A CASE STUDY ON THE ROLE OF EXERCISE IN THE MANAGEMENT OF PARKINSON'S DISEASE

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A CASE STUDY ON THE ROLE OF EXERCISE IN THE MANAGEMENT OF PARKINSON'S DISEASE

BY

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fulfilment of the requirements for the degree of
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ABSTRACT

Exercise has been heralded by many as the therapeutic medium for managing stress, enhancing well being, controlling weight, and preventing illness. In fact, many people attach more credibility to exercising, as a means to achieving or maintaining satisfactory health, then any other form of medical intervention.

There are however, an infinite number of people who envision physical activity as something that is reserved for the young and healthy. The infirmed are either non-candidates for any form of physical exertion or, it is generally felt, beyond help. Because of the preponderance of effort and time required to attend or adhere to a pattern of regular exercise coupled with the belief that exercise might further aggravate a medical condition, those who are ill prefer the comfort and noncommittal nature of remaining sedentary.

This paper is a qualitative investigation centred primarily around an endeavour to obtain information that describes the experiences of living with a medical condition called Parkinson's disease and participating in an exercise program. The quantitative research has already established that there is a positive change in gait, muscular strength and flexibility but there is very little research that describes the impact of these improvements. Initial discussions with participants in the program indicated that they felt some temporary relief of one of the major symptoms of the illness, rigidity. They indicated an improvement in their ability to extend their limbs and manoeuvre about

obstacles in a room. They were able to dress themselves with greater efficiency, get into and out of a car by themselves and exercise more independence in all aspects of their lives. Many felt that the key to avoiding total incapacitation was to maintain a regime of regular exercise. Patients felt some consolation at not having to rely so heavily on others to accomplish routine tasks. The class also provided the opportunity to converse with others in similar predicaments. For some, the class was the only form of socialization they encountered in the week. Continued discussions with the patients revealed that exercise was responsible for restoring self confidence, providing the muscular agility to enjoy hobbies they had given up because of the condition, and generally giving them the power to influence some control over the progression and severity of their symptoms. These factors alone allowed me to conclude that the role of exercise in the management of Parkinson's disease was monumental and that exercise should be an automatic recommendation by the neurologist diagnosing this condition.

ACKNOWLEDGEMENTS

I would be remiss if I did not reserve this space to acknowledge the encouragement and support that I received from a few special people. Dr. Maureen Connolly, who found my self confidence when I thought I had lost it forever, whose "thumbs up" and triumphant smile signalled me to keep going each semester I hovered over the number eight on the telephone to end graduate school once and for all; Greg Wood whose friendship, and faith in my project provided the impetus for my perseverance; Bob Hillier, a colleague and past director of the Department where I am employed, for being flexible and understanding in allowing me to manipulate my hours of work to attend classes; to the members of the Parkinson's exercise class, whose situation and strength of character continue to motivate me, and finally to my family: Mom and Dad, Karen and Al, Alan and Susan... there are not enough words to describe the intensity of the gratefulness I feel for knowing that you were always there even when I wasn't.

DEDICATION

I wish to dedicate this thesis to the members of the Parkinson's exercise class who gave so freely their consciousness, insights, and time. Their contribution and friendship has made this endeavour an experience I shall always remember.

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CHAPTER I

STATEMENT OF THE PROBLEM

Search for the Question

My permit to register arrived two weeks before the start of the university semester. Neatly printed in bold type was my intended major. "My father is going to love this," I remember thinking as I ran to our garage to show off the evidence that I was really leaving home. "I hope that university teaches you how to set a rabbit lead," he said; "forestry huh?" Three weeks later I was calling collect, distraught over the difficulty of a first year chemistry course. "I'm coming home Dad!" I cried. But I persisted and after another agonizing week of atoms and molecules, I exploded from the Chemistry building and charted a course for the Physical Education faculty. I had always been athletic, and loved sports so I surmised that Physical Education would be the next best thing to Forestry; besides there would be no chemistry.

I was accepted into the faculty and after several years, faced another dilemma. Physical education was turning into a nightmare. There was so much emphasis on skill mastery, rules examinations, and team sports that I wondered if this was the sort of thing that I would be involved in if I ever obtained a teaching position. It was then that I decided that I would prefer the opportunities associated with a career in health and recreation. I informed my faculty advisor that I was switching to the "recreation" option of the degree program. I thought that at least in this field, I would be able to administer programs that were less structured, involved the outdoors a little more, and permitted some imagination in programming.

After graduation, I eventually obtained a job with the Provincial Government as a Fitness Consultant. In this capacity, I was responsible for the design and implementation of programs that encouraged Newfoundlanders and Labradorians to adopt healthier lifestyles. I had a great deal of autonomy with my position and was responsible for the conception of a fitness project that involved almost 16,000 students in primary and elementary school. It was the first of a number of personal triumphs.

It has been eight years since I accepted the position and I have a lot to be thankful for. It is great to be employed in a field that you love so much. Most of the people that you meet have a real desire to enhance their lives with physical activity and learn more about the process of doing it. It is rewarding to feel that you have facilitated their goals. I started graduate school in 1985. In the early phases of the Masters program, I was required to complete several research projects. In every instance I found myself wandering the annals of the medical school library in search of information on the role of exercise and diet in the prevention of heart disease. This field was of great interest to me as my family had more than one instance where "heart attack" maliciously showed up on death certificates. I guess I believed that it could have been prevented if they had exercised a little more prudence in their lifestyle choices. Convinced that my father was next on the "hit list," I initiated a personal crusade to learn all that I could about heart disease. I agressively forwarded all information collected to my family. I became a CPR (Cardio-pulmonary resuscitation) instructor, investigated cardiac risk factors in children for my quantitative research course, and presented a major paper on exercise and cholesterol at the annual general meeting of the provincial Heart and Stroke Foundation. Yes indeed, I was convinced that my thesis would uncover some startling facts about coronary risk factors until...

January 1990... I was stretched out in my office one day pondering my "things to do" list when I received a call from Vicki, a physiotherapist with a local hospital. She enquired about the possibility of having one of the Fitness Consultants work with a group of patients at a local hospital, each of whom had a common neurological illness called Parkinson's disease. After discussing it with my supervisor and colleagues, my co-worker and I decided that this situation presented the unique opportunity to acquire experience working with people who had disabilities and who were also older adults.

We were informed that the group met once a week in the White Room at the medical centre. It was a five minute drive from our office. The class would consist of forty minutes of locomotor movements, at a beginners level. Having had no experience working with persons with a disability, I was a little ambivalent about the task ahead.

My co-worker and I arrived at the medical centre on a frosty Monday morning and immediately charted our course for the White room. My first impressions were less than ecstatic. The exercise room was cluttered with old wooden chairs, decrepit oak shelves, and several larger tables. Immense heaters sat along the pale gypsum walls blasting hot air angrily in all directions. The stifling smell of cigarette smoke lingered in the air from the Bingo game held on the previous night. We contorted our faces over the odour, and ran to open some of the massive windows. For such a big room, there was so little space! Our optimism was fading fast.

The patients arrived gradually. Vicki informed us that many of them would have difficulty moving and appear less than enthusiastic about the upcoming hour. We were told that this was a typical symptom of the disease as the tight muscles in their faces made smiling and many other emotional expressions difficult. Several arrived in wheel chairs and others shuffled in. A few individuals, who were not patients at the hospital, arrived in cars. Amidst the confusion, it was difficult to tell who had Parkinson's disease and who did not, as many spouses also attended.

Contrary to my expectations, they seemed to be a very pleasant group of people, smiling and chatting with one another about the latest happenings in their lives. One lady puttered over to us and with a voice that was hardly intelligible, welcomed us to the gathering.

Vicki announced the start of the class and eagerly slid her cassette in the tape recorder. Gentle music resounded from the speakers as she proceeded to put the patients through a series of choreographed movements. I wondered how I was ever going to remember her exercises, having agreed to teach the next class. At first, my exercise routine was a little rusty but it improved with time. I realized the importance of volunteers, for when we had no assistance it was impossible to include a lot of walking in the class as some of the patients had trouble moving on their own. I discovered later that one gentleman seemed to move better when he was unassisted!

At the end of the class, many of the participants walked out of the room a little smoother than when they arrived. One gentleman, who rarely moved from his wheel chair, welcomed the opportunity to stack the chairs away after the session and at times, would teach a minute or two of the class! His pride always seemed to shine when he was the centre of attention.

Another couple drove 45 miles every Monday, just to attend the session. Then there was Mrs. Kean; she was not able to do a great deal, but attended faithfully every week. After she died of a heart attack I was informed by her son that the class was one of the few things in life that she looked forward to. It was then that I began to ask myself what it was about this exercise class that had such an appeal. I made several assumptions, but also reminded myself of the danger of concluding the unknown. It was then that I decided to pursue a research topic that might answer some of these questions. It is with this history that the present research question evolved.

Purpose of the Study

An infinite amount of literature has been written pertaining to the psychological and physical benefits of exercise. There is research that suggests that exercise might retard the aging process, that it enhances mental health, and helps to prevent heart disease. In partnership with a good diet, it also helps to control body weight, define and strengthen muscles and improve cardiorespiratory endurance.

Exercise, which has a close relationship with general health, is often cited as a solution over pills for controlling many of the aches and pains associated with daily stress. For many people, it becomes their prescription for preventing future health inadequacies. Most people think of fitness as being an activity for the young, healthy, and able. But there are several exercise programs in the city designed for individuals with chronic illnesses; a local hospital has a program for post cardiac patients; another facility in town has an exercise class specifically designed for individuals with arthritis. In 1990, a class for parkinsonians was established. Its purpose was to help patients maintain their strength and suppleness, to interact with others who share their condition, to learn more about their illness, and to have a little fun. These are fairly superficial reasons for attending and as this paper will attempt to demonstrate, the benefits of the class extend much deeper than those cited above.

A review of the literature reveals strong support for including exercise on the parkinsonian's prescription. However, there is very little written about the emic or insider's experience of being a participant and taking part in an exercise program. Heather Devine (1989) wrote an article entitled: "The Workout: A Phenomenology of Training." She writes a personal experience below:

> "I know, deep inside of me, that everyday I come for that strength, that thrill of it running through my arms and legs, that independence, that autonomy, that need to imprint myself on something touchable, real, concrete, to hold onto my physical being as I get sucked away by the

> riptides, pulled and prodded and knocked off my feet by all those things that are stronger than me. I need to own myself for a few minutes."
> (p. 2)

Heather Devine is articulating her experience with exercise in language that yields a powerful message to the reader. Perhaps her description may be interpreted by some individuals as being similar to their own. Put so eloquently, it conjures up images and appeal that a text book definition could never achieve.

I felt that a qualitative research methodology would allow the data collected to have a personal and humanistic flavour. The stories have a unique and individual nature with which many of the readers can identify. Perhaps they might gain some insights into the mysteries of their predicaments, and find solutions for some of their own difficulties with the disease. It is my hope that these personal accounts will help others to acquire some of the skill to manage their own illness a little better.

Statement of the Problems

1. How has Parkinson's disease affected the lives of those afflicted?
2. What is it about Parkinson's disease that needs management?
3. What management strategies do parkinsonians use for dealing with their condition?
4. What role does each strategy play in the management of the Parkinson's disease?
5. What role does exercise play in the management of Parkinson's disease?

Research Objectives

1. Field notes and interview data collected over the course of the study will document patient experiences with Parkinson's disease and management strategies adopted.
2. The case study design will attempt to demonstrate how exercise affects patients symptomology and general well being.
3. The collection and analysis of data will lead to a greater understanding of Parkinson's disease and the role that exercise plays in its management.

Operational Definitions

Introduction

Definitions for the following terms have been extrapolated from the Oxford English Dictionary (1989) with the intention of providing readers with a more thorough understanding of the meaning used to explore the research question.

Role is described as "the typical or characteristic function performed by someone or something." Figuratively it can be delineated as "to play a role." The question posed for this paper is: "What role does exercise play in the management of Parkinson's disease?" Undoubtably, there are many factors playing roles in the comprehensive management of this disease but my focus will primarily concentrate on one; exercise.

Exercise means "practice for the sake of training or improvement, either bodily, mental or spiritual; exertion of the muscles, limbs and bodily powers, regarding with reference to its effect on the subject, especially such exertion undertaken with a view to the maintenance or improvement of health." An attempt will be made to ascertain the role that exercise has in the phenomenological "lived world," of the patient from these universal themes or focus. Other questions that haunt my thoughts at present are: How does exercise help the symptoms of the disease? What forms of exercise do patients adopt to deal with their condition? What would happen if they did not exercise?

Management is "the action or manner of managing in: the application of skill or care in the manipulation, use, treatment, or control of things or persons, or in the conduct of an enterprise or operation; the use of contrivance, prudence, or ingenuity for effecting some purpose."

The connotations of this definition implies that management is an ability that a person can employ to some aspect of their personal lives; financial, property, lifestyle etc. The parkinsonian must acquire a deftness for manipulating aspects of their lives for the sole purpose of minimizing the negative effects of the disease. By doing so, they are in effect engaging "management strategies." Some are better at the application then others; they have more tools, and they know how to use them. My questions are: "What does management mean to a person with Parkinson's disease and how do they apply it to their personal situation?" Has the management strategy of exercise affected any changes in their lives?

Delimitations

The study was delimited to include only those parkinsonians enroled in the exercise program spoken about earlier. Ten parkinsonians ranging in ages from 56 - 77 comprised the initial research participants.

Limitations

The data analysis and findings are relevant to the parkinsonians participating in this research project. The individuals in this study are at various stages in the disease, some having symptoms that are more profound then others. Naturally, their perspectives and experiences of the disease will be foreign to some readers. As the disease is progressive however, it is generally felt that some of the encounters spoken of by parkinsonians in later stages, will ultimately be felt by those in the beginning stages. Because the researcher's data analysis employed an existentialist investigation, the majority of themes that emerged might also represent all individuals who travel the incremental road of Parkinson's disease.

CHAPTER II

PARKINSON'S DISEASE

One Lived Experience

Life was beautiful in 1978. My marriage was solid, and my husband and I were feeling better than ever about our relationship. We were pleased with our children, now grown and married to individuals whom we loved dearly. My career as an educator was at its peak and I was feeling very productive. I was 47 years old. Physically, I never felt better.

Was it on July 3, 1978, on December 24, 1979, or some other date that I first felt a change? I really can't say. I do know that "it" sneaked up on me as I went my way. Once in a while, my right arm felt clumsy as I walked or stood, as though I didn't know what to do with it. But I ignored it. Doesn't everyone feel a bit awkward once in a while? At times, my husband lost patience with my pace when we were walking, and would ask me to speed up. He complained that if he slowed down for me, I would slow down even more. I assumed that this was his problem, not mine; he was always in a hurry.

Then one day in the summer of 1980 when I was writing a letter to my daughter Susan, my fingers became balky. The smooth flow of my writing was lost. I was annoyed, but said nothing.

School reopened, and things were almost back to normal. But I

> continued to be nagged by physical problems: Why was I getting so tired? Why was I really dragging by noon? What were the weird sensations I felt from time to time? My legs especially seemed to feel strange and heavy. They would jerk or would feel as though a rubber band were around them. But I felt that I must not complain; if I didn't tell anyone, these sensations would go away.
>
> I had been reading a medical column in the daily newspaper, in which the reader had been asking about the symptoms of a particular disease. The doctor's answer described my symptoms: "The earliest signs are apt to be a difficulty in handwriting, a slight trembling of the hand, and a jackknife effect when you put two fingers together." Overcome by anxiety, I knew; but I still didn't tell anyone about my symptoms. I still hoped I was wrong. I couldn't possibly have Parkinson's disease. (Wotton Atwood, 1991, p. 2)

A Historical Perspective

Duvoisin (1991) wrote that the first accounts of Parkinson's disease were first noted in 1817 when James Parkinson, a practising physician in Shordith, England published a small monograph entitled **An Essay on the Shaking Palsy** (p. 152). In its pages were descriptions of six individuals who exhibited symptoms of the disease that now bears his name. Parkinson's depictions were thus based primarily on field notes and showed remarkable accuracy to accounts that appeared in the current medical journals. His opening chapter begins with the following epigrammatic, yet comprehensive definition:

> Involuntary tremulous motion, with lessened muscular power, in parts not in action and even when supported; with a propensity to bend the trunk forwards, and to pass from a walking to a running pace: the senses and intellects being uninjured. (p. 25)

Duvoisin (1991) noted that some of the symptoms described by James Parkinson had been reported long before. He referred to an account by an ancient Greek-Roman physician named Galen who described individuals with a tremor of the hand at rest and distinguished it from a tremor occurring during movement. Duvoisin also relayed a historical account of a German poet by the name of Goethe who, with limited medical training, noted that "the innkeeper in Rembrandt's sketch of 'the Good Samaritan' stood in stooped posture holding his hands before him with the thumbs opposing the fingers or as patients with Parkinson's disease often do" (p. 157).

Since 1817, a number of physicians and researchers have contributed to the current knowledge of Parkinson's disease, not only enlarging James Parkinson's definition, but suggesting possible precipitating factors for developing this condition (Parkinson believed that there was an abnormality in the spinal column that was responsible for the symptoms described in his manuscript).

What is Parkinson's Disease

Parkinson's disease is a neurological disorder thought to be a result of the degeneration of a particular group of brain cells known as the substantia nigra (the cause of this degeneration is unknown). These cells are located in the basal ganglia, which is a small centre or nucleus at the base of the brain, and produce a substance called dopamine. Dopamine is sent to another area of the brain called the striatum, the area that controls movement, balance, and walking. In the striatum, dopamine counteracts another chemical messenger, acetylcholine. In a normal person, dopamine and acetylcholine are in balance, but in Parkinson's disease, the shortage of dopamine creates an imbalance which cause the major symptoms of the disease.

The cell loss in the substantia nigra is extremely slow and many times when a patient is diagnosed, nearly half of the cells have already degenerated. Sometimes the remaining cells compensate for the loss but eventually the first symptoms of Parkinson's appear. The disease is progressive but the rate varies among individuals. Godwin-Austen (1984) wrote: "before the days of effective treatment some patients deteriorated so rapidly that their disease deprived them of independence within three or four years of the time of diagnosis. In others, more than twenty years could pass before the disease had progressed to this point. Today, the progressive nature of Parkinson's disease may be entirely concealed by effective drug treatment" (p. 7).

Myths

Many of the patients who have Parkinson's disease cannot pinpoint the exact time that they felt a significant change in their bodies. In most cases, it was a family member or friend who had persuaded them to visit the physician; the degree of disability not being severe enough that they would have gone on their own initiative. Things like dropping a glass, chronic fatigue, and muscle pain were easily dismissed as the side effects of a stressful day.

When a diagnosis of Parkinson's disease is finally established, some individuals start to wonder if they had inherited it, had eaten something, contracted a virus, or been exposed to toxic waste. Others think that perhaps they had been in a serious childhood accident and that the disease had surfaced as a result of this trauma. Others think that they will ultimately develop Alzheimers disease, and succumb to total helplessness. The ensuing pages will demonstrate that these preconceived notions have no foundation; that Parkinson's disease is not nearly as bad as one would believe; that there are things that can be done to make life easier; and that there are still things in life that are worth living for.

