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THE IMPACT OF GROUP EXERCISE AND ACTIVITY ON
PERSONS WITH PARKINSON'S DISEASE

A Thesis

Presented to

The Faculty of the Department of Occupational Therapy
San Jose State University

In Partial Fulfillment
of the Requirements for the Degree
Master of Science

by
Michelle Lozano
August, 1997

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ABSTRACT

THE IMPACT OF GROUP EXERCISE AND ACTIVITY ON PERSONS WITH PARKINSON'S DISEASE

by Michelle Lozano

This study was designed to investigate the impact of participation in a 10 week exercise and activity class on activities of daily living and morale of people with Parkinson's disease. Christenson (1985) originally studied this topic and found a positive relationship; however, she concluded that the research design was weak and warranted duplication. In the current study, the variables were measured using a pre-test and post-test design incorporating the Barthel Index (modified) to measure activities of daily living and the Kutner Morale scale to measure morale in twenty-three subjects. A small increase was found in the activities of daily living and morale scores; however, the change was not statistically significant, nor was the relationship between the variables. Questions remain as to the sensitivity of the assessment tools and the insight of the participants in the study, as well as whether any defense mechanisms prevented accurate responses.

ACKNOWLEDGEMENTS

This study is dedicated to all the participants of the exercise and activity class and the instructors of the classes who so willingly participated in this research. Without their assistance, this thesis would not have been possible. Despite their struggle in almost every aspect of daily life from the effects of Parkinson's disease, I have found this group to be extremely helpful and concerned individuals.

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encouragement, understanding, belief in my abilities, and sense of humor helps me to keep the important things in life in mind and helps me to strive to be the best I can be. He is the love of my life and my best friend.

Among three moves, two jobs, getting married, and many other life changes, this thesis has been completed. It is such a relief to FINALLY have the answer to the question, "Have you finished that thesis yet?".

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CHAPTER 1

INTRODUCTION

Purpose

The purpose of this study was to determine the relationship between the morale and performance of activities of daily living following a 10 week group exercise and activity program for people with Parkinson's disease. The results of this study were compared to a study completed by Christenson in 1985.

Statement of the Problem

Parkinson's disease affects one percent of the population greater than 50 years old and occurs in all races (Duvoison, 1991). The prevalence of the disease has not changed considerably over the last century (Duvoison, 1991). Life expectancy has increased since the discovery and distribution of levodopa and further advances in pharmacological management (Kurtzke & Murphy, 1990). Medications are a central aspect of medical treatment; however, even with optimal drug therapy, limitations in function occur which may be addressed with additional treatment (Szekely, Kosanovich, & Sheppard, 1982).

Physicians often recommend exercise and recreation in the early stages of the disease but, as Weiner and Singer (1989), Mitchell, Mertz, and Catanzaro (1987) found, there is limited evidence to support this advice other than the belief that people with Parkinson's disease should continue to be involved in the things they enjoy. As the disease progresses, physical therapy is most commonly prescribed, as gait instability becomes an issue. Utilization of other rehabilitation professionals, however, is not as frequent (Gauthier, Dalziel, & Gauthier, 1987). In a review of adjunctive forms of treatment, Weiner and Singer

(1989) state that “objective studies to confirm the role of physical therapy, occupational therapy, and speech therapy in the patient with Parkinson's disease are scarce” although “each of these therapy modalities can play a certain role in the management of the appropriate patient” (p. 362).

Using an earlier study as a model, the current research was proposed to add to the body of knowledge on the efficacy of adjunctive forms of treatment. In 1985, Carolyn Christenson, an occupational therapist, conducted a study in which she found an increase in both morale and independence in activities of daily living as well as a positive relationship between the two variables following the subjects' participation in a 10 week group exercise and activity program for people with Parkinson's disease. Limitations related to the design of that study are discussed in the review of the literature.

Research Questions

The questions developed for this research were:

- (1) Is there an increase in the perceived quality of performance in activities of daily living of people with Parkinson's disease following a 10 week exercise and activity program?
- (2) Is there an increase in the perceived morale of the participants of a 10 week exercise and activity program for people with Parkinson's disease?
- (3) Is there a correlation between the quality of performance in activities of daily living and morale for people with Parkinson's disease who participated in a 10 week exercise and activity program?
- (4) Do the findings of this study compare favorably or unfavorably with those of the Christenson (1985) study?

Definitions

The following definitions were utilized in this research:

Activities of daily living are defined as in daily life activities including, but not limited to, bathing, dressing and grooming, including the use of motor skills, sensation, cognition, and psychosocial components. Those which were measured in this study are listed on an adapted version of the Barthel Index (1965) (See Appendix A).

Barthel Index is a scale described by Mahoney and Barthel (1965) to measure the functional level of a person with disability in the areas of self-care and mobility. It includes 15 different areas of performance, with three rating categories. The best possible score is 100, the worst is 0.

Barthel Index (adapted) is, for the purpose of this study, a modified version of the original index. Three areas of measurement were not included: Putting on brace or artificial limb, controlling urination, and controlling bowel movements, since these three areas are not applicable to the current study. Hence, the best possible score is 85 and worst possible score is 0. Additionally, the subjects complete the scale themselves. See Appendix B for the adjusted rating scale.

Group approach is a context for treatment which can be defined as “associations between two or more persons who are in some kind of interdependent relationship with one another” (Sampson in Hopkins & Smith, 1988).

Kutner Morale Scale is a “morale measurement instrument developed by Kutner in 1956 with the following scale: (a) score 0-2, low morale, (b) score 3-4, medium morale, (c) score 5-6, high morale” (Brantl & Brown, 1973, p.49). (See Appendix C for scale and Appendix D for scoring.)

Morale is, for the purpose of this study, “a continuum of responses to life and living problems that reflect the presence of satisfaction, optimism and expanding life perspectives” (Kutner, 1956, p. 48). Morale was measured by the subjects' scores on the Kutner Morale Scale.

10 Week Parkinson's Disease Exercise and Activity Program consists of the classes held at Kirk Community Center in San Jose, California and DeAnza College in Cupertino, California for persons with Parkinson's disease. Classes were designed specifically for the deficits affecting people with Parkinson's disease. All classes include the following areas (1) greetings, (2) warm-up, (3) exercises in chairs or on mats, and (4) educational or recreational activity. See Appendix E for details related to class design.

Parkinson's disease is a chronic, progressively degenerating disease of the central nervous system characterized by tremor, rigidity, and slowness of movement (Duvoisin, 1991). For the purpose of this study, it is determined by a physician diagnosis.

Participation is defined as an average attendance in 15 of 20 possible class meetings in a 10 week class held two times per week for 90 minutes each session.

Significance of the Study

It is commonly believed that physical activity is important in maintaining health and well being. It may be of particular importance to the individual with Parkinson's disease because of the tendency for people with this diagnosis to withdraw from their usual activities and maintain a sedentary lifestyle (Duvoisin, 1991). Group treatment with physical activities has also been shown to be beneficial for people with this diagnosis (Gauthier, Dalziel, & Gauthier, 1987;

Palmer, Mortimer, Webster, Bistevins, & Dickenson, 1986; and others).

Although several studies have investigated the effects of exercise (Comella, Stebbins, Brown-Toms, & Goetz, 1994 and others), few researchers have studied performance in activities of daily living in combination with psychosocial status (Christenson, 1985; Gauthier, Dalziel, & Gauthier, 1987). This is an essential area of study for two reasons. First, optimal psychological functioning is important for people with Parkinson's disease. Hyman (1972) found that psychosocial factors may limit the effectiveness of levodopa therapy. Secondly, performance in functional tasks may be the best determinant of the effectiveness of exercise since improvement may occur in activities of daily living without neurologic changes (Andrews, 1981).

The current study examined the group approach to treatment which may be a therapeutic and cost-effective way of helping people with Parkinson's disease; it only requires one or two therapists per 20 participants and is based in the community rather than the hospital setting. Cost containment, competition, and a growing elderly population are three major trends affecting current and future health care systems (Baum, 1990). As private and public insurance carriers decrease the type and amount of services allowed, alternatives to traditional inpatient treatment are necessary. Group and outpatient therapy are interventions that will allow people with disabilities access to necessary treatment within the constraints of the system. Eliminating the need for any insurance carrier intervention may be an even better approach since the participant may have better control of the frequency and duration of treatment. The community college and community recreation systems are vehicles through which this can be done. Since the costs are generally low for participation in

these systems, people with chronic diseases can afford continuous therapy without the need for insurance carrier approval.

It has become important to document the effectiveness of this genre of therapy: a cost-effective and therapeutic way by which people with Parkinson's disease can remain independent in the community and continue to be served during the disease progression. As the elderly population continues to grow, so will the number of people with the disease since Parkinson's disease generally affects older adults. The incidence in the United States is approximately 1% of the population over 50 years of age (Pedretti & McCormack, 1990). Baum (1991) cites Coil who states, "In 1980, one out of every nine Americans was over the age of 85 and by the year 2010, one out of five will be over that age. Clearly, elderly persons will comprise a large segment of our population, and this group places heavy demands on the health care system" (p. 809). By documenting the results of this type of intervention, it may support the implementation of similar programs.

Assumptions

The following assumptions were made regarding the problem addressed in this study:

- (1) The subjects would participate in class and answer the questions of the survey.
- (2) The subjects would answer the questions honestly and accurately.
- (3) The three exercise programs and exercise instructors would be similar enough in terms of type of exercise and social support of the class so that the results will be similar from class to class.

(5) The variations in the subjects' medications or other medical issues would not have an adverse effect on the study.

Limitations

The limitations of this study are as follows:

- (1) The subjects were volunteers; thus they may differ from the rest of the population with Parkinson's disease in terms of motivation to attend the class, morale, or family support, so they may have different psychological coping strategies. Their scores on the morale scale may be higher than would be true for the general population.
- (2) The results are not generalizable to the entire population of people with Parkinson's disease, since the sample was not randomized and since the sample was chosen from a certain geographical area.
- (3) The people who participated in this exercise program could differ from non-participants in the same stage of the disease process.
- (4) Some of the subjects have participated in previous exercise classes, and due to the effects of repetition, any change as a result of participation in this session may not be as great as someone who participated for the first time.
- (5) The exercise classes held for this study may have been slightly different from the classes held in the previous study; thus it may be difficult to compare the data.
- (6) Due to the nature of Parkinson's disease, fluctuations occur throughout the day which may affect performance. Subjects may have given their best average performance as the response. Medications have a direct impact on physical abilities.

- (7) The 10 week class period may not have been sufficiently long enough to show change.
- (8) No comparison group was used.

CHAPTER 2

LITERATURE REVIEW

A variety of non-pharmacological treatment programs for people with Parkinson's disease are addressed in the literature, but few studies investigate performance in activities of daily living and morale either individually or combined. This literature review encompassed (1) an overview of Parkinson's disease, (2) an analysis and critique of Christenson's (1985) study, (3) review of related research since 1983, and (4) a discussion of the theoretical framework for occupational therapy intervention used in the current study.

Overview of Parkinson's Disease

The history; presentation and prognosis; etiology; pathology; clinical manifestations; classification system; psychological, cognitive and personality changes; and medical management (pharmacological and surgical) of Parkinson's disease will now be described.

History of Parkinson's Disease

In 1817, James Parkinson first described and named a condition in his "Essay on the Shaking Palsy" characterizing what is now known as Parkinson's disease. He observed "involuntary tremulous motion, with lessened muscular power, in parts not in action and even when supported; with a propensity to bend the trunk forward and to pass from a walking to running pace, the senses and intellect being uninjured" (Beal, Richardson, & Martin, 1991, p. 2065). Paralysis agitans, meaning "shaking palsy" is another term for Parkinson's disease (Duvoison, 1991) and parkinsonism is a word referring to other disorders related to Parkinson's disease (Hooks, 1989).

Presentation and Prognosis

The average presentation of Parkinson's disease is 50-70 years of age (Weiner & Singer, 1989) with equal distribution between men and women (Melnick, 1990). The disease is rarely seen in people under the age of 30 (Hooks, 1989). Race and climate do not change incidence (Trombly, 1985) and familial incidence is low, approximately 1-2% (Beal, Richardson & Martin, 1991). Because the onset is usually insidious, one to two years of mild symptoms may occur without diagnosis (Weiner & Singer, 1989). Usually, tremor is the symptom that leads the patient to seek medical consultation. Family members often notice other difficulties in daily activities, such as the amount of time it takes to get dressed. The disease usually progresses slowly, lasting from 2 to 20 years (Wroe & Greer, 1973). There is speculation that two clinical variations of Parkinson's disease, the type with tremor and the type with postural instability and gait difficulty, may be separate entities with different etiology (Jankovic & Marsden, 1993). The group with the gait disturbance typically has more memory impairment and the condition is more progressively degenerating than in the group with tremor (Jankovic & Marsden, 1993).

A serious complication of Parkinson's disease is bronchopneumonia secondary to decreased activity and decreased chest expansion due to trunk rigidity (Melnick, 1990). Consequently, common causes of death in people with Parkinson's disease are respiratory complications (Schenkman & Butler, 1989) and the mortality rate is greater than that of the general population (Melnick, 1990).

Etiology

Parkinson's disease is a slowly progressive disease which is usually diagnosed by a set of clinical features. Since a specific biological marker or diagnostic test does not exist, an autopsy is the only way of diagnosing the disease with certainty (Jankovic, 1992). Even with specific diagnostic criteria, one study showed that "24% of the 100 patients clinically diagnosed with Parkinson's disease were found to have conditions other than Parkinson's disease at autopsy" (Jankovic, 1992). Disorders frequently misdiagnosed as Parkinson's disease include progressive supranuclear palsy, multiple system atrophy, Alzheimer's disease, and vascular disease (Jankovic, 1992).

Duvoison (1991) has discussed six types of Parkinson's disease etiology: idiopathic (unknown cause), drug-induced, postencephalic, arteriosclerotic, symptomatic, and Parkinsonism plus. Idiopathic Parkinson's disease is the most common form of the disease. In this form of the disease abnormal nerve cells called "Lewy Bodies" are found in certain nerves throughout the brain and spinal cord. The cause of the Lewy Bodies is unknown, but they are not found in other forms of Parkinson's disease.

A second type is the drug-induced parkinsonism which can be caused by toxins such as a MPTP (1-methyl-4-phenyl-1,2,3,6-tetrahydropyridin), found in a synthetic form of heroin, and phenothiazines or other drugs that block Dopamine receptors. "Postencephalic Parkinsonism" is a third type which can follow a viral infection of the brain, or encephalitis. In the years after World War I, a worldwide epidemic occurred which was called "epidemic encephalitis" or "encephalitis lethargica" because of the sleepiness that initially occurred. It was also known as "Von Economo's Encephalitis" after an Austrian neurologist,

Constantine Von Economo, who described the disease. Parkinsonism which was chronic and slowly progressive occurred following illness with this encephalitis. After the initial epidemic, a few cases occurred in the 1930's and 1940's but not since that time. Arteriosclerotic Parkinson's disease, the fourth type, is a result of several minor strokes. Some experts do not include this type as a true form of the disease.

A fifth type, symptomatic parkinsonism, is considered a symptom of other disease processes, such as diseases and intoxications which involve the substantia nigra or the corpus striatum. Head injuries, tuberculosis, syphilis, carbon monoxide poisonings, or congenital malformations can be the cause. "Parkinsonism plus" has the characteristics of Parkinson's disease in addition to low blood pressure and other autonomic symptoms (Jankovic, 1992). This sixth type of Parkinson's disease does not have the clinical symptom of resting tremor and does not respond as well to drug therapy by levodopa. It is of note that while various causes of Parkinson's disease have been identified, the clinical manifestations are similar (Davis, 1977).

Pathology

The symptoms of all forms of Parkinson's disease result from a similar pathology with differing causes. Although extensive research has been completed on the subject of its pathology, it is still not fully understood (Antel & Arnason, 1991). Following the onset of parkinsonism in young people who had used a synthetic form of heroin and been exposed to a contaminant in the process, MPTP, further studies began. Using MPTP to induce parkinsonism in laboratory animals, researchers noted the damage caused to the substantia nigra and the classic symptom development. A model for the system pathology

was developed.

Duvoisin (1991) and Marsden (1982) discussed the underlying dysfunction of the disease. Initially, there is a decrease in the amount of dopamine in the substantia nigra of the midbrain and the presence of “Lewy Bodies” which are intracellular inclusions (Melnick, 1990). With the loss of dopamine, there is a loss of input to the corpus striatum (putamen, globus pallidus, and caudate nucleus) resulting in difficulty with posture, associated movements, and righting reactions. When the system lacks dopamine, norepinephrine cannot influence the transmission of acetylcholine. An imbalance of alpha and gamma motor neuron activities occur due to uncontrolled excitatory impulses.

Clinical Manifestations

As a result of this pathology, three main clinical manifestations commonly occur. These are:

(1) resting tremor typically with unilateral onset, called “pill rolling” in the hands, usually with 4-6 beat per second frequency. Tremor can also be noted in the jaw or tongue, lips, neck and eyelids. The tremor may initially disappear with intentional movement.

(2) muscle rigidity, tightness, stiffness and achiness and/or “cogwheel rigidity” in which when a hypertonic muscle is stretched, it releases in a “jerky” fashion. This may be an inability to relax the muscle.

(3) slowness in movement, known as “bradykinesia”, or difficulty in initiating or continuing a movement, known as “akinesia”. This exhibits itself in decreased mobility, increased time necessary for activities of daily living, and is associated with decreased automatic associated movement such as eye blink,

arm swing, and postural instability with impaired righting reactions and protective responses.

Other symptoms include a lack of spontaneous facial expression known as “masked facies”, difficulty with writing, micrographia (writing in which the letters of a sentence become continually smaller), postural abnormalities, including simian posture (a slouched posture with the head flexed forward). Other dysfunctions include: changes in speech including soft, monotone and rapid speech, swallowing disorders, festinating gait exhibited by quick, shuffling steps, retropulsion (walking backwards), sluggish bowel and bladder activity, skin changes (usually seborrhea), increased sweating, sexual dysfunction, and visual and perceptual changes. Dysfunction of sensorimotor integration and proprioception is an additional issue (Schneider, Diamond & Markham, 1987).

Occasionally, the symptoms may be influenced positively or negatively by external factors. In times of anxiety, the symptoms may be aggravated. For example, in a buffet line, the person with Parkinson’s disease may become self-conscious, which may increase the tremor, causing the person embarrassment by spilling food.

Classification System

A gross classification system to describe the stages of Parkinson’s disease was developed by Hoehn and Yahr in 1967. The scale was developed to allow universal terminology to be used in discussing the functional status of a patient. Variability in the evolution of Parkinson’s disease, extent of disability, and the rate of progression are all variables for which this classification system

was not designed to describe. The stages, according to Hoehn and Yahr (1967) are as follows:

Stage I: Unilateral involvement only, usually with minimal or no functional impairment.

Stage II: Bilateral or midline involvement, without impairment of balance.

Stage III: First sign of impaired righting reflexes. This is evident by unsteadiness as the patient turns or is demonstrated when he is pushed from standing equilibrium with the feet together and the eyes closed.

Functionally the patient is somewhat restricted in his activities but may have some work potential depending upon the type of employment.

Patients are physically capable of leading independent lives, and their disability is mild to moderate.

Stage IV: Fully developed, severely disabling disease; the patient is still able to walk and stand unassisted but is markedly incapacitated.

Stage V: Confinement to bed or wheelchair unless aided (p. 433).

Generally, there is a progression through the stages of the disease, but individual differences occur in terms of the symptoms that have the greatest impact and the areas of function that are effected.

Psychological, Cognitive and Personality Changes

In addition to physical manifestations, Parkinson's disease impacts psychological status, cognition, and personality. It also involves several personal losses, according to a phenomenological study by Marr (1991). Accepting the diagnosis, decreasing physical and social activity and emotional losses were the primary experiences described by people with Parkinson's

disease. Because of the loss of and difficulty with mobility, subjects felt a lack of energy which affected even simple activities of daily living. There was also a loss of socialization, as the person began to withdraw from his/her regular social situations due to fatigue and embarrassment from the unwanted attention drawn to them from their symptoms. Third, the emotional loss of Parkinson's disease includes a loss of "normality" and self concept which are changed as a result of the disease. The participants in the study, according to Marr (1991), tended to "have lowered levels of self-esteem when they perceived themselves as being unable to independently carry out activities" (Marr, 1991, p. 327). They had "feelings of irritation, upset, and anger" when attempting to perform activities of daily living (Marr, 1991, p. 327).

Mayeux (1990) asserted that James Parkinson was the first to describe depression in people with Parkinson's disease in his essay that characterized the patient as a "previously sanguine man...now dejected and melancholic" (p. 20). Depression is one of the most frequent psychiatric disorders in people with Parkinson's disease. Estimates of the prevalence of depression varies from 37 to 90% (Mitchell, Mertz, & Catanzaro, 1987); however, the existence and origin of depression in people with Parkinson's disease remains a controversial topic in the literature. Although estimates of depression vary, Mayeux (1990) estimates 40% of people with Parkinson's disease suffer depression with major depression and dysthymic disorder being the two most prevalent clinical types found in equal proportions. Traditional methods for rating depression can be confounded by symptoms of the disease process of Parkinson's disease. Mayeux reported that depression is more prevalent in people with Parkinson's disease than age matched controls, in spite of the

difficulties with some of the studies.

Four main theories exist in the literature regarding the origin of depression in Parkinson's disease: (1) it is reactive to the physical disability, (2) it is endogenous and not a result of the physical handicap, (3) it is related to the neurobiological substrates, and (4) the cause is multifactorial. A reactive depression is supported by the evidence that people with other physical disabilities, such as rheumatoid arthritis, which are equally disabling, exhibit depression in similar proportions to those with Parkinson's disease (Gotham, Brown, & Marsden, 1986). The endogenous depression theory is supported by studies showing an onset of depression prior to Parkinson's disease (Santamaria, Tolosa, & Valles, 1986). People with greater functional disability are also associated with greater rates of depression (Starkstein, Mayberg, Leiguarda, Preziosi, & Robinson, 1991).

The neurobiological substrate theory is supported by evidence that a greater percentage of depression (measured by the Beck Depression Inventory and the Present State Examination) was found in patients with Parkinson's disease who were primarily affected on the left side with the corresponding neurobiological changes in the right hemisphere (Fleminger, 1991). The author states that "striatal dopamine depletion in the right cerebral hemisphere is more likely to be associated with depressive symptoms than left striatal dopamine depletion...supporting a biological explanation for some of the depression experienced by patients with Parkinson's disease" (p. 635). Logically, if the depression was a result of the psychological response to the functional deficits, and the majority of the population is right-handed, more people with Parkinson's disease exhibiting deficits on the right side would be expected to

be depressed.

Serotonin, another neurotransmitter, is also being studied in its relationship to depression in people with Parkinson's disease. Serotonin increases chances of depression because of the assumed effect of serotonin on mood (Van Pragg & de Haan, 1979). A relationship between reduced serotonin levels and depression in people with and without Parkinson's disease was investigated (Mayeux, 1990). The fact that depression exists in some but not all people with decreased serotonin levels gives evidence that a single factor is not the only prerequisite for depression.

A multifactorial theory of depression has also been proposed (Mayeux, 1990). Since psychosocial status may influence the effectiveness of drug therapy in people with Parkinson's disease (Hyman, 1972), a better understanding of the origin of depression and of the impact of adjunctive treatment on depression is indicated.

Depression may be related to the stage of disease but a linear relationship is not consistently found. Celesia and Wanamaker (1972) found that, according to the Hoehn and Yahr stages, depression occurred more frequently in stages I, III, and IV, and less commonly in II and V. Dakof and Mendehlson (1989) found, however, more of a relationship between disease severity and psychological adjustment. In this study, 44 people in various stages of the disease were assessed. The researchers concluded that patients who felt "dysphoric and apprehensive" had lower Hoehn and Yahr staging compared with subjects who were "depressed" and "resigned". A common clinical assumption is that depression is found more often in people with early age of disease onset. Kostic, Filiporic, Lecic, Momcilovic, Sokiv, and Sternic

(1994) studied age of onset and frequency of depression in 169 people with Parkinson's disease. When the researchers controlled for length of disease, this relationship was not found. The authors proposed that depression may be related to deficits in activities of daily living more than age of onset.

Brown and Jahanshahi (1995) grouped the current literature on depression and Parkinson's disease into four common themes. First, certain subgroups may be more depressed: (1) early stage of illness, (2) early age of onset, (3) advanced disease stages, and (4) rapid progressive deterioration. Second, depression in Parkinson's disease does not necessarily follow a linear progression, meaning that the depression may not increase in proportion to the disease progress. Third, the consequences or results of the disease may have more of an impact than the specific symptoms themselves. Finally, a multivariate model of depression in Parkinson's disease needs to be considered.

The number of people with Parkinson's disease who also suffer from dementia is estimated between 10 to 15%, with the incidence of dementia in people with Parkinson's disease being significantly higher than a cohort group of the same age without Parkinson's disease (Mayeux et al., 1990). Depression has been shown to be significantly associated with cognitive deficits in people with Parkinson's disease (Starkstein & Robinson, 1991). People with major depression had significantly worse performance than people without depression on frontal lobe tasks and other neuropsychological testing (Starkstein, Mayberg, Leiguarda, Preziosi, & Robinson, 1989). There is a linear relationship between age of subject and age of onset with cognitive impairment and rapid progression (Celesia & Manamaker, 1972). Longitudinal studies

found that dementia in Parkinson's disease is related to older age, length of disease and older age of onset (Biggens, Boyd, & Harrop, 1992). Some, but not all of the deficits, such as short term memory impairments, can be related to medication side effects. Significant cognitive deficits have been shown in some studies. Sixty newly diagnosed but untreated people with Parkinson's disease were matched with control subjects and tested on various dimensions of cognition (Cooper, Sagar, Jordan, Harvey, & Sullivan, 1991). The Parkinson's disease group showed deficits in immediate verbal recall, sequencing, visuomotor construction, as well as other areas. According to the Cooper et al. study, frontal lobe deficits are exhibited even in early and untreated Parkinson's disease.

In addition to psychological and cognitive responses to Parkinson's disease, personality changes are also described in the literature and relationships discussed. In a study by Mendelsohn, Dakof, and Skaff (1995), people with Parkinson's disease and their spouses were matched with a community sample and given an "adjective checklist" to determine personality change. "Sharp, pervasive, and uniformly negative change" (p. 233) in personality was found in the patient's and spouse's descriptions. The community sample also demonstrated change but to a lesser degree. The authors concluded that illness magnifies and accelerates changes in later life. The cause of the change remains unclear.

Medical Management

Pharmacological treatment is currently the most potent form of medical therapy available but surgical advances are also being made. Because

dopamine does not cross the blood-brain barrier, the discovery of levodihydroxyphenylalanine (L-dopa or levodopa) in the late 1960's changed the treatment of Parkinson's disease due to the drug's ability to cross the blood-brain barrier. In combination with an enzyme inhibitor, carbidopa, its use has helped the management of certain side effects such as bradykinesia and rigidity (Melnick, 1990). According to Richardson and Martin (1991), "usually anticholinergic drugs are most effective for suppressing tremor at rest, and propranolol or primidone is best for action tremor, levodopa improves akinesia and postural imbalance; anticholinergic drugs have little effect on these two abnormalities" (p. 2066). The time for initiation of drug treatment is controversial, but it usually begins when impairments in activities of daily living and/or occupation or decreased balance become significant (Weiner & Singer, 1989). It is recommended that the Hoehn and Yahr stages be used to determine the type of drug treatment. As the disease progresses, drug therapy becomes more difficult to manage effectively and less therapeutic, and after 10 years or more, receptors become less sensitive to levodopa (Morris, 1989).

Drug side effects are another issue in medical management and vary among the types of medication. Potential side effects include but are not limited to: confusion, urinary retention, changes in blood pressure, skin changes, edema, nausea and vomiting, loss of drug efficacy, and the "on-off phenomena" in which fluctuations or sudden variations in response to drugs occur. Dietary intake, especially the amount and timing of protein consumption, can significantly influence the therapeutic effect of drugs. Most Parkinson's disease experts believe that if a person does not respond well to levodopa, Parkinson's disease may likely be ruled out as a cause of the symptoms (Jankovic, 1992).

In addition to medical therapy, several types of surgical procedures are used in trials. Some of these procedures may significantly impact the management of this disease in the future. Two main types of surgical interventions exist: functional procedures such as thalamotomy, ventral intermediate stimulation and medial pallidotomy and neural grafting such as fetal mesencephalic transplants.

Functional procedures involve placing lesions or stimulating areas of the brain with stereotactic technique to the thalamus or globus pallidus.

Thalamotomy is a procedure which has benefits for patients with tremor and rigidity. This procedure is rarely done, but helpful to some. Relief of symptoms may be of short duration (Melnik, 1990). Ventral intermediate stimulation involves high frequency stimulation of the thalamus and may be beneficial for those with tremor. Some foresee this as the most promising procedure of the future (Olanow, Marsden, Lang, & Goetz, 1994).

Neural grafting is one of the most controversial surgical approaches and is receiving the most attention from researchers. This procedure involves transplanting "fetal mesencephalic, dopamine-producing cells in the denervated striatum" (Olanow et al., 1994, p. S17) which clinically results in a decrease of motor fluctuation. Many scientific questions remain regarding the use of this technique, and it is still in the experimental phase (Olanow et al., 1994). Controversial political and ethical issues also surround the research. At one time, research funds were threatened to be withheld from the National Institute of Health when some officials believed that support of this research would be supportive of abortion (Kassirer & Angell, 1992). Although patients who received the implants were still significantly impacted by their disease,

improvements were seen in their ability to perform activities of daily living and their need for medication was less (Spencer et al., 1992). Another study found the same benefits as the prior study in addition to improvement in the Parkinson's Disease Rating Scale and their Hoehn-Yahr Score 12 to 46 months after surgery (Freed et al., 1992). A third study claimed improvement in 70% of the patients after five years (Lopez-Lozano et al., 1995). These types of outcome are positive support for further research in this area.

Analysis and Critique of Christenson (1985) Study

Christenson's (1985) study showed a positive relationship between "functional performance" and morale following participation in a 10 week exercise and activity class. However, Christenson pointed out that the design of the study was descriptive correlational, one of the weaker research designs. The reader is referred to the original research for a comprehensive list of the limitations of the study that were thoroughly identified by Christenson. It is worth noting that the limitations of the study are extensive and significant and include problems with internal validity, experimenter expectancy, and small sample size.

In that study, Christianson used a questionnaire entitled the "Occupational Therapy Functional Evaluation Rating Scale" to survey the functional status of the students. This scale was an adapted form of the Comprehensive Occupational Therapy Evaluation Scale (Christianson, 1985). The original scale was developed for use by occupational therapists, not for client self-report, and it is not standardized. It is questionable whether or not the subjects could accurately respond to the scale without specific training in understanding the components of each area. Given the cognitive deficits well

documented in the literature, the ability of the participants to accurately respond to a lengthy and complicated form is also questioned. According to a study by van Hilten, van der Zwan, Zwiderman, and Roos (1994), people with Parkinson's disease are not able to accurately respond to questions regarding motor symptoms but can accurately report on activities of daily living. Although Christenson (1985) showed a positive effect of group exercise and activity, further research was indicated to enhance the power of the study.

Research on Adjunctive Treatment Since 1983

Christenson's study was completed in 1985 and the following literature review focuses mostly on non-pharmacological treatment for Parkinson's disease conducted since 1983. Two main categories of non-pharmacological treatment exist: exercise and psychosocial support. The American Parkinson Disease Association, well known as the most comprehensive association, supports both exercise, through the publication and distribution of an exercise guide designed to address the deficits of Parkinson's disease, and psychosocial support, by establishing local support groups. The literature on the benefit of exercise and/or psychosocial support was further subdivided into various methods or techniques. Some studies, however, found that the specifics of the treatment were not as important as the benefit of exercise in and of itself and that the psychological benefit of exercise played a significant role in many of the programs (Weiner & Singer, 1989).

Exercise and Activity Programs

The benefit of exercise for young healthy individuals is studied extensively and well-documented. Even for older individuals not affected by a progressively degenerating disease, many benefits of exercise exist.

Seventy-two “healthy” adults over the age of 60 participated in long term low or moderate-intensity exercise (Stevenson & Topp, 1990). Significant improvements were found in sleep quantity, mental status (attention, memory, higher cognitive functions), perception of health (outlook on health) and cardiovascular fitness (including heart rate, oxygen consumption, exercise time). The low intensity group benefited as much as the moderate intensity group.

A study conducted at Tel-Aviv University demonstrated the effectiveness of physical therapy for people with Parkinson’s disease using “whole-body participation”, such as moving the body’s center of gravity in a coordinated fashion in tasks like throwing and catching in combination with a problem solving approach (Yekutieli, 1992). Each subject was treated individually on a biweekly basis over a three month period and overall, the subjects achieved significant gains in speed of mobility tasks when they were timed in three different tests.

Another study found benefits of a four week intensive physical rehabilitation program. Pre-test and post-test scores on the Parkinson’s Disease Rating Scale found objective benefits from the program for people in moderate stages of the disease because following the resumption of normal activity without exercise, their improvements were lost after only six months (Comella, Steggins, Brown-Toms, & Goetz, 1994).

Hurwitz (1989) investigated the impact of an individual exercise program developed by the National Parkinson’s Disease Foundation which was provided in private homes by visiting home nursing students. The participants of the weekly routine exercise group had significant improvement in memory,

less urinary incontinence, diminished nausea, and improved oral control (sucking ability) than the group without the exercise intervention.

Independence in self-care also improved, but not significantly. Subjective and objective ratings were utilized.

Pedersen, Oberg, Insulander, and Vretman (1990) studied 10 people with mild to moderate Parkinson's disease who participated in an exercise program. The group training sessions were held biweekly for 12 weeks and a home exercise program was also given. Pre-test and post-test scores of gait analysis and muscle strength were used. Objective improvements were not attained by the researchers, but the participants subjectively reported benefits from the training program. The authors cite various theories for the lack of objective improvement including atrophy of fast twitch muscle fibers and disrupted muscle fiber recruitment patterns. They concluded that group training and exercise should be given to people with Parkinson's disease, despite the lack of definite results for this study.

There is a general consensus within the literature that exercise is beneficial for the person with Parkinson's disease, although there is no conclusive agreement on the exact method. Only one study was found in the literature that expressed doubt about the use of therapy or exercise for people with Parkinson's disease. Gibberd, Page, Spence, Kinnear, and Hanksworth (1981) published the results of their study that questioned the use of therapy for people with stable Parkinson's disease, finding negligible benefits and suggesting resources could be used more effectively. In the following issue, Andrews (1981) challenges this study, citing specific problems with the research design, such as the use of a five point subjective scale, which may

have been too small to detect any change, and an “inactive treatment group” which, in Andrews' opinion, was just another form of therapy.

Group Approach

The group approach to treatment may be beneficial for the person with Parkinson's disease. Occupational therapy often uses groups because of the many benefits of group treatment. Group treatment is more expedient and cost effective for some goals of therapy. More importantly, the interaction among group members can be an effective way of reaching individual treatment goals. As Gauthier, Dalziel, and Gauthier (1987) found, group settings promote more behavioral changes than individual treatment and may be more beneficial to people with chronic degenerative diseases who may be more depressed and socially isolated. Another benefit of group participation is that the peer group can provide feedback which may be accepted more readily than feedback from an individual who is not affected by Parkinson's disease (Szekely, Kosanovich, & Sheppard, 1982).

Depression, social isolation, and a sedentary lifestyle are problems in many chronic illnesses, including Parkinson's disease. One study investigated the effects that chronic illness has on the lives of the individuals with various diseases (Charmaz, 1983). Four major themes were found: leading a restricted life, being socially isolated, being discredited, and burdening others. These combine to contribute to a “loss of self” by people with chronic illness. Group treatment may help to change the perception of their restricted life and social isolation. A phenomenological study, previously mentioned, on the experience of living with Parkinson's disease found that the impact of the disease not only deals with the social isolation of the disease, primarily due to fatigue and

discomfort in social settings, but also with the emotional losses of a changed “normal” life (Marr, 1991). Participants acknowledged the importance of being with other people with Parkinson’s disease because of the similar experience of living with a chronic disease.

The benefits of group treatment has been shown in the healthy elderly. Following a group exercise program, improvement in the well-being of healthy elderly was shown (Ray, Gissal, & Smith, 1983). It seems reasonable that group treatment could also benefit individuals with Parkinson’s disease. The group approach for people with Parkinson’s disease has been studied by several other investigators, with Davis (1977), an occupational therapist, being a strong influence in promoting multidisciplinary group treatment. More recently, group versus non-group treatment was the topic of one study completed by two occupational therapists and a physician (Gauthier, Dalziel, & Gauthier, 1987). The researchers studied people with idiopathic Parkinson’s disease who were randomly assigned to individual or group treatment, followed by evaluations immediately post treatment, six months, and one year later. The sessions were held for a five week period with two hour biweekly meetings and included socialization, mobilization, dexterity tasks, and functional activities. The measurement instruments utilized were the Barthel Index, Purdue Pegboard Test, the Extrapyrmidal Symptom Rating Scale, and The Bradburn Index of Psychological Well-Being. The experimental group, which received group treatment, maintained the same functional level after one year, whereas the control group, which received individual treatment, experienced a functional decline, giving credence to group treatment for Parkinson’s disease.

Palmer, Mortimer, Webster, Bistevins, and Dickinson (1986) also studied

the effects of exercise on patients. The subjects were randomly selected for participation in one of two 12 week exercise groups. One group participated in the United Parkinson's Foundation Exercise program, while the other group was trained in upper body karate techniques. At the completion of the study, both groups showed significant improvement in gait, tremor, grip and motor coordination as measured by the Parkinson's Disease Motor Battery, Nine-hole Pegboard Test, and the Minnesota Placing and Turning Test. The authors stated that the value of the changes that occurred is "evident from the subjective assessment of patients who expressed increased confidence and feelings of well-being as a result of the exercise programs" (Palmer et al., 1986, p. 745).

In one study, conducted by a group of nurses, the physical as well as psychosocial effects of a group exercise program for seven individuals with Parkinson's disease were investigated (Mitchell, Mertz, & Catanzaro, 1987). After eight weekly sessions, mobility significantly improved objectively and subjectively and overall function significantly improved as measured by a Parkinson's Assessment Tool (developed by the researchers) as well as the Social Dependency Scale. Furthermore, the research report states, "these data suggest that simple exercise in a social group setting was useful in symptom management for these persons (Mitchell et al., 1987, p. 244)." However, as noted by the researchers, further investigation must be completed since the study is limited by a small sample size ($N = 7$) and an absence of a control group.

Szekely, Kosanovich, and Sheppard (1982) measured the effects of a 13 week exercise and education group program with objective measurements of walking speed, balance, posture, and time required to execute their signature.

Subjective measurements were obtained with an activities questionnaire, the Bradburn Affective Balance Scale, and the Beck Depression Inventory. A unique component of this study was the emphasis on home practice of the exercises and the existence of a family and caregiver support group. Improved gait was the only statistically significant change measured, and the Beck Depression Inventory showed a non-significant change toward less depressed. Researchers, however, observed that, despite the lack of empirical evidence, the patients were highly motivated to attend the group and that they verbally reported improvement in ability to perform activities of daily living when interviewed.

In summary, the benefits of group treatment has been well supported in the literature, as evidenced by the studies noted. No literature was identified that challenged this premise. The theoretical framework for this study will now be discussed.

Theoretical Framework for this Study

The foundation of the format of the exercise class stems from several different areas including group interaction, psychosocial functioning, and functional performance, thus several different frames of reference guided the therapy investigated in this research. The three frames of reference are: developmental, occupational performance and biopsychosocial.

An occupational therapist may approach the treatment of a person with Parkinson's disease in several different ways. The person with Parkinson's disease, usually an older adult or elderly individual, continues her/his growth and development. The developmental frame of reference espouses the concept that humans grow and mature in the environment throughout the lifespan.

Facilitating that developmental process is the primary focus of treatment, since physical or psychological disability may interrupt continued growth. Activity and exercise groups address the “horizontal” development of humans with activities addressing each area: exercise addresses physical and neurophysiological development, the group setting addresses psychological and psychodynamic issues, and the activity portion of the class covers social language, activities of daily living and sociocultural issues. Unfortunately, with a progressively degenerating disease, the chronological development can encompass deterioration thus mastery of the developmental requirements of the stage may never be reached.

Enabling the person with a disability to perform life roles and maintain function in work, self-care, rest, and play has been a traditional focus of occupational therapy intervention. Since disease or injury may impact the person’s ability to meet the roles of that developmental stage, dissatisfaction may result when this intrinsic need to master the environment is not met. According to Reilly (Deusen, 1988), the utilization of play as a method of adapting to life roles is a means of obtaining that goal. In the activity portion of the class, play is a central theme giving quality of life and pleasure to people with Parkinson’s disease through adaptation.

Currently, the medical model is the predominant approach utilized by many health care professionals in treating a person with a disability. In this model, the disease is viewed as a physical entity with a physical cure. The biopsychosocial model, described by Mosey, provides a holistic approach to treatment within occupational therapy. It promotes the use of mind, body, and environment. The individual with Parkinson’s disease is viewed holistically,

since the disease affects so many aspects of the person's life and functioning. This approach is also very logical to use in a community based setting.

The central theme of occupational therapy is functional performance, the subskills of which assist the engagement in activities and tasks of occupational performance and the performance our occupational roles (Llorens, 1991). To achieve a holistic perspective of individuals with Parkinson's disease, it is important to know the person's functioning in the area of occupational performance, particularly self-care more than in the subskill areas, such as balance or coordination. However, the subskills may be addressed in treatment by the exercise and activity program with the presumption that by addressing the performance enablers, adaptive processes would be stimulated, in turn, affecting occupational performance (self-care). Subjects with Parkinson's disease have been found to accurately rate activities of daily living scales (Brown et al., 1989).

Summary of the Literature

Current literature on Parkinson's disease was discussed in this chapter focusing on a review of the disease itself and of non-pharmacologic treatment for people with Parkinson's disease. A summary of Christenson's (1985) study and the frame of reference for therapy in the study was also completed.

Parkinson's disease is usually a slow progressively degenerating disease mainly affecting older adults. Six etiologies of the disease are: idiopathic, drug-induced, postencephalic, arteriosclerotic, symptomatic, and parkinsonism-plus. Idiopathic Parkinson's disease is the most common form of the disease. Diagnosis of the disease is generally made through identification of a set of clinical features. The pathology of the disease begins with a

decrease of dopamine in the substantia nigra which in turn effects communication with the corpus striatum, eventually affecting other neurotransmitters. As a result of this system pathology, three main symptoms commonly occur: resting tremor, muscle rigidity, and bradykinesia (or akinesia). This symptom triad affects the person in a variety of ways and impacts his/her ability to perform activities of daily living.

Psychological, cognitive, and personality changes are also associated with the disease. The existence of depression in people with Parkinson's disease is commonly cited in the literature, but theories regarding the cause vary. Dementia and other cognitive deficits such as impairments in immediate verbal recall and sequencing are also cited. Personality changes, in a negative direction, are also cited. Medical management of Parkinson's disease usually focuses on drug treatment, but recent surgical advances are a focus of researchers' attention at the present time.

CHAPTER 3

DESIGN AND METHODOLOGY

The purpose of this study was to investigate the relationship between morale and functional activities of people with Parkinson's disease who attended one of two 10 week group exercise classes. The questions formulated for this study were:

(1) Is there an increase in the perceived quality of activities of daily living performance of people with Parkinson's disease following a 10 week exercise and activity program?

(2) Is there an increase in the perceived morale of the participants of a 10 week exercise and activity program for people with Parkinson's disease?

(3) Is there a correlation between the quality of performance in activities of daily living and morale for people with Parkinson's disease who participated in a 10 week exercise and activity program?

(4) Do the findings of this study compare favorably or unfavorably with those of the Christenson (1985) study?

Subjects

A sample of convenience of adults with Parkinson's disease who voluntarily attended a 10 week exercise and activity program were subjects for this study. The exercise and activity program classes were offered by Kirk Community Center in San Jose, California, and DeAnza College in Cupertino, California during the winter semester of 1994. These classes were chosen because they were the only classes in the San Jose and San Francisco Bay area that were exclusively designed for people with Parkinson's disease. The

subjects were notified about the exercise classes through the community center class schedule or community college class schedule which were distributed periodically throughout the community (Appendix E). Other referral sources included the class members themselves, physicians, Parkinson's disease newsletters, and local support groups. Approximately 50 students participated in the classes.

To attract participants to the study, an announcement was made on the first day of each class. Subjects were assured that their participation was voluntary and that non-participation would not affect their status in the exercise class. They were also informed that no compensation would be provided. Any person with Parkinson's disease who was willing to participate was accepted.

Course Content

The classes at the two facilities had similar course content. They were facilitated, however, by different instructors. Each class consisted of a greeting and welcoming phase, the warm up phase, the exercise portion (either chair exercises or mat exercises), and the activity phase (which could include games such as chair volleyball, groups walks around a course, education from community health specialists, and relaxation technique education), then the closure or farewell phase. An informal support group for caregivers was an additional component of the class.

The course instructor at Kirk Community Center was Merry Lee Hooks, OTR who has her Bachelor's Degree in Occupational Therapy. In addition to her work in the community, Merry Lee Hooks also provided consultation for Occupational Therapy at the California Parkinson's Foundation. Ruth Haynes was the instructor at the DeAnza College program. She was a Master's

Candidate in Physical Education who specialized in Adaptive Physical Education.

Prior to the beginning of the class and the initiation of the study, permission was received from DeAnza College and San Jose community recreation systems in accordance with the human subjects protocol (Appendix G). Approval was also obtained from the Human Subjects Institutional Review Board (Appendix H).

Design and Procedure

The design of the study was descriptive and pre-test and post-test methodology was used. On the first day of class, the students were asked by the researcher to volunteer to participate in the study and sign a consent form (Appendix F). Each participant was assigned a number to maintain confidentiality and to designate each of the questionnaires. The subjects completed three forms: Demographic Data Information Sheet, Kutner Morale Scale, and the Barthel Index (adapted) (see Appendices I, C, and A, respectively). The exercise instructors maintained an attendance sheet and were not made aware of who agreed to participate in the study. On the last day of class, the subjects who agreed to participate and who attended fifteen of twenty, or 75%, of class meetings were asked to complete the Kutner Morale Scale and the Barthel Index. Some subjects were unable to complete the study due to absence from the final collection day or they did not attend enough classes to qualify for the study.

Data Collection Techniques

Three instruments were utilized: Demographic Data Information Sheet, Barthel Index, and Kutner Morale Scale. The researcher utilized large and dark

print to accommodate visual changes that frequently occur with older adults as well as those associated with Parkinson's disease (Duvoisin, 1991). (The side effects of anticholinergic drugs commonly used by people with Parkinson's disease are often associated with visual changes.) Additionally, felt tipped pens and firm writing surfaces were provided to the participants to minimize any difficulty the students might experience with writing. It has been confirmed that people with Parkinson's disease are able to reliably report on ratings of disability even in the presence of depression (Brown, MacCarthy, Jahanshahi, & Marsden, 1989). However, since concomitant cognitive deficits are well documented in the literature (Cooper, Sagar, Jordan, Harvey, & Sullivan, 1991), easy to follow and non-complicated assessments were chosen. In addition, these assessment forms were selected for time and budget considerations during test administration and scoring.

The demographic data collected included information on age, gender, length of time since diagnosis, the presence of other disabilities or conditions, current medications, effect of disease on left or right sides, employment status, whether or not they felt that friends and family were seen frequently enough, attendance at support groups, and participation in exercise outside of class.

The Barthel Index (adapted) was the second instrument used in the study. This survey was not employed in the Christenson study, as she used an adapted version of the Comprehensive Occupational Therapy Evaluation (COTE) Scale. The Barthel Index was chosen over the COTE Scale for its validity rating, brevity, and ease of use. The adapted version addressed questions related to the following daily activities: eating, drinking, dressing, grooming, washing, getting in and out of a chair, getting on and off a toilet,

getting in and out of a shower, walking on a level surface and climbing stairs (Appendix A). The original version of the index includes questions on bowel and bladder control which were eliminated from this study to increase compliance. The subject can choose from one of three responses, "Can do by myself", "Can do with help of someone else or with device" and "Cannot do at all". Each of the responses have a corresponding weighted score (Appendix B). The test is quite reliable in its pure form; it has been shown to have a high interrater reliability with coefficients $>.95$, and high test-retest reliability with coefficients $.89$, with evidence of concurrent and predictive validity (Christiansen, 1991). Additionally, the total score has been found to be "discriminating and valid and changes over time deemed to be a reliable measure of observed functional change" (Christenson, 1985). Modifications in the Barthel Index were made to increase ease of use with the subjects; however, this limited its reliability for this study.

The Barthel Index was assessed for utility in monitoring progress in a rehabilitation setting (Granger, Albrecht, & Hamilton, 1979). Score ranges were given to distinguish the degree of severity of disability. Since three items were eliminated from this study (bowel and bladder control and wheelchair mobility), the scales were adjusted accordingly. The responses were subdivided into three categories: (1) Marked dependence in self-care and mobility is associated with scores of 45 or below for the adapted scale (which is 60 or below for the standard scale) (2) Severe dependence in self-care and mobility is associated with scores of 20 or below for the adapted scale (and 40 or below for the standard scale), (3) Total dependence in self care and mobility is associated with scores 5 or below (and 20 or below for the standard scale). A perfect score

on the scale, 85 on the adapted version and 100 on the original version, would not indicate that a person is able to live independently since this instrument does not address the complex activity of daily living skills such as home management or safety in the community setting.

The third scale was the Kutner Morale Scale which utilized seven questions that addressed areas such as life satisfaction and happiness with three adjective responses to each. For example, one of the statements is "Things just keep getting worse and worse for me as I get older" with the responses of "Agree" "Disagree" and "Not Sure" (Appendix C). Each of the responses has a corresponding score (Appendix D). According to the scale, a person is considered to have "high morale" with a score of five or six, "medium morale" with score of three or four, and "low morale" with a score of zero to two.

This instrument was incorporated in this study as it was in Christenson's (1985) study and because of its validity, brevity, and ease of use. Kutner (1956) demonstrated that the seven items of the scales have a coefficient of 90% reliability which is considered acceptable reliability. The simplicity and brevity of this scale make it an excellent tool; however, its "content is limited, its language ponderous, and its brevity a liability in terms of its capacity to measure accurately a complex concept" (Brantl & Brown, 1973, p. 48).

When the data were collected, the answers to all the questionnaires were scored and tabulated by the researcher according to the frequency distribution and analyzed using a Students' T-test. Responses from the Barthel Index (adapted) address the first question of the study regarding the performance in activities of daily living. The Barthel Index (adapted) responses address the question regarding the perceived morale of the participants. A comparison of

the results of the two instruments address the the third question regarding the correlation between performance in activities of daily living and morale. When feasible, the results were compared with the Christenson (1985) study.

CHAPTER 4

DATA ANALYSIS AND RESULTS

The data were collected using the Barthel Index (adapted) and the Kutner Morale Scale. Demographic data were obtained with a multiple choice questionnaire. In the following section, the demographic data will be discussed. When appropriate, percentages are reported for clarity. The responses to the Barthel Index (adapted) and the Kutner Morale Scale will be described. The data will be compared with Christenson's (1985) study when possible. In conclusion, the research questions will be addressed.

Demographic Data

Subjects

Twenty-three subjects met the criteria for minimum level of participation in the class. A demographic profile of those who completed the study is described below.

Age

The most common age range was 71-80 years, in which 11 subjects, or 48% of the subjects responded. The second most common age range was 81-90 years old, in which 30% of the subjects classified themselves. Four respondents, or 17% of the subjects, were in the 61-70 year age range, while only one subject (4%) was in the 51-60 year age range (Figure 1).

Gender

A total of 17 males and 6 females were involved in the study, with the percentages of males and females being 74 and 26%, respectively (Figure 2).

Figure 1. Age of subjects. (N = 23)

Figure 2. Gender distribution of subjects. ($N = 23$)

Length of Time Since Diagnosis

The length of time since diagnosis ranged from less than one year to more than nine years, with the average being six years since time of diagnosis.

Other Disability/Other Medical Condition

Seventeen of the subjects, 74%, had no disability or medical condition other than Parkinson's, while six subjects, 26%, had another "disability" (Figure 3). Four subjects (18%) had a cardiac condition such as hypertension, while two subjects (8%) had an orthopedic problem such as a history of total hip replacement.

Described Effect of Disease on Right Versus Left Sides

Six (26%) of the subjects reported no difference in the effect of the disease on one side of their body versus the other. For nine (40%) of the subjects, the left side was more effected than the right, while the remaining eight subjects (35%) felt the effects on the right side more than the left.

Medications

All the subjects took medications to control the symptoms and many took combinations of drugs, which is very common among people with Parkinson's disease. Most commonly, Eldepryl™(selegiline hydrochloride) and Sinemet™ (levodopa and carbidopa) were taken in combination, with 44% of the subjects reporting. A combination of Sinemet™ with another drug was second most common (31%). Four subjects (17%) took only Sinemet™, one subject (4%) took only Eldepryl™, and one subject took a drug which was part of a research protocol (Figure 4).

Figure 3. Other disability or medical condition in addition to Parkinson's disease. (N = 23).

Figure 4. Current medications for Parkinson's disease taken by subjects. ($N = 23$)

Employment Status

Twenty-one subjects (91%) were retired, one was unemployed (4%), while one subject continued to work part time (4%).

Perception of Support from Family and Friends

In response to the question, "Do you feel you see friends and family frequently enough?", 19 respondents (83%) answered affirmatively, while four subjects (17%) responded negatively.

Attendance to Support Group

Thirteen (57%) of the participants in the study attend a support group outside of class while 10 (43%) do not.

Regular Exercise Program

Fourteen (61%) of the subjects reported participating in a "regular exercise program" while nine (39%) do not.

Comparison to Christenson (1985) Study

Compared to the Christenson (1985) study, the participants of this study were older (common age was 71-80), while for Christenson the average age was 67.5. The ratio of men to women was slightly lower in her study with 70% males and 30% females participating, or 28 males to 12 females, compared to this study in which 74% males and 26% females participating, or 17 males and 6 females. The length of time since diagnosis was the same, a six year average in both studies. Fewer subjects were retired in the Christenson (1985) study, 33 of 40 subjects (82%) were retired, compared to 21 of 23 subject retirement rate (91%) in the current study. Data regarding other disability, medications, effect on one side of the body, and opinions about family and friend support, exercise involvement and support group attendance were not addressed in the

Christenson (1985) study, therefore, comparisons cannot be made.

Barthel Index (adapted)

The Barthel Index (adapted) was tabulated and converted to percentages for ease of description. In the following section, each of the responses to the survey will be discussed individually for the pre-test and post-test and then they will be compared. The average scores will then be discussed. The results of this section cannot be compared to the Christenson (1985) study since the author utilized a different scale for measuring function in activities of daily living.

Although the total Barthel Index (adapted) scores reflect a more important and holistic viewpoint, individual responses are given and a summary provided. The twelve questions of the survey had three responses "Can do by myself" meaning they are independent, "Can do with help of someone else or with device" meaning they require assistance, "Cannot do at all" meaning they are dependent.

For the pre-test scores, in response to the statement, "Drinking from a cup", 100% of the subjects stated they were independent. For "Eating, which includes cutting food, opening containers" as well as "Dressing upper body, includes buttoning, zippers" 20 subjects (87%) rated themselves independent while 3 (13%) stated that assistance was required.

The category "Lower body dressing includes pants, shoes, laces" received the lowest scoring of all areas. Seventeen (74%) responded that they were independent, five (22%) stated they needed assistance, and one (4%) stated they were dependent.

Nineteen (83%) of the respondents classified themselves as independent and four (17%) were assisted in the categories of "washing or

bathing” and “grooming”. For “Getting in and out of a chair”, 18 subjects (78%) ranked themselves independent and 5 (22%) ranked themselves assisted. Whereas “Getting on and off toilet” and “Getting in and out of tub or shower” were slightly higher with 19 subjects (83%) stating that they were independent and 4 subjects (17%) stating they needed assistance. For “Walking 50 yards on the level” and “Walking up/down one flight of stairs” 20 subjects (87%) were independent and 3 (13%) were assisted. None of the participants were not walking.

As a result of the survey some changes were discovered following the 10 week exercise and activity class. In the post-test, improvements were noted in eating, which improved in 22 (96%) of the subjects responding that they were independent, an increase from 21 (87%), and 1 (4%) needing help; grooming in which 21 of the subjects (91%) reported independence, an increase from 19 (83%), and 4 (17%) needing help; getting up from a chair improved with 19 of the respondents (83%) who became independent from 18 (78%), while 2 (9 %) needed help; and getting up from a toilet improved to 21 subjects (91%) being independent compared with 19 (83%) in the pre-test and 2 (9%) still needing assistance. Their reported ability to drink from a cup, complete upper body dressing, bathe, get in and out of tub or shower, and walking 50 yards remained the same. Lower body dressing had a mixed response. More subjects, 21 of 23, (87%) became independent (increasing from 17 (74%), while 2 subjects (13%) were now not able to dress their lower body, compared to 1 (4%) in the initial test. The ability to manage stairs also demonstrated a decline to only 19 subjects (83%) being independent and 4 subjects (17%) requiring help or a device. The reader is referred to Figure 5 for a graphic illustration of pre-test

and post-test individual scores.

Overall, the average scores for the Barthel Index (adapted) improved minimally from 77 to 79 points (Figure 6); however, this was not statistically significant at the $p = .05$ level. The score was elicited by summing the points according to the scoring system and taking an average. The score range is 0-85 with a higher score indicating better functional performance. According to the Granger, Albrecht, and Hamilton (1979) study, the subjects in both the pre-test and post-test remained above the “marked dependence range” which is designated to be at a score of 45 or below for the adapted scale.

Kutner Morale Scale

The Kutner Morale Scale consisted of seven questions with three responses to each statement. Individual questions will not be discussed in this section since the overall scale is a better indicator of morale. The scores were calculated according to the scale and tabulated into pre-test and post-test total results as well as tabulated into each morale category (low, medium, and high).

The average pre-test score was 3.9 and the average post-test score was 4.0 (Figure 7). These scores were both in the range of medium morale and according to analysis using the Students' T-test, the change was not statistically significant at the $p = .05$ level.

In terms of the morale categories, in the pre-test, 5 of 23 respondents (22%) showed low morale scores, 8 of 23 subjects (35%) showed medium morale scores, and 11 of 23 subjects (48%) showed high morale scores.

In the post test, 4 of 23 subjects (17%) showed low morale scores, 11 of 23 participants (48%) showed medium morale scores, and 8 of 23 (35%) showed high morale scores (Figure 8).

Figure 5. Pre-test and post-test responses to Barthel Index (adapted) statements in percentage response to each category: "independent", "assisted", and "dependent". (N = 23)

continued...

Figure 5. (continued)

continued...

Figure 5. (continued)

Figure 6. Pre-test and post-test total scores of the Barthel Index (adapted). ($N = 23$)

Figure 7. Pre-test and post-test total scores of the Kutner Morale Scale. ($N = 23$)

Figure 8. Pre-test and post-test responses to Kutner Morale Scale:
Percent of subjects whose scores fell in each response
category. ($N = 23$)

In conclusion, the research questions are addressed in the following:

(1) Is there an increase in the perceived quality of activities of daily living performance of people with Parkinson's disease following a 10 week exercise and activity program? Overall, there was a slight increase in performance as reflected in the Barthel Index (adapted). The change was not statistically ($p < .05$) significant; however, and the subjects remained in the same category of independence.

(2) Is there an increase in the perceived morale of the participants of a 10 week exercise and activity program for people with Parkinson's disease? There was a minimal change with the average scores in a positive direction, but it was not statistically significant with ($p < .05$). The scores averaged toward medium morale.

(3) Is there a correlation between the quality of performance in activities of daily living and morale for people with Parkinson's disease who participated in a 10 week exercise and activity program? The average scores both minimally increased to the more independent and higher morale range; however, there is no statistically significant correlation between the two.

(4) Do the findings of this study compare favorably or unfavorably with those of the Christenson (1985) study? All findings of the two studies could not be compared as was expected at the initiation of the study due to the differences in the design of the two studies. The morale findings can be compared. The morale scores were higher for the subjects of the current study when compared with the Christenson study.

In summary, the scores on the Kutner Morale Scale did not change significantly, and there was a tendency toward medium morale following

participation in the exercise class when an average is taken (Refer to Figure 8).

Since the Christenson (1985) study reported only post-test scores, only the post-test scores from the two studies can be compared. In the Christenson study, following the exercise and activity class, 45% of the respondents showed low morale scores, 30% of the respondents showed medium morale scores, and 25% of the respondents showed high morale scores, compared to the 17% with low morale scores, 48% with medium morale scores, and 35% with high morale scores in the present study. Overall, the morale scores in this study were generally higher.

CHAPTER 5

SUMMARY, IMPLICATIONS, AND RECOMMENDATIONS

The purpose of this study was to determine if a group exercise and activity class would effect performance in activities of daily living or morale for people with Parkinson's disease and if there was a correlation between performance in activities of daily living and morale. In 1985, Carolyn Christenson studied the same factors with a group of subjects with Parkinson's disease using a post-test design and two rating scales, a modified version of the Comprehensive Occupational Therapy Evaluation Scale (COTE) and the Kutner Morale Scale. Although Christenson (1985) found a positive relationship between morale and independence in activities of daily living as well as a positive correlation between the two variables, the author reported that the research design was weak due to the use of only post-test scores and a tool which was not designed for patient self-report. The present study was conducted in part to enhance the potential of the Christenson study.

In the current study, scores on the Kutner Morale Scale and the Barthel Index (adapted) showed that the study participants demonstrated a slight improvement in a positive direction, but the findings are not statistically significant. However, there was an increase in perceived quality of activities of daily living performance following participation in the class and in the perceived morale of the class participants. There was no significant correlation between quality of performance in activities of daily living and morale of the participants. Further, the findings of this study could not, for the most part, be compared with those of Christenson.

Discussion

Although many studies have shown difficulty with demonstrating objective benefits from a specific technique or treatment for people with Parkinson's disease (Pederson et al., 1990; Szekely et al., 1982), the benefits of exercise for improving performance in activities of daily living has been shown (Gauthier et al., 1987; Mitchell et al., 1987; Szekely et al., 1982) with some researchers believing that the benefits derived from a specific type of exercise per se is not as essential as group or even individual exercise for the psychosocial benefits that occur (Weiner & Singer, 1989; Gauthier et al., 1987; Mutch et al., 1986).

Although there is no empirical evidence from this study that reinforces the benefits of group exercise and activity program, anecdotal evidence supports this belief. First, despite the difficulty with mobility and transportation for most of the subjects, attendance at the exercise groups was fairly consistent. There is a possibility that benefits were derived by the participants, but the benefit factor could not be accurately measured by the scales that were used. Secondly, group cohesiveness developed through participation in the exercise and activity groups with friendships forming among the members and caregivers, evidenced by people greeting each other by name at the final class meeting. The subjective positive effect of group treatment for people with this diagnosis is supported by many researchers (Mitchel et al., 1987; Pederson et al., 1990).

Dealing with a progressively degenerating disease is in itself a limiting factor of this study. The assessment tools were found not to be sensitive enough to measure the type of change observed, or perhaps other variables could have been selected for measurement. The initial scores on the

assessment tools were high; the Barthel Index showed 70% scoring 85, the maximum allowed, on the pre-test while the Kutner Morale scale showed 43% of the participants scored a five or six which indicates high morale, on the pre-test. The question of whether the scale was too limited with its response categories or responses must be raised. Further, the question must be raised regarding whether the subjects were able to respond accurately. Van Hilten et al. (1994) has stated that non-depressed people with Parkinson's disease can provide accurate judgements of their functional disability. However, initially it could be observed that participants in the class had a decline in self-care skills. The participants appeared disheveled, with buttons undone, poor grooming, and unsteady balance; however, they still claimed on their pre-test evaluations that they were independent. Perhaps patients with depression may be unable to accurately rate themselves in self-care. Brown et al. (1989) stated that depression has little impact on ability to rate self in activities of daily living. However, it could be argued that those with major depression did not perform self-care at the level at which they were capable. Starkstein et al. (1991) stated that people with major depression progress through disease stages faster, so it may be that they were experiencing a rapid functional decline, but this was not evidenced by the scores.

Other questions to be asked are: Were the subjects able to recognize deficits initially or did they become obvious to them only as their attention was drawn to them by the questions asked for the study? And were the participants engaged in denial or were they simply unaware of them? Szekely et al. (1982) indicated that many people with chronic disorders, particularly in people with Parkinson's disease, use a defense mechanism to deny the severity of the

disease. It is possible that the subjects reported "maximum" rather than "typical" performance, as they were instructed to do. The person with Parkinson's disease may desire to appear independent and the caregiver may be the only one who truly knows how much assistance the individual with Parkinson's disease receives or requires.

One must question whether morale was the variable to measure to determine the psychosocial impact of the disease. It was not shown to change in healthy independent older adults despite the subjects' perceptions of the benefits of exercise (Ray et al., 1982).

The theoretical frames of reference represented in the program studied in this research were developmental, occupational behavior, and biopsychosocial frames of reference. According to the developmental model, illness is "seen as either psychological or physical stress that is potentially threatening to a client's optimum skill level" (Shortridge, 1988, p. 83). The role of the occupational therapist is to provide activities and relationships to facilitate growth and development both simultaneously and chronologically. This frame of reference helps to explain the rationale of the activity and exercise class for people with Parkinson's disease. Skills, abilities, and relationships were addressed with the use of sensorimotor, interpersonal, developmental, and daily living activities. The premise of the class is not to cure the disease process, but rather to help prevent undue dysfunction. This idea corresponds with Llorens' belief that occupational therapy intervention should occur "at a stage that can be identified before trauma becomes overwhelming" allowing the individual to progress with growth and development (Shortridge, 1988, p. 83). The results of this study, that morale and performance in activities of daily living increase

following participation in an exercise and activity class, also corresponds with this theory. Participants were regressing to earlier stages as a result of the disease process, but the activities and tools of the occupational therapist helped to create a positive change. A significant change in the positive direction was not attained. Possible reasons, in accordance with this theory, may include that the activities did not effectively impact performance, or that changes occurred in other developmental areas not addressed by the study.

According to occupational behavior frame of reference, humans have an "intrinsic need to master and improve [our] environment through skills acquired in [our] various life roles. If this need is blocked by disease or injury [we] suffer dysfunction and dissatisfaction." The impairments in self-care and the impaired morale of the participants correspond with the concepts of this theory. The role of the occupational therapist is to engage people actively in their life role tasks, since dysfunction occurs when disease or injury blocks the need for human beings to master their environment, leading to occupational role dysfunction. Play is an important component throughout life. The exercise and activity class for people with Parkinson's disease uses play and other activities to address dysfunction in daily activities. This theory also helps to explain why dysfunction and dissatisfaction occur, but one would expect a significant improvement in morale and activities of daily living following engagement in the life roles and activities of the class.

The biopsychosocial frame of reference supports the utilization of assessing other life roles that the disease affects, such as homemaker, worker, grandparent or spouse. According to this theory, occupational therapy is concerned with promoting functional independence through intervention

directed toward facilitation of participation in roles...and that performance components are fundamental to development of these roles (Ludwig, 1988, p. 45). Activity to promote mental health is a major premise of this theory. A possible explanation for the change that occurred following participation in the class could be that the class helped to empower the individual to take charge of the disease and effecting change in their relationships outside of class.

Implications for Occupational Therapy

Despite a lack of empirical evidence to support the Parkinson's disease exercise and activity class, subjective benefits reported by the participants were found. There is a small, but positive, effect from exercise and group interaction on morale and performance in activities of daily living. Occupational therapists can develop additional classes at community colleges, recreation centers, or health clubs and utilize this format--exercise with an activity and psychosocial component to help this population. Occupational therapy has much to offer this group--the holistic approach of the occupational therapist is beneficial.

The implication of the results for occupational therapy is that occupational therapists may need to study a variety of roles to determine the effectiveness of a given intervention. In addition, other methods of assessment should be utilized with this population to determine if cognition and insight have an effect on a person's ability to judge progress.

Recommendations for Further Research

Several recommendations are proposed to further advance knowledge about the effectiveness of Parkinson's exercise and activity classes for people with Parkinson's disease:

1. Complete a long term study (more than three months) of participants who

only attend the class for the first time who do not perform exercise or attend support groups outside of class and compare with a control group which attends support groups only and does not exercise (i.e. from a Parkinson's Disease Support Group).

2. Using scales that measure "higher level" skills, such as home management, study the effects group exercise and activity.
3. Use a different scale to measure psychosocial status such as The Bradburn Affective Balance Scale so that quality of life issues could also be addressed.
4. Using the Mini-Mental Scale, determine cognitive functioning and ability to accurately complete the assessment forms.
5. Using caregiver reports of participants performance in activities of daily living in combination with the subjects self assessment to help determine accuracy of response.
6. Complete phenomenological studies with participants of the exercise and activity class to determine the factors that stimulate their participation in the exercise and activity class.

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APPENDIX A
BARTHEL INDEX (ADAPTED) RATING FORM

Please answer all of the following questions. Place a check in the box corresponding to the category which describes you best.

	"Can do by myself"	"Can do with help of someone else or with device"	"Cannot do at all"
1. Drinking from a cup			
2. Eating Includes cutting food, opening containers			
3. Dressing upper body Includes buttoning, zippers			
4. Dressing lower body Includes pants, shoes, laces			
5. Grooming			
6. Washing or bathing			
7. Getting in and out of chair			
8. Getting on and off toilet			
9. Getting in and out of tub or shower			
10. Walking 50 yards on the level			
11. Walking up/down one flight of stairs			
12. IF NOT WALKING: Pushing own wheelchair			

APPENDIX B
BARTHEL INDEX (ADAPTED) SCORING

Barthel Index (adapted) Scoring

	"Can do by myself"	"Can do with help of someone else or with device"	"Cannot do at all"
1. Drinking from a cup	4	0	0
2. Eating Includes cutting food, opening containers	6	0	0
3. Dressing upper body Includes buttoning, zippers	5	3	0
4. Dressing lower body includes pants, shoes, laces	7	4	0
5. Grooming	5	0	0
6. Washing or bathing	6	0	0
7. Getting in and out of chair	15	7	0
8. Getting on and off toilet	6	3	0
9. Getting in and out of tub or shower	1	0	0
10. Walking 50 yards on the level	15	10	0
11. Walking up/down one flight of stairs	10	5	0
12. IF NOT WALKING: Pushing own wheelchair	5*	0	0

Barthel Total: Best Score 85; Worst Score 0

* This score is included in "best score"

APPENDIX C
KUTNER MORALE SCALE

CODE # _____

Below is a list of questions and statements which have to do with how you feel about life. Please CHECK the answer which best describes your feelings.

