# The Relationship of Stage of Parkinson's Disease and Caregiver Role Strain to Mood States of Spouse Caregivers

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#### ABSTRACT

Title:

The Relationship of Stage of Parkinson's Disease and Caregiver Role Strain to

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This quantitative study examined the relationship of the stages of Parkinson's disease and caregiver role strain to the mood states of spousal caregivers. This study used secondary data from DATEMATE (Stewart, Carter & Archbold, 1992). The sample included 303 spouses of persons in Stage 1 (n = 67), Stage 2 (n = 175), Stage 2.5 (n = 42) and Stage 3 (n = 19). Instruments for this study were caregiver role strain scales, POMS subscales and the Hoehn and Yahr staging system. Reliabilities for caregiver role strain scales ranged from .58 to .93 and POMS subscales ranged from .75 to .94. A one-way analysis of variance (ANOVA) was used to examine the association between the stage of PD and mood. Pearson correlations were used to examine the association between caregiver role strain and mood. Student's t-test was used to compare the mean POMS scores of spousal caregivers to the mean of a normative older adult sample (Kaye et al., 1988). This study found that spouses of persons with PD did not differ in their mood across stage of PD. However, spouses with greater role strain reported more negative mood. Seven dimensions of caregiver role strain and mood stage, including tension. depression, anger and confusion, were more highly correlated for spousal caregivers of persons with in middle stage PD than for spouses of persons in early stage PD.

Spousal caregivers of persons with PD scored lower on the POMS subscales of tension, depression, fatigue and confusion than older adults.

Implications for nursing practice include the need for nurses caring for PD patients to also understand the experiences of spousal caregivers of the person with PD. Nurses should consider that spousal caregivers may experience strain and mood disturbance when persons with PD progress to advanced stages.

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#### CHAPTER 1

#### INTRODUCTION

Parkinson's disease (PD) is a chronic progressive neurologic disorder. The incidence of Parkinson's disease is 1.6 cases per 10,000 per year or 40,000 new cases every year. The onset of symptoms occurs at a mean age of 58-62 years (Bunting & Fitzsimons, 1994). Currently, with the rapid growth of the aging population, the trend is an increasing prevalence of Parkinson's disease (Linde, 1993). The elderly who have Parkinson's disease may have the associated signs and symptoms of tremor, rigidity, bradykinesia, autonomic and postural disturbances (Habermann-Little, 1991).

Because Parkinson's disease is a progressive disease, a staging method has been developed by Hoehn and Yahr (1967). In the Hoehn and Yahr staging, there are five stages of Parkinson's disease, each one associated with increasing disability. It is likely that the family caregiver caring for an elder with PD has greater strain as the disease progresses and the elder's functional impairment increases (Carter et al., 1997). Other studies also demonstrated that higher levels of functional impairment are related to higher levels caregiver strain (Carey, Oberst, McCubbin & Hughes, 1991; Deimling & Bass, 1986). Family caregivers caring for an elder with Alzhemer's disease also experience more anxiety and depression with increased severity of illness (Lieberman & Fisher, 1995).

Spouses are expected to care for each other. Spousal caregivers were shown to have more role responsibilities than did adult child caregivers (Barnes, Given & Given, 1992). The spousal caregiver had more strain than other caregivers (Cantor, 1983). Many studies show a relationship between caregiver strain and caregiver psychological distress. Family caregivers caring for an elder with Alzheimer's disease experiences more strain,

depression and anxiety as the disease progresses (Fisher & Liberman, 1994; Neundorfer, 1991; Vitaliano et al.,1991). Family caregivers caring for persons with cancer also reported more strain and fatigue with increased demands on their schedule (Jensen & Given, 1991). Because caregiver strain increases with the higher stages of PD, it is possible that spousal caregivers may also report greater psychological distress as stages of PD increase. The purpose of this study is to examine the relationship of the stage of PD and caregiver role strain to mood states of spouses of a person with PD.

#### **CHAPTER 2**

#### REVIEW OF THE LITERATURE

The search strategy used to identify literature reviewed included the text words:

(a) POMS, depression, anxiety and fatigue with stage of Parkinson's disease, functional status, functional impairment, strain, burden, and disability; (b) Parkinson with spouse, caregiving, strain; and (c) Hoehn & Yahr with spouse. The search procedures were expanded by using the author search including Zarit, S.H., Deimling, G. T., Montgomery, R. J. V., Borgatta, E. F., Given, B. A., Given, C. W., Lawton, M. P., Pearlin, L. I., Cartor, M. H., Robinson, B. C., and Mui, A. C. The following years were searched: in Medline 1966 through May 1996; CINAHL 1982 through March 1996; Health 1975 through December 1995, and PsychoINFO 1984 through June 1996. These search strategies identified 593 non overlapping articles. The criteria for choosing the articles included in this review were: (a) the relationship between caregiver role strain and caregivers' mood, or (b) the relationship between the elder's functional impairment and caregivers mood. Fourteen articles were included in the literature review.

The review of literature will focus on 3 concepts: a) The stages of Parkinson's disease b) caregiver role strain and c) mood states, and their relationship to stage of disease and strain.

#### The Stages of Parkinson's Disease

Parkinson's disease was first described in 1819 by Dr. James Parkinson.

Parkinson's disease is a movement disorder characterized most frequently by tremors,
muscle rigidity and slowness of movement (Lannon, Thomas, Bratton, Jost & LockhartPretti, 1986). In 1967, Hoehn and Yahn (1967) described five stages of Parkinson's

disease. These stages are:

Stage 1: Unilateral disease with minimal or no functional impairment

Stage 2: Bilateral disease without impairment of balance

Stage 3: Moderate bilateral disease, some impairment of balance and walking

Stage 4: Severe disabling disease with markedly impaired balance and walking

Stage 5: Completely immobile; confined to bed or wheelchair

By definition, persons with Parkinson's disease in Stages 1, 2 and 3 are minimally disabled and persons in Stage 4 and 5 are severely disabled (Hoehn & Yahr, 1967).

#### Caregiver Role Strain

The concept of caregiver role strain was developed from qualitative research with caregivers to older persons and Role Theory (Archbold & Stewart, 1992). This concept focuses on the family caregiver role. Providing care to a family member can cause strain, which may have a strong negative effect on the caregiver and family. An early qualitative study of family caregiving identified nine dimensions of strain for which measures were developed (Archbold, Stewart, Greenlick & Harvath, 1992); a tenth dimension was added later. Currently, 10 measures of caregiver role strain are used; strain from direct care, lack of resources, worry, role conflict, economic burden, mismatched caregiving role expectations, increased tension, feelings of being manipulated, frustration from communication problems, and global strain scale (Carter et al., 1997).

#### Mood

Mood refers to "a sustained emotional state that modulates a person's perception of himself or herself and his or her surroundings" (Coffey & Cumming, 1994, P.10).

Affect is used to describe the emotional tone of a person's internal feeling such as elation,

happiness, pleasure, frustration, anger, or hostility (Cook & Fontaine, 1991). The two states usually change together. Mood and affect may influence behavior in a particular situation. McNair, Lorr and Droppleman (1971) developed the Profile of Mood States (POMS) for measuring a person's affect and mood over the previous week. This instrument measures six identifiable moods or affective states with six subscales: Tension-Anxiety; Depression-Dejection; Anger-Hostility; Vigor-Activity; Fatigue-Inertia; and Confusion-Bewilderment.