The Diagnosis

A diagnosis of Parkinson's disease can be a shattering experience for some people. Many of the individuals I spoke with about the disease remember feeling rage, anger and fear when learning that they had it. Others were relieved to learn that their symptoms were medically recognizable, and not imagined, and that it was not cancer or other terminal illness. As it mainly affects the elderly, some feel thankful that it wasn't Alzheimers, Cerebral Palsy or some other more debilitating chronic condition. Whatever the reaction, it takes a considerable amount of time to adjust to the knowledge, to learn more about it, and to adopt measures to deal with the psychological and physical changes that invariably accompany this disorder.

Today the patient has the benefit of improved drug therapy, exercise therapy, occupational therapy, support groups, and better education. With the knowledge base advancing as quickly as it is, the patient might also live in hope that researchers are finger tips away from a cure.

Incidence and Prognosis

Parkinson's disease has established itself in history texts as well as medical journals. "Harry Truman, Mao tse Tung, Francisco, and Adolf Hitler were all reported to have had the disease. In fact, more than 70,000 Canadians have Parkinson's disease with an estimated 1,100 Parkinsonians living in Newfoundland and Labrador at the time of this writing (Newfoundland and Labrador Chapter of the Parkinson's Association of Canada, 1991).

Parkinson's disease is one of the most common neurological disorders, usually beginning between the ages of 50 and 65; however an occasional patient may develop the disease before his or her fortieth birthday. Grimes (1986) wrote: "It is much more common with advancing age, with prevalence at its peak in the 70 to 79 age group. A juvenile form exists, but it is extremely rare" (p. 7).

Parkinsonism occurs equally in both sexes contrary to the belief that it is more dominant in males. Research (Godwin-Austin 1984, Grimes 1986, Kurtzke 1982) regarding the familial incidence is inconsistent, but the majority of authors attribute cases where more then one relative develops the disease as statistically insignificant. Only one of the patients in this research had one or more family members with the disease. In her case, it was her mother and grandmother.

Causes of Parkinson's Disease

The cause of Parkinson's disease is not yet known. Research has failed to reveal a toxic agent or primary metabolic effect, and viral studies have been inconclusive. Kurtzke (1982) noted: "Parkinson's disease has been shown to be more prevalent in farming communities where insecticides are used and well-water consumed. The most likely sequence of events at present is that the age of onset could be related to the duration of exposure to an unidentified environmental agent; this combined with age-related neuronal loss in the brain results in the clinical signs and symptoms of Parkinson's disease" (p. 78). Seven of the ten participants in this paper enjoy or enjoyed gardening as one of their major hobbies. This, may simply be a strong coincidence.

Another theory about the cause has been related to certain gases. When carbon monoxide poisoning occurred in a few individuals, they demonstrated very similar characteristics as those with Parkinson's disease (Grinker, 1926; Nielson, 1943). The same trend occurred with chronic manganese and mercury poisoning (Bidstrup, Bonnell, Harvey & Locket, 1952).

Oliver (1959) noted that "parkinsonian effects sometimes occurred as a result of midbrain compression" (p. 10). Thus traumas to the head might be a possible explanation as to why an individual might have developed the disease, or a form of it (perhaps this is an explanation as to why Mohammed Ali exhibits signs similar to that of a parkinsonian). One of the parkinsonians in this project had been in a severe car accident two years prior to his diagnosis. There may or may not be any connection.

In 1987, an unusual outbreak of severe Parkinson's-like symptoms occurred amongst some young Californians. They had been abusing a drug which was contaminated with a brain toxin, MPTP. In this tragedy lay important clues for researchers, and as a result Parkinson's research sky-rocketed. Many in the field now think that Parkinson's disease may be due to the life-long effects of chemicals which are similar to MPTP. For example, it is known that some foods contain such substances. It turns out, however, that MPTP alone is not the problem; it is converted in the brain to a toxin MPP+. It was found that a group of drugs used against depression could inhibit this chemical conversion. Research is ongoing in this area (The Parkinson's Study Group, 1989).

Mortality

A review of literature failed to find a consensus about the life expectancy for a diagnosed parkinsonian. Before the introduction of levodopa therapy, most texts estimated the life expectancy to be between 9 or 10 years, with a considerable range of 1 to 33 years (Pritchard, & Netsky, 1980). Because levodopa treatment substantially improved the symptoms of Parkinson's disease, including the quality of life, some researchers have hypothesized that life expectancy for parkinsonians might exceed that of the normal population (Diamond, 1976; Marttila, & Rinne, 1977).

Disease Symptoms

There are three major symptoms connected with Parkinson's disease: tremor, rigidity, and bradykinesia. A number of secondary symptoms are also associated with this condition, sometimes a result of the primary symptoms and sometimes arising from side effects of the medication.

Primary Symptoms

Tremor is the most obvious and familiar manifestation of the disease affecting approximately 75% of patients. It is usually the first symptom that prompts a person to visit their physician. Duvoisin (1991) noted that the hand on one side is usually affected; sometimes one foot is involved. It typically occurs at rest. Tremor is caused by an alternating contraction of opposing muscle groups. It is regular and rhythmic with a frequency of five to six beats per minute" (p. 27).

Parkinson's disease patients are characterized as having a resting tremor, which means that the tremor ceases when reaching or performing some activity. Some patients report that the tremor disappears when they remember to swing their arms when walking. It also subsides when they sleep.

This symptom has been described as the most embarrassing and annoying evidence of the disease, yet it does little harm except that it may interfere with employment where balancing or fine motor control is necessary. One patient had to take an early retirement from his position as a Ship's Officer because, as he described, "when I navigated with a clear radar screen all was well. As soon as I got a target, I would become quite shaky, unable to write and become prone to navigating errors" (Clarke, 1991a2, p. 1).

Tremor is often more pronounced during stressful situations. Patients can chose to avoid predicaments that excite the shaking limb or attempt to hide it by shoving it into a pocket or concealing it behind their other hand. Many patients are so self-conscious about their tremor that they tend to avoid socializing altogether.

Rigidity is the symptom which gives patients the most difficulty with this disease because unlike tremor, it can involve the muscles of the face, neck, shoulders, torso, and also the limbs. If rigidity does affect these areas, many problems can arise.

Rigid or frozen face muscles produce a fixed or masklike appearance of the face and eyes. Speech tends to become nasal, monotone, and of an indistinct quality, although actual verbalization is never lost. The neck muscles in the front are stronger than in the back so as they tighten, they tend to draw the head downward and cause the upper back to become rounded and hunched. Rigid muscles sometimes causes headaches, back pain, and general discomfort. Improvements in posture, massage therapy, and medications sometimes help to alleviate aches.

With the head drawn downward and forward, the centre of gravity shifts forward and subsequently a tendency to lurch forward on the balls of the feet develops. It can become quite terrifying as falls are frequent if there is nothing to stop this forward momentum.

Bradykinesia, as reported by Godwin-Austin (1984) is "the biomechanical term used to describe slowness of movement. It is not as severe an impediment as tremor or rigidity, although in pronounced form it may hamper the patient in everyday life" (p. 17). Duvoisin (1991) elaborated:

> Common problems caused by bradykinesia include difficulty getting up from a chair, trouble getting out of a car, turning over in bed, donning a coat or jacket. The activity begins all right but slows down and falters before it is successfully completed. Patients remark that they felt as if their batteries had run down. Others feel the bradykinesia as an external force restraining their movement... To the patient it seems that something

> which should be done easily and without a thought requires effort and constant attention. One patient complained that getting out of a deep, upholstered chair required a campaign of instruction to every muscle involved. (p. 35)

On a more technical scale, the motor units of the muscles do not charge frequently enough, thus affecting the agonist (muscle responsible for a particular movement) and antagonists (muscle opposing the movement). Therefore there is slow execution of movement and increased movement time recruitment, which increases dramatically with the complexity of the task. More time and effort may be needed to do the normal activities of daily living. One parkinsonian noted: "My daughter does not have the patience to wait for me to do even the simplest of things and in her frustration, ends up doing things for me, furthering my anxiety over my continuing loss of independence (Clarke, 1991b2, p. 1).

Patients also experience difficulty shifting and generating new strategies for accomplishing tasks. Some have difficulty with several simultaneous movements such as placing a box on a shelf, or raising a hand in the air while walking across the room.

Secondary Symptoms

Posture and balance are often the cause of major disability in patients. Some individuals in the beginning stages, may exhibit only a slight reduction in arm swing when walking and have a tendency to drag the leg on the affected side. Stern & Hurtig

(1988) reported that "as the disease evolves, the affected limb is held in a flexed, adducted position, and steps may become short and shuffling (festination). Associated arm movements are lost" (p. 6).

Patients have difficulty turning corners, initiating gait, and maintaining an upright posture. One patient lamented that she would literally "topple" over if someone were to give her the slightest poke. She added: "most of us don't even realize that we look so hunched" (Clarke, 1991d1, p. 5). Observations of some of the parkinsonians in the exercise group show a scene where some patients meticulously navigate about the room, faithfully placing each foot in precise position. As a volunteer leader, trying not to impose too much on their independence, it is important to stay in close proximity should they lose their upright posture and lurch uncontrollably forward. These plunges have a way of disheartening patients especially when bruises, the size of soccer balls, appear every time a "crash" occurs. Several of the patients have displayed their discoloured limbs, demonstrating the damage the disease can do when one fights to exercise some independent maneuvering.

Eventually, loss of postural reflexes can confine patients to a wheel chair or even the bed, resulting in other health problems like pneumonia or thromboembolic pneumonia (a blood clot blocks a blood vessel in a lung).

Range of motion is severely reduced in the parkinsonian both at rest, and during the execution of a movement pattern. Patients report that they cannot reach as high as they once could. They also note that their stride shortens when walking. This is partially because the agonists tend to shorten while the antagonists tend to lengthen. In advanced stages, some parkinsonians resemble the famous "hunchback of Notre Dame."

Muscle strength diminishes over the duration of the disease. When muscles do respond, it is much slower than normal. There is sometimes a failure to activate the agonist as well as failure to inhibit the antagonist. Subsequently, patients experience a "freezing" sensation and are unable to move at times. Phasic stretch reflex (muscle length while still) is intact while the tonic stretch (muscle length while moving) is impaired.

The stiff and weakened shoulders make dressing difficult, and it often necessary to ask for assistance. Not only is this humiliating for the patient, but it also makes them feel that they are a burden. Stiff finger muscles impair the skilful act of buttoning clothes, writing, and some house chores. Again, patients must rely on others to help them with tasks requiring finger dexterity. Many of them have had to abandon or modify their hobbies and relinquish their efforts to write letters, noting that even they could not read their own handwriting.

Inflexible back muscles can make turning in bed, getting up in the morning, and stepping into a car a tiresome task. Sometimes the effort becomes too much and the parkinsonian resigns to the fact that it's not worth the aggravation and effort to leave the house. Eventually, some do not even leave the chair or the bed. The result is a body that is not challenged to move. The muscle tissue deteriorates and connective scar tissue infiltrates the muscle causing it to shrink and shorten. The patient is then left without the option of moving or not moving.

Deformities develop because the flexor muscles of the body become stronger than the extensors. Sometimes the fingers will twist uncontrollably, the toes may curl under, causing the legs to cramp, or the chest may pull the body into a slouched posture inducing episodes of back pain.

Depression is common to many in society but probably more so in individuals who have illnesses that prohibit them from doing the things that they want to do. While highs and lows accompany Parkinson's disease, the reason for periods of depression is medically based. Lieberman (1989) wrote that "there is a reduction in certain chemicals (dopamine, norepinephrine, and serotonin) and it is believed to be related to the depression experienced by many of the patients (p. 6).

Sleep disturbances occur when patients experience difficulties falling asleep, and remaining asleep thus leading to feelings of exhaustion the following day. It then becomes necessary to schedule several naps throughout the day which is often seen as inconvenient and disruptive to the evening sleep. Some describe this as a "Catch 22" situation.

Because of the difficulty of turning over in bed, patients cannot make frequent shifts in their position to make themselves more comfortable. When they feel so awkward, it is arduous to relax and drift off to sleep.

Forced eyelid closure results when the eyelids snap together and refuse to open. A caretaker or family member must skilfully employ strategic maneuvering to pry them open. Sometimes efforts to open the eyes are left in vain. The inability to see, where sight is possible, is sorrowful.

Speech problems result in changes in volume, phonation or articulation of the voice and is a common problem in patients with advanced rigidity of the facial muscles. The voice may become monotonous, lacking variation, and feeling. Words become slurred, unclear, and run together. It often becomes necessary to rehearse certain vowels and consonants every day as part of a speech therapy program.

Difficulty swallowing arises from an inability to force the food down the throat because the muscles cannot forcefully contract to move the meal along. Patients must place smaller portions in the mouth, chew and swallow carefully and slowly.

Other secondary symptoms: Constipation, swelling of the ankles, writing, dizziness, sexual problems, and drooling have all been identified as possible side effects of the medication or the primary symptoms. Other authors have described an unlimited collection of these and other secondary symptoms. Those presented recognize the most common.

Stage of Progression

In 1967 Hoehn and Yahr (1967) devised a chart to describe five clinical stages of this illness: Many of the current studies use this scale to classify parkinsonians according to the stage of progression:

Stage I: Mild one sided tremor or rigidity; with or without slowness of movement. Patients at stage one may not need any treatment.

Stage II: Moderate tremor or rigidity occurring on both sides with bradykinesia. Symptoms will be improved with drug therapy.

Stage III: Significant tremor, rigidity and/or bradykinesia. This is accompanied by mobility problems. Difficulties in postural control develop; there is unsteadiness on turns, and hesitations, halts, and freezes when starting to walk.

Patients begin to notice fluctuations in their level of functioning during a day and may experience dyskinesia (levodopa-induced involuntary movements). The major new problem at this stage is balance difficulty.

Stage IV: More severe disability, but still mobile and able to function independently. Bradykinesia is more severe. If fluctuations are present they too will be more severe.

Stage V: Loss of ability to function independently. Postural defects are severe and independent mobility is impossible.

The rate at which patients progress from one stage to the other varies with the individual. One patient noted that she has been in stage II for seven years (Clarke, 1991c1, p. 1).

CHAPTER III

REVIEW OF LITERATURE

Introduction

Patients with Parkinson's disease experience a myriad of physical and psychological changes. Responsibilities for dealing with all aspects of a chronic disease, for both patient and family, are endless. Daily attention must be garnered to deal with the effects of the illness on the person's life as well as the effects that it has on those of the caregiver. Vernon and Stern (1988) note that there are several well-defined stages that the patient and family experience:

1. Confronting the reality of having a chronic illness.
2. Identification of problem areas and initiation of adaptation strategies.
3. Emergence of successful coping mechanisms, participation in therapy and an acceptance of Parkinson's disease as a partner in one's life (p. 103).

The journey through these stages will vary from person to person, with some individuals never really accepting their predicament. Patients and family may feel trapped in a maze of negative emotions including denial, hostility, regression, dependence, and depression. Patient's self-esteem, changes in functional ability, employment status, financial encumbrances, social isolation, sexuality, and disease fluctuations are additional problem areas that frequently arise. It is imperative that those who have Parkinson's disease recognize these difficulties and discuss them with their physician, others in similar situations, or their families. Only then can successful management strategies materialize.

The front line assault to this illness usually begins with drug therapy. There is no shortage of material in the literature on this subject as it is felt that medication is the primary weapon in the doctor's arsenal for treating the symptoms. Experts in the area of chronic illnesses have identified a number of other management strategies that patients can employ to deal more effectively with their predicament. Some of these include: obtaining a conscientious physician, learning about occupational therapy, assuming self responsibility, enjoying copious quantities of love and laughter, joining a support group, and getting plenty of exercise. These will be discussed following a brief overview of the first and most important management strategy, drugs.

Management Strategies

The Drugs

Amantadine (Symmetrel) is often used as the first drug treatment for Parkinson's Disease. It acts by releasing dopamine from the cells of the substantia nigra, thus promoting smoother muscle function. Amantadine is also used in the prevention of influenza, and this may be a plausible explanation why the flu is relatively uncommon in the parkinsonian.

Anticholinergic drugs may be added or substituted if the patient's response to Amantadine decreases or side effects develop. It is also useful in preventing the action of acetylcholine, which is out of balance in the brain because of the reduction in dopamine. This drug is effective against rigidity and tremor, but not against bradykinesia. Side effects may include: dryness of mouth blurred vision, mental changes, or difficulty in voiding. Some patients also experience hallucinations, forgetfulness, or delusions.

Antidepressant drugs are sometimes administered to improve patient's mood and relieve some of the secondary symptoms. Side effects may also develop.

Bromocriptine (Parlodel) is a dopamine agonist which stimulates the dopamine receptors. It is limited in ability because it does not stimulate all of the receptors. It is very useful in relieving slowness of movement, rigidity, and leg cramping. This drug must be taken on a full stomach as it tends to irritate the stomach lining.

Patients with moderate Parkinson's disease have increasing difficulty with balance and walking. Most of their symptoms result from the deficiency of dopamine in the striatum, which cannot be corrected by giving dopamine itself as it will not cross the blood into the brain.

Levodopa (Sinemet) or a dopamine antagonist such as Parlodel would be the choice for patients in the above predicament. Levodopa crosses into the brain where it is changed to dopamine. Most patients respond positively to this drug, but the effects usually last two to five years. Side effects of nausea and vomiting may be present.

Inhibitors are drugs that block the conversion of levodopa to dopamine outside the brain, while not affecting this conversion inside the brain. About 90 percent of levodopa (when used alone) is changed outside the brain to dopamine. Dopamine cannot cross from the blood to the brain, thus it is desirable to block the conversion through the use of inhibitors.

Deprenyl (Selegine) is one of the latest drugs used in the management of parkinsonian symptoms. Used in conjunction with levodopa (Sinemet), it helps to reduce the dosage of Sinemet thereby also diminishing the intolerable side effects. Research suggests that Deprenyl may delay the onset of the disability associated with early, otherwise untreated Parkinson's disease (New England Journal of Medicine, 1989). It is believed that early intervention with this drug delays the need for Sinemet, and thus patients could continue to work longer in their jobs before being forced into retirement. For some parkinsonians, deprenyl smoothes out the "on-off" and "wearing off" phenomena (Wotton Atwood, 1991, p. 72). It has been described by patients as the "wonder drug" in the battle against Parkinson's disease.

There are other drugs that are used in carefully calculated dosages and combinations to best fit the patient's response. A management scheme is best, when patients are able to monitor the positive and negative effects of the drugs, the duration of these effects, and together with the physician, agree upon the best combination for them.

Glenna Wotton Atwood (1991) says that "knowing your disease and the treatments available for it makes you an educated medical consumer. You are an informed patient who can discuss with your doctor the best treatment for you. You can discuss the medications and dosages used in your stage of Parkinson's and their relative merits for your symptoms" (p. 86).

By carefully monitoring the pills and their effects, it is possible that small discoveries made by the patient and shared with the doctor may lead to better management. A story by Victor Holman (1985) reinforces this idea:

> This morning, instead of taking one tablet, I took only a half, at least an hour earlier, and here I am unable to walk, and full of leg-heaviness. I have taken another tablet but I shall have to wait until the dopamine begins to work before I can continue. At this time I made another discovery that has been of vital importance in my Parkinson pilgrimage. Immobilized in my classroom without my cane (I often left it in my car out of vanity), I took an extra tablet to see if it would help to get me going, absentmindedly chewing it instead of swallowing it, and finding to my amazement that I could move after only a short delay. This taught me that my akinesia was dosage related and that by chewing the tablet, I had speeded up the absorbtion of the drug. Both my physician and pharmacist

> confirmed that this was correct since the Sinemet begins to have a direct effect via the saliva where digestion already begins. (p. 6)

The Physician

The physician is a vital component of any management plan that is intended to minimize the negative consequences of this disease. His or her accurate diagnosis and subsequent recommendations for implementing the most effective drug therapy strategy is vital for maintaining a quality of living. Physicians who are perceived as insensitive and who ignore the complaints and concerns of the patient, do little to ease the psychological burden of having a disease such as this. Additionally, a doctor who fails to keep up to date on the advancements in the field, or ways that a patient can enhance the quality of life, through educational materials, or occupational devices and physical therapy do their patients an injustice. Finding a doctor that you can trust and work with is vital in the management of this disease.

Occupational Therapy

In its later stages, parkinsonians may find that their physical symptoms disable them to the point where they are barely functional. Walking in the home, doing the dishes, eating, buttoning clothes, and tying shoe laces become awkward and cumbersome tasks, and may sometimes require special adaptations unknown to the patient. Through education, human and written resources, devises, or modifications in the home, one can facilitate independent living and promote an increase in self-esteem.

Self Responsibility

A famous proverb states, "You can lead a horse to water, but you cannot make him drink." Self responsibility is important for any illness where medications are concerned. Parkinsonians must take their pills in precise quantities and times each day, and monitor the effects that the pills have on their health. It is their responsibility to relay this information to their physician so that necessary modifications can be made to treat the disease. It is also recommended that patients learn all that they can about the disease, stress management, and other coping techniques.

In addition to the medication, the patient who can remain positive and optimistic will have a better time in dealing with their illness then someone who surrounds themself with doom and gloom.

Love and Laughter

Sidney Dorros (1981), a long time parkinsonian, tells readers to "find a purpose in life, give and receive love, and have fun" (p. 101). The therapeutic effects of love and laughter have also been well described by Sacks (1974), and Cousins (1979). Emotional flexibility, a sense of humour, and above all, a sense of irony can reduce stress and tension in the struggle to cope with the adversities of Parkinson's disease.

Support Groups

Support groups can provide a forum for the exchange of ideas, personal accomplishments, and set-backs, emotional trials and tribulations, and peer emotional support. Patients, family and friends are important participants in the support group, so as to minimize the potential for individual isolation and loneliness that is often experienced by someone with this condition.

Local chapters liaise with provincial and national chapters of the Parkinson's society in availing current information to its members that might otherwise escape their watchful eyes. Local groups are also useful in establishing support groups where none exist, thus opening up new avenues for promoting an effective management strategy.

Exercise

Most people acknowledge that exercise is important for mental and physical well being. Those who are active on a regular basis have various reasons for participating. When most people think about exercise, they see someone young and healthy huffing and puffing their way to fitness.

Yet, there is a significant part of the population who are exercising to save their lives! Bijnen, Mosterd, & Jongbloed (1992) lists inactivity as one of the risk factors leading to the development of coronary heart disease, yet many people wait until they have had at least one heart attack before they make any plans to refurbish their lives and include daily exercise in it. Throughout Canada there are many people who will tell you that they would be crippled from arthritic pain if it were not for a daily routine involving a significant amount of physical exercise. Cousins (1976) tells the story of Mr. Charles Thierry, who at the age of 93, still adventured on long vigourous walks in the country every day. At the age of 103 he contracted influenza and had a stormy convalescence. He was seen by Dr. Paul Dudley White, who urged him to resume his daily walks regardless of the weather. Thierry recovered but later died of pneumonia at 108 years of age, largely due to his own negligence (p. 13)! Cousins tells of another man's experience with exercise:

> I meet Pablo Casals for the first time in his home in Puerto Rico. I was fascinated by his daily routine. About 8:00 a.m. his lovely young wife Marta would help him to start the day. His various infirmities made it difficult for him to dress himself. Judging from his difficulty in walking and from the way he held his hands, I guessed he was suffering from rheumatoid arthritis. His emphysema was evident in his laboured breathing. He came into the living room on Marta's arm. He was badly stooped. His head was pitched forward and he walked with a shuffle. His hands were swollen and his fingers were clenched.
>
> Even before going to the breakfast table, Don Pablo went to the piano - which, I learned, was a daily ritual. He arranged himself with some difficulty on the piano bench, then with discernible effort raised his swollen and clenched fingers above the keyboard.

> I was not prepared for the miracle that was about to happen. The fingers slowly unlocked and reached toward the keys like the buds of a plant toward the sun. His back straightened. He seemed to breath more freely. Now his fingers settled on the keys. Then came the opening bars of Bach's "Wohltemperierte Klavier,"played with great sensitivity and control. I had forgotten that Don Pablo had achieved proficiency on several musical instruments before he took up the cello. He hummed as he played, then said that Bach spoke to him here-and he placed his hand over his heart.
>
> Then he plunged into a Brahms concerto and his fingers, now agile and powerful, raced across the keyboard with dazzling speed. His entire body seemed fused with music; it was no longer stiff and shrunken but supple and graceful and completely freed of arthritic coils.
>
> Having finished the piece, he stood up by himself, far straighter and taller then when he had come into the room. He walked to the breakfast table with no trace of shuffle, ate heartily, talked animatedly, finished the meal, then went for a walk on the beach. (p. 72)

(Pablo Casals was ninety years old at the time of this account).

Dr. Alexander Leaf, of Harvard Medical School, in his studies of very old people around the world, led him to suggest that longevity was correlated with a rather frugal diet, but of well balanced composition, vigourous physical activity and involvement in community affairs to the end of one's life. He noted that a complete retirement from active life did not seem to be a good way to reach a very old age (Cousins, 1976).

For the parkinsonian, exercise has many roles. Once diagnosed with this illness, there is a tendency to become immobilized. A lifestyle with minimized movement also creates a body unprepared to deal with the stresses of everyday living. It is not uncommon for sedentary individuals to experience constipation, edema, weakened immunity, weight gain and loss of flexibility.

Many of the texts on Parkinson's disease reserve a paragraph or two to echo the accolades of regular participation in an exercise program. But a paragraph, or even a page cannot do justice to one of the most important management strategies, cited by some active parkinsonians, as one of the most important tactics in the comprehensive management of their illness.

Physicians and neurologists (Duvoisin, 1984; Hurwitz, 1989) also recognized exercise therapy as important and necessary strategies in the management of Parkinson's disease. Many active parkinsonians are quick to note the same opinions, yet when patients are first diagnosed, many physicians give the impression that this is a medical matter best dealt with by the medical profession. The only responsibility placed on the patient is to take the pills in the prescribed amount and at the recommended time each day.

Annette, a parkinsonian living in Newfoundland noted that only one in six neurologists that she visited recommended any form of exercise (Clarke, 1991d2, p. 1).

In fact, only one individual of the ten surveyed in this paper could admit that their doctor had recommended they participate in regular exercise in their initial consultation. With such little emphasis on exercise, it is no wonder that attempts to find information about it are often disappointing.

Of the material that was available on Parkinson's disease, strong support for continuing or beginning an exercise program was overwhelming. Duvoisin (1991) wrote:

> Physical activity in amounts commensurate with one's ability and strength can make an important contribution to health and well-being. Activity is necessary to maintain the body's musculature. Unused muscles quickly atrophy... Exercise also improves the heart and circulation... It is a common observance that physically active people have less trouble with constipation than those who lead sedentary lives. Finally, physical activity has a good effect on the mind. It is relaxing, calming, and often provides a welcome change of ideas. A sense of satisfaction and well-being is commonly experienced following exercise.
>
> Those obvious truisms merit repetition here because, alas, Parkinson patients tend gradually to withdraw from their usual activities...To combat this tendency it is a good idea to follow a regular routine to assure a reasonable amount of physical activity every day... The specific nature of the activity is not important. I am not discussing physical activity as a treatment but as a means of maintaining a degree of

> physical fitness. No amount of physical fitness can alter the basic disease process in the nervous system. However, a patient who remains physically active is better able to cope with the various symptoms of Parkinson's disease as the years go by. (p. 133)

Elizabeth Cross (1991), a physiotherapist and international speaker on Parkinson's disease, wrote about the benefits of group exercise classes to the parkinsonian:

> There is improvement in general mobility, dexterity of movement, and activities of daily living such as bathing, dressing and eating. Additionally, patients benefit from education and treatments available from the instructor and other Parkinsonians in the class. There is improved socialization, improved motivational levels, better interpersonal and family relationships and an increased level of self esteem. (p. 4)

Kim Furlong (1991), physiotherapist for the Newfoundland and Labrador Chapter of the Parkinson's Foundation of Canada, noted that exercising was a very important activity for the person afflicted with Parkinson's disease. She said:

> Because muscles tend to favour constriction, the parkinsonian's joints have a tendency to become stiff and flexed. Their posture deteriorates and they can quickly become stooped. Without regular exercise their movements become more and more difficult, their feet stick to the floor and they find it harder to get out of a chair or car. With regular exercise to music, the parkinsonian can stretch, rotate and extend their joints allowing for freer

> movement and more flexibility. With postural exercises, the parkinsonians walk taller, look people in the eye, and breathe easier. (Clarke, 1991m, p. 2)

Schenkman et al (1989) presented a rationale for early physical therapy intervention for the patient with Parkinson's disease. They believed that this intervention was designed to minimize musculoskeletal limitations and postural deformity that accompanied the disease, thereby improving the patient's capability for independent functioning for as long as possible. In the first of two case studies, the researchers noted that the patient had improvements of balance, gait and functional movement after adhering to a ten week exercise program. The patient in this study was not receiving medication for the disease. In the second case study the same improvements were recorded with the one exception: the patient was receiving medication for his illness.

Gauthier (1989) noted that exercise was vital for combatting one of the major symptoms of the disease - rigidity. Muscles which are not exercised regularly tend to shorten and deteriorate, thus complicating efforts to perform simple locomotor tasks. Daily stretching is necessary to lengthen the tightening flexor muscles, for without it, the body attempts to contract creating hunched shoulders, crunched fingers, shortened hip and toe flexors and ruining posture. This stooped position makes sleeping difficult as patients are unable to lay extended in bed for any period of time. The resulting lack of sleep more then likely contributes to the continual exhaustion that many feel accompanying them throughout the day. Exercise is critical for combatting the muscles desire to pull the head towards the toes!

Godwin-Austin (1988) noted that "exercise gives encouragement and moral support, especially if the wife or husband joins in with the patient by doing their exercises together...Getting out of the house enabled individuals to meet people, as well as having a strong physical effect" (p. 54).

Gauthier and Gauthier (1987) conducted an experiment in which 59 patients with Parkinson's disease were assigned to an experimental group or control group. The experimental group received rehabilitation treatment which included an exercise program and the control group did not. A neurologist recorded the impressions the patients had concerning the severity of their symptoms at six month post-treatment. The experimental group perceived a regression of the severity of their symptoms; the control group reported no change. The experimental group also reported behavioural changes in that they were more cognizant about the disease and therefore had less fear of it. The researchers noted that there was an apparent change in attitude from the first to the tenth session. Patients progressed from an egocentricity at the beginning, to interested, to concerned involvement with others, at the end. The group situation furnished all patients with an opportunity for greater socialization and communication. Also, an important factor was the presence of family members, because they too learned about Parkinson's disease and witnessed the residual potential of their affected relative.

Palmer et al (1986) studied the outcomes of two different 12-week exercise therapy programs for parkinsonians. The findings indicated that the majority of patients in both groups showed improvements in gait, tremor, grip strength and motor coordination on tasks requiring fine motor control. Subjective impressions based on patient questionnaires demonstrated that most patients had feelings of increased well-being and more confidence in walking.

It is quite easy to listen to people talk about the experiences of others, yet the stories cannot help but lose their richness, personality and meaning when related through the eyes of a third person, or reported under impersonal, laboratory conditions. This paper allows the reader the privilege of reading about Parkinson's disease from the perspective of those who live with it. Chapter IV elaborates on the choice of research methodology.

CHAPTER IV

METHODOLOGY

Introduction

The review of literature does not dispute the value of exercise in improving the overall symptomology of Parkinson's disease. In fact most of the physicians, physiotherapist, and other researchers left little doubt that regular exercise enhanced well being, affected positive changes in attitude, offered opportunities for moral support, and even improved motor functioning.

It is doubtful however, that parkinsonians would rush out and join an exercise program based on these findings. The problem with some quantitative research is that it fails to solicit any emotional attachment. To write that patients experience positive changes in attitude, without describing the experience, does an injustice to the full implications of the findings.

Qualitative research, by its nature, allows researchers the licence to explore an idea or concept, and thus portray a more compassionate and realistic picture of it. One member of the Parkinson's exercise group wrote of his participation in the exercise class in a recent newsletter:

> We are a group of some 25 souls whose claim to fame is Parkinson's disease. We meet on Wednesday mornings for physical exercise, an activity meant to flex our rigid muscles. It is a job to decide who is looking at whom as we gather round our instructor waiting for the signal

> to begin.
>
> Susan, our mentor, guide, counsellor, and friend comes from Grand Falls. Her approach is upbeat, enthusiastic, and original; witness our quick marching round the hall to the splendid swell of Handel's Alleluia Chorus. Susan's blond hair, smiling face, and ridiculous jokes conceal a strong and determined person.
>
> Our meeting place is the corner of the White Room at the Medical Centre. We sit and stand, stretch, and bend, keeping in time with the musical accompaniment. The physical effort is bracing; we participate to the extent our individual restrictions allow. There is fellowship here, a dedication too, as shown by the couple who attend regularly, driving 45 miles from their home. (Rendell, 1991, p. 2)

The images created by his command of this experience reinforce the value that this environment has in authenticating the claim that exercise classes build moral support for some participants. It is the testimony of the participant living the benefit, not some omniscient writer who feels that he or she can write about the advantages of exercise based on instinct or some pen and pencil survey. Statistical analysis, in my opinion, could never conjure up the same images or offer such a rich and descriptive account of such a one dimensional statement, ie., exercise classes build moral support.

The choice to use qualitative methods was based on a second consideration. The group who had agreed to participate in this research project represented various stages of Parkinson's disease. They all experience the disease differently. No two people share the same symptoms, the same reactions to the medication, or the same management strategies. To apply a quantitative methodology would be an exercise in futility as the number of presiding variables are beyond the control of the researcher.

Multiple realities are at work in understanding the role that exercise has on the management of Parkinson's disease. Qualitative research allows the opportunity of exploring the data, going back for more, endulging in angles that were not previously considered and so forth . This liberty creates the opening to portray as many aspects of the disease as possible and perhaps discover themes and insights that were not previously in the literature.

The Case Study Method

The methodology for this paper is the case study and was so chosen because it is the best method for providing an intensive description and analysis of the phenomenon under investigation (Patton 1990; Marriam, 1989; Miles & Huberman, 1984). Case study research can illuminate numerous and unique themes and meanings which may help construct tentative hypotheses for continued research. Additionally it can help to advance the knowledge base of existing research, especially considering the fact that there is limited information available about the phenomenon under study.

Case study research can potentially yield an insurmountable amount of data. Because of this, the number of people participating had be limited. With this in mind, the sampling chosen for the paper was "purposive sampling," that is, the sample was specifically chosen because this group represented the best population for learning the most about the research question; they are the only individuals in Newfoundland and Labrador who attend a homogeneous exercise class specifically for parkinsonians.

When this research was initiated, all of the people who were members of the exercise group, agreed to contribute their opinions and experiences to this project. The primary study group consisted of six men and four women, all of whom had been diagnosed by a neurologist as having Parkinson's disease. Their ages ranged from 57 to 77 with a mean age of 63.

The number of members has since escalated and the temptation to open the doors and allow the new members to have their input, has been strong. Some of these participants probably could articulate their experiences in far richer detail, offer deeper insights into some of the issues, and maybe explore other matters skirted by some of the people in the original group. Yes, it was very tempting to secretly toss some of my original transcripts in the garbage and substitute some of the observations of the newer and less advanced parkinsonians. But, I remained faithfully patient and to my surprise, those who said very little in class, sometimes made comments in our private sessions that yielded the most remarkable insights of all. All contributions to my investigation were represented honestly and faithfully.

Due to the diverse nature of the member's involvement with this disease, and the potential to become sidetracked exploring ideas that are very similar to the inquiry, investigation concentrated exclusively on the exercise program in which all of the study group participated.

The Exercise Program

All of the participants in this enquiry attend an exercise class designed specifically for individuals with Parkinson's disease. They meet once a week in an isolated wing of a local hospital and together with the instructor, move their limbs through a series of specifically fashioned routines. The class lasts approximately 40 minutes after which participants enjoy refreshments, and some relaxing conversation. Before the class begins, the group are given the opportunity to share the latest joys and hardships with each other and make any announcements about their individual lives.

The class has been operating for over two years. Ten people comprised the initial class and to date there are almost twenty-five parkinsonians who faithfully attend. The session follows a specific format. The group sits on plastic chairs for the first two music selections and initiate their involvement in the class by executing movements designed to warm up the upper and lower body. There is a substantial concentration of shoulder and arm extensions that involve the whole range of motion, symmetrical and asymmetrical movement patterns, coordination activities, and upper body rotation. Movements of the lower body are aimed at stretching the abductors, adductors, flexors, and extensors of the hip. Additionally, there is considerable attention focused on stretching the anterior and internal rotators of the lower leg.

Following the warm up, the pace of the music quickens and the group is asked to stand and take a position in front of their chairs. Some individuals prefer the security of having a chair placed in front of them in the event they lose their balance. This portion of the class is designed to elevate the heart rate slightly by conditioning the larger muscles of the lower body. Participants perform exercises such as heel touches, knee lifts to the front and back, marching, side steps and short marches to the front of the room and back again. Attempts are often made to incorporate arm sequences with the leg movements but some of the participants find it difficult to concentrate when they are expected to move more then one body part at a time.

The instructor will then isolate a portion of the class for building up the endurance and range of motion of the muscles of the upper body, particularly the extensors and rotator muscles. After thirty minutes, the class is asked to sit in the chairs. The music tempo remains high while the instructor has participants march their feet on the spot, extend their legs, flex the knees and other similar movements. At times, the class will use special equipment such as towels, sponges, and wands, to work on their muscular strength and endurance. Four minutes are reserved at the end, to work on improving the dexterity of the muscles in the lower arms, hands and face.

Confidentiality

When asked to participate in the present research, the informants were notified that their identities would be protected at all times. Pseudonyms were used in the field notes, journal, and interviews. These names remain consistent throughout the research period.

The Study Group - Stage of Progression

The Hoehn and Yahr (1967) staging criteria indicated that none of the patients were at stage I of the disease, four were at stage II, five were stage III, and one was at stage IV. The mean disease duration was 7.5 years.

Data Collection

- Personal histories were obtained from the parkinsonians who participated in the research project. Some of the information collected asked members to note their age at diagnosis, occupation, educational background, and exercise habits.

- Several interviews were conducted with the members. Discussions were taped and transcribed verbatum.

- Participants were asked to complete a survey that asked them to write about some of their personal experiences and management strategies with Parkinson's disease.

- Participant were observed, through video taped footage, before, during, and after class as well as in their homes, where all of the interviews were conducted. On each occasion, field notes were meticulously recorded and filed.

- A journal was kept at all times during the research investigation to record and document any personal insights, suspected biases, gut feelings and suspicious incidents. Any comments made by spouses, other members of the class, caregivers or even friends were also duly noted.

The use of multiple methods of data collection is a major strength of case study research because "the flaws of one method are often the strengths of another, and by combining methods, observers can achieve the best of each, while overcoming their unique deficiencies" (Denzin, 1970, p. 313). Marshall and Rossman (1989) wrote:

> Multiple sources of information are sought and used because no single source of information can be trusted to provide a comprehensive perspective of the program. By using a combination of observations, interviewing, and document analysis, the field worker is able to use different data sources to validate and cross check findings. Using a combination of data types increases validity as the strengths of one approach can compensate for the weaknesses of another approach. (p. 79)

The Interview as Method

Interviewing is a common technique of data gathering both in quantitative and qualitative analysis. In this study, the researcher conducted person to person interviews, following the guidelines suggested by Weber (1986) whereby "the interview became a less clinical structured aspect of methodology and more an opportunity to advance understanding through conversation and dialogue" (p. 65). Patton (1980) said:

> We interview people to find out from them those things that we cannot directly observe... We cannot directly observe behaviours that took place at some previous point in time. We cannot observe situations that preclude the presence of an observer. We cannot observe how people have organized the world and the meaning they attach to what goes on in the world - we ask people questions about those things. The purpose of interviewing, then, is to allow us to enter into the other person's perspective. (p. 278)

The Interviews

Four to five interviews were held in the homes of each study participant. During the first interview participants were asked to discuss how they discovered they had the disease, their initial reaction to the diagnoses, their experiences with their physician, family and friends, and how the disease had affected their lives.

The second interview was conducted through a questionnaire and explored some of the emotional aspects of the disease as well as some of the management strategies that each one had put in place. Questions were asked about what made them happy, frustrated, and sad; what loss meant to them, how they coped and persevered, and finally about their emic view of how they saw themselves in the world.

The third interview tied up any unanswered questions from the first two meetings, and explored some of the thoughts that might not have been fully described in the initial engagement. As well, symptomology (primary and secondary) was addressed.

The fourth interview was reserved for discussions about their participation in the exercise class. Questions were asked about how they became involved with the class, their likes and dislikes about exercise, how they felt it helped their illness, and what aspects of their lives were affected by choosing to attend.

The fifth interviews were conducted with some of the spouses alone. In this interview, spouses were asked to give their observations of the patient. All questions asked of the patient were also asked of the spouse e.g., "What do you think bothers your wife/husband the most about having Parkinson's disease?" All interviews were tape recorded (number two written), and transcribed verbatum.

Researcher's Position

The participants in this study eagerly submitted to my desire to enter their lives and learn more about the condition that had become a part of everything they did. As the instructor for their exercise session, I had also developed a keen interest in their well being. On many occasions, I was invited to several of their homes for purely social reasons.

I wondered if I might have been advantaged or disadvantaged by the close relationship that I had cultivated during the preceding two years. When I think about it however, I am confident that my association with each of them has enabled them to relax and confide their episodes with Parkinson's disease in a relaxed manner. This disease is a very personal, humiliating, and embarrassing condition. It is not easy to talk about at times. Patients are more at rest and open to discussion when they are in the company of someone with whom they feel a certain degree of comfort. Thus, as a friend, I am more then likely privileged to be the recipient of their personal management strategies and other incidents that round out their involvement with this disease.

"Perhaps my association with the class might lead them to bias their opinions about the exercise class," I thought. In rationalizing the validity of the data I had collected, I surmised that these individuals would not waste their time for almost two years, coming to something that they did not feel was of any benefit. Comments made by family members, and friends reaffirmed my conviction that these people thoroughly enjoyed the exercise experience and attended in the belief that it was a fundamental part of their desire to influence the progress of the illness.

Quinn Patton (1990), a noted authority on qualitative research methodologies, wrote:

> There are no formulas for determining significance. There are no ways

> of perfectly replicating the researcher's analytical thought processes. There are no straight forward tests for reliability and validity. In short, there are no absolute rules except to do the very best with your full intellect to fairly represent the data and communicate with the data given the purpose of the study. (p. 372)

By following these recommendations and guidelines throughout the entire research journey, I have confidence that the proof of validity rests with the assumption that I have indeed been true to the data and that the data has been true to me.

CHAPTER V

THE PARTICIPANTS

Introduction

I could not do justice to the data analysis presented in the following chapter without first offering a brief introduction to the men and women who contributed the information. The scope of the study cannot merit complete analysis of all data and personal histories constructed. The volume of information collected is simply too great. I will however, include one personal history following the introductions, in an effort to provide a more comprehensive and accurate picture of the phenomenological lived experience of having Parkinson's disease.

My Contributors

James is the youngest member of the group and at the age of 63, is probably more active than most people half his age. He has lived with Parkinson's disease for a little more then two years and from the onset of diagnosis was encouraged to attend the exercise class by his two daughters, both of whom are registered nurses. James and his wife drive over 45 kilometers every week to attend the class. On the days that he does not come to town, he can usually be found walking, skating on the frozen ponds in his community, or gardening and swimming in the summer. James's biggest symptom of Parkinson's disease is a noticeable tremor in his right arm which is more pronounced under stress. He feels that the exercise class has helped him to accept the diagnosis, relax a little more and learn from the others about the road ahead. He also notes that he can now put his jacket on without any assistance and that when he extends both arms to the front, his left and right arm are at equal length. They had been noticeably uneven prior to his attendence at the exercise class.

Henry has only been diagnosed with Parkinson's disease for one year and readily admits that if it were not for the doctors telling him that he had the thing, he wouldn't have known it. He believes that his diabetes is far worse than Parkinson's disease, which he characterizes as a "flamin' nuisance." At 77 years old he is treasurer of a Provincial Senior Citizens club. Henry is also an avid weaver and painter and enjoys copper etching and paper tole. Currently, he does not find that his condition interferes with his hobbies.

When he first attended the class, he seldom spoke to the others and seemed to be very shy. After 18 months, he surprised everyone when he presented each of them with a copy of the Senior's newspaper. He smiled and joked about his picture which appeared on the second page and seemed very proud of his involvement.

His wife accompanies him to every class. They get a taxi every week just to attend. Both believe that the exercises help them to socialize with new friends and improve their circulation.

Marian is seventy years old and a retired nurse. In that capacity she was familiar with Parkinson's disease before she was officially diagnosed, although she is not convinced that she truly has this condition. She remembers having a tremor when she was a teenager but noted that it went away as she got older.

A widow, Marian has exhibited many ups and downs over the years, losing her husband, her home, having to retire, and then developing the disease. Recently her youngest son married and left home leaving her exceedingly lonely.

A short time ago, she took a three month hiatus from the class to visit relatives in the United States. When she returned she had gained more then ten pounds, and had to use a wheel chair to travel the 200 meters to get to the exercise room. At my encouragement, she chose to walk back to her ward and remarked how good it felt to finally move and be with the others.

Daniel is the oldest member of the group at the age of 77, but looks much younger. Parkinson's disease has hit him with a vengeance attacking his legs so that any exercise requiring mobility is challenging. His posture is severely stooped from a combination of kyphosis and Parkinson's and he finds that the pills offer very little relief. He depends heavily on his wife to get through the day. Daniel insists that he cannot do most things but careful encouragement from others reveal that he is more than adept at completing most tasks, even though it may take time. He was a member of a choral group in his church for over 50 years before the disease left him the impression that he could not sing. Recently, the class sang "Happy Birthday" to one of the members and I noticed that Daniel's gentle voice echoed the most pleasing and smooth tenor I had heard in a long time. I have no idea why he feels that he can no longer sing.

Daniel enjoys coming to class especially because the exercises help to loosen his taut muscles and joints, and provide him the opportunity to get out of the house and socialize with friends, the only time in the week that he does so.

Alister is one of the more articulate and humorous characters in the class and has authored several books of poetry and prose. He insists that he might fall victim to the wrath of his wife if he were to miss the class. He is 65 years old and has had Parkinson's disease for three years. Additionally, he has also had two episodes of cancer in the past two years, from both of which he rebounded with a full recovery. Alister is one of the few people who honestly believes that his condition has improved since diagnosis. He attributes this to the recent advances in medication, the wide range of occupational devises available, the fellowship and good nature of the exercise group, and the pretty young nurses that sit with him when his wife is away.

Geraldine, a petite and kind lady, has had Parkinson's disease for 12 years. One would hardly believe that she had it at all, with the exception of a tremor in her right arm, which is far more noticeable when she constantly tries to hide it. Her family is very supportive, her husband never failing to attend the class with her, and her son currently president of the local Parkinson's chapter.

Geraldine is one of the more sociable members of the group, always seeing to it that juice and cookies are provided at the end of the class, and always checking on the well being of other members of the group. She finds it difficult to explicate the reasons why she enjoys the class, except to say that it is wonderful and helps her muscles relax. Geraldine is very active outside of class, walking every day and trying to remain active with household duties.

Paul arrives faithfully every week in his wheelchair, his frail legs looking far too thin to support his body if he were to try and walk. He has had Parkinson's disease longer then anyone in this group, almost 17 years. His wife first noticed the condition when they were eating dinner. Paul's hand froze in mid air and he was unable to guide the fork full of food to his waiting mouth. They immediately recognized that something was wrong and made an appointment to visit their doctor.

Paul has little evidence of tremor, and while his speech is almost inaudible, it is a fair assumption to conclude that he enjoys the class as evidenced by his facial exuberance when his achievements are signalled out. He is the first to embark on the "half-time" walk that is a regular part of the class, even though he experiences severe bouts of festination and has even lost his balance on several occasions.

Additionally, Paul exhibits an over zealous commitment to perform the exercise routines to the greatest extent that his limbs allow. He remembers a darker period in his life when a doctor informed him that his condition had weakened his legs so much that it would be doubtful if he would ever walk again. While he still relies on the wheel chair to cover long distances, he is more then adept at performing short walks, and exercising some independence in his home. He has his own stretching and muscle strengthening routine that he attempts daily to help him maintain mobility and independence.

William is 64 years old and has a Masters degree in Arts. He speaks three languages and enjoys listening to classical music. He is also an avid traveller having been to Hawaii and Greece within the last year. Of all of the patients who attend the exercise class, William seems to be the one that has been badgered most by this disease. His anxieties about the illness have taken over his body to the point where he now exhibits bouts of severe depression. He is obsessed with medication and keeps a secret diary detailing every episode in which he ingests a pill, the time and his reactions to it. He feels that no one cares about his increasing anxiety. Recently, (March 25, 1992) he remarked that the hospital was a terrible place to be for someone like him as the atmosphere was probably the main reason he was as anxious as he was. "It seems to disappear when I am out of there," he remarked (Clarke, 1992b1, p. 5). Despite his apparent decrease in active participation both in the physical part of the class and the preceding and proceeding discussions, William still insists on coming to the group, noting that he feels much better afterwards. When class is over, I often take time out for William alone to walk about the room undisturbed by the watchful eyes of the rest of the group. He needs exaggerated encouragement and compliments about his progress seem to perk him up.

He truly believes that the exercise class is a great thing but feels that lately, it is a little too exhausting for his deteriorating condition. He does lack the initiative to take responsibility for steering himself away from the depression by following the advice of the nurses and doctors. Both have encouraged him to read, listen to classical music, walk, and get more fresh air. William feels that their advise is ridiculous as he has very little energy to follow it. Attendance records and field notes reveal that he participated fully prior to an extended absence of three months from class, when he was hospitalized for depression. Upon his return, he had lost a great deal of weight, seemed to have aged several years, and exhibited extremely poor posture.

Annette is one of the more knowledgeable and active members of the exercise group and at age 58, shows no signs of slowing down. The taxi drivers know her quite well as she frequently avails of their services to shuttle her about town. If she isn't checking the stock market, organizing events for the Parkinson's foundation, or visiting friends, then she is more then likely writing a book, gardening or refurbishing her home.

Annette was first diagnosed in 1980, although she remembers having symptoms at least five years prior. She visited a number of doctors who attributed her complaints to the natural process of aging. When asked about her initial reaction to the statement that she had Parkinson's disease, she noted that it was no surprise as she had been the one to tell the doctor what she had. Her mother and her grandmother had both been parkinsonians.

Annette is an articulate, intelligent and insightful lady who seems to know more about this illness then most physicians. There is very little that you can tell her that she hasn't read about or experienced. A science graduate, she is very familiar with the research world and hopes to live long enough to eventually see a cure.

Her philosophy is simple. "I manage to live with Parkinson's disease," she says, "by never never letting thoughts of what it has done to my plans and hopes for the future and my family take root in my mind" (Clarke, 1991d1, p. 1).

Charlotte - Personal History

Charlotte was a very active and bright child who loved to mix with friends and travel whenever the opportunity arose. She was president of several committees in her school days and was also a member of a couple of health facilities in town. She married at the age of 25 and eventually had four children. Today they are no longer living in Newfoundland but she attempts to visit them whenever she finds the time.

"Finding time" is one of the few things that Charlotte complains about. There is rarely an opportunity for her to sit and relax. She is a member of a seniors' fitness program, participates in the parkinsonian exercise program, swims and walks on a regular basis, enjoys gardening and is also a member of a couple of committees in the city. If she is not doing one of these things, you might find her dropping in to pay a friendly visit to someone in need of companionship. She hardly finds the time to think about her Parkinson's disease which she has had for almost 7 years!

Charlotte looks very young for her 55 years. Perhaps it is because of her youthful and refreshing attitude. Perhaps it's because she is more active than most nineteen year olds. She walks gracefully into each exercise session wearing a smile from ear to ear, bursting to tell the others about her latest adventures or family news. I am always anxious to see what she is wearing for the session. She chooses her wardrobe meticulously, and often accents her hand-made sweaters with delicate broaches and other jewellery. This is laudable considering the time it must take to button a sweater, clip on a broach or powder a little make-up on her olive complexion. Having to seek assistance to look nice, doesn't seem to affect her in the least and she is very comfortable accepting that there are just some things that she is unable to do because of Parkinson's disease.

Despite an arthritic shoulder and a couple of "small" strokes, her will to remain active and positive has shown all who know her what strength of character truly means. It is not surprising that she has many friends, all of whom empathize with her but at the same time enjoy her company. She has an attitude of which few people without any illness at all can boast.

She is frank about her condition, making no apologies for the things that she can no longer do. "I stopped worrying about whether or not the furniture gets dusted more than once a week. If it bothers you when you come to visit, then you'd better go home" (Clarke, 1991c2, p. 5). Certainly a lot of modifications in attitude are necessary if one is to cope effectively with this disease. Charlotte feels that "it's not the medical symptoms that bother you, it's whether you got a good attitude to start with and that's more of a help than any drugs" (Clarke 1991c2, p. 10).

Charlotte first noticed something was not right with her body when she was unable to read a letter that she had written. "I first noticed it in my writing and all of a sudden my writing, even me, I couldn't read it never mind anybody else and taking notes...yeah, I couldn't read my notes..." (Clarke, 1991c2, p. 1). After she had spilled a couple of drinks, and began to find that her actions were causing her personal embarrassment, she decided to visit the doctor.

There are no tests for Parkinson's disease as such; it's more of a matter of what you can and cannot do. Aging seems to lend itself to the propensity to have declining ability, but the process is more gradual than it is with Parkinson's disease. When a young and vibrant woman like Charlotte walks across the room with a deliberate gait, little arm swing and a slight tremor in the arm, the neurologist might then pencil Parkinson's disease as a possible suspect. It must be a difficult thing to accept, when you associate these bodily irregularities with old age and you are still young.

Charlotte makes several references to the word "difference," noting that the symptoms of the disease has bought taken for granted routines into a bothersome consciousness. Almost everything that she does has to be undertaken with calculated action, careful planning, and meticulous contingency plans. Differences can signal triumphs or defeats. Her friends cannot see any difference in her condition from one day to the next and this naturally brings a modest smile to her face, even though she is aware that her condition does oscillate between ability and disability.

When diagnosed with the disease, she felt that there was not a lot of room to have an emotional outburst, primarily because she felt that her condition hardly fit her preconceived notions about the disease:

> When I found out I had it, it was a jolt because if you had told me my arthritis was getting ten times worse, I would have said "I'm not surprised," because my mother had it very severely but nobody I had ever heard of had Parkinson's. I knew what it was sort of, but I associated it with people shuffling along, needing a cane and hanging on to somebody and that didn't fit my description by any stretch of the imagination and I was surprised that I could have something like Parkinson's, which is severe in its own way, and still not have it affect any part of me except my hands being slow and doing up buttons...(Clarke, 1991c2 p. 2)

Nevertheless, Charlotte felt that she needed to know everything about it. In today's society, many people want to know about the things that are taking place in their body, especially if they feel that they can affect some influence on its progress.

> I went in and I got an early appointment with the neurologist and I went

> to him and said, I don't know about the rest of your patients, but this one needs to know what I'm facing and I don't care how bad it is or how good it is, to me it's important that I know what I'm doing...It helps me to know that if I suddenly feel tired, it's not through any fault of mine. I'm not the one who caused me to be like that by doing something silly. There's nothing I can do that's going to stop me from beating that tiredness. (Clarke, 1991c2, p. 4)

Charlotte realizes that half of the battle in the war against Parkinson's disease is fought from within. If the patient accepts this inhospitable visitor into his or her body without a fight, then the disease will win every time. It is important that the parkinsonian attempt to lead as normal a life as humanly possible, accepting that certain things are outside of the realm of their capability and realizing that "choice" is still a safe asset. One can choose to stay in the chair and wait to die or decide to make the most of what competencies they still possess. Being realistic is also an important coping tool:

> ...but if you feel that you're beginning to become dependent and Oh Lord, I can't do this anymore, and I can't do that and I'm going to have to stop doing that and no one is going to want me around and no one is going to want you around, and I think that attitude makes a big difference. You're willing to try and do something. (Clarke, 1991c2, p. 5)

There was a time when socializing played a big role in Charlotte's calendar and it was not uncommon to see many neighbours, friends and family sitting down to several courses of the best gourmet food that she could concoct for the occasion. The house was spotless and everything had its place. How things have changed!

> I love entertaining six or eight people to dinner, like thinking about it this morning. I ring them up and say "Will you come and have dinner?" - and four or five courses and not think anything about it but I don't do that anymore because I get half way through and either I wind down or I've forgotten this...(Clarke, 1991c2, p. 6).

Loneliness is a common emotion with most illnesses and Parkinson's disease is no different. "I have a kind of lonely feeling which is what I always associated Parkinson's with and still do because unless you're talking to someone who has it, it's very difficult to understand what you're going through" (Clarke, 1991c2, p. 2). This is why support groups play a dynamic role in the management of Parkinson's disease. Among others to share similar heartaches, frustrations and symptoms, parkinsonians feel that they are not alone and perhaps may be a little useful in shouldering some of the hard times that others are going through. Charlotte feels that she is a good example for others with the same condition. Because she is doing so well with the illness, she feels that she can be an important role model for others.

> In some ways it's great because it probably helps others who have it to realize that it can't be all that bad. You can face it head on but I would say it's lonely because you can't talk or you can talk to them but people don't really understand...(Clarke, 1991c2, p. 2)

With any chronic illness, there are bound to be periods when things are not going as great as you would like and thus depression is bound to set in at one point or another.

> I get days when I wouldn't say rock bottom but I am even more depressed then I would be normally, but again, it's that part of me. I'm certainly not going to take drugs for any depression, not that severe. It's just a matter of sitting down and waiting it out. I mean it's going to pass. It's not going to stay with me. (Clarke, 1991c2, p. 8)

Time can be on her side in this matter because with the passing moments come a healing effect for this symptom. Thus investing patience and understanding is a small price to pay for the rewards of feeling psychologically better later. It appears that this disease is a roller coaster of good and bad health and that time represents the machinery that influences the cycles.

When Parkinson's disease became a part of Charlotte's world, she adopted several strategies to deal with it. Several of these have already been mentioned but the primary management plan deserves the final pages of her story.

> Well one of the things I have done right from the beginning, and I laugh of course, is that I was already into an exercise program and I know that my neurologist said that as far as he's concerned, it's as beneficial to me as any drugs that I take and he says if I didn't exercise there would be a big difference. (Clarke, 1991c2, p. 6)

The difference of course would be in the severity and progression of the symptoms. Charlotte is certain of this because she can notice the changes in her body when, for some reason, she is away from her exercise routine for any length of time:

> If I go away and don't exercise for ten days or so, I'm all creaky to say the least...I'm all stiff in my arms, where I can take it and bring it full range, I can feel it right there, but if I don't do exercises for a week or two weeks I can come here (demonstrates) but I can't go back here and it's harder to go up and down and I can't do exercises that require me to bend my knees to kind of sit. I just don't work very well if I go two weeks without doing anything especially ones that are very important as far as I'm concerned and the same thing with pointing your toes and what ever and these kind of ones. If you don't do them, you're soon going to seize up. (Clarke, 1991c3, p. 1)

Charlotte continues to note the therapeutic value that exercise has on her ability to do things when she says: "If I had to give up one or the other, I would be better off giving up the medication than the exercise" (Clarke, 1991c3, p. 1). Charlotte is a member of a local fitness facility where she exercises three times a week. In the winter, she makes it a point of going to the local shopping mall, before it opens, to walk her usual two miles:

> I find that it keeps me mobile so that I don't have real problems getting up or sitting down and I can, I don't walk a great deal not outside; I can solve the problem of walking in the winter time by going to the mall. I

> park the car way down and I walk through the mall, right through on the lower levels to the escalators and up and back down the other way and it's, I think they told me it's 5/8ths of a mile if you walk that. Someone said "what about all the people?" And I said well as long as I don't go noon hour or you know that kind of thing. If I go earlier in the morning or late in the afternoon it's not too bad. I wouldn't be foolish enough to go on a Saturday, not to do walking like that. I don't go with the class, there's an exercise class that walks out at the mall but they do it in the hour before the mall is open so they have it. I just walk for my own benefit. I take the escalators at both ends, I take the escalator at one and walk the other one and do it that way (Clarke, 1991c3, p. 2).

The advantages of walking in the mall can be extended to include the availability of benches that she can sit on when fatigued. This exercise opportunity has definitely be meticulously masterminded. Charlotte starts each day with a morning ritual:

> I do it from the first time I get up in the morning and I sit on the edge of the bed and put my feet on the floor and reach though I was trying to pull something down from the ceiling on both sides and then I bend forward, right over, and come up again. I start myself moving; I can move and I don't stumble down the hall and I...it is certainly beneficial. I wouldn't stop it for the world (Clarke, 1991c3, pp. 4-5).

Exercise means time and effort but the rewards are worth it for without it, there is loss. The individual whose muscles are comfortable at rest work to remain at rest and subsequently lose their strength and suppleness. The person pays by becoming trapped in a nonresponsive body. The mind has to transcend the body and make it do things it would rather not. Charlotte's morning routine enables her to move more freely and go about her daily activities without the aggravations of complaining muscles. "I find that it keeps me mobile so that I don't have problems getting up or sitting down" (Clarke, 1991c3, p. 2). Getting up or sitting down are two activities that most abled bodied people hardly give a second thought but once deprived of the ability to do it at will, it becomes a big frustration.

> When I don't do exercise, I get dopey and I get tired and when I'm overtired and I find I don't read as much and I have no interest in doing things, baking and other things. When I'm overtired and havn't done any exercise, I'm satisfied to just sit which is ridiculous and that's not good for me. If I havn't done exercise, I just sit a lot more and watch the tube and that's not a good idea, so I just keep going to exercise. (Clarke, 1991c3, p. 3)

The dangers of physical inactivity are very evident especially when it leads to mental stagnation. When a person has retired, the children are away and they are limited in what they can do, there is a tendency to spend a fair amount of time in what might be considered, meaningless activity. When the mind is not stimulated, feelings of emptiness and loneliness set in and the quality of life suffers. At least when the person is exercising, they are doing something that makes them feel good, gives them energy and the will to become more productive inside and outside of the home. "We've seen so many people who didn't do exercise and just sat in the lazyboy chair and looked at the tube and read, suddenly get into an exercise class; they're walking! This makes a difference" (Clarke, 1991c3, p. 3).

The size of the "difference" warrants the activity in most cases. The experience becomes the catalyst for additional encounters and the benefits achieved are the fuel for continued participation. Charlotte noted: "A good many of them are 50% better off then they were before" (Clarke, 1991c3, p. 4).

Charlotte is a firm believer in exercise. That cannot be disputed. I was naturally interested in the feelings that her doctor had about her preoccupation with activity:

> In my case, I've been fortunate when I got, when I first got my symptoms, he said I think this is out of my league (her GP) and he named off two or three and he said take your choice so I said I would like to go to Dr. Johnson. I didn't know him but it was fine as far as I'm concerned. He was highly recommended and he, as I say. when he decided that yes, it was Parkinson's, he did say to me right away that yes, you should be doing some exercising. (Clarke, 1991c3, p. 4)

She has been fortunate to have the encouragement of this man. Some people need a boost to get them going and when it comes from someone as esteemed as a specialist, the recommendation has a better chance of being materialized.

> Maybe the doctors need to be pushed a bit to recommend that people do exercise. I don't think enough of them do. I know my GP has never mentioned it to me and he was the one originally who sent me to the specialist but he's never said, are you exercising. You ought to be doing something. (Clarke, 1991c3, p. 4)

The time that Charlotte has invested in making an effort to remain physically active has not been in waste. "I've been doing that ten years or more and its really paid off" (Clarke, 1991c3, p. 1). Exercise and a positive attitude are high on her management plan for Parkinson's disease and when you compare how well she is doing with the disease, compared with others who have not had it for nearly half as long, it makes you wonder if these two strategies have had anything to do with its progression. She has taken the chance. Others would be wise to make the same gamble.

CHAPTER VI

DATA ANALYSIS

Lifeworld Existentials as Guides to Reflection

van Manen (1990) notes that the grounding level of human existence may be studied in its fundamental thematic structure. He writes: "there are four fundamental existential themes which probably pervade the lifeworlds of all human beings, regardless of their historical, cultural or social situatedness: corporeality (lived body), spaciality (lived space), relationality (lived relationships), and temporality (lived time). These themes are especially helpful guides for reflection in the research process" (p.101).

Parkinson's disease is a condition that dramatically affects the way the patient perceives and experiences body, space, relationships, and time. My investigation was concerned with the role that exercise had on each of these encounters.

Sifting Through the Data

Having decided to use the lifeworld existentials as the basis for establishing themes and sub-themes for this research, the next step was to undertake a comprehensive search for evidence. At times I felt like a detective, probing and rummaging through colossal amounts of paper looking for clues that might help solve the mystery of my question. It wasn't that simple! I scrutinized each interview several times until I felt that I could easily give a thirty minute dissertation on the lived experience of becoming saturated! The paper mill where my father is employed was humorously alerted to the potential for paper shortage as I accumulated small mountains of it in my home. Each page of each interview had more scribbles, pen scratches, and toast crumbs then I care to remember. This certainly wasn't my usual organized nature but these "instinct notes," less the crumbs, were responsible for some of the themes that surfaced. The more I read, the more the data let me see. References to body, space, relationships, and time were abundant in almost every thing I read.

I felt like a child as I colour coded each of the themes and then instructed my reliable computer to donate several thousand bytes to the discussions about each. This, I came to understand, was what my professor meant when she said that I must "sift through the data". Metaphorically, it felt as if I had been mining for precious minerals and as I filtered out the impurities (extraneous and non-related material), the remaining nuggets represented my inestimable gems (my lifeworld existentials). I imagined that I was placing each onto four separate trays. As I probed farther, it became obvious that my four minerals had very distinct and unique characteristics but also had fragments of each other. I had to acquire additional trays. In computer vernacular, I created sub-directories. In thesis talk, I was establishing sub-themes. At times I felt confused about the material that lay before me. Trying to decide which theme was more dominant was agonizing. Perhaps it was a combination and so to prevent further anguish and maintain some order of sanity, I justified my decision on its placement by noting that the choice to differentiate was intended to make that theme more explicit, to sharpen its focus, realizing that calling forth a particular theme was in all probability, calling forth characteristics of others.

The data analysis is presented here in the order of corporeality, spaciality, relationality and temporality. The sub-themes or mini-themes that follow each major theme represent a more focused particularity of that theme. Each of the sub-themes were established based on commonalities that emerged in the discussions and observations of the interviews and field notes. References are cited in the discussions that follow. I do not presume to ascertain the correctness of parkinsonians' responses to the questions concerning their condition. They speak from experience. It would be rather presumptuous to think that I, as a well person, could ever make judgements about their perceptions toward their condition. Thus these findings are in no way an attempt to establish any cause and effect relationships.

The chapter is a presentation by the people who contributed the information. I am merely telling their story with the hope that the material will give readers a more dramatic and pragmatic panorama of the way that this illness is lived and managed.

Corporeality - Living in an Unresponsive Body

In Parkinson's disease, the degeneration of the basal ganglia nerve cells in the brain stem means that the supply of the neurotransmitter dopamine becomes random and uneven. The symptoms that emerge are all physical manifestations resulting from the disruption in the flow of this chemical. These changes in the body have been responsible for major renovations in the way parkinsonians live and perceive their lives. For example, loss of the ability to drive has tremendous repercussions. People in this predicament note that it is like losing a leg, suddenly being cut off from opportunity and the gift of spontaneity. Annette noted that she felt like a incessant "beggar" (Clarke, 1992d1, p. 10). Being so dependent makes one feel like a child living in an adult body. It is difficult to understand if you are not in this situation.

Living in an unresponsive body may be responsible for the perception by some patients that Parkinson's is like having a person living in their body. This is a complex relationship that might make a very riveting research project for some aspiring scholar. As one can already see, the body is the real backbone of the other universal themes.

Management strategies to deal with the multitude of changes in the body are necessary and instrumental if one is to influence the progression and severity of the illness. Numerous approaches have already been identified that detail ways in which the parkinsonian can cope. This section delineates the major sub-themes that originate from the viewpoint of living in an unresponsive body: physical appearance, disconnectedness, deception, loss of efficacy, confrontations, and attitude. It will also report the role that attending an exercise program has on the management of Parkinson's disease.

Physical Appearance

The symptoms (tremor, rigidity, slowness of movement...) dramatically alter the physical appearance of the parkinsonian. Very conscious of the way they look, the tendency to shrink from casual excursions in public can be very strong. It takes a special person with an exceptional attitude to venture into territory that feels as if land mines have been littered about it. If that is not enough to deter patients' inclinations to step outside, there is a society that tends to spare little tolerance for individuals whose bodies may be unsightly. At least three of the patients interviewed in this paper noted that they had been told that they resembled someone who had too much to drink. "I sometimes lose confidence when I feel people are staring at me as if I've had one drink too many," Marian commented (Clarke, 1991e2, p. 2).

The ordeal of having to undergo surveillance every time you show yourself in public is enough to keep even the most obstinate parkinsonian hidden away. Patients who let their pride become an impediment to the amount of social appearances they generate, unknowingly restrict the size of their world until they eventually feel that they have become not only a prisoner in a frustrating body, but a prisoner in their own home.

Tremor is the major advertisement Parkinson's disease chooses to let the world know it exists. Some patients cope very well with this unpleasant manifestation by ignoring it or hiding or holding the afflicted body part. Others feel so humiliated and embarrassed about it that they shut themselves off from social engagements. This situation is apparent in the following interview. Marian noted:

> I think it's very embarrassing sometimes to go some places and you know say you're invited some place and nine chances out of ten nobody notices

> only you...I get a feeling that everyone is looking at me...That's the worst part for me; being embarrassed in situations. (Clarke, 1991e2, p. 4)

Patients must garner the psychological fortitude to transcend perceptions that people are staring at them and do their best to remain a vital and active member of society. A homogenous exercise class, like the Parkinson's class, is wonderful for those who feel uncomfortable around a normal exercise class. The pace and activities are maintained at a suitable level for all participants and they feel a strong sense of accomplishment when they complete their forty minutes of exercise. Geraldine noted one day after class: "It makes me feel good to know that I can keep up with the rest of the group. The exercises are not too difficult" (Clarke, 1991g, p. 6).

Disconnectedness

Medically, a disconnection exists in the body because the neurotransmitter "dopamine" is insufficient to relay messages from the brain to the muscles. There are strategies that the parkinsonian can employ to dupe the brain into establishing a more cooperative relationship with the body. A recipe that includes appropriate medication, time management, biomechanical adjustments, together with a sizable portion of sheer will power can sometimes restore the damaged connection. Annette elaborated:

> ...you have to think about getting up out of the chair and then you have to think about which muscles you're going to get the message to... you got to figure it out instead of doing it naturally...It's just like the wires

> have been cut in the telephone between here (gesture to head) and here (gesture to bum) and there's just no instructions. The instructions are firing, firing, firing in the head and they just aren't getting anywhere at all so its weird. This is extraordinary you know, it's very hard to get other people to understand. (Clarke, 1991d2, p. 5)

Charlotte also empathized with Annette's account of the detached relationship between the muscles and the brain: "...I know that it takes a lot of effort for me to get things in my left hand and right hand to work at the same time (Clarke, 1991c2, p. 8).

Some patients feel that they have an irreparable short circuit in their bodies. Frustrations run rampant. Many will verbalize that this is the dominant emotion that accompanies them throughout life. Disappointments are common because they have such an intense desire to accomplish a task, but the mind has to comply with the disease's schedule. The capabilities of the muscles seem so diminished and unpredictable, the patients lose faith and perceive that non-functioning body parts equate with a form of disembodiment. "One of the first things to disappear is the muscles" noted Annette one day (Clarke, 1991d1, p. 1).

Exercise has been cited, by some patients, as the magical element that can restore the sensations of vitality taken away by the disease. William noted in one of our conversations that during the exercise program: "I feel the blood coursing around in my veins. I don't see the immediate effect, but it's a good feeling..." (Clarke, 1991b3, p.

5). Annette remarked about the power the exercises had in refining some of her awkward movements:

> ...the symptoms can relieve themselves with exercise. Now it's awfully hard to do them yourself but the exercise group, you watched us, and now we walk better at the end and we are smoother with our walk after exercises...(Clarke, 1991d4, pp. 1-2)

It is fair to conclude that exercise plays a significant role in re-establishing the connection that exists between the desire to do something and the ability to accomplish it.

Deception

> He arrived in a wheelchair, eyes cast to the floor. The sorrowful gaze on his weary face reminded me of the aging patients I had observed in the desolate halls of the chronic care unit. His legs appeared thin and much too fragile to support his slight build. When he stood, I held my breath. He quivered and wavered as he maneuvered his stooped torso in position to sit in the wooden chair provided. His whole body seemed to pulsate as if protesting for having been disturbed. Long scrawny fingers curled angrily into rigid positions as he attempted to grasp the security of a steel pole that stood beside him. He snatched at the new chair and with one massive effort, threw his body into it then squirmed to attain an upright

> posture. Large watery eyes gazed ahead and a remnant of a smile seemed to appear. His nurse coddled his effort and with a child's voice, announced: "Now my love, you stay there and I'll be right back to get you." I wondered if he understood. (Clarke, 1991j1, p. 2)

One of the first impressions most people have of Parkinson's disease is that it is an illness similar to Alzheimers. They mistakenly think that the afflicted individual has no ability to reason or rationalize or to make his or her own decisions. Because the body sometimes reacts independently of the mind, contorting itself into awkward configurations that are, for numerous people, unpleasant to look at, some people naturally assume that the mind has also taken a cognitive holiday. George, described in the preceding paragraph is fully functional, having graduated from university with an Arts degree, presently involved in extensive historical research and even writing his own programs on his personal computer. He is also an avid member of the Parkinson's exercise group. He is not the only one who has felt the discerning eyes and attitudes of public ignorance. He has been spoken too as if he was a child, ignored as if he was not even in the room and treated as if he had a social disease. A friend recently related the story of a time when she had to be put in a wheelchair for three days. Upon her arrival at the hospital, she discovered that personnel had somehow concluded that she was deaf and incapable of responding to questions about her health. All inquiries about her health were directed toward her daughter who was accompanying her (the daughter in disgust quickly alerted the attending nurses to her mother's sound sagacious nature and extraordinary auditory capacity). Annette had a similar experience:

> I've run into an awful lot of people, more among elderly people, and they treat Parkinson's disease like they got a socially transmitted sexual disease; that they're embarrassed and ashamed that they've got it...people have a cast on their leg and they go out and they limp around and they make a big scene about it... What's the difference? I get out and I have to be helped along and I've got Parkinson's and why should I be embarrassed? People ..will be quite open that they've got lung cancer and lung cancer you've caused yourself, nine chances out of ten, by smoking cigarettes... and yet there's nothing that you do in your life that gives you Parkinson's. (Clarke, 1991d4, p. 3)

The fact that this condition is connoted with the word "disease" (the Americans refer to it as Parkinsonism) implies something that is offensive and repugnant. Some people believe that it is hereditary or contagious. It is not surprising that patients want to keep their diagnoses to themselves: Geraldine recalled:

> Dr. Smith had me examined from head to toe and he came up with it right away. It was Parkinson's and I started to cry...and I thought that I wouldn't tell anyone. It wouldn't be right and I came home, I was working at the time and when I came home, now I said go to work anyway and I was really feeling tired at the time so I never told anyone

> until the next day when Danny came home and I told Danny and then it must have been a full year before I told anyone else. (Clarke, 1991g2, p. 1)

It must be very difficult to exist in a society where your appearance can be the determinant people use to draw inferences about your mental and physical capacities.

Patients who know very little about the illness have already manufactured their own catalogue of symptoms so that if they are diagnosed with the illness, thoughts of what will happen to their bodies can be quite terrifying. I asked Charlotte about her initial reaction to the diagnosis and she responded:

> Well I found it was a jolt because you know if you told me my arthritis was getting ten times worse I would have said I'm not surprised because my mother had it very severely but nobody that I had ever heard of ever had Parkinson's. I knew what it was, sort of but I associated Parkinson's with people shuffling along, needing a cane and hanging on to somebody and that didn't fit my description by any stretch of the imagination and I was surprised that I could have something like Parkinson's which is severe in its own way and still not have it affect any part of me except my hand being slow and doing up buttons and that began with things like that. (Clarke, 1991c2, p. 2)

Ironically, as awful as many people feel about having this illness, those in the early stages could deceive anyone into believing that they were perfectly healthy. I can only imagine their amazement when I was first introduced to the program and could not discern those with the condition from those without it. There had been numerous volunteers attending the program and like myself, they were baffled about the health status of the group. Charlotte has lived with the illness for over seven years and is something of an enigma amongst her friends: "...Somebody says to me, are you the caregiver and I laugh and say, if I don't do exercise and if I don't take medication, I wouldn't be doing this. I wouldn't be able to" (Clarke, 1991c2, p. 5). Charlotte exudes confidence. It could possibly be a side effect of remaining active and positive in everything she does.

In January 1992, three ladies, each having had Parkinson's disease diagnosed within the preceding year, joined the class. All admitted that they were very hesitant to enrol, and that they were a little curious about what would be expected of them. One lady noted that to become a member in a class such as this probably meant accepting the fact that you had the disease and that this was something that most people probably hated having to acknowledge. Whatever the reasons these ladies chose for coming the class, they remain faithful in their attendance. Many of their initial fears have been quashed as they learn more about their illness. Friendships flourish and the loneliness of living in a body that is "distinctive" dissipates. They also realize, like Charlotte, that things do not have to be as bad as the mind would have you believe and that appearances may be deceiving.

Attending the exercise class is therapy for the mind as well as the body. Quick visual assessments of patients in the class note obvious physical differences from the time they enter to the time that they leave. My observations are often reinforced when participants comment that they find it easier to move their limbs through a greater range of motion after class, put on their jackets without assistance, tie their own shoe laces, and walk with an increase in stride length. It is fulfilling to see the metamorphoses that comes over some of these patients from the time that they arrive to the time that they leave. George, the gentleman in the initial anecdote, is able to participate in every exercise that the class entails. With the assistance of a volunteer he can enjoy the five minute walk that takes place half way through the program, and even waltz to the cheerful sounds of "The Blue Danube".

The exercise class concentrates on movements that extend the contracted muscles on the anterior portion of the body (pectoralis major and minor, rectus abdominous, external and internal intercostals, anterior deltoid, rectus femoris, iliopsoas) and the gastrocnemius and soleus located on the posterior calf. Significant time is also spent strengthening the opposite muscles of those noted above (trapezius, latissimus dorsi, posterior deltoid, rhomboids, rotator cuff, gluteals, hamstrings, tibialis anterior, extensor hallucis longus). The exercise expertise of the instructor allows the patients to enjoy the benefits of a safe structured program that is designed to specifically counteract some of the muscular symptoms of Parkinson's disease. Many feel that they would not follow this program if left to their own accord and would almost certainly omit, through ignorance, many of the important exercises. (Specific exercises are detailed in Appendix C). Even with it written on paper, patients sometimes misunderstand the instructions or skip some of the moves. It is not very motivating to follow a program by yourself at home.

Some people are surprised that there is an exercise program in the city for parkinsonians and even more astounded by the fact that there are exercise videos available. The participants in the videos (Parkinson's Disease Foundation, 1989; Moment Du Pont Canada Inc., 1989) all have Parkinson's.

Loss of Efficacy

Because of Parkinson's disease, many patients lose the ability to manage their homes, jobs, hobbies, social engagements, driving and other everyday tasks. Many note that loss of ability is probably the most horrific, disappointing, and frustrating change that they have to deal with over the course of their illness. Medication helps to enhance efficiency, when it is working. However, once the potency of the medication diminishes so does the ability to operate effectively. The drugs have been miraculous for a few patients in restoring some quality in their lives. Alister concurred: "I can do everything I could do before, just about everything, yeah - talk better, sing better, look better... Everything that requires muscular activity is to my advantage" (Clarke, 1991i2, p. 2).

Alister was on his way to medical school prior to a major illness that robbed him of the opportunity. Today he is a fine pianist and has authored several books. Getting Parkinson's disease was devastating for him and he felt the disappointment of having to abandon some of his dreams. Fortunately he found a medication that powered his muscles into action, and before too long he was writing, playing the piano and enjoying living in the upright position again. He no longer felt like a burden and was able to enjoy being alive again. He often commented that he felt like less then a man at having to rely so heavily on his wife to exist. One can only imagine the indignity of having to have a family member assist you in just using the toilet. One hardly stops to think of the skills needed to get to the facility, remove the clothing, accomplish the deed, get out of the seated position, dress, and exit. When a person can do this independently, satisfaction, self-esteem, and honour is restored. Medication is wonderful but one must maintain dexterity, strength and suppleness in the muscles to remain efficient at most tasks. This in turn promotes the feeling of self-worth noted previously. Alister also commented: "There has to be some boost to one's physical feeling, any type of exercise is to some extent" (Clarke, 1991i4, p. 3). In addition to the benefits of the time invested in an exercise program, the actual movements yield a powerful psychological sensation. Wotton Atwood (1991) noted, "walking is excellent for me because it gets me into the fresh air and gives a lift to my spirits" (p. 49).

The joys of accomplishment and the knowledge that the patient is influencing some control on the progress and intensity of the symptoms has a significant role to play in the overall management of this disease.

Confrontations

We seldom look at a chair and see it as anything more then that, yet a patient with advancing Parkinson's disease views this piece of furniture with trepidation, very conscious of the possibility that sitting in it may mean a brief imprisonment. Daniel has an electric chair to assist him. During a power outage one summer, he was trapped in it for over two hours, his legs being too weak to free him. When a person is entombed in the body of a parkinsonian, everything from stairs and zippers to toothbrushes and ovens present a series of unique challenges. Occupational aids, biomechanical adjustments, and exercise therapy increases the functional potential of the body. In other words, maintaining strength and flexibility helps parkinsonians access their space and view their homes, the furniture, and other devices with less anxiety and uneasiness.

Parkinson's disease leads one to personify their condition as an impassioned monster who resides in the body. Patients often develop a curious relationship with the disease, sometimes referring to it as "the Parkinson's," "the thing," "it". This affiliation is similar to the disconnectedness that was discussed earlier. Each day signifies a series of mini-battles between the disease and the body. Depending on the severity of the illness and the attitude of the patient, the score usually balances out.

Most of the patients in this group live as active a life as they possibly can, gardening, walking, taking part in community events, and attending exercise classes. Other parkinsonians in the community are content to surrender and await the ultimate end. Charlotte noted that you have to "face it head on" (Clarke, 1991c1, p. 3). She elaborated:

> I feel it's much easier for a lot of them if they face it because if they're not going to face it then their family is always kind of pussy footing around. If mother has Parkinson's and you know she has Parkinson's but isn't going to talk about it or isn't going to admit that she has it, it's harder for the family. (Clarke, 1991c2, p. 4)

The disorder will win every time if someone dwells in negative thinking. Confrontations do not necessarily have to be perturbing. If a patient encounters a task that is outside of the realm of his or her ability, they can seek assistance or as Annette stated one day, "if at first you don't succeed, try another way" (Clarke, 1991d4, p. 6). Patients also note that there were many things that they could not do prior to their enrolment in the exercise program. They do not look on certain tasks with the same trepidation as they once had, now that they have garnered a little extra strength and flexibility in the muscles.

Attitude

Paul has been living with Parkinson's disease for 17 years. He falls an average of three times a day, sometimes managing to escape without injury. He relies on a wheelchair if he is to travel any great distance yet will opt for walking whenever he can, believing that the effort will help him strengthen his muscles. He testifies that he has a daily exercise routine designed to improve his flexibility and relax his muscles. He sometimes hires a taxi to escort him to a local museum so that he can research his family tree. In addition he has been involved in a research project with the hospital. He is also a member of the executive for the Newfoundland and Labrador Chapter of the Parkinson's Association of Canada and has been a guest on several television and radio shows, despite the fact that his sentences rarely employ more then three words and the effort to have them understood is more then most could bear. Clearly his robust attitude, the desire to remain active in the community, and the conviction to push the abilities of the faculties he has working in his body is evidence that opportunities can be pried open when they seem most inaccessible. There are a couple of individuals whose symptoms are not nearly as severe as this gentleman, yet they seldom step outside the door. They live in the belief that the disease (their bodies) will not tolerate disobedience and that their home is the sentence they've received for having Parkinson's disease.

Living in a body with this condition is understandably a constant struggle for most patients. There are days when many feel so low that they would prefer to simply stay in bed and endure the day from that vantage point, but as Annette remarked after exercise class one day, "you just wait it out and before you know it you're free to go about in the world again" (Clarke, 1991d1, p. 5). It is an easy philosophy, but difficult to adopt. Ian, who was with the group from its inception, recently succumbed to his growing depression and had to be admitted to a chronic care facility. The ups and downs of a disease like this can imprison even the strongest of heart but an attitude that involves perseverance and a positive outlook can vie to keep the world around them from closing in. Annette noted: "...At the beginning you get a bit of depression. One way to cope is to take hold of your life and take control and by going to an exercise program and being independent at home, you are taking control..." (Clarke, 1991d4, p. 3).

The role of exercise, in the opinion of this parkinsonian, is vital in her tool box of control devices for remaining independent. Some illnesses leave the patient with little choice for affecting a change in their condition, but this disease has a vulnerability - attitude. By choosing to work hard and maintain strength and suppleness in the muscles, the patient can avail of opportunities that deteriorating muscles would not be able to tolerate. Annette continued: "What Parkinson's does is that it tightens up certain muscles, it shortens them so that others get longer and flabbier and weaker so you constantly have to work against the effects of the disease and therefore you have to do so much exercise" (Clarke, 1991d4, p. 1).

Many illnesses are perceived by those afflicted as mortal enemies that need to be beguiled and deceived. Dorros (1989) wrote a slogan that epitomizes an exceptional attitude for coping with the illness. He said "accommodate without surrender" (p. 2).

An attitude like this helps patients believe that they can still have some influence on the progression of their symptoms and that they are still strong enough to make the decisions about how they run their lives. This is clearly evident in the following conversation. Annette notes:

> ...what I try to do is keep on doing what I would like to do in spite of the disease. Now I can't always do things all the time, the same time I would like, because feeling like I am now you know, there's no possible hope of being able to go for a walk, about being able to do anything. By managing to be more cunning than the disease, I can manage to do things that I want to do...You have to give up trying to do things like hand sewing because no matter what you try, you'll never succeed but you have to figure out something you will succeed at and try to do it, because you have to start with a tool. (Clarke, 1991d3, p. 3)

Henry, has knowingly had Parkinson's disease for one year, often the toughest period in the road to acceptance. Already he exhibits an extraordinary attitude about his condition: "There's not much point in sitting around the house worrying about Parkinson's disease" (Clarke, 1991f2, p. 2). He has not imposed any mental barriers on the environment that lies outside of his home and so chooses to travel in it with the same degree of flexibility he enjoyed prior to his diagnosis. He does recognize the importance of stopping for frequent rest periods, and maintaining the strength in his legs thus accommodating rather then surrendering to the illness. Finally, the importance of a good attitude is reinforced by Charlotte:

> I think it's not the medical symptoms that bother you, it's whether you got a good attitude to start with. I think that maybe that's more of a help to you then any amount of any drugs, but if you feel that you're beginning to become dependent and "oh lord, I can't do this anymore, and I can't do that, and I'm going to have to stop doing that, and no one is going to want me around," then no one is going to want you around, and I think that attitude makes a big difference. (Clarke, 1991c2, p.5)

The exercise class is the only social obligation that some of the people in the class have on their calender. One of the wives admitted that her husband would not leave the house if it were not for the class. It makes him feel better to get out and be with others in similar predicaments. Being able to execute and complete the movements choreographed for the forty minute class helps patients to feel better about themselves and feel that they are affecting some positive change in their progression. James noted that he could now put his coat on without assistance, extend both hands to the same height, and hopefully stall the rate at which the symptoms advance (Clarke, 1991a1, p. 6). He believed his participation in the exercise class had been responsible for the changes in his body and the resultant difference in attitude. His wife concurred.

Spaciality - Lived Space

Space, to a child, probably extends no larger then the immediate home or that of the neighbours. As we age and acquire independence, space extends farther and farther until eventually the only limits to your travels are financial restraints, holiday time, attitudes and so on. It isn't until you experience a debilitating illness that you really understand the significance of a "shrinking" world. A consciousness about the reducing environment is finally felt when the things that had been taken for granted suddenly require a preponderance of effort. Homes become mazes of navigational hazards and confrontations. Carpets, stairs, corners, high cupboards, and toilets are a few of the household attachments that make parkinsonians' space unmanageable due to the significant amount of delicate motor ability required to maneuver them.

Personal space opens and closes in response to the severity of the symptoms and the body's reaction to the medication. The patient must work against the disease to keep it from creating inescapable boundaries not only in the world but also the body.

Thus the loss of space together with the complications that surround space, herein called spacial adversaries, constitute the two sub-themes under spaciality.

Space and Deprivation

The loss of space for the parkinsonian can be geometrically likened to a downward and inward spiral. The opening of the design signifies the infinite possibilities for travel. The age of 55-65 generally signifies a time when one is planning activities for retirement. It is also the most vulnerable age for the onset of Parkinson's disease and if that becomes one's destiny, plans become shelved because planning is almost inconceivable. This is an unpredictable illness.

Paul was employed with the provincial government for over thirty years and had many plans and dreams for his eventual retirement. Today he cannot fathom a trip to anything more exotic then a local park. The disappointment of unfulfilled desires, the inability to walk anymore then a few steps, not being able to eat independently, and the incapacity to even talk about the disappointment is really more then most could bear. William's space has metaphorically looped to the bottom of the spiral.

For some parkinsonians, the symptoms settle in the legs. Daniel speaks from experience:

> It's all down in the legs, even my legs don't tremor too much, but ah, I don't know. In the mornings and thank God not lately, it's like I got ten pounds on each foot. I can hardly lift my legs. I can't get out much because I can't walk very far. My legs start to give away and when I go to the mall, I walk a little bit, then I got to sit in one of those chairs there. (Clarke, 1991h2, p. 3)

Daniel lives by a beautiful lake centrally located in town. There was a time when he knew its five kilometer perimeter intimately, having travelled it more times then he could recall. He can only stare at the scenery now and travel the route in his imagination. There are days in which he feels that the journey could be attempted, but the subconscious alerts him to the reality that large spaces like this are restricted. The time involved to traverse the periphery, allied with his weakened body, is simply too much for his current health. He feels that a shorter excursion is also inconceivable, noting that his legs will not permit him to extend his world much beyond the front door without the help of a caregiver. Keeping with the discussions surrounding the spiral analogy, Daniel may be half way down, able to travel with some assistance and still managing to exercise some independence in the things that he does in the home. Gradually however, even the home becomes difficult to manage.

> I can't do all the things I've always liked to do is all sorts of things around the house. Some of the things are my own cleaning, my curtains and all that...I'll probably come to a point where I have to leave everything and go and lie down for 10 or 15 minutes then after a while I begin to feel much better. (Clarke, 1991g2, p. 2)

Geraldine is and has been a housewife for over twenty-five years, and in that capacity, felt that it was her responsibility to manage the household. Her self-worth plummeted when she began to realize that her living accommodations would not be as easy to engineer as she had been used to. Being unable to organize her space, and arrange her living quarters in the same manner that she had in the past levelled disappointment and frustration. She also had feelings of uselessness at her inability to maintain her home to the high standards that she had set prior to her diagnoses.

In addition to the sense of deprivation felt about not being able to maneuver and manage the home, most parkinsonians feel a noticeable loss in their personal space, or the immediate range of the limbs when stationary. This would be the stage that one might liken to being at the bottom of the spiral. Annette described the sensation of not being able to extend her body parts in the following statement: "You feel as if you're encased in a body cast." (Clarke, 1991d2, p. 10). She continued to elaborate:

> It's like being in jail, like being in prison. There's a wonderful quotation from a girl in a book and she said something about her skeleton collapsing onto itself. I feel...everybody feels different symptoms but I feel, I feel stiff... and then I'm shaking like I am now. (Clarke, 1991d3, p.1)

Oliver Sacks (1990) wrote of one of his patient's description of an episode of paralysis:

> It's not as simple as it looks. I don't just come to a halt, I am still going, but I have run out of space to move in...You see, my space, our space, is nothing like your space: our space gets bigger and smaller, it bounces back on itself, and it loops itself around until it runs into itself." (p. 339)

Having been stiff and sore after an unaccustomed bout of strenuous physical activity, I can easily reflect on the strange and frustrating discomfort experienced when attempting to extend a tender body part into space in which it did not want to go. Luckily, the pain diminished as the muscle repaired itself. The parkinsonian does not have the luxury of muscles that recondition over time. Without medication and exercise, the muscles lose the little ability they have until finally they render a state of total incapacitation.

The loss of personal space is something that progresses with the illness, and as evidenced, many afflicted individuals have compensatory tactics such as patience, strong will, determination, medication, and exercise for dealing with it. Almost all of the participants in this research paper felt that exercise increased their personal space during class, after class, and for several hours during the day. This allowed them the freedom to execute tasks that otherwise seemed arduous and time consuming. In referencing the exercises, Charlotte noted: "If you don't do them, you're soon going to seize up" (Clarke, 1991c4, p. 2).

Daniel articulated the gain in his ability to move as a result of his participation in the exercise class: "By exercising you're certainly getting your muscles in shape you know so that when you do walk you can walk type of thing" (Clarke, 1991h4, p.3). To him there is a distinction between shuffling to get to a location and walking to arrive somewhere. In his eyes, shuffling along did not constitute walking but being able to travel to parts of the exercise room that he could not at the beginning of the class, and being able to walk to the car using a widened stride and a more upright posture did, for him, define walking. He still requires the assistance of his wife to attend the exercise class and sometimes the effort to get ready and endure the uncomfortable ride down overwhelms him to the point that he would rather stay at home. But the encouragement of a strong and supportive wife provides the motivation for his attendance, and more often then not he is at the door with a smile, ready to begin. He feels tired after the forty minutes of movement but notes that it is a beneficial kind of tired because the time he has invested has helped him to unlock the stiffness in his joints and do some of the things that he couldn't do prior to the class: "...to a certain extent you have better control over what you're doing, like enjoying meals, writing your signature and this and that - better control..." (Clarke, 1991h3, p. 3). To him, it signifies a breakthrough that is not often felt with this illness. Observations of Daniel also note a more youthful and zesty appeal in his character after the class. He jokes with the others and walks about the room with far greater ease then when he first arrived. Clearly, he is able to negotiate his space with greater confidence and ability then when he first arrived.

Evidence that exercise can provide a key to the condemnatory prison experienced by some parkinsonians is also related through the following conversation: "...with all the exercises I've gone to, people become a little more flexible and normal with their posture and movements back in twenty minutes or so with exercising..." (Clarke, 1991d4, p. 2). The exercise class has been very therapeutic in restoring and preserving a certain degree of muscle strength and suppleness so that patients might also function more efficiently in accomplishing household chores: Geraldine testified: "...I enjoy all of the exercises, the ones I do with the arms, I find really good...helps them to move better...Sometimes I have my arm up like this (motions) then after, I can do this (reaches farther). It really helps it, relaxes the muscles...I find it helps me all over" (Clarke, 1991g3, p. 6) "... I come home after exercise and I feel I can do anything" (p. 8). The effort contributed to attend the class and complete the exercise routine in effect, purchases more space.

Spatial Adversaries

All of the occupational devices in the world will not make the home the easiest place to live. For a parkinsonian there will always be corners, high places, narrow halls, furniture, floors, and doors. Each of these things can cause mobility problems for the patient and may be looked upon with apprehension. Depending on the stage at which the disease resides, or the effects the medication is having at a particular time, patients may find that they can relate to the incidents that Annette describes below:

> ... I'm going to have a bowl of cereal and I get the fridge open and I'm behind the fridge door to get to the open part...I have to be really careful to hold the milk jug because I get stuck and frozen stuck to the floor...I have to be able to get hold of something else to pull myself over to the table and then I can't get over there...then I can't reach high in the cupboard...in order to get yourself seated properly in the chair, instead of the wiggle people use, you have to sit, stand up and sit down again.
>
> ... You go to a corner cupboard in the kitchen and you may never get out because you can get caught in a corner...It's sad to get stuck. (Clarke, 1991d2, p. 3)

Annette lives in a huge two story house of approximately 4000 square feet. Her husband has made several modifications in the home to accommodate Annette's difficulty in managing it. He has removed the carpets in many of the rooms, installed a bathroom and shower on the first floor, and resituated many of the cupboards and appliances for easier access. Even with these modifications, the biomechanics of reaching, turning, getting up and down, opening a jar etc., require strength and flexibility in the muscles. Patients sometimes have to recruit other body parts, devises, and human assistance to deal with the objects in their immediate stretch. The exercise class provides a forum for the exchange of ideas and the assimilation of some of the skills needed to get about the home and the world beyond it.

Paul has also accessed a number of therapeutic devises to help him manage the obstacles in his home. His wife elaborated:

> I think that you have to modify the home for anyone who has Parkinson's disease. There are many things that can be helpful such as hand rails. We also have grab bars in the bathroom either by the sink or by the toilet and certainly in the bath. You have to have grab bars because without them, they could not manage. They are good for all of us and especially for him. (Clarke, 1991j2, p. 5)

Certainly these modifications to the home have facilitated movement about it, but using these devises still requires upper and lower body strength, and with that prerequisite, Paul realizes the importance of exercise in collaboration with his medication. Together they form a partnership that makes his space accessible. His wife noted that Paul could now rise from his bed without her assistance, having accumulated sufficient strength to hold his grab bar and pull his body out of his reclined position. The independence has been responsible for an increase in his self-esteem and some relief for his over burdened wife.

Relationality - Lived Relationships

"No matter what you were before the diagnoses, you are now different" noted Annette (Clarke, 1992d2, p.6). First of all you come to be known as a "parkinsonian", and then your role in the home dramatically changes. This will become evident in the discussions under the sub-theme of "changing roles".

A diagnosis of Parkinson's disease seldom prepares one for the nebulous and obscure road ahead. There are times when thoughts of the future paralyses one's outlook on life. Naturally it can be disconcerting for family and friends if the one they care about is suffering mental and physical anguish. Relationships are bound to feel the strain. Additionally, the symptoms of Parkinson's disease play havoc with daily schedules and socialization diminishes. With that comes a significant decline in the sphere of friends that were once in their periodic company. This too can be likened to the downward and inward spiral portrayed in the discussions under spaciality. It becomes harder and harder to maintain friendships, and eventually the patient feels estranged from society.

As the disease is chronic, parkinsonians ultimately form bonds with their physicians. Respect for the medical profession vacillates between disdain and respect. Evident throughout the interviews was a feeling that most doctors did not respect their patients and failed to react to some of their requests and concerns. Few were able to suggest additional ways that the patient might manage their illness. Thus many of the patients found that they were not aware of services and opportunities available to make their illness more manageable. They ultimately sought others in similar predicaments for commiseration and answers to some of their questions. Support becomes paramount in a management strategy. This will be the third item of discussion.

Changing Roles

The introduction to this section made mention of the idea that Parkinson's changed a person. This referred not only to the myriad of physical and mental transformations that the patient endured, the changes that went on in the physical environment, and so on but also the changes that went on within the family structure. "I was the mother looking after my husband and children. Now my husband and children are looking after me and I'm only in my 50"s!" Annette elaborated (Clarke, 1992d2, p. 7). She related a story about getting the groceries that really made the impact of these comments stand out:

> My husband has to do all the grocery shopping, bring them into the home, and put them away. Do you know what my role is? Well, I get to fold

> the bags. It's demeaning but it's a job that I can contribute - like a child where you give him something to do to make him feel important. I need to exercise my fingers. If you don't exercise your fingers, you won't be able to contribute. You're like dead weight. It's gross. (Clarke, 1992d2, p.7)

Spouses are called upon to assist with almost everything: dressing, mobility, cleanliness and so forth. Daniel commented: "I'd be having spells. You know one day you'd be alright and the next you wouldn't be able to move and now today, I'm not doing too badly. Other days, Ruby's got to take me by the hand" (Clarke, 1991h2, p. 2).

Glenna Wotton Atwood (1990) referred to the parkinsonian as an "adult child". An elderly friend of mine felt that having an illness when one was old was comparable to the saying: "once a man, twice a child" (Clarke, 1991f3, p.6). It is a common feeling experienced by those who feel that their independence has dwindled to the point where they are totally dependent on the ability of someone else. If this becomes a production, the burden of feeling so reliant can create intense feelings of frustration and sadness. Marian sadly noted: "I see myself as not being very useful in the world", (Clarke, 1991e, p. 2). If it becomes a task where the family feels that they are enduring the illness together, it then becomes a more tolerant illness.

Many of the spouses faithfully attend the support groups and exercise classes. Others show their interest by being actively involved in helping the Parkinson's

Association achieve their goals and objectives. I can only imagine the isolation that must be felt by a parkinsonian whose family distance themselves from any activity or function for them or fail to become involved in their overall welfare. See the caring and loving relationships that surround patients whose family feel that the illness is something they endure together. I can see evidence of it in the exercise program.

Estrangement

Once Parkinson's disease has been officially determined, relationships with friends and relatives endure a peculiar metamorphoses. Some parkinsonians noted that since their diagnosis, friends seemed to be a rare commodity. People feel uncomfortable visiting an individual with an unpleasant illness. If the individual cannot communicate, as in advanced cases of Parkinson's, then it becomes more of a challenge to maintain a close friendship. As a friend remarked, "it's not nice to see soup dribbling down the front of your friend's shirt, to see his saddened eyes, to want for conversation but there's so little to talk about."

Ironically, it may be because the individual with the condition unknowingly alienates him or herself from the rest of the world. Some are so self-conscious about the changes in their body that the comfort and protection of the home is a more desirable haven: Charlotte commented about a couple of people who fit this description:

> There are two ladies that I know here in town. They have Parkinson's and neither one of them will talk to anyone. I've given them my number

> and the hotline number and I know who they are but "don't you tell anyone sort of thing" but they're making the big mistake not me. (Clarke, 1991c3, p. 5)

Having benefitted from living an active lifestyle, Charlotte feels confident when she says that these ladies are making a big mistake. It reminds me of a quote that I heard from a motivational speaker one time: "The greatest mistake a person can make is to be afraid of making one." Many people in the exercise class noted that it took a great deal of courage to attend the first session. Annette remembered going to classes in Toronto. She drove 45 minutes to get there and when her hand gripped the door handle of the exercise studio, she panicked and raced back to her home. To date she has been going to exercise classes for over five years. I don't think her attendance would be that persistent if she didn't feel the benefits.

The relationship between the physician and the patient sometimes evolves into something a little deeper then the traditional patient doctor association. In many cases, the frequency of visitations to the clinic establishes a special bond between them. The doctor is the individual that provides the precious prescription, personally tailored to the unique needs of the patient. If the dosages are doing more harm then good, the doctor is expected to alter the course of treatment to something more tolerable.

Additionally, some patients expect their doctor to be more then a drug dispenser. He or she should also be the primary information disseminator for alternative or supplementary management strategies such as support groups, physical therapy, new research, and so forth. Perhaps the doctors need to be aware that news such as a diagnoses of Parkinson's disease may be more devastating then the brave face in the front of him reveals. Charlotte commented: "I think that maybe the doctors need to be pushed a bit to recommend that people do exercising. I don't think enough of them do. I know that my GP has never mentioned it..." (Clarke, 1991d3, p. 4). The exercise class is one avenue that might help to prevent patients from becoming a memory to their friends in the outside world.

Support

Because of the unique way it affects people, Parkinson's disease has been described as a very lonely disease. No two people share the same symptoms, the same manifestations, or the same reaction to the medication. Thus it is difficult for someone to empathize with the one afflicted. Charlotte described her feelings about the condition.

> .... Kind of a lonely kind of feeling...because unless you're talking to someone who has it, it's very difficult to understand what you're going through. I find in my case because I don't <u>show</u> the symptoms and my hands shake. But if I take my medicine on time even that will stop... but I would say it's lonely because you can't talk or you can talk to them but people really don't understand. Nobody can understand Parkinson's or how I feel when I can't stand on the edge of a flower bed and pick

> flowers without falling head first into the flower bed. I'm the only one that knows that. (Clarke, 1991c3, p. 6)

If it is difficult for one parkinsonian to relate to another, it is even more arduous for someone without the illness, like a family member or friend, to understand the complexities faced daily by their loved one. Charlotte continued: "...I really don't want to talk to anyone who hasn't got it..." (Clarke, 1991c2, p.3)

Despite the frustrations of feeling so empty at times, some consolation is achieved when those with the condition share their experiences, trials and tribulations, and findings with others. I asked Charlotte if she still felt the loneliness that she had experienced with her initial diagnoses. She responded:

> Yeah, I still feel lonely; yes I still get spasms of it. When I've been to one of the meetings or something, this is where the support groups come in...but Doctor saw the others in the group or me and see them, I know things are not really as bad as you think they are. You can always find someone worse off then you are. (Clarke, 1991c2, p.3)

Fortunately, the loneliness is a temporary emotion that seems to be relieved through social engagements and periodic discussions with friends about the condition. It is medicine for the mind to discover that your situation is not as extreme as your imagination lets you believe. The support of others in similar predicaments, the understanding of those familiar with the disease because they are associated with parkinsonians and the friendship of family and friends helps to make the illness more manageable.

I had attended a few functions with the Parkinson's Association and noticed that several individuals came who were relatives of individuals with Parkinson's disease. Apparently, the ones with the illness could not bring themselves to attend. I asked Charlotte how we might get these people out of the home and back in the social milieu. She replied:

> Well I think the first thing we have to do with them is get them involved or come to an exercise class...and talk about it and then you realize that the most important thing of all is that there's always someone worse than you are. That's the biggest thing of all, to realize that there's always someone worse off then you...(Clarke, 1991c3, p. 3)

The exercise class is not only a therapeutic forum for muscular conditioning, but an opportunity for individuals with a common bond to interact, share concerns, and to give: compassion, an understanding ear, encouragement, and support.

Temporality - Lived Time

The hours of a clock do not exist for someone with Parkinson's disease because the body can only function efficiently and independently for brief periods. Drugs are the major determinant of functional ability and as mentioned, are unpredictable in their potency. Thus the patient feels as if he or she were running on "medicated" time.

Translated, this means that there is no such thing as sleeping in, changing the dinner hour, being spontaneous, or attempting to do something of any significance when the medication is wearing off. The medication, in effect, is responsible for regimenting the day.

Any deviations from the regime means that the patient has to pay a price. In other words, if one stays out late to a party, it may take two or three days to recover the energy expended to remain active for that social function. Subsequently, ruptures in the daily schedule are common and unavoidable.

The progressive nature of Parkinson's means that the severity of the symptoms become more pronounced as time goes by. In order to remain functional, the patient and physician must experiment with different medications to achieve the timetable that works best. In addition, it was discussed that the patient might spend time learning about the condition, attending support groups, acquiring occupational aids, and exercising. In effect, this would be an investment toward their functional ability. Those who do not take advantage of these ancillary services do not enjoy the quality of life as those who do.

Finally, it appears that an antithesis of time exists in the world of the parkinsonian, primarily because the passage of time can be either positive or negative. This would depend on the way that the patient is feeling. They want time to pass quickly during a bad spell and slowly during a good spell. Ironically, it doesn't work that way. Operable time is simply too unpredictable and thus the patient can only hope that their condition has more compassion then wrath. The effects are as if time has been personified with the illness and that the Parkinson's and time are in some sort of diabolical relationship, sometimes working together, sometimes working apart.

Regimented Time

> What happens is that the pills, you take a pill at 8 in the morning, it takes effect about quarter to 9 it used to last until say 11:00 and then you'd take another one, but now it doesn't take effect quite as quickly and it runs out much faster so you go right, take it being able to do something and then zap you're suddenly unable to do something about an hour earlier then you were expecting it... I feel very frustrated because when you've got as much time as I've had recently, by being clever you could manage it. You could manage to squeeze in the duties of the day and there'd be hours that you were functional. The hours have shortened up so much now that it's damned near impossible, so I really juggle 25 uncompleted projects at a time. (Clarke, 1991d2, pp. 3-4)

It is very difficult for parkinsonians to plan projects where success depends on being able to follow a clock. Annette can surely attest to that in the above conversation. Cooking creates havoc in many cases because often things have to be completed on a schedule, and for many patients this is just not possible. It is too difficult to persevere when the body beseeches you to quit. Thus it is not surprising that many parkinsonians feel that the hours in the day do not exist anymore. For them, time can only be forecast in terms of minutes. To take the chance that you might be functioning an hour away is too great a gamble.

The number one strategy for managing Parkinson's disease has been identified as drug therapy. Unfortunately it is the big culprit in regimenting time. If time is judged by the things that you actively accomplish, then it is not surprising that many patients feel that a good deal of time during the day is non-existent. There is a large quantity of time spent "waiting" in the world of the parkinsonian. They are terribly dependent on their medication for its restorative magic. Patience must be one of their strongest attributes. Annette noted:

> Somebody said it wouldn't be painful but it's worse then pain and you go inside yourself on a bad day. James says he can see it in my face when I'm having a bad spell and inside myself and I'm just waiting, waiting until time will pass and the pill will take effect. (Clarke, 1991d3, p. 2).

When planning to attending an exercise program or participating in any other physical activity, the parkinsonian must schedule their pills to take effect when they are required to move. If the dosage is insufficient, taken too early, or too late, patients find that they lack the energy to make it through the session. In a lot of cases they choose to sit in a chair until they feel the vitality returning.

By taking part in an exercise program however, participants discover that they can obtain a temporary stay in the stiffness that is so pronounced during sedentary times, that the rigidity in certain parts of their bodies is not quite as dramatic, and that the ability to move more efficiently is heightened. Evidence of this was related in conversations reported in the two preceding sessions.

Parkinsonians have the power to influence the functional hours of the day by investing time in exercise class and complying with their medication schedule. Some of them become amateur researchers, manipulating the time they take their pills or the amount that they take to give them maximum time for accomplishing tasks and enjoying life. The "on" and "off" cycles of the disease gives patients a new clock to contend with, but given a little ingenuity and imagination, patients can predict their bodily reactions and schedule social activities when they are most energetic.

Ruptures in Time

Many of the participants in this study related stories of things that they felt they could no longer do. In some of the situations I discovered that it wasn't a case of loss of ability that made them reach their conclusions, but a case where the task's success was judged by how long it took to complete it. If a hobby took too long to execute, it was judged as a failure. Charlotte commented:

> ... some of the others do gardening and it doesn't bother them but I find it terribly tiring and I don't bother with it because I'm more conscious of my Parkinson's when I'm doing something like that then I am at any other time...(Clarke, 1991c3, p. 3)

The longer one persists at a task, the more the body fights by becoming fatigued and demanding a break - a rupture in time. One of the wives noted that her husband had to lie down for almost three hours to recover from something strenuous. To her it symbolized a loss of time in his life.

Many of the patients felt that time had an inestimable quality when it was filled with accomplishments. Finishing the housework, walking to the bank, and attending and completing the exercise class were all things that generally made patients feel that time had not been wasted. These were some of the things that gave them the feeling that time had actually passed quickly. The ruptures in time occurred when their body fatigued upon exertion and they had to leave a job half done to lie down. Many felt defeated and longed for an energy reserve so their functional hours could be extended.

By taking part in an exercise program, patients can work on the endurance of the muscles to buy the additional time required to complete things. Had they chosen to lead a sedentary existence, never challenging their muscles to move, it is doubtful that their limbs would respond to any assignment that required a preponderance of endeavour. James noted: "If you don't use your muscles they get all cramped up" (Clarke, 1991b3, p. 7). Charlotte concurred: "If I don't do exercises for ten days or so, I'm creaky to say the least... I just don't work very well if I go two weeks without exercises" (Clarke, 1991c4, p. 2).

Ruptures in time will always occur with this condition. It is possible to reduce the frequency by remaining an active and vital member of society.

Investment

The parkinsonian readily admits that it takes them considerably more time to accomplish even the simplest of tasks. I observed one of my friends in the exercise class get into my car one day:

> She opened the door with delicate precision and shuffled meticulously to the left so that it would swing clear of her stooped body. Once this was accomplished she gazed in at the interior as if she needed to be persuaded that it was indeed safe and wouldn't refuse her. I held my breath as she rocked back and forth on tiny feet that seemed disproportioned to the awkward body it was expected to shift. With a final heave, she hoisted her left foot just high enough to make it to the lip of the doorway. Some time later, she swung about and fell into the seat. "I need to rest", she gasped. When she had caught her breath she entered what I concluded was the second phase, pulled her other leg in to join the first, shifted her buttocks several times until she felt secure. "Lets go," she whispered. (Clarke, 1991c, p.15)

A sign in my office reads: "Adopt the pace of nature: her secret is patience". Many of the parkinsonians can still remain fairly independent given patience and understanding. They lose the independence when these compassions are robbed. The more the patients can do for themselves, the more they feel the rewards of accomplishment and the benefits of challenging their muscles. I overheard William remark that his family had little tolerance for him of late and in many cases, rushed him through life. He seemed very anxious and upset by these revelations.

In the earlier situation, Annette had to experiment with several body positioning techniques to ascertain the best sequence of movements to accomplish the feat of getting into a car. She had several other strategies for accomplishing other tasks as well - most parkinsonians do. There are schemes for escaping from a frozen position, washing dishes, dressing, and turning corners. Many of these techniques require extra time, especially if they are attempted without the assistance of another person. James, who has only been diagnosed for a year, related his experiences about time expenditure: "To cope you have to drive a little slower behind the wheel, when working after an hour or so, rest for a half hour or so then go again and try to pace yourself to the condition" (Clarke, 1991a, p. 4). He has to invest time to remain independent.

Exercise can also be viewed as an investment for its immediate benefits, for it's long term value, and for the power it has in possibly delaying the progress of the illness. Charlotte described her participation in a local exercise program for older adults:

> ...I've been doing exercise group, 3F, and that's geared for the over 50 crowd so the exercises I do over at the 3F twice a week are really the same exercises that I do on Wednesdays with the Parkinson's except at a different pace. I can go faster with the other group. I've been doing that for ten years so it's really paid off... (Clarke, 1991c4, p. 1)

Charlotte has echoed the benefits as they accumulate over a long duration. She can also testify to the power that exercise has in the present sense: "...you reap the benefits almost immediately". (Clarke, 1991c4, p. 3). Geraldine smiled and recalled the sensation the after effects of the class yielded: "I feel it afterwards, all afternoon; more energy, looser muscles" (Clarke, 1991g3, p. 7).

Daniel also related his experiences with exercise and the consequential effects it had on powering his medication: "It seems to get the pills that I took beforehand circulating you know and there's times when you feel it kick in..." (Clarke, 1991h3, p. 4).

The investment of time and energy is really an expenditure that purchases the same thing back: "Oh yes, it's beneficial. We do a lot of marching and walking in the class, so the more I can do of that without tiring, the better it is for myself" Daniel continued (Clarke, 1991h4, p. 2). Exercise makes one feel good, mentally and physically. It has the potential to empower the individual, and it also helps to stimulate and arouse the insubordinate limbs. In brief, exercise is an investment with large payoffs, continuing independence, emotional enhancement and social enrichment.

Those of us who rush through tasks never really feel that time has been invested because the quality isn't felt or perceived in the same sense. Slowing down and experiencing the spiritual aspect of the deed enforces the notion that time has been spent. Attending the exercise class is a healthy investment.

Time and Disease - A Diabolical Combination

Parkinsonians have their own perceptions about the concept of time. For some, time is a precious ally, for others a fiend. For others, time is comprehended as oscillating somewhere between friend and betrayer. These attitudes seem to correspond to a number of factors, including the stage at which the disease resides, the effects of the medication, and the attitude of the individual with the illness. The following transcript describes Charlotte's beliefs about the effect of time in the development of the disease:

> ...A friend of my daughter's did some research and he said that they think that if you start off slow, the Parkinson's will take a while for the next symptom to come and that it will probably take a long time before you become incapacitated as opposed to if you start out quickly and all of the symptoms are there at once, then the prognosis is not nearly as good... (Clarke, 1992c2, p. 10)

Parkinson's disease is an incessant and unrelenting condition that ignorantly moves in and progressively toys with the body and the soul. It collaborates with time to diminish all functional ability in the patient before it is satisfied to rest in eternal slumber. The sad reality of living with chronic illness is reported by Geraldine:

> One thing that disappoints me about the Parkinson's is that you can live so long with it and you could be an invalid. She's (her neighbour's sister) over there now in Baxter House, not that Cherington Place, she's over there 17 years, a complete invalid and she's more or less paralysed

> because she can't do a thing. She can't even pull up the blankets up over her. She can't hold anything. She's just like a real baby. That's a disappointment. (Clarke, 1991g2, p. 3)

Unlike terminal illnesses, Parkinson's disease does not kill a person. It is the complications that result from the loss of functioning or the secondary symptoms that may ultimately cause death. In a lot of cases, patients die from heart failure, pneumonia or some other illness. There isn't a lot of pain and many of the patients remarked that Parkinson's disease was more desirable than other illnesses, like cancer or diabetes, for this reason. Others were thankful that they did not have Alzheimer's disease because that condition was a greater burden on the family. At least with Parkinson's disease, one could still maintain some independence as long as those around them had patience and understanding at the amount of time it took to do certain things.

One gentleman felt the frustrations of having a chronic disease and his description portrayed Parkinson's as a lamentable sentence of life imprisonment with some unpleasant stranger. Alister responded to his initial diagnosis by saying: "it was the finality of the diagnosis and the statement that I was never going to get rid of this thing" (Clarke, 1991i2, p. 3).

The disease seems to sadistically enjoy toying with individuals, granting them false hopes and impishly taking them away again. Daniel reinforces this notion: "It's funny you know, you really have trouble and all of a sudden BANG and you're fine and the same thing can happen in reverse. I'm alright watching T.V. or something and by the time I'm ready to get into bed, I got to crawl. I go right down you know" (Clarke, 1991h3, p. 2).

Time management has been cited as one of the main strategies for dealing with the limitations imposed by the illness: "Planning is necessary for me. I must allow for the "on" and "off" periods which occur any time during the day..." Daniel commented (Clarke, 1991h, p. 3). Attending the exercise class requires careful planning and intention to carry it through. Annette elaborated: "It's very hard to get going but you have to...you have to work against it - like working against gravity. You have to struggle and you have to pick a time; it's hopeless to do it when you're not functional" (Clarke, 1991d4, p. 1). Yet the exercise class gives the patient the feelings that they are influencing control over the illness and in that regard, lessening the severity of the symptoms for varying amounts of time. Things do not seem as bad when therapy unlocks the stiffness in their joints.

Conclusion

The role of exercise is an important component of any management strategy adopted to improve the quality of life for the parkinsonian. This was evident in the preceding excerpts from the participants' interviews and my observations. The benefits of the increases in flexibility and strength,together with the improvement in general mobility is more important to their struggle to remain functional and independent for as long as possible. The value of exercise therapy reaches much deeper for someone with a chronic illness like Parkinson's. A well person might find it truly difficult to truly understand the importance of a class such as the one those in the study attend. This is why the attitudes, insights, and experiences of the people who live this condition were so necessary for this investigation.

Chapter 7 explores the role of exercise from the instructor's experiences and observations. It concludes with a brief synopsis of the implications the findings of this paper have for the implementation and design of subsequent programs and the possible modification of existing ones.

CHAPTER 7

DISCUSSION

Keep the faculty of effort
alive in you by a little
gratuitous exercise every day.

-William James

Introduction

The Parkinson's exercise group has been a very rewarding experience for me. I have been somewhat humbled by the mental fortitude and acceptance garnered around each member who attends faithfully each week. I have acquired so much knowledge about a disease I didn't even feel I had an affinity for until now. The profession that I have chosen for a career has more then a stake in the welfare of individuals with physical challenges, and while they may realize it, few programs still exist that do anything about it. Universities, communities and health clubs, medical schools, and governments have little to offer persons with special needs. Perhaps they feel the population is too small, that it is not financially feasible, or that physical activity is easier to program if you are a young educated urban professional.

The benefits of exercise have been heralded, not only in the review of literature, but also by the participants in this study. There is very little to dispute about its value. Why is it then that there are so few programs in Newfoundland and Labrador that cater to individuals with medical conditions. Perhaps it is the lack of leadership, funding, and facilities, or misconceptions about the need, feasibility and legal implications.

When the Parkinson's exercise class began two years ago, a young physiotherapist enlisted the help of a local fitness leader and sent letters to members of the regional Parkinson's Association. Ten people comprised the initial gathering. Word of mouth is largely responsible for the escalating numbers today, and at twenty-five participants, the facility can hardly tolerate another increase.

I remember an incident on the first day that I arrived to teach the program. Charlie Andrews, an elderly man, arrived early slumped in a haggard wheel chair, saliva dripping onto his soiled cotton shirt. His bald head hovered just above his tattered grey trousers. Without lifting his head, he raised his eyes in my direction and quickly returned his gaze back to the floor. His drooping eyes and expressionless face was void of any interest in the surrounding clamour. He seemed so unhappy and I felt a familiar ache in my throat as I stared at him. The nurse encouraged Charlie to sit up straight so that she could remove him from his current location and resituate his tired body in one of the chairs provided for the exercise class. I glanced at him from time to time throughout the class as he sat pensively in the same position for the entire forty minutes. He was oblivious to the real intent of his presence and made no effort to raise his arms or legs when suggested to do so.

Charlie died recently. His friends noted that he probably wasn't even aware that he was alive. I felt saddened by the news as he had eventually become one of my favourite participants. Each time he would attend class there would be noticeable improvement in his alertness, physical capabilities, and attitude. He told a joke one time, although it was agony trying to understand his speech. I remember one particular day in June, six months after the class was initiated. We secretly changed places in his wheelchair and he pushed me down the hall. We laughed so hard I thought he would die on the spot. We reversed positions before we got to the nurses station. I can't say whether the exercises had anything to do with the metamorphosis that came over Charlie during those months. Perhaps it might have been the drug treatment. There were many things about him I feel were known only to the class. I do not think the nursing staff were aware that he stacked the chairs away after class, that he would sometimes lead a portion of the class, and that he laughed periodically when we teased him about his favourite group - "New Kids on the Block." It seemed that he was never allowed to do anything on his own, constantly being reminded to stay where he was, spoken down to, and encouraged not to move without someone present, yet I noted that he walked better unaided then he did when a volunteer or nurse attached themselves to his hip! He never displayed these abilities in front of others as he was constantly in his wheelchair and very despondent when outside the class. I know because I had asked the staff and spent time on the ward where he was a member.

It was a sad day when he was hospitalized with cancer. He never returned to the class after that and I felt a little empty without his company. The group was always interested in his well-being. You don't see that very often in a regular exercise class.

When Charlie first came to our group, I could almost sense the fear in some of the patients who were in the early stages of Parkinson's; fear that his condition was their impending reality. It must be terrifying to them to think that they might end up like that.

Yet when Charlie Andrews was diagnosed, medical breakthroughs were scarce, and other management strategies, especially exercise, were not recognized.

The front line assault for this disease has always been drugs, but as Annette noted, pills only give you the ability to move. If you fail to move the pills are of very little benefit. I have already witnessed the remarkable differences in patients who have been coming regularly to the program. There is not only a difference in their physical abilities, but an improvement in attitude, self-esteem, group dynamics, and socialization - all excellent avenues to be explored in future research endeavours.

The people who expressed the biggest fears about the future felt some comfort in acknowledging the benefits exercise has reaped on them, and believe that perhaps they could have a say in just how severe the disease would become in the future. By keeping the body strong, the possibility that they might succumb to total incapacitation could be minimal.

At a recent international medical conference on health and fitness, I overheard a physician discussing research that indicated the possibility that exercise might be responsible for lower mortality rates, yet ironically he seemed to disapprove of this notion. He believed that maintaining a high quality of life and remaining independent for as long as possible was a greater concern of the aging and ill population then actually adding years to a life that was burdened with a medical condition. Harry Kerrison (1992), Program Director for the Secretariat in the Third Age, noted that as we grow older, the most cherished and sought after state or condition in life is independence. He says: "Physical independence relies upon an optimum degree of cardio-respiratory efficiency, muscular strength and endurance plus flexibility" (p. 1). If one's physical ability is hampered to the degree that walking, reaching, getting into and out of bed, lifting or carrying things about the house, is negatively affected, dependency results, and we have read about the feelings associated with that.

Although relatively healthy, my grandmother and her sister, 91 and 95 respectively, both live on their own. Their greatest fears are that they will lose their independence and have to rely on someone else to get through the day. The same fears reside with many of the members of the exercise class. Becoming a burden is one of their biggest fears. Physical independence is contingent on many factors, some of which cannot be controlled but one thing individuals can do is keep the "faculty of effort alive" as the poem says, "by a little gratuitous exercise every day. "Exercise not only adds years to your life, but life to your years. The following discussion will summarize the role that exercise plays in fostering independence and maintaining the dignity so vital to the people who have Parkinson's disease.

Benefits of Group Exercise Class

To recapitulate the role that exercise plays in the management of Parkinson's disease is to summarize some of the text book benefits and recapitulate the lived experiences of some of the parkinsonians who helped me to write this document. For example, general mobility has been highlighted as one of the major benefits of exercise therapy. In the data analysis, patients often spoke of the ordeals of being helplessly motionless. When movement was restored, thanks to the yielding effects of medication, the body first responded with sluggishness, and then proceeded to assimilate the movements of the so-called normal population. It is hard to imagine being side-swiped by a refrigerator door because you were not quick enough to escape it's course, or missing your mouth with the toothbrush, scrubbing cheek instead of teeth. It's not that easy to understand what it's like to walk without an arm swing, to cover distance at a painstaking pace, being unable to lift the feet from the floor, yet a session of exercise enables patients to maintain more normalized movement. Parkinsonians report that they can get into and out of cars, chairs, and beds with greater ease; that they can do this sometimes without assistance and at their own schedule. Thus dexterity of movement and enhancement of activities in daily living is a wonderful compensation for the time invested in a session of therapeutic exercise.

Some patients and some excellent researchers suggested that following exercise, parkinsonians experienced temporary relief of the rigidity seizing some of the muscles, particularly the flexors. By concentrating on movements that stretched opposing muscle groups, patients reported that they could reach further, turn with greater ease and feel some temporary relief of the discomfort accompanying taut body parts. Try to imagine the frustration of not being able to get things from a cupboard you've always been able to reach, or turn in your car to secure a seat belt. Witness the pain in the eyes of someone experiencing toes and fingers curling defiantly into rigid positions. Listen to the thankfulness echoed when the muscles comply and respond to the desires of the mind.

The self image and confidence of the patient certainly receives a boost when disability becomes ability, when differences are felt and noticed and when the harsh symptoms of the disease subside and patients begin to feel well. There are only a few things that can foster these feelings; exercise is definitely one.

The literature reports an increase in socialization and motivation when parkinsonians are in a homogeneous group. The data analysis highlighted the feelings of stress, embarrassment, and loneliness that accompanied this disease. It is not as pronounced when in the company of others in the same predicament. Thus, the exercise class was one situation where excuses were not fabricated to avoid attending. In fact, patients looked forward to the good nature and positive attitudes exhibited by members of the group. Individuals who absorb themselves in negative emotions are encouraged to attend and witness the cohesiveness of the group. There has never been a situation where a person has come to the class and not returned. This is the validation of the role of exercise.

Participants sometimes arrive with family members. It is refreshing to see the support levied on the parkinsonian by the spouse and other members of the family. Going through the ordeal as a couple enhances coping mechanisms and promotes a better understanding of the disease. For others, the class frees the spouse to attend to personal matters both are thankful for their independent time.

While there are many benefits obtained from attending the exercise class, I feel that space should be allotted for one more. The exercise class fosters self expression and emotional release. Many of the participants initially arrived at the class with the trepidation an elephant apparently feels for a mouse. When initially diagnosed, patients experienced apprehension and uncertainty about their future. Now that they know a little more about the illness they are more comfortable with it and note that their initial fears were probably a little extreme.

Implications of the Research

There was significant evidence cited throughout this research document to support the notion that exercise had an important role to play in the management of Parkinson's disease. Even more notable was the fact that parkinsonians preferred the services of a structured group exercise program specifically designed for them, over a personalized program that they did at home. Daniel commented: "...unless you go to a group of some sort, you won't do it, or rarely do it. You can pretty well be convinced in your own mind that you won't do it" (Clarke,1991h2, p. 1).

The actual physical therapy was important to patients but the fringe benefits of getting out of the home and socializing in a relaxing and sometimes humorous atmosphere was paramount in enhancing their quality of life and empowering them to strive to "keep the faculty of effort" alive.

A few comments reinforce the emotional value the exercise class had for the participants:

> Marian: "It turns you into a person. It's one situation where you are able to give, you know, encouragement, advice, and knowledge" (Clarke, 1992d1, p. 8).
>
> Charlie Andrews: "It was the one thing in my life that was fun" (Clarke, 1992d1, p. 9).
>
> Pricilla Kean: "It gives me something to look forward to" (Clarke, 1992d1, p. 9).
>
> Annette: "I can get out and run my own life, be accepted. People understand there. You're a person first, not a parkinsonian. It gets you away from being controlled by the disease" (Clarke, 1992d1, p. 9).
>
> Alister: "The fellowship is a great thing" (Clarke, 1991i3, p.3).

There are many things to consider in designing an exercise program for parkinsonians. The following areas of importance were emphasized by the class members:

Leadership: "The instructor has to have the right personality, not too jolly and not too stiff, a good listener, and willing to learn about Parkinson's disease" Annette elaborated. (Clarke, 1992d1, p. 9). Having been involved in the administration and leadership of over 100 fitness training workshops and a participant for the past twelve years, I can concur with the statement that the instructor must have an effervescent nature as well as a safe, fun, and effective program. It would be difficult to acclaim this program if I truly didn't live this conviction. Participants reinforce my confident assumptions:

> "Patti, our mentor, guide, counsellor, and friend comes from Grand Falls. Her approach is upbeat and enthusiastic, witness our quick marching round the hall to the splendid swell of Handel's Alleluia Chorus. Patti's blond hair, smiling face and ridiculous jokes conceal a strong and determined person" (Rendell, 1991).

and

> "You're a good one, always making us laugh with the stories of those boyfriends" Geraldine noted (Clarke, 1991g2, p. 6).

It is vital that instructors have recognized fitness leadership training and perhaps have attended a speciality workshop dealing with exercise considerations for older adults. When I was first introduced to the Parkinson's exercise class, I must confess that I had never even seen a person with the disease. I had followed some materials that I had obtained from the local Chapter, and implemented some of the suggestions of a physiotherapist but truly believe the real education came from the group. They were the ones with the expertise, telling me about the body parts that felt uncomfortable, suggesting alterations on certain exercises, and proposing other things that might make the class more enjoyable.

I have been even more fortunate to be involved in writing this paper. The real learning came on this journey and here I am on page 135 feeling like an expert! They have taught me so much. I hope I can return the favour.

Social Element: This was highlighted in many of the preceding conversations and should be considered when planning a program. Time should be allotted before, during, and after the class for the exchange of ideas, anecdotes, and phone numbers! Our class initiates with a "show and tell" where members are encouraged to relate personal achievements, stories about their families, travels or other incidents. It is important that all exercisers be heard over the duration and sometimes it is necessary for the instructor to prompt a story from a shyer participant, even if he or she responds with only a one word answer. At least they are included. Several of the more gregarious members have taken it upon themselves to serve as a "welcome" committee for new members. They are not only assisting the instructor in promoting a comfortable and non-threatening environment, but taking an active role in the program. It makes them feel genuinely valuable. At the end of the class, juice and cookies are available and the more mobile participants serve the less ambulatory.

Several luncheons to celebrate the anniversaries of the class have also been held and highly attended. These functions seem to escalate the participant numbers over and above the average class attendance. It is also an event where we see more spouses attending. Thus the network becomes stronger.

Facility: The current facility for the exercise class is less then ideal. The description of it in Chapter 1 supports that. There is very little space for moving about and what space there is is cluttered with support beams, heaters, old wooden chairs, pool tables, ping-pong tables, one piano, and several large cartons. But, as the saying goes, it's better then nothing. It is available at no cost, the parking lot lies adjascent to the exercise room, it is wheelchair accessible, located in a hospital (important but not necessary), bathrooms are close, and there are copious chairs for participants to sit on when tired. They are also utilized in the exercise class. These are all important things to consider in a facility.

The Exercises: Like anything, there will be components in the class that are outside of the realm of ability for some patients and perhaps not challenging enough for others. The instructor must strive to maintain a class structure with which 80-90 percent of participants can attempt, the quality of execution not being the determinant of success. Some things to keep in mind for the choreography include:

- keeping the exercises simple, using only one body part at a time,
- executing the moves at half time; single time if the music is of a slower tempo or if the participants are sitting,
- proper cuing and saying precisely what you want participants to do. There should not be any confusion about your routine,
- assuring that you do enough repetitions to establish a pattern but not so many that participants tire,
- having a song devoted to exercising the muscles of the face and another for working the muscles of the forearm (fingers),
- choosing music that is lively, with a dominant base, familiar and enjoyable for all members, and
- using forwards, backwards, and sideways travelling with volunteers to assist patients who are at risk for falling.

Miscellaneous: Volunteers, spouses, and family should be encouraged to attend. It is not advisable to extend membership in the class to anyone who does not have Parkinson's disease. This is what some participants call an exclusive group and the cohesive nature of it would be jeopardized if participants felt their homogeneity threatened.

Unfortunately, the program is not for every person who has Parkinson's disease either. Those whose mental functioning is unstable or who are totally immobile receive little benefit as they are generally unresponsive to the instructors suggestions. They also demand too much attention and in the face of limited volunteers it is not practical to have them attend. Their needs distract from the needs of those who can benefit the most. Individuals whose symptoms require medical attention, (loss of bladder functioning, periodic eyelid closure...) are probably not the best candidates for the class especially if there are no nurses in attendance with the expertise and legal right to assist. If the patient is in severe stages of the illness, the seriously ill patient may also be detrimental to the other patient's optimism and outlook for the future. It also takes away from the good natured atmosphere of the class, if a participant is suffering.

Periodically the class has enjoyed being photographed for the local newspaper, video taped for medical conferences, and featured on television and radio. The class is something of a novelty to Newfoundland and Labrador and it is the desire of the parkinsonians to encourage others to make exercise a part of their management plans.

Recommendations

- It is impossible to offer exercise programs for individuals with physical disabilities without properly trained instructors and thus universities and fitness training institutions should provide the educational opportunities for those who may be interested and perhaps create opportunities for the knowledge to be enhanced by working with individuals with these special needs. Other programs should be initiated across the province, perhaps by local Y's, hospitals, and recreation departments, for persons with medical conditions. Special grants should be made available to defray the costs. Time and time again reports are published that note the long term savings of keeping people healthy and out of the hospitals.

- Doctors should be encouraged to recommend their patