AN ASSESSMENT OF COPING AND ADJUSTMENT IN INDIVIDUALS WITH PARKINSON'S DISEASE AND THEIR CAREGIVERS

By

NEVA E. J. SANDERS

Bachelor of Science
Oklahoma State University
Stillwater, Oklahoma
1993

Master of Science
Oklahoma State University
Stillwater, Oklahoma
1994

Submitted to the Faculty of
the Graduate College of
Oklahoma State University
in partial fulfillment of
the requirements for
the degree of
DOCTOR OF PHILOSOPHY
December, 1998

AN ASSESSMENT OF COPING AND ADJUSTMENT IN INDIVIDUALS WITH PARKINSON'S DISEASE AND THEIR CAREGIVERS

Dissertation Approved:

Larry L Mullins
Dissertation Advisor

J Chaney

Carrie Winterowd

Wayne B. Powell
Dean of the Graduate College

ACKNOWLEDGEMENTS

I would like to express my sincere gratitude to my major advisor, Dr. Larry Mullins, for the exorbitant amount of time and effort he put forth to aid me in the completion of this project. His unending support and encouragement was deeply respected and appreciated. My sincerest appreciation is also extended to my other committee members, Dr. John Chaney, Dr. Sue Orsillo, and Dr. Carrie Winterowd, whose guidance, assistance and patience was immeasurable.

I would also like to give special thanks to Ben Balderson, my fellow graduate student who extended an exorbitant amount of time helping me enter data and run hundreds of analyses. His efforts played an invaluable part in the completion of this project.

My sincerest gratitude is extended to Seth G. Dewey, M.D., who continuously provided the assurance and motivation that helped me persist with this endeavor. His positive attitude was infectious and propelled me through the final year of this project's completion.

Finally, I would like to thank my mom and dad, Ron and Joy Sanders, for their undying support and encouragement throughout not only this project, but all of my academic career. They were my source of inspiration and I credit them in every way for my obtainment of this Ph.D.

TABLE OF CONTENTS

Chapter Page

LIST OF TABLES

APPENDICES

Page

Introduction

It has been estimated that in the United States alone, approximately 1 in 100 people over the age of 50 will be affected with Parkinson's disease (Duvosin, 1984). Parkinson's disease (PD) is a crippling, neurodegenerative condition that consists of a triad of physical symptoms: tremor, rigidity, and bradykinesia (Dakof & Mendelsohn, 1986; Wooten, 1990). In addition to these three core symptoms, patients with PD often experience other disease-related problems, including cognitive impairment (e.g., deficits in memory and language), and psychological distress (e.g., depression, anxiety; Growden, Corkin, & Rosen, 1990). Although symptom severity can drastically fluctuate from day to day and can be temporarily managed with medication, gradual deterioration of the patient's health and cognitive status is inevitable. A diagnosis of PD represents for the patient the prospect of a diminishing ability to accomplish simple activities of daily living such as walking, eating, dressing, and writing. The anticipation of such a deterioration in capacity and continuing health degradation can often result in the patient feeling both helpless and hopeless about the future (e.g., Dakof & Mendelsohn, 1986).

Decreased ability to perform tasks can affect several facets of the patient's life. For example, activities such as going to the store or visiting friends becomes difficult as decreased motor control and weakness impedes normal functioning. As a result, the individual with PD may experience some indirect consequences of the disease such as social anxiety, a lack of motivation and/or stress-dependent increases in motor difficulty (Ellgring et al., 1993). These conditions, as well as the disease symptoms themselves, may lead to a gradual decrease in the participation of activities that are social in nature (e.g., dining out, involvement in community activities).

Numerous studies have focused on the psychological impact of PD on the identified patient (Seiler et al., 1992; Dakof & Mendelsohn, 1986; Ellgring et al., 1993). More specifically, clinical depression is the most often reported psychological disturbance identified in patients with PD (Gotham et al., 1986). An estimated 50% of Parkinson's patients report significant levels of clinical depression (Leiberman, 1992). It is unknown, however, whether depression in individuals with Parkinson's is independent of the disease, a consequence of the neurobiological concomitants (i.e., neurotransmitter dysfunction), reactive in nature (i.e., emotional reaction to the permanent, debilitating nature of the disease) or some combination of these factors (Seiler et al., 1992). Further, it assumed that other symptoms associated with a depressive state (e.g., anxiety, decreased ability to concentrate) will occur more frequently in individuals experiencing a chronic illness (Ehman, Beninger, Gawel, & Riopelle, 1990). Although seemingly important, few studies have examined the relationship between both general adjustment and more specific mood states (e.g., depression) reported by individuals with PD and their functional status (Merriman, Owen, Chew, & Tan, 1994; Santamaria, Tolosa, & Valles, 1986).

It is believed that various factors including, stage of disease, functional ability, and use of particular coping strategies may contribute to both general and depression-related symptoms (e.g., anxiety, decreased ability to concentrate). For example, individuals identified as moderately functionally impaired by the PD condition who report few depressive type symptoms may utilize particular coping strategies that result in the reduction of these symptoms. A thorough examination of individuals affected (both directly and indirectly) by the PD condition with decreased levels of general and specific mood states could provide beneficial information regarding factors that may lead to poorer levels of overall adjustment.

Regardless of the cause, the presence of adjustment difficulties and depression may further contribute to difficulties in the patient's overt physical condition that ultimately effects his/her functional status. Previous research in the field of behavioral medicine has clearly shown the connection between psychological distress (coping and adaptation following disease diagnosis) and physical well-being (Larsen, 1990; Palmore & Luikart, 1972; Seiler et al., 1992). This research has demonstrated that the stressors experienced in daily life profoundly influence the patient's psychological state (i.e., depression, anger, feelings of hopelessness). More specifically, it appears that the impact of the physical and psychological aspects of PD are circular; a diagnosis may lead to an anticipated loss of functioning (psychological distress) which negatively influences the patient's physical condition (i.e., compromised immune system functioning). For example, individuals with PD who are depressed may evidence decreased motor activity, which, in turn, can impact physical health and feed back into one's negative perceptions regarding his/her current state of affairs (i.e., not feeling good about self due to inactivity). Given the supporting data on psychological stressors increasing one's susceptibility to illness (Ellgring et al., 1993) and diminishing one's capacity to perform basic activities of daily living, it appears critical to evaluate the contributing factors to such distress in order to develop appropriate clinical interventions.

One area of research regarding the psychological aspects of PD has involved an examination of the coping strategies utilized by identified patients. Coping is defined as an effortful process of adapting to potentially challenging, threatening or harmful circumstances associated with a disease condition (Pearlin & Schooler, 1978). Numerous authors have investigated the association between the coping strategies (i.e., thoughts or actions) employed by individuals with a chronic illness and the impact of utilizing such strategies on psychological adjustment (e.g., Felton & Reverson, 1984; Hainsworth, Eakes, & Burkes, 1994). A variety of coping responses (e.g., information seeking, avoidance, seeking comfort from others, wish-fulfilling fantasy) have been associated with stressors accompanying specific disease conditions such as diabetes (e.g., Marrero, 1981), PD (e.g., Ehmann, Benninger, Gawel, & Riopelle, 1990), and rheumatoid arthritis (e.g., Lambert, 1981). Despite extensive research regarding individual coping responses to health-related stressors, there is a paucity of information regarding the specificity of their use according to the type and severity of the stressor encountered, the characteristics of the individual employing the strategies, or the extent to which the response used attenuates the stressful situation (Moos & Billings, 1980). Further, an examination of the relationship between demographic variables (e.g., age, education, occupation) and method of coping utilized is warranted as it may provide critical information as to the utility of particular intervention strategies with particular patients.

Additional studies have focused on the coping strategies utilized by caregivers and their reported levels of psychological well-being (Quayhagen & Quayhagen, 1988; Stephens et al., 1988). Whereas both the patient and caregiver literature individually address the relationship between use of specific strategies and reported levels of psychological adjustment, no research has synthesized these areas to determine if the strategies independently employed by the patient and the caregiver influence each other's level of adjustment. More specifically, certain strategies employed by patient and caregiver dyads may facilitate the adjustment process, while other combinations may hinder it. An examination of this type of information gleaned from patient-caregiver dyads could provide information critical for the development of beneficial interventions. It is believed that such interventions could promote circular patient and caregiver well-being (i.e., the more positively adjusted the caregiver feels, the better care they provide for the patient, which ultimately effects the patient's perception of well-being, and vice versa).

The ability to effectively cope with a chronic illness is additionally influenced by the predictability of the disease condition. Research with other disease states (e.g., cancer; Patterson, 1981), has demonstrated that chronically ill individuals who experience increased levels of uncertainty (i.e., they are less able to predict the outcome of the disease state) report diminished levels of overall adjustment to the condition. Previous work by Webster and Christman (1988) demonstrated a relationship between increased levels of uncertainty and use of affectively driven coping strategies, with lower levels of uncertainty being related to increased use of problem-focused coping methods. Overall, uncertainty in illness has been found to be a robust predictor of adjustment processes across a variety of disease states (e.g., Mullins, Chaney, Hartman, & Pace, 1997).

Thus, the purpose of the current research was as follows: 1) to identify the type of coping style predominantly used by patients and caregivers, 2) to identify the relationship between the coping strategies predominantly used by patients and his/her caregivers and their reported level of general adjustment and depression, and 3) to identify the relationships between level of uncertainty and the level of general adjustment and depression reported by patients and their respective caregivers. Additionally, exploratory analyses were conducted to determine: 1) the combined relationship of patient and caregiver variables (i.e., coping strategy, functional ability, level of uncertainty) to general adjustment and depression, and 2) the reciprocal influence of patient participants' general adjustment, coping strategy, and uncertainty on caregiver adjustment (and vice versa).

The following will be a review of the literature regarding Parkinson's disease, coping and adjustment to a chronic illness, and information regarding the caregivers and support systems of individuals afflicted with a chronic illness. First, the pathogenesis of Parkinson's disease is presented, followed by the physiological and psychological aspects of the condition. Next, an overview of the coping research regarding the patient and his/her caregivers/support systems will be provided. Finally, the research questions posed in the current study are specified.

Review of the Literature

History and Pathogenesis

In 1817, James Parkinson recognized a constellation of symptoms occurring among certain individuals characterized by resting tremors, abnormal posture, and difficulties in gait. These physical symptoms appeared to run a progressive course that was degenerative in nature (Parkinson, 1814). Parkinson believed that although the patient's physical condition appeared to deteriorate as a result of the disease, the "senses and intellect" remained intact. Further, Parkinson identified other psychological consequences of the disease, including demoralization and "increasing debilitation that causes the influence of the will over the muscles to fade away" (Parkinson, 1814, p.8). It was also recognized that patients differed both in their adaptation to the disease, and how the disease affected their ability to complete the activities of daily living (e.g., irritability, diminished hand writing skills, difficulties with gross motor movements). Parkinson's initial description of the psychological sequelae surrounding Parkinsonianism was later elaborated upon by many researchers and clinicians, who subsequently elucidated concomitant conditions of the disease, such as depression, stubbornness, and irritability (Ball, 1812; Konig, 1912; Oppenheim, 1908; all as cited by Mjones, 1949).

Two separate perspectives, termed the "psychosomatic" and the "somatopsychic" viewpoints, evolved in relation to the etiology of the psychological conditions associated with Parkinson's disease. Researchers supporting the early "psychosomatic" position believed that the conditions underlying Parkinson's disease, both physical and psychological in nature, occurred as a result of intrapsychic conflict (Patrick & Levy, 1922). The psychosomatic proponents hypothesized that psychological trauma or loss predisposed individuals to the disease and that the motor symptoms identified with the disease were actually physical manifestations of suppressed unconscious hostility (Jelliffe, 1940). Jelliffe likened the typical Parkinsonian stance to that of a "boxer or wrestler prepared to battle their opponent" (Jelliffe, 1940, p.33). This stance purportedly represented hostility and a preparedness to lash out aggressively. Contemporary research and knowledge of the disease process, however, suggest that the psychosomatic interpretation of Parkinson's disease was grossly inadequate and credulous. This perspective, however, was historically important in that it represented an era that failed to acknowledge the biochemical processes underlying various medical and psychological conditions (e.g., migraine headaches, ulcers). Knowledge of the physiological mechanisms of PD were not adequately gleaned or understood until the 1960's (Praag, 1979).

In contrast to the psychosomatic perspective, the viewpoint of individuals favoring the "somatopsychic" perspective was ahead of its time. Such adherents believed that the psychological symptomatology demonstrated by individuals with Parkinson's disease was a result of the disabling nature of the disease itself. Wilson (1921) suggested that the psychological symptoms of the disease were the "natural outcome perhaps of an incurable disease...explicable by the nature of the ailment" (p.7). The somatopsychic perspective hypothesized that while the motoric difficulties identified in patients with Parkinson's disease were organically based, they had a significant effect on the patient's family relations, concept of self, and emotions. The social and psychological impairments that occurred in Parkinsonian patients were expected and were regarded as secondary reactions to the primary physical symptomatology of the disease (Machover, 1957; Diller & Riklan, 1956). Such psychological symptoms were viewed as normal "psychopathology" that occurred in relation to the patients' inability to perform tasks that were previously standard functions of daily life. This view was later supported by Riklan, Weiner & Diller (1959), who found that patients with more severe physical impairments were significantly more emotionally distressed.

During the 1960's and 70's, research investigating the neurochemical underpinnings of Parkinson's disease began to flourish. Of importance was the examination of the role of one particular neurotransmitter, dopamine, in the symptoms identified as Parkinsonian in nature. The role of dopamine was elucidated by three major findings: a) discovery of dopamine in the substantia nigra, b) significantly less dopamine in the substantia nigra of people who had died from Parkinson's in comparison to individuals who had died of other causes, and c) evidence that Parkinson's patients treated with large doses of L-dopa (i.e., direct precursor of Dopamine which boosts activity at dopaminergic synapses) demonstrated a significant temporary reduction in identified symptoms. These discoveries resulted in a transition in clinical examination of the psychological/physical conditions of Parkinson's disease from one focusing on the psychosocial correlates to one with biomedical underpinnings.

Structural Pathology

With the advent of scientific technology [e.g., Magnetic Resonance Imaging (MRI), Positron Emission Tomography (PET), immunocytochemical methods], the brain structures affected by Parkinson's disease have become better understood (e.g., Martin & Palmer, 1989). Five anatomically and functionally interconnected subcortical structures, collectively called the basal ganglia, appear to be associated with Parkinson's disease (Emson et al., 1989; Young & Penney, 1988). The components of the basal ganglia include the caudate nucleus, putamen (neostriatum), the globus pallidus (internal and external segments), the subthalamic nucleus, and the substantia nigra.

The most identifiable overt physical anomalies, which can only be recognized post-mortem, are located in the substantia nigra. The pathological manifestations of PD in the substantia nigra include; 1) degeneration and loss of pigmented neurons in the pars compacta (subdivision of the substantia nigra), and 2) the presence of Lewy and hyaline bodies. Typically, 60-80 percent of the nigral striatal neurons have degenerated in patients demonstrating the characteristic symptoms of PD. For patients in the advanced stages of the disease, or those who have a long history of PD (Roberts, Leigh, & Weinberger, 1993), nigrostriatal deterioration may almost be complete. Lewy and hyaline bodies are composed of free fatty acids, polysaccharides, proteins, and sphingomyelin. Among individuals with PD, Lewy and hyaline bodies appear intraneuronally as halo encapsulated bodies of radially arranged filament material of approximately 5-10nm in diameter (Jellinger, 1989). Although the presence of Lewy bodies are a tell-tale sign of PD (essential for post-mortem pathological diagnosis of PD), such anomalies are identified in approximately 5 percent of the normal population (i.e., not diagnosed with PD) of individuals over 65 who experienced no PD-type symptoms during their lifetime (Roberts et al., 1993). An increased presence of Lewy bodies inhibit the appropriate interrelated functioning of the substantia nigra and the other components of the basal ganglia, and ultimately leads to the physical characteristics of PD (Wooten, 1990).

Pathophysiology

The basal ganglia (i.e., neostriatum, globus pallidus, subthalamic nucleus, substantia nigra) are highly interconnected with other areas of the brain such as the neocortex, the ventral thalamus, and the superior colliculus. For individuals with PD, the influence of the basal ganglia's neurochemical output, via the ventral anterior and ventral lateral thalamus, on the areas of the cortex is of significance. Here, the neurophysiological functioning (or malfunctioning) of these localized mechanisms [i.e., hyperactivity (i.e., over activity) or hypoactivity (i.e., inhibition of activity)] is directly associated with the observable triad of PD symptoms. The relationships between the structures of the basal ganglia, and the influence of their output on the cortex via the nigro-striatal pathway will be discussed so as to elucidate the pathophysiological mechanisms of PD (Delwaide & Gonce, 1993).

The neostriatum receives inputs from the central cerebral cortex, and projects this information (via the pallidal and nigral systems) to the thalamus, which in turn projects to the neocortex (Young & Penney, 1988). This communication system is termed a regulatory loop whereby the subthalamic nucleus forms a reciprocal pathway (glutamatergic) with the globus pallidus (Delwaide & Gonce, 1988). Some information leaving the basal ganglia utilizes a different pathway. Efferent neurons branching from the pars reticulata of the substantia nigra (SNR) project directly to the peduncular pontine nucleus and superior colliculus, which directly effect the brain stem reticular formation (associated with cortical tone and certain aspects of posture) and systems regulating eye movements. The neostriatum also receives afferent projections from the pars compacta of the substantia nigra (SNC), and from the ventral tegmental area [(VTA) (Beckstead, Bomesick, & Nauta, 1979)]. In Parkinson's disease, there appears to be a pathological increase in the activity of the projections from the neostriatum to the external segment of the globus pallidus. This increase in activity is with the neostriatal release from inhibition by the degenerated nigrostriatal pathway, which leads to an increase in excitatory output activity of the subthalamic nuclei (STN). The projection of STN neuronal activity to the internal and external segments of the globus pallidus is increased resulting in a surge of GABAergic neuronal firing from the Globus pallidus internal which ultimately suppresses neurons in the ventral thalamus (Penney & Young, 1981). The communication which takes place within and across these structures are neurochemical in nature. These neurochemicals, called neurotransmitters, play a critical role in the interrelated functioning of the brain structures. Simplistically stated, changes in neurotransmitter availability or the ability for neurons to appropriately communicate may result in the symptoms such as those identified with PD as the interrelated operations of the brain structures required for proper functioning have been altered.

Neurochemical pathology of PD

The dopamine hypothesis of PD was generated in the 1960's as a byproduct of the development of technology allowing researchers to examine the biochemical underpinnings of various diseases. Degeneration of specific dopaminergic neurons is identified in the pars compacta area of the substantia nigra. Ehringer and Hornykiewicz (1960) demonstrated that individuals with PD showed significantly reduced levels of dopamine concentration. Such dopamine deficiency in the neostriatal system (more specifically the putamen), conjointly with the demonstration of the triad of physical symptoms, provide the evidence for a PD diagnosis (an actual PD diagnosis can only be given post-mortem with identification of Lewy bodies). Routine Positron Emission Tomography (Pet) scans using F-dopa can easily detect such depletion in the caudate nucleus and the putamen. Whereas it is normal for dopamine levels to decrease as a function of age, the characteristic motoric symptoms of PD occur with accelerated nigral dopaminergic neuronal loss (60-70%) which results in neostriatal dopamine levels to decrease by approximately 80 percent. Decreased dopaminergic activity in the striatum is believed to be associated with symptoms of PD such as akinesia (Hornykiewicz, 1966; Bernheimer, Birkmayer, Hornykiewicz, Jellinger, & Geitelberger, 1973), however research has failed to elucidate the actual physiologic role of the basal ganglia in producing such motor movement.

Etiology

PD symptoms appear to begin when approximately 80% of the dopaminergic neurons have been depleted (Levin & Katzen, 1995). Three hypotheses have been developed to explain the "premature" deterioration of neurons in the substantia nigra that results in striatal dopamine depletion. First, a deficiency in the number of neurons in the substantia nigra could occur as a result of genetic irregularity (Lang, 1987). Such a genetic link has been refuted, however, due to a lack of evidence demonstrating either twin concordance or familial incidents of PD (Marttila, Kaprio, Kostenvuo, & Rinne, 1988; Ward et al., 1983). Second, it has been suggested that PD occurs as a result of an accelerated aging process in the brain. Research has demonstrated that individuals with PD have significantly fewer adequately functioning substantia nigra neurons (e.g., parts of the neurons may be missing a histone coat which leaves them vulnerable to mutagenesis), but such research is in it's infancy and few findings have been substantially supported empirically (Shapira et al., 1990a). A third hypothesis suggests that accelerated dopamine deficiency occurs as a result of a traumatic event (i.e., head injury, encephalitis; Godwin-Austen, Lee, Marmot & Stern, 1982; Mattock, Marmot, & Stern, 1988; Stern, Dulaney, & Gruber, 1991), or contact with an environmental toxin (Young & Perry, 1986). It is believed that such injuries do not, in and of themselves, cause PD, but may result in acute loss of neurons, which is subsequently compounded by the typical degradation of neuron functioning that occurs with age.

Signs and symptoms

PD symptoms emerge in an insidious, gradual manner and are often apparent initially as non-specific minor aches, pains, and cramping that may be identified as typical signs of aging (Marsden, 1994). The patient or his/her relatives may notice a general "slowing" of fine motor movements in the hands (evidenced by small, increasingly unintelligible writing), gross motor movements of the body (difficulty in gait or dressing), and dexterity. A physician can typically diagnose PD merely by having the affected individual sit next to his/her unaffected spouse or partner (Liberman, 1992). The patient's characteristic facial appearance, body posture, and gait are easily discernible when placed next to a "normal" individual.

Typical symptoms of PD include tremor at rest, akinesia, and rigidity (Delwaide & Gonce, 1988). Approximately 80% of individuals suspected of having PD exhibit tremor at rest (usually in the hands) at some point during their illness. Unilateral and bilateral tremor, while an important diagnostic feature of PD, is but one of the requisite symptoms for a PD diagnosis. Rigidity, akinesia and bradykinesia, and postural and gait difficulties must be thoroughly assessed in order to differentially diagnose PD from other neurological disorders such as hemiparesis, supranuclear palsy, or stroke. Akinesia and bradykinesia refer to motor problems such as poverty of motor movement, decelerated motor movement, and difficulty in initiating movements that require dexterity. Stiffness or rigidity are other common symptoms demonstrated by individuals with PD that is evidenced by an increased resistance to passive limb and trunk movement. Problems with the lower extremities are also noted in abnormalities of gait and posture. Typically, individuals with PD demonstrate a hurried gate comprised of small shuffling steps interrupted by states of frozen stiffness. Such postural difficulties understandably result in an increased risk for falls.

The progression of PD, and its resulting effect on an individual's motoric ability, has historically been categorically measured via a variety of disability rating scales. One of the most noted scales is the Hoehn and Yahr rating scale (e.g., Lee et al., 1994;

MacCarthy & Brown, 1989), developed in the late 1960's. This scale provides a relatively rough estimate of the stage of illness progression identified by gait disturbance, postural stability and functional disability (i.e., walking and falling). Affected individuals are categorized into one of five stages of illness advancement. At stage I, the patient exhibits only unilateral symptoms and minimal functional disability (e.g., weakness in one hand and no difficulties with ambulation). By stage V, severe impairment is noted and the patient is typically bed-ridden and completely dependent on others to maintain the tasks of daily living for him/her. Gotham, Brown, and Marsden (1988) further categorized patients utilizing this system by identifying stages I and II as mild, stages III and IV as moderate, and stage V as severe. In general, the Hoehn and Yahr scales provides a means by which to classify disease progression in identified patients and thus allows for a common ground on which to make comparisons within and between groups of individuals afflicted by the disease. Based on the notion that individuals with PD experience a gradual and progressive decline in health that are both physical and emotional in nature, an examination across these domains is important in order to develop appropriate interventions targeting areas of potential decreased functioning.

Treatment of PD

Elucidation of the biochemical process (dopamine hypothesis) underlying the physical symptoms of PD led to extensive research on pharmacological treatments for PD symptoms. Some of these symptoms are believed to occur as a result of the neurotransmitter dopamine being "unavailable" in the synaptic cleft for transmission to subsequent neurons (Bernheimer et al., 1975; Wooten, 1990). Absence of dopamine in the cleft can occur as a result of the ingestion of drugs such as reserpine or tetrabenazine which block the vesicles that store dopamine leading to inhibition of it's release. This explains how non-PD patients can demonstrate Parkinsonian type symptoms as particular medications prescribed for other medical conditions can result in behaviors that are overtly identical to those symptoms identified with PD (e.g., tardive dyskinesia, tremors). Accessibility of dopamine in the synaptic cleft can be mediated by pharmacological agents, such as D-amphetamine and trihexyphenidyl, and can act as agonists by blocking the vesicles from which the dopamine was released. This process inhibits dopamine from rapid reuptake and thus allows for prolonged accessibility and action of dopamine in the cleft. Such treatment can only be beneficial, however, if sufficient levels of dopamine are formed and, ultimately, released into the synaptic cleft. It is believed that the symptoms identified with individuals with PD typically occur in relation to the depleted levels of dopamine found in the neuronal tissues which decreases the availability of neurotransmitters for dispersal by the vesicle.

Although it would seem logical to treat Parkinson's patients by providing them with the neurotransmitter in which they are deficient, direct administration of dopamine is ineffective as the blood-brain barrier prevents the dopamine in the blood from crossing-over into the brain. Currently, the overall drug treatment of choice for the dopamine insufficiency associated with PD is laevodopa (L-dopa). L-dopa is unaffected by the blood-brain barrier and is readily converted to dopamine by a substance, labeled l-AAD (L-aromatic main acid decarboxylase), that is located in the brain. The effects of L-dopa are quite significant as it drastically reverses the triad of characteristic Parkinsonian symptoms [(i.e., tremor, bradykinesia, rigidity), (Melamed, 1988)]. The conversion of L-dopa to dopamine, however, becomes jeopardized as dopaminergic neurons progressively die in PD patients, ultimately decreasing the number of potential sites for the conversion process to take place (Carlson, 1986). Thus, continuous treatment with

L-dopa appears to lose its effectiveness after approximately five years (Roberts et al., 1993; Wooten, 1990). Future directions in pharmacotherapy for PD look towards the development of pharmacological agents that stimulate dopamine receptors without requiring metabolic conversion. Formulation of these agents, however, is in its infancy (Wooten, 1990). In essence, long-term pharmacological treatment for PD is currently non-existent.

Although the biomedical research on the physical manifestations of PD has been conducted for less than fifty years, vast strides have been made in this area particularly concerning the possible reversal of PD symptomatology. During the years since the identification of PD as a chronic illness, other critical research has also been conducted in regards to the psychological substrates of the disease. The following sections are a review of the general research examining the premorbid personality factors and psychological sequelae of PD associated with PD. The role of these factors was examined in relation to their influence on the caregiver's and patient's ability to adjust to the disease condition.

PD "personality" and premorbid factors

Theories associated with the underlying neurochemical mechanism of PD patients suggest that premorbid factors shape their affective state and, ultimately, their resulting personality structure. Research associated with the pre-morbid PD personality has proliferated over the last 30 years with the ultimate hope of identifying individuals at risk for the development of PD. Various factors identified as being linked to the development of PD include upholding rigid moral codes (Camp, 1913), the industrial revolution (Mitscherlich, 1960), "teetotaling," and unresponsive parents [(Prick, 1966), (as stated by Hubble and Koller, 1995). More specifically, these researchers believe that a thorough examination of one's background could expose a history of behaviors that seemingly promoted the development of the conditions of PD. This research, while intriguing, has relied on ex post facto data (i.e., gathered historical information from patients following diagnosis) and is believed to be distorted by the patient's current level of functioning (Hubble & Koller, 1995). Empirically derived data regarding the development of a PD "personality" has yet to be found.

Psychological sequelae of PD

In addition to the physical sequelae of PD, individuals with PD also appear to suffer considerably from various psychosocial problems that emerge as secondary symptoms to their primary physical symptomatology (Ellgring et al., 1990). The most prominent of these psychosocial difficulties is clinical depression. Although depression is a typical feature of many chronic illnesses such as cancer (e.g., Weisman, 1979), stroke (e.g., VanderPlate, 1984), and multiple sclerosis (e.g., Beatty, 1993), research has demonstrated that individuals with PD report significantly higher levels of depression than patients with other disease conditions (Ehmann et al., 1990; Cartell et al., 1986; Horn, 1974; Robins, 1976). Such findings, however, may be a function of the type of measure utilized to assess affect in each of these populations. Although not all individuals with PD evidence clinical levels of depression, prevalence rates average between 30% and 50% (Cummings, 1993; Lieberman et al., 1979; Mayeux, Williams, Stern & Cote, 1984). Brown and Jahanshahi (1995) suggested that the stage of the individual's disease condition is related to prevalence rates as disruption of brain monoamines, which are the neurotransmitters implicated in the neurobiological basis of depression, become more severely effected with disease progression. Whereas the contribution of neurobiological factors to the presence of affective disturbance in PD is supported in the literature (Cummings, 1993; Huber, 1992; Mayberg, Starkstein, & Sadzor, 1990), the degree to which these factors actually contribute to depressive symptomatology in PD patients is unknown.

Brown and Jahanshahi (1995) suggest that the influence of individual psychological, unique medical (e.g., stage of illness, symptom severity), and general social factors on depressive symptoms in PD should be examined. These researchers hypothesize that psychological and social factors individually contribute to specific depressive symptoms in each patient at various stages of the disease process. Significant relationships, however, have only been identified between age of onset and depression (Starkstein et al., 1990; Gotham et al., 1988), rapid progression of disease symptomatology and depression (Brown, MacCarthy, Jahanshahi, & Marsden, 1989), and disability and depression (Starkstein et al., 1992).

Overall, other studies in this area have provided contradictory results, leading to the overall impression that disease-related factors are not always linked to the occurrence of clinical depression. It is suggested, however, that specific subgroups of PD (i.e., early onset, late stage) patients be more closely examined as they may be more vulnerable to affective disturbance. More specifically, these groups may be at risk for difficulties as they are either given a diagnosis that presents a grim future (i.e., early onset), or are experiencing a heightened expression of disease symptoms (i.e., late stage). Another explanation for the contradictory results may be the influence of other nondisease-related variables associated with the individual with PD (e.g., marital status, involvement in social activities) rather than a function of the disease condition itself. For example, divorced or single males diagnosed with PD may report higher levels of depressive symptoms than do their married counterparts.

Many debates continue to focus on whether depression occurs as a function of the biochemical underpinnings of PD or as a reaction to the diagnosis (Huber, 1992; Starkstein & Robinson, 1993). Regardless of the initial cause of the patient's depression, various factors in the patients' life can serve to propagate such feelings and ultimately intensify the patient's negative emotionality (e.g., chronicity of disease, impending deterioration, and increased inability to carry out typical daily functions). Due to the significant impact depression has on patient's overall well-being, the factors contributing to these depressive symptoms have been examined (e.g., Ehman, et al., 1990; Horn, 1974; MacCarthy & Brown, 1989). These influences, including background characteristics (e.g., age, education level) and previous situational experiences (e.g., how an individual handled previous situations involving stress), will be discussed for purposes of understanding variables that may contribute to, or be correlated with, the PD condition.

Throughout the course of a chronic illness, numerous problematic situations (e.g., variable changes in symptom presence, illness task demands, uncertainty associated with the illness) arise that necessitate the use of coping strategies by the patient and his/her caregiver. A close examination of the various types of coping responses used by individuals in stressful situations (e.g., chronic illness) and resultant levels of adjustment (i.e., depression) could provide critical information on the types of coping responses that lead to poorer overall adjustment. Whereas some research has investigated the use of particular coping strategies by individuals with PD (Ehmann et al., 1990), these findings are not generalizable to all individuals effected by the disease condition. Thus, additional research is needed that investigates the use of particular coping strategies by individuals with PD. In the next section, literature on the use of coping strategies will be reviewed in relation to the PD condition.

Coping literature

The stress experienced by individuals with PD is hypothetically mitigated by the number and severity of symptoms present, the degree to which these symptoms interfere with daily task demands (e.g., work, family, social), availability and use of a support system, and the patients perception of disease manifestation (Blenner, 1992; Crawford & McIvor, 1987; Gurkies & Menkes, 1988; Fennell & Smith, 1990; Larsen, 1990; Matsen & Brooks, 1977; Pollack, Christian, & Sands, 1990; Wineman, 1990). The influence of these variables on resulting adjustment is believed to be mediated by the process of coping (Folkman & Lazarus, 1988; Warren, 1990).

Coping has been defined as any belief or behavior that deals with some aspect of a situation evaluated by an individual to be taxing or exceeding his/her emotional or cognitive resources (Lazarus, 1993). Coping is a process whereby strategies are employed in the hopes to avoid the negative consequences (e.g., depression, stress) of encountering the conflicts and demands in life (Lazarus & Folkman, 1984; Pearlin & Schooler, 1978). Efforts have been made to classify these coping strategies as either method-based or focus-based according to the intent or goal of the individual employing the strategy (Moos & Billings, 1981). Method-based coping is divided into active cognitive or behavioral strategies geared toward resolving the event (e.g., seeing the positives of the situation, seeking additional information), or avoidant responses whereby stress is reduced by avoiding active confrontation of the problem (e.g., keeping feelings to yourself, engaging in eating or smoking behaviors to indirectly reduce tension). Focused-based coping is composed of two categories: problem-focused and emotion-focused coping (Lazarus, 1980; Pearlin & Schooler, 1978). Problem-focused coping strategies are geared towards modifying or eliminating the sources of stress through one's own behavior (e.g., identify a route to work that bypasses traffic and thus reduces stress), while emotion-focused strategies are geared towards venting feelings in order to regulate emotions in situations deemed unchangeable. Often this type of coping involves seeking support and assurance from others. Due to the amount of research on the problem- and emotion-based approaches in the chronic illness literature, the coping responses of interest to the present study will be limited to the focus-based system.

Research has demonstrated that in situations involving generalized stressors (i.e., not specific to health issues), problem-focused coping is the most widely used strategy (Cohen & Lazarus, 1979). Folkman and Lazarus (1988) found that planful problem solving (problem-focused strategy) was associated with less negative and more positive emotions, unlike distancing (an emotion-focused strategy), which was significantly correlated with a negative emotional state. These researchers found that in certain situations involving significant long term health problems, emotion-focused coping strategies were more likely to be used than problem-focused strategies (Folkman & Lazarus, 1980). Lazarus (1993) suggests the rationale behind differential use of these strategies is associated with the situation's amenability to change; when stressful conditions are perceived as refractory to change, problem-focused strategies would be futile and thus emotion-focused coping predominates. Lazarus (1993) suggested that the efficacy of either strategy is dependent upon the particular person using it, the stressor encountered, and what modality is being studied. More specifically, neither coping strategy should be identified as "good" or "bad"; rather, use of one strategy versus the other under some circumstances may result in better or worse adjustment.

The efficacy of a coping strategy, be it problem-focused or emotion-focused in nature, is measured by the degree to which the perceived stress of the event is attenuated, not whether use of the strategy led to complete cessation of the stressful situation (Pearlin & Schooler, 1978). More specifically, individuals typically attempt to deal with the stress experienced within these situations as they arise, rather than attempt to decrease/control the likelihood of the event's occurrence, which, in the case of a chronic illness like PD, is impossible. How individuals cope may significantly impact the adjustment to stressful situations, including stress that arises as a function of having a chronic disease. Information on the use of particular coping methods used by patients and caregivers affected by PD may aid in the development of literature for use by these individuals to increase the likelihood of better general adjustment to the disease condition. To date, no research has investigated the relationship of coping strategies utilized by individuals with PD and their caregivers and overall adjustment.

The ability of chronically ill patients to control or manage their symptoms, maintain a positive outlook, adjust to major role changes, and to feel "normal" is a constant, daily struggle. This struggle is further complicated by the uncertainty of their disease's cause or progression, and the severity of impending disability. Because PD is such an insidious and unpredictable disease, an examination of the role of perceived uncertainty and coping is critically important.

Uncertainty in Illness

The perception of control an individual experiences in stressful situations is typically associated with the amenability of that situation to change, which is typically determined by the information available regarding the details of that event. With the appropriate amount of information, one can determine whether they will be able to control the consequences of an event and thus could act accordingly. For example, a work deadline is given for the end of the week for which I have adequate information to know what is expected, and can plan my schedule so that I can meet that deadline. In this example, an individual can predict with relative certainty the outcome of the event based on the information they possess regarding that situation.

In situations associated with health related issues, uncertainty is defined as a person's inability to determine the meaning of the illness-related events. Uncertainty is described by Mishel and Epstein (1990) as a "cognitive state created when the person cannot adequately structure or categorize an event due to a lack of sufficient cues" (p. 1). In these situations, the individuals directly or indirectly affected by the health issue cannot accurately predict the outcome of the condition (e.g., symptoms, severity of illness, impact on future). Whereas the notion of uncertainty has been examined with some disease conditions, such as Post-polio syndrome (Balderson, Sanders, & Mullins, 1998), adult cancer (Patterson, 1981), adolescent cancer (Neville, 1998), and HIV/AIDS (Brashers, et al., 1998), no research has examined a PD population in regards to their use of emotion- or problem-focused coping strategies under conditions of perceived uncertainty. The current study will address this issue by surveying the patient and his/her caregiver's level of uncertainly regarding PD, and the relationship between respective levels of uncertainty and reported levels of adjustment.

In addition to the stress experienced by patients regarding the prospects of physical degradation and emotional maladjustment, is the awareness of the negative consequences that the disease condition may have on his/her significant others. Individuals in the initial stages of PD may recognize that the progressive deterioration of the disease may result in their placing a significant burden on immediate family members. As symptom severity increases, care providers are introduced to new and more encumbersome responsibilities that typically result in increased levels of emotional and physical stress. Although a seemingly important area of research, literature regarding the impact of caring for a chronically ill individual is in it's infancy.

Caregivers/support systems

The effects of an individual's chronic illness on his/her caregivers and/or family members are areas of research gaining more attention in recent years (e.g., Compas, Worsham, Ey, & Howell, 1996; Dura, Haywood-Niler, & Keicolt-Glaser, 1990; Lutzky & Knight, 1994). Several recent articles have focused primarily on the reciprocal impact of the patient-caregiver relations on general physical and emotion functioning (e.g., Shelly & Quittner, 1998; Williamson, Shaffer & Shelly, 1998). Caregiving to a chronically ill or disabled friend or family member is typically viewed as inducing stress that may place the caregiver at an increased risk for physical or emotional hardships (Compas et al., 1990; Deimling & Bass, 1986; George & Gwyther, 1986; Speer, 1993). Strudiwick, Mutch & Dingwall-Fordyce (1990), found that of 227 PD patients, only 27% lived in a hospital or residential setting, while 73% of the remaining 173 patients required some form of aid in completing his/her daily routine at home. Thus, based on previous literature, it appears that the majority of patients with PD reside with a caregiver, and, when coupled with the knowledge of the impending degradation of the afflicted individual, makes research in this area critically important.

Tausing (1992) examined the influence of social networks and identified support systems on caregivers reported levels, and perception of burden. This research suggests that the level of support caregivers receive is a critical factor as it facilitates their being able to provide the required assistance to the chronically ill or disabled individual. Lutzky & Knight (1994) examined gender differences in caregiver distress. Of importance is their finding that male caregivers may be utilizing coping techniques that appear to result in decreased levels of depression and feelings of burden as compared to females caregivers. These researchers found that the majority of women tended to utilize emotion-focused coping strategies (e.g., avoiding confrontation, accepting personal blame, relying on social support), while men used more problem-focused, direct methods of coping. Extrapolation of this data must be done cautiously however, as it may be confounded. More specifically, individuals identified as caregivers may differ in that male caregivers tend to be the spouse of the affected individual, while female caregivers are either wives or daughters (Lutzky & Knight, 1994). It is logical to assume that of the female caregivers, those who are daughters may encounter increased levels of stress as they may be confronted with other issues, such as role reversal with the chronically ill parent and attempting to maintain other life roles (e.g., wife, mother).

Carter and Carter (1994) and Dura et al. (1990) specifically examined spousal adjustment and spousal caregiving thereby eliminating all other relative caregivers. The Carter and Carter (1994) study focused on the effects of a chronic illness on marital adjustment and examined patient's health and gender as predictors of reactions to the disease condition. Results indicated that males who were married adjusted significantly better to the caretaker role than did single individuals, or females in general. Dura et al. (1990) examined spousal caregivers of PD patients with dementia to those of Alzheimer's patients with senile dementia (SDAT). Results from this study suggest that caregivers of PD and SDAT patients did not differ on measures of distress regardless of SDAT's insidious onset and precipitous decline as compared to the gradual deterioration of PD. The similarities between these groups of care providers examined by Carter & Carter and Dura et al., could be a function of the likeness of symptoms demonstrated by patients afflicted with a chronic illness.

Speer (1993) examined the relationships among PD patient's functional impairment and patient and caregiver psychosocial adjustment both cross-sectionally and longitudinally. The results of this study suggest that initial caregiver support, level of depression and sense of burden predicted patient's malaise, as defined by increased scores on the Sheikh and Yesavage Geriatric Depression Scale (1986) and the distress scale of the Duke-North Carolina Health Profile (Parkerson et al., 1981). Further, poor initial caregiver adjustment was negatively associated with the patient's sense of physical well-being over time. A relationship was also demonstrated between reported levels of patient and caregiver depression. Overall, this study was a preliminary attempt to individually examine both the patient and the caregiver with the intent of elucidating the relative influence of each individual's (patients and caregivers) adjustment on each other. Although such research is intriguing, the small sample size, lack of differentiation among PD severity type, and use of questionably appropriate assessment devices (e.g., questions unable to be answered by PD patient due to cognitive impairment) limits this study's generalizability. Further, it is unclear as to whether caregivers were informed to fill out particular measures with answers regarding themselves, or their interpretation of how the patient would respond to such an item. Regardless, it is apparent that acquisition of information on the factors that may affect caregiver and patient participant's ability to adjust to a chronic is disease state is an area demanding additional attention. Procurement of this information could facilitate more positive interactions between the patient-caregiver dyad, as well as increase the general adjustment process to the disease condition.

Statement of Purpose

Due to the progressive and deteriorating nature of PD across family interaction dimensions, and emotional and physical functioning, it is important to identify risk factors that contribute to negative adjustment to the disease condition. Thus, the purpose of the current study was: 1) to identify the type of coping responses predominantly used by patients and caregivers, 2) to identify the relationship between the coping strategies predominantly used by patients and his/her caregivers and their reported level of adjustment, and 3) to identify the relationships between level of uncertainty and the level of general adjustment and depression reported by the patient and his/her respective caregiver. It is believed that a thorough examination of the responses both within and between the patient and caregiver groups would provide information as to how these individuals cope with stressful situations in general, and whether one method of coping used by patients is correlated with decreased levels of adjustment reported by caregivers (and vice versa). The following hypotheses are made in conjunction with these investigations:

1. Patients and their caregivers would utilize more emotion-focused coping than problem-focused coping. Consistent with Folkman and Lazarus (1980), it is believed that patients would predominantly utilize coping strategies that alter their feelings regarding the stress resulting from their diagnosis (i.e., emotion-focused strategies), as the conditions inherent in this situation are considered unchangeable or uncontrollable.

2. Individually analyzing caregiver and patient populations, those participants utilizing emotion-focused strategies would have poorer levels of adjustment (as measured by increased SCL-90-R scale scores), and increased levels of depression [as measured by the Inventory for Diagnosing Depression (IDD)] than those using a problem-focused approach.

3. Caregivers and patients with higher levels of uncertainty would also report poorer overall adjustment (as measured by the SCL-90-R subscales and the GSI scores, and the IDD).

Exploratory analyses were also conducted to determine those factors which may influence the level of adjustment (as measured by the SCL-90-R GSI scores and the IDD depression scores) reported for both patients and caregivers. Specifically, the ability to complete activities of daily living (ADLs), use of emotion/problem-focused coping strategies and the level of uncertainty (MUIS) were examined separately for both patient and caregiver participant groups to determine the degree to which these variables contributed to the prediction of GSI and depression. A zero-order correlation was also conducted to determine if the Clinical Disability Scale (Hoehn & Yahr, 1967), which assesses the stage of disease progression, was related to either the GSI or IDD. Additional exploratory analyses were performed to examine the relative influence of specific patient variables (i.e., level of adjustment, coping strategy used, level of uncertainty, level of depression) on caregiver's reported level of global adjustment and depression. Identical analyses examining the relationship between caregiver variables (i.e., level of adjustment, coping strategy used, level of uncertainty, level of depression) and patient global adjustment and depression were also completed.

Method

Participants

Individuals who attended local PD support groups affiliated with the American Parkinson's Disease Association (APDA) were recruited to participate in the study. To be included, participants were determined to be a patient-caregiver dyad in which both members were willing to participate. All participants were asked to complete their questionnaires at home and return the packets via a self-addressed stamped envelope. A total of 44 patient-caregiver dyads (70%) returned completed protocols.

The total patient participant sample was comprised of 31 males (71%) and 13 females (29%), with a mean age of 72.8 (SD = 7.2) and a range of 49 to 88 years of age. The caregiver sample included 11 males (25%) and 32 females (73%: one caregiver did not complete all portions of the questionnaire), with an average age of 70 (SD = 8.3) and an age range of 47 to 87. The mean age of the patient population at the time of diagnosis was 66 years (SD = 7.9). Thus, average duration of illness was 6.5

years (SD = 3.8). Ninety-one percent of the patient population and 93% of the caregiver population reported their marital status as married. Nine percent of the patient sample and sixteen percent of the caregiver population reported that they were currently employed.

On the Hoehn and Yahr Clinical Disability rating scale, 39% of the patients were rated as "moderately" impaired with the remaining 59% being distributed across the "mild", "mild-moderate", "moderate-severe," and "severe" categories (22%, 17%, 19%, and 2%, respectively). Thus, 78% of the sample fell into the mild to moderate range of functioning. Average income for both the patient and caregiver samples was an estimated $30,000 to $40,000 annually per household; education level averaged 15 years (SD = 3) for the patient participants and 14 years (SD = 2) for the caregivers. Ninety-six percent of the patient participants and eighty-six percent of the caregiver participants reported that they were currently attending a Parkinson's disease support group. Ninety-one percent of the dyads were classified as spousal relationships, five percent were parent-child relationships, and the remaining four percent were comprised of hired help or constituted missing data. No statistical differences were found across dependent measures based on the type of patient-caregiver relationship (husband-wife vs. parent-child; all p values > .05).

Measures

Demographic Information. Following acquisition of a signed informed consent form for participation (see Appendix A), the first set of items provided to the subject contained questions pertaining to demographic information. Two separate demographic forms (patient and caregiver versions) were used (see Appendix C and D; Appendix B is an informational sheet containing directions for the subject and potential referral sources if psychological services were warranted).

Inventory for Diagnosing Depression (IDD). The Inventory for Diagnosing Depression (IDD; Zimmerman et al., 1986) was utilized as a general measure of emotional adjustment to the PD condition (see Appendix E). The IDD is a self-report inventory comprised of items designed to diagnose major depression and the severity of depressive symptomatology. The criteria delineated in the DSM-III-R (APA, 1987) was utilized to develop item inclusion on the IDD (diagnostic criteria did not change for the DSM-IV), resulting in applicability of scores to the diagnosis of clinical depression. The IDD is an internally consistent and reliable measure of depression-related symptoms and is significantly correlated with other depression inventories and with diagnoses based on clinical judgment (Goldston, O'Hara, & Schartz, 1992).

Patient and caregiver IDD summary scores (with higher scores being associated with decreased adjustment) were used to examine the relationship between depressive symptomatology and specific variables including the MUIS, WOCL (both problem- and emotion focused), ADLs, and stage of PD rating scale (See Tables IIa and IIb). The IDD was also utilized as a criterion variable in exploratory multiple regression analyses to determine the relationship between patient participant's depression and a variety of caregiver predictor variables (e.g., MUIS, GSI). Additional identical analyses were conducted to explore the relationship between caregiver participant's depression and a variety of patient participant variables.

Activities of Daily Living (ADL). The ADL measures used in the current study are revisions of the Instrumental Activities of Daily Living (IADL; Lawton & Brody, 1969), which was developed to measure functional ability (see Appendix F and G). Whereas the basic information assessed by each item was maintained, wording of the items on the revised versions was simplified in order to facilitate readability for participants. Two separate measures were developed with wording changes to individually target caregivers (e.g., "When using the phone, the individual with PD typically...") and patients with PD (e.g., "When using the phone, I..."). Frequency data, with values between zero and two, were tabulated across items with zero representing mild to no impairment, and two indicating severe deficits in functional impairment. These measures provide information regarding the extent to which patient's ability to accomplish the tasks of daily living is effected by the physical manifestations of PD. The ADL measure was used in exploratory hierarchical multiple regression analyses to determine the relative influence of patient's ability to complete these tasks on both patient and caregiver participant level of adjustment (GSI) and symptoms of depression (IDD).

Hoehn & Yahr Clinical Disability Rating Scale-Revised. The original Hoehn and Yahr (H-Y; 1967) measure of clinical disability is a self-report measure utilizing a five-point rating system to categorize the stage of illness manifestation (see Appendix H). This measure was minimally modified for the current study so that caregivers could act as informants regarding the patient's current level of disability. Although the criteria for each stage of disability was maintained, additional descriptions of criteria and examples of behaviors identifiable at each stage were provided in order to facilitate appropriate categorization of each patient. The rationale regarding the utilization of third party informants is two-fold; 1) physical self-assessment by individuals with PD has low validity (Golbe & Pae, 1988), and 2) the measure is somewhat complex and time consuming, which may lead to undue frustration for the patient. Overall, it is believed that the observations made by the primary caregiver during the course of providing care are sufficient for accurate identification of a patient's current stage of disability.

PD ratings were used to examine the relationship between severity of disability and variables assessing measures of adjustment (GSI, IDD), type of coping strategy utilized (problem- or emotion-focused), and level of uncertainty (MUIS). These analyses were exploratory in nature.

Mishel Uncertainty in Illness Scale-Community Form (MUIS-CF). The MUIS-CF (Mishel, 1981) is a self-report instrument that measures subjective feelings of uncertainty in relation to five illness-related categories: 1) symptoms, 2) diagnosis, 3) treatment, 4) relationships with caregivers (patients), and 5) plans for the future (see Appendix I and J). Separate forms were developed for use with patients (23 items) and with caregivers (29 items). Normative data was compiled from eight samples of individuals with medical condition (e.g., cancer, Myocardial Infarction, Multiple Sclerosis). For this study, the 23 items that are identical in content but different pronouns were used (e.g., I feel that the doctors are doing their best for me, versus I feel that the doctors are doing their best for him/her). Participants rated each item on a five-point Likert scale ranging from 1 (strongly disagree) to 5 (strongly agree). Mishel's scoring system was used wherein point values for each item are totaled, resulting in a summary score for the measure with higher scores representative of higher uncertainty. The measure has been used extensively with chronically ill populations (Stetz, 1989; Webster &

Christman, 1988) to assess the influence of illness-related events. The MUIS has a moderate reliability estimate of .71 for the normative sample. For this study internal consistency was high for the caregiver participant sample (alpha = .82) and moderate for the patient sample (alpha = .63).

Revised Ways of Coping Checklist (WOCL). The WOCL is a measure used to determine the specific coping strategies utilized by individuals to cope with a stressor that recently occurred in the participant's life. The WOCL was given to both patient and caregiver participants in the current study (see Appendix K). To maintain consistency with the basic purpose of this measure (Folkman & Lazarus, 1980), participants were asked to rate a general stressful situation experienced within the previous month rather than requesting information on a specific disease-related stressor. Previous research suggests that focusing on disease-specific rather than general stressors does not increase the amount of variance explained when examining the level of adjustment in medically involved participants (Beatty, 1993; Jean, 1996; Sanchez, 1996). Thus, how individuals cope with daily or general life stressors may be a better predictor of psychological adjustment than would information on how these individuals cope with disease-specific stressors.

Based on this rationale, participants in this study were asked to provide information on a recent general stressful situation (e.g., location of the event, individuals involved, occurrences in the situation) and responded to questions assessing use of emotion- or problem-focused coping. Responses were recorded via a four-point Likert type scale with endpoints of "0", representing no use of a particular strategy, and "3" representing a strategy that is often employed (Folkman & Lazarus, 1988).

Eight different factors or subscales have been identified. Seven of these scales are described as emotion-focused (escape-avoidance, distancing, self-controlling, confrontative coping, accepting responsibility, positive reappraisal, and seeking social support) and one is described as problem-focused (planful problem-solving). To facilitate analyses, coping strategies were categorized as either emotion- or problem-focused coping. Reliability information for the emotion- and problem-focused coping scales was high for both patient participants (alphas = .77 and, .83 respectively) and caregiver respondents (alphas = .89 and .91, respectively).

Coping responses can be scored using both relative scores (percent of effort) and mean subscale scores (frequency count). Relative scores were utilized in the present study as they have been identified as presenting a more accurate reflection of individual coping differences (Vitaliano, Mauino, Russo, and Becker, 1987). Relative scores were obtained by dividing each mean subscale score (i.e., raw scores divided by the respective number of items on that scale) by the sum of the other mean subscale scores (including the numerator subscale). Relative scores were utilized for both the problem-focused and emotion-focused scales.

Symptom Checklist-90-Revised (SCL-90-R). The SCL-90-R is a self-report inventory consisting of 90 items used to measure the emotional adjustment of both the patient participant and his/her caregiver to PD (see Appendix L). The SCL-90-R was designed to assess the presence of psychopathology in psychiatric and/or medical settings. The measure takes an average of 20 minutes to complete, has high internal consistency (.77-.90), high test-retest reliability (.78-.90), and has separate gender norms and norms for both community and psychiatric patients. Community norms were used for the purpose of the study. The SCL-90-R's nine clinical subscales that assess psychological distress include: somatization (som), obsessive-compulsive symptoms (obs), interpersonal sensitivity (ins), depression (dep), anxiety (anx), phobic anxiety (pho), psychoticism (psy), paranoid ideation (par), and hostility (hos). The SCL-90-R also provides a composite index, the Global Severity Index (GSI), which is a combination measure of the intensity of perceived distress (PSDI), and the number of symptoms experienced. The GSI was used as the primary criterion variable in hierarchical multiple regression models assessing the influence of predictor variables on level of adjustment for both patient and caregiver participants. The GSI was also used as a predictor variable to determine it's influence on the level of depression reported by participants. Based on previous studies which have examined the psychosocial aspects of disease syndromes (Beatty, 1993; Dakof & Mendelsohn, 1986; Tate et al., 1993), the SCL-90-R GSI, Somatization, Depression, Anxiety, Obsession/Compulsion, Hostility, and Interpersonal Sensitivity subscales were also used as secondary dependent variables in the current study.

The clinical significance of subscale score elevations can be assessed through examination of T-scores (i.e., M=50, SD=10) and via caseness (Derogatis & Spencer, 1989). The caseness criterion for maladaption has been utilized to assess adaptation to chronic illness (Thompson, 1985: Thompson et al., 1992). Caseness is defined as a GSI score, or two or more subscale scores, equal to or greater than 63.

Procedures

The methods, participants and procedures used in this study were developed in accordance with American Psychological Association guidelines and were approved by Oklahoma State University's Institutional Review Board prior to its initiation. Subjects were recruited during the monthly APDA support group meetings held in three metropolitan cities. Subjects were provided both verbal and written instructions for completing the questionnaire packet. In addition, each packet, which was marked to identify individual dyads, included the researchers' phone numbers for any questions that might arise while completing the packet at home. One dollar was donated to the National Parkinson's Disease Foundation for each completed packet.

Two separate packets were provided for the patient-care provider dyads. Both packets included the following measures: the Symptom Checklist-90 Revised (SCL-90-R; Derogatis & Spencer, 1989), the Inventory for Diagnosing Depression (IDD; Zimmerman et al., 1986), Mishel's Uncertainty in Illness Scale-Community form (MUIS-CF; Mishel, 1981), and a demographic questionnaire. Packets also included separate caregiver and patient versions of the Ways of Coping Checklist (WOCL; Folkman & Lazarus, 1988). Caregiver packets also included a revised version of the Hoehn and Yahr clinical disability rating scale.

Overview of Analyses

The overall purpose of the current research was to identify the type of coping strategy predominantly utilized by individuals with PD and their caregivers, elucidate the relationship between patient and caregiver use of particular coping strategies and general adjustment and depression; and to examine the relationship between perceived level of uncertainty toward their chronic condition and overall adjustment. Psychological adjustment, as measured by the SCL-90-R GSI and the IDD scores, were used as the criterion variables, while the remaining variables (i.e., functional ability, coping strategy, level of uncertainty) were used as predictors of adjustment to the disease condition. To provide a context for interpretation of results, Derogatis and Spencer's (1989) criteria for caseness, a more stringent diagnostic criteria for the SCL-90-R, was also used to determine the percentage of the current total sample evidencing psychological or emotional maladaption. IDD scores were also analyzed to determine the percentage of the caregiver and patient participants reporting symptoms consistent with DSM-IV criteria for diagnosis of Major Depression. Means and standard deviations for each of these measures by group can be found in Table 1.

To examine hypothesis 1, relative coping scores were calculated for both the patient and the caregiver groups to determine the type of coping strategy predominantly employed by members of each group. For hypothesis 2, which targeted use of emotion-focused coping and its association with level of overall adjustment, zero order correlations were performed to examine the relationship between SCL-90-R T-scores, IDD scores, and emotion-focused coping. To examine the relationship between level of uncertainty (MUIS) and overall adjustment (Hypothesis 3), zero order correlations were conducted on MUIS scores and variables assessing adjustment level (SCL-90-R subscale and GSI scores, and the IDD).

Due to the potential for shared variance between demographic, functional ability, coping strategies utilized and adjustment, exploratory hierarchical multiple regressions were also conducted in order to examine the relative contribution of these factors to adjustment of both patients and caregivers. Thompson's Transactional Stress and Coping Model (Thompson et al., 1992; Thompson et al., 1994), which is based on Folkman and Lazarus' model of coping and adaptation, was employed as a guide for variable selection and order of entry. This model utilizes a multivariate conceptual framework that identifies chronic illness as a stressor to which the individual and his/her associated systems (e.g., caregivers) attempt to adapt. Thompson's model incorporates a variety of factors (e.g., disease parameters, demographics) believed to influence the adjustment outcome of individuals and has been used in various other studies examining adjustment to chronic illness (Thompson et al., 1994). Thus, this model was used to determine the unique variance contributed by variables believed to mediate the illness-outcome relationship above and beyond the contribution of illness and demographic parameters. Based on this theoretical framework, GSI and IDD scores were used as the criterion variables. For patient and caregiver groups, separate models were constructed with simultaneous entry of age and gender first, followed by functional ability (ADL), coping strategy (emotion- or problem-focused), step 4 represented level of perceived uncertainty, and lastly, an interaction variable of MUIS and the coping strategy entered in step 3.

Additional analyses were conducted to explore the influence of caregiver participant use of emotion- or problem-focused coping and level of uncertainty on patient adjustment using the GSI and IDD as separate criterion variables. An identical regression model was constructed to determine if patient scores on these measures contributed to the prediction of caregiver GSI and/or IDD.

Results

Preliminary Analyses

A series of preliminary analyses were first performed to examine the effects of the patient's gender and employment status on all primary measures. A 2 X 2 (gender x employment status) multivariate analysis of variance revealed no main effects or interactions for the SCL-90-R Global Index Score (GSI), the IDD, the MUIS, or the WOCL (both problem- and emotion-focused strategies; all p values > .05). An identical Manova examining caregiver gender and employment status revealed no main or interaction effects on the aforementioned measures (all p values > .05). A Manova was also performed to examine patient-caregiver relationships on all dependent measures. This procedure allowed for the examination of all main effects and possible interactions among interrelated dependent measures. Analysis of data in this study demonstrated no main effects or interactions among the patient and caregiver dependent measures (all p values > .05). An additional Manova was performed to determine if differences on the dependent measures occurred due to the type of dyads utilized in this study (marital versus parent-child or hired help). No significant main effects or interactions occurred among these dyads on these measures.

T-scores for patient participants on the SCL-90-R scales of Depression, Anxiety, Somatization, Obsessive-compulsiveness, and GSI, were all at least one standard deviation above the normative group mean of 50. On the MUIS, the patient participant mean score was one standard deviation above the normative sample.

For the caregiver participant sample, the means for each SCL-90-R subscale were all within one standard deviation of the normative mean. For the MUIS, the caregiver participant group's mean score was at least one standard deviation above the normative group mean. The IDD mean summary score for the caregiver participant group was not clinically significant.

The data was then further examined to ascertain level of adjustment as measured by the SCL-90-R and IDD. Using Derogatis and Spencer's (1989) criteria for caseness, 77% of the patient population (n=33) and 30% of the caregiver population (n=12) evidenced significant levels of maladaption as defined by caseness. Further, eighteen percent of the patient participants, and five percent of the caregiver participants met DSM-IV criteria for diagnosis of Major Depression based on their IDD scores.

Zero-order correlations were then computed for the SCL-90-R scale scores, IDD scores, emotion- and problem-focused coping strategies, age, functional ability (ADLs), disability ratings, and uncertainty for the patient (see Table IIa) and caregiver participants (see Table IIb). For the patient participant sample, the depression subscale of the SCL-90-R was significantly positively correlated with PD disability rating ($p < .001$) and functional ability ($p < .01$). IDD summary scores for the patient participants were significantly positively correlated with level of uncertainty [(MUIS), $p < .05$] and functional ability [(ADL), $p < .01$). The ADL was also significantly positively correlated with the Global Severity Index subscale (GSI) of the SCL-90-R.

Caregivers' age was negatively correlated with the SCL-90-R depression scale ($p < .05$), anxiety scale ($p < .05$), somatization scale ($p < .01$), hostility scale ($p < .01$), obsessive/compulsiveness scale ($p <.01$), and the GSI scale ($p < .01$; See Table IIb). Caregiver participants scores on the MUIS were significantly positively correlated with the SCL-90-R depression subscale ($p < .05$), anxiety subscale ($p < .05$), and the GSI subscale ($p < .05$), and the IDD ($p < .01$). Caregiver participant's report on the patient's functional ability and the stage at which they are functioning did not significantly correlate with any of the SCL-90-R subscales or the IDD summary score.

Correlations were then conducted between patient and caregiver variables (See Table IIc). Significant correlations emerged between patient and caregiver MUIS ($p < .005$) and IDD ($p < .05$) scores, and patient participant's IDD summary score and both the caregiver participant's SCL-90-R depression subscale score ($p = .05$) and reported level of uncertainty ($p < .05$). No other significant correlations were noted between the participant groups on the dependent measures (i.e., MUIS and SCL-90-R subscale p values > .05).

Research Question 1: Type of coping style used by patient and caregiver participants

Examining the patient and caregiver groups separately, patient participants reported using relatively more problem-focused coping (52%) than emotion-focused coping (48%). Differences also occurred between caregiver's use of coping strategies (problem-focused: 57%; emotion-focused: 43%). Whereas patient and caregiver participant's use of more problem-focused than emotion-focused coping strategies was contrary to prediction, these percentages, while statistically significant are not believed to be clinically.

Research Question 2: Relationship between coping style and psychological adjustment.

For patient participants, emotion-focused coping was significantly correlated with increased scores on the SCL-90-R scales of depression, anxiety, obsessive/compulsiveness, and hostility, as well as the global measure of adjustment, the GSI (See Table IIa). Emotion-focused coping was also significantly and positively correlated with IDD scores. Notably, there was an inverse correlation between use of problem-focused coping and scores on the hostility and depression scales of the SCL-90-R. Consistent with hypothesis 2, the results indicate that use of emotion-focused coping was related to lower levels or poorer overall adjustment, while use of problem-focused coping was related to higher levels or better adjustment.

For caregivers, due to the significant correlation between age and level of GSI, semi-partial correlations were utilized to control for the effects of this variable on the remaining primary measures. Results of this analysis indicated that caregiver participants' utilization of emotion-focused coping was significantly and positively correlated with all subscales of the SCL-90-R, except the somatization scale (See Table IIb). A significant positive correlation was also found between use of emotion-focused coping and IDD summary score. Consistent with patient participant results, use of emotion-focused coping by caregiver participants was related to poorer overall adjustment and higher levels of depression. In contrast, caregiver participants' use of problem-focused coping was also related to increased levels of depression and hostility as measured by the SCL-90-R depression and hostility subscales. This relationship did not emerge between problem-focused coping and the IDD, which is a more stringent measure of depressive symptomatology.

Research Question #3: Relationship between level of Uncertainty and Adjustment

Zero-order correlations were computed for patient and caregiver participants on the MUIS and all scales of the SCL-90-R and the IDD summary score (See Tables IIa and IIb). Patient participants' MUIS scores were not significantly correlated with any of the SCL-90-R subscales or GSI scores (all p values > .05), but were significantly correlated to the IDD summary score ($p < .05$; See Table IIa). For caregiver participants, MUIS scores were significantly correlated with the SCL-90-R Depression ($p < .05$), Anxiety ($p < .05$), and GSI ($p < .05$) subscales and the IDD summary score ($p < .05$).

Overall, bivarate and semi-partial correlations were used to analyze three separate questions associated with patient participants with PD and their caregivers. Contrary to hypothesis 1, both the patient and caregiver participants reported using relatively more problem-focused coping than emotion-focused coping. Results largely supported hypothesis 2, which stated that use of emotion-focused coping would be associated with decreased levels of adjustment for both patient and caregiver participants. Partial support was also found for hypothesis 3, which concerned the relationship between increased uncertainty and poorer overall adjustment for caregiver participants and increased uncertainty and increased depressive symptomatology for patients. To better understand the relationships between the constructs examined in this study, several exploratory hierarchical multiple regression analyses were subsequently conducted.

Exploratory Analyses

Regression Analyses

Exploratory hierarchical multiple regression analyses were then performed on the patient and caregiver data to examine the relative contribution of demographic variables (gender, age), functional ability (ADLs), coping strategy, and uncertainty to the prediction of general adjustment (GSI scores) and depression (IDD scores). The Hoehn and Yahr (1967) Clinical Disability Scale (used to assess stage of disease progression) was not incorporated into the models as this instrument did not significantly correlate with the GSI scale or the IDD summary score for either the patient or caregiver participant samples. Thompson's (1985) Transactional Stress and Coping model was used to guide the entry of the variables into the model. For each equation, demographic data was entered simultaneously on the first step (age, gender), followed by functional ability, and then entry of emotion-focused or problem-focused coping (in separate models). Uncertainty scores were then entered on step 4 of each equation, followed by subsequent entry of an interaction variable comprised of a MUIS total score and emotion-focused coping (or MUIS total score and problem-focused coping; See Tables III-VI). Thus, the regression analyses were hierarchical between sets and stepwise within sets (Cohen & Cohen, 1983).

A stepwise multiple regression analyses was conducted using demographic variables (i.e., age, gender), functional ability, level of uncertainty, and use of emotion- or problem-focused coping strategies to predict level of general adjustment (GSI score). For the patient population, results revealed that age and gender (step 1) and functional ability (ADL) significantly contributed to the prediction of global adjustment (See Table III). In equation 1 of this model, after controlling for steps 1 (age and gender) and 2 (functional ability), the remaining variables [problem-focused coping, level of uncertainty (MUIS), and the combined interaction variable of MUIS and problem-focused coping] did not contribute significant variance to the GSI. In equation 2, however, after controlling for the demographics variables and for functional ability, emotion-focused coping was found to be a significant predictor of global adjustment on the GSI ($p <.005$). The MUIS variable (step 4) and the interaction variable of MUIS and emotion-focused coping were not significant.

For the caregiver population, after controlling for demographic parameters, functional ability, and use of problem-focused coping (all p values > .05), only the MUIS variable contributed significant unique variance to the prediction of GSI in equation 1 (See Table IV). In equation 2, after controlling for the demographic variables and functional ability (ADLs), both the emotion-focused coping variable (step 3) and the MUIS variable (step 4) significantly contributed to the prediction of the GSI. There were no interaction effects obtained between the MUIS and the individual coping strategies in either equation 1 or 2 of this model.

Hierarchical multiple regressions were also performed to examine the relative contribution of demographic parameters (age and gender), functional ability, coping strategies, and uncertainty to depressive symptoms as measured by the IDD (See Tables V and VI). Separate patient and caregiver models were developed, each beginning with simultaneous entry of age and gender, followed by functional ability summary score, and individual entry of emotion- or problem-focused coping. Uncertainty was entered on step 4, followed by an interaction term of uncertainty and one of the coping strategies on step 5.

For patients, after controlling for demographic parameters, a significant main effect emerged between functional ability and depressive symptomatology as measured by the IDD (See Table V). No other main effects were found for the remaining variables in equation 1 of this model (problem-focused coping, MUIS, and the interaction variable of MUIS and problem-focused coping) and the IDD. In equation 2, after controlling for demographic variables and functional ability on step 1 and 2, emotion-focused coping significantly contributed to the prediction of depressive symptoms as measured by the IDD (See Table V). No effects were found for either the MUIS variable or the interaction variable of MUIS and emotion-focused coping on depressive symptomatology in equation 2.

Results for identical analyses with the caregiver participants demonstrated that after controlling for demographics and functional ability, steps 3, 4, and 5 of equation 2 (i.e., emotion-focused coping, MUIS, and the interaction variable of the MUIS and emotion-focused coping) all significantly contributed to the prediction of IDD. This suggests that individuals who may be experiencing higher levels of uncertainty may resort to more emotion-focused coping strategies which may result in higher levels of depressive symptomatology.

Finally, additional exploratory hierarchical multiple regression analyses were performed to examine the relative contribution of caregiver participant variables (GSI, emotion/problem-focused coping, level of uncertainty) to the prediction of patient participant's level of adjustment (GSI; See Table VII). No significant main effects emerged (all p values > .05). Analyses were also conducted to determine the contribution of the patient participants' variables (GSI, coping strategy and uncertainty) to the prediction of caregiver participants' GSI (See Table VIII). In this model, a significant main effect emerged for patient use of problem-focused coping and caregiver GSI scores.

Discussion

The purpose of the present study was to identify the type of coping style predominantly used by patient and caregiver participants, and to determine the relationship between both the type of coping strategies used, and the level of uncertainty on overall level of adjustment (GSI and depression) of participants with PD and their caregivers. Primary predictors of overall level of adjustment used in this study included functional ability, emotion- and problem-focused coping strategies, and level of uncertainty. More specifically, the study focused on determining if patient participants with PD and their caregivers predominantly use one type of coping strategy, whether use of one type of coping strategy was associated with problems of adjustment, and if the inclusion of the level of uncertainty experienced by the participant was also significantly related to adjustment (i.e., GSI, IDD).

Based on the assumption that chronic medical conditions involve various demands and stressors that are perceived as unchangeable or uncontrollable (e.g., physical degradation, progressive deterioration), it was hypothesized that individuals with PD would more often utilize coping strategies that involve affect (i.e., emotion-focused), rather than ones geared toward modifying the situation (i.e., problem-focused) which may appear to be ineffective given the circumstances of the disease state. Counter to predictions and previous research on individuals with chronic medical conditions (Billings & Moos, 1981; Compas et al., 1996; Folkman & Lazarus, 1980), participants with PD utilized significantly more problem-focused coping than emotion-focused strategies. Such results may be due in part to the unique characteristics of individuals involved in chronic disease support groups. These individuals may represent a subset of the PD population that is more actively confrontive in their approach to addressing the problems that arise with the PD condition. The underlying goal of these support groups is the dispersion of information on how best to manage the PD condition, which in and of itself defines use of problem-focused coping. Thus, patients may actively engage in behaviors suggested by their peers as being helpful in the management of their disease (e.g., mix your medication with ginger ale in the morning and you will avoid the symptoms of nausea typically experienced when taking this pill alone). Although speculative, it may also be that patients' increased use of problem-focused coping is a result of their compliance with caregiver suggestions/aide regarding management of disease related tasks.

Also contrary to prediction and previous literature (e.g., Pratt, Schmall, Wright, Cleland, 1985), it was found that caregiver participants' predominately used problem-focused coping versus emotion-focused coping. Again, it may well be that the reported use of more problem-focused methods may be inherently related to the task of providing direct care to the patient. More specifically, the intrinsic role of the caregiver is to attenuate the difficulties experienced by the patient (e.g., facilitating the accomplishment of daily tasks for the patient) which demands the use of active problem-solving strategies (e.g., needing to install rails in the shower to facilitate bathing). Thus, the relatively higher use of active strategies by caregiver participants may be functional in that some day-to-day difficulties can be managed through use of active problem-solving strategies.

Consistent with other investigations of individuals with chronic medical conditions (Cummings, 1993; Ehmann et al., 1990; Larson, 1978; Palmore & Likert, 1972), individuals with PD appear to be at significant risk for experiencing increased levels of both general and specific distress as compared to healthy counterparts. In comparison to community norms, the current results indicate that individuals with PD evidence higher levels of distress as measured by examination of SCL-90-R scale scores and the IDD. Patient participants in this sample reported significantly higher levels of depression, anxiety, obsessive/compulsiveness, somatization and Global Symptom Severity (as measured by the GSI) in comparison to available norms. Of particular note is the disproportionately high percentage of patient participants (77%) meeting the SCL-90-R caseness criteria. This finding is important as it indicates that individuals in the patient participant group are experiencing significant difficulty in adapting to their chronic illness (Thompson, 1985: Thompson et al., 1992) that is not being "picked up" by more specific measures of maladaption such as the IDD. Thus, these individuals appear to be experiencing significant difficulties in mood across a variety general indices that, while not clinically diagnosable in any one area, combined may contribute to significant difficulties in overall adjustment.

Assessment of depressive symptoms (IDD) in the patient participants suggested that approximately 18% of this sample reported symptoms indicative of a Major Depressive Disorder. Previous research on depression in older adults found that approximately 3% of older adults presenting in a medical setting (Koenig & Blazer, 1992), and 3% of individuals in a community setting (Blazer et al., 1997) present with symptoms that can be diagnosed as Major Depressive Disorder. It was also found that stage of disease progression (Hoehn & Yahr, 1967) and decreased functional ability (measured by the ADL) were significantly correlated with the depression subscale of the SCL-90-R. These results indicate that as the disease progresses and affects more facets of the patient's physical functioning, their emotional functioning is placed in higher jeopardy as well.

Whereas the 5% of the caregiver participants reported symptoms that would warrant a diagnosis of Major Depression, when individually examining the severity of summary scores on the IDD, a large proportion of these scores were elevated (50%). Further, 30% of this participant group met the SCL-90-R caseness criteria which suggests they are experiencing a heightened difficulty in adjusting the disease condition. These findings are consistent with those of Shelly and Quittner (1998) who found that levels of depression increased in caregivers as the demanding and often unpleasantness of the tasks inherent in providing care to a chronically ill individual increased. In addition, research by Williamson, Shaffer, and Shelly (1998) suggests that caregivers' affect increases after having "helped" the person for which they provide care.

As hypothesized, patient use of emotion-focused coping strategies was significantly correlated with increased scores on the IDD which suggests a presence of a marked inability to cope with the stress associated with the chronic disease state. Also as predicted, use of emotion-focused coping by the patient participants was significantly correlated with increased SCL-90-R scores for depression, anxiety, hostility obsessive/compulsiveness, and global severity subscales. It is speculated that individuals with PD, like individuals with other disease conditions (Folkman & Lazarus, 1988; Lazarus, 1993), who may be feeling overwhelmed or hopeless may "give up" on taking active steps to make changes in their overall situation. More specifically, rather than identifying ways to decrease the effects of the condition, they may be focusing on the negative aspects of their disease which ultimately affects mood, or may be so riddled with symptoms of the condition (either directly or indirectly) that they are unable to take active steps to lessen the disease's affects on functioning in daily life. Whereas problem-focused coping may utilized more frequently by this sample, the relationship is evident that for those who resort to more emotion-based strategies, higher level of distress are noted.

Similar findings resulted for the caregiver population. Caregiver participant's use of emotion-focused coping was significantly correlated with increased IDD summary scores and SCL-90-R scores on the depression, anxiety, hostility, obsessive/compulsiveness, and overall global severity (GSI) subscales. It is speculated caregiver participants may resort to more emotion-focused coping strategies when problem-focused methods appear futile in the attempt to manage the affects of the patient's impending degradation on daily life events.

Of importance is the significant level of uncertainty reported the patient population in the current study. Means on the MUIS for the patient participants in this sample were much higher (x = 71) than those reported by Mishel (1990) for individuals with other general medical conditions, such as Myocardial Infarctions (x = 49), Coronary Artery Bypass (x = 60) and Multiple Sclerosis (x = 63). For patient participants in this study, increased levels of uncertainty was also significantly related to higher IDD summary scores. Based on this finding, it is speculated that increased levels of uncertainty about a disease (e.g., lack of knowledge regarding various facets of the chronic condition such as trajectory of degradation, time-line of disease progression) may have an adverse affect on the level of depressive symptomatology experienced by the individual diagnosed with the condition. Whereas a significant positive correlation emerged between patient participant's level of uncertainty and depressive symptomatology, the MUIS did not correlated with any other dependent measure in this study for this participant group. These findings may be due in part to the functional status of those participating in this study. Participants in this study were largely represented in the advancing stages of PD and, thus, it is surmised that their ability to anticipate impending physical degradation and disease progress may have been hampered. More specifically, assessment of uncertainty in these individuals may not be appropriate as they are less able to foresee changes in their health status or may no longer be cognizant of the possible course of their disease.

The MUIS appears to be a more salient predictor of adjustment for the caregiver participants in this study. For caregivers, increased scores on the MUIS was signficantly positively correlated with poorer general adjustment (GSI), and increased scores on the IDD and the SCL-90-R depression and anxiety subscales. Further, the MUIS was a significant predictor of general adjustment and depressive symptomatology above and beyond the effects of the coping strategy used or the patient's level of functional ability. It is postulated that caregivers may be significantly negatively affected by the uncertainty of disease manifestation, as increased symptomatology represents additional caretaking responsibilities. Logically, the addition of new caretaking obligations may result in the development of negative mood-related symptoms and lead to poorer overall adjustment.

Thus, the level of uncertainty encountered by both individuals directly (patient) and indirectly (caregiver) affected by the PD condition appears to be quite important in relation to their resultant emotional adjustment. The current findings may suggest that a general lack of information concerning the disease itself, and details regarding the anticipated progression of disease symptoms, may leave the patient and his/her caregiver more vulnerable to increased distress. Thus, appropriate dissemination of information regarding the general aspects of the disease and issues/symptoms to anticipate arising may potentially effect the severity of distress encountered. At the same time, it may well be that patients and caregivers may have adequate information about the disease, but still feel uncertain. In this regard, future research will need to ascertain the relationship between knowledge and uncertainty.

Exploratory analyses provided information as to additional variables that affect the level of overall adjustment for the patient population. It was demonstrated that age, gender, functional ability (ADL) and use of emotion-focused coping were all significantly associated with decreased adjustment and higher levels of depressive symptomatology. Logically, as people's age increases, the ability to complete the tasks of daily living becomes more difficult to complete due to natural physical changes that impede flexibility and mobility. Shelly and Quittner (1998) found that while only 4% of non-institutionalized individuals under the age of 55 require additional aide with accomplishing personal needs, this rate increases dramatically for individuals over 55 years of age. For this patient population, it is believed that the natural physical changes that occur may be perceived as advancing disease which, in this study, appears to have a deleterious affect on mood. It is surmised that patients experiencing impairment in their ability to complete the Activities of Daily Living (ADLs) may experience symptoms of the Learned Helplessness Phenomenon. More specifically, these individuals may enter a downward spiral of physical and emotional degradation: as their physical health decreases, their ability to complete the tasks of daily living may become compromised which may lead to feelings of hopelessness/helplessness. With several unsuccessful attempts to complete these tasks, they may lose confidence about their functional ability, and may ultimately give up on trying to accomplish these tasks all together. As a result of these changes in mood state, patient's may become less able to take a more active, problem-solving approach to coping and may resort to using more emotion-focused methods.

Examination the caregiver participant data indicates that the patient's functional ability, and the caregivers reported use of emotion-focused coping and level of uncertainty all contribute to the prediction of adjustment and depressive symptomatology in the caregiver participant sample. Such results suggest that caregivers providing care for individuals with decreased functional ability, under conditions of high uncertainty, tend to utilize coping strategies that are emotion-focused. It may be that providing these caregivers with techniques to both manage daily stressors associated with caring for an individual with a chronic disease and decreasing uncertainty, could change the type of coping strategy used, thereby enhancing their mood and ultimately their overall level of adjustment. This belief is supported by research conducted by Williams, Shaffer, and Shelly (1998) who found that caregivers reported higher levels of affect subsequent to providing aid that appeared to benefit the patient (e.g., changing the patient's position in bed and having the patient state they feel much more comfortable). Based on the information from the current study, caregivers who use emotion-focused coping (less direct, problem solving approach to patient care) may not receive this "positive" feeling as they may not be engaging in caregiving behaviors that result in ostensible, immediate (or long-term) benefit to the patient (e.g., scheduling a time for a bath rather than breaking down the steps needed to complete the task).

Lastly, the reciprocal influence of patient and caregiver variables on overall adjustment was examined. Surprisingly, the only significant correlation occurred between patient use of problem-focused coping and decreased caregiver adjustment. Such a relationship may have resulted from "head-strong" patients who attempt to manage their own condition, which may run counter to the strategies attempted by the caregiver (e.g., the caregiver believes one particular standing sequence is appropriate while the patient vehemently uses his own method to stand from a seated position). Whereas it is apparent that the physical and emotional state of each member of the dyad has an effect on the other [e.g., zero-order correlations for patient and caregiver participant's MUIS ($p < .05$) and IDD ($p < .05$)], the underlying mechanisms of interaction between these patient and caregiver variables are unknown. Additional research in this areas is warranted as it would provide more specific information about complex patient-caregiver dyad relationships that could facilitate the development of interventions targeting adjustment to the disease condition.

Several limitations are recognized within the current study. First, all participants utilized in this study were obtained from PD support groups. Individuals who seek/obtain help from support groups may possess characteristics/variables that are intrinsically different than non-participatory patients with PD and their caregivers. More specifically, the results of this study may reflect the type of coping strategies used, and levels of uncertainty and adjustment of individuals who seek self-help. To obtain a less biased participant sample, it is suggested that future studies include patients and caregivers obtained from sites independent from PD support groups (e.g., physicians specializing in geriatric medicine, geriatric day care facilities). An additional limitation of the current participant groups in the inclusionary criteria of a patient-caregiver dyad. In this sample, over 90% of these dyads reported their relationship as marital in nature. Consequently, the participants may represent a subset of the PD population that present with differential characteristics specific to the marital relationship. Thus, their marital satisfaction and/or the marital relationship they had prior to PD diagnosis may significantly impact how these individuals have adjusted to the disease condition. Individuals who do not have a spousal caregiver may have less support/nurturance and thus may react differently to the disease process.

A second limitation of this study is the use of self-report measures. Use of this form of data collection can result in a variety of method variance problems (e.g., high inter-item correlations). In order to decrease the potential for this to occur, future studies would benefit from incorporating a variety of independent measurement modalities (e.g., structured interviews, chart review, physical ratings). Further, the financial status (the majority of participants in the current study would be considered middle class with minimal financial strain) and education level of this study's participants limits it's generalizability. Recruiting patient participants from a variety of SES backgrounds would minimize this limiting factor.

An additional limitation of this study was the failure to include a "normal" control group. Obtaining information on individuals with similar demographics (age, education, financial status) could increase support for the significant results found in this study. Without information from a normal control, we cannot be certain that the results obtained are truly "significant" and related to the variable targeted in this study (PD), or merely what may be considered "normal" for age-matched individuals with similar background characteristics.

Several suggestions are made for future research with this population. An examination of the relationship between use of PD specific medications (e.g., types, doses, times taken) currently being used by patient participants and both mood and the ability to complete ADLs could provide information on more efficacious treatment approaches. With the advent of more advanced medical treatments (e.g., gamma knife) and pharmacological agents, more research is warranted to better predict positive treatment outcomes (e.g., increased adjustment) and to anticipate potential negative treatment outcomes.

To more closely examine the relationship between use of particular coping strategies and adjustment to PD, it is suggested that researchers request information on two types of situations requiring the use of coping strategies. One situation should involve disease-related stressors, while the other situation would contain a more general, daily life stressors. This would allow for the acquisition of information on how coping strategies may change in response to the type of stressor for which they are used, or how individuals tend to resort to using the same type of coping strategy regardless of the situation at hand. Information of this sort could be used to determine if individuals with rigid coping repertoires (i.e., use the same type of coping strategy regardless of the stressor) or with a more flexible approach to coping have better overall adjustment to the disease process.

Lastly, it would behoove future researchers to gather information on specific stressors and task demands experienced by both patients and caregivers that have been minimally examined in empirical studies. During the acquisition of the data for this study, several topics of concern were routinely broached by both patients and caregivers across the various supports groups attended by this researcher. These issues include the development of severe sleep disturbance (most commonly symptoms indicative of REM behavioral disinhibition) subsequent to ingestion of particular medications used to treat PD, possible interactions of PD medications with over the counter drugs (e.g., antihistamines), changes in personality, and interest in sex. Addressing these questions may dramatically improve the general coping and adjustment for both the patient and caregivers as these issues may dramatically impact the daily functioning of these individuals.

In conclusion, while this study has provided useful information as to how individuals with PD attempt to cope with their chronic condition, it is apparent that the accumulation of information in this area is in it's infancy. Although gains are being made in understanding the broad reaching effects of the diagnosis of PD on both patients and caregivers, a critical link is missing in the conversion of the information obtained by researchers and the dissemination of this knowledge to those who would benefit most. Ideally, rather than merely identifying the symptoms and mechanisms of PD, future research in this area should address intervention efforts for individuals directly and indirectly affected by the disease with the hopes to ameliorate the struggles occurring in their daily life.

References

Beatty, W.W. (1993) Cognitive and emotional disturbances in multiple sclerosis. Behavioral Neurology , 11, 189-204.

Beckstead, R.M., Bomesick, V.B., & Nauta, W.J.H. (1979). Efferent connections of the substantia nigra and ventral tegmental area in the rat. Brain Research , 175, 191-217.

Bernheimer, H., Birkmayer, W., Hornykiewicz, O., Jellinger, K., & Geitelberger, F. (1973). Brain dopamine and the syndromes of Parkinson and Huntington. Journal of Neurological Sciences , 20, 415-455.

Billings, A.G., & Moos, R.H. (1984). Coping, stress, and social resources among adults with unipolar depression. Journal of Personality and Social Psychology , 46, 877-891.

Blenner, J.L. (1992). Stress and mediators: Patients' perceptions of infertility treatments. Nursing Research , 41(2), 92-97.

Brashers, D. E., Neigid, J. L., Reynolds, N. R., Haas, S. M. (1998). Uncertainty in illness across the HIV/AIDS trajectory. Association of Nurses AIDS Care Journal , 9, 66-77.

Brown, R.G., MacCarthy, B., Jahanshahi, M., & Marsden, C.D. (1989). Accuracy of self-reported disability in patients with Parkinsonism. Archives of Neurology , 46, 955-959.

Brown, R. & Jahanshahi, M. (1995). Depression in Parkinson's disease: A psychosocial viewpoint. In W.J. Weiner and A.E. Lang Eds. Advances in Neurology vol. 65: Behavioral Neurology of Movement Disorders . Raven Press: New York, 61-84.

Burke, M.L., Hainsworth, M.A., Eakes, G.G., & Lindgren, C.L. (1992). Current knowledge and research on chronic sorrow: A foundation for inquiry. Death Studies , 16, 231-245.

Camp, C.D. (1913). Paralysis agitans, multiple sclerosis and their treatment. In W.A. White, S.E. Jelliffe, & H. Kimpton (Eds.), Modern Treatment of Nervous and Mental Disease Vol. 2 (pp. 651-657). Bradford: Philadelphia.

Carter, R. E. & Carter, C.A. (1994). Marital adjustment and effects of illness in married pairs with one or both spouses chronically ill. American Journal of Family Therapy , 22, 315-326.

Cohen, F., & Cohen, P. (1983). *Applied multiple regression/correlation analysis for the behavior sciences* (2nd ed.). Hillsdale, NJ: Erlbaum.

Cohen, F., & Lazarus, R.S. (1979). Coping with the stresses of illness. In G.C. Stone, N.E. Adler, & F. Cohen (Eds.), *Health Psychology* (pp. 217-254). San Francisco: Jossey-Bass.

Compas, B. E., Worsham, N.L., Ey, S., & Howell, D.C. (1996). When mom or dad has cancer: II. Coping, cognitive appraisals, and psychological distress in children of cancer patients. Health Psychology , 15(3), 167-175.

Crawford, J.D., & McIvor, G.P. (1987). Stress management for multiple sclerosis patients. Psychological Reports , 61, 423-429.

Cummings, J.L. (1993). The neuroanatomy of depression. Journal of Clinical Psychiatry , 54 (Suppl. 11), 14-20.

Dakof, G.A., & Mendelsohn, G.A. (1986). Parkinson's disease: The psychological aspects of a chronic illness. Psychological Bulletin , 99(3), 375-387.

Deimling, G.T., & Bass, D.M. (1986). Symptoms of mental impairment among elderly adults and their effects on family caregivers. Journal of Gerontology , 41, 778-784.

Delwaide, P.J., & Gonce, M. (1988). Pathophysiology of Parkinson's signs. In J. Jankovic, & E. Tolosa (Eds.), Parkinson's Disease and Movement Disorders, (pp. 59-74). Urban & Schwarzenberg: Baltimore.

Delwaide, P.J., & Gonce, M. (1993). Pathophysiology of Parkinson's signs. In J. Jankovic and E. Tolosa (2 Eds.). Parkinson's Disease and Movement Disorders . Williams & Wilkins: Baltimore, 77-92.

Derogatis, L.R. (1977). SCL-90: Administration, Scoring and Procedures Manual for the Revised Version. Clinical Psychometric Research: Baltimore.

Diller, L., & Riklan, M. (1956). Psychosocial factors in Parkinson's disease. Journal of the American Geriatric Society , 4, 1291-1300.

Dura, J.R., Haywood-Niler, E., & Kiecolt-Glaser, J.K. (1990). Spousal caregivers of persons with Alzheimer's and Parkinson's disease dementia: A preliminary comparison. The Gerontologist , 30, 332-336.

Duvoisin, R.C. (1984). *Parkinson's disease: A guide for patient and family* (2nd ed.). New York: Raven Press.

Ehmann, T.S., Beninger, R.J., Gawel, M.J., & Riopelle, R.J. (1990). Depressive symptoms in Parkinson's disease: A comparison with disabled control participants. Journal of Geriatric Psychiatry and Neurology , 3, 3-9.

Ellgring, H., Seiler, Nagel, U., Perleth, B., Gasser, T., & Oertel, W.H. (1990). Psychosocial problems of Parkinson Patients: Approaches to assessment and treatment. In M.B. Streifler, A.D. Korczyn, E. Melamed, and M.B. H. Youdim (ed.). Pathology, and Therapy . Raven Press: New York, 349-354.

Ellgring, H., Seiler, S., Perleth, B., Frings, W., Gasser, T., & Oertel, W. (1993). Psychological aspects of Parkinson's disease. Neurology , 43 (Suppl 6):S41-S44.

Emson, P.C., Augood, S.J., Buss, T.N., Shoham, S., Price, J., Crossman, A.R., & Marsden, C.D. (1989). Studies on the chemical anatomy of the Basal Ganglia in Parkinson's disease and in animal models of Parkinson's disease. In D.B. Calne et al., (Eds.), Parkinsonism and Aging Vol. 36, (pp. 9-24). Raven Press: New York.

Felton, B.J., & Revenson, T.A. (1984). Coping with chronic illness: A study of illness controllability and the influence of coping strategies on psychological adjustment. Journal of Consulting and Clinical Psychology , 52(3), 343-353.

Fennell, E.G., & Smith, M.C. (1990). Neuropsychological assessment. In S.M. Rao (Ed.), Neurobehavioral Aspects of Multiple Sclerosis, (pp. 63-81). New York: Oxford University Press.

Folkman, S., & Lazarus, R.S. (1988). Manual for the Ways of Coping Questionnaire. Palo Alto, CA: Consulting Psychologists Press.

Folkman, S., & Lazarus, R.S. (1985). If it changes it must be a process: Study of emotion and coping during three stages of a college examination. Journal of Personality and Social Psychology , 48, 150-170.

Folkman, S., & Lazarus, R.S. (1980). An analysis of coping in a middle-aged community sample. Journal of Health and Social Behavior , 21, 219-239.

George, L.K., & Gwyther, L.P. (1986). Caregiver well-being: A multidimensional examination of family caregivers of demented adults. Gerontologist , 26, 253-259.

Godwin-Austen, R.B., Lee P.N., Marmot M.G., & Stern G.M. (1982) Smoking and Parkinson's Disease. Journal of Neurology, Neurosurgery, and Psychiatry , 45, 577-581.

Golbe, L.I., & Langston, J.W. (1993). The etiology of Parkinson's disease: New directions of research. In J. Jankovic and E. Tolosa (2 Eds.) Parkinson's Disease and Movement Disorders . Williams & Wilkins: Baltimore, 93-102.

Golbe, L.I. & Pae, J. (1988). Validity of a mailed epidemiological questionnaire and physical self-assessment in Parkinson's disease. Movement Disorders , 3, 245-254.

Gotham, A.M., Brown, R.G., & Marsden, C.D. (1988). "Frontal" cognitive function in patients with Parkinson's disease "on" and "off" loevadopa. Brain , 11, 299-321.

Gotham, A.M., Brown, R.G., & Marsden, C.D. (1986). Depression in Parkinson's disease: A quantitative and qualitative analysis. Journal of Neurology, Neurosurgery, and Psychiatry , 49, 381-389.

Growden, Corkin, Rosen (1990). Distinctive aspects of cognitive dysfunction in Parkinson's Disease. In M.B. Seiler, A.D. Korczyn, E. Melamed, and M.B.H. Youdines. Advances in Neurology, vol. 53. Parkinson's Disease: Anatomy, Pathology, and Therapy .

Gurkies, J.A., & Menkes, E.M. (1988). Identification of stressors and use of coping methods in chronic hemodialysis patients. Nursing Research , 37(4), 236-239.

Hainsworth, M.A., Eakes, G.G., & Burke, M.L. (1994). Coping with chronic sorrow. Issues in Mental Health Nursing , 15, 59-66.

Hoehn, M.M., & Yahr, M.D. (1967). Parkinsonism: Onset, progression and mortality. Neurology , 17, 427-442.

Horn, S. (1974). Some psychological factors in Parkinsonism. Journal of Neurology, Neurosurgery, and Psychiatry , 37, 27-31.

Hornykiewicz, O. (1966). Dopamine (3-hydroxy tyramine) and brain function. Pharmacological Review , 18, 925-964.

Hubble, J.P., & Koller, W.C. (1995). The Parkinsonian personality. In W.J. Weiner & A.E. Lang (Eds.), Behavioral Neurology of Movement Disorders (pp. 43-48). Raven Press: New York.

Huber, S.J., & Rao, S.M. (1991). Depression in multiple sclerosis. In Starkstein S.E., Robinson, R.G., eds. Depression in neurologic Disease (pp.84-96). Baltimore Md: Johns Hopkins University Press.

Hyman, M.D. (1972). Sociopsychological obstacles to L-DOPA therapy that may limit effectiveness in Parkinsonism. Journal of the American Geriatric Society , 20, 200-208.

Jean, V. M. (1996). The relationship between neuropsychological test performance and coping strategies in individuals with Multiple Sclerosis. Unpublished doctoral dissertation. University of Oklahoma.

Jelliffe, S.E. (1940). The Parkinsonian body posture: some considerations on unconscious hostility. Psychoanalytic Review , 27, 467-479.

Jellinger, K. (1989). Cytoskeletal pathology of Parkinsonism and aging brain. In D.B. Calne et al., (Eds.) Parkinsonism and Aging (pp. 35-56). Raven Press: New York.

Jellinger, K. (1990). New developments in the pathology of Parkinson's disease. Advances in Neurology, vol.53: Parkinson's disease: Anatomy, pathology, and therapy . Raven Press: New York, 1-16.

Lambert, V.A. (1981). Factors affecting psychological well-being in rheumatoid arthritic women. Unpublished doctoral dissertation, University of California, San Francisco, School of Nursing.

Lang, A.E. (1987). The genetics of Parkinson's disease. In W.C. Koller Eds. Handbook of Parkinson's Disease. Marcel Dekker: New York.

Larsen, P.D. (1990). Psychological adjustment in multiple sclerosis. Rehabilitation Nursing , 15, 242-247.

Larson, R. (1978). Thirty years of research on the subjective well-being of older Americans. Journal of Gerontology , 33U, 109-129.

Lawton, M.P., & Brody, E.M. (1969). Assessment of older people: Self-maintenance instrumental activities of daily living. The Gerontologist , 9, 179-186.

Lazarus, R.S., & DeLongis, A. (1983). Psychological stress and coping in aging. American Psychologist , 38, 245-254.

Lazarus, R.S. (1993). Coping theory and research: Past, present, and future. Psychosomatic Medicine , 55, 234-247.

Lazarus, R.S., & Folkman, S. (1984). *Stress, Appraisal, and Coping*. New York, Springer.

Lee, K.S., Merriman, A., Owen, A., Chew, B., & Tan, T.C. (1994). The medical, social and functional profile of Parkison's disease patients. Singapore Medical Journal , 35, 265-268.

Levin, B.E., & Katzen, H.L. (1995). Early cognitive changes and nondementing behavioral abnormalities in Parkinson's disease. In W. J. Weiner and A.E. Lang's Behavioral Neurology of Movement Disorders (pp. 43-48). Raven Press: New York.

Lieberman, A., Dziatolowski, M., Kupersmith, M., Serby, M., Goodgold, A., Korein, J & Goldstein, M. (1979). Dementia in Parkinson's disease. Annals of Neurology , 6, 355-359.

Lieberman, A. (1992). An integrated approach to patient management in Parkinson's disease. Neurologic Clinics , 10, 553-565.

Lutzky, S.M., & Knight, B.G. (1994). Explaining gender differences in caregiver distress: The roles of emotional attentiveness and coping styles. Psychology and Aging , 9(4), 513-519.

Machover, S. (1957). Rorschach study on the nature and origin of common factors in the personalities of Parkinsonian. Psychosomatic Medicine , 19, 332-338.

Marrero, D. G. (1981). Problem-focused versus emotion-focused coping styles in adolescent diabetics: A preliminary study. Paper presented at the American psychological Association, Los Angeles.

Martin, W.R.W., & Palmer, M.R. (1989). The nigrostriatal system in aging and Parkinsonism: In vivo studies with Positron Emission Tomography. In D.B. Calne et al., (Eds.), Parkinsonism and Aging (pp. 165-172). Raven Press: New York.

Marttila, R.J., Kaprio, J., Kostenvuo, M.D., & Rinne, U.K. (1988). Parkinson's disease in a nationwide twin cohort. Neurology , 38, 1217-1219.

Matsen, R.R., & Brooks, N.A. (1977). Adjusting to multiple sclerosis: An exploratory study. Social Science and Medicine (Vol. 2, pp. 2-16). New York: Pergamon Press.

Mattock, C., Marmot, M., & Stern, G., Could Parkinson's disease follow intra-uterine influenza-a speculative hypothesis (1988). Journal of Neurology, Neurosurgery, and Psychiatry , 51, 753-756.

Mayberg, H.S., Starkstein, S.E., & Sadzor, B. (1990). Selective hypometabolism in the inferior frontal lobe in depressed patients with Parkinson's disease. Annuals of Neurology , 28, 57-64.

Mayeux, R., Williams, J.B.W., Stern, Y., & Cote, L. (1984). Depression and Parkinson's disease. Neurology , 40, 241-251.

Melamed, E. (1988). Mechanism of action of exogenous L-Dopa Is it a physiological therapy for Parkinson's disease? In J.Jankovic & E. Tolosa (Eds.), Parkinson's Disease and Movement Disorders (pp. 87-94). Urban & Schwarzenberg: Baltimore.

Mishel, M.H. (1981). The measurement of uncertainty in illness. Nursing Research , 30, 258-263.

Mishel, M., & Epstein, D. (1981). Uncertainty in Illness Scales. Nursing Research , 30, 258-263.

Mitscherlich, M. (1960). The psychic state of patients suffering from Parkinsonism. Advances in Psychosomatic Medicine , 317-324.

Mjones, H. (1949). Paralysis agitans: A clinical and genetic study. Acta Psychiatrica et Neurologica , (Suppl. 54), 1-195.

Neville, K. (1998). The relationships among uncertainty, social support and psychological distress in adolescents recently diagnosed with cancer. Journal of Pediatric Oncology in Nursing , 15, 37-46.

Palmore, E., & Luikart, C. (1972). Health and social factors related to life satisfaction. Journal of Health and Social Behavior , 13, 68-80.

Parkerson, G. R., Gehlbach, S. H., Wagner, E. H., James, S.A., Clapp, N. E., & Muhlbaier, L. H. (1981). The Duke-UNC health profile: An adult health status instrument for primary care. Medical Care , 19, 806-828.

Patrick, H.T., & Levy, D.M. (1922). Parkinson's disease: A clinical study of 146 cases. Archives of Neurology & Psychiatry , 7, 711-720.

Pearlin, L.I., & Schooler, C. (1978). The structure of coping. Journal of Health and Social Behavior , 19, 2-21.

Penney, J.B., & Young, A.B., (1981). GABA as the pallidothalamic neurotransmitter: Implications for basal ganglia function. Brain Research, 207, 195-199.

Poewe, W., Karamat, E., Kemmler, G.W., & Gerstenbrand, F. (1990). The premorbid personality of patients with Parkinson's disease: A comparative study with healthy controls and patients with essential tremors. In M.B. Streitler, A.D. Korczyn, E. Melamed, and M.B.H. Youdim (Eds). Advances in Neurology, Vol.53: Parkinson's Disease: Anatomy, Pathology and Therapy . Raven Press: New York.

Pollack, S.E., Christian, B.J., & Sands, D. (1990). Responses to chronic illness: Analysis of psychological and physiological adaptation. Nursing Research , 39, 300-304.

Praag, H.M. (1979). Dopamine and the development of disorders of human behavior. In A. S. Horn, J. Korf, & B.H.C. Westerink (Eds.), The Neurobiology of Dopamine (pp. 655-677). Academic Press: New York.

Pratt, C. C., Schmall, V. L., Wright, S., & Cleland, M. (1985). Burden and coping strategies of caregiver to Alzheimer's patients. Family Relations , 34, 27-33.

Prick, J.J.G. (1966). Genuine Parkinsonism A psychosomatic, anthropological-psychiatric approach. Abs Work Congress of Psychiatry Madrid. Sandorama, special Number IV.

Quayhagen, M.P. & Quayhagen, M. (1988). Alzheimer's stress: Coping with the caregiver role. The Gerontologist , 28(3), 391-396.

Riklan, M., Weiner, H., & Diller, L. (1959). Somato-psychologic studies in Parkinson's disease. Journal of Nervous &Mental Disease , 129, 263-272.

Roberts, G.W., Leigh, P.N., & Weinberger, D.R. (1993). Neuropsychiatric Disorders . Wolfe: Baltimore.

Robins, A.H. (1976). Depression in patients with Parkinsonism. British Journal of Psychiatry , 128, 141-145.

Sanchez, D. (1996). Stress, coping and psychological adaptation of individuals with Post-polio sequelae. Unpublished doctoral dissertation. Oklahoma State University.

Santamaria, J., Tolosa, E., & Valles, A. (1986). Parkinson's disease with depression: A possible subgroup of idiopathic Parkinsonism. Neurology , 36, 1130-1133.

Seiler, S., Perleth, B., Gasser, T., Ulm, G., Oertel, W.H., & Ellgring (1992). Partnership and depression in Parkinson's disease. Behavioural Neurology , 5, 75-81.

Sheikh, J. I., & Yesavage, J. A. (1986). Geriatric Depression Scale (GDS): Recent evidence and development of a shorter form. In T. L. Brink (Ed.), *Clinical gerontology: A guide to assessment and intervention.* New York: Haworth Press.

Shelly, R. & Quittner, A. L. (1998). Caregiving for children and adults with chronic conditions: Introduction to the special issues. Health Psychology , 17, 107-111.

Steta, K. M. (1989). The relationship among background characteristics, purpose in life, and caregiving demands on perceived health of spouse caregivers. Scholarly Inquiry for Nursing Practice , 3, 133-153.

Shapira, A.H.V., Cooper, J.M., Dexter, D.T., Jenner, P., Clark, J.B., & Marsden, C.D. (1990a). Mitochondrial complex I deficiency in Parkinson's disease. Journal of Neurochemistry , 54, 823-827.

Speer, D.C. (1993). Predicting Parkinson's disease patient and caregiver adjustment: Preliminary findings. Behavior, Health, and Aging , 3(3), 139-146.

Starkstein, S.E., Boldere, P.L., Mayberg, H.S., Preziosi, T.J., Robinson, R.G. (1990). Depression in Parkinson's Disease. Journal of Nervous and Mental Disease , 178, 27-31.

Starkstein, S.E., Mayberg, H.S., Preziosi, T.J., Anrezejewski, P., Leiguarda, R., & Robinson, R.G. (1992). Reliability, validity, and clinical correlates of apathy in Parkinson's disease. Journal of neuropsychiatry and Clinical Neuroscience , 4, 134-139.

Stern, M., Dulaney, E., Gruber, S.B. (1991). The epidemiology of Parkinson's disease: A case-control study of young-onset and old-onset patients. Archives of Neurology , 48, 903-907.

Stephens, M.A.P., Norris, V.K., Kinney, J.M., Ritchie, S.J. W., & Grotz, R.C. (1988). Stressful situations in caregiving: Relations between caregiver coping and well-being. Psychology and Aging , 3, 208-209.

Strudwick, A., Mutch, W.J., & Dingwall-Fordyce, L. (1990). Parkinson's disease-function impairment and who helps. Clinical Rehabilitation , 4, 213-216.

Tate, D., Forchheimer, M., Kirsch, N., Maynard, F., & Roller, A. (1993). Prevalence and associated features of depression and psychological distress in polio survivors. Archives of Physical Medicine Rehabilitation , 74, 1056-1060.

Tausig, M. (1992). Caregiver network structure, support and caregiver distress. American Journal of Community Psychology , 20, 81-96.

Thompson, R., Jr. (1985). Coping with the stress of chronic childhood illness. In O'Quinn, A. (ed.), Management of Chronic Disorders of Childhood , G.K. Hall, Boston, MA, pp. 11-41.

Thompson, R., Jr., Gustafson, K., Hamlett, K., & Spock, A. (1992). Psychological adjustment of children with cystic fibrosis: The role of child cognitive processes and maternal adjustment. Journal of Pediatric Psychology , 17, 741-755.

Toedes, C.F. & Lees, A.J. (1985). The pre-morbid personality of patients with Parkinson's disease. Journal of Neurology, Neurosurgery, and Psychiatry , 48, 97-100.

VanderPlate, C. (1984). Psychological aspects of multiple sclerosis and its treatment: Toward a biopsychosocial perspective. Health Psychology , 3, 253-272.

Vitaliano, P.P., Maiuro, R.D., Russo, J., & Becker, J. (1987). Raw versus relative scores in the assessment of coping strategies. Journal of Behavioral Medicine , 10, 1-18.

Warburton, J.W. (1967). Depressive symptoms in Parkinson patients referred for thalamotomy. Journal of Neurology, Neurosurgery, and Psychiatry , 30, 368-370.

Ward, C.D., Duvoisin, R.C., Ince, S.E., Nutt, J.D., Eldridge, R., & Calne, D.B. (1983). Parkinson's disease in 65 pairs of twins and in a set of quadruplets. Neurology, 33, 815-824.

Warren, S. (1990). The role of stress in multiple sclerosis. In S.M. Rao (Ed.), Neurobehavioral Aspects of Multiple Sclerosis (pp. 196-209). New York: Oxford University Press.

Webster, K. K., & Christman, N. J. (1988). Perceived uncertainty and coping post myocardial infarction: A pilot study. Western Journal of Nursing Research , 10, 384-400.

Weisman, A.D. (1979). Coping with Cancer . New York: McGraw-Hill.

Williamson, G.M., Shaffer, D.R., Shelly, R. (1998). Activity restriction and prior relationship history as contributors to mental health outcomes among middle-aged and older spousal caregivers. Health Psychology , 17, 152-163.

Wilson, S.A.K. (1921). Diseases of the central nervous system. Oxford Medicine , 6,6-21.

Wineman, N.B., Durand, E.J., & Steiner, P.R. (1994). A comparative analysis of coping behaviors in persons with multiple sclerosis or a spinal cord injury. Research in Nursing and Health , 17, 185-194.

Wineman, N.B. (1990). Adaptation to multiple sclerosis: The role of social support, functional disability and perceived uncertainty. Nursing Research , 39, 294-299.

Wooten, G.F. (1990). Parkinsonism. In A.L. Pearlman & R.C. Collins (Eds.), Neurobiology of Disease (pp. 454-466). Oxford University Press: New York.

Young, V.W., & Perry, T.L. (1986). Monoamine oxidase B, smoking, and Parkinson's disease. Journal of Neurological Sciences , 72, 265-272.

Young, A.B., & Penney, J.B. (1988). Biochemical and Functional Organization of the Basal Ganglia. In J. Jankovic, & E. Tolosa (Eds.), Parkinson's Disease and Movement Disorders, (pp. 1-11). Urban & Schwarzenberg: Baltimore.

Zimmerman, D.E. Coryell, A. F. Corenthal, C. D., & Wilson, W. R. (1986). Inventory for Diagnosing Depression.

Table I. Means and Standard Deviations for All Dependent Measures

	Patient		Caregiver	
Dependent Measures	Mean	SD	Mean	SD
SCL-90-R				
Global Index Score	66.8*	8.96	55.0	10.5
Somatization	64.7*	10.7	51.5	11.1
Depression	67.2*	9.10	56.4	9.72
Anxiety	65.3*	10.6	53.2	9.57
Obs/Comp	68.8*	9.90	57.6	8.51
Hostility	52.1	11.3	50.7	9.44
MUIS	70.6*	11.5	67.3*	11.3
WOCL-PF	40.7	7.48	41.2	10.0
WOCL-EF	52.4	10.0	44.2	12.0
IDD	17.4	0.09	8.71	7.34

* Indicates at least one standard deviation above the mean
SCL-90-R = Symptom Checklist, 90 items, revised
MUIS = Mischel's Uncertainty in Illness Scale
WOCL-PF = Ways of Coping Checklist, Problem-focused
WOCL-EF = Ways of Coping Checklist, Emotion-focused
IDD = Inventory for Diagnosing Depression

Table IIa. Correlations for Patient Participants on Dependent Measures

	WOCL-PF	WOCL-EM	MUIS	AGE	ADL	PD Rating
SCL-90-R **GSI**	-.26	.49****	.14	-.16	.33*	.11
Somat.	-.17	.19	-.09	-.08	.16	-.12
Depress.	-.31***	.35***	.21	-.07	.43**	.33***
Anxiety	-.26	.36***	.20	-.21	.26	.17
Ob/Com	-.18	-.47**	.17	.21	.38*	.18
Hostility	-.32***	.27***	.13	.24	.23	.32
IDD Sum. Score	-.21	.39*	.17*	-.003	.53**	.19

*p < .05, **p < .01, **p < .005, ***p < .001, ****p < .0005.

GSI = Global Severity Index
Somat. = Somatization subscale
Depress. = Depression subscale
Ob/Com = Obsessive/Compulsive subscale
IDD Sum. = Inventory for Diagnosing Depression
WOCL-PF = Ways of Coping, Problem-focused
WOCL-EM = Ways of Coping, Emotion-focused
MUIS = Mishel's Uncertainty in Illness Scale
ADL = Activities of Daily Living Scale
PD Rating = Hoehn and Yahr's Stage of Disability Scale

Table IIb. Correlations for Caregiver Participants on Dependent Measures

	WOCL-PF	WOCL-EM	MUIS	AGE	ADL	PD Rating
SCL-90-R **GSI**	.23	.55*****	.33*	-.36*	-.16	-.04
Somat.	.14	.22	.13	-.45**	-.14	-.28
Depress.	.41***	.72*****	.35*	-.33*	-.04	.07
Anxiety	.12	.35*	.33*	-.27*	-.26	-.20
Ob/Com	.24	.54*****	.23	-.52**	-.21	-.14
Hostility	.28*	.47****	.07	-.50**	-.03	-.20
IDD Sum. Score	.09	.49****	.40**	-.12	.07	.05

*p < .05, **p < .01, ***p < .005, ****p < .001, *****p < .0005
GSI = Global Severity Index
Somat. = Somatization subscale
Depress. = Depression subscale
Ob/Com = Obsessive/Compulsive subscale
IDD Sum. = Inventory for Diagnosing Depression
WOCL-PF = Ways of Coping, Problem-focused
WOCL-EM = Ways of Coping, Emotion-focused
MUIS = Mishel's Uncertainty in Illness Scale
ADL = Activities of Daily Living Scale
PD Rating = Hoehn and Yahr's Stage of Disability Scale

Table IIc. Correlations for all Participants on Dependent Measures

	Patient Variables								
	Age	Gender	MUIS	IDD	SCL-Dep	SCL-Anx	SCL-Som	SCL-Host	SCL-GSI
Caregiver Variables:									
Age	.70***	.04	.28*	.09	.03	.02	-.09	.09	.01
Gender	.14	.78***	-.06	-.04	.42***	.09	-.03	.35*	.30*
MUIS	.30*	.03	.57**	.30*	.23	.22	-.01	.22	.25
IDD	-.09	.02	.20	.29*	.07	-.01	-.01	-.01	.07
SCL-Dep	-.24	-.05	.23	.27*	.10	.11	-.04	-.02	.11
SCL-Anx	-.26	.08	.23	.02	-.04	.06	-.02	-.07	.03
SCL-Som	-.39**	.04	.06	-.11	-.07	.09	-.09	-.03	-.04
SCL-Hos	.05	.12	-.04	.24	.02	.02	.19	-.07	.05
SCL-GSI	-.16	-.04	.16	.14	.03	.09	-.04	-.01	.06

*p < .05, **p < .01, ***p < .005
MUIS = Mishel's Uncertainty in Illness Scale
IDD = Inventory for Diagnosing Depression
SCL-Dep = SCL-90-R Depression Subscale
SCL-Anx = SCL-90-R Anxiety Subscale
SCL-Som = SCL-90-R Somatization Subscale
SCL-Hos = SCL-90-R Hostility Subscale
SCL-GSI = SCL-90-R Global Severity Index

Table III. Hierarchical Multiple Regression Analysis Predicting Patient Participant Adjustment (GSI) Controlling for ADL, Coping Strategy, Uncertainty and Uncertainty/coping strategy interaction variable.

	Step	Predictor Variable	B	R^2 Change	F Change
Equation #1					
	1	Age	-.17	.22	4.40*
		Gender	-.43		
	2	ADL	.40	.15	7.61**
	3	Prob-Foc Coping	-.09	.01	.36
	4	MUIS	.12	.01	.53
	5	MUIS x Prob-Foc	-.98	.01	.51
Equation #2					
	3	Emot-Foc Coping	.41	.16	10.6***
	4	MUIS	.03	.001	.06
	5	MUIS x Emot-Foc	-1.8	.05	3.50

*p < . 05, **p < .01, ***p < .005

ADL = Activities of Daily Living

Prob-Foc Coping = Problem-Focused Coping Strategy

Emot-Foc Coping = Emotion-Focused coping Strategy

MUIS = Mishel's Uncertainty in Illness Scale

MUIS x Prob- (Emot) Foc = Mishel's Uncertainty in Illness Scale and Coping strategy interaction variable.

Table IV. Hierarchical Multiple Regression Analysis Predicting Caregiver Participant Adjustment (GSI) Controlling for ADL, Coping Strategy, Uncertainty and Uncertainty/coping strategy interaction variable.

	Step	Predictor Variable	B	R^2 Change	F Change
Equation #1					
	1	Age	-.34	.12	2.36
		Gender	-.08		
	2	ADL	-.07	.004	.15
	3	Prob-Foc Coping	.20	.04	12.4
	4	MUIS	.51	.23	12.4**
	5	MUIS x Prob-Foc	-.92	.12	.68
Equation #2					
	3	Emot-Foc Coping	.54	.26	14.5**
	4	MUIS	.36	.11	7.50*
	5	MUIS x Emot-Foc	-1.77	.03	1.82

*p < .01, **p < .001

ADL = Activities of Daily Living

Prob-Foc Coping = Problem-Focused Coping Strategy

Emot-Foc Coping = Emotion-Focused coping Strategy

MUIS = Mishel's Uncertainty in Illness Scale

MUIS x Prob- (Emot) Foc = Mishel's Uncertainty in Illness Scale and Coping strategy interaction variable.

Table V. Hierarchical Multiple Regression Analysis Predicting Patient Participant Depression (IDD) Controlling for ADL, Coping strategy, Uncertainty, and Uncertainty/coping strategy interaction variable.

	Step	Predictor Variable	B	R^2 Change	F Change
Equation #1					
	1	Age	-.02	.01	.18
		Gender	-.10		
	2	ADL	.60	.34	16.7**
	3	Prob-Foc Coping	.03	.001	.05
	4	MUIS	.03	.03	1.51
	5	MUIS x Prob-Foc	-2.5	.07	3.67
Equation #2					
	3	Emot-Foc Coping	.34	.11	6.40*
	4	MUIS	.13	.01	.83
	5	MUIS x Emot-Foc	-.47	.003	.19

*$\underline{p} < .05$, **$\underline{p} < .005$

ADL = Activities of Daily Living

Prob-Foc Coping = Problem-Focused Coping Strategy

Emot-Foc Coping = Emotion-Focused coping Strategy

MUIS = Mishel's Uncertainty in Illness Scale

MUIS x Prob- (Emot) Foc = Mishel's Uncertainty in Illness Scale and Coping strategy interaction variable.

Table VI. Hierarchical Multiple Regression Analysis Predicting Caregiver Participant Depression (IDD) Controlling for ADL, Coping strategy, Uncertainty, and Uncertainty/coping strategy interaction variable.

	Step	Predictor Variable	B	R^2 Change	F Change
Equation #1					
	1	Age	-.07	.01	.24
		Gender	-.11		
	2	ADL	.12	.03	.29
	3	Prob-Foc Coping	.05	.03	.08
	4	MUIS	.46	.22	1.8
	5	MUIS x Prob-Foc	.13	.22	1.4
Equation #2					
	3	Emot-Foc Coping	.52	.18	3.0*
	4	MUIS	.33	.27	3.7*
	5	MUIS x Emot-Foc	.71	.24	3.0*

*$p < .05$

ADL = Activities of Daily Living

Prob-Foc Coping = Problem-Focused Coping Strategy

Emot-Foc Coping = Emotion-Focused coping Strategy

MUIS = Mishel's Uncertainty in Illness Scale

MUIS x Prob- (Emot) Foc = Mishel's Uncertainty in Illness Scale and Coping strategy interaction variable.

Table VII. Hierarchical Multiple Regression Analysis Predicting Patient Participant Adjustment (GSI) Controlling for the Caregiver Variables of Adjustment (GSI), Coping Strategy, and Uncertainty

	Step	Predictor Variable	B	R^2 Change	F Change
Equation #1					
	1	Cr. Adjustment	.05	-.03	.10
	2	Cr. Prob-Foc Coping	.22	.04	.68
	3	Cr. Uncertainty	.21	.08	.91
Equation #2					
	2	Cr. Emot-Foc Coping	-.03	.06	.05
	3	Cr. Uncertainty	.18	.06	.35

Cr. Adjustment = Caregiver Adjustment as measured by the SCL-90-R GSI subscale
Cr. Prob-Foc Coping = Caregiver Problem-focused Coping Strategy
Cr. Emot-Foc Coping = Caregiver Emotion-focused Coping Strategy
Cr. Uncertainty = Caregiver level of uncertainty as measured by the MUIS

Table VIII. Hierarchical Multiple Regression Analysis Predicting Caregiver Participant Adjustment (GSI) Controlling for the Patient Variables of Adjustment (GSI), Coping Strategy, and Uncertainty.

	Step	Predictor Variable	B	R^2 Change	F Change
Equation #1					
	1	Pt. Adjustment	.15	.02	.67
	2	Pt. Prob-Foc Coping	.49	.24	4.5*
	3	Pt. Uncertainty	.16	.26	3.2*
Equation #2					
	2	Pt. Emot-Foc Coping	.38	.07	.67
	3	Pt. Uncertainty	-.04	.04	2.2

*$p < .05$

Pt. Adjustment = Patient Adjustment as measured by the SCL-90-R GSI subscale
Pt. Prob-Foc Coping = Patient Problem-focused Coping Strategy
Pt. Emot-Foc Coping = Patient Emotion-focused Coping Strategy
Pt. Uncertainty = Patient level of uncertainty as measured by the MUIS

Appendix A

Consent for Participation

I,____________________________, hereby voluntarily consent to participate (or, in cases of legal guardianship, sign consent for said individual) in the present research project. I understand that the purpose is to gain information regarding how individuals with Parkinson's Disease and their caregivers cope and adjust to the condition. In this study, I will be given a packet of questionnaires to complete that ask questions regarding the physical symptoms and emotional consequences related to the disease. Further, background information was solicited in order to determine if these factors contribute to how one adjusts to the stresses associated with a chronic illness such as Parkinson's Disease.

Participation in this research is of minimal risk psychologically and represents no more risk than would be normally encountered in a routine psychological evaluation.

I understand that I am free to withdraw from the study at any time (or withdraw said individual from participating) and that all information I provide will be kept confidential. All data cited by the researchers will emphasize group rather than individual performances.

This research is being conducted by Neva Sanders Durazzo, M.S. under the supervision of Larry Mullins, Ph.D., in association with the Oklahoma State University's Department of Psychology. I understand that I am may contact either Neva Sanders Durazzo, M.S. at (405)744-6027, Larry Mullins at (405)744-6951, or Gay Clarkson, Executive Secretary, Oklahoma State University Research Services, 305 Whitehurst, (405)744-5700 if I wish further information regarding this research.

I fully understand the information contained in this form as presented to me. I sign it freely and understand that my participation is completely voluntary.

________________________________ ________________________
Signature of Subject (or legal guardian) Date

I certify that I have personally explained all areas of this form prior to the subject signing it.

________________________________ ________________________
Signature of Researcher Date

Appendix B (page 1 of 2)

Please detach this piece of paper and keep it!!

The researchers wish to thank you again for your participation. In the past, researchers have found that after completing questionnaires in some research projects some individuals notice behaviors or activities that they wish to change. Psychologists and other mental health professional can help you if you are experiencing difficulty or have some problems you would like to discuss. If you feel that you would like some help or need some more information about receiving services, please contact one of the following knowledgeable referral sources.

<u>Family Mental Health Center</u>
2725 E. Skelly Drive
Tulsa, OK 74105
(918)749-3030 or (918)749-8022 (V/TDD)

<u>Associated Centers for Therapy, INC.</u>
7010 S. Yale, Suite 215
Tulsa, OK 74136-5705
(918)492-2554 (V/TDD)

<u>Parkside, INC.</u>
1620 E. 12th
Tulsa, OK 74120-5499
(918)582-2131 (V/TDD)

<u>Star Community Mental Health Center</u>
3604 N. Cincinnati
Tulsa, OK 74106-1536
(918)452-5526

Appendix B (page 2 of 2)

Information Statement

This packet contains questionnaire items that are to be filled out specifically by the patient or the caregiver. Each set of questions begins with instructions for how to complete those items. Please read each of these statements carefully. If you are not sure how to answer an item- give it your best shot, please do not leave any items blank. If you are unsure what particular questions are asking of you, please ask one of the researchers. If you are completing this packet at home and have questions, please feel free to contact us at (405) 377-9759.

**Patients- if you need any help in manually completing these forms, please ask your care provider to assist you. If this occurs, let your care provider fill out the items with the responses you provide them.

**Caregivers- If the patient requires any assistance in manually completing these forms, please feel free to help them. If this occurs, please mark each item with the answers provided by the patient, not by how you think the patient would respond (unless they are unable to provide you with adequate information).

Again, your participation is much appreciated. Results of this research will be presented in a future edition of the APDA newsletter.

Appendix C:

Background Information-Patient

Subj. #______

1. **Name:**____________________
2. **Date of Birth (mo/dy/yr):**____________
3. **Age:**__________
4. **Gender (circle one):** Male Female
5. **Marital Status (check one):**
   - ___Married
   - ___Divorced
   - ___Widowed
   - ___Separated
   - ___Never Married
6. **If married, does your spouse work outside the home? (circle one)** YES NO
7. **Do you currently work outside the home? (circle one):** YES NO
   - a. **If YES, how many hours per week do you work?**_______
   - b. **If NO, is this due to the Parkinson's disease?** ______
8. **Annual income before taxes for individual <u>or</u> combined if married (check one):**
   - ___$10,000 or less
   - ___$10,001-20,000
   - ___$20,001-30,000
   - ___$30,001-40,000
   - ___$40,001-50,000
   - ___$50,001-60,000
   - ___$60,001 or more
9. **Highest level of education you obtained:**
   - ___Less than 12 years (did not graduate High School)
   - ___Completed High school (12 years completed)
   - ___Less than one year of college
   - ___1-2 years of college course work
   - ___2-4 years of college course work
   - ___College Graduate (Bachelors degree obtained)
   - ___Some post-graduate work completed
   - ___Post graduate degree obtained (M.A., Ph.D., M.D., etc.)

THE FOLLOWING QUESTIONS ALL RELATE TO THE DIAGNOSIS OF PARKINSON'S DISEASE

10. Age in years when Parkinson's disease was officially diagnosed: ____

11. Number of years disease symptoms were present before diagnosis made: ___

12. Years since Diagnosis: ____

13. Are you currently taking medication for Parkinson's disease? YES NO
14. Do you currently attend a Parkinson's disease support group? YES NO

15. What relation to you is the individual whom is your primary care provider?

___Spouse
___Daughter
___Son
___Parent
___Friend
___Significant Other ("boyfriend" or "girlfriend")
___No relation, individual is hired help

16. Total years you have known the care provider:

___less than 1 year
___1-5 years
___6-10 years
___11-20 years
___21-30 years
___more than 30 years

17. Number of years you knew your care provider <u>before</u> you were diagnosed with PD:

___did not know the individual prior to PD diagnosis
___less than 1 year
___1-5 years
___6-10 years
___11-20 years
___21-30 years
___more than 30 years

Appendix D:

Background Information-Caregiver

Subj. #________

1. **Name:**____________________

2. **Date of Birth (mo/dy/yr):**____________

3. **Age:**__________

4. **Gender (circle one):** Male Female

5. **Marital Status (check one):**
   - ___Married
   - ___Divorced
   - ___Widowed
   - ___Separated
   - ___Never Married

6. **If married, does your spouse work outside the home? (circle one)** YES NO

7. **Do you currently work outside the home? (circle one):** YES NO
   - a. **If YES, how many hours per week do you work?**_______
   - b. **If NO, is this due to your taking care of the individual with PD?**________

8. **Annual income before taxes for individual <u>or</u> combined if married (check one):**
   - ___$10,000 or less
   - ___&10,001-20,000
   - ___$20,001-30,000
   - ___$30,001-40,000
   - ___$40,001-50,000
   - ___$50,001-60,000
   - ___$60,001 or more

9. **Highest level of education you obtained:**
   - ___Less than 12 years (did not graduate High School)
   - ___Completed High school (12 years completed)
   - ___Less than one year of college
   - ___1-2 years of college course work
   - ___2-4 years of college course work
   - ___College Graduate (Bachelors degree obtained)
   - ___Some post-graduate work completed
   - ___Post graduate degree obtained (M.A., Ph.D., M.D., etc.)

THE FOLLOWING QUESTIONS ALL RELATE TO THE DIAGNOSIS OF PARKINSON'S DISEASE

10. Age of the individual when they were officially diagnosed with Parkinson's disease: ____

11. Number of years disease symptoms were present before diagnosis made: ___

12. Years since Diagnosis: ____

13. Is the individual currently taking medication for Parkinson's disease? YES NO
14. Do you currently attend a Parkinson's disease support group? YES NO

15. What relation to you is the individual with Parkinson's disease?

___Spouse
___Daughter
___Son
___Parent
___Friend
___Significant Other ("boyfriend" or "girlfriend")
___No relation

16. Total years you've known the individual with Parkinson's disease:

___less than 1 year
___1-5 years
___6-10 years
___11-20 years
___21-30 years
___more than 30 years

17. Number of years you knew the individual before they were diagnosed with PD:

___did not know the individual prior to PD diagnosis
___less than 1 year
___1-5 years
___6-10 years
___11-20 years
___21-30 years
___more than 30 years

Appendix E:

INSTRUCTIONS

1. On this questionnaire are groups of 5 statements.
2. Read each group of statements carefully. Then Pick out the ONE statement in each group that best describes the way you have been feeling the PAST TWO WEEKS. Circle the number next to the statement you picked.

****

1.
    0 I do not feel sad or depressed.
    1 I occasionally feel sad or down.
    2 I feel sad most of the time, but I can snap out of it.
    3 I feel sad all the time, and I can't snap out of it.
    4 I am so sad or unhappy I can't stand it.

2.
    0 My energy level is normal.
    1 My energy level is occasionally a little lower than normal.
    2 I get tired more easily or have less energy than usual.
    3 I get tired from doing almost anything.
    4 I feel tired or exhausted almost all of the time.

3.
    0 I have not been feeling more restless and fidgety than usual.
    1 I feel a little more restless or fidgety than usual.
    2 I have been very fidgety, and I have some difficulty sitting still in a chair.
    3 I have been extremely fidgety, and have been pacing a little bit almost everyday.
    4 I have been pacing more than an hour per day, and I can't sit still.

4.
    0 I have not been talking or moving more slowly than usual.
    1 I am talking a little slower than usual.
    2 I am speaking slower than usual, and it takes me longer to respond to questions, but I can still carry on a normal conversation.
    3 Normal conversations are difficult because it is hard to start talking.
    4 I feel extremely slowed down physically, like I am stuck in mud.

5.
    0 I have not lost interest in my usual activities.
    1 I am a little less interested in 1 or 2 of my usual activities.
    2 I am less interested in several of my usual activities.
    3 I have lost most of my interest in almost all my activities.
    4 I get no pleasure from any of the activities which I usually enjoy.

6.
    0 I get as much pleasure out of my activities as usual.
    1 I get a little less pleasure from 1 or 2 of my usual activities.
    2 I get less pleasure from several of my usual activities.
    3 I get almost no pleasure from most of the activities which I usually enjoy.
    4 I get no pleasure from any of the activities which I usually enjoy.

7. 0 I have not been feeling guilty.
1 I occasionally feel a little guilty.
2 I often feel guilty.
3 I feel quite guilty most of the time.
4 I feel extremely guilty most of the time.

8. 0 I do not feel like a failure.
1 My opinion of myself is occasionally a little low.
2 I feel like I am inferior to most people.
3 I feel like a failure.
4 I feel I am a totally worthless person.

9. 0 I haven't had any thoughts of death or suicide.
1 I occasionally think life is not worth living.
2 I frequently think of dying in passive ways (such as going to sleep and not waking up), or that I'd be better off dead.
3 I have frequent thoughts of killing myself, but I would not carry them out.
4 I would kill myself if I had the chance.

10. 0 I can concentrate as well as usual.
1 My ability to concentrate is slightly worse than usual.
2 My attention span is not as good as usual and I am having difficulty collecting my thoughts, but this hasn't caused any problems.
3 My ability to read or hold a conversation is not as good as it usually is.
4 I cannot read, watch TV, or have a conversation without great difficulty.

11. 0 I make decisions as well as I usually do.
1 Decision making is slightly more difficult than usual.
2 It is harder and takes longer to make decision, but I do make them.
3 I am unable to make some decisions.
4 I can't make any decisions at all.

12. 0 My appetite is not less than normal.
1 My appetite is slightly worse than usual.
2 My appetite is clearly not as good as usual, but I still eat.
3 My appetite is much worse now.
4 I have no appetite at all, and I have to force myself to eat even a little.

13. 0 I haven't lost any weight.
1 I've lost less than 5 pounds.
2 I've lost between 5-10 pounds.
3 I've lost between 11-25 pounds.
4 I've lost more than 25 pounds.

14.
0 My appetite is not greater than normal.
1 My appetite is slightly greater than normal.
2 My appetite is clearly greater than usual.
3 My appetite is much greater than usual.
4 I feel hungry all of the time.

15.
0 I haven't gained any weight.
1 I've gained less than 5 pounds.
2 I've gained between 5-10 pounds.
3 I've gained between 11-25 pounds.
4 I've gained more than 25 pounds.

16.
0 I am not sleeping less than normal.
1 I occasionally have slight difficulty sleeping.
2 I clearly don't sleep as well as usual.
3 I sleep about half my normal amount of time.
4 I sleep less than 2 hours per night.

17.
0 I am not sleeping more than normal.
1 I occasionally sleep more than normal.
2 I frequently sleep at least 1 hour more than usual.
3 I frequently sleep at least 2 hours more than usual.
4 I frequently sleep at least 3 hours more than usual.

18.
0 I do not feel discouraged about the future.
1 I occasionally feel a little discouraged about the future.
2 I often feel discouraged about the future.
3 I feel very discouraged about the future most of the time.
4 I feel that the future is hopeless and that things will never improve.

Appendix F:

Activities of Daily Living-Patient Version, Adapted

Now I'd like to ask you about some of the activities of daily living, things that we all need to do as part of typical daily life. Your answers to these questions should be from your perspective--the level at which you can currently accomplish these tasks. I would like to know if you can do these activities without any help at all, with minimal help, or if you are no longer able to do these tasks at all.

Be sure to read all of the choice alternatives and circle the letter of the answer that best describes your **CURRENT** abilities.

1. When using the phone, I...

a. need no help (can look up numbers and dial on my own).

b. need some help (can answer phone, but need a special phone or help in getting a number or dialing).

c. cannot use the phone at all (unable to do this task).

2. For places that are out of walking distance, I...

a. need no help (can drive my own car or travel alone by bus/taxi).

b. need some help (need someone to drive, get a taxi, locate the appropriate bus for me).

c. cannot travel unless it is an emergency situation (in an ambulance).

3. When shopping for groceries or clothes (assuming I have transportation), I...

a. need no help (can do all aspects of shopping on own).

b. need some help (someone must always go with me as I need help with some aspect of shopping such as writing a check or making a decision).

c. cannot shop at all.

4. When preparing meals, I...

a. need no help (can plan and cook full meals on own).

b. need some help (can prepare some things, but can't cook full meals on own).

c. cannot prepare meals at all.

5. For housework or odd jobs around the house, I...

a. need no help (can scrub floors, vacuum, etc).

b. need some help (can do easy tasks, but need help with more difficult tasks).

c. cannot do any housework or odd jobs.

6. When taking medicine, I...

a. need no help (take the correct dosage at the appropriate time).

b. need some help (able to take medicine if someone prepares it for me or tells me when it is time to take it).

c. cannot take medicine without total supervision.

7. When handling money, I...

a. need no help (can balance the checkbook, pay bills, etc).

b. need some help (can handle some minor day-to-day financial interactions, but can't balance the checkbook or pay bills).

c. cannot handle money related issues.

8. When eating, I...

a. need no help (able to feed myself completely).

b. need some help (cutting, putting food in mouth, etc).

c. cannot eat anything on my own (I rely on others to feed me).

9. When dressing or undressing, I...

a. need no help (can pick out clothes, dress and undress self)

b. need some help (for example, putting on socks, buttoning shirt).

c. cannot dress or undress myself at all (others dress me).

10. For tasks associated with grooming/appearance, I...

a. need no help (can comb hair, brush teeth on own).

b. need some help (assistance needed to apply make-up or shave).

c. cannot maintain my appearance without full assistance.

11. In terms of walking, I...

a. need no help (completely ambulatory)

b. need some help (use cane, crutches, or walker)

c. cannot walk at all.

12. When getting out of bed, I...

a. need no help.

b. need some help (either from a person or a mechanical device).

c. am totally dependent on someone or something to lift me.

13. When taking a bath or shower, I...

a. need no help.

b. need some help getting into/out of the tub, or use a special attachment in the tub.

c. cannot bathe on own (rely on others to bathe me).

14. I have trouble getting to the bathroom on time...

a. Never b. Rarely c. Occasionally d. Frequently

15. The previous questions (1-14) were completed by...

a. the individual with PD.

b. a caregiver completed the questions with the answers provided by the patient.

c. a caregiver answered the questions based on his/her impressions of what the patient "would have" answered.

Appendix G:

Activities of Daily Living-Caregiver Version, Adapted

Now I'd like to ask you about some of the activities of daily living, things that we all need to do as part of typical daily life. Your answers to these questions should be from your perspective on how the individual with PD is <u>currently</u> able to accomplish these tasks. I would like to know if the individual can do these activities without any help at all, with minimal help, or if he/she can't do them at all.

Be sure to read all of the choice alternatives and <u>circle</u> the letter of the answer that <u>best</u> describes the **<u>CURRENT</u>** abilities of the individual with PD.

1. **When using the phone, the individual with Parkinson's Disease (PD) typically...**

a. needs no help (can look up numbers and dial on own).

b. needs some help (can answer phone, but needs a special phone or help in getting a number or dialing).

c. cannot use the phone at all (unable to do this task).

2. **For places that are out of walking distance, the individual with PD...**

a. needs no help (can drive own car or travel alone by bus/ taxi).

b. needs some help (needs someone to drive, get a taxi, locate the appropriate bus).

c. cannot travel unless emergency situation (in an ambulance).

3. **When shopping for groceries or clothes (assuming they have transportation), the individual with PD...**

a. needs no help (can do all aspects of shopping on own).

b. needs some help (someone must always go with him/her as help is needed with some aspect of shopping such as writing a check or making a decision).

c. cannot shop at all.

4. When preparing meals, the individual with PD...

a. needs no help (can plan and cook full meals on own).

b. needs some help (can prepare some things, but can't cook full meals alone).

c. cannot prepare any meals at all.

5. For housework <u>or</u> odd jobs around the house, the individual with PD...

a. needs no help (can scrub floors, vacuum, etc).

b. needs some help (can do easy tasks, but needs help with more difficult tasks).

c. cannot do any housework or odd jobs.

6. When taking medicine, the individual with PD....

a. needs no help (takes the correct dosage at the appropriate time).

b. needs some help (able to take medicine if someone prepares it for him/her and prompts the individual when it is time to take it).

c. cannot take medicine without total supervision.

7. When handling money, the individual with PD...

a. needs no help (can balance the checkbook, pay bills, etc).

b. needs some help (can handle some minor day-to-day financial interactions, but can't balance the checkbook or pay bills).

c. cannot handle money related issues.

8. When eating, the individual with PD...

a. needs no help (able to feed self completely).

b. needs some help (cutting, putting food in mouth, etc).

c. cannot eat anything on own (relies on others to feed him/her).

9. When dressing or undressing, the individual with PD...

a. needs no help (can pick out clothes, dress and undress self)

b. needs some help (for example, putting on socks, buttoning shirt).

c. cannot dress or undress self at all (others must dress him/her).

10. For tasks associated with grooming/appearance, the individual with PD...

a. needs no help (can comb hair, brush teeth on own).

b. needs some help (assistance needed to apply make-up or shave).

c. cannot maintain his/her appearance without full assistance.

11. In terms of walking, the individual with PD...

a. needs no help (completely ambulatory)

b. needs some help (uses cane, crutches, or walker)

c. cannot walk at all.

12. When getting out of bed, the individual with PD...

a. needs no help.

b. needs some help (either from a person or a mechanical device).

c. is totally dependent on someone or something to lift him/her.

13. When taking a bath or shower, the individual with PD...

a. needs no help.

b. needs some help getting into/out of the tub, or uses special attachments in tub.

c. cannot bathe on own (relies on others to bathe him/her).

14. Does the individual with PD have trouble getting to the bathroom on time?

a. Never b. Rarely c. Occasionally d. Frequently

Appendix H: **Clinical Disability Scale**

Please place a mark next to the category that best describes the characteristics demonstrated by the individual with Parkinson's disease. Only place an X next to one of the categories (I,II,III,IV or V).____

____ **I.** Only one side of the body appears to be affected at the present time. The patient shows minimal or no functional impairment the majority of the time.

Characteristics of individuals identified by this category:

__symptoms of PD rarely exhibited and on only ONE side of the body.
__people who don't know the patient well probably wouldn't know they had PD.
__minor weakness, aches, or stiffness on one side of the body (daily tasks unaffected).
__ability to walk is not affected.

____ **II.** Both sides of body appear to be affected, but only minimally. The patient demonstrates no impairment of balance.

Characteristics of individuals identified by this category:

__symptoms of PD demonstrated on both sides of body (e.g., tremors in both hands, weakness in both legs).
__may demonstrate minor stoop in posture that does not effect balance.
__no difficulties in balance when either standing or walking.

____ **III.** Both sides of body are effected. Patient demonstrates an unsteadiness when attempting to turn while standing. If patient was given a slight push while standing with feet together and eyes closed, they would have difficulty regaining balance. The patient is somewhat restricted in ability to perform daily activities, but is capable of leading an independent life.

Characteristics of individuals identified by this category:

__symptoms of PD hinder the patient's ability to perform tasks as easily as they once did (e.g., driving, exercising, cutting/preparing food).
__lives independently without others fearing safety (i.e., no fear of patient falling down stairs due to motor weakness, or unable to eat since can't prepare any food for self).
__symptoms are not severe enough to effect ability to drive or maintain employment.

____ **IV.** Symptoms of PD are fully developed and greatly impede patient's ability to function normally. Disease has severely debilitated the patient in that they are markedly incapacitated, yet, they are still able to walk/stand with minimal assistance.

Characteristics of individuals identified by this category:

__may need some assistance when dressing
__still able to maintain physical appearance on own (brush hair, wash face).
__patient no longer able to drive or work outside the home.
__demonstrates decreased involvement in social activities.
__utilizes a cane for mobility.
__marked impairment in penmanship

____ **V.** Patient requires assistance in most or all areas of living. He/she is typically confined to a bed or a wheelchair unless considerable assistance is provided.

Characteristics of individuals identified by this category:
__utilizes wheelchair for mobility or is confined to a bed.
__relies on others to feed, dress, bathe him/her.
__unable to write legibly.

Appendix I:

MISHEL UNCERTAINTY IN ILLNESS SCALE
COMMUNITY FORM-PATIENT

Instructions:

Please read each statement. Take your time and think about what each statement says. When place an "X" under the column that most closely indicates how you are feeling TODAY. If you agree with a statement, then you would mark under either "Strongly Agree" or "Agree." If you disagree with a statement, then mark under either "Strongly Disagree" or "Disagree." If you are undecided about how you feel, then mark under "Undecided" for that statement. Please respond to every statement.

1. I don't know what is wrong with me.

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
_____	_____	_____	_____	_____

2. I have a lot of questions without answers.

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
_____	_____	_____	_____	_____

3. I am unsure if my illness is getting better or worse.

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
_____	_____	_____	_____	_____

4. It is unclear how bad my symptoms will be.

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
_____	_____	_____	_____	_____

5. The explanations they give about my condition seem hazy to me.

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
_____	_____	_____	_____	_____

6. The purpose of my care is clear to me.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
(5)	(4)	(3)	(2)	(1)
______	______	______	______	______

7. My symptoms seem to change unpredictably.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
(5)	(4)	(3)	(2)	(1)
______	______	______	______	______

8. I understand everything explained to me.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
(5)	(4)	(3)	(2)	(1)
______	______	______	______	______

9. The doctors say things to me that could have many meanings.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
(5)	(4)	(3)	(2)	(1)
______	______	______	______	______

10. My treatment is too complex to figure out.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
(5)	(4)	(3)	(2)	(1)
______	______	______	______	______

11. It is difficult to know if the treatment or medications I am getting are helping.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
(5)	(4)	(3)	(2)	(1)
______	______	______	______	______

12. Because of the unpredictability of my illness, I cannot plan for the future.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
(5)	(4)	(3)	(2)	(1)
______	______	______	______	______

13. The course of my illness keeps changing. I have good and bad days.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
(5)	(4)	(3)	(2)	(1)
______	______	______	______	______

14. I have been given many differing opinions about what is wrong with me.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
(5)	(4)	(3)	(2)	(1)
______	______	______	______	______

15. It is not clear what is going to happen to me.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
(5)	(4)	(3)	(2)	(1)
______	______	______	______	______

16. The results of my tests are inconsistent.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
(5)	(4)	(3)	(2)	(1)
______	______	______	______	______

17. The effectiveness of my treatment is undetermined.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
(5)	(4)	(3)	(2)	(1)
______	______	______	______	______

18. Because of the treatment, what I can and cannot do keeps changing.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
(5)	(4)	(3)	(2)	(1)
______	______	______	______	______

19. I'm certain they will not find anything else wrong with me.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
(5)	(4)	(3)	(2)	(1)
______	______	______	______	______

20. The treatment I am receiving has a known probability of success.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
(5)	(4)	(3)	(2)	(1)
______	______	______	______	______

21. They have not given me a specific diagnosis.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
(5)	(4)	(3)	(2)	(1)
______	______	______	______	______

22. The seriousness of my illness has been determined.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
(5)	(4)	(3)	(2)	(1)
______	______	______	______	______

23. The doctors and nurses use everyday language so I can understand what they are saying.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
(5)	(4)	(3)	(2)	(1)
______	______	______	______	______

24. The seriousness of my condition has been determined.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
(5)	(4)	(3)	(2)	(1)
______	______	______	______	______

Appendix J:

MISHEL UNCERTAINTY IN ILLNESS SCALE
COMMUNITY FORM-CAREGIVER

Instructions:

Please read each statement. Take your time and think about what each statement says. Then place an "X" under the column that most closely indicates how you are feeling about the individual with Parkinson's Disease TODAY. If you agree with a statement, then you would mark under either "Strongly Agree" or "Agree." If you disagree with a statement, then mark under either "Strongly Disagree" or "Disagree." If you are undecided about how you feel about the individual with PD, then mark under "Undecided" for that statement. Please respond to every statement.

1. I don't know what is wrong with him/her.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
(5)	(4)	(3)	(2)	(1)
______	______	______	______	______

2. I have a lot of questions without answers.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
(5)	(4)	(3)	(2)	(1)
______	______	______	______	______

3. I am unsure if his/her illness is getting better or worse.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
(5)	(4)	(3)	(2)	(1)
______	______	______	______	______

4. It is unclear how bad his/her symptoms will be.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
(5)	(4)	(3)	(2)	(1)
______	______	______	______	______

5. The explanations they give about him/her seem hazy to me.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
(5)	(4)	(3)	(2)	(1)
______	______	______	______	______

6. The purpose of his/her treatment is clear to me.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
(5)	(4)	(3)	(2)	(1)
______	______	______	______	______

7. When he/she has symptoms, I know what this means about his/her condition.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
(5)	(4)	(3)	(2)	(1)
______	______	______	______	______

8. His/her symptoms continue to change unpredictably.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
(5)	(4)	(3)	(2)	(1)
______	______	______	______	______

9. I understand everything explained to me.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
(5)	(4)	(3)	(2)	(1)
______	______	______	______	______

10. The doctors say things to me that could have many meanings.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
(5)	(4)	(3)	(2)	(1)
______	______	______	______	______

11. I can predict how long his/her illness will last.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
(5)	(4)	(3)	(2)	(1)
______	______	______	______	______

12. His/her treatment is too complex to figure out.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
(5)	(4)	(3)	(2)	(1)
______	______	______	______	______

13. It is difficult to know if the treatment or medications he/she is getting are helping.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
(5)	(4)	(3)	(2)	(1)
______	______	______	______	______

14. Because of the unpredictability of his/her illness, I cannot plan for the future.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
(5)	(4)	(3)	(2)	(1)
______	______	______	______	______

15. The course of his/her condition keeps changing. He/she has good and bad days.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
(5)	(4)	(3)	(2)	(1)
______	______	______	______	______

16. I have been given many differing opinions about what is wrong with him/her.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
(5)	(4)	(3)	(2)	(1)
______	______	______	______	______

17. It is not clear what is going to happen to him/her.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
(5)	(4)	(3)	(2)	(1)
______	______	______	______	______

18. I usually know if he/she is going to have a good or bad day.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
(5)	(4)	(3)	(2)	(1)
______	______	______	______	______

19. The results of his/her tests are inconsistent.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
(5)	(4)	(3)	(2)	(1)
______	______	______	______	______

20. The effectiveness of the treatment he/she receives is undetermined.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
(5)	(4)	(3)	(2)	(1)
____	____	____	____	____

21. I can generally predict the course of his/her condition.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
(5)	(4)	(3)	(2)	(1)
____	____	____	____	____

22. Because of the treatment, what he/she can and cannot do keeps changing.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
(5)	(4)	(3)	(2)	(1)
____	____	____	____	____

23. I'm certain they will not find anything else wrong with him/her.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
(5)	(4)	(3)	(2)	(1)
____	____	____	____	____

24. The treatment he/she is receiving has a known probability of success.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
(5)	(4)	(3)	(2)	(1)
____	____	____	____	____

25. They have not given him/her a specific diagnosis.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
(5)	(4)	(3)	(2)	(1)
____	____	____	____	____

26. His/her physical distress is predictable; I know when it is going to get better or worse.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
(5)	(4)	(3)	(2)	(1)
____	____	____	____	____

27. His/her diagnosis is definite and will not change.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
(5)	(4)	(3)	(2)	(1)
______	______	______	______	______

28. The seriousness of his/her condition has been determined.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
(5)	(4)	(3)	(2)	(1)
______	______	______	______	______

29. The doctors and nurses use everyday language so I can understand what they are saying.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
(5)	(4)	(3)	(2)	(1)
______	______	______	______	______

Appendix K:

Revised Ways of Coping Checklist

In order for this questionnaire to have meaning, it is necessary that you first list an event/person /experience that is currently of concern to you. Please list the major stressor in your life.

____

____

The items below represent ways that you may have dealt with the stressor you listed above. We are interested in the degree to which you have used each of the thoughts/behaviors represented in these items in order to deal with the stressor you listed above. Please check the appropriate column if the thought/behavior was never used, rarely used, sometimes used, <u>or</u> regularly used.

<u>THOUGHTS/BEHAVIORS</u>	**Never <u>Used</u>**	**Rarely <u>Used</u>**	**Sometimes <u>Used</u>**	**Regularly <u>Used</u>**
1. Bargained or compromised to get something positive from the situation.	_____	_____	_____	_____
2. Talked to someone to find out about the situation	_____	_____	_____	_____
3. Blamed myself.	_____	_____	_____	_____
4. Concentrated on something good that could come out of the whole thing.	_____	_____	_____	_____
5. Criticized or lectured myself.	_____	_____	_____	_____
6. Tried not to burn my bridges behind me, but left things open somewhat.	_____	_____	_____	_____
7. Hoped a miracle would happen.	_____	_____	_____	_____
8. Asked someone I respected for advice and followed it.	_____	_____	_____	_____
9. Kept others from knowing how bad things were.	_____	_____	_____	_____
10. Talked to someone about how I was feeling.	_____	_____	_____	_____
11. Stood my ground and fought for what I wanted.	_____	_____	_____	_____
12. Just took things one step at a time.	_____	_____	_____	_____

THOUGHTS/BEHAVIORS	Never Used	Rarely Used	Sometimes Used	Regularly Used
13. I knew what had to be done, so I doubled my efforts and tried harder to make things work.	_____	_____	_____	_____
14. Refused to believe that it had happened.	_____	_____	_____	_____
15. Came up with a couple of different solutions to the problem.	_____	_____	_____	_____
16. Wished I were a stronger person—more optimistic and forceful.	_____	_____	_____	_____
17. Accepted by strong feelings, but didn't let them interfere with other things too much.	_____	_____	_____	_____
18. Wished that I could change what had happened.	_____	_____	_____	_____
19. Wished that I could change the way that I felt.	_____	_____	_____	_____
20. Changed something about myself so that I could deal with the situation better.	_____	_____	_____	_____
21. Daydreamed or imagined a better time or place than the one I was in.	_____	_____	_____	_____
22. Had fantasies or wished about how things might turn out.	_____	_____	_____	_____
23. Thought about fantastic or unreal things (like the perfect revenge or finding a million dollars) that made me feel better.	_____	_____	_____	_____
24. Wished that the situation would go away or somehow be finished.	_____	_____	_____	_____
25. Went on as if nothing had happened.	_____	_____	_____	_____
26. Felt bad that I couldn't avoid the problem	_____	_____	_____	_____
27. Kept my feelings to myself.	_____	_____	_____	_____
28. Slept more than usual.	_____	_____	_____	_____

THOUGHTS/BEHAVIORS	**Never Used**	**Rarely Used**	**Sometimes Used**	**Regularly Used**
29. Got mad at other people or things that caused the problem.	_____	_____	_____	_____
30. Accepted sympathy and understanding from someone.	_____	_____	_____	_____
31. Tried to forget the whole thing.	_____	_____	_____	_____
32. Got professional help and did what what they recommended.	_____	_____	_____	_____
33. Changed or grew as a person in a good way.	_____	_____	_____	_____
34. Made a plan of action and followed it.	_____	_____	_____	_____
35. Accepted the next best thing to what what I wanted.	_____	_____	_____	_____
36. Realized I brought the problem on myself	_____	_____	_____	_____
37. Came out of the experience better than I went in.	_____	_____	_____	_____
38. Talked to someone who could do something concrete about the problem.	_____	_____	_____	_____
39. Tried to make myself feel better by eating, drinking, smoking, taking medication, etc	_____	_____	_____	_____
40. Tried not to act too hastily or follow my own hunch.	_____	_____	_____	_____
41. Changed something so that things would turn out all right.	_____	_____	_____	_____
42. Avoided being with people in general.	_____	_____	_____	_____
43. Made light out of the situation; refused to get too serious about it.	_____	_____	_____	_____
44. Didn't let it get to me; refused to think about it too much.	_____	_____	_____	_____
45. Joked about it.	_____	_____	_____	_____

THOUGHTS/BEHAVIORS	Never Used	Rarely Used	Sometimes Used	Regularly Used
46. Accepted it, since nothing could be done	_____	_____	_____	_____
47. Looked for the "silver lining," so to speak; tried to look on the bright side of things.	_____	_____	_____	_____
48. Went along with fate; sometimes you just have bad luck.	_____	_____	_____	_____
49. Got made at the people or things that caused the problem.	_____	_____	_____	_____
50. Took it out on others.	_____	_____	_____	_____
51. Figured out who to blame.	_____	_____	_____	_____
52. Blamed others.	_____	_____	_____	_____
53. Found out what other person was responsible.	_____	_____	_____	_____
54. Thought that others were unfair to me.	_____	_____	_____	_____
55. Thought how much better off I am than others.	_____	_____	_____	_____
56. Told myself things could be worse.	_____	_____	_____	_____
57. Told myself how much I have already accomplished.	_____	_____	_____	_____
58. Focused on the good things in my life.	_____	_____	_____	_____
59. Counted my blessings.	_____	_____	_____	_____
60. Compared myself to others who are less fortunate.	_____	_____	_____	_____

In response to the following question, please check the degree to which the statements below apply to the stressor you previously listed.

"In general, the stressor that I listed above is one that..." :

	Strongly Disagree	Both Agree & Disagree	Disagree	Agree	Strongly Agree
1. ...I can change or do something about it.	_______	_______	_______	_______	_______
2. ...I must accept or get used to it.	_______	_______	_______	_______	_______
3. ...I need to know more before I can act.	_______	_______	_______	_______	_______
4. ...requires that I hold myself back from doing what I want to.	_______	_______	_______	_______	_______
5. ...is very important to me.	_______	_______	_______	_______	_______
6. ...I have some control over	_______	_______	_______	_______	_______
7. ...will be resolved in one year.	_______	_______	_______	_______	_______
8. ...will be resolved in four years.	_______	_______	_______	_______	_______
9. ...I think about often.	_______	_______	_______	_______	_______
10. ..will always be a problem in my life.	_______	_______	_______	_______	_______
11. ..is very threatening.	_______	_______	_______	_______	_______
12. ..I have experienced before.	_______	_______	_______	_______	_______
13. .. is ambiguous.	_______	_______	_______	_______	_______
14. ..is the result of my own shortcomings.	_______	_______	_______	_______	_______

Appendix L:

OKLAHOMA STATE UNIVERSITY
INSTITUTIONAL REVIEW BOARD
HUMAN SUBJECTS REVIEW

Date: 10-15-96 **IRB#:** AS-97-014

Proposal Title: AN ASSESSMENT OF COPING AND ADJUSTMENT IN INDIVIDUALS WITH PARKINSON'S DISEASE AND THEIR CAREGIVERS

Principal Investigator(s): Larry Mullins, Neva S. Durazzo

Reviewed and Processed as: Expedited

Approval Status Recommended by Reviewer(s): Approved

ALL APPROVALS MAY BE SUBJECT TO REVIEW BY FULL INSTITUTIONAL REVIEW BOARD AT NEXT MEETING, AS WELL AS ARE SUBJECT TO MONITORING AT ANY TIME DURING THE APPROVAL PERIOD.
APPROVAL STATUS PERIOD VALID FOR ONE CALENDAR YEAR AFTER WHICH A CONTINUATION OR RENEWAL REQUEST IS REQUIRED TO BE SUBMITTED FOR BOARD APPROVAL.
ANY MODIFICATIONS TO APPROVED PROJECT MUST ALSO BE SUBMITTED FOR APPROVAL.

Comments, Modifications/Conditions for Approval or Reasons for Deferral or Disapproval are as follows:

Signature: John H. Wycoff
Chair of Institutional Review Board

Date: November 1, 1996

VITA

Neva E.J. Sanders

Candidate for the Degree of

Doctor of Philosophy

Dissertation: AN ASSESSMENT OF COPING AND ADJUSTMENT IN INDIVIDUALS WITH PARKINSON'S DISEASE AND THEIR CAREGIVERS

Major Field: Psychology

Biographical:

Education: Graduated from Stillwater High School, Stillwater, Oklahoma in May 1989; received Bachelor of Science Degree in Psychology from Oklahoma State University, Stillwater, Oklahoma in May 1993; received Master of Science Degree in Clinical Psychology from Oklahoma State University in June 1994. Completed the requirements for the Doctor of Philosophy in Clinical Psychology at Oklahoma State University in July 1998.

Academic Awards/Scholarships: McAlester Scottish Rite Fellowship 1996-1997. Second place, graduate student research, Oklahoma Psychological Association Convention, 1995.

Professional Memberships: American Psychological Association, Division 38;OSU Psychology Graduate Student Association; Oklahoma Psychological Association; Southwestern Psychological Association; Association for the Advancement of Behavior Therapy, Society for Behavioral Medicine.