-being (Scherbring, 2002; Schumacher et al., 2007; Schumacher et al., 2008), even when they had to provide for a greater level of caregiving demands (Schumacher et al., 2007). Simply put, caregivers who are better-prepared are likely to experience a healthy caregiving transition and that could help them to be capable of continuously providing care at home (Ducharme et al., 2011; Schumacher et al., 1998). Given its protective effect, caregiver preparedness can be seen as a positive caregiving-related factor that helps facilitate healthy transitions in the caregiving process (Carter et al., 2010; Schumacher et al., 2007). However, little is known about whether or how caregiver preparedness changes over time, or what the early-warning signs for low levels of caregiver preparedness are. Having this knowledge, interventions targeting caregivers who might be vulnerable to the long-term negative effects of caring for a spouse with PD at home could be crafted and implemented early in the illness' trajectory.

Caregiver preparedness over time in PD spousal caregiving.

Given the unpredictability of PD symptoms, caregivers of a relative with PD have to manage their caregiving roles and responsibilities on a day-to-day basis over the course of the illness. Thus, there is a potential for change over time in PD caregiving (Carter, Stewart, & Archbold, 2008) and, possibly, in caregiver preparedness (Giarelli et al., 2003; Schumacher et al., 1998). However, no existing studies have investigated whether caregiver preparedness changes over time in PD caregiving. Only two cross-sectional studies have described preparedness among spouse caregivers of persons with PD. The first study (Carter et al., 1998) examined caregiver preparedness across the five stages of PD (*n*=380), while the second study (Carter et al., 2010) examined caregiver preparedness by caregiver's age (young: aged 40-55 years (*n*=37); older: aged 70 and older *(n*=28)). Findings of *t*-test analyses suggested that preparedness did not differ either across the stages of the disease (Carter et al., 1998) or between age-groups (younger versus older) (Carter et al., 2010).

This inability to detect differences in preparedness might be an effect of the unique character of PD (Carter et al., 1998) and limitations in the study design (Carter et al., 2010). The unique character of PD lies in its unpredictability of the symptoms and the progression of PD, especially in the disease's later stages (Carter, Stewart, & Archbold, 2008; Habermann, 1999, 2000). There is also a great deal of change in the PD caregiving situation across the stages of the disease (Carter et al., 1998). Other than the small sample size in the study of Carter et al. (2010), it should be noted that age was used as a categorical variable, and that not all age groups or all stages of PD were included. Caregivers who were between 55 and 70 years of age, the group generally comprising the majority of caregivers in PD, and those who provided care to patients in the later stages of disease were excluded from the analysis (Carter et al., 2010). These factors may substantially explain how and why caregiver preparedness was found stable in these scenarios and may indicate that they would be better evaluated using a longitudinal, rather than a cross-sectional study design. Moreover, there are other factors related to either caregiver or patient characteristics which may also play a role in how stable preparedness is across the stages of the disease and age-groups.

Although preparedness did not significantly differ across the stages of PD and age-groups, it should be emphasized that there was some variability around the mean preparedness score at each stage (Carter et al., 1998) and in each age-group (Carter et al., 2010). Importantly, these variations in preparedness were not examined from a longitudinal perspective, in which the same caregivers were followed over time so that more conclusive findings could be obtained. Although a cross-sectional study can provide an estimate of the types and magnitudes of changes likely to be found in a longitudinal study (Carter et al., 1998), it cannot tell us whether or not there was stability or variability in the level of caregiver preparedness in PD caregiving. Consequently, the important link between caregiver preparedness and the early-warning signs of being unprepared over time in PD spousal caregivers has yet to be examined. No known existing longitudinal studies have specifically examined caregiver preparedness over time in PD caregiving, particularly spouse caregivers, or purposefully targeted participants from a wide range of personal demographics and characteristics in order to investigate differences in spouse caregiver preparedness. This dissertation study addressed these limitations along with successive gaps in the literature that were found in previous studies.

Caregiver preparedness over time in other caregiving situations.

Only two prior caregiving studies have put forth an effort to examine change in caregiver preparedness longitudinally. Both studies were conducted in cancer caregivers (Giarelli et al., 2003; Scherbring, 2002). In the study by Scherbring (2002) caregiver preparedness was measured 3 times: post hospital discharge (*M* = 3.53, *SD* = .72), one-week (*M* = 3.49, *SD* = .89), and one-month post discharge (*M* = 3.53, *SD* = .86). ANOVA analyses revealed change in preparedness over time was borderline statistically significant (*p* = .06; *N* = 59), while a generalized estimating equation using a Poissen regression model found it was not significant (Scherbring, 2002). Moreover, in a longer longitudinal study by Giarelli et al. (2003), which involved three waves of data collected over a 6 month post-surgery time period, found no significant change in caregiver preparedness either within or between intervention (*n* = 56) and control (*n* = 60) groups. However, qualitative data revealed that caregivers felt their levels of preparedness had improved over time. They also perceived that they were not well-prepared and still needed to be prepared for the different duties that caregiving required from time to time (Giarelli et al., 2003).

The discrepancy in the quantitative and qualitative findings from these studies suggests that whether caregiver preparedness remains stable or changes over time is still unknown, particularly outside of the cancer context. It is also important to note that only whether caregiver preparedness changed over time, but not how it changed or what predicted the changes, was the focus of these two studies. There are several potential explanations from a research methodology stand point which could be made regarding the lack of consistent knowledge about whether caregiver preparedness changes over time from the studies reviewed here. Included among these would be the short duration of study, the time points of measurement, the sample size, and the statistical analysis approach that was used.

Only one previous study attempted to simultaneously determine whether and how caregiver preparedness changes over time (Leutz et al., 2002). Leutz et al. (2002) examined changes in preparedness and its predictive factors in a sample of caregivers of frail older adults. The *t*-test analysis revealed that post-intervention caregiver preparedness significantly increased compared to the pre- intervention score ($n = 320$). Increases in caregiver preparedness over time were found in caregivers who were married ($\beta = 0.75$, $p < .05$), co-resided with a care receiver ($\beta = -0.76$, $p < .05$), had a good or excellent health status ($\beta = 0.74$, $p < .05$), helped with instrumental activities of daily living (IADLs; $\beta = 0.11$, $p < .05$), and provided care to their male relatives ($\beta = 1.22$, $p < .01$). Additionally, preparedness in caregivers who worked outside their home and were spousal caregivers was likely to increase as well. Even though the study was very helpful for guiding the study, there are limitations that need to be addressed. Given its data analysis approach, it was not possible to describe the pattern of change in preparedness in terms of how much it increased. Moreover, it is suggested that the time at which the preparedness is measured is critical (Meleis et al., 2000). However, the study of Leutz and colleagues (2002) only stated that caregiver preparedness was measured twice, at the first session and the last sessions of the workshops. How far apart these two sessions were was not clearly stated.

Factors that may predict caregiver preparedness over time.

Family caregiving researchers have paid little attention to identifying the predictors of caregiver preparedness. For the most part they have assessed caregiver preparedness as a predictor of caregiving outcomes in general and not as an outcome in its own right, or in other words, not as the condition being predicted. Presently, only the work of Ziemba (2002) has purposefully examined factors predicting caregiver preparedness in adult child caregivers of an elderly parent. This sole study was cross-sectional in its design. Caregiver preparedness was associated with the quality of the relationship with the care receiver before and after caregiving, first time experience with caregiving, caregiving demands, the care receiver's autonomy, and co-residence (Ziemba, 2002).

Guided by the studies of Leutz et al. (2002) and Ziemba (2002) and the chosen framework (Meleis et al., 2000), factors that may predict caregiver preparedness over time are transition conditions. Included were intrapersonal conditions (patients and caregivers characteristics) and interpersonal conditions (e.g. relationship quality). Moreover, factors that are associated with caregiver preparedness in various other caregiving literature, mainly related to older adults and cancer caregiving, such as environmental conditions (e.g. formal and informal support) might have an effect on caregiver preparedness over time. Additionally, the cross-sectional studies of Carter et al. (1998; 2008; 2010) in spouse PD caregiving also suggested that it would be interesting to examine other variables such as caregiver's age, stage of disease, clinical symptoms, and predictability in the same caregivers over time. This dissertation study took into account these significant variables and viewed them as potential factors that may predict caregiver preparedness over time in PD caregiving. These theory-based selected study variables are discussed in detail as follows.

Transition Conditions.

Intrapersonal Conditions.

Intrapersonal conditions include caregiver and patient characteristics. Each element of the dyad exerts its own influence on how caregivers perceive their caregiver preparedness over time (Meleis & Trangenstein, 1994). In the caregiving literature there was no consensus over whether spouse or patient characteristics predict caregiver preparedness. In this study, spouse caregiver characteristics including age, gender, educational level, physical function, and depressive symptoms as well as the patient’s stage of disease and clinical symptoms were examined.

Spouse Characteristics.

Age, gender, and educational level. Research has suggested that differences in a caregivers’ age, gender, and educational level can play a vital role on how they respond to and perceive their caregiving situation (Carter et al., 2010; Han & Haley, 1999; Hooker et al., 2000; Rusinak & Murphy, 1995; Schumacher et al., 2007; Shyu et al., 2010; Yee & Schulz, 2000; Ziemba, 2002). Across caregiving situations caregiver preparedness was not statistically significantly associated with age (Carter et al., 2010; Schumacher et al., 2007; Shyu et al., 2010) or gender (Rusinak & Murphy, 1995; Schumacher et al., 2007).

On the other hand, a caregiver's educational level was positively and significantly correlated to knowledge and skill but negatively related to preparedness, indicating that caregivers who are highly educated are more knowledgeable and skilled but feel less-prepared for caregiving (Rusinak & Murphy, 1995). Interestingly, knowledge and skills were not correlated with caregiver preparedness (Rusinak & Murphy, 1995). Ziemba (2002) concluded that knowledge and skills are important components of caregiver preparedness. Clearly, the feeling of being prepared to assume the caregiving role is complex and it is not simply associated with these caregivers characteristics. In order to more fully understand the role of spouse demographic variables in predicting caregiver preparedness, the current study included spouse age, gender and educational level.

***Spouse physical function and depressive symptoms*.** The caregiver's physical and mental healths have previously been examined as both predictors and outcomes of caregiving (Berry & Murphy, 1995; Bookwala, Yee, & Schulz, 2000; Schulz & Sherwood, 2008). The incidence of chronic illness increases with age and many spouse caregivers are themselves aged and may have a chronic illness. This may impair their physical function and ability to provide care, and this can consequently induce caregiver depressive symptoms. Moreover, research has found that providing care to a relative is associated with worsening of a caregivers' physical and mental health (Schulz & Sherwood, 2008) and an increase in mortality in spouse caregivers (Schulz & Beach, 1999). This study explored how spouse physical function or depressive symptoms affected spouse preparedness. Research found that the relationship between caregiver preparedness and a caregiver's physical function or depressive symptoms are not consistent across different caregiving situations (Kneeshaw et al., 1999; Rusinak &

Murphy, 1995). Kneeshaw, Considine, and Jennings (1999) found that caregivers who reported that they had poor physical function felt that they were not well-prepared for caregiving, contrary to findings by Rusinak and Murphy (1995).

With respect to spouse depressive symptoms, while preparedness was found to be associated with depressive symptoms, and was a predictor of depressive symptoms in cancer caregiving (Schumacher et al., 2007; Schumacher et al., 2008), these findings were not replicated in caregivers of elderly persons with dementia (Shyu et al., 2010). In PD caregiving, higher levels of depressive symptoms were found in spouses whose patients with PD were in advanced stages of the disease (Carter et al., 1998). However, predicting the effect of depressive symptoms on preparedness in PD caregiving has not been studied previously.

Number of direct care activities. There is no consensus over whether the number of direct care activities is associated with caregiver preparedness across caregiving situations. Some previous research found that the number of direct care activities and caregiver preparedness were statistically significantly associated (Samartkit, 2008; Ziemba, 2002) while some found that they were not (Silver et al., 2004). .

Patient Characteristics.

Patient characteristics that may predict caregiver preparedness over time include the stage of disease and clinical symptoms.

Stage of disease. Staging of PD is based on a structured assessment that denotes the severity of the symptoms of PD and the extent to which they interfere with everyday living (Goetz et al., 2004). There is neither a clear correlation between the stage of PD and any perception of prognosis or life expectancy, nor is there an accurate way of predicting how soon the individual will progress to the next stage of the disease, unlike other medical conditions such as cancer. Interestingly, the stage of PD was not associated with caregiver preparedness in a cross-sectional study (Carter et al., 1998).

Clinical symptoms. The negative effects of the clinical symptoms of the patient with PD, categorized as motor and non-motor symptoms, on caregiver distress are well-documented (Carter, Stewart, Lyons et al., 2008; D'Amelio et al., 2009; Schrag et al., 2006). Carter and colleagues (2008) revealed that non-motor symptoms (delayed recall and depression) accounted for around 8-12% of additional variance in caregivers' role strain and depressive symptoms above and beyond that explained by motor symptoms (ADL impairment). While the link between caregiver preparedness and distress is well-documented (Archbold et al., 1990; Schumacher et al., 2007; Schumacher et al., 2008), its relationship to clinical symptoms has never been studied. Given the effects of clinical symptoms on day-to-day caregiving it would be beneficial to better understand the role of the patient's clinical symptoms, including depression and ADL impairment, on caregiver preparedness in spouse caregivers over time.

Interpersonal conditions.

Caregiving is a process that is comprised of two parties, the caregiver and care receiver. Hence, what happens between them, or relates to either of them, would have an effect on the transition process. The feeling of being connected is seen as an interpersonal factor that helps smooth the caregiving transition. In this study, mutuality constitutes the feeling of being connected, and its predicting effect on preparedness over time was examined.

Feeling of being connected: Mutuality.

Mutuality is the positive relationship quality between the caregiver and care receiver arising from shared beliefs, outlooks, and connections (Archbold et al., 1990). Generally speaking, mutuality is a critical variable in family caregiving which assists caregivers in transitioning into and maintaining a caregiver role. Caregivers, who have a high level of mutuality or a better relationship quality with the care receiver were able to continue caring in spite of objectively difficult caregiving situations (Chesla, Martinson, & Muswaswes, 1994; Hirschfeld, 1983) which could be a result of being better prepared (Ziemba, 2002).

Clearly, mutuality serves as a vital positive factor in the caregiving process (Archbold et al., 1990; Samartkit, 2008; Schumacher et al., 2007) and is positively associated with preparedness (Samartkit, 2008; Schumacher et al., 2007; Shyu et al., 2010; Ziemba, 2002). It is also known that high levels of preparedness and mutuality simultaneously protected caregivers from negative caregiving outcomes when caregiving demand was high (Schumacher et al., 2007). The predicting effect of mutuality on preparedness has not been studied yet.

In PD caregiving, mutuality and caregiver preparedness have been viewed as positive aspects of caregiving that could balance the effects of negative caregiving outcomes on caregivers (Carter et al., 2010; Konstam et al., 2003). In older adult caregiving, high caregiver preparedness in caregivers was predicted by high mutuality (Ziemba, 2002). If this holds true in PD caregiving, mutuality may be associated with or predict preparedness and changes in preparedness over time. In fact, the associations among them remain unknown in PD caregiving and in spousal caregivers in particular. It is known that spouses providing care to their spouse with PD at home experience multiple losses of relationship, intimate relationship, and shared future over a long period of caregiving (Cutson, Zhu, Whetten, & Schenkman, 2004; Davis et al., 2011). In addition, tension within the relationship becomes a source of friction and disagreement over how to manage daily care (Davis et al., 2011). Examining the effects of mutuality on caregiver preparedness over time in these contexts can provide new insight.

Environmental conditions.

Environmental conditions that may predict change in preparedness are receiving informal and formal support. Informal support in providing home care can range from receiving practical caregiving information and support from a support group (Abendroth, 2010) to receiving unpaid assistance and help from relatives (Carter et al., 1998). On the other hand, formal support could include help from professionals and home care services that spouse caregivers pay to receive in the home.

Informal and formal Support.

One of the main sources of informal support for caregivers is the family unit. Family support is a natural interaction among family, even when there is no illness. However, when there is an illness, it becomes more intense because it goes beyond the bounds of usual care where assistance from any support resources would help (Abendroth, 2010). On the other hand, caregivers also receive help and assistance from professionals and from paying individuals to help provide care to their care receivers at home when informal support resources become unavailable or when care and assistance needed is beyond the caregiver’s own ability to provide. Research found that either informal resources, such as relatives, or formal support such as help from professionals or help from paying someone to provide in-home care generally reduced the degree of burden on caregivers (Abendroth, 2010; Ali & Ward, 2011; Given, Stommel, Collins, King, & Given, 1990; Vrabec, 1997).

With regard to how much help is received from either formal or informal support networks in PD caregiving, available results are inconsistent. One study found that spouse caregivers received help from both support sources and, as the disease progressed, received significantly greater help (Carter et al., 1998), whereas another study found that most caregivers received no assistance (Konstam et al., 2003). It should be emphasized cultural and health care system differences may play a role in the inconsistency in these findings.

Availability or use of informal support groups.

During the caregiving process, caregivers have expressed that practical caregiving-related information was one of the most needed types of support and that the practical information they needed also varied over time dependent on the recent changes in their caregiving situation that had occurred (Giarelli et al., 2003). Support groups could be resources for providing practical caregiving-related information from members with similar first-hand experience. It has been reported that interventions that provided available on-going support between the interventionist and the family helped to increase the feeling of being prepared among caregivers (Archbold et al., 1995; Ducharme et al., 2011; Grant, Elliott, Weaver, Bartolucci, & Giger, 2002; Shyu, Chen, Chen, Wang, & Shao, 2008). It should be cautioned that the availability and utilization of support groups were not related. Support groups have their own dynamics and family caregivers may need to visit more than one group to find the best match for their needs (Abendroth, 2010; Leutz et al., 2002). In the study, being a member of a local support group represents the availability or use of informal support groups.

Nature of PD caregiving.

Predictability.

Although it is an important element, the lack of ability to predict or exert control over the PD caregiving situation has never been studied in relation to caregiver preparedness over time. The course of PD is dynamic, with ebbs and flows. When PD progresses the fluctuations in motor symptoms become more prominent (Carter et al., 1998; Habermann, 1999) causing persons with PD and their caregivers to have good and bad days (Abendroth, 2010; Habermann, 1999, 2000; Habermann & Davis, 2005; NINDS, 2006) and these days are unpredictable in nature, even when medications or interventions are administered appropriately (Abendroth, 2010).

It is hypothesized that when the caregiving situation is predictable, even when there are physical or psychological limitations, the spouse can predict what to expect, make a plan, and have a sense of control (Carter, Stewart, & Archbold, 2008). A sense of control over changes in connection with the progression and symptoms of PD, termed predictability, can have a positive effect on the PD caregiving situation in everyday life (Carter, Stewart, & Archbold, 2008). Carter and colleagues (1998) suggested that with the greater caregiving demands in the late stages of PD, which were accompanied with unpredictable and uncontrolled symptoms and complications, spouse caregivers lived with unpredictability and lost the sense of control over their daily life. As a consequence spouse caregivers experienced higher levels of role strain (Carter et al., 1998) that could be a result of a lack of preparedness, which is well-documented as a precursor of role strain (Archbold et al., 1990; Scherbring, 2002). On the other hand, limitations in predictability of, and control over, the disease itself forces spouse caregivers to manage these changes on a daily basis. Hence, it is less likely that spouse caregivers would have felt well-prepared for their PD caregiving or that their preparedness would have significantly changed over time. Information on the relationship between the perception of predictability and the change in preparedness would be of interest.

In summary, previous studies have clearly shown that there is no consensus about the factors affecting caregiver preparedness in older adult and cancer caregiving. That might be a result of differences in the nature of the caregiving situations, the types of relationships between caregivers and care receivers (spouses vs. not spouses), and the diversity of independent variables and their measures. It should be emphasized that although the concept of caregiver preparedness and its measure was applied consistently across these studies, the predictors of caregiver preparedness and the way they were operationalized were not consistent. As with the predictors in PD caregiving, the diversity in caregiving situations and predictor variables, as well as the inconsistency of measures used across studies, limits comparison. What is known in the PD spouse caregiving situation is that the stage of disease and the caregiver’s age group were not associated with caregiver preparedness. However, how, or if, caregiver preparedness changes over a protracted period in PD caregiving is still not known. There is either stability or change in preparedness, but there has been no systematic investigation to determine which exists (Schumacher et al., 1998).

Summary and Conclusion

This study is focused on an important topic—caregiver preparedness in those individuals who care for a spouse with PD at home. Parkinson's disease (PD) affects more than 1.5 million Americans, 80% of whom are cared for at home. Spouses provide most of the care and support during the protracted course of this illness (Schrag et al., 2006). Providing care to a relative with PD at home is known for its negative impact on caregivers (Berry & Murphy, 1995; O'Reilly et al., 1996; Schrag et al., 2006). Previous studies have indicated an important association between a caregiver's level of caregiver preparedness and levels of negative well-being (Archbold et al., 1990; Schumacher et al., 2007; Schumacher et al., 2008). Hence, caregiver preparedness can be viewed as a protective factor against the negative outcomes of caregiving on caregivers over a caregiving transition. There is a paucity of research regarding whether, and how, caregiver preparedness changes over time.

Prior research, especially that of Lutz et al (2002), Ziemba (2002), Scherbring (2002) and Giarelli, McCorkle, and Monturo (2003) has made a valuable contribution to our understanding of whether, and how, caregiver preparedness changes over time. None of the research was specifically conducted in the PD caregiving context, which has a unique character and nature, particularly with regard to its predictability, which is quite different from the cancer and older adult caregiving contexts. Moreover, these longitudinal studies have limitations, including, but not limited to, studying change in caregiver preparedness over a short period of time, ranging from a one month to a 6-month period with a short lapse of time between each measuring point, and applying conventional statistical approaches rather than advanced statistic techniques (Giarelli et al., 2003; Scherbring, 2002). With such a short study period, a significant variation in preparedness was less likely to be detected. The longer period of time in a longitudinal study design (Hricik et al., 2011) in concert with the application of advanced statistical approaches may provide a greater chance of capturing change in preparedness over time (Dilworth-Anderson, Goodwin, & Williams, 2004).

The knowledge regarding factors that may predict caregiver preparedness over time also is limited. Thus, research investigating caregiver preparedness from a cross-sectional approach was included in this review. With regard to caregiver characteristics, caregiver preparedness was found to be correlated with the number of direct care activities (Samartkit, 2008; Silver et al., 2004; Ziemba, 2002), and the stage of disease (Carter et al., 1998; Cummings et al., 1998), but the findings were not consistent across the studies**.** Caregiver preparedness was negatively associated with the educational level of caregivers (Rusinak & Murphy, 1995), but positively associated with mutuality (Samartkit, 2008; Schumacher et al., 2007; Shyu et al., 2010). While these prior studies provided valuable data supporting the important role of feeling prepared to take on the caregiving process, they had limitations that warranted further consideration. These included differences in the caregiving situations and the types of caregiver-receiver relationships, which were not specifically limited only to spouse caregivers of a patient with PD, the area of interest in this study.

Importantly, these prior studies focused on the factors affecting preparedness cross-sectionally and, thus, were unable to examine the predictors of caregiver preparedness over time (Linendoll, 2008). Moreover, caregiver preparedness over time and factors that predicted such changes were not studied simultaneously (Giarelli et al., 2003; Scherbring, 2002; Ziemba, 2002). These studies also did not take into account patient characteristics, such as the clinical symptoms of the patient, and environmental conditions which may predict caregiver preparedness over time (Giarelli et al., 2003; Scherbring, 2002; Ziemba, 2002). Examining these variables in spouse caregivers of patients with PD may provide new insights and lead to more effective interventions targeting a spouse caregiver who may be vulnerable to the negative long-term effects of caregiving due to a low level of caregiver preparedness. Prior research has found no variance in preparedness in the PD caregiving context. However, those findings are from cross-sectional studies rather than from a longitudinal study. It is theorized that, should the same caregivers be followed over time, conclusive findings might be obtained through a longitudinal study (Carter et al., 1998).

This study addressed these gaps in knowledge about whether and how caregiver preparedness changes over time. This study had two primary aims. The first aim was to describe caregiver preparedness over a 10-year period of caregiving. While there was no change in caregiver preparedness over time found in previous longitudinal studies of limited duration in cancer caregiving, it has not yet been studied in PD caregiving. To overcome this shortcoming, this study used a 10-year study period data set that had been collected across North America with a larger sample size and applied advanced statistical approaches to the analysis. The second aim was to investigate the extent to which transition conditions and the nature of PD caregiving at baseline were predictive of caregiver preparedness over time.

The study hypothesized that average change in preparedness over a 10 year period and variability around this average was influenced by transition conditions (i.e.

intrapersonal, interpersonal, and environmental conditions) and the nature of PD caregiving at baseline (at Time 1). Intrapersonal conditions were the characteristics of the spouse caregiver (i.e., age, gender, educational level, caregiver physical function, depressive symptoms, and the number of direct care activities) and those of the patient (i.e., stage of disease and clinical symptoms). Interpersonal conditions included: feelings of being connected (i.e., mutuality). Environmental conditions included such things as the availability of and accessibility to caregiving-related formal and informal support resources (i.e., the availability or use of PD support groups and the amount of help and assistance received from formal and informal support networks). The nature of the PD caregiving transition included in this study was a measure of predictability.

This study's aims and hypotheses were driven by a thorough review of existing literature on caregiver preparedness and the unique characteristics of spousal PD caregiving which were viewed through the lens of transitions theory (Meleis et al., 2000). This study had two specific aims:

1. To describe caregiver preparedness in PD spouse caregivers over a 10-year period.

2. To identify factors that predict caregiver preparedness over time.

CHAPTER 3

Research Design and Methods

The study was aimed at describing caregiver preparedness over time in spouses of an individual with Parkinson's disease (PD) and examining factors that may predict caregiver preparedness over time. In this chapter the study design and methods are described, including the setting, samples, and data collection methods employed in the Parkinson's Spouse's Project (PSP), the source of the data used in the study, and the data analysis plan. Additionally, the limitations and benefits of using the PSP data set are discussed.

Research Methods

Study Design

A secondary data analysis of the Parkinson's Spouse's Project (PSP) study data set was employed to address the research questions. The PSP data set had three waves of data that were collected over a 10-year period from 1992 to 2002 (at baseline, year 2 and year 10). This longitudinal data involved uneven intervals of measurement with a large gap between the year 2 and year 10 data. Given the nature of the data set, a multilevel modeling (MLM) approach was applied to determine the trajectory of caregiver preparedness changes over time and its predictive factors. Further detail is provided on this in the statistical data analysis plan section later in this chapter.

The parent study.

The PSP study was an ancillary study of the DATATOP (**D**eprenyl **a**nd **T**ocopheral **A**ntioxidative **T**herapy **o**f **P**arkinsonism) study. The DATATOP study was a 30-site clinical trial conducted by the Parkinson Study Group (PSG) that evaluated neuroprotection in 800 early-stage PD patients. The DATATOP study was an in-person evaluation of this cohort, beginning in 1987 and continuing until 1995, and a final follow-up which was concluded in 1997, after two additional years of telephone interviews. The inclusion criteria for the DATATOP clinical trial study participants were patients with idiopathic PD within 5 years of onset, at an early stage of disease (defined as a modified Hoehn and Yahr stage of 1-2), aged between 30-79 years old, with no significant dementia (patients with Mini-Mental State Exam scores of 22 or less were excluded) or depression (patients with Hamilton depression scores of 16 or more were excluded), and who did not take or require anti-Parkinson medication (Carter et al., 1998; Parkinson Study Group, 1989).

Sample and Setting

The participants for the PSP study were spouse caregivers who were recruited from 23 of the 30 DATATOP clinical trial sites across North America in the 5th year after the beginning of the clinical trial. The primary purpose of the PSP study was to examine the consequences and outcomes of caregiving on the healthy spouses who were affected by the progression of their spouse's PD over time from an early stage of the disease (Parkinson Study Group, nd). The PSP study included 321 spouses who provided care for their PD spouses at home at baseline, were deemed by the site investigator to be capable of reliably self-reporting, and were willing to complete the questionnaires and to sign the consent forms. In light of the inclusion criteria for the DATATOP project, participants of the PSP were spousal caregivers of patients aged between 30 to 79 years, who were in early stage PD, who had no significant dementia or depression at baseline, and were not in receipt of anti-Parkinson medication. The attrition rates for participants were 28% and 51% at Time 2 and Time 3 (2 years and 10 years post initiation), respectively.

Based on previous publications using the PSP data set, the baseline data collection (Time 1) was undertaken in 1992 with a sample of 321 spouses who completed mailed surveys. The second wave of data collection was undertaken in 1994 (year 2 / Time 2). Of the original 321 participants from Time 1, 232 spouse caregivers participated in Time 2. Of the 89 participants not included at Time 2, 68 agreed to be contacted. The 28% loss of the Time 1 sample participants (*n* = 89) was comprised of those who refused to participate in the year 2 assessment, could not be located, or were ineligible (i.e., due to death of the PD patient or the PD patient residing in a care facility).

The third wave of data collection occurred in 2002 (year 10 / Time 3). Of the 232 spouses participating in the Time 2 data collection, the 209 subjects who agreed to be contacted again for a future study plus 57 of the participants who were not included at Time 2 were considered to be eligible for the Time 3 study sample yielding a sample of 266 out of the original 321 spouse caregivers. It is important to note that 57 spouse caregivers who did not participate at Time 2 due to ineligibility or inability to be located but who agreed to be re-contacted for a future study were placed back into the Time 3 sample pool due to the general interest of examining the long term effect of caregiving on spousal caregivers. One hundred and fifty-six spousal caregivers from this sample pool completed and returned the surveys. The thirty-nine percent of the baseline sample that was lost at Time 3 (*n* = 127) included spouse caregivers who refused to continue participation in the study or were ineligible (i.e., spouse caregivers were divorced, or were in a care facility or cognitively impaired themselves), while 12% could not be located (Carter et al., 1998; Lyons, Carter et al., 2004; Lyons, Stewart, Archbold, & Carter, 2009; Lyons, Stewart, Archbold, Carter, & Perrin, 2004), yielding a 51 % reduction in the total sample from baseline. For further details regarding recruitment and data collection, see Carter and colleagues (1998) and Lyons, Stewart and team (2004; 2009). See Lyons, Carter and colleagues (2004) regarding the locating and retaining of samples.

The sample for the study was drawn from all three time points, and the sample of each wave was described. The completeness of the data on the study variables was a factor in relation to the sample size. Missingness is further described in the data analysis plan.

Data Collection

As previously described, the data collection of the PSP study was conducted three times over a 10 year period using a mail survey. This longitudinal approach was employed to attain the PSP study's goal to better understand the long-term changes in caregivers' health and well-being in relation to PD caregiving transitions, such as care facility placement and bereavement. At baseline, the DATATOP coordinator at each study site approached the spouse caregivers who met the inclusion criteria and invited them to join the study. Once they agreed to participate in the study, a package containing a consent form, a stamped, self-addressed envelope, and a survey was mailed to them. At Time 2, the site investigator located the baseline participants who had previously agreed to be re-contacted and sent the mail survey to those who could be located and were still eligible and interested in participating in the study.

At Time 3, the baseline participants who were involved in caring for a patient with PD, either at home or in a care facility, or those whose spouse with PD had died were included in the sample pool. Once those participants who were eligible for inclusion were located and agreed to participate in the study, the appropriate version of the survey (ongoing, care facility, or bereavement) was sent to them.

Data Used in the Present Study

The research questions guided the selection of study concepts and their variables. All data used in this study were collected as part of the PSP study, and no additional data were collected. The data from the PSP study used for this study are presented in relation to the study's conceptual framework (see Figure 2 in Chapter 2). The data on caregiver preparedness at Time 1, 2, and 3 were used to determine spouse caregiver preparedness over a 10 year period as described by Aim 1. Next, the data on transition conditions (i.e., intrapersonal, interpersonal, and environmental conditions), and the nature of PD caregiving transitions (i.e., predictability) at Time 1 were used to examine their predictive effect on caregiver preparedness over time in accordance with Aim 2. These factors are independent variables (See Table 3.1).

Measures

The questionnaire used in the parent study was the *Living with a Person who has Parkinson's Disease: the Spouse's Perspective* survey, a revised version of the *Family Caregiving Inventory* (FCI). The *FCI* was a questionnaire comprised of multiple family caregiving measures developed by Archbold and Stewart, to which additional standard measures of physical and mental well-being were added for use in the PSP study (Carter et al., 1998; Lyons, Carter, Stewart, & Archbold, 2003). The Preparedness for

Caregiving, Predictability, Mutuality, and Amount of Direct Care scales in the *FCI* have been evaluated in previous family caregiving studies, demonstrating acceptable evidence of reliability and validity (Archbold et al., 1990; Archbold et al., 1995; Schumacher et al., 2007; Schumacher et al., 2008). The measures were all self-administered, Likert-type scale measurements and were mailed surveys completed by spouse caregivers. On the other hand, patient's characteristics including stage of disease, and clinical symptoms were obtained by trained clinicians during clinical visits. A detailed description is presented below.

Table 3.1

Summary of Concepts and Scales

Concepts /Variables	Measures	Number of items	Example of items	Cronbach's alpha
Caregiver Preparedness	Preparedness for caregiving scale	8	How well prepared do you think you are to take care of your spouse's physical needs?	.72-.92
SP Age, Gender, Educational level	Demographic data sheet	3	What year were you born?	N/A
SP Physical function	The physical functioning subscale of the SF-36 Health survey	10	Does your health limit you in these activities: Bathing or dressing yourself?	.84-.93
SP Depressive symptoms	CES-D	20	During the past week: I was bothered by things that usually don't bother me.	.85-.90
The number of direct care activities	Amount of Direct Care scale	50	Do you have to assist your spouse with getting around outside the house?	0.94

Table 3.1

Continued

Concepts /Variables	Measures	Number of items	Example of items	Cronbach's alpha
PT Stage of disease[a]	The Modified Hoehn and Yahr PD severity scale	N/A	N/A	N/A
PT clinical symptoms[a]: PT Depression	A single item	1	Patients were asked how depressed they thought they were over past week.	N/A
PT clinical symptoms[a]: ADL impairment	A single item	1	Patients were asked how impaired they were in performing their ADLs.	N/A
Mutuality	The Mutuality scale	15	To what extent do the two of you see eye to eye?	.87-.95
Formal support: Help from professionals or paid help	A single item	1	Overall, how much help have those whose job it is provided in caring for your spouse?	N/A
Informal support: Be a member of a local support group	A single item	1	Are you a member of a local PD support group?	N/A
Informal support: Help received from relatives	A single item	1	Overall, how much help have relatives provided in caring for your spouse?	N/A
Predictability	The Predictability scale	6	How predictable is your caregiving routine, or the activities that you do for your spouse?	.75-.91

Note: SP = Spouse. PT = Patient. CES-D= Center of Epidemiologic Studies Depression Scale. ADL = Activity of daily living. [a]The data were obtained by trained clinicians, neurologist or trained clinical trial personnel.

Caregiver preparedness over time.

Caregiver Preparedness.

Caregiver preparedness was defined as a spouse caregiver's feelings of being prepared to carry on the caregiver role. It was conceptualized as a domain-specific concept; in other words, its dimensions refer to domains of caregiving (Schumacher et al., 1998). The measure consists of eight items regarding provision of physical care, emotional support, setting up in-home support services, caregiving-related stress handling, making caregiving activities satisfying for both the caregiver and their spouse, emergency situation handling, and getting help and practical information from health care providers. Each domain-specific item of the scale assessed how well prepared the spouse caregiver thought she/he was to perform that particular aspect of caregiving, even if she/he was not currently doing so. The scale also included a global item asking about the overall perceived readiness for caregiving (Carter et al., 1998; Schumacher et al., 2008). A five-point response format was used, ranging from 0 (not at all prepared) to 4 (very well prepared). The scale was scored by calculating the mean of all items, so possible scores range from 0 to 4, with high scores meaning spouse caregivers had a high level of preparedness. Cronbach alphas of .72 - .92 have been reported in prior studies (Archbold et al., 1990; Carter et al., 1998; Schumacher et al., 2008).

Transition Conditions: Intrapersonal.

Spouses' age, gender, and educational level. Age, gender, and educational level were measured using three items on the demographic sheet. Age was calculated from the year they were born, while educational levels ranged from 1 (completed 8th grade or less) to 6 (completed college).

Spouse physical function. Spouse physical function was measured using the physical functioning subscale of the SF-36 Health Survey. The physical functioning subscale consists of 10 items to which the participants responded using a 3-point response: 1 (yes, I am limited a lot), 2 (yes, I am limited a little), and 3 (no, not limited at all). The 10 items were re-coded (1 = 0, 2 = 50, and 3 = 100), and averaged to create a scale with a range from 0 to 100, with a high score indicating good physical function. The physical functioning subscale had Cronbach's alpha internal consistency estimates of .84 to .93 in prior studies (Lyons, Stewart et al., 2004; Ware Jr & Gandek, 1998). It is considered to be the most valid scale for measuring physical health (Lyons, Stewart et al., 2004).

Spouse depressive symptoms. Spouse depressive symptoms were measured by the Center for Epidemiologic Studies Depression scale (CES-D) (Radloff, 1977). The components of the scale include depressed mood, feelings of worthlessness, and feelings of hopelessness, loss of appetite, poor concentration, and sleep disturbance. The scale is a composite of 20 items of which four items, items 4, 8, 12 and 16, are worded in a positive direction to control for response bias. The spouse caregivers were asked to rate each item on a scale of 0 (rarely or none), 1 (some or little), 2 (occasionally or moderate), and 3 (most or all) based on their feelings over the past week. The potential range of summed scores is 0 to 60; with higher scores indicating spouses were experiencing more depressive symptoms. A score of 16 or higher indicates further assessment (Hann, Winter, & Jacobsen, 1999; Radloff, 1977). The CES-D scale has been established as a valid and reliable measure of depressive symptomatology in different populations, including older adult patients and caregivers (Hann et al., 1999; Lyons, Stewart et al., 2004). It has shown good internal consistency in caregiving studies with Cronbach's alphas ranging from .83 to .89 (Hooker, et al., 1992; Lyons, Stewart et al., 2004)

The number of direct care activities. The number of direct care activities was measured by using the amount of direct care subscale in the *FCI* which asked the spouses if they had completed any of the 50 different care activities (each rated yes or no) included in the scale. The total number of care activities performed by the caregivers was used in the analysis. The internal consistency estimate of the instrument was .94 in a prior study (Carter et al., 1998).

Patient's stage of disease. Stage of PD was measured using the modified Hoehn and Yahr (HY) scale, which is widely used by clinicians to rate the severity of PD. The scale has six definitive stages (1, 2, 2.5, 3, 4, and 5) that characterize the progressive trajectory of PD where higher numbered stages indicate more severe states of the disease (Carter et al., 1998; Goetz et al., 2004). The HY staging of PD can be grouped as being early-, middle-, or late-stage. A person in stage 1 or 2 was considered to be in an early-stage of PD, a person in stage 2.5 or 3 was viewed as in the middle-stage, and a person in either stage 4 or 5 was considered to be in late-stage PD (Carter et al., 1998).

Patient's clinical symptoms. In the DATATOP study a number of patient clinical symptoms were assessed during in-person evaluations by a neurologist or trained clinical trial personnel. Clinical symptoms data were obtained from patients as part of the clinical trial protocol (Carter, Stewart, Lyons et al., 2008). Therefore, the selection of clinical symptoms for this study was limited by which symptoms were chosen to be included in the 1992 patient data set. Only two patient-derived clinical symptoms are included in this study, depression, and activity of daily living (ADL) impairment. For the purposes of this analysis, depression represents psychological disturbances in persons with PD. It was viewed as a non-motor symptom, while ADL impairment was viewed as a limitation in physical functioning or a motor symptom of PD (Carter, Stewart, Lyons et al., 2008). These two clinical symptoms of PD patients were deemed to be major factors that may affect caregiver preparedness in PD care situations over time.

Depression was measured with a single- item the neurologist or trained clinical trial personnel used to ask the patient if they were depressed over past week. The clinician rated the patient’s response using the response categories 0 (not present), 1 (periods of sadness or guilt greater than normal), 2 (sustained depression for1 week or more), 3 (sustained depression with vegetative symptoms), and 4 (sustained depression with vegetative symptoms, suicidal thought or intent). The possible scores ranged from 0 to 4 and higher scores indicate greater levels of depression.

ADL impairment was assessed with a single item. The patient was asked about his/her ability to carry out his/her ADLs and the clinician rated the response based on the categories 0 (full ADL function or no impairment), 1 (mild impairment), 2 (moderate impairment), and 3 (severe impairment).The possible scores ranged from 0 to 3 with higher scores indicating greater levels of ADL impairment.

Transition Conditions: Interpersonal.

Mutuality. Mutuality was measured by the Mutuality Scale to assess the quality of the relationship between the caregiver and care receiver which was characterized by a great deal of love, shared pleasurable activities, common values, and reciprocity (Archbold et al., 1992). This scale was completed by the spouse caregivers. It was a 15-item scale with a 5-point response ranging from 0 (not at all) to 4 (a great deal). High scores indicated high relationship quality (mutuality). Internal consistency estimates of .87 to .95 were reported in prior studies (Carter et al., 1998; Cooke, Grant, Eldredge, Maziarz, & Nail, 2011; Eldredge et al., 2006).

Transition Conditions: Environmental.

Formal support.

Help received from professionals or paid help. The spouse caregivers were asked to rate the amount of help and assistance they received from professionals or from paying someone to help with providing care to their patients with PD at home. The term "paid help" was used to represent the concept of formal support and this variable throughout the study. The possible responses ranged from 0 (not at all) to 4 (a great deal). Higher scores indicated that a greater amount of paid help was received.

Informal support.

Being a member of a local support group. Being a member of a local support group represents informal support that may facilitate healthy transition in the caregiving process. The spouses responded to one single item-measurement asking spouses if they were a member of a local support group. Responses were coded as yes = 1, or no = 0.

Help received from relatives. One item asking spouses how much help they received from relatives, overall, was used to measure help received from relatives. The responses ranged from 0 (not at all) to 4 (a great deal) for each item. Higher scores indicated more help was received.

The nature of PD caregiving transitions.

Predictability. Caregiver predictability was defined as the degree to which caregivers viewed their situation as being predictable, so that spouses could predict what to expect, make a plan, and have a sense of control over the situation (Carter, Stewart, & Archbold, 2008). Caregiver predictability was measured by the Predictability scale to assess the consistency in the caregiving situation and how predictable the patient's needs, care activities, and caregiver's routines were. It was a 6-item scale using a 5-point response scale ranging from 0 (not at all predictable or never) to 4 (very predictable or always) where higher scores indicated higher predictability. Internal consistency estimates of .75 to .91 were reported in prior studies (Carter et al., 1998; Cooke et al., 2011; Eldredge et al., 2006).

Protection of Human Subjects and Ethical Considerations

There is an ethical responsibility and concern to protect people who participated in this research from any potential harm or risk that might occur due to their data being used in the study. In the parent study, signed consent forms were obtained from all participants. Potential risks and discomforts related to becoming emotionally upset in response to questions that may seem personal or that deal with private or sensitive issues were clearly presented to the potential participants. Procedures to handle respondents who had a high depression score were included in the study protocols. Benefits for the subjects from participating in the study were also explained to the potential study participants. These included the contribution of new information which may benefit other caregivers and PD patients in future. With regard to the confidentiality of study participants, all information that could be used to identify or recognize the original participants individually was kept secured and separate from the anonymous data set. Therefore, no further consent was required with respect to permission to use the data collected from original study participants.

With regard to human subject protection and ethical considerations when conducting a secondary analysis, permission to use the data set was obtained from the researchers who collected the original data. Permission was granted to access the anonymous data set without access to the participants' confidential information. Thus, the potential risk of harm that may arise from a breach of confidentiality was extremely low and the potential benefit of this study outweighed the potential risk of harm, if any. It should be noted, however, that even when data has been rendered anonymous, there is still a risk that participants could become identifiable through the data analysis or reporting of findings. However, in this study there was no method of analysis that combined variables in a way which would make identifying small groups within a large sample, or identifying individuals who had distinctive characteristics, possible. Thus the probability of identifying the original participants individually was extremely low. Nevertheless, any additional actions to ensure that promises of anonymity were maintained were taken as needed.

Before conducting this secondary analysis, approval for the research project was obtained from the Institutional Review Boards of the Oregon Health & Science University. Because no new data was collected for the study, there was no additional consent that was required to be obtained from the original participants.

Statistical Data Analysis Plan

The original data collected in the PSP project was entered into the SPSS program, and verified. The existing PSP data set consisted of longitudinal data collected at three irregularly spaced time points, as previously discussed. In order to best describe caregiver preparedness over time, the data was analyzed by multilevel modeling using Hierarchical Linear Modeling (HLM) statistic software.

Preliminary descriptive analysis.

Prior to the MLM analysis of the data, a preliminary descriptive analysis of the data was conducted to explore data distribution and examine normality and outliers of data for each of the selected variables. Any actions required ensuring the validity and accuracy of the data of this study was taken at this stage of the analysis. To avoid redundancy among predictor variables, which can lead to inflated error terms, a series of zero-order correlations between predictors was performed. When collinearity (a high correlation between two variables) was found a decision to remove one of the variables was made based on its importance in relation to spousal transition and caregiver preparedness in the PD caregiving situation.

In order to identify bivariates for potential inclusion in the growth curve model in a Level-2 model, a series of zero-order correlations between the spouse caregiver and patient characteristic variables and the caregiver’s baseline preparedness was performed. These spouse caregiver predictors included the age, gender, educational level, depressive symptoms, and the number of direct care activities while those of the patient were stage of disease and clinical symptoms (i.e., depression, and ADL impairment).

Missing data.

This longitudinal data set may be missing some data on selected variables. Generally speaking, observed data may be missing due to a participant’s responses not being measured, either due to an occasional drop out or wave non-response. Employing statistical techniques that are able to extrapolate and account for missing data during analysis is a way to increase the precision of the estimates and the power of the statistical tests (Hox, 2010). The pattern of missing data of selected variables in the study was examined to maintain the inferential validity of the data (the ability to draw valid and efficient conclusions about the population of interest) of the data. Change in caregiver preparedness over time in a sample having all 3 waves of data and a sample having at least 1 wave of data also was compared. Ignoring missing data values can lead to biased estimates of the statistical parameters, as well as a lack of power and poor reliability of the study's findings. On the other hand, it is important to note that certain manners of handling missing data can lead to the underestimation of standard errors in analyses, so that the chance of Type 1 error rates is increased (Enders, 2010; Hox, 2010).

HLM is a statistical model that has the ability to deal with missing data, making an assumption that data is missing at random. Missing at random is a less restrictive type of missingness than missing completely at random. Enders (2010) stated that data that are missing at random when the probability of missing data on a variable Y is related to other measured variables in the analysis model, but is not related to values of Y itself on the complete data. The assumption of missing at random holds true when variables in the observed data contain sufficient information about both the missing data and the probability of data that is missing. Therefore, the data was examined for missingness and variables associated with missingness were included in the HLM analyses to increase the validity of estimates.

HLM applies the maximum likelihood estimation approach to handle missing data. Maximum likelihood estimation is an iterative process that uses all available data across waves of measurement and their covariates at baseline to obtain unbiased parameter estimates that have been adjusted for missingness (Lyons et al., 2009). Ability to deal with missing data is a key design advantage of HLM.

Measuring caregiver preparedness over time and identifying its predictors.

The study employed a multilevel modeling (MLM) approach to estimate variation in caregiver preparedness over time in PD spouses and to identify the baseline variables which may predict caregiver preparedness over time. Employing this analytical approach allowed the average trajectory of caregiver preparedness over time and individual variability around this average, as well as their correlates, to be examined. The MLM approach has many benefits for the design of the study. In multilevel modeling of longitudinal research there is an assumption that a series of several distinct observations are nested within individuals when the participant’s responses are repeatedly measured over a period of time. MLM provides a powerful and flexible statistical approach to describe individual change over time and the rate of change over time. This is possible because, unlike other conventional statistical approaches, MLM has a unique and inherent ability to control for the dependencies of repeated measurements (Lyons, Stewart et al., 2004). Moreover, it can handle longitudinal data which includes variation in the number of waves of measurement, spacing of measurement, and numbers of respondents in the presence of sample attrition (Raudenbush & Bryk, 2002). This includes situations where the data is not measured at regularly spaced time points, is measured at uneven intervals, or when each respondent has a different number of observations. In addition, MLM does not require balanced data. In other words, the amount of available data is not required to be the same for all respondents. This characteristic of MLM is an advantage when random missing data occurs in longitudinal data (Hox, 2010). These were significant strengths of using multilevel modeling over conventional statistics. Employing MLM to describe caregiver preparedness over time offers a significant improvement in the strength of the study over previous research studies on this subject.

Given the nature of the existing PSP data set, which involved both uneven spacing of measurement and missing data, it was appropriate to use MLM for the analysis of variation in caregiver preparedness over time and its predictors. Several statistical packages are available for conducting multilevel analysis including the Hierarchical Linear Model (HLM) statistical program used in this study. The HLM analysis involves data that varies at two levels: repeated measurements within individuals (Level 1) and the variations between individuals (Level 2). At Level 1, a set of unique parameters, termed the intercept (an average outcome variable) and slope (the rate of change) captures a trajectory representing an individual's change over time, and the average rate of change over time can be determined as well as individual variability around that average. At Level 2, an average outcome variable over time and the rate of change over time become dependent variables to be explained by a set of independent variables (Lyons, Stewart et al., 2004) as a way to determine the factors predicting the change. The Level 1 units of analysis are the time points of the measurements, while those for Level 2 are the individual participants.

To conduct a multilevel analysis using HLM, the first step is to fit the Level 1 (the unconditional linear) model with a dependent variable, in this case caregiver preparedness, with time centered at baseline. The Level 1 model output provides estimates of the average preparedness at baseline and the rate of change over time, thereby capturing the average pattern of change over time and the variation around the average preparedness at baseline and the rate of change in preparedness over time. If there is significant variation around the average preparedness at baseline and the rate of change in preparedness over time among spouse caregivers, a Level 2 (between individuals) model could be further examined. In other words, when the Level-1 model suggests that there is significant variation in caregiver preparedness between individuals over time, regardless of whether average preparedness for caregiving changes or remains stable, a Level 2 model is fit in order to determine baseline factors playing a predictive role in that variability. At Level 2, independent variables are included in the model to explain the variation in the average intercept and slope which have become dependent variables in this model (Hox, 2010; Lyons, Stewart et al., 2004). In this study, all independent variables would be fit into the model at the same time. This decision was made based on the study's conceptual framework guided by transitions theory (Meleis et al., 2000).

Sample attrition.

Sample attrition is an important methodological issue in conducting a secondary data analysis with a longitudinal data set. Sample attrition of this study was examined to ensure sample representativeness of the population of interest. To determine the representativeness of the Time 3 (Year 10) sample, a series of *t*-test and *Chi-square* tests were conducted on the baseline variables, including caregiver preparedness, comparing the participants who were and those who were not in the Time 3 sample. From the work of Lyons and team in 2009, which used the same PSP data set, it was found that those spouses who were in the Time 3 sample were significantly younger and healthier at baseline, which may provide some indication of the sample representativeness in this current study (Lyons et al., 2009).

Expected Findings

According to the theoretical model, it was expected that change in preparedness over time and significant variation around the average preparedness at baseline and the rate of change would be detected. Another possible outcome was that no change in caregiver preparedness over time would be found (i.e., stability) along with significant variability around the average trajectory or the rate of change. If one of these scenarios was found, it would indicate that the data are sufficient to enable us to better understand change, or stability, in preparedness over time and its predictive factors. It is also possible that stability in preparedness could be found with no significant variability around the average trajectory or rate of change. In this case, it would not possible to proceed with a Level 2 model to examine factors predicting stability in preparedness longitudinally. Alternative statistical approaches would then be employed to determine the factors predicting preparedness at a single point in time.

Alternative Statistical Approaches

Alternative statistical approaches that could be employed to examine change in caregiver preparedness and its predictive factors, instead of using a multilevel regression model, include paired t-test, analysis of variance (ANOVA), multiple regression, and repeated measures ANOVA. A paired t-test can be used to describe either short-term or long-term change in preparedness between two time points. However, this approach only uses two time points to measure change and that limits the ability to fully examine the complexity of caregiver preparedness over time.

The other choice of statistical technique is the repeated measures ANOVA. Nevertheless , the analyses of caregiver preparedness over time and individual variability may not be accurately detected because this approach assumes that all samples of a group have the same mean profile over time and individual variation is viewed as error in this approach (Lyons, Stewart et al., 2004), which is not always true. Moreover, this approach requires complete data for all three waves on preparedness and an even spacing of measures while the spacing of the PSP data measurements was uneven. Lastly, the multiple regression analysis approach can be used to determine the factors predicting caregiver preparedness cross-sectionally and how much of the variation can be explained by sets of independent variables grouped based on theory.

Benefits and Limitations of Using the PSP Data Set

The longitudinal PSP study data set offered a unique opportunity to examine caregiving transition process outcomes from the perspective of spouse caregivers of persons with PD from the early stages of the disease. Given that the late stages of PD have been described as a floundering period for caregivers (McLaughlin et al., 2011), a view of caregiving at PD's early stages was essential to have an accurate picture of how spouse caregivers perceive their readiness for caregiving in the early stages. The PSP data set also enabled us to examine other caregiving transition factors from an early stage and how they could have an effect on caregiver preparedness over time. Most prior PD studies have examined PD caregiving from the middle to late stages of the disease and it has been recommended that the focus on PD caregiving transition be broadened to include those who were in an early stage of the disease (Lyons, Stewart et al., 2004).

Moreover, having caregiving data obtained over a 10-year period from multiple trial sites across North America, the study exceeded previous studies with regard to caregiver preparedness over time. There have been no other studies examining caregiver preparedness over such an extensive period of time and across such a large area of the continent. Additionally, the inclusion of patient clinical symptoms in this study may provide us with some new information regarding factors from the patient's side of the equation that may affect caregiver preparedness over time. These benefits of using the PSP data set would allow the study to shed a clearer light on clinicians' capabilities to determine who is at risk for an unhealthy caregiving transition over time with regard to caregiver preparedness, as well as when and how to initiate proper interventions to promote caregiver preparedness.

Regarding the study design, the use of existing data to generate new information and make a contribution to the body of scientific knowledge can be a cost-effective procedure. On the other hand, using data that has already been collected could pose challenges regarding methodological issues in terms of threats to validity. Threats to internal validity may arise from measurement issues, including a lack of control over the framing and wording of survey items (i.e., the concept of interest may have been defined differently from what would be in an original study), choice of measurement selections (i.e., the measurements used to measure a similar concept of interest may differ from what a researcher would have used had he or she collected his/her own data), and completeness of measurement (i.e., a single-item versus a multiple-item measurement or a short-form versus a full-length measurement). Threats to external validity may arise from a lack of control over sampling and data collection procedures, while ignoring missing values may lead to biased estimates and a lack of power of analysis (Raudenbush & Bryk, 2002).

Fortunately, the PSP data set was comprised of concepts that were defined and measured in a manner consistent with the way in which they would be defined and measured in this study had the researcher performed the data collection. The concepts were measured with the full-length measurements of the Family Care Inventory, which is consistent with the approach that would have been used had data been collected for the current study. Moreover, the data in the parent study was collected in the same manner in which it would have been collected in this study. Most important, it was unlikely that threats to internal validity of the findings of the study would have been created by using the PSP data set. However, there could be a threat to external validity in terms of generalizability of the findings due to the specificity of the participants included in the parent study. The findings of this study can be generalized only to spouse caregivers who are taking care of the patients who are in an early stage of PD and who have no significant dementia or depression at baseline. These findings could not be generalized to other types of caregivers, such as adult children or siblings, or caregivers who provide care to their PD spouses in the late stages of PD.

Even though the data set seems to fit well with the research questions of this study, there are some methodological limitations that need to be addressed. Given that the data involved was collected only at three time points over a 10-year period and was collected at uneven intervals the data would allow examination of the average caregiver preparedness over time from baseline to year 10, but it would not allow the inclusion of time-varying covariates, such as mutuality in the model (Lyons et al., 2009). Moreover, with only three time points of data, it was not possible to fit a quadratic model into the analysis, meaning that only a linear model could be examined. Additionally, given the large gap between year 2 and year 10, it must be assumed that the rate of change in caregiver preparedness over that period is linear (Lyons et al., 2009; Lyons, Stewart et al., 2004) while, in fact, it may or may not have been the case.

The parent study also included data collected from the spouse caregivers at an individual level, while data at the individual PD patient and dyadic levels were not taken into account simultaneously. It has been recommended that a caregiving process should be viewed as a dyadic process composed of the dyad of a caregiver and patient. Thus the complete picture of the complex caregiving process may not have been fully captured by the data set in this study.

CHAPTER 4

Results

The primary aim of this study was to describe caregiver preparedness over time in spouses of persons who have Parkinson's disease (PD). The secondary aim was to identify factors that may have an effect on caregiver preparedness over time. The demographic characteristics of the sample and reliability statistics for the instruments will be presented first followed by the results, which are reported according to the specific aims.

Sample

The sample for this study was drawn from the Parkinson's Spouses Project (PSP). The eligibility of the sample for the current study was determined based on the specific aims and statistical data analysis plan, multilevel modeling. To address the study aims using multilevel modeling (MLM), participants were required to 1) have complete data on the set of baseline predictor variables (selected from the conceptual framework) and 2) have at least one wave of data on the study outcome variable, caregiver preparedness. Based on these criteria, of the 321 baseline participants in the parent study, two were missing data on the current study's outcome variable, caregiver preparedness, at all three waves and 68 cases did not have complete data on the set of 14 baseline study predictor variables. These 70 participants were, therefore, ineligible for the current study, resulting in a final sample of 251 spouse caregivers who had at least one wave of preparedness across the study and complete data on baseline predictor variables.

Description of the Sample at Baseline

The baseline sample of 251 spouses had a mean age of 62.47 years (*SD* = 9.97; range = 32-87). The overall sample was predominantly female (70%), Caucasian (96%), and retired (56%). The majority had post- high school education (68%). The median annual household income category was $40,000 -$49,999. The spouses and the persons with PD had been living together for an average of 36.94 years (*SD* = 12.03), ranging from 4 to 64 years. At baseline, the average length of caregiving was 3.79 years (*SD* = 1.98), ranging from 0.25 to 8 years (See Table 4.1).

The mean number of caregiving tasks provided by spouses at baseline was 12.9 (*SD* = 7.70) out of a possible total of 50 tasks, with a range of 0 to 49. The average help received from relatives was 0.31 (*SD* = 0.81), ranging from 0 to 4. Few of them received help from professionals or paid help (9%), and were a member of a local support group (20%).The average physical functioning score among spouses was 83.65 (*SD* = 19.16) on a 0 to 100 point-scale and the level of depressive symptoms on the CES-D scale was 7.84 (*SD* = 6.86) where 13% of the 251 baseline sample had scores of 16 and above, indicating that these spouses had good physical function and were not, on average, depressed (See Table 4.1).

Table 4.1

Spouse Socio-Demographics at Baseline (N=251)

Spouse characteristics	%	Mean (SD)	Range
Age (years)		62.47 (9.97)	32-87
Gender (% female)	70.1		
Race (% Caucasians)	95.6		
Educational level (% post HS)	67.6		
Employment – % retired	56.2		
– % employed	27.4		
Household Income (range)		40,000-49,999	
Duration of living together (years)		36.94 (12.03)	4-64
Duration of knowing each other (years)		40.13 (12.30)	4-71
Duration of caregiving (years)		3.79 (1.98)	0.25-8
Physical function[a]		83.65 (19.16)	5-100
Depressive symptoms[b]		7.84 (6.86)	0-33
Number of direct care activities[c]		12.90 (7.70)	0-49
Paid help (% received)	9		
Help received from relatives[d]		0.31 (0.81)	0-4
Being a member of a local support group (% yes)	20		

Note: HS = High school. [a]Higher scores indicate better physical function. [b]Higher scores indicate more depressive symptoms. [c]Higher scores indicate provided more care. [d]Higher scores indicate received more help from relatives.

As described in chapter 3, the parent study was an ancillary study to the national DATATOP clinical trial, which focused only on patients who were in an early stage of PD, without dementia or depression. However, by the beginning of data collection in the parent study, 5 years later, some patients had already progressed into middle stage disease. The stage of PD is classified by clinicians using the Hoehn and Yahr Scale in which the PD stage is categorized from Stage 1 to Stage 5 based on the severity of their motor disability. Of the 251 spouses, 81% cared for a spouse with early-stage PD (Stage 1, 23.1%; Stage 2, 57.4%) and about one fifth provided care for a spouse in middle-stage PD (Stage 2.5, 13.1%; Stage 3, 6.4%) at baseline. Additionally, the other criteria of the DATATOP study were that patients must have no significant dementia (patients with

Mini-Mental State Exam scores of 22 or less were excluded), or depression (patients with Hamilton depression scores of 16 or more were excluded). Similar to the parent study, the participants of the current study were spouses who provided care to relatives who were primarily physically impaired rather than cognitively impaired. As mentioned above, most PD patients in this current study were not depressed (81%). As the majority of these patients were in early stage PD, 65% of the 251 patients reported no problems performing activities of daily living (ADL) with the remaining one third having only mild ADL impairment (See Table 4.2). Conversely, most of these patients (97%) were already receiving some assistance from their spouse based on the numbers of direct care activities provided (*M* = 12.90; *SD* = 7.70) (See Table 4.1).

Table 4.2

Patient Characteristics at Baseline (N =251)

Patient characteristics	%	Mean (SD)	Range
Age (years)		64.5 (9.46)	37-83
Gender (% male)	70.5		
Stage of PD			
Early stage	80.5		
Middle stage 2	19.5		
Depression (% no depression)	80.5		
ADL impairment			
(% no impairment)	64.9		
(% mild impairment)	32.7		

Sample Attrition

Sample attrition in the parent study at Time 2 and Time 3 was due to participants who refused to participate, were unable to be located, or were ineligible as described in detail in the previous chapter. Given the goal of the current study to examine caregiver preparedness, only spouses who provided care in their home at the time of data collection, had at least one wave of preparedness scores, and complete data on the set of 14 Time 1 study predictor variables were included. Therefore, out of the 251 baseline sample, only 190 and 95 spouses had available data at Time 2 (Year 2) and Time 3 (Year 10), respectively.

Missing Data

As mentioned above, after removal of the two cases that had data missing on caregiver preparedness at all three waves, the missingness of study predictor variables was examined. Originally, a set of 19 predictor variables was proposed to be studied in this study, based on the conceptual framework described in chapter 2. However, an examination of missing data resulted in a decision to remove five variables to maximize the sample size, as well as to maintain the conceptual framework.

The rewards of caregiving measure was not available at baseline due to an overwhelming amount of missingness on the scale related to an error in how the mail survey was assembled. Two predictors, including delayed recall (a patient clinical variable) and duration of caregiving, were removed due to the large amount of missingness on these variables. Of the 251 participants, 85% and 64% did not have available data on these variables. Two other predictors, help received from friends and neighbors and being a member of national PD associations, were also removed in order to avoid redundancy among predictors. Help received from friends and neighbors was highly correlated with help received from relatives ($r = .49$, $p < .001$) and paid help ($r = .62$, $p < .001$), while the latter was correlated with being a member of a local support group ($r = .30$, $p < .001$).

It is important to note that, even though the set of predictor variables was modified, all decisions were guided by the conceptual framework of this proposed study. In other words, the constructs to be tested remained the same. These decisions resulted in a sample of 251 spouses with no missing data on a set of 14 predictors representing the transitions theory. Of the final baseline sample of 251 spouses, 85 spouses had caregiver preparedness scores at all three waves, 53 had only one wave (Time 1 or Time 2), and 113 had two waves. In summary, 249, 190, and 95 spouses had preparedness scores at Time 1, Time 2 and Time 3, respectively (See Table 4.3).

Table 4.3

Group Differences on Caregiver Preparedness between Spouses Who Had Three Waves of Preparedness Data and Spouses Who Did Not at Each Wave (N=251)

Caregiver preparedness		Spouses with 3-waves-preparedness			Spouses without 3-waves-preparedness				
	N	*M*	*SD*	*n*	*M*	*SD*	*n*	*df*	*t*
Time 1	249	2.34	0.98	85	2.48	0.80	164	143.86	1.11
Time 2	190	2.39	0.90	85	2.49	0.71	105	157.17	0.80
Time 3	95	2.33	0.97	85	2.06	1.21	10	93.00	-0.81

Note: No group difference at $p < .05$.

The *t*-tests revealed there was no difference in Time 1, Time 2 and Time 3 caregiver preparedness between the 85 spouses who had caregiver preparedness scores at all three waves and the spouses at each wave who did not, $t(143.86) = 1.11$, $p = .27$; $t(157.17) = 0.80$, $p = .43$; $t(93) = -0.81$, $p = .42$, respectively (See Table 4.3).

Sample Representativeness

At Year 10, the final sample of Time 3 was comprised of 95 participants. A comparison of the spouses who were in the Time 3 sample (n = 95) to those who were not in the Time 3 sample (n = 156) using a series of t tests and chi-square analyses was conducted on the set of 14 Time 1 predictors. As expected, the participants who were in the Time 3 sample were significantly younger ($t(245) = 5.45$, $p < .001$), healthier ($t(244.83) = -3.81$, $p < .001$), provided a fewer number of direct care activities ($t(234.73) = 3.04$, $p < .001$), received less help from relatives ($t(237.23) = 2.22$, $p < .05$), and their patients with PD experienced less depression at baseline ($t(244.33) = 2.69$, $p < .01$) than those who were not in the Time 3 sample (See Table 4.4).

Table 4.4

Group Differences for Continuous Time 1 Predictor Variables between Spouses Who Did and Did Not Participate in Time 3 (N=251)

Time 1 variables	In Time 3 (n=95)		Not in Time 3 (n=156)			
	M	*SD*	*M*	*SD*	*df*	*t*
Preparedness	2.29	0.99	2.52	0.78	164.47	1.91
Age	58.39	8.66	65.12	9.89	245	5.45***
SP depressive symptoms	7.11	6.32	8.22	7.11	245	1.23
SP Physical function	88.73	13.73	80.20	21.43	244.83	-3.81***
The number of direct care activities	11.06	5.72	14.11	8.52	234.73	3.04***
PT Stage of disease	1.92	0.71	2.12	0.86	245	1.92
PT Depression	0.14	0.35	0.30	0.59	244.33	2.69**
PT ADL impairment	0.34	0.48	0.41	0.59	229.85	1.04
Mutuality	3.37	0.65	3.24	0.80	245	-1.41
Help from relatives	0.19	0.49	0.39	0.96	237.23	2.22*
Predictability	2.97	0.74	2.86	0.65	245	-1.25

Note: SP = Spouse. PT = Patient. *$p < .05$. **$p < .01$. ***$p < .001$.

However, the two groups did not significantly differ ($p > .05$) on caregiver preparedness ($t(164.47) = 1.91$), spouse depressive symptoms ($t(245) = 1.23$), stage of disease ($t(245) = 1.92$), PT ADL impairment ($t(229.85) = 1.04$), spouse mutuality ($t(245) = -1.41$) (see Table 4.4), amount of paid help received by the spouse ($\chi^2(1, N = 247) = 1.28$), the spouse being a member of a local support group ($\chi^2(1, N = 247) = 0.20$), spouse gender ($\chi^2(1, N = 247) = 0.10$), or spouse educational level ($\chi^2(1, N = 247) = 0.03$) (See Table 4.5 for results of Chi-square comparisons).

Table 4.5

Comparisons on Categorical Time 1 Predictor Variables between Spouses Who Did and Did Not Participate in Time 3 (N=251)

Time 1 Predictor Variables	In Time 3 (n= 95)	Not in Time 3 (n=156)	χ^2
SP Gender (1 = Female)	68	106	0.10
SP Education level (1= some college)	53	83	0.03
Paid help received by spouses (1=Yes)	6	16	1.28
Being a member of a local support group (1=Yes)	21	30	0.20

Note: SP = Spouse. No significant difference at $p < .05$.

Preliminary data analyses

The current dissertation study examined caregiver preparedness in spouses who provided care for their spouses who had Parkinson's disease (PD) in their home over a 10 year-period. Preliminary data analyses were conducted including internal consistency of measures, and examination of collinearity, and bivariate associations were conducted.

Reliability: Internal Consistency

Reliability tests demonstrated acceptable evidence of internal consistency for each scale. Cronbach’s alphas ranged from .74 to .96 (See Table 4.6).

Table 4.6

Means, Standard Deviations, Ranges and Cronbach’s Alphas of Study Variables (N=251)

Variables	%	*M*	*SD*	*α*	Range		Skewness
					Potential	Actual	
Outcome Variable							
Time 1 Preparedness		2.43	0.87	.93	0-4	0-4	-0.30
Time 2 Preparedness		2.45	0.80	.92	0-4	0-4	-0.22
Time 3 Preparedness		2.30	0.99	.94	0-4	0-4	-0.31
Time 1 Predictor Variables							
Spouse characteristics							
Age		62.47	9.97	N/A		32-87	-0.38
Gender (% female)	70.1	-	-	N/A	1-2	1-2	0.88
Education (% post HS)	67.6	-	-	N/A	1-6	1-6	-0.55
Physical function[a]		83.65	19.17	.88	0-100	5-100	-1.72
Number of direct care activities[b]		12.90	7.70	.91	0-50	0-49	1.09
Depressive symptoms[c]		7.84	6.86	.86	0-60	0-33	1.10
Patient characteristics							
Stage of disease[d] (% early stage)	80.5	-	-	N/A	1-5	1-5	0.93
Depression		0.23	0.51	N/A	0-3	0-3	2.34
ADL impairment		0.38	0.55	N/A	0-3	0-3	1.23
Interpersonal condition							
Mutuality [1]		3.30	0.75	.96	0-4	.6-4	-1.68
Environmental conditions							
Paid help (% received)	9	-	-	N/A	0-1	0-1	2.9
Help received from relatives		0.31	0.81	N/A	0-4	0-4	2.80
Being a member of a local support group (% yes)	20	-	-	N/A	0-1	0-1	1.48
Nature of PD caregiving							
Predictability[2]		2.90	0.69	.74	0-4	0.67-4	-0.63

Note: HS = High School. [a]Physical functioning subscale of SF -36, higher scores indicate better physical function. [b]Amount of direct care scale. [c]Center of Epidemiologic Studies Depression scale, higher scores indicate more depressive symptoms. [d]Hoehn and Yahr scale. [1]Higher scores indicate higher mutuality. [2]Higher scores indicate more predictability.

Collinearity

In order to avoid redundancy among the 14 predictor variables, which can lead to inflated error, a series of zero-order correlations between all 14 baseline predictors was conducted. Correlations among the final 14 predictors ($N = 251$) showed no evidence of collinearity. The bivariate *Pearson-r* correlations ranged from .01 to .42 (See Table 4.7). Seven pairs of predictor variables were found to have moderate associations (*r ranging from* .30 to .42) which were not considered large enough to eliminate from analysis (Cohen, 1988; Munro, 2005). These seven pairs of predictor variables were: stage of disease and the number of direct care activities ($r = .41$, $p < .001$); ADL impairment and stage of disease ($r = .36$, $p < .001$); mutuality and spouse depressive symptoms ($r = -.42$, $p < .001$); help from relatives and the number of direct care activities ($r = .41$, $p < .001$), or paid help ($r = .39$, $p < .001$); and predictability and spouse depressive symptoms ($r = -.31$, $p < .001$), or mutuality ($r = .37$, $p < .001$).

Table 4.7

Zero-order Correlation Matrix among the 14 Time 1 Predictor Variables (N=251)

Time 1 Predictor Variables	1	2	3	4	5	6	7	8	9	10	11	12	13
1. Age	--												
2. Gender	.15*	--											
3. Education level	-.04	.02	--										
4. Physical function	-.29***	.15*	.15*	--									
5. Number of direct care activities	.02	-.07	.06	-.13*	--								
6. SP Depressive symptoms	-.07	-.20 **	-.09	-.20 **	.15*	--							
7. PT Stage of disease	.10	-.14*	.00	-.07	.41***	.13*	--						
8. PT Depression	-.03	.05	.06	-.07	.29***	.09	.21***	--					
9. PT –ADL impairment	-.04	-.10	-.12	-.01	.27***	.05	.36***	.26***	--				
10. Mutuality	.12	.14*	-.06	-.09	-.23***	-.42***	-.19**	-.19**	.02	--			
11. Paid Help	-.04	-.03	.03	-.03	.20**	.10	.05	.18**	.13*	-.09	--		
12. Help from relatives	.05	-.10	-.05	-.21**	.41***	.15*	.26***	.19**	.27***	-.13*	.39***	--	
13. Being a member of local support group	.10	-.01	.13*	-.10	.04	.03	-.02	.04	-.02	.11	.05	-.03	--
14. Predictability	.15*	.03	.20**	.03	-.25***	-.31***	-.07	-.12	-.08	.37***	-.13*	-.20**	.02

Note: SP = Spouse. PT= Patient. **p* < .05. ***p* < .01. ****p* < .001.

Bivariate Associations

Examination of the bivariate correlations between caregiver preparedness and the 14 Time 1 predictor variables was conducted. The significant correlates of caregiver preparedness at Time 1, Time 2 and Time 3 were mutuality ($r = .40$ to .46, $p < .001$), predictability ($r = .32$ to .38, $p < .01$), and spouse depressive symptoms ($r = -.38$ to -.41, $p < .001$), respectively. Age was only significantly correlated to preparedness at Time 2 ($r = .23$, $p < .05$, See Table 4.8).

Table 4.8

Zero-Order Correlations between Baseline, Time 2 and Time 3 Caregiver Preparedness and Time 1 Predictor Variables (N=85)

	Study Variables	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16
1	Time 1 preparedness	--															
2	Time 2 preparedness	.76***	--														
3	Time 3 preparedness	.78***	.78***	--													
4	Age	.12	.23*	.13	--												
5	Gender	-.07	.09	-.00	.19	--											
6	Education level	.10	.03	.18	-.12	-.11	--										
7	SP Physical function	-.01	.08	.10	-.17	.09	.11	--									
8	Number of direct care activities	.05	.01	.02	-.09	.15	.20	.06	--								
9	SP-Depressive symptoms	-.41**	-.38**	-.40**	-.09	-.11	-.11	-.16	.06	--							
10	PT-Stage of disease	.09	.02	.02	.10	.18	.26*	.14	.27*	-.03	--						
11	Pt-depression	-.19	-.01	-.00	.07	-.05	.03	.08	-.03	.17	.05	--					
12	PT-ADL impairment	.06	.10	.03	.10	-.03	-.24*	.09	.05	.08	.08	.15	--				
13	Mutuality	.40***	.43***	.46***	.00	-.02	.11	.03	.03	-.34**	-.09	-.17	.08	--			
14	Paid help	-.04	.09	-.00	-.06	.09	-.04	-.10	.12	.00	-.13	.07	-.04	-.03	--		

Note: SP=Spouse. PT=Patient. $*p < .05$. $**p < .01$. $***p < .001$.

Table 4.8

Continued

	Study Variables	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16
15	Help from relatives	-.06	-.08	-.14	.10	.04	-.04	-.08	.28**	.12	.04	.00	-.03	-.15	.29***	--	
16	Being a member of local support group	.03	.11	.05	.04	.01	.18	-.19	.15	.02	.06	-.06	-.02	.18	.15	-.07	--
17	Predictability	.32**	.38**	.32**	.04	-.12	.27*	.15	-.16	-0.43***	.02	-.03	-.02	.42***	-.12	-.21**	.00

Note: SP=Spouse. PT=Patient. *p < .05. **p < .01. ***p < .001.

Results

Specific Aim 1: Describing Caregiver Preparedness over Time

Overall, the means of preparedness at baseline, Time 2, and Time 3 were 2.43 (*SD* = 0.87, n = 249), 2.45 (*SD* = 0.80, n = 190), and 2.30 (*SD* = 0.99, n = 95). Skewness was not a concern at any time point (See Table 4.6). A series of *t*-tests revealed preparedness scores in a sample of 85 spouses with preparedness at all three waves, at Time 1 *(M* = 2.3*5*, *SD* = *0*.95), Time 2 *(M* = 2.3*9*, *SD* = *0*.90), and Time 3 *(M* = 2.3*3*, *SD* = *0*.96), were not statistically significantly different at *p* < .05. Bivariate correlations revealed that there were statistically significant associations between caregiver preparedness at Time 1 and Time 2 (*r* = .71, *p* < .001), Time 2 and Time 3 (*r* = .78, *p* < .001), and Time 1 and Time 3 (*r* = .74, *p* < .001), showing strong stability in the measure over time.

HLM Level 1 model: Average pattern of change in preparedness over time.

In order to address specific aim 1 using the HLM statistical approach and three available time points of data, only two growth parameters, an intercept and linear slope, could be estimated. An intercept-linear slope model that included both intercept and linear slope (rate of change) parameters was fit to examine the average level of caregiver preparedness and the rate of change. The rate of change is a function of time in a series of repeated measures, and it was fit with the actual time points of data collection (Year 0, 2 and 10), rather than waves of data collection (Time 1, 2 and 3), so it represented the true uneven spacing of the data collections in the study. Thus, the rate of change is coded in years where 0 =Year 0, 2 = Year 2, and 10 = Year 10. Time was centered at baseline

(Year 0). Hence, the intercept represents the average level of preparedness at baseline and the linear slope represents the rate of change over time in years.

Table 4.9

Unstandardized Coefficient and Variance Estimates for the Intercept and Linear Slope Model of Caregiver Preparedness (N=251)

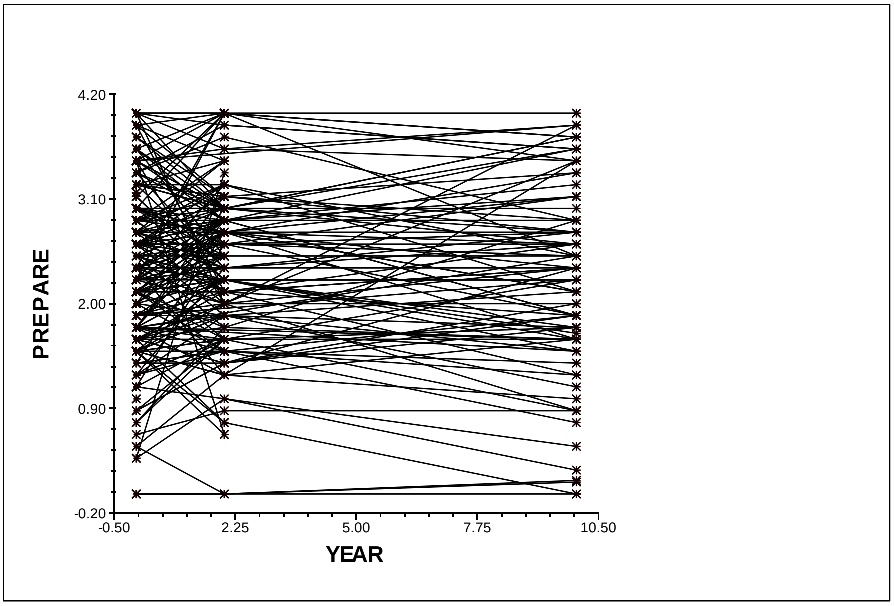
Parameters	Unstandardized Coefficient	*t*-ratio
Fixed effect		
Intercept	2.45	48.29***
Linear rate of change	-0.002	-0.30
Random effect	Variance	χ^2
Intercept	0.49	842.68***
Linear rate of change	0.000	200.47

****p* < .001.

In Table 4.9, the intercept, which represented the average preparedness scores across spouse caregivers at baseline, is 2.45 (*SE* = 0.05) on a 0 (not at all prepared) to 4 (very well-prepared) point-scale. The intercept is significantly different from zero, $p < .001$, but the rate of change is not significantly different from zero ($B = -0.002$ ($SE = 0.00$), $p > .05$). This suggests that, even though average baseline caregiver preparedness differed significantly from zero, there was no significant change in caregiver preparedness over time. Thus, on average, spouse caregivers felt somewhat well-prepared for their spouse caregiver role at baseline and their preparedness remained stable over a 10-year period. Additionally, there was significant variability around the intercept ($\chi^2 = 842.68$, $p < .001$), but not the linear rate of change ($\chi^2 = 200.47$, $p > .05$). In other words, baseline preparedness varied across spouses, but there was no variability around the average trajectory over time. Spouses who felt less prepared at baseline were likely to feel less-prepared over the course of caregiving.

A similar pattern of results was found when an analysis was done on only the 85 spouses with preparedness at all three waves (See Appendix A). In Figure 3, each line represents the individual preparedness scores of the 251 participants over the three waves of data collection. The graph illustrates variation of preparedness at baseline with flat trajectories of changes across waves of data collection showing the large gap between Time 2 (Year 2) and Time 3 (Year 10). The illustration visually supported the evidence of overall homogeneity in the rate of change found by the HLM model.

Figure 3. Caregiver Preparedness Scores across Three Waves (Ordinary Least Squares data, N=251)



Specific Aim 2: Examining Factors Predicting Caregiver Preparedness

Due to the lack of statistically significant variability in the rate of change in preparedness, performing a Level 2 HLM analysis to determine what factors accounted for variability was not warranted. In other words, based on the conceptual framework for this study, the PSP data set did not support the original focus of this study to determine the factors that predict change in preparedness over time. However, two hierarchical multiple regressions were used to cross-sectionally examine the role of caregiving transitional conditions and the nature of PD caregiving in predicting preparedness at baseline and Time 3, based on the transitions theory. The decision to examine a Time 3 model, despite overall stability in preparedness, was due to the changes in the care context found over the ten-year period (See Table 4.11). It was, therefore, of interest to examine whether transitions theory predictors of preparedness differed between Time 1 and Time 3. A Time 2 model was not examined due to the minimal changes in care context between Time 1 and Time 2.

Guided by the transitions theory, caregiver preparedness was regressed on the set of predictor variables in the following sequence: Step 1) spouse characteristics, Step 2) patient characteristics, Step 3) interpersonal condition, Step 4) environmental conditions, and Step 5) the nature of PD caregiving.

The role of baseline variables in predicting baseline caregiver preparedness.

Table 4.10 presents the results of baseline preparedness regressed on progressive blocks of baseline spouse characteristics, patient characteristics, interpersonal and environmental conditions, and the nature of PD caregiving. At Step 1 spouse characteristics (i.e., age, gender, educational level, physical function, number of direct care activities, and depressive symptoms) were entered into the equation. Together, these spouse characteristics accounted for approximately 10% of the variance in preparedness (R^2 =.10, F(6, 242) = 4.62, $p < .001$) with spouses who were older (B = 0.01, p = .039), and experienced less depressive symptoms (B = -0.04, $p < .001$) being significantly better prepared. Patient characteristics (i.e., stage of disease, depression and ADL impairment) were entered in step two. None was significant. In step three, mutuality was entered and it accounted for an additional 5% of the variance explained (R^2 change =.05, F(1, 238) = 13.68, $p < .001$) with higher mutuality being associated with higher preparedness (B = 0.31, $p < .001$). Depressive symptoms remained significant but spouse age was no longer significant when mutuality was added in. In step 4, environmental conditions (i.e., paid help, help from relatives, and being a member of a local support group) were entered, although none was significant. In the final step, predictability also was not significant while depressive symptoms and mutuality remained significant. Over all, the set of 14 baseline predictors accounted for 16% of the variance in baseline caregiver preparedness (See Table 4.10).

Table 4.10

Hierarchical Regression Analysis Summary for Time 1 Predictor Variables Predicting Time 1 Preparedness (N=251)

Step	1	2	3	4	5
Block and Variables	B	B	B	B	B
Block 1: SP characteristics					
Age	0.01*	0.01*	0.01	0.01	0.00
Gender	-0.07	-0.05	-0.09	-0.09	-0.07
Educational level	0.03	0.04	0.04	0.04	0.03
Physical function	-0.00	-0.00	0.00	0.00	0.00
Number of direct care activities	0.00	0.00	0.01	0.01	0.01
Depressive symptoms	-0.04***	-0.04***	-0.02*	-0.02*	-0.02*
Block 2: PT characteristics					
Stage of disease		-0.00	0.03	0.03	0.02
PT depression,		-0.12	-0.05	-0.06	-0.06
ADL impairment		0.05	-.02	-0.03	-0.03
Block 3: Interpersonal condition					
Mutuality			0.31***	0.30***	0.27**
Block 4: Environmental condition					
Paid help				-0.05	-0.04
Help from relatives				0.04	0.04
Be a member of a local support group			0.07	0.08	
Block 5: Nature of PD caregiving					
Predictability					0.11
R^2	.10	.11	.16	.16	.16
R^2	.10	.00	.05	.00	.00
F Change	4.62***	0.4	13.68***	0.14	1.66

Note: SP = Spouse. PT = Patient. **p* < .05. ***p* < .01. ****p* < .001.

The role of Time 3 predictors in predicting Time 3 caregiver preparedness.

As the long term goal of this study was to examine how caregiving transition conditions and the nature of PD caregiving affects caregiver preparedness after 10 years, the role of Time 3 variables in predicting Time 3 preparedness was tested. At Time 3, only 9 of the 14 predictor variables were available. They were spouse characteristics (i.e. age, gender, depressive symptoms, physical function, number of direct care activities), interpersonal conditions (mutuality), environmental conditions (i.e. paid help, and help from relatives), and the nature of PD caregiving (predictability).

The Time 3 sample and the changing context of PD caregiving.

Of the total 95 spouses at Time 3 who were included in this current study, 88 spouses had complete data on the set of 9 predictors and Time 3 preparedness to be included in this regression model. Characteristics of this sample were similar to that of the 95 spouses (See Tables 4.4 and 4.5 for more details). It is important to note that ten years into the caregiving trajectory, spouses physical function had significantly declined ($t = 4.95$, $p < .001$), and they experienced more depressive symptoms ($t = -3.92$, $p < .001$) with 26% of the 88 spouses experiencing depressive symptoms above the clinical cut-off of 16. Compared to baseline, the context of PD caregiving in Time 3 had also significantly changed with spouses providing significantly more caregiving tasks ($t = -14.71$, $p < .001$). On average, the number of caregiving tasks provided had doubled ($M = 24.40$ compared to $M = 11.17$ at baseline). Moreover, the types of caregiving tasks provided had changed with more personal care provided at Time 3 compared to Time 1 (See Appendix B). Spouses also received more paid help ($t = -2.85$, $p < .01$) and help from relatives ($t = -7.00$, $p < .001$), they experienced less predictability in the care situation ($t = 5.05$, $p < .001$) and less mutuality with their spouse with PD ($t = 5.93$, $p < .001$ (See Table 4.11).

Table 4.11

Differences between Time 1 and Time 3 Predictor Variables in Spouses Who Were Available at Time 3 (*N* = 88)

Predictor Variables	Time 1		Time 3		
	M	*SD*	*M*	*SD*	*t*
Age	58.74	8.39	68.70	8.42	-394.02***
SP Physical function	88.95	13.11	79.19	21.67	4.95***
SP Depressive symptoms	6.77	6.61	10.33	8.67	-3.92***
Number of direct care activities	11.17	5.86	24.40	9.02	-14.71***
Mutuality	3.41	0.63	2.94	0.92	5.93***
Paid help	0.18	0.72	0.61	1.28	-2.85**
Help received from relatives	0.17	0.46	1.08	1.24	-7.00***
Predictability	3.02	0.72	2.63	0.60	5.05***

Note: SP = Spouse. ***p* < .01. ****p* < .001.

Description of study variables at Time 3.

Descriptive statistical tests of the Time 3 study variables and testing for collinearity and bivariate associations were conducted. Skewness of these Time 3 predictor variables and internal consistency for each scale were not of concern (See Table 4.12). It is evident that there are three pairs of predictors that were highly correlated to one another within this set of 9 predictor variables: mutuality and depressive symptoms (*r* = -.66); mutuality and predictability (*r* = .46); and depressive symptoms and predictability (*r* = -.50). However, each pair represents a different construct to be tested, so none of them were excluded (See Appendix C). The bivariate *Pearson- r* correlations between Time 3 caregiver preparedness and 9 Time 3 predictor variables revealed that significant correlates of Time 3 caregiver preparedness were similar to those at baseline. Additionally, help from relatives was significant at Time 3 (See Appendix D).

Table 4.12

Means, Standard Deviation, Cronbach's Alphas, Ranges and Skewness of Time 3 Study Variables (N=88)

Time 3 Study Variables	*M*	*SD*	α	Range		Skewness
				Potential	Actual	
Preparedness	2.37	0.95	.94	0-4	0-4	-0.31
Age	68.70	8.42	N/A	-	44-85	-0.55
Gender	1.30	0.46	N/A	1-2	1-2	0.97
SP-Physical function	79.19	21.67	.91	0-100	5-100	-1.33
SP-Depressive symptoms	10.33	8.67	.88	0-60	0-47	1.43
Number of direct care activities	24.40	9.02	.90	0-50	5-46	0.27
Mutuality	2.94	0.92	.97	0-4	0.33-4.00	-0.74
Paid help	0.61	1.28	N/A	0-4	0-4	1.91
Help received from relatives	1.08	1.24	N/A	0-4	0-4	1.05
Predictability	2.62	0.60	.79	1-4	1-4	-0.29

Note: SP= Spouse.

Table 4.13

Summary of Hierarchical Multiple Regression Analysis for Time 3 Variables Predicting Time 3 Preparedness (N=88)

Step	1	2	3	4
Block and Variables	B	B	B	B
Block 1: SP characteristics				
Age	0.01	0.01	0.01	-0.01
Gender	-0.23	-0.26	-0.23	-0.23
Physical function	0.01	0.01	0.00	0.00
Number of direct care activities	0.02	0.02	0.01	0.02*
Depressive symptoms	-0.04*	-0.02	-0.03*	-0.02
Block 2: Interpersonal condition				
Mutuality		0.17	0.23	0.11
Block 3: Environmental condition				
Paid help			0.08	0.02
Help from relatives			0.23**	0.28***
Block 4: Nature of PD caregiving				
Predictability				.71***
R^2	.14	.16	.27	.39
R^2	.14	.02	.11	.12
F Change	2.68*	1.50	5.95**	15.81***

Note: SP = Spouse. PT = Patient. *$p < .05$. **$p < .01$. ***$p < .001$.

Table 4.13 presents the results of Time 3 caregiver preparedness regressed on the progressive blocks of Time 3 spouse characteristics, mutuality, environmental conditions and predictability. Results differed from the Time 1 model. At Step 1, spouse characteristics accounted for 14% of the variance in preparedness (R^2 =.14, F(5, 82) = 2.68, $p < .05$) with spouses who experienced less depressive symptoms (B = -0.30, p = .05), reporting higher levels of preparedness. In step two, mutuality was entered and was not significant. In Step three, environmental conditions (i.e., paid help and help received from relatives) were entered. They accounted for an additional 11% of the variance in preparedness (R^2 change =.11, F (2, 79) = 5.95, $p < .01$) with receiving more help from relatives associated with greater preparedness ($B = 0.28$, $p = .004$). In the final step, predictability was entered into the equation and accounted for an additional 12% of the variance in preparedness (R^2 change =.12, F (1, 78) = 15.81, $p < .001$) with high predictability in PD caregiving ($B = 0.71$, $p < .001$) associated with feeling better prepared. In the final step when predictability was added, depressive symptoms was no longer significant. Number of direct care activities also became significant in the final step with providing more direct care activities ($B = 0.02$, $p < .05$) associated with higher levels of preparedness. Overall, the set of 9 Time 3 predictors explained 39% of the variance in Time 3 caregiver preparedness.

Compared to the Time 1 model, spouse depressive symptoms, and mutuality were not significantly associated with caregiver preparedness. To address the role collinearity between these two variables (*Pearson* $r = -.66$) may have played, two additional regression models that included either depressive symptoms or mutuality were examined. Compared to the full model at Time 3, a similar pattern of results in the final step was found in each model. Either depressive symptoms or mutuality itself were significant in earlier steps, but fell out when predictability was included in the model. Number of direct care activities and help received from relatives were also significant in the final step (See Appendices E and F).

Summary of the Two Regression Models

It was interesting to find that, even though the level of preparedness at Time 1 and Time 3 are not statistically significantly different, the factors predicting preparedness at each time point were not the same. In the baseline final model, spouse depressive symptoms and mutuality significantly predicted preparedness with lower levels of preparedness significantly more likely to be found in spouses experiencing higher levels of depressive symptoms and lower levels of mutuality. Mutuality accounted for the most amount of variance explained in baseline preparedness. In the Time 3 final model, the number of direct care activities, help received from relatives and predictability of PD caregiving were all significant with predictability accounting for the most amount of variance. Spouses who provided more care, received less help from relatives, and experienced less predictability in PD caregiving were more likely to report lower levels of preparedness.

Summary of Results

The main findings from this study were that there was no change, on average, in caregiver preparedness over time and no variation around that change to be examined by a Level-2 model of the HLM statistical approach. Cross-sectionally, hierarchical multiple regressions revealed that Time 1 spouse depressive symptoms and mutuality significantly predicted Time 1 caregiver preparedness. Importantly, at Time 3, three different predictors (the number of direct care activities, help from relatives, and predictability) significantly predicted Time 3 preparedness. Differences in the context of caregiving in terms of transition conditions and nature of PD caregiving at each time point seemed to play important roles in difference in significant factors predicting preparedness.

Chapter 5

Discussion

Guided by transitions theory (Meleis et al., 2000) the current study conceptualized caregiver preparedness as a process indicator of a healthy caregiving transition. The study had two specific aims: 1) to describe caregiver preparedness over time and 2) to examine the roles of transition conditions and the nature of PD caregiving in predicting preparedness in a sample of spouse caregivers of persons with Parkinson's disease (PD). It was the first study that examined preparedness in an early stage of PD over a 10-year period. This chapter interprets the findings of the study in the context of the PD literature, identifying its implications, strengths, and limitations, and providing insight for future directions of research. The findings are discussed as they relate to transitions theory (See Figure 4) and the PD caregiving transition process.

Figure 4. Conceptual Framework.

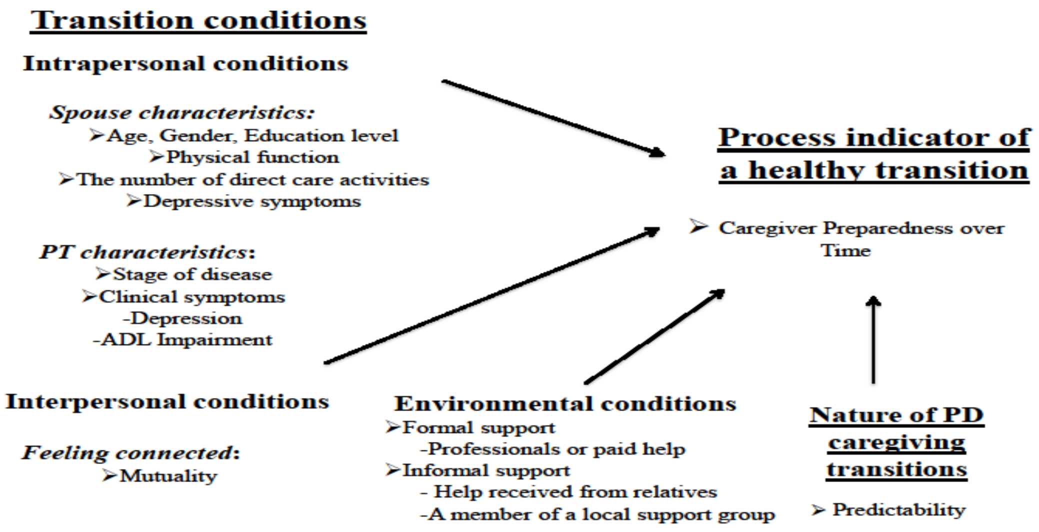


Figure 4 illustrates the major components of transitions theory as it was adapted for the current study. The conceptual framework posited that caregiver preparedness is affected by transition conditions, including intrapersonal (spouses and patient characteristics), interpersonal (mutuality), and environmental conditions (formal and informal support network), and the nature of the PD caregiving situation (predictability).

Major Findings

There were two major findings in this study. First, it was found that although levels of preparedness at baseline varied significantly from spouse to spouse, there was no change in caregiver preparedness over time and no significant variability around the average trajectory of caregiver preparedness in the sample of 251 spouse caregivers, despite the context of PD caregiving having changed substantially. Both the lack of change over time and variability around the average trajectory prevented a full examination of Aim 2 (predicting change in caregiver preparedness). However, it was still possible to discover new knowledge about the role of transitions theory factors in predicting preparedness at two time points (baseline and Time 3, or ten years later) in the PD caregiving process.

Second, there were two different sets of factors which predicted preparedness at these two discrete time points. At baseline, the factors significantly associated with preparedness were spouse depressive symptoms and mutuality, with spouses who experienced more depressive symptoms and less mutuality with their patients with PD reporting lower levels of preparedness. At Time 3, the significantly associated factors were the number of direct care activities provided, help received from relatives, and predictability. Spouses who provided more caregiving tasks, received more help from relatives, and experienced more predictability in the PD care situation reported lower levels of preparedness.

Caregiver Preparedness Did Not Change Over Time

This study was a secondary data analysis of a three-wave data set from the PSP, an ancillary study of the DATATOP clinical trial. In this study, the spouse caregivers perceived their preparedness for caregiving as “somewhat well-prepared” at baseline with no change in their level of preparedness occurring over time. Previous research on caregiver preparedness revealed comparable results. The average level of preparedness reported among caregivers in this study at baseline was consistent with the findings from previous studies (Archbold et al., 1990; Rusinak & Murphy, 1995; Samartkit, 2008; Scherbring, 2002; Shyu et al., 2010). Scherbring (2002) reported that caregivers rated themselves as being “somewhat” to “pretty well” prepared to care for their patient with cancer before and just after hospital discharge, while Rusinak and Murphy (1995) found that elderly spouse caregivers were moderately prepared to help and assist with the needs of their spouse recently diagnosed with cancer.

Similar results were also reported by Archbold et al. (1990) in caregivers providing care prior to and post hospitalization, by Schumacher et al. (2007; 2008) in caregivers caring for patients with cancer, by Shyu et al. (2010) in caregivers of patients with dementia in Taiwan, and by Samartkit (2008) in caregivers of traumatic brain injury survivors in Thailand. It was quite interesting to find that caregivers reported their levels of preparedness for the caregiving role in a similar manner, as moderate or pretty well-prepared, regardless of the caregiving situation, the place in the caregiving trajectory, and the cultural differences in their context of caregiving.

On the other hand, the findings of Giarelli et al (2003) demonstrated that there was discrepancy between global and specific-task feelings of being prepared. They reported that while caregivers felt “pretty” to “very” well-prepared for caring for their husband after prostate removal surgery in general, they still felt unprepared for some specific caregiving tasks, which differed over time. For example, at three months post surgery they felt that they were not prepared for symptom management while at 6 months their concerns were related to managing emotional changes such as dealing with frustration and uncertainty. The findings suggested that a caregiver may never feel fully prepared and that preparedness should be viewed as an ongoing process of skill attainment and refinement rather than as an achieved state of readiness for caregiving (Giarelli et al., 2003).

Moreover, the finding of stability in caregiver preparedness over time in this study was also consistent with prior short-term studies in cancer caregiving situations (Giarelli et al., 2003; Scherbring, 2002). All three studies (two previous studies and this current study), found caregiver preparedness to be stable over time. Scherbring (2002) reported no change in preparedness in a sample of caregivers of adults with cancer over a month post discharge period, and Giarelli and colleagues (Giarelli et al., 2003) reported no difference in preparedness over a six-month period in a sample of wives caring for their husbands with prostate cancer post surgery. The consistency of these findings in studies conducted over short and long periods suggested that the duration of the study may not be the primary reason for the stability in caregiver preparedness found among caregivers.

There are several potential explanations for the stability in preparedness over time with no significant variability around its average trajectory found in this study. One explanation may include the time at which the data were collected in the parent study (at least 5 years post diagnosis). Another explanation may be the unique characteristics of the sample, wherein most of the spouse caregivers were providing care to patients in an early stage of PD where no care and assistance to minimal care and assistance had to be provided. Caregiving is what caregivers have learned after entering into the role, not what they knew prior to entering it (Archbold et al., 1992), so these spouses may not have known what they would or would not be prepared for. However, several other important explanations must be considered including the global concept of caregiver preparedness and its measurement, the potential that it is a personality trait, and the nature of the data collected.

First, being conceptualized as a domain-specific concept (Archbold et al., 1990), the levels of preparedness for caregiving were measured at a global level in this study instead of at the level of specific caregiving tasks. As a global construct, the general degree to which one feels prepared is more likely to remain stable, although it may vary from one point in the caregiving trajectory to another (Skaff, Pearlin, & Mullan, 1996). The discrepancy between the levels of preparedness in general and those for specific caregiving tasks at a given time point in the caregiving trajectory reported by Giarelli and colleagues (2003) suggested that the lack of a demonstrable change in preparedness might be due to the overall level of preparedness being balanced. It also suggested that while the level of caregiver preparedness might be measured with a global measurement such as the preparedness for caregiving scale that was employed in this study, assessing the level of preparedness with more specific measurements at critical and sensitive points and events during the caregiving experience is also needed (Meleis et al., 2000). In addition, it has been suggested that the lack of a sufficiently sensitive measure to capture change over time might also be a factor of the inability to detect changes in preparedness in existing studies (Schumacher et al., 1998). Thus, the development of a tool with sufficient sensitivity to measure preparedness for the caregiving role at the level of specific tasks is necessary to fully understand this concept and whether it changes over the care trajectory.

Second, the finding that the levels of preparedness at baseline differed significantly among participants but remained stable over time in an individual might be due to the fact that preparedness for caregiving is likely to be a personality trait, similar to other concepts such as optimism and pessimism. In other words, the perceptions of caregivers' ability to carry out their caregiver role instead of their actual ability to complete particular tasks were major components of caregiver preparedness. Moreover, the significant correlation between preparedness and optimism (*Pearson r* ranged from .49 to .56, $p < .001$, $N = 85$), suggested that there was sufficient overlap between preparedness and optimism to conclude that personality or outlook is an important component of preparedness but that they are not synonymous. Importantly, previous studies using the same data as this study reported that baseline optimism and pessimism have a long-term effect in predicting depressive symptoms and role strain, as caregiving outcomes, among spouse caregivers of patients with PD (Lyons et al., 2009; Lyons, Stewart et al., 2004). These finding were also consistent with previous work using other samples (Hooker, et al., 1992; Hooker, Monahan, Bowman, Frazier, & Shifren, 1998).

Future study needs to further examine the relationship between personality as a personal transition condition and caregiving outcomes.

Last, as a secondary data analysis, the aims of this current study were not borne in mind when the parent study was designed. Hence, all desired data by this investigator were not available. For example, only data from spouse caregivers at an individual level were included in this study and limited clinical data from individual patients with PD; dyadic data were not comprehensively available in the parent study. Having data from both caregivers and patients at individual and dyadic levels simultaneously would provide a more accurate picture of the complex caregiving transition process (Lyons, Zarit, Sayer, & Whitlatch, 2002). Moreover, a secondary data analysis is less likely to have control over its sample. For example, in this study patients who were depressed or cognitively impaired were not included in the parent study, and that cannot be overlooked. Depression and cognitive impairment are common symptoms in PD patients and are known to have a strong impact on their caregivers (Bogard, 2010; Carter, Stewart, Lyons et al., 2008; D'Amelio et al., 2009). The lack of control over the parent study's sample acquisition resulted in having a homogeneous sample and a lack of sample representativeness that may have also played a role in the inability to detect variation in caregiver preparedness over time in this study. Future research needs to address these issues.

The Role of Transition Conditions and Nature of PD Caregiving in Predicting Preparedness

In accordance with the study's second aim the findings showed that, as expected, some intrapersonal, interpersonal, and environmental conditions of the transitions in the caregiving process, as well as the nature of PD caregiving, played a role in predicting caregiver preparedness. Whereas the average levels of preparedness at baseline and Time 3 were similar, the set of factors that predicted preparedness at these two points in the caregiving trajectory were different. At baseline the factors significantly predicting preparedness were the spouses' inter- and intrapersonal conditions (spouse depressive symptoms and mutuality), while at Time 3 they were care context-related factors (the number of direct care activities, help received from relatives, and predictability in the care situation). The differences in the samples at these two time points limited comparison between the two sets of predictors and the factors predicting preparedness were examined cross-sectionally, limiting the ability to draw causal inference from the data. These limitations will be discussed in more detail in the following sections.

Time 1: Spouse depressive symptoms and mutuality were significantly associated with preparedness.

Depressive symptoms.

The study confirmed previous results by finding that spouse depressive symptoms were significantly associated with preparedness with spouse caregivers who experienced more depressive symptoms reporting lower levels of preparedness (Schumacher et al., 2008; Shyu et al., 2010). In this sample, spouse caregivers of individuals with PD experienced depressive symptoms even when they were in the beginning stages of caregiving when minimal care is needed or when they may not even have considered themselves as a caregiver. The observed depressive symptoms may be the result of worry about the future (Carter et al., 1998), anxiety, and frustration, especially in a situation where care provision routines have not been established (McLaughlin et al., 2011). On the other hand, preparedness for caregiving has some overlap with optimism and pessimism, which are known to be significantly associated with depressive symptoms (Bromberger & Matthews, 1996; Lyons, Stewart et al., 2004). It could also be that those who do not feel prepared to provide care feel depressed as a result of their lack of perceived preparedness.

Having a spouse with PD proposes a future life filled with uncertainty (Davis et al., 2011; Edwards & Scheetz, 2002; Martinez-Martin et al., 2008; McLaughlin et al., 2011). Living with uncertainty may have an effect on depressive symptoms, which are known to increase over the course of caregiving. Increases in depressive symptoms can be a result of experiencing low levels of preparedness at the beginning of the caregiving trajectory, and remaining being less prepared over time, or the other way around.

Mutuality.

The study found higher levels of mutuality in spouse caregivers to be significantly associated with higher levels of preparedness at baseline. In other words, early on in their caregiving before actual care and assistance in PD caregiving had occurred, the general degree to which spouse caregivers perceived their preparedness was based primarily on the relationship quality with their spouses with PD. In the case of spouses who did not have good relationship quality, and did not share values or pleasurable activities with their spouses, caring for their patients with PD could be more challenging. Spouses who had low mutuality would be more likely to feel unprepared for providing care at the beginning of caregiving and throughout the entire caregiving trajectory. Providing care to spouses with chronic illness is also known to affect the marital relationship (Kramer & Lambert, 1999) and that may make the situation even worse for spouses who did not originally have a high relationship quality with their patients with PD in relation to feeling prepared for caregiving.

Prior research has found that relationship quality (termed mutuality) serves as a vital protective factor against increased negative caregiving outcomes (Archbold et al., 1990; Lyons et al., 2009). Evidently, low mutuality places caregivers at risk for negative caregiving outcomes even when care demand is low (Schumacher et al., 2007) and they may end up experiencing more depressive symptoms and feeling less prepared for their caregiving role. It is important to detect and intervene in cases of low mutuality to help build a stronger relationship quality or to ensure it would not become lower, given mutuality is also known to decline over time (Aneshensel, Pearlin, Mullan, Zarit, & Whitlatch, 1995; Carter et al., 1998). Such interventions might be couple-based, focusing on care dyads of both patients and spouse caregivers simultaneously, as it has been done previously in patients with advanced cancer and their spouse caregivers (Kuijer, Buunk, de Jong, Ybema, & Sanderman, 2004; McLean et al., 2008).

Time 3: Number of direct care activities, help received from relatives and predictability were significantly associated with preparedness.

The number of direct care activities.

Consistent with prior research (Samartkit, 2008; Ziemba, 2002) this study found that greater numbers of direct care activities provided by the caregivers was significantly associated with higher levels of caregiver preparedness, controlling for other transition conditions. In this case, the potential explanation may be due to caregivers who have provided more care over the years in their caregiving role having gained more experience and knowledge about what to expect and how to provide the care needed. This finding might not always hold true if it is assumed that brand-new caregivers who provide more care early on in the caregiving trajectory would feel as well prepared as veteran caregivers who provide the same level of care. Therefore, the place where spouse caregivers are at in the caregiving trajectory should be taken into account when preparedness is considered within this context.

On the other hand, the number of direct care activities provided may be a proxy for disease progression. In this study, bivariate correlation analysis showed that providing a greater number of direct care activities was significantly related with PD progression, less predictability in the care situation, higher levels of patient depression, higher levels of patient ADL impairment, and more help received from relatives. Ten years into the caregiving experience, the number of caregiving tasks spouses provided had doubled in comparison to the beginning of their caregiving experience, reflecting the significant changes in the caregiving situation and the greater needs of the person with PD. It also reflected the greater experience in the caregiving role of spouse caregivers, which supported the finding of the regression model that the greater number of care tasks provided was directly associated with higher levels of preparedness reported by these spouse caregivers.

Help received from relatives.

In this sample of spouse caregivers, the person with PD needed minimal care and assistance and spouses provided less personal care at baseline than they did ten years later. Thus, help from relatives may be less needed at baseline. On the other hand, in later stages, when patients with PD increasingly rely on others to meet their needs, the help spouses received from relatives increased correspondingly, which was consistent with the previous study of Carter et al (Carter et al., 1998). In this study, bivariate correlation analysis showed that help received from relatives itself was not correlated to caregiver preparedness at any point in time. However, after controlling for other transition factors and when less predictability was experienced, a regression analysis showed that a greater amount of help received from relatives was significantly associated with spouse caregivers reporting higher levels of preparedness. It is understandable that when a patient's needs exceed the care that their spouse caregiver is able to provide, especially when uncontrolled PD symptoms are experienced that make it harder to predict what will happen and when, receiving help and assistance from informal support sources would help increase the sense of being prepared. When the caregiving tasks become too difficult to bear alone, relatives are generally the first resources offering assistance to caregivers (Abendroth, 2010). Research has shown that help from relatives generally reduced the degree of burden among caregivers (Given et al., 1990; Vrabec, 1997). Clinicians should educate caregivers about when and how to ask for and receive help and assistance from their relatives when it is needed (Abendroth, 2010), and this may enhance their feelings of being prepared for caregiving.

Predictability.

PD caregiving is an ongoing process in which the severity and unpredictability of PD symptoms increases in the natural course of the disease (Abendroth, 2010; Carter et al., 1998; Habermann, 1999) even when medications are administered appropriately (Abendroth, 2010; Bogard, 2010). Consistent with prior studies, this study found that predictability in PD caregiving had decreased over the 10 year period of caregiving. At the early stages of PD the care situation was perceived as being much more predictable than it was after ten years of caregiving. When controlling for other transition factors, this study found experiencing less predictability, a hallmark of PD, to be significantly associated with reporting lower levels of preparedness only at the Time 3 wave, where predictability appeared to have the greatest effect on caregiver preparedness.

At this point in time (Time 3), further into the disease, it is more likely that there are greater “On/Off” fluctuations in PD symptoms and more “freezing” episodes Furthermore, anti-Parkinsonism medications can cause a number of complications including involuntary twitching or jerking movements and a drop in blood pressure when standing which results in more fluctuations in mobility that are poorly controlled. These types of symptoms are difficult to predict and control and both the patients with PD and their spouse caregivers, as a couple living with chronic illness, have to deal with unpredictability not only on a moment to moment basis, but over a long period of time (Habermann, 1996; Pretzer-Aboff et al., 2009).

Unpredictability in the care situation is a unique characteristic of PD. This study is one of a few studies to examine predictability in PD caregiving from the early to middle stages, and it found that predictability had a lot to do with the caregiver’s level of preparedness later on in the caregiving trajectory when more care and assistance are required. Clinicians should use the level of predictability as a hint, and intervene in cases of experiencing less predictability in the care situation as they were likely to also feel less prepared for caregiving. In this care situation, it seems like there is not much that can be done to increase the ability to predict or control the PD symptoms and day to day living conditions, especially when patients are in the late stages of PD. On the other hand, the previous work of Archbold et al. (1995) demonstrated that the PREP system of nursing intervention targeting abilities to increase preparedness, enrichment, and predictability using different strategies among caregivers of older adults may be helpful for PD couples (Archbold et al., 1995). Importantly, such an intervention and any practical information regarding the ability to handle a less predictable PD care situation should be provided well in advance to PD couples so they could live with the disease and work through it as a team.

Comparison of Time 1 and Time 3 predictors.

The comparison between factors predicting caregiver preparedness at these two discrete points in the caregiving trajectory in this study was limited due to the differences in the two samples. At baseline, the spouses in the Time 3 sample were younger, healthier, provided fewer direct care tasks, and their patients with PD were less depressed compared to the spouses who did not participate at Time 3, suggesting that the two samples were somewhat different. Additionally, as this is among the few studies examining factors predicting preparedness, comparison of the findings to previous studies was also limited. However, the findings can be added to the pool of known factors predicting preparedness wherein higher levels of caregiver preparedness were also found in caregivers who were in good physical health, married, and lived together with their care receivers (Leutz et al., 2002).

There were several noteworthy differences between the two predictive models in this study when the context of care situation was taken into account. First, differences in the point in the caregiving trajectory and the amount of care needed resulted in differences in the factors predicting preparedness, a process index of a healthy caregiving transition. Early on in the caregiving trajectory and at times when minimal care and assistance were needed, factors predicting preparedness were much more about the spouse caregivers' well-being and relationship quality with the patients, not the care. On the other hand, later in the caregiving trajectory at Time 3, when more care and assistance were needed, it was care-related factors that were significantly associated with preparedness including unpredictability in the care situation, the number of care tasks, and help received from relatives.

Second, mutuality made the largest contribution to preparedness at baseline while it was predictability at Time 3. This suggested that interpersonal transition conditions were a vital factor impacting caregivers' level of preparedness early on in the caregiving trajectory when less care is needed. Attention should be paid to spouse-patient relationship quality when spouses first enter into the caregiving role. Ten years further along the disease's course, higher levels of unpredictability in the care situation were more predictive of preparedness. This is understandable since less predictability would mean that the care situation would be more difficult to control, making it harder to make a plan and follow through with it, resulting in the caregivers experiencing lower levels of preparedness. Third, it is important to note that at Time 3, depressive symptoms was significantly associated with preparedness until mutuality and predictability were entered, and it fell out when controlling for help received from relatives. That is, depressive symptoms or mutuality alone still have some effect on preparedness, but it is not statistically significant when less predictability in the care situation is experienced by caregivers.

Finally, the variance in preparedness left unexplained by the set of predictors at baseline and Time 3 were different with the unexplained variance at Time 1 preparedness

(84%) being larger than that at Time 3 (61%). That could be influenced by several different factors, including the conceptual framework, the sample characteristics, and life events that may have occurred simultaneously during a caregiving transition. In this study, the framework did not take into account some spouse characteristics that might have an effect on preparedness, such as spouse co-morbidity, personality, duration of caregiving, previous caregiving experience, and the level of caregiver strain, anxiety, or frustration related to the care situation (McLaughlin et al., 2011; Rusinak & Murphy, 1995). Other life-event transitions, such as working outside the home and changes in financial status, which may have occurred simultaneously with caregiving and may also complicate caregiving transitions and affect level of preparedness, were also not included in the model (Schumacher & Meleis, 1994). On the other hand, including more data from patient beyond clinical symptoms, for example, mutuality, feeling of preparedness or worry about illness and future, might help explain caregiver preparedness.

More importantly, in this study factors that may affect preparedness were only examined at the individual level while, in fact, the nature of the caregiving transition process was comprised of the caregivers and the patients who should be viewed as care dyads, especially when spousal caregiving is the focus of the study. As a care dyad, anything that happens to or between the members of the caregiving dyad is important and may have a care partner cross-effect on how caregivers perceive their level of preparedness. At Time 3 the unavailable data on patient characteristics, including the stage of disease, patient depression, and ADL impairment, could possibly be another origin of issues affecting the amount of unexplained variance in preparedness at Time 3.

Implications

Implications for Theory

The data used in this study were well-fitted to the theoretical framework for studying preparedness as a process indicator of the caregiving transition process in PD caregiving. The comprehensive components of transitions theory enable the study to include caregiving transition conditions from different levels and multiple aspects in its conceptual framework. For example, not only could intrapersonal conditions be incorporated into the conceptual framework, but interpersonal conditions that resonated closely with the nature of the caregiving process could also be included (Lyons et al., 2002). The findings of this study provided further evidence of the impact of intrapersonal conditions, including spouse depressive symptoms, the number of direct care tasks provided, and interpersonal conditions, mutuality in this case, an environmental condition (help received from relatives viewed as an informal support network) and the nature of PD caregiving (predictability, a unique characteristics of PD) on preparedness, a process indicator of a healthy transition in spouse caregivers of patients with PD. The findings supported Meleis's transitions theory as a useful tool for research and were consistent with previous studies (Weiss & Lokken, 2009; Weiss et al., 2007; Wilkins & Woodgate, 2006).

Additionally, transitions theory appeared to be a comprehensive framework that would enable examination of the role of transition conditions and the nature of caregiving transition in relation to either process indicators or outcome indicators of a healthy transition, or both (Im, 2011; Weiss et al., 2007; Young, Sikma, Johnson Trippett, Shannon, & Blachly, 2006), where other caregiving frameworks may not be as well suited to achieve the goals of the study. Moreover, transitions theory can guide either cross-sectional or longitudinal studies in design, although it seemed to better fit longitudinal studies as it proposes a sense of passing from one state to another, for instance, from being a spouse to being a spouse caregiver.

Directions for Future Research

Parkinson’s disease has been a focus in many areas of research and the results of this longitudinal study can provide an in-depth look into phenomena such as caregiver preparedness and the long-term effects on caregiving outcomes. There are numerous areas of research that can be pursued based on the findings of this study. First, potential outcome indicators of a healthy caregiving transition, such as caregiver role strain and the decision to remain in or discontinue their caregiver role as a result of experiencing a healthy or unhealthy caregiving transition, were not a focus of this study. One of the main recommendations for research beyond this study would be to examine the role of caregiver preparedness as a process indicator for predicting the outcome indicators of an unhealthy transition (for instance caregiver role strain) longitudinally as a means to better understand the whole process of caregiving transition. This could also extend to the current knowledge regarding the protective effect of preparedness on negative caregiving outcomes and the role of preparedness in identifying caregivers who may be vulnerable to an unhealthy caregiving transition.

As a global construct caregiver preparedness does not seem likely to change over time and it did not vary across the stages of PD, (Carter et al., 1998), different age-groups of caregivers, or care situations (Giarelli et al., 2003). Potential direction for future research includes examining competence in performing caregiving–specific tasks with a newly developed tool to measure preparedness at specific levels over a shorter time in relation to the critical turning points in the PD caregiving trajectory. This new study would have a sample that is more representative to the general population of PD patients by including patients with depression and cognitive impairment in the study. Doing so would help increase the heterogeneity and representativeness of the sample and increase the ability to capture change in task-specific caregiving preparedness.

Future research using different tools to capture the feeling of being prepared for caregiving on both global and specific levels is also recommended as there was some discrepancy regarding how caregivers perceived their preparedness at different levels. As a global construct, caregiver preparedness seemed to be stable but it seemed to change when viewed from the caregiving task level. At the global level tools that examine confidence in dealing with caregiving, such as the caregiving competence and preparedness for caregiving scales, which have been successfully used in studies of caregivers of persons with dementia, may be used (Ducharme et al., 2011). At task-specific levels, instruments like the revised scale for caregiving self-efficacy, for example, would be recommended. Moreover, the point in time within the caregiving trajectory should also be considered as it would allow us to take into account caregivers' specific needs in context. If these factors related to caregiving role transition and global and caregiving task-specific caregiver preparedness could be better captured and understood, then more sensitive interventions could be better tailored to address the caregivers' needs.

In addition, the current study has included data only from spouse caregivers at an individual level. Future studies should include transition conditions from caregivers and patients at both individual and dyadic levels. The caregiver and patient should be viewed as a care dyad and be measured as a single dyadic unit. Examining caregiving transition process as a dyadic process would provide a more accurate picture of the complexity of caregiving (Lyons et al., 2002).

Next, from the point of view of dyadic family studies, caregiving is seen as a dyadic process where the care dyads are likely to be “care partners” in caregiving rather than solely passive care receivers or active caregivers (Lyons et al., 2002). The patient and family member can take on a collaborative care partnership in order to engage in self-caring and caregiving, especially in persons who are primarily physical impaired such as spinal cord injury or early to middle stage of PD. Examining incongruence in perceptions regarding caregiver preparedness for caregiving-specific tasks from the dyadic perspective could yield valuable new knowledge. Such studies would identify, for example, patient (PT)-family member (FM) incongruence (how much the patient and family member differ) regarding caregiver preparedness in performing caregiving-specific tasks (as reported by both PT and FM), and identify individual and dyadic-level variables associated with this incongruence. In this case, dyadic-level predictors may be mutuality (as reported by PT and FM). Findings from a study like this would help to understand patterns of patient-family incongruence over time, variables that predict incongruence and the effect of incongruence on their health and well-being. It would potentially provide a way to help facilitate healthy caregiving transitions among care dyads.

Lastly, caregivers who have a more positive outlook about their caregiving are more likely to report fewer negative caregiving outcomes (Hooker et al., 1998; Lyons et al., 2009; Lyons, Stewart et al., 2004). The caregiver's personality could play an important role when a person does not make a healthy transition and the overlap between optimism and preparedness suggests that personality could be a component of caregiver preparedness. Further investigation to tease these relationships out more thoroughly is needed. The results from these studies could help set up future research to better understand caregiver preparedness as a means of helping to facilitate a healthy caregiving transition among couples living with chronic illness such as PD.

Implications for Clinical Practice

This study found that although levels of preparedness at baseline varied from person to person, it remained stable over time within the individual. That is, some spouse caregivers reported lower levels of preparedness while others reported higher levels of preparedness at baseline. However, their levels of preparedness did not change over the course of their individual caregiving experience, or at least up to the middle stages of PD. Therefore, clinicians should assess preparedness at the individual level to identify less-prepared caregivers and introduce appropriate interventions on an individual basis. Identifying spouses who experience more depressive symptoms and less mutuality with their patients with PD early on in their caregiving trajectory, or when there is no to minimal care and assistance needed, may be helpful as they are likely to be less prepared for their caregiving role. In the case of low mutuality early on in the caregiving trajectory, couple-based interventions targeting both spouses and patients as a couple would be recommended. The caregiver's well-being and the relationship quality are significantly associated with preparedness at this point of caregiving with the relationship quality being the most important factor. Moreover, caregivers who felt unprepared may have been those who were depressed or vice versa. The current study was unable to determine causality.

Previous research has demonstrated an important association between a high level of preparedness and lower levels of role strain and negative well-being (Schumacher et al., 2007; Schumacher et al., 2008), which were considered indicators of experiencing an unhealthy caregiving transition, in caregivers. A lack of preparedness can be viewed as a precursor of negative outcomes of caregiving on caregivers (Archbold et al., 1990). Knowing the spouses' baseline preparedness scores could help clinicians and researchers anticipate the level of preparedness caregivers would have further along in the caregiving trajectory and understand how critical the caregiver's level of preparedness for caregiving is to a healthy transition. A healthy transition into, and remaining in, a spouse caregiver role can help preserve caregivers' health and well-being (Meleis et al., 2000). A decline in health status from providing care to a family member is linked to discontinuing the caregiver role (Ducharme et al., 2011; Schumacher et al., 1998).

It was noted that the factors predicting preparedness are more likely to change in response to changes in the context of the care situation; however, the ability to evaluate causality was limited. For example, as the disease progressed spouses who provided less direct care were likely to report lower levels of preparedness. Nevertheless, it was not clear whether the spouses provided less direct care due to not being well-prepared for caregiving or vice versa. When appropriate and sensitive interventions are considered, a comprehensive assessment should also be made. Moreover, facilitating access to available resources and support networks, including creating a circle of informal support resources and encouraging spouse caregivers to ask for and accept help from relatives to ease the responsibility of their caregiving tasks, would be possible (Abendroth, 2010; Bogard, 2010). Psycho-educational interventions focusing on increasing problem-solving skills along with accessing and developing resources have been effective in increasing levels of preparedness in caregivers of frail older adults (Leutz et al., 2002) and persons with dementia (Ducharme et al., 2011). The same type of interventions may be beneficial for PD spouse caregivers; however, appropriate and sensitive interventions should be tailored to the needs of the individual caregivers (Abendroth, 2010; Bogard, 2010).

Strengths and Limitations

Strengths

Several strengths of the present study are worth noting. First, this study was the first to examine long-term changes in caregiver preparedness. This study was in contrast to previous studies that have determined caregiver preparedness over shorter periods of time with smaller sample sizes and using traditional statistical approaches (Giarelli et al., 2003; Scherbring, 2002). The current study addressed these limitations by examining the phenomenon over a period of 10 years using the longitudinal PSP study data set focused on spousal caregivers. Specifically, findings from this study can inform the development of interventions that are spouse-based or couple-based (i.e., aimed at facilitating a healthy caregiving transition as a couple), and targeted at unprepared spouse caregivers who are likely to experience negative caregiving outcomes. Secondly, the study focused on spouse caregivers of persons who primarily had physical functional impairment. The majority of previous research has been focused on persons with cognitive impairment, for instance dementia, rather than those impacted by functional impairments such as persons with PD. This study has added valuable information to the existing knowledge about preparedness related to situations involving physical impairment.

Third, the PSP data set also offered a unique opportunity to study caregiver preparedness from the perspective of spouse caregivers of persons with PD from the early stages of the disease. Most prior PD studies have looked at PD caregiving from the middle to late stages of the disease. Given that the late stages of PD have been described as a floundering period for caregivers (McLaughlin et al., 2011), examining spouses who were in an early stage of the disease over a 10-year period helps to better understand that caregiver preparedness did not change over the course of caregiving, at least from the early stage to middle stages of PD. As recommended, the results of this study helped to broaden and create a more accurate picture of preparedness for caregiving (Lyons, Stewart et al., 2004). Furthermore, having patient clinical symptoms included in the study also provided us new information showing that, as expected, a patient’s depression and ADL impairments were not correlated to caregiver preparedness. However, this information should be used with caution given the fact that patient depression and ADL impairment data were available only at Time 1, when the majority of patients with PD were not depressed and not physically impaired, and was measured with a single-item assessment. Moreover, having caregiving data obtained over a 10-year period from multiple trial sites across North America, the study exceeded previous studies with regard to caregiver preparedness over time. There have been no other studies examining caregiver preparedness over such an extensive period of time and across such a large area of the continent.

Lastly, the present study employed an advanced statistical approach, multilevel modeling (MLM) to examine change over time. Employing MLM to describe caregiver preparedness over time offered a significant improvement over the previous research on preparedness. This methodology maximized the accuracy of the finding of stability in preparedness over time with its ability to control for autocorrelations of repeated data nested within individuals and to examine individual differences (Lyons, Stewart et al., 2004). Moreover, HLM can handle longitudinal data which includes missing data, unequal spacing of data collection points, and unequal numbers of samples and waves of data as were seen in the current study (Raudenbush & Bryk, 2002).

Limitations

This study also had several limitations which need to be addressed. The first was that the role of transition conditions and the nature of PD caregiving in predicting preparedness was examined cross-sectionally, thus causality or directionality of preparedness and associated factors is limited. In other words, it could not be determined which occurred first and gave rise to the other. For example, with the significant associations between preparedness and depressive symptoms, it could either be that it was preparedness that predicted depressive symptoms, or vice versa. However, preparedness was found to remain stable over time while depressive symptoms increased. Further study guided by this study's theoretical framework should examine the role of preparedness in predicting depressive symptoms.

Next, this study used several single-item measures to assess a number of constructs of interest. While a single-item tool can be an effective screening tool for clinicians, its reliability and measurement error in terms of research is a concern. A single-item tool has less ability to tease out information on constructs as complex in nature as patient depression and ADL impairment. Further, reliability is higher with multiple-item tools. Thus, using multiple-item tools to measure these constructs would be highly recommended in order to understand the various dimensions of depression and ADL impairment that are important to PD caregiving as well as to have more accurately reflective measures. Furthermore, as previously mentioned, this study focused on spouse caregivers of persons with PD. Hence, the generalizability of its findings to other types of caregivers, such as adult child or sibling caregivers is also limited. Other types of caregivers may respond to caregiving differently than spouse caregivers.

Next, the number of data waves limited the type of models tested. The existing data set for the study had only three waves of data, thereby limiting the analysis to a linear model. If the data set had more than three waves of data then a nonlinear model, such as a quadratic model, could have been included in the analysis. Moreover, the data set also had uneven spacing between the waves of data collection: baseline, Year 2, and Year 10. With such a large gap between year 2 and 10, any change in preparedness over time that might occur would be assumed to be linear. However, the current study found that preparedness was stable and there was no variability around the average trajectory, which is consistent with previous work in cancer caregiving (Giarelli et al., 2003; Scherbring, 2002). Therefore, since no change in preparedness was found across time, stage of PD, age-groups, and care situations in any of these studies, it is probable that if this study had more than three waves of data with equal intervals of data collection, the findings of this study would be the same, Finally, the sample of patients with PD in this study was not representative of the general population of PD patients due to the exclusion criteria of the DATATOP study which screened out patients who were depressed or cognitively impaired when it is a known fact that both motor and non-motor symptoms are common in PD. Non-motor symptoms can have greater impact on caregiver's depression than motor symptoms (Carter, Stewart, Lyons et al., 2008). Additionally, the sample of spouse caregivers also did not reflect the racial composition of society at large. Spouses were predominantly Caucasian (96% of the baseline sample). Thus, the study findings may not hold true for minority caregivers.

Summary

This study focused on caregiver preparedness as a process indicator of a healthy caregiving transition in spousal caregivers of patients in early stages of PD, guided by transitions theory. This study found that the levels of preparedness varied among spouse caregivers at baseline but remained stable over a ten year period, even when the context of care had changed, and that the factors predicting caregiver preparedness at baseline and Time 3 were different. Early in the trajectory, preparedness has more to do with caregivers' well-being and the relationship quality with the patient compared to later on when care-related factors were significantly associated with caregivers' level of preparedness, controlling for other caregiving transition conditions. Most studies have examined PD caregiving from middle to late stage, with only a few looking at it from the early to middle stages. This study offered a unique opportunity to fill that gap by describing factors that predict caregiver preparedness at two different points in the caregiving trajectory (early stage and middle stage). The findings of this study also set the stage for the development of sensitive interventions to help ensure healthy transitions for PD spouse caregivers at different points in the caregiving trajectory.

Although this study primarily focused on spouses at an individual level and brought to light valuable information related to caregiver preparedness, this study has also opened our eyes to areas which require further inquiry, including the effect of preparedness from the patient's perspective and at the dyadic level. Examining the relationships that transition conditions have with preparedness and predicting potential negative outcomes from the dyadic perspectives is one clear path for future inquiry. Describing preparedness in relation to the caregiver–care receiver as a dyadic unit would provide an opportunity to better understand the complex relationships and interactions of both dyad members and the caregiving situation. That also could help pave the way for the development of couple-based interventions that incorporate the needs of both spouses and patients in the caregiving situation, as a means to facilitate a couple's healthy transition in relation to their chronic illness such as PD. Such interventions would help care dyads establish and maintain their care partnerships in a manner that will enable them to live with the disease and work successfully as a team throughout the long-term care trajectory.

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Appendices

Appendix A Unstandardized Coefficient and Variance Estimates for the Intercept and Linear Slope Model of Caregiver Preparedness in a Sample of Spouses Having All Three Waves of Preparedness (*N*= 85)

Appendix B The 20 Most Common Caregiving Tasks Provided at Time 1 and Time 3

Appendix C Zero-order Correlations between Time 3 Predictor Variables (*N*=88)

Appendix D Zero-order Correlations between Time 3 Preparedness and Predictor Variables (*N*=88)

Appendix E Summary of Hierarchical Multiple Regression Analysis for Time 3 Variables Predicting Time 3 Preparedness Without Mutuality (*N*=88)

Appendix F Summary of Hierarchical Multiple Regression Analysis for Time 3 Variables Predicting Time 3 Preparedness Without Depressive Symptoms (*N*=88)

Appendix G Consent Form

Appendix H Instruments

Appendix A

Unstandardized Coefficient and Variance Estimates for the Intercept and Linear Slope Model of Caregiver Preparedness in a Sample of Spouses Having All Three Waves of Preparedness (N= 85)

Parameters	Unstandardized Coefficient	*t*-ratio
Fixed effect		
Intercept	2.36	24.47***
Linear Rate of Change	-0.003	-0.43
Random effect	Variance	χ^2
Intercept	0.67	525.73***
Linear Rate of Change	0.000	83.60

***$p < .001$.

Appendix B

The 20 Most Common Caregiving Tasks Provided at Time 1 and Time 3

	Time 1 (N= 251)		Time 3 (N=95)	
Order	Caregiving tasks	%	Caregiving tasks	%
1	Sit and spend time with	81	Sit and spend time with	96
2	Cook or prepare meals	80	Take to other places	93
3	Make financial decision	79	Cook or prepare meals	92
4	Do light housekeeping	76	Check in CR is OK	85
5	Hold hands or rub back	71	Make financial decision	85
6	Change bed linens	61	Take to medical appointment	85
7	Fix or maintain house	61	Do light housekeeping	84
8	Take to other places	54	Help with legal matters	81
9	Completing necessary forms	51	Keep MD informed	80
10	Check in CR is OK	50	Completing necessary forms	75
11	Help with legal matters	49	Fix or maintain house	74
12	Make major health decisions	46	Hold hands or rub back	72
13	Banking or financial matters	45	Change bed linens	70
14	Take to medical appointment	44	Make major health decisions	67
15	Assist with shopping or errands	43	Help with problems with fatigue	67
16	Emotion ups and downs	42	Help with slowness moving	67
17	Keep MD informed	29	Dressing or undressing	59
18	Dressing or undressing	28	Help with emotion ups and downs	56
19	Slowness in moving	24	Assist with shopping or errands	55
20	Listen, answer repetitive ques	20	Protect from falls	53

Appendix C

Zero-order Correlations between Time 3 Predictor Variables (N=88)

Study Variables	1	2	3	4	5	6	7	8
1. Age	--							
2. Gender	.21*	--						
3. SP Physical function	-.29**	.09	--					
4. SP Depressive symptoms	-.33**	-.24*	-.16	--				
5. Number of direct care activities	-.03	-.12	-.21*	-.24*	--			
6. Mutuality	.21	.25*	.19	-.66***	-.13	--		
7. Paid help	-.14	.02	-.21	.38***	.21	-.34**	--	
8. Help received from relatives	-.02	-.12	.08	.15	.30	-.16	.24*	--
9. Predictability	.37***	.22*	.02	-.50***	-.28**	.46***	-.13	-.19

Note: SP = Spouse. PT = Patient. *p < .05. **p < .01. ***p < .001.

Appendix D

Zero-order Correlations between Time 3 Preparedness and Predictor Variables (N=88)

Study Variables	1	2	3	4	5	6	7	8	9
1. Time 3 Preparedness	--								
2. Age	.13	--							
3. Gender	-.02	$.21^{*}$	--						
4. SP Physical function	.12	$-.29^{**}$	.09	--					
5. SP Depressive symptoms	$-.31^{**}$	$-.33^{**}$	$-.24^{*}$	-.16	--				
6. Number of direct care activities	.06	-.03	-.12	$-.21^{*}$	$-.24^{*}$	--			
7. Mutuality	$.30^{**}$	.21	$.25^{*}$	.19	$-.66^{**}$	-.13	--		
8. Paid help	-.01	-.14	.02	-.21	$.38^{**}$	$.21^{a}$	$-.34^{**}$	--	
9. Help received from relatives	$.28^{**}$	-.02	-.12	.08	.15	.30	-.16	$.24^{*}$	--
10. Predictability	$.40^{**}$	$.37^{**}$	$.22^{*}$	.02	$-.50^{**}$	$-.28^{**}$	$.46^{**}$	-.13	-.19

Note: SP = Spouse. PT = Patient. $^{*}p < .05$. $^{**}p < .01$. $^{***}p < .001$.

Appendix E

Summary of Hierarchical Multiple Regression Analysis for Time 3 Variables Predicting Time 3 Preparedness Without Mutuality (N=88)

Step	1	2	3
Block and Variables	B	B	B
Block 1: SP characteristics			
Age	0.01	0.01	-0.01
Gender	-0.23	-0.18	-0.21
Physical function	0.01	0.01	0.01
Number of direct care activities	0.02	0.02	0.03*
Depressive symptoms	-0.04*	-0.04*	-0.02
Block 2: Environmental condition			
Paid help		0.06	0.01
Help from relatives		0.23**	0.28***
Block 3: Nature of PD caregiving			
Predictability			0.74***
R^2	.14	.24	.39
R^2	.14	.10	.14
F Change	2.68*	5.26**	18.52***

Note: SP = Spouse. PT = Patient. *$p < .05$. **$p < .01$. ***$p < .001$.

Appendix F

Summary of Hierarchical Multiple Regression Analysis for Time 3 Variables Predicting Time 3 Preparedness Without Depressive Symptoms (N=88)

Step	1	2	3	4
Block and Variables	B	B	B	B
Block 1: SP characteristics				
Age	0.02	0.02	0.01	-0.00
Gender	-0.14	-0.25	-0.21	-0.22
Physical function	0.01	0.01	0.01	0.01
Number of direct care activities	0.01	0.01	0.01	0.02*
Block 2: Interpersonal condition				
Mutuality		0.30**	0.38**	0.19
Block 3: Environmental condition				
Paid help			0.05	0.01
Help from relatives			0.23**	0.28***
Block 4: Nature of PD caregiving				
Predictability				0.75***
R^2	.06	.13	.23	.38
R^2	.06	.07	.10	.15
F Change	1.32	6.88**	5.10**	18.65***

Note: SP = Spouse. PT = Patient. *p < .05. **p < .01. ***p < .001.

Appendix G Consent Form

IRB# _______________
Approved: (current approval date)

OREGON HEALTH & SCIENCE UNIVERSITY
Consent Form

TITLE: Spousal Caregiving to Patients with Parkinson's Disease: A Follow-up Study

PRINCIPAL INVESTIGATOR:	Karen Lyons, Ph.D.	(503) 494-3975
CO-INVESTIGATOR(S):	Julie Carter, MS, ANP	(503) 494-7235
	Barbara Stewart, Ph.D.	(503) 494-3835
	Patricia Archbold, RN, DNSc, FAAN	(503) 494-3840

SPONSOR: Medical Research Foundation, OHSU

PURPOSE:
You have been invited to participate in this research study because you participated in our original study of spousal caregiving to an individual with Parkinson's disease. As we mentioned on the phone, the purpose of this study is to look at changes in your health and also changes in your experiences in caring for your spouse over the past 8 to 10 years. This will be done using the Family Care Inventory (FCI), which is a standardized questionnaire developed by researchers.

PROCEDURES:
If you decide to participate in this study, please complete the written questionnaire enclosed with this consent form as best you can. You will be asked about your health, caring for your spouse, and how things have been going for you lately.

RISKS AND DISCOMFORTS:
The questionnaire will require about 90 minutes for you to complete. Some of these questions may seem personal and deal with private or sensitive issues. The questionnaire may cause you to become emotionally upset. During the follow-up interviews, if we find that you have a high depression score, we will suggest you make an appointment with your primary health care provider or contact a local support group to talk about your depression.

BENEFITS:
You may or may not personally benefit from participating in this study. However, by serving as a participant, you may contribute new information, which may benefit other caregivers and PD patients in the future. For example, some respondents report feeling good that they may be helping other people in the future by participating in this research. In addition, some respondents report that reviewing their own situation is helpful.

To thank you for sharing your experiences and opinions with us, we have enclosed $15 in your questionnaire envelope for you to keep.

ALTERNATIVES:
You may choose not to participate in this study. You may also refuse to answer individual questions, or may discontinue answering the questionnaire at any time and return the uncompleted questionnaire in the envelope provided.

CONFIDENTIALITY:
Your part in this study is confidential. Neither your name nor your identity will be used for publication or publicity purposes. The findings of the study may be used for medical publication. For Oregon Residents only, under Oregon Law, suspected child or elder abuse must be reported to appropriate authorities.

COSTS:
There is no cost to you for participating in the study.

LIABILITY:
The Oregon Health & Science University is subject to the Oregon Tort Claims Act (ORS 30.260 through 30.300). If you suffer any injury and damage from this research project through the fault of the University, its officers or employees, you have the right to bring legal action against the University to recover the damage done to you subject to the limitations and conditions of the Oregon Tort Claims Act. You have not waived your legal rights by signing this form. For clarification on this subject, or if you have further questions, please call the OHSU Research Support Office at 503-494-7887.

PARTICIPATION:
The decision whether or not to take part in this study is up to you. You do not have to participate. If you decide to take part in the study, you may quit at any time. Karen Lyons, Ph.D. (503) 494-3975 has offered to answer any questions you may have about this study. If you have any questions regarding your rights as a research participant, you may contact the Oregon Health & Science University Institutional Review Board at (503) 494-7887. You may refuse to participate, or you may withdraw from this study at any time without affecting your relationship with or treatment at the Oregon Health & Science University.

Your signature below indicates that you have read the foregoing and agree to participate in this study. Please sign both copies of the consent form and return one to us with your completed questionnaire in the envelope provided. The other one you may keep for your own records.

Participant ______________________ Date ____________

Principal Investigator ______________________ Date ____________

Appendix H Instruments

Demographic data sheet

Tell Us about You

Fill in the blank or circle the answer that describes you.

1. In what year were you born? 19____
2. Are you female or male?

   Female………………..1

   Male ………………….2
3. What is your race?

   African American……………..…..1

   Asian/Pacific Islander………..…..2

   Hispanic…………………………..3

   Native American Indian……….....4

   White……………………………..5

   Other…………………………..…..6
4. What is the highest grade in school that you completed?

   Completed 8th grade or less…………..…..1

   Attended high school……………….......2

   Completed high school…………………..3

   Post high school vocational training……..4

   Attended college…………………………5

   Completed college………………………..6

Tell us about your spouse

“Spouse” refers to your husband, wife or significant other with Parkinson’s disease. Pease tell us about your spouse who has Parkinson’s disease. (Fill in the blank or circle the answer that describes your spouse.)

1. In what year your spouse was born? 19____
2. Is your spouse female or male?

   Female……1

   Male………2
3. What is your relationship to the person with Parkinson’s disease?

   You are his or her:

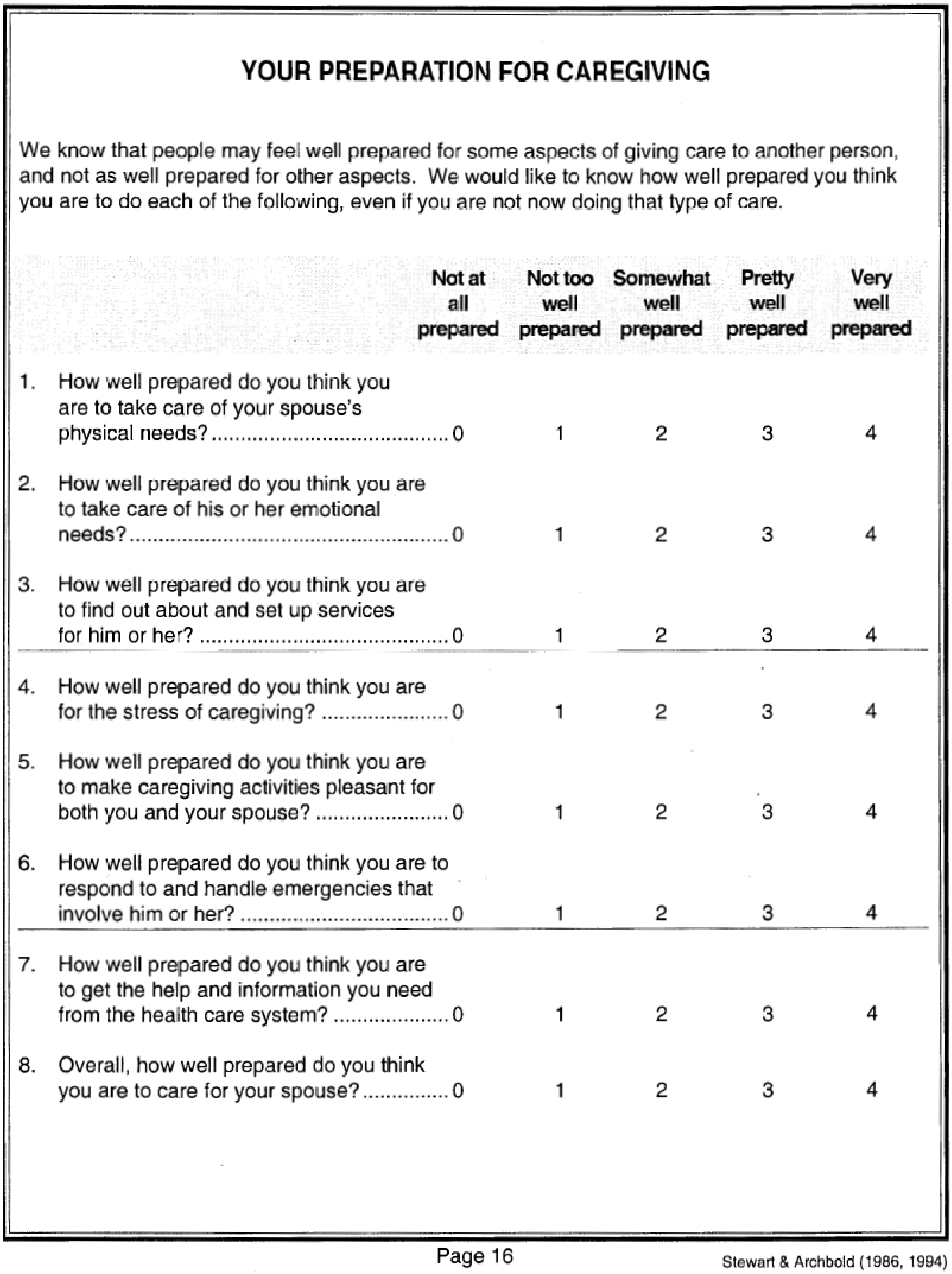
   Husband…….………..…1

   Wife………………………..2

   Other (explain_______)……3
4. …….
5. ……..
6. ……..
7. Approximately how many years have you and your spouse known each other?

   _____ years
8. How many years have you been living with him or her? ____years
9. In about what year did your spouse receive the diagnosis of Parkinson’s disease? In 19___

The preparedness for caregiving scale



YOUR PREPARATION FOR CAREGIVING

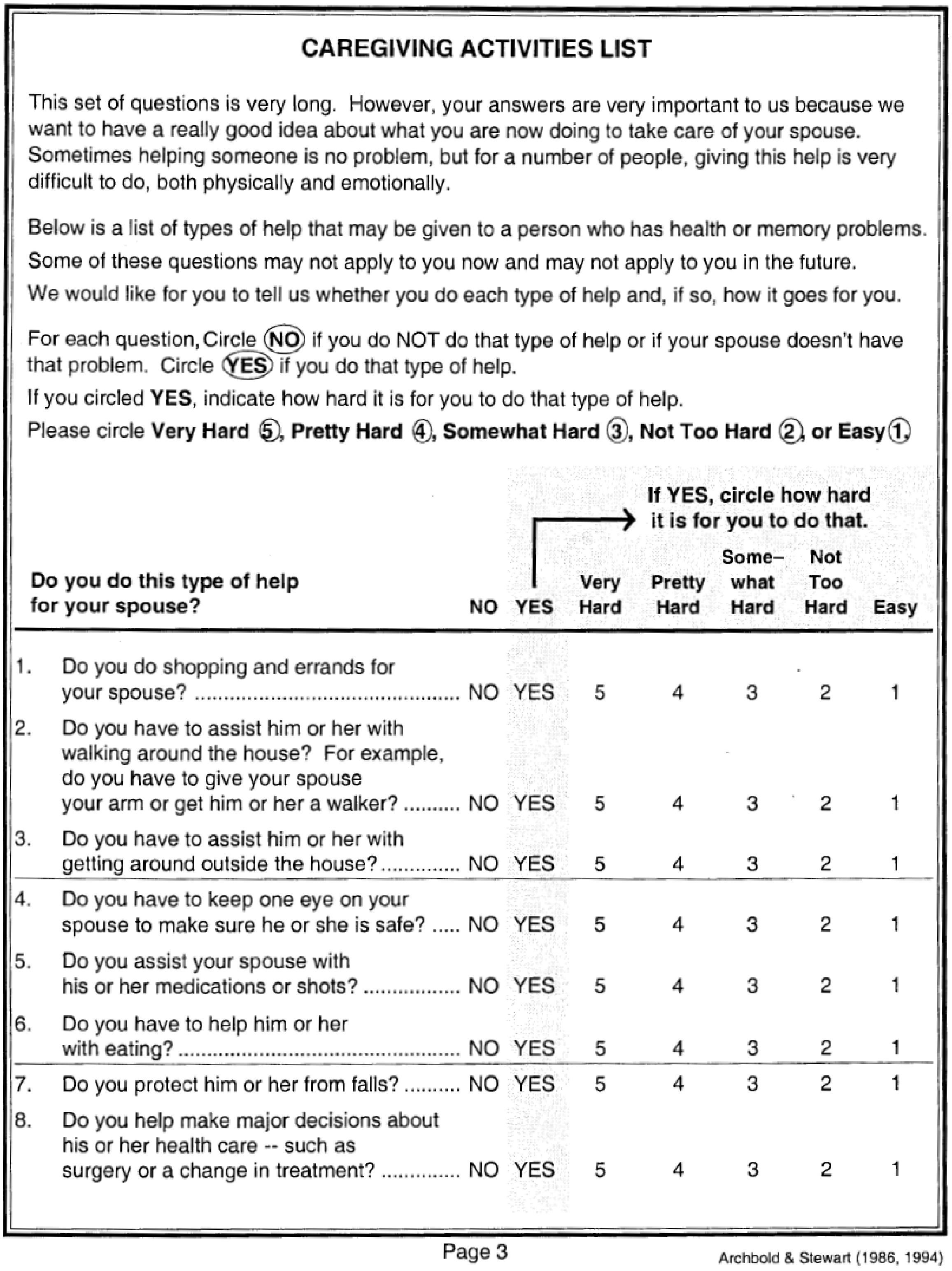
We know that people may feel well prepared for some aspects of giving care to another person, and not as well prepared for other aspects. We would like to know how well prepared you think you are to do each of the following, even if you are not now doing that type of care.

	Not at all prepared	Not too well prepared	Somewhat well prepared	Pretty well prepared	Very well prepared
1. How well prepared do you think you are to take care of your spouse's physical needs?	0	1	2	3	4
2. How well prepared do you think you are to take care of his or her emotional needs?	0	1	2	3	4
3. How well prepared do you think you are to find out about and set up services for him or her?	0	1	2	3	4
4. How well prepared do you think you are for the stress of caregiving?	0	1	2	3	4
5. How well prepared do you think you are to make caregiving activities pleasant for both you and your spouse?	0	1	2	3	4
6. How well prepared do you think you are to respond to and handle emergencies that involve him or her?	0	1	2	3	4
7. How well prepared do you think you are to get the help and information you need from the health care system?	0	1	2	3	4
8. Overall, how well prepared do you think you are to care for your spouse?	0	1	2	3	4

Page 16

Stewart & Archbold (1986, 1994)

The amount of direct care scale



CAREGIVING ACTIVITIES LIST

This set of questions is very long. However, your answers are very important to us because we want to have a really good idea about what you are now doing to take care of your spouse. Sometimes helping someone is no problem, but for a number of people, giving this help is very difficult to do, both physically and emotionally.

Below is a list of types of help that may be given to a person who has health or memory problems.

Some of these questions may not apply to you now and may not apply to you in the future.

We would like for you to tell us whether you do each type of help and, if so, how it goes for you.

For each question, Circle NO if you do NOT do that type of help or if your spouse doesn't have that problem. Circle YES if you do that type of help.

If you circled **YES**, indicate how hard it is for you to do that type of help.

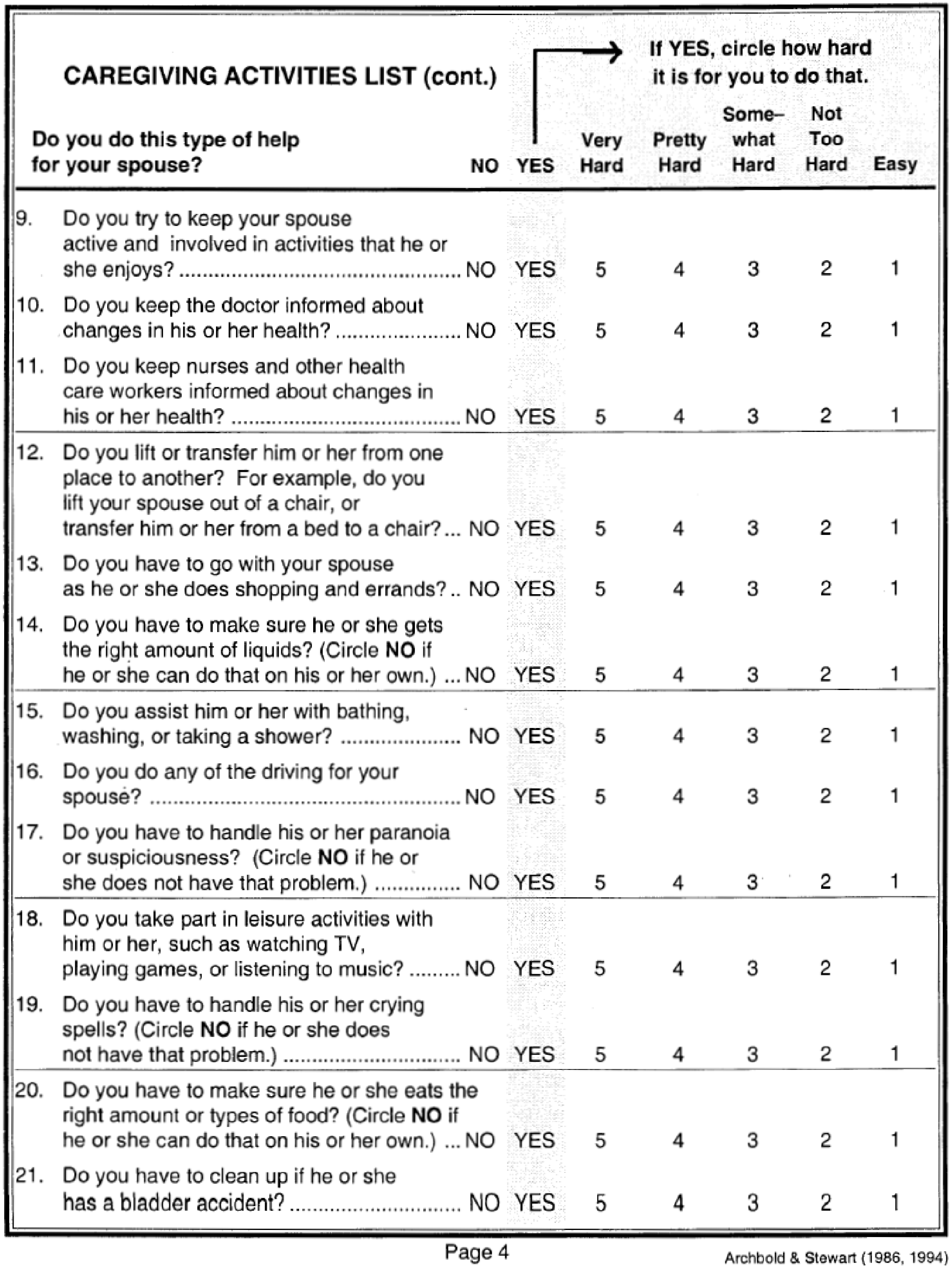
Please circle **Very Hard** ⑤, **Pretty Hard** ④, **Somewhat Hard** ③, **Not Too Hard** ②, **or Easy** ①

If YES, circle how hard it is for you to do that.

	Do you do this type of help for your spouse?	**NO**	**YES**	**Very Hard**	**Pretty Hard**	**Somewhat Hard**	**Not Too Hard**	**Easy**
1.	Do you do shopping and errands for your spouse?	NO	YES	5	4	3	2	1
2.	Do you have to assist him or her with walking around the house? For example, do you have to give your spouse your arm or get him or her a walker?	NO	YES	5	4	3	2	1
3.	Do you have to assist him or her with getting around outside the house?	NO	YES	5	4	3	2	1
4.	Do you have to keep one eye on your spouse to make sure he or she is safe?	NO	YES	5	4	3	2	1
5.	Do you assist your spouse with his or her medications or shots?	NO	YES	5	4	3	2	1
6.	Do you have to help him or her with eating?	NO	YES	5	4	3	2	1
7.	Do you protect him or her from falls?	NO	YES	5	4	3	2	1
8.	Do you help make major decisions about his or her health care -- such as surgery or a change in treatment?	NO	YES	5	4	3	2	1

Page 3

Archbold & Stewart (1986, 1994)



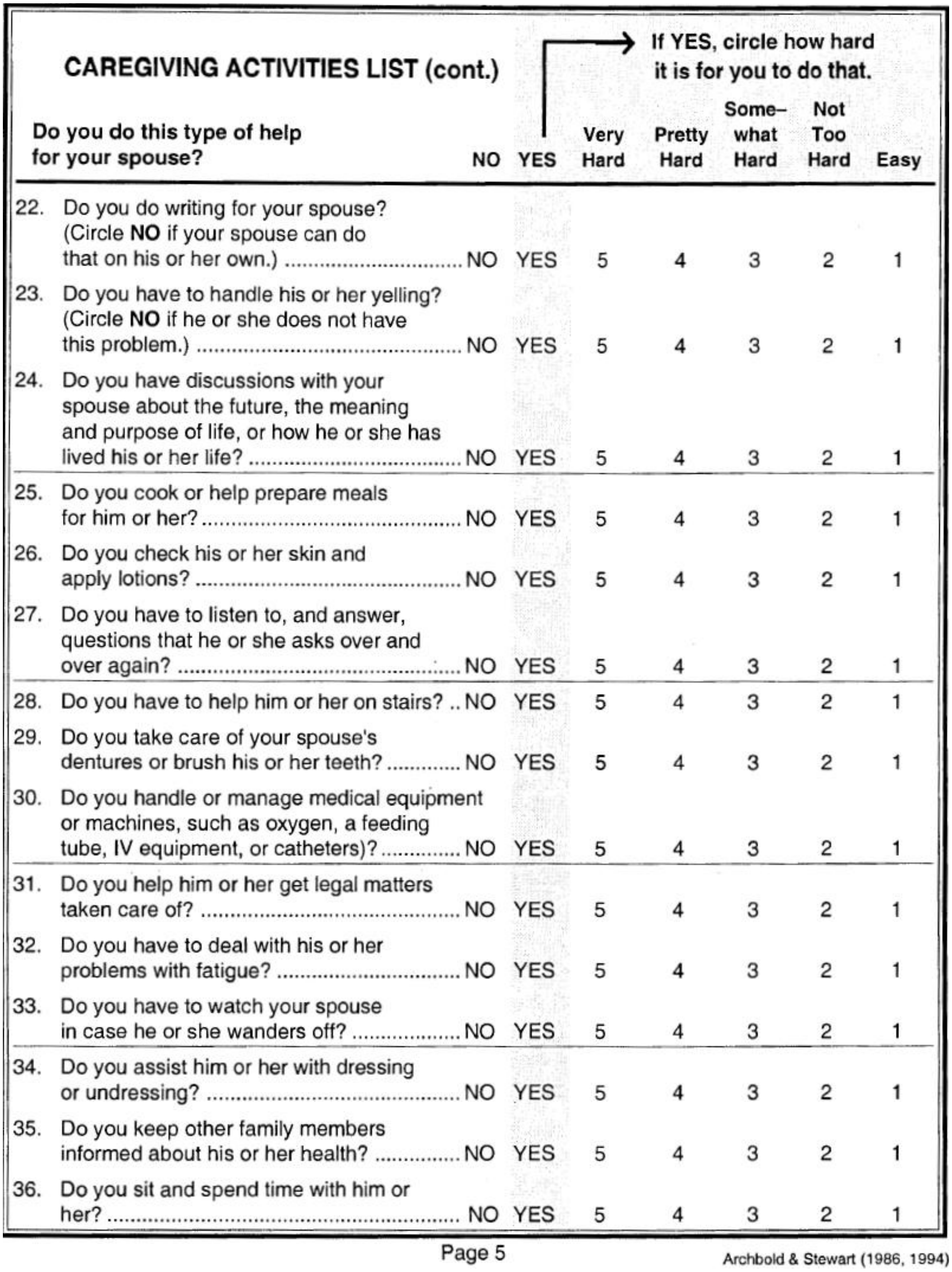
CAREGIVING ACTIVITIES LIST (cont.)

If YES, circle how hard it is for you to do that.

Do you do this type of help for your spouse?	NO	YES	Very Hard	Pretty Hard	Some–what Hard	Not Too Hard	Easy
9. Do you try to keep your spouse active and involved in activities that he or she enjoys?	NO	YES	5	4	3	2	1
10. Do you keep the doctor informed about changes in his or her health?	NO	YES	5	4	3	2	1
11. Do you keep nurses and other health care workers informed about changes in his or her health?	NO	YES	5	4	3	2	1
12. Do you lift or transfer him or her from one place to another? For example, do you lift your spouse out of a chair, or transfer him or her from a bed to a chair? ...	NO	YES	5	4	3	2	1
13. Do you have to go with your spouse as he or she does shopping and errands? ..	NO	YES	5	4	3	2	1
14. Do you have to make sure he or she gets the right amount of liquids? (Circle **NO** if he or she can do that on his or her own.) ...	NO	YES	5	4	3	2	1
15. Do you assist him or her with bathing, washing, or taking a shower?	NO	YES	5	4	3	2	1
16. Do you do any of the driving for your spouse?	NO	YES	5	4	3	2	1
17. Do you have to handle his or her paranoia or suspiciousness? (Circle **NO** if he or she does not have that problem.)	NO	YES	5	4	3	2	1
18. Do you take part in leisure activities with him or her, such as watching TV, playing games, or listening to music?	NO	YES	5	4	3	2	1
19. Do you have to handle his or her crying spells? (Circle **NO** if he or she does not have that problem.)	NO	YES	5	4	3	2	1
20. Do you have to make sure he or she eats the right amount or types of food? (Circle **NO** if he or she can do that on his or her own.) ...	NO	YES	5	4	3	2	1
21. Do you have to clean up if he or she has a bladder accident?	NO	YES	5	4	3	2	1

Page 4

Archbold & Stewart (1986, 1994)



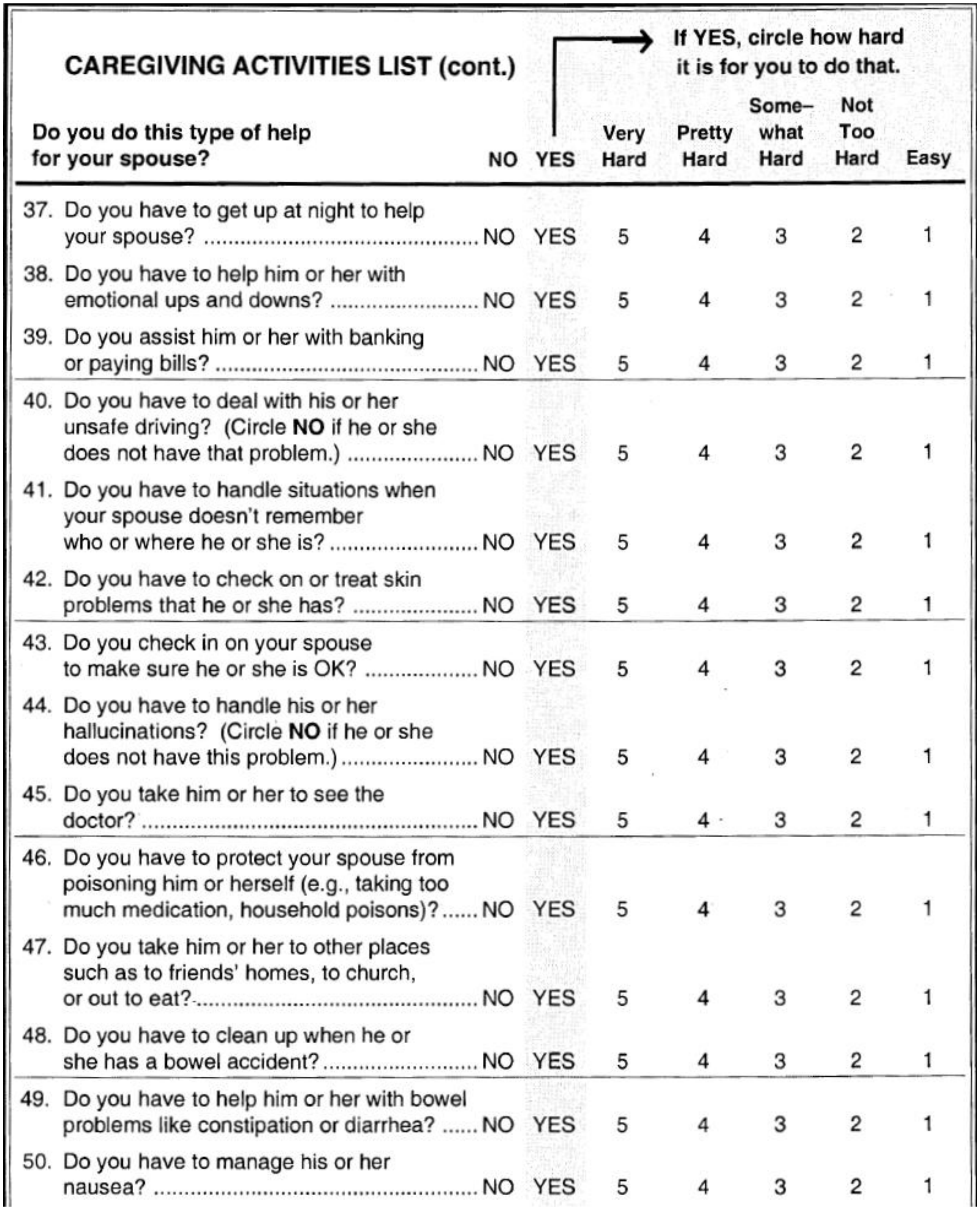
CAREGIVING ACTIVITIES LIST (cont.)

If YES, circle how hard it is for you to do that.

	Do you do this type of help for your spouse?	NO	YES	Very Hard	Pretty Hard	Some–what Hard	Not Too Hard	Easy
22.	Do you do writing for your spouse? (Circle **NO** if your spouse can do that on his or her own.)	NO	YES	5	4	3	2	1
23.	Do you have to handle his or her yelling? (Circle **NO** if he or she does not have this problem.)	NO	YES	5	4	3	2	1
24.	Do you have discussions with your spouse about the future, the meaning and purpose of life, or how he or she has lived his or her life?	NO	YES	5	4	3	2	1
25.	Do you cook or help prepare meals for him or her?	NO	YES	5	4	3	2	1
26.	Do you check his or her skin and apply lotions?	NO	YES	5	4	3	2	1
27.	Do you have to listen to, and answer, questions that he or she asks over and over again?	NO	YES	5	4	3	2	1
28.	Do you have to help him or her on stairs?	NO	YES	5	4	3	2	1
29.	Do you take care of your spouse's dentures or brush his or her teeth?	NO	YES	5	4	3	2	1
30.	Do you handle or manage medical equipment or machines, such as oxygen, a feeding tube, IV equipment, or catheters)?	NO	YES	5	4	3	2	1
31.	Do you help him or her get legal matters taken care of?	NO	YES	5	4	3	2	1
32.	Do you have to deal with his or her problems with fatigue?	NO	YES	5	4	3	2	1
33.	Do you have to watch your spouse in case he or she wanders off?	NO	YES	5	4	3	2	1
34.	Do you assist him or her with dressing or undressing?	NO	YES	5	4	3	2	1
35.	Do you keep other family members informed about his or her health?	NO	YES	5	4	3	2	1
36.	Do you sit and spend time with him or her?	NO	YES	5	4	3	2	1

Page 5

Archbold & Stewart (1986, 1994)

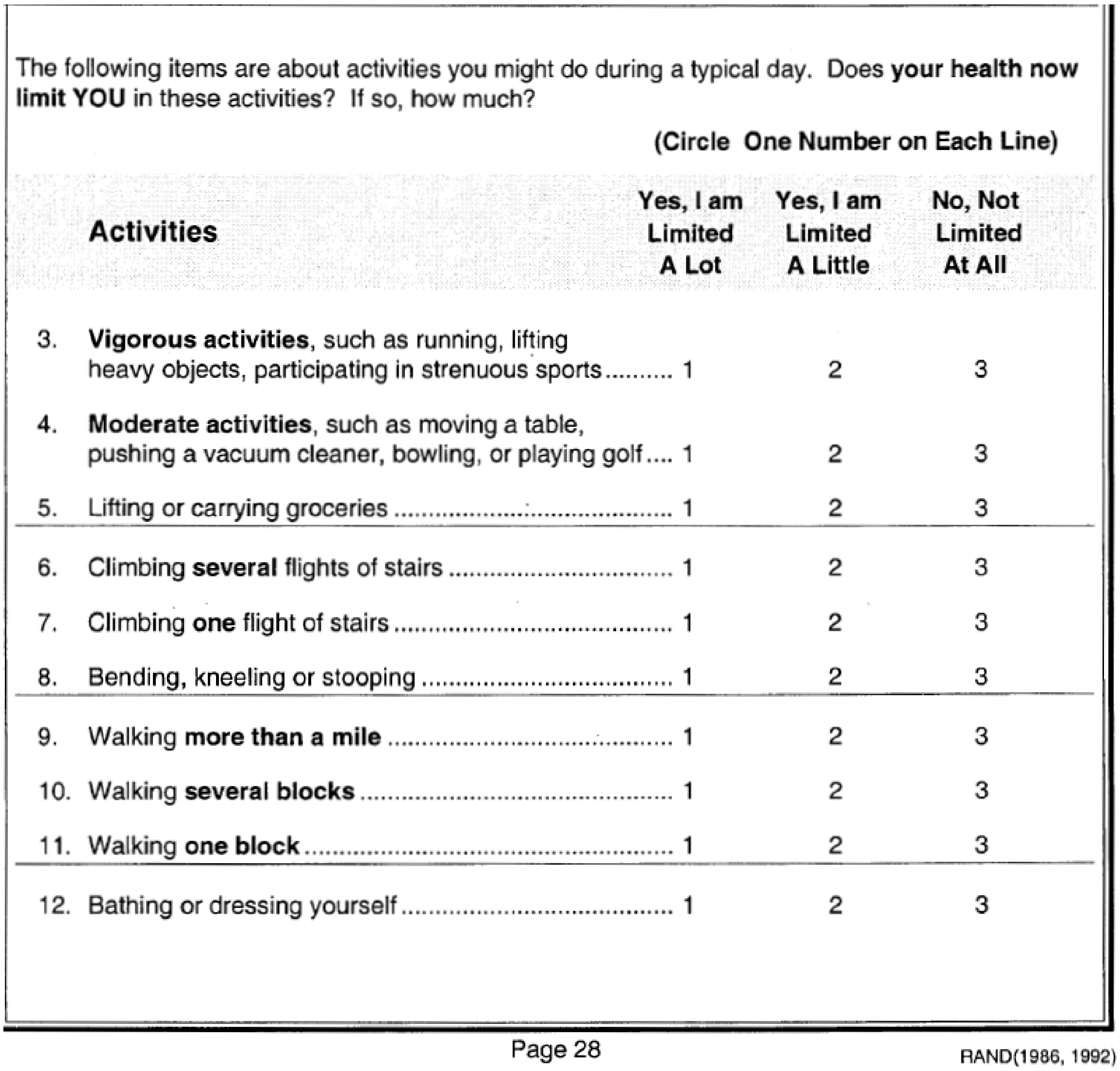


CAREGIVING ACTIVITIES LIST (cont.)

If YES, circle how hard it is for you to do that.

Do you do this type of help for your spouse?	NO	YES	Very Hard	Pretty Hard	Some–what Hard	Not Too Hard	Easy
37. Do you have to get up at night to help your spouse?	NO	YES	5	4	3	2	1
38. Do you have to help him or her with emotional ups and downs?	NO	YES	5	4	3	2	1
39. Do you assist him or her with banking or paying bills?	NO	YES	5	4	3	2	1
40. Do you have to deal with his or her unsafe driving? (Circle **NO** if he or she does not have that problem.)	NO	YES	5	4	3	2	1
41. Do you have to handle situations when your spouse doesn't remember who or where he or she is?	NO	YES	5	4	3	2	1
42. Do you have to check on or treat skin problems that he or she has?	NO	YES	5	4	3	2	1
43. Do you check in on your spouse to make sure he or she is OK?	NO	YES	5	4	3	2	1
44. Do you have to handle his or her hallucinations? (Circle **NO** if he or she does not have this problem.)	NO	YES	5	4	3	2	1
45. Do you take him or her to see the doctor?	NO	YES	5	4	3	2	1
46. Do you have to protect your spouse from poisoning him or herself (e.g., taking too much medication, household poisons)?	NO	YES	5	4	3	2	1
47. Do you take him or her to other places such as to friends' homes, to church, or out to eat?	NO	YES	5	4	3	2	1
48. Do you have to clean up when he or she has a bowel accident?	NO	YES	5	4	3	2	1
49. Do you have to help him or her with bowel problems like constipation or diarrhea?	NO	YES	5	4	3	2	1
50. Do you have to manage his or her nausea?	NO	YES	5	4	3	2	1

The physical functioning subscale of the SF-36 Health survey



The following items are about activities you might do during a typical day. Does **your health now limit YOU** in these activities? If so, how much?

(Circle One Number on Each Line)

	Activities	**Yes, I am Limited A Lot**	**Yes, I am Limited A Little**	**No, Not Limited At All**
3.	**Vigorous activities**, such as running, lifting heavy objects, participating in strenuous sports	1	2	3
4.	**Moderate activities**, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	1	2	3
5.	Lifting or carrying groceries	1	2	3
6.	Climbing **several** flights of stairs	1	2	3
7.	Climbing **one** flight of stairs	1	2	3
8.	Bending, kneeling or stooping	1	2	3
9.	Walking **more than a mile**	1	2	3
10.	Walking **several blocks**	1	2	3
11.	Walking **one block**	1	2	3
12.	Bathing or dressing yourself	1	2	3

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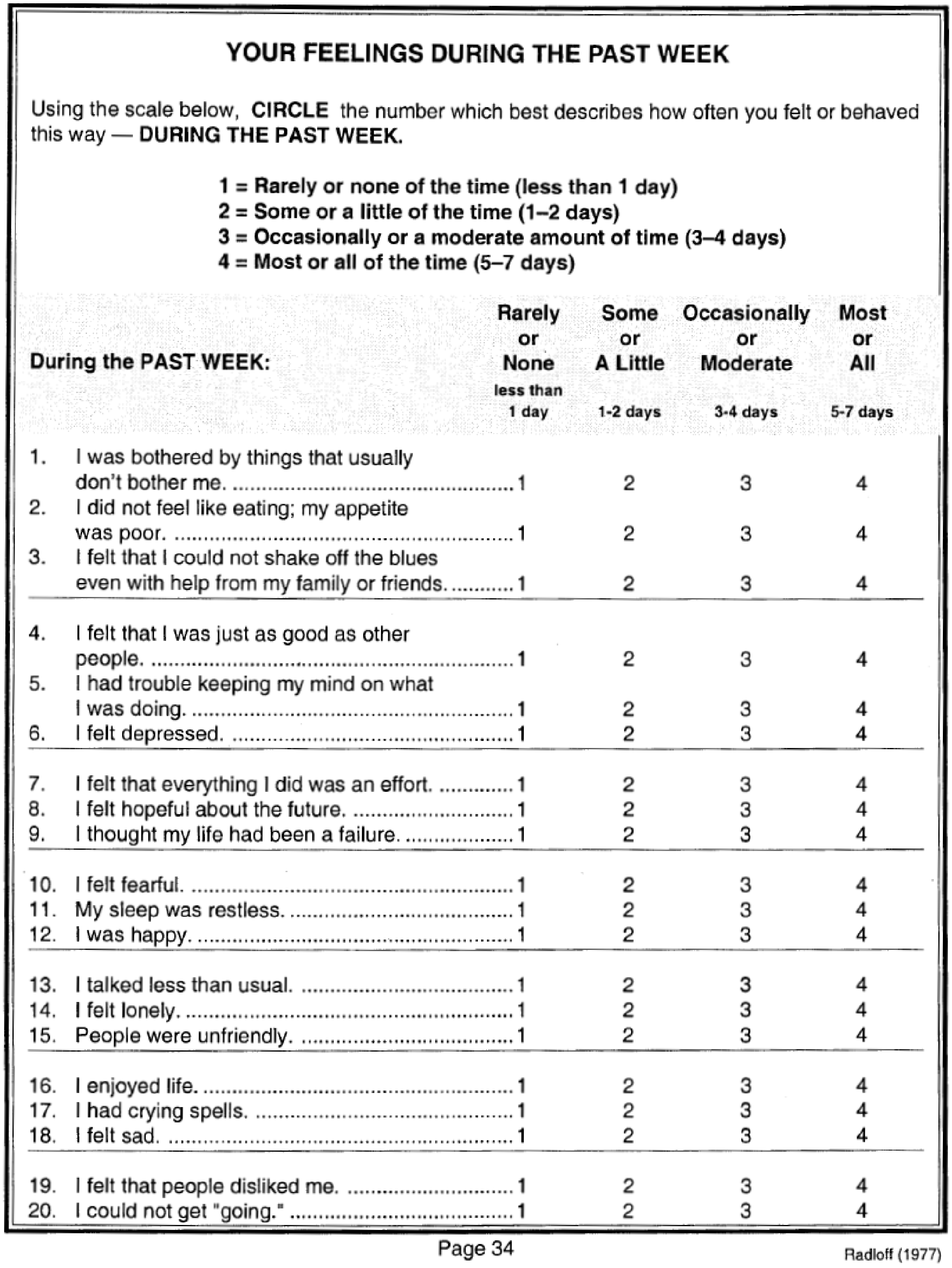
RAND(1986, 1992)

The Center of Epidemiologic Studies Depression Scale



YOUR FEELINGS DURING THE PAST WEEK

Using the scale below, **CIRCLE** the number which best describes how often you felt or behaved this way — **DURING THE PAST WEEK.**

1 = Rarely or none of the time (less than 1 day)
2 = Some or a little of the time (1–2 days)
3 = Occasionally or a moderate amount of time (3–4 days)
4 = Most or all of the time (5–7 days)

During the PAST WEEK:	**Rarely or None** less than 1 day	**Some or A Little** 1-2 days	**Occasionally or Moderate** 3-4 days	**Most or All** 5-7 days
1. I was bothered by things that usually don't bother me.	1	2	3	4
2. I did not feel like eating; my appetite was poor.	1	2	3	4
3. I felt that I could not shake off the blues even with help from my family or friends.	1	2	3	4
4. I felt that I was just as good as other people.	1	2	3	4
5. I had trouble keeping my mind on what I was doing.	1	2	3	4
6. I felt depressed.	1	2	3	4
7. I felt that everything I did was an effort.	1	2	3	4
8. I felt hopeful about the future.	1	2	3	4
9. I thought my life had been a failure.	1	2	3	4
10. I felt fearful.	1	2	3	4
11. My sleep was restless.	1	2	3	4
12. I was happy.	1	2	3	4
13. I talked less than usual.	1	2	3	4
14. I felt lonely.	1	2	3	4
15. People were unfriendly.	1	2	3	4
16. I enjoyed life.	1	2	3	4
17. I had crying spells.	1	2	3	4
18. I felt sad.	1	2	3	4
19. I felt that people disliked me.	1	2	3	4
20. I could not get "going."	1	2	3	4

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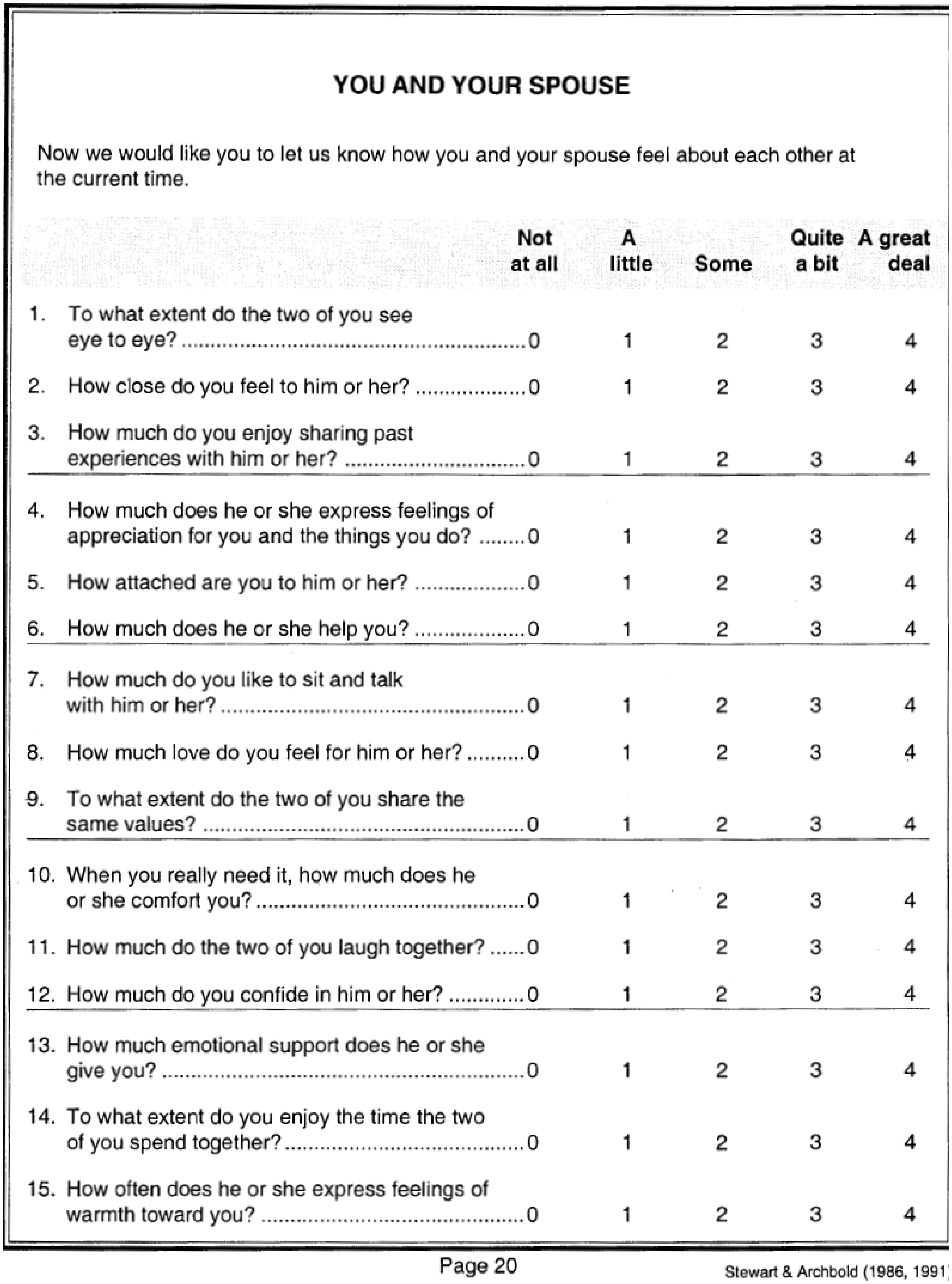
Radloff (1977)

The mutuality scale



YOU AND YOUR SPOUSE

Now we would like you to let us know how you and your spouse feel about each other at the current time.

	Not at all	A little	Some	Quite a bit	A great deal
1. To what extent do the two of you see eye to eye?	0	1	2	3	4
2. How close do you feel to him or her?	0	1	2	3	4
3. How much do you enjoy sharing past experiences with him or her?	0	1	2	3	4
4. How much does he or she express feelings of appreciation for you and the things you do?	0	1	2	3	4
5. How attached are you to him or her?	0	1	2	3	4
6. How much does he or she help you?	0	1	2	3	4
7. How much do you like to sit and talk with him or her?	0	1	2	3	4
8. How much love do you feel for him or her?	0	1	2	3	4
9. To what extent do the two of you share the same values?	0	1	2	3	4
10. When you really need it, how much does he or she comfort you?	0	1	2	3	4
11. How much do the two of you laugh together?	0	1	2	3	4
12. How much do you confide in him or her?	0	1	2	3	4
13. How much emotional support does he or she give you?	0	1	2	3	4
14. To what extent do you enjoy the time the two of you spend together?	0	1	2	3	4
15. How often does he or she express feelings of warmth toward you?	0	1	2	3	4

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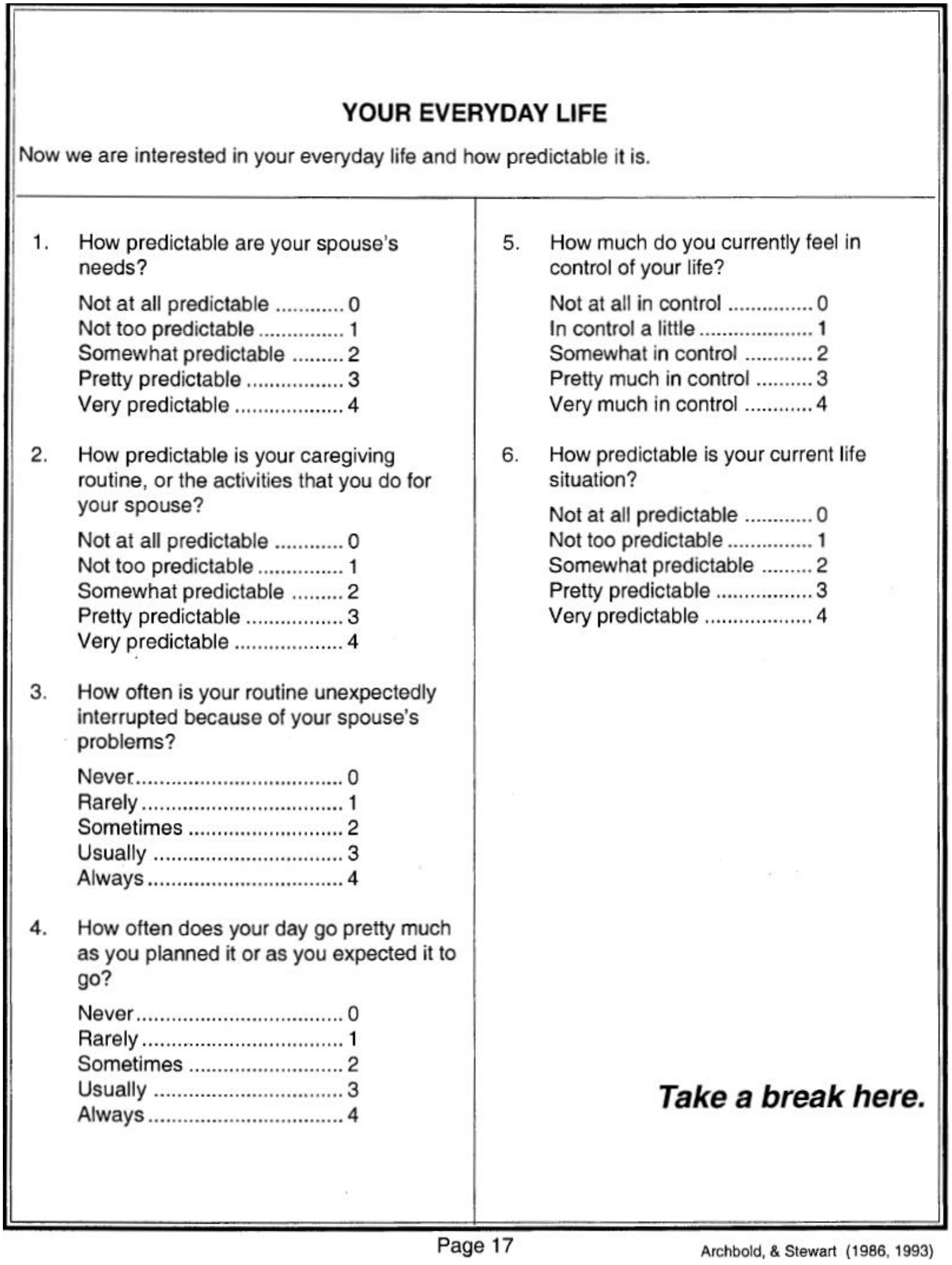
Stewart & Archbold (1986, 1991

The predictability scale



YOUR EVERYDAY LIFE

Now we are interested in your everyday life and how predictable it is.

1. How predictable are your spouse's needs?

Not at all predictable	0
Not too predictable	1
Somewhat predictable	2
Pretty predictable	3
Very predictable	4

2. How predictable is your caregiving routine, or the activities that you do for your spouse?

Not at all predictable	0
Not too predictable	1
Somewhat predictable	2
Pretty predictable	3
Very predictable	4

3. How often is your routine unexpectedly interrupted because of your spouse's problems?

Never	0
Rarely	1
Sometimes	2
Usually	3
Always	4

4. How often does your day go pretty much as you planned it or as you expected it to go?

Never	0
Rarely	1
Sometimes	2
Usually	3
Always	4

5. How much do you currently feel in control of your life?

Not at all in control	0
In control a little	1
Somewhat in control	2
Pretty much in control	3
Very much in control	4

6. How predictable is your current life situation?

Not at all predictable	0
Not too predictable	1
Somewhat predictable	2
Pretty predictable	3
Very predictable	4

Take a break here.

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Archbold, & Stewart (1986, 1993)

Single-item tools

Help received from professionals

1. How much help have people whose job it is (such as professionals or a paid helper) given to your spouse?
   None at all…………0
   A little…………..…1
   Some………………2
   Quite a bit…………3
   A great deal……..…4

Help received from relatives

1. How much help have your relatives given to him or her?
   None at all……..…0
   A little…………..…1
   Some…….……..…2
   Quite a bit…………3
   A great deal….……4

Being a member of a local support group

1. Are you a member of a local support group?
   No….…0
   Yes ..…1