#### Relationship of Stage of Parkinson's Disease to Mood

The potential for caregiver stress in providing home care to the person with Parkinson's disease increases with the progression of the disease. The functional impairment of the person with Parkinson's disease can cause frustration, anger and fatigue in the caregiver (Bunting & Fitzsimmons, 1994). Bass, McClendon, Deimling and Mukherjee's (1994) study of 576 primary caregivers and their care recipients diagnosed with mental impairment found higher levels of caregiver depression with increased spousal functional impairment. Thompson, Bundek and Sobolew-Shubin(1990) studied 40 primary caregivers of persons with stroke. They also found higher depression levels in caregivers of persons with higher levels of physical impairment. Wineman, O' Brien, Nealon and Kaskel (1993) studied 61 married couple where one spouse had multiple sclerosis. They examined the differences in the perception of illness uncertainty between the husband and wife and investigated how this perception influenced emotional well-being. They found that the spouses caring for family members with more severe functional loses had more negative moods. In contrast to the findings of these studies, Schmacher, Dodd & Paul (1993) in a study of cancer patients and their caregivers found that the patients'

functional status did not predict caregiver depression (see Table 1). Parkinson's disease is more similar to multiple sclerosis and stroke which are chronic conditions that effect function than it is cancer. The findings from these studies suggest that higher stages of PD may be associated with more negative mood.

#### Relationship of Strain to Mood

The review of the literature showed a positive relationship between caregiver strain and mood states including depression, anxiety and fatigue. Thomspon, Bundek and Soblew-Shubin (1990) explored the relationship between caregiver burden and depression in a sample of 40 caregivers of stroke patients. This study found that caregivers who reported greater burden also reported higher depression. Lawton, Moss, Kleban, Glicksman & Rovine's (1991) study of 330 spouses and adult caregivers found that caregiver burden was associated more highly with depression than with caregiver positive affect. Fisher & Liberman's (1994) study of 67 patients with Alzheimer's disease and their caregivers found that higher levels of caregiver strain were associated with higher levels of caregiver anxiety and caregiver depression. Glodstein, Regnery and Wellin (1981) examined the role of caregivers of patient with chronic illness. Using a sample of 30 caregivers, they found that increasing demands of caregiving and caregiving difficulty are associated with higher level of caregiver fatigue. O'Brien, Wineman and Nealon (1995) in a study of 61 caregiver of person's with Multiple Sclerosis found that the caregiver's objective burden was positively associated with negative caregiver mood. However, Schumacher, Dodd and Paul's (1993) study of 75 families with a cancer patient found caregiver strain did not predict caregiver depression (see Table 1).

In summary, the literature reviewed identified several studies showing relationships among functional impairment of the ill person, caregiver strain and depression, anxiety, and fatigue. Results of the studies using chronically ill samples consistently support the positive relationships among functional impairment of care recipients, caregiver strain and caregiver's negative mood state. However, it is difficult to relate these phenomena to caring for persons with Parkinson's disease because each disease may have different demands of caregiving. The studies cited use different instruments for measuring outcomes. The review of the literature revealed no studies that investigated variables specific to spousal caregiving of persons with Parkinson's disease. Each stage of Parkinson's disease has different disabilities. Therefore, this study will explore the relationship between the stage of Parkinson's disease, caregiver role strain and mood of the spouse caregiver. The nurse may then be better able to assess and target interventions to spouse caregivers at risk for mood distress. Interventions to decrease role strain and mood distress may be useful for both the spouse and the person with Parkinson's disease. Research Questions

- 1) How are the stages of Parkinson's disease and caregiver role strain associated with the mood state of spouses of persons with Parkinson's disease?
- 2) How does the mood of spouses of persons in early stage Parkinson's disease compare to normative data on the POMS?

Based on results of analyses comparing mean role strain across Hoehn and Yahr stage (Carter et. al, 1997), it was hypothesized that caregivers of persons at Stage 2.5 or Stage 3 of PD would report higher mood levels in the areas of tension, depression, and fatigue than caregivers of persons at Stage 1 or Stage 2 of PD. Levels of vigor were

expected to be lower in caregivers at Stage 2.5 and 3 when compared to caregivers at Stage 1 and 2. No hypotheses were made for the confusion or anger scales of the POMS.

In addition, the relationship between caregiver role strain and mood state were hypothesized as follows:

<u>Hypothesis 1</u>. Spouse caregivers with higher strain from worry will experience higher tension.

<u>Hypothesis 2</u>. Spouse caregivers with higher strain from economic burden will experience higher tension, fatigue and lower vigor.

<u>Hypothesis 3</u>. Spouse caregivers with higher strain from frustration due to communication problems will experience higher tension and anger.

<u>Hypothesis 4</u>. Spouse caregivers with higher strain from role conflict will experience higher tension.

<u>Hypothesis 5</u>. Spouse caregivers with higher strain from direct care will experience higher fatigue and lower vigor.

<u>Hypothesis 6</u>. Spousal caregivers with higher strain from mismatched expectations will experience higher tension, depression and anger.

<u>Hypothesis 7</u>. Spouse caregivers with higher strain from increased tension will experience higher tension and depression.

<u>Hypothesis 8</u>. Spouse caregivers with higher strain from manipulation will experience higher tension, depression and anger.

<u>Hypothesis 9</u>. Spouse caregivers with higher strain from lack of resources will experience higher depression, fatigue, and lower vigor.

<u>Hypothesis 10</u>. Spouse caregivers with global strain will experience higher tension, depression and fatigue, and lower vigor.

Summary of Family Caregiving Studies Related to Functional Status, Caregiver Strain and Mood Table 1

Author	Purpose	Samples	Measures	Findings
Bass, McClendon, Deimling & Mukherjee (1994)	To identify the effects of patient's diagnosis on caregiving strain	Stratified sample of 586 primary caregivers caring for persons with mental impairment	<ul> <li>(a) Care recipient impairment;</li> <li>functional dependencies( ADL),</li> <li>cognitive incapacity, disruptive</li> <li>behavior, and the ability for social</li> <li>interaction;</li> <li>(b) Clinical diagnosis;</li> <li>(c) Caregiver strain: Dyadic</li> <li>Relationships Strain and Activity</li> <li>Restriction by Margaret Blenker</li> </ul>	Increased functional dependency significantly predicts increased depression for caregiver caring persons with mental impairment (R <sup>2</sup> = .265, p<.001)
	To identify differences in the perception of illness uncertainty in the spousal caregiver and to explore how	A sample of 61 Multiple Sclerosis patients and their spouses	Acsearch Center, Depression by Zung Depression Scale  (a) Perception of illness; The community version of the Mishel Uncertainty in Illness Scale;  (b) Emotion well-being: POMS	Well spousal caregivers' mood was associated with patients' functional loss ( $r =32$ , p<.01).

Table 1 (Continued)

Findings	Caregivers' depression was associated with patient physical functioning (r =33, p<.05) and caregivers' perceptions of burden(r = .2836, p<.05) Patient physical functioning predicted caregiver depression (β=35, p<.05)	Patients' functional status was associated with caregiver
Measures	<ul> <li>(c) Functional capacity of the spouse with Multiple Sclerosis: the Kurtzhe Incapacity Status Scale</li> <li>(a) Psychological adjustment: the Geriatric Depression Scale (GDS)</li> <li>(Brink et al., 1982);</li> <li>(b) Patient functioning physical limitations subscale of the Questionnaire on Resources and Stress (QRS) (Holroyd, 1974);</li> <li>(c) Caregiver perception of work and burden: four subscales from the short form of The QRS (Holroyd, 1974)</li> </ul>	(a) Depression. POMS(McNair, Lorr, & Droppleman, 1971)
Samples	A sample of 40 primary caregivers of cerebrovascular accident patients	A sample of 75 patients with cancer and their caregivers
Purpose	these differences affect caregivers' emotional well- being To identify the relationships between four variables (patient impairment, caregiver perception of burden, caregiver relationship with the patient, and caregiver interpretations of their situation) and caregiver depression	To explore relationship between caregiver strain and depression
Author	Thomson, Bundek & Sobolew- Shubin (1990)	Schumacher, Dodd& Paul(1993)

Table 1 (Continued)

Author	Purpose	Samples	Measures	Findings
			<ul> <li>(b) Caregiver strain: Caregiver Strain Index (CSI) (Robinson, 1983);</li> <li>(c) Coping; the efficacy of the repertoire of coping strategies;</li> <li>(d) Perceived adequacy of social support: a 10-cm visual analog scale</li> <li>(e) Patient functional status: the Karnofsky Performance Scale (KPS)</li> <li>(Karnofsky &amp; Burchenal)</li> </ul>	depression (r =27,p<.05) and caregiver strain was associated with caregiver depression (r.33.p<.01). Neither patients' functional status nor Strain predicted caregiver depression.
Fisher & Leiberman (1994)	To identify multigeneration family systems which affect the relationship between the demands of Alzheimer's disease on the family and the health and well-being of the caregivers	A sample of 67 patients and caregivers (spouses, offspring, in laws ) with Alzheimer's disease	<ul><li>(a) Severity of disease; assessed by clinic staff;</li><li>(b) Caregiver Strain: 11-item Scale Scale(Niederehe and Fruge, 1984);</li></ul>	Caregiver Strain was predicts caregiver anxiety and Caregiver depression (Spousal caregiver: $\beta$ =.532, P<.001, offspring caregiver: $\beta$ =.195,p<.01 in law caregiver $\beta$ = .267, p<.001)

Table 1 (Continued)

	was I. (r = han .6,
Findings	Spousal caregiver burden was associated with depression (r = .63 p<.05) more strongly than with positive affect (r = .26, p<.05)
Measures	<ul> <li>(c) Health and well-being: Anxiety and Depression Scale( Pearlin, liederman, Menaghan and Mullan's, 1981)</li> <li>(a) Symptoms: derived from lists used in other such studies (Poulshok &amp; Deimling, 1984: Zarit et al., 1980);</li> <li>(b) caregiver assistance: determined by symptom severity of the impaired person;</li> <li>(c) Personal resources: a four-item index of self-rated health from the Multilevel Assessment Instrument (Lawton, Moss, Fulcomer &amp; Kleban, 1980);</li> </ul>
Samples	A sample of 330 of spouses and adult caregivers of patients with Alzheimer's disease
Purpose	To test the model of how caregiving burden and satisfaction affect psychological well-being
Author	Lawton, Moss, Kleban, Glicksman, & Rovine (1991)

Table 1 (Continued)

Findings	he Burden 980); 5: The 3S) the spouse with Caregiver objective burden was associated with caregiver mood bundera, & (r =53, P<.001). Caregiver objective burden predicted caregiver mood (r =298, p <.05)  Sbjective and <.05)
Measures	<ul> <li>(d) Social resources;</li> <li>(e) Caregiving appraisal: The Burden Interview (Zarit et al., 1980);</li> <li>(f) Psychological well-being: The Affect Balance Scale (ABS)</li> <li>(Bradburn, 1969)</li> <li>(a) Functional capacity of the spouse with MS: The Kurtzke Incapacity status Scale (Holland, Francabundera, &amp; Wiesel-Levinson, 1986; Kurtzke, 1986);</li> <li>(b) Caregiver Strain: The Objective and Subjective Burden Inventory (Montgomery et al., 1985)</li> </ul>
Samples	A sample of 61 caregivers with the persons with Multiple sclerosis
Purpose	To identify predictors of general health, mood, family and life satisfaction
Author	O'Brien, Wineman, Nalon (1995)

Table 1 (Continued)

Findings	
Measures	<ul> <li>(c) Family coping: F- COPES</li> <li>(McCubbin, Larsen, and Olson, 1982)</li> <li>(d) Social Support: Social Network list and Support System Scale (Becker &amp; Coppel);</li> <li>(e) Caregiver out come: Health Questionaire (Goldberg &amp; Hillier, 1979), The Profile of mood states-Bipolar Form (Mcnair, Lorr, and Doppleman, 1971/1981), the Family Satisfaction Scale (Olson et al., 1989), and the Life Satisfaction Index-2 (Wood, Wylie &amp; Sheafor, 1969)</li> </ul>
Samples	
Purpose	
Author	

Table 1 (Continued)

Findings	Increasing demands of caregiving difficulty can cause the caregiver fatigue
Measures	
Samples	A sample of 30 caregiver caring for patient with chronic illness.
Purpose	To examine the role of the caregiver
Author	Goldstein, Regnery & Wellin (1981)

#### CHAPTER 3

#### **METHODS**

Sample

This study was a substudy of DATEMATE (Stewart, Carter & Archbold, 1992) and was conducted in association with the DATATOP study of the Parkinson Study Group (Shoulson, 1992). DATATOP, a clinical trial of Deprenyl, enrolled persons in Stages 1, 2 and 2.5 of PD who had not previously received antiparkinson medication and who had no history of depression or dementia. Spouses of patients in DATATOP were included in DATEMATE if they were judged by the site investigator as able to read and write in English.

There are several reasons that spouses of PD patients were chosen for DATEMATE. The majority of the PD patients in DATATOP were married or partnered (82%). Currently, in the United State the likelihood of having a spouse as an elder is increased because people are living longer and more people are married (Himes, 1992). Also, compared to adult child caregivers, spouses are older with declining health; therefore they may experience more difficulty in caring for an elderly person with PD because of their own increased functional impairment.

At the beginning of DATEMATE recruitment, the DATATOP PD patients had been in the clinical trial for up to 5 years and some had advanced beyond Stage 2.5 of PD. Mail questionnaires were sent to spouses of persons in Stage 1, 2, 2.5, 3, and 4 of PD. Of these, 327 were returned. Six of the questionnaires did not meet the 75% completeness criterion and were eliminated. Hoehn & Yahr stage scores were missing from an additional 15 cases. Because there were only 3 spouses of persons in Stage 4 of PD, these subjects

were eliminated from the analyses. The final sample included 303 spouses of persons in Stage 1 ( $\underline{n}$  = 67), Stage 2 ( $\underline{n}$  = 175), Stage 2.5 ( $\underline{n}$  = 42) and Stage 3 ( $\underline{n}$  = 19). Information on demographic variables appears in Table 2. The age range of spouses was from 32 to 87 years with a mean of 63 (SD = 10). Of the 303 spouse caregivers, 219 (72.3%)were female and 292 (96.4%) were Caucasian. More than half (52.8%) of the caregivers were retired. More than half (52.5%) of the caregivers had attended or completed college. The average yearly household income was in the \$30,000-39,999 range.