1. How often do you feel that there's just no point in living?
☐ OFTEN
☐ SOMETIMES
☐ HARDLY EVER
2. Things just keep getting worse and worse for me as I get older.
☐ AGREE
☐ DISAGREE
☐ NOT SURE
3. How much do you regret the chances you missed during your life to do a better job of living?
☐ NOT AT ALL
☐ SOMEWHAT
☐ A GOOD DEAL
4. All in all, how much happiness would you say you find in life today?
☐ ALMOST NONE
☐ SOME, BUT NOT VERY MUCH
☐ A GOOD DEAL
5. On the whole, how satisfied would you say you are with your way of life today?
☐ VERY SATISFIED
☐ FAIRLY SATISFIED
☐ NOT VERY SATISFIED
6. How much do you plan ahead the things you will be doing the next week or the week after?
☐ MANY PLANS
☐ A FEW PLANS
☐ ALMOST NONE
7. As you get older, would you say things seem better or worse than you thought they would be?
☐ BETTER
☐ WORSE
☐ SAME

APPENDIX D
KUTNER MORALE SCORING

Kutner Morale Scale Scoring

1. How often do you feel that there's just no point in living?
 - 0 OFTEN
 - 0 SOMETIMES
 - 1 HARDLY EVER
2. Things just keep getting worse and worse for me as I get older.
 - 0 AGREE
 - 1 DISAGREE
 - 0 NOT SURE
3. How much do you regret the chances you missed during your life to do a better job of living?
 - 1 NOT AT ALL
 - 0 SOMEWHAT
 - 0 A GOOD DEAL
4. All in all, how much happiness would you say you find in life today?
 - 0 ALMOST NONE
 - 0 SOME, BUT NOT VERY MUCH
 - 1 A GOOD DEAL
5. On the whole, how satisfied would you say you are with your way of life today?
 - 1 VERY SATISFIED
 - 0 FAIRLY SATISFIED
 - 0 NOT VERY SATISFIED
6. How much do you plan ahead the things you will be doing the next week or the week after?
 - 1 MANY PLANS
 - 1 A FEW PLANS
 - 0 ALMOST NONE
7. As you get older, would you say things seem better or worse than you thought they would be?
 - 1 BETTER
 - 0 WORSE
 - 0 SAME

MORALE SCALE RATINGS:

LOW MORALE 0-2

MEDIUM MORALE 3-4

HIGH MORALE 5-6

APPENDIX E
DESCRIPTION OF EXERCISE CLASS

KIRK COMMUNITY CENTER CLASS

Course Title: Parkinson's Exercise Class

Days, Times, Location: Mondays and Wednesday
9:30-10:30 AM and 11-12 PM
Kirk Community Center San Jose

Fee: \$25.00

Instructor: Merry Lee Hooks, OTR

Description of Class (from the City of San Jose Parks and Community Services Brochure): "This exercise program is designed for individuals with Parkinson's Disease and is instructed by Merry Lee Hooks, a registered Occupational Therapist. Components of the program include range of motion, static and dynamic balance skills, coordination exercises, posture training, and guest speakers."

Requirements: Registration form and liability release, fee payment

DeANZA COLLEGE CLASS

Course Title: Parkinson's Exercise Class

Days, Time, Location: Tuesday and Thursday
9- 10:30 AM
Sunnyvale Campus of DeAnza College

Fee: Based on one-unit credit at the college

Instructor: Ruth Haynes

Description of Class: "The purpose of this program is to provide an atmosphere which allows support, education, socialization, balance activity, stretching, games, and relaxation techniques"

Requirments: Registration form, medical form (completed by M.D.), fee payment

APPENDIX F
AGREEMENT TO PARTICIPATE IN RESEARCH

School of Applied Arts and Sciences • Department of Occupational Therapy
 One Washington Square • San José, California 95192-0059 • Main Office 408/924-3070 • Fieldwork Office 408/924-3078

AGREEMENT TO PARTICIPATE IN RESEARCH SAN JOSE STATE UNIVERSITY

Responsible Researcher: Michelle Lozano

I agree to participate in Michelle Lozano's study. I understand that she is a student at San Jose State University and that this study will satisfy partial requirements for a Master's Degree in Occupational Therapy. I am aware that the purpose of the study is to determine the effects of participation in a Parkinson Exercise Class on my performance of functional activities of daily living and my sense of well-being.

I understand that my participation in this study is voluntary and that I can withdraw at any time. I am aware that my participation in this study is not connected to the exercise class or San Jose State University and that if I refuse to participate at any time, this will not affect my class enrollment or my relations with San Jose State University. There are no risks nor benefits associated with my participation in this study.

I also understand that information I give will be held confidential. I am aware that I will be assigned a code number and my name will not be used in the study. No photographs will be taken as part of the study. No review of medical records will be required for the study.

I understand that the results from this study may be published, but any information from this study that can be identified with me will remain confidential.

Any questions about my participation will be answered by Michelle Lozano, the researcher, (415) 922-8573. Complaints about the procedures may be presented to Dr. Lela Llorens (408) 924-3072. For questions or complaints about research subjects rights, contact Serena Stanford, Ph.D. at (408) 924-2480.

I agree to complete a set of questionnaires at the beginning and at the end of the class. One questionnaire asks basic information about my age and length of illness. On another questionnaire I will rate myself on my sense of well-being. On a third questionnaire I will rate myself in my performance in daily activities. I am aware that the tests will take 30-45 minutes to complete and that no compensation will be provided.

YOU ARE MAKING A DECISION WHETHER OR NOT TO PARTICIPATE. YOUR SIGNATURE INDICATES THAT YOU HAVE DECIDED TO PARTICIPATE HAVING READ THE INFORMATION PROVIDED ABOVE.

 Witness signature

 Participant's Signature

 Date

 Researcher's Signature

APPENDIX G
LETTERS OF PERMISSION FROM
THE CITY OF SAN JOSE and DeANZA COLLEGE

CITY OF SAN JOSE, CALIFORNIA
DEPARTMENT OF RECREATION, PARKS AND COMMUNITY SERVICES

OFFICE OF THERAPEUTIC SERVICES

1530 Blossom Hill Rd., San Jose, CA 95118-3302

Voice/TDD (408) 267-0200

February 12, 1993

Michelle Lozano, OT
175 Gladys Avenue, #5
Mountain View, California 94043

Dear Michelle,

My apologies for being so late in getting this letter to you. The first part of this year has been inundated with budget preparation and my move to the Office of Therapeutics.

My communication on your project has been through Gary Okazaki and I have indicated to him that you have my approval to proceed.

I look forward to meeting you and know that you will receive much support for your project through Gary. Good luck to you!

Sincerely,

A handwritten signature in cursive script, appearing to read "Rita Oosterman".

Rita Oosterman
Recreation Superintendent
Office of Therapeutic Services

RO:ps

August 18, 1993

"The Effects of a Group Exercise and Activity Class
on Morale and Performance of Activities of Daily
Living for People with Parkinson's Disease"

To whom it may concern,

I have reviewed Michelle Lozano's packet describing her graduate study to determine the relationship between the morale and performance of activities of daily living following a ten-week group exercise and activity program for people with Parkinson's Disease. I am impressed with her study and consider it an important area of research to be studied.

The Parkinson's Disease exercise class at De Anza College, Cupertino agree to let Michelle Lozano conduct her study at the beginning of the exercise class and at the end of the ten-week exercise class.

Sincerely,

Jim Haynes
Jim Haynes
Adaptive Physical
Education Coordinator

Ruth Haynes
Ruth Haynes
Adaptive Physical
Education Instructor

APPENDIX H

HUMAN SUBJECTS - INSTITUTIONAL REVIEW BOARD APPROVAL

A campus of The California State University

Office of the Academic Vice President • Associate Academic Vice President • Graduate Studies and Research
One Washington Square • San Jose, California 95192-0025 • 408/924-2480

To: Michelle Lozano
1884 A Filbert St
San Francisco, CA 94123

From: Serena W. Stanford *Serena W. Stanford*
AAVP, Graduate Studies and Research

Date: September 1, 1993

The Human Subjects-Institutional Review Board has approved your request to use human subjects in the study entitled:

"The Effects of a Group Exercise & Activity on
Morale & Performance of Activities of Daily Living
for People with Parkinson's Disease"

This approval is contingent upon the subjects participating in your research project being appropriately protected from risk. This includes the protection of the anonymity of the subjects' identity when they participate in your research project, and with regard to any and all data that may be collected from the subjects. The Board's approval includes continued monitoring of your research by the Board to assure that the subjects are being adequately and properly protected from such risks. If at any time a subject becomes injured or complains of injury, you must notify Dr. Serena Stanford immediately. Injury includes but is not limited to bodily harm, psychological trauma and release of potentially damaging personal information.

Please also be advised that each subject needs to be fully informed and aware that their participation in your research project is voluntary, and that he or she may withdraw from the project at any time. Further, a subject's participation, refusal to participate or withdrawal will not affect any services the subject is receiving or will receive at the institution in which the research is being conducted. If you have questions, please contact me at 408-924-2480.

APPENDIX I
DEMOGRAPHIC DATA INFORMATION SHEET

Code # _____

Please answer each of the following questions.

1. Age: ☐ 30-40 ☐ 41-50 ☐ 51-60 ☐ 61-70 ☐ 71-80 ☐ 81-90 ☐ 90 +
2. ☐ Male ☐ Female
3. Length of time since diagnosis of Parkinson's Disease:
☐ less than 1 year ☐ 1-2 years ☐ 2-3 years ☐ 3-4 years
☐ 4-5 years ☐ 5-6 years ☐ 6-7 years ☐ 7-8 years ☐ 9+ years
4. Do you have another condition in addition to Parkinson's disease
 (ie: hip fracture or stroke)?
☐ no ☐ yes (SPECIFY) _____
5. CURRENT Medications taken for Parkinson's Disease:

☐ Artane	☐ Eldepryl	☐ Madopar
☐ Kemadrin	☐ Sinemet	☐ Parlodel
☐ Akineton	☐ Symmetrel	☐ Permax
☐ Cogentin	☐ Larodopa	☐ Doperpine
☐ Tremin	☐ Selegiline	
☐ Parsidol	☐ OTHER (Specify) _____	
6. Does the disease affect one side greater than the other?
☐ no ☐ yes If yes, which side? ☐ Left ☐ Right
7. Employment status:
☐ Part time employed
☐ Full time employed
☐ Unemployed (ie: want to return to work)
☐ Retired
8. Do you feel you see friends and family frequently enough?
☐ yes ☐ no
9. Do you attend a Parkinson's support group in addition to the exercise class? ☐ yes ☐ no
10. Do you have a REGULAR personal exercise program in addition to the exercise class? ☐ yes ☐ no