Table 2

Demographics of Sample (N = 303)

Characteristic	Frequency	Percent
Age		
30-39	3	1
40-49	23	9
50-59	72	24
60-69	119	39
70-79	73	24
80-89	9	3
<u>Gender</u>		
Female	219	72.3
Male	84	27.7
Race		
Caucasian	292	96.4
Hispanic	3	1.0
Native American Indian	2	0.7
African American	2	0.7
Asian/Pacific Islander	2	0.7
Other	2	0.7

Table 2 (continued)

Characteristic	Frequency	Percent
Employment status		
Retired	160	52.8
Looking for employment	2	0.7
Never employment	18	5.9
Part-time or on call	31	10.2
Full-time	70	23.1
Education		
Completed 8 <sup>th</sup> grade	18	5.8
Attended high school	26	8.6
Completed high school	61	20.1
Post high school vocational	38	12.5
Attended college	63	20.8
Household income		
Under \$ 10,000	8	3.0
\$ 10,000- \$ 19,999	33	12.5
\$ 20,000- \$29,999	44	16.6
\$ 30,000- \$ 39,999	49	18.5
\$ 40,000- \$ 49,999	41	15.5
\$ 50,000- \$ 74,999	52	19.5
\$ 75,000- \$ 99,999	23	8.7
\$ 100,000 or more	5	5.7

#### **Instruments**

The instruments used in this study were caregiver role strain scales (Stewart & Archbold, 1986), the Profile of Mood States (POMS) (Mc.Nair, Lorr & Droppleman, 1971) and the Hoehn and Yahr staging scale (Hoehn & Yahr, 1967).

Caregiver Role Strain Scales. Caregiver role strain has been defined by Archbold and Stewart (1995) as the "felt difficulty in performing the caregiver role" (p.5). The 10 caregiver role strain scales contained in The Family Caregiving Inventory were used to measure this concept. Caregiver role strain scales measure strain from: direct care (51 items), frustration from communication problems (3 items), lack of resources (5 items). worry (12 items), role conflict (11 items), economic burden (4 items), mismatched expectations (5 items), increased tension (4 items), feelings of being manipulated (4 items), and global strain (4 items). The caregiver role strain scales use a 5-point response format and usually include the response options not at all (0), a little (1), some (2), guite a bit (3), and a great deal (4). Reliability and validity evaluation of all but the frustration from communication scale was performed with 78 caregivers (Archbold, Stewart, Greenlick & Harvath, 1990). Cronbach's alpha reliability for seven of the nine strain scales ranged from .64 to .94; for two scales Cronbach's alpha was not computed because of legitimate missing responses. The correlational stability of these scales over an 8-month period ranged from .62 to .80.

Support for construct validity was obtained by testing the hypothesized relationships between strain and mutuality and preparedness. As predicted, higher scores on mutuality and preparedness were associated with lower strain from direct care, increased tension, and global strain. In addition, mutuality was associated with lower

strain from feelings of being manipulated, mismatched expectations and role conflict.

Further, higher levels of preparedness were associate with lower strain from worry.

Archbold et al. (1995) studied the PREP system of nursing interventions. This was a pilot test with a sample of 22 families caring for older members. The internal consistency of the role strain scales was measured in this sample using Cronbach's alpha. Reliability for the strain scales ranged from .77 to .99.

The Profile of Mood States. The Profile of Mood States has been used to measure mood states in a variety of populations (McNair, Lorr & Droppleman, 1971). The POMS is a 65-item questionnaire which contains six subscales. The subscales are: Tension-Anxiety, Depression-Dejection, Anger-Hostility, Vigor-Activity, Fatigue-Inertia, and Confusion-Bewilderment. The POMS uses a 5-point response format including not at all (0), a little (1), moderately (2), quite a bit (3), and extremely (4). The scores range from 0 to 4. Higher scores in subscales other than Vigor reflect mood state distress. Lower scores on Vigor reflect mood state distress. Based on data from 350 male and 650 female psychiatric outpatients, internal consistency reliability of the POMS subscales was .90 or above. Test-retest reliability was used to assess the stability of the POMS in 100 psychiatric outpatients who continued in treatment for least 6 weeks. Test-retest correlations over a 6-week period ranged from .65 to .74. Correlations are somewhat low for reliability, but are what might be expected during treatment. The concurrent validity of the POMS was supported by correlations with other instruments such as the Hopkins Symptom Distress Scale ( $\underline{r} = -.21$  to .83, p < .01)

Kaye et al.(1988) examined responses on the POMS in a sample of 505 persons 65 and over. The reliability of the POMS in the elderly population was demonstrated by

moderate to high values of Cronbach's alpha; reliabilities of six subscales were Tension (.87), Depression (.87), Anger(.89), Fatigue (.93), Vigor (.91) and Confusion (.72). The construct validity of the POMS was supported in this sample by correlations with psychological well-being and competence. That ranged from -.38 to -.19 (p<.05).

Theis, Moss and Peason (1994) studied the effect of respite on distress in family caregivers of elderly family members. This study used the POMS to measure the outcome of respite care programs. The subjects were 130 caregivers. Cronbach's alpha reliability coefficients the POMS subscales for this sample were Tension (.85), Depression (.93), Anger (.91), Vigor (.68), Fatigue (.89), and Confusion (.62).

The Hoehn and Yahr staging. Hoehn and Yahr staging is the most commonly used method for staging Parkinson's disease. The stages of PD range from Stage 1 through 5 and are rated by a physician or nurse practitioner. Hoehn and Yahr staging was designed to measure the specific clinical characteristics of the disease and to classify the person with PD according to the progression of their disease (Pentland 1991). For this study persons with PD were in stage 1, 2, 2.5 or 3. No one in stage 4 or 5 was included.

There are several reasons for choosing the Caregiver Role Strain Scales, the Profile Mood States, and Hoehn and Yahr staging scales in this study. The literature reviewed indicates that the reliability coefficients for the Caregiver Role Strain Scales and POMS are adequate (.70 and above) (Polit & Hunger, 1995). The correlational stability of those scales was above .6 indicating they are stable over time. The construct validity of these instruments was also supported. In addition, the caregiver role strain measures have worked well in many studies. The POMS has achieved wide acceptance as a measure of psychological distress in a variety of healthy, physically ill and psychiatric populations.

The Hoehn and Yahr staging scales is used worldwide for assessment and staging of Parkinson's disease in clinical practice.

The reliability of instruments in this study. The reliability of the Caregiver Role Strain Scales and POMS in the 303 spousal caregivers of persons with early stage of PD was assessed using Cronbach's alpha. Reliability for the strain scales range from .58 to .93. Reliabilities for POMS subscales ranged from .75 to .94 (see Table 3).

Scale	Number of items	Cronbach's alpha
Compained and attacks		
Caregiver role strain		
Worry	11	.87
Economic burden	4	.67
Frustration due to communication	3	.91
problems		
Role conflict	11	.89
Direct care	51	-
Mismatched expectations	5	.58
Tension	4	.92
Manipulation	4	.93
Lack of resources	5	.85
Global strain	4	.75
POMS subcales		
Tension	9	.88
Depression	15	.94
Anger	12	.92
Vigor	8	.91
Fatigue	7	.92
Confusion	7	.75

#### Procedure

At each of 23 DATEMATE sites, coordinators, most of whom were nurses, called eligible spouses of persons with Parkinson's disease and asked them to participate in the DATEMATE study. Coordinators explained the purpose of this study and asked if the spouse was willing to participate. The coordinator mailed the survey instrument to the spouses who were willing to participate. The envelope contained:

- a letter describing the study and thanking the spouse for agreeing to participate,
- 2. a stamped, self-addressed envelope for the spouse to use in returning the completed instrument to the investigators at the Portland site, and
- 3. a \$ 10 bill.

The coordinator did not mention the \$10 until the spouse agreed to participate in the survey so that the money would not be an incentive for participation. The spouse was given the money as an expression of appreciation for his or her participation. At each site, the nurse coordinators kept a list of names and addresses of the spouses who agreed to participate in the study. Each spouse was given a survey identification number to maintain confidentiality. Those who did not return the survey were tracked by these numbers. When the spouse did not return the survey, the nurse coordinator made a follow-up phone call to make sure that spouse received the survey instrument and to offer assistance in completing the survey if he or she had any trouble.

#### Data Analysis

The variables in this study are stage of PD, caregiver role strain and mood. To examine the association between the stage of PD and mood, we used a one-way analysis

of variance (ANOVA) with stage of PD the independent variable and mood the dependent variable. We used Pearson's correlations to examine the association between caregiver role strain and mood. Finally, we used a Student's <u>t</u>- test to compare the mean POMS scores of spouse caregivers to the mean of a normative elderly adult sample.

However, there was tremendous variability in the magnitude of these 60 correlation (r = .14 to .69). Therefore, we did scatterplots for the group as a whole. In addition, we computed the correlations and did scatterplots for early stage and middle stage separately. Although there appeared to be general pattern in which the middle stage correlations were larger than the corresponding early stage correlations, the presence of outliers made it difficult to draw accurate conclusions. Therefore, we trimmed observations that exceeded 4 standard deviations above their respective early or middle stage mean scores, and replaced the outlying value with the next lowest score that fell below 4 standard deviations. Then we recomputed all correlations.

#### CHAPTER 4

#### RESULTS

Research Question 1: How are the stage of Parkinson's disease and caregiver role strain associated with the mood state of spouses of persons with Parkinson's disease?

Results from a one-way ANOVA indicated that there were no significant differences by stage of PD in mean scores on the POMS subscales measuring the mood states of spouses of person with PD (see Table 4). The hypotheses that caregivers of persons in Stage 2.5 or Stage 3 would exhibit more tension, more depression, more fatigue, and less vigor than caregivers of persons in Stage 1 or Stage 2 were not supported.

All aspects of caregiver role strain were significantly correlated (p<.05) with the mood state of spouses of persons with PD, with 56 of the 60 correlations significant at p<.001. Thus, all hypotheses about the relationship between caregiver role strain and mood were supported (see Table 5). Because these corelations varied so widely, from .14 to .69, correlations between strain and mood were also computed separately for early stage and middle stage. These correlations also varied markedly in magnitude with values of correlation ranging from .09 to .73 and appeared to differ for early and middle stage. To facilitate examination of the correlations, the following cutoffs were selected for display in Table 6. In addition, a Z-test for independent correlations was used to compare the early stage correlations between strain and mood to the middle stage correlation (see Table 7). The results show that correlations between some dimensions of strain and mood for spousal caregivers of persons in middle stage PD were significantly larger than correlations for early stage PD.

Of the 60 correlations between strain and mood, 34 were larger for spousal caregivers of persons in middle stage compared to early stage. These 34 correlations were:

- Strain from being manipulated with tension, anger, depression, confusion and fatigue.
- Strain from direct care with anger, tension, depression and confusion.
- Strain from role conflict with anger, tension, depression, confusion and vigor.
- Strain from lack of resources with anger, depression, confusion and tension.
- Strain from increased tension with depression, anger, tension and confusion.
- Global strain with tension, depression, anger and confusion.
- Strain from frustration due to communication problems with anger, depression, tension and confusion.
- Strain from mismatched expectation with depression, tension and anger
- Strain from worry with anger.

Of the 60 correlations between strain and mood, 8 were significantly smaller for middle stage than early stage. The positive correlations of global strain, worry, role conflict and economic burden with fatigue were smaller for spousal caregivers of person in middle stage than early stage. In addition, the positive correlation of economic burden with confusion was smaller for spousal caregivers of person in middle stage than early stage. The negative correlation among lack of resources, direct care and worry with vigor were smaller for spousal caregivers of person in middle stage than early stage.

The 18 correlations between strain and mood that were not significantly different when comparing correlations of spousal caregivers of persons in middle stage to correlations in early stage were:

- Strain from being manipulated with vigor.
- Global strain with vigor.
- Strain from direct care with fatigue.
- Strain from lack of resources with fatigue.
- Strain from increased tension with fatigue and vigor.
- Strain from frustration due to communication problems with fatigue and vigor.
- Strain from mismatched expectation with fatigue, confusion and vigor.
- Strain from economic burden with anger, depression, tension and vigor.
- Strain from worry with tension, depression and confusion.

The magnitude of correlations between caregiver role strain and POMS subscales were categorized using stem and leaf displays and grouped by POMS subscales and stage of PD (see Table 8). The correlations between strain and POMS are similar for tension, depression and anger in that the typical median correlations for the early stage are .36, .35 and .34. The median correlations for tension, depression and anger for middle stage are .54, .54 and .60, approximately .20 higher than early stage. For early stage the correlations of strain and with tension ,depression and anger tend to be between .30 and .40 with an average in mid .30s. For middle stage the correlations tend to range from .30 to .60, with the typical correlation in the mid .50s or up to .60. The correlations between strain and POMS tension, depression and anger subscales of spousal caregivers in early stages of PD are moderate whereas these correlations for spousal caregivers in middle stage are high.

The correlations between of strain and POMS confusion in spouses of person with early stage tend to be in the .20s and .30s with a median correlation of .30. For spouses of persons with middle stage PD correlations from strain and confusion tend to be in .30s and

.40s with a median correlation of .40.

There are no differences between early and middle stage for POMS vigor correlation with strain or POMS fatigue with strain. Vigor and strain differ somewhat, however, in the magnitude. For vigor the correlation with strain tends to be in the .10s and .20s a with a median correlation of -.24 to -.22, and for fatigue and strain the correlation tend to be in the .30s and .40s. The median correlation is .37-.39.

As seen in the stem and leaf displays of correlations between strain and POMS grouped by strain scales and stage of disease, the correlation between strain and POMS in spousal caregivers of persons in middle stage were higher than early stage (see Table 9). The median correlations for strain and POMS in middle stage and early stage are increased tension .58 and .48, lack of resources .56 and .38, frustration due to communication problem.50 and .41, global strain .50 and .39, feelings of being manipulated .46 and .31, role conflict .39 and .26, and direct care .44 and .25.

There was on difference in the correlation of POMS with mismatched expectations between early stage and middle stage. The correlation of POMS with mismatched expectations tend to be in the .20s and .30s with a median correlation .24 to.33.

There was no difference in the correlation of POMS with economic burden was between spouses of persons with early stage and middle stage PD. The correlation of POMS with economic burden tend to be in the .20s and .30s, with a median correlation of .30 to.22.

No difference was found in the correlation of POMS with worry between early stage and middle stage PD. The correlation of POMS with worry tend to be in the .30s and .40s, with the median correlation .42 to .43.

Table 4

<u>Summary of ANOVAs on POMS Subscale by Stage of PD</u>

				M	lean	
POMS	df	F ratio		(Standard	l Deviation)	
Subscale			Stage 1	Stage 2	Stage 2.5	Stage 3
			n = 67	n = 175	n = 42	n = 19
Tension	3, 289	0.16	0.61	0.66	0.65	0.62
			(0.58)	(0.64)	(0.52)	(0.71)
Depression	3, 286	0.05	0.28	0.30	0.28	0.30
			(0.50)	(0.55)	(0.40)	(0.73)
Anger	3, 286	0.33	0.23	0.30	0.28	0.35
			(0.42)	(0.54)	(0.57)	(0.77)
Vigor	3, 289	0.55	2.34	2.28	2.18	2.45
			(0.85)	(0.82)	(0.91)	(0.68)
Fatigue	3, 287	0.25	0.75	0.81	0.71	0.69
			(0.88)	(0.83)	(0.70)	(0.78)
Confusion	3,287	0.07	0.50	0.53	0.54	0.56
			(0.46)	(0.51)	(0.56)	(0.67)

Table 5

Pearson Correlations Between Caregiver Role Strain and Mood State for Overall Sample (N = 303)

Caregiver role strain			P	OMS		
	Tension	Depression	Anger	Vigor	Fatigue	Confusion
Strain from worry	.46	.46	.41	30	.43	.38
Strain from economic burden	.32	.32	.24	16 <sup>b</sup>	.26	.25
Strain from frustration due to communication	.44	.47	.50	26	.39	.36
problem  Strain from role conflict	.26	.27	.26	18 <sup>b</sup>	.32	.29
Strain from direct care	.29	.27	.27	22	.27	.20
Strain from mismatched expectations	.26	.23	.26	14ª	.28	.23
Strain from tension	.53	.54	.55	24	.43	.42

Table 5 (continued)

Table 5 (continued)

Caregiver role strain			PC	OMS		
	Tension	Depression	Anger	Vigor	Fatigue	Confusion
Strain from manipulation	.40	.42	.51	17 <sup>b</sup>	.35	.36
Strain from lack of	.49	.46	.43	32	.56	.43
Global strain	.44	.43	.45	27	.40	.39

Note All but four correlations are significant at p < .001

Table 6

<u>Cut-off levels for correlation values</u>

Correlation	Magnitude	
.60 and above	Very high	
.5059	High	
.4049	Moderately high	
.3039	Moderate	
.20-,29	Moderately low	
.19 or less	Low	

a p<.05 (one correlation)

b p< 01 (three correlations)

Table 7 (Continued)

Table 7

Correlations Between Caregiver Role Strain and POMS Categorized by Magnitude of Correlations in Early Stage and Middle Stage

			POMS			
Caregiver role strain Scale	Very high correlation $(r = .60 \text{ and above})$	High correlation (r = .5059)	Moderately High correlation $(r = .4049)$	Moderate correlation (r= .3039)	Moderately low correlation (r = .2029)	Low correlation $(r = .19 \text{ or less})$
			Early Stage (n = 242)	(n = 242)		
Increased Tension $M = 0.69$ $SD = 0.80$	1	Tension .50 Anger .50	Fatigue 46 Depression 49	Confusion 36	Vigor - 24	I
			Middle Stage (n = 61)	e (n = 61)		
Increased tension $M = 1.04$ $SD = 1.15$	Depression 69* Anger 69* Tension 66*	I	Confusion .49* Fatigue .46	1	Vigor 27	1

Caregiver role strain			POMS			
Scale	Very high correlation (r = .60 and above)	High correlation (r = .5059)	Moderately High correlation (r = .4049)	Moderate correlation (r= .3039)	Moderately low correlation (r = .2029)	Low correlation (r = .19 or less)
			Early Stage (n = 242)	(n = 242)		
Lack of resources $M = 0.39$	I	Fatigue 57	Tension .46	Depression .38 Confusion .37	ī	l
SD = 0.63				Vigor37 Anger .33		
			Middle Stage (n= 61)	ge (n= 61)		
Lack of resources $M = 0.65$	Depression64* Anger62*	Fatigue 57 Tension 56*	î	1	1	Vigor18 <sup>NS*</sup>
SD = 0.68		Confusion .51*				

Table 7 (Continued)

Careoiver role strain			PC	POMS			
Scale	Very high correlation (r = .60 and above)	High correlation (r = .5059)	Moderately High correlation (r = .4049)	Moderate on correlation (r= .3039)	ate tion (39)	Moderately low correlation (r = .2029)	Low correlation (r = .19 or less)
			Early S	Early Stage (n = 242)			
Worry	ı	1			.37	L	I
$\mathbf{M} = 1.00$ $\mathbf{SD} = 0.72$			Tension 44 Depression 44	44 Vigor 44	32		
			Confusion 40	0			
			Middle	Middle Stage (n =61)			
Worry	I	ţ	а			Vigor - 26*	Ľ
$\mathbf{M} = 1.40$ $\mathbf{SD} = 0.82$			Anger  Depression	.49 Confusion .48	55.		

Table 7 (Continued)

Caregiver role strain				POMS			
Scale	Very high correlation (r = 60 and above)	High correlation (r = .5059)	Moderately High correlation (r = .4049)		Moderate correlation (r= .3039)	Moderately low correlation $(r = .2029)$	Low correlation (r = .19 or less)
			Early	Early Stage (n = 242)	242)		
Frustration due to	ī	I	Anger	.46 Con	Confusion .32	Vigor - 25	1
communication			Depression	45			
problems			Tension	42			
$\mathbf{M} = 0.75$			Fatigue	40			
SD =0 .93							
			Mide	Middle Stage (n=61)	(61)		
Frustration due to	Anger 66*	Depression .57*	Confusion	*47*	ı	Vigor - 27	r
communication		Tension .53*	Fatigue	42			
problems							
M = 1.10							
SD = 1.11							

Table 7 (Continued)

riento o los societos de la constitución de la cons			FOIMS			
Caregiver role strain. Scale	Very high correlation (r = .60 and above)	High correlation (r = .5059)	Moderately High correlation (r = .4049)	Moderate correlation (r= .3039)	Moderately low correlation (r = .2029)	Low correlation $(r = .19 \text{ or less})$
			Early Stage (n = 242)	(n = 242)		
Global strain $M = 0.60$ $SD = 0.59$	l	1	Fatigue .45 Anger .41	Tension 39 Depression 39 Confusion 35	Vigor - 29	I
			Middle Stage (n = 61)	ge (n = 61)		
Global strain $M = 0.94$	Tension .62* Depression .62*		Confusion .41*	Fatigue .38*	Vigor - 24 <sup>NS</sup>	l
SD = 0.85	Anger 60*					

Caregiver role strain			POMS			
Scale	Very high correlation (r = 60 and above)	High correlation (r = .5059)	Moderately High correlation (r = .4049)	Moderate correlation (r= .3039)	Moderately low correlation (r = .2029)	Low correlation $(r = .19 \text{ or less})$
			Early Stage (n = 242)	n = 242)		
Feelings of being	1	Ţ	1	Anger 36	Confusion .24	Vigor17
Manipulated				Fatigue 33		
M = 0.24				Tension .31		
SD = 0.57				Depression 31		
			Middle Stage (n = 61)	e (n = 61)		
Feelings being	Anger .73*	1	Fatigue 49*	I	I	Vigor17 <sup>NS</sup>
manipulated	Depression .66*		Confusion .48*			
M = 0.50	Tension 62*					
$\mathbf{SD} = 0.81$						

Table 7 (Continued)

Careoiver role strain			POMS	ЛS		
Scale	Very high correlation (r = .60 and above)	High correlation (r = .5059)	Moderately High correlation (r = .4049)	Moderate correlation (r= .3039)	Moderately low correlation (r = .2029)	Low correlation (r = .19 or less)
			Early Stag	Early Stage (n = 242)		
Economic burden $\mathbf{M} = 0.37$	1	l	I	Tension .33 Depression .32	Confusion .27 Anger .23	Vigor18
0C-0-0C			Middle St	Œ		
Economic burden $M = 0.44$	.1	I	I	Depression 32 Tension 30	Anger .23 <sup>NS</sup> Confusion .21 <sup>NS*</sup>	Vigor14 <sup>NS</sup> Fatigue .09 <sup>NS*</sup>
SD = 0.65						

Table 7 (Continued)

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Caregiver role strain Scale	Very high correlation (r = .60 and above)	High correlation (r = .5059)	Moderately High correlation (r = .4049)	Moderate correlation (r= .3039)	Moderately low correlation $(r = .2029)$	Low correlation (r = .19 or less)
			Early Stage (n=242)	( n= 242)		
Role conflict	I	ı	ı	Fatigue .39	Confusion .29	Anger .18
M = 0.25					Depression .26	Vigor14
SD = 0.53					Tension 25	
			Middle Stage (n =61)	ge (n =61)		
Role conflict	1	Anger .51*	Tension 40*	Depression 39*	ı	İ
M = 0.45				Confusion .39*		
SD = 0.68				Vigor35*		
				Fatigue .31*		

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Scale	Very high correlation $(r = .60 \text{ and above})$	High correlation (r = 5059)	Moderately High correlation $(r = .4049)$	Moderate correlation (r= .3039)	Moderately low correlation $(r = .2029)$	Low correlation (r = .19 or less)
			Early Stage (n = 242)	; (n = 242)		
Direct care	ı	1	I	Fatigue .33	Vigor26	Confusion .18
M = 0.32					Tension 26	
$\mathbf{SD} = 0.44$					Depression 24	
				Arm	Anger .21	i in the second
			Middle Stage (n = 61)	ge (n = 61)		
Direct care	I	Tension 57*	Ĩ	Fatigue 37	Ī	Vigor - 19 <sup>NS*</sup>
M = 0.57		Anger 57*		Confusion 36*		
SD = 0.64		Depression 50*				

Table 7 (Continued)

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Scale	Very high correlation $(r = .60 \text{ and above})$	High correlation $(r = 50-59)$	Moderately High correlation $(r = .4049)$	Moderate correlation (r= 30-39)	te on 39)	Moderately low correlation $(r = .2029)$		Low correlation (r = .19 or less)	relation or less)
			Early Stage ( n = 242)	( n = 242)					
Mismatched	1	I	1	Fatigue	.30	ے		Vigor	- 16
expectation $M = 0.47$						Anger Confusion	.25 .24		
SD = 0.67						Depression	.22		
			Middle Stage ( n =61)	ge ( n =61)					
Mismatched	Ţ	ā	ı	Fatigue	.35	Confusion .20 <sup>NS</sup>		Vigor	- 10 <sup>NS*</sup>
expectations				Tension	.34*				
M = 0.81				Depression 33*	*33*				
SD = 0.80				Anger	.33*				

\*p < .001

Table 8

Stem and Leaf Displays of the Magnitude of Correlations Between Caregiver Role Strain and POMS Subscales, Grouped by POMS

Subscales and Early vs Middle PD stage

	_	-									
POMS Confusion	Middle	ampura		.50	.4 1689	.3 568	.2 01			.2050	40
POMS (	Farly	( in the second			0 4.	.3 2568	.2 3478	.18		.1840	.30
POMS Fatigue	Middle			.57	.4 269	.3 14677			8 0.	0857	37
POMS	Early			.57	.4 0566	.3 02338				.3057	.39
POMS Vigor	Middle					35	2 4667	1 04789		10-(35)	22
POM	Early					3 27	2 4569	1 4678		14-(-,37)	24
POMS Anger	Middle	.73	.6 269	.5 17	6 4.	.33	.23			.2373	09
POMS	Early			.50	.4 16	.3 367	.2 135	.18		.1850	.34
POMS Depression	Middle		.6 2469	.5 07	8 4.	.3 239				.3269	.54
POMS I	Early				.4 559	.3 1289	.2 246			.22-49	.35
POMS Tension	Middle		<b>.6</b> 226	.5 367	.4 09	.3 04				.3066	.54
POMS	Early			.50	.4 256	<b>.3</b> 239	.2 556			.2550	.36
Magnitude of r with	Strain	.7079	69:-09	.5059	40-49	30-39	.2029	1019	60 -00	Range of r	Median r

Table 9

Stem and Leaf Displays of the Magnitude of Correlations Between Caregiver Role Strain and POMS Subscales, Grouped by Caregiver Role Strain Scales and Early vs Middle PD stage

strain	Middle		.6 022		.4 1	.3 8	-2.4			.2462	-50
Global Strain	Early		·		,4 15	.3 599	-,29			.29-45	39
Frustration Due to Communication Problem	Middle		99.	.5 37	.4 27		2 7			27-66	.50
Frustration D Communicat Problem	Early				.4 0256	.3 2	25			.2546	.41
Worry	Middle				.4 899	.3 58	26			.2649	.43
Wo	Early				.4 0446	.3 27ª				32-46 .2649	.42
Lack of resources	Middle		.6 24	.5 167				18		18-64	95
Lack of 1	Early			.57	.46	.3 3778				.3357	38
d Tension	Middle		669 9.		.4 69		27			.2769	.58
Increased	Early			.5 00	.4 69	.36	2 4			24-50	48
Magnitude of r with	Strain	70-79	69:-09:	.50-59	.40-49	30-39	.2029	.1019	60'-00'	Range of r 2450	Median r

a : the correlation of .32 is negative (-.32)

Table 9 (continued)

Table 9 (continued)

	_										
Mismatched Expectations	Middle					.3 3345	.20	10		.1035	33
Misn Expe	Early					30	.2 2455	16		16-30	.24
Direct Care	Middle			.5 077		.3 67		19		1957	44.
Direct	Early					.3 3	.2 1466 <sup>b</sup>	.18		.1833	.25
Role Conflict	Middle			.s.	.40	.3 1599				.3151	39
Role C	Early					.39	.2 569	.1 48ª		14-39	26
Economic Burden	Middle					<b>.3</b> 02	.2 13	14	60.	09-32	.22
Economi	Early					.3 223	.2 37	18		.1833	30
of being ulated	Middle	.73	.6 26		.4 89			17		.1773	.46
Feeling of being Manipulated	Early					.3 1136	.2 4	17		1736	31
Magnitude of r with	Strain	6L-0L	69-09	50-59	.4049	.3039	.20-29	.1019	60'-00	Range of r	Median r

a. The correlation of 14 is negative (-.14)

b: The correaltion of .26 is negative (-.26)

Research Question 2: How does the mood of spouses of persons in early stage

Parkinson's disease compare to normative data on the POMS?

To answer research question 2, we compared the mean score on each POMS subscales for this sample with normative data from an older sample (Kaye et al., 1988). The student's t-test results indicate that the mean mood scores of spouses of persons with PD were significantly lower than mean scores from the sample of older adults for 12 of the 18 tests (see Table 10).

Spousal caregivers of persons with PD who were younger than 64 had significantly lower mean scores on tension, depression and confusion than Kaye's older sample. There were no significant differences in anger, vigor and fatigue. Of all comparisons with Kaye's older sample, only the mean anger score of spouses younger than 64 was higher than the norms, but not significantly.

Spousal caregivers of persons with PD who were 65 and older had significantly lower mean scores on tension, depression, anger, fatigue and confusion than Kaye's older sample. There were no significant differences in vigor

The overall sample of spouses of persons in the early to middle stages of PD had significantly lower mean scores on tension, depression, fatigue, and confusion than older adults. There were no significant differences in anger nor vigor.

Table 10

Spouses of Persons in Early and Middle Stage of PD: Mean Scores of POMS Compared with Older Adults

Mean         Mean         Mean           Tension         7.68         6.26           (6.22)         (6.02           Depression         7.97         5.10           Anger         3.92         4.12           Vigor         18.88         18.13           Vigor         (7.22)         (6.83           Fatigue         6.70         5.70           (6.40)         (5.87)	Younger than 64 n = 147-149	4	65 and older n = 142-145	re 53	Overall $n = 293$	II 13
7.68 (6.22) on 7.97 (8.95) 3.92 (5.51) 18.88 (7.22) 6.70 (6.40)	Mean (SD)	+	Mean (SD)	ļ t	Mean (SD)	l t
7.97 (8.95) 3.92 (5.51) 18.88 (7.22) 6.70 (6.40)	6.26 (6.02)	-2.51*	5.46 (5.00)	-4.48***	5.85 (5.54)	***60"01"
3.92 (5.51) 18.88 (7.22) 6.70 (6.40)	5.10 (9.18)	-3.36***	3.69 (6.44)	-6.37***	4.41 (7.97)	-5.79**
18.88 (7.22) 6.70 (6.40)	4.12 (7.61)	0.30	2.64 (4.86)	-2,68**	3.40 (6.44)	-1.15
6.70 (6.40)	18.18 (6.83)	-1 08	18.47 (6.49)	-0.65	18.32 (6.66)	-1.11
	5.70 (5.87)	-1.78	5.15 (5.63)	-2.88**	5.43 (5.75)	-2.88**
Confusion 5.95 3.70 (3.92) (3.81)	3.70	-6.27***	3.64 (3.40)	***6 9-	3.67 (3.16)	-8.32***

\* P< .05 \*\* p< .01 \*\*\* P< .001

### CHAPTER 5

### DISCUSSION

The purpose of this study was to examine the relationships of the stage of PD and caregiver role strain with the mood states of spousal caregivers. This chapter discusses the results in relation to the research questions and hypothesis statements. Possible explanations of the results are also discussed. In addition, limitations of the study, implications for practice and future research are identified.

## Discussion of Research Question 1

A study of spousal caregivers to persons with PD found that caregiver role strain increased with Stage of PD (Carter et. al,1997). Other studies which examined mood states of caregivers of persons with chronic illness show a relationship between functional impairment and negative mood. In this study, spouses of persons with PD did not differ in their mood across stage of PD.

These findings may be due to the fact that this study was cross sectional. In a cross sectional study, data are gathered at a fixed point in time. Some of spousal caregivers may not have psychological distress from caring for persons with PD when they responded to the questionnaire. Some distressed spouses may have discontinued caregiving, or found methods to alleviate distress, or some may have little distress because the person with PD is stable at that time.

All spouses in the sample were still married and willing to participate. Caregivers in the sample reported high level of mutuality in caring for persons with PD (Carter et. al, 1997). High mutuality is usually associated with lower levels of strain (Archbold et. al, 1990). This may have had on effect on their mood state. In addition, some participants

may have wanted to express only positive attitudes in caring for their partners because of social desirability bias.

In this study the participants were from higher socioeconomic class. They may have more resources which could decrease negative mood. In the literature reviewed, socioeconomic variables were related to depression. Results from Schulz and Williamson's (1991) longitudinal study of depression among 174 primary caregivers caring a the person with Alzheimer's disease indicated that caregivers who had higher income had lower levels of depression. Robinson's (1989) study of the predictors of depression among wife caregivers in 78 women also found caregivers with higher social status had lower levels of depression.

As was hypothesized, when spousal caregivers of persons with PD report greater role strain, they also report more negative mood. The findings from this study, as well as findings from previous studies, showed that caregivers caring for persons with functional impairment who have higher strain have more negative moods including depression, anxiety and fatigue (Glodstein, Rgnery, & Wellin, 1981; Thomspon, Bundek & Soblew-Shubin, 1990; Lawton, Moss, Kleban, Glickman & Rovine, 1991; Fisher & Liberman, 1994). Although all of the hypotheses tested in this study were supported, the correlations between POMS vigor and strain were low. The reasons for this finding may be due to the wording of POMS questionnaire. The POMS vigor subscales contains only positively worded items whereas most of the items on the role strain scales are negatively worded.

In addition, these findings show that in the middle stage of PD caregiver role strain is more highly correlated with POMS tension, depression anger and confusion than in the early stage. However the correlations of strain with POMS vigor and fatigue are not

different among spousal caregivers of persons with PD in middle and early stages.

In middle stage PD, caregiver responses to POMS subscales are more highly correlated with strain from increased tension, lack of resources, frustration due to communication problems, global strain, feelings of being manipulated, role conflict and direct care than in the early stage. However, the correlation of POMS with strain from worry, economic burden and mismatched expectations were not different among spousal caregivers of persons with PD in the middle and early stage.

The correlation of the POMS subscales with economic burden (early stage: range = .18 to .33, median = .30, middle stage: range = .09 to .32, median = .22) and mismatched expectations (early stage: range = .16 to .30, median = .24, middle stage: range .10 to .35, median = .33) were low similar among spousal caregivers in the middle and early stage. It may be from restriction of range because economic burden has only 4 items and mismatched expectations has only 5 items. 4 of which are dichotomous. In this study, both economic burden and mismatch expectation have low reliability .67 and .58 respectively.

# Discussion of Research Question 2

The analysis of data showed that spousal caregivers of persons with PD score lower on the POMS subscales of on tension, depression, fatigue and confusion than older adults. It is possible that the gradual decrease in functional ability associated with PD allowed the spousal caregiver to adapt emotionally. Rabins, Fitting, Eastham and Zabora's (1990) study of 32 caregivers of persons with Alzheimer's disease and 30 caregivers of persons with recurrent metastatic cancer interviewed them three times over a 2-year period. The study findings showed both groups had a decline in anxiety and negative

mood. In addition, the older spousal caregivers in this study may have more experience so that caring for a persons with PD does not lead to mood disturbance. The study of the psychosocial impact on 16 caregivers who were caring for persons with stroke in the 9-months period following the stroke indicated that caregivers who had high incomes and were older were least depressed over time (Schulz & Williamson, 1991).

# Limitations of the Study

A limitation of this study is that it examines spousal caregivers of persons with PD in early and middle stage so it can not be generalized to stage 4 and 5. Because this study only examines spouses, it can not generalized to other primary caregivers.

# <u>Implications for Nursing Practice and Future Research</u>

The findings of this study may be useful for nurses caring for spousal caregivers of persons with PD. Based on the study findings spousal caregivers with greater strain will experience higher mood disturbance. Seven dimensions of caregiver role strain and mood state including tension, depression and anger were more highly correlated for spousal caregivers of persons with PD in middle stage than for spouses of persons in early stage PD. Therefore, the nurse can consider spouses of person in middle stage PD to be at higher risk for strain and mood disturbance than spousal caregivers of persons with early stage PD. Nurses should consider that spousal caregivers may experience strain and mood disturbance when persons with PD progress to advance stages. Nurses can then provide counseling or facilitate resources such as support groups or respite care for spousal caregivers. These may alleviate caregiver role strain and mood disturbance.

Even though the study findings showed the average mood score of spousal caregivers is better than that of older adults, there are some spousal caregivers whose

mood scores were high. Therefore, the nurse still needs to assess mood in spousal caregivers and provide nursing interventions to decrease mood disturbance as appropriate.

Recommendation for further research are as following:

- 1) Research using primary caregivers of persons with PD in all stages including stage 1, 2, 2.5, 3, 4 and 5 to futher understand the relationship of strain and mood disturbance of family caregivers of persons with PD.
- 2) Research regarding the predictors of caregiver role strain as mutuality and preparedness in caregiver of persons with PD. This finding will guide nursing practice to prevent negative consequences of caregiving in caregivers of person with PD.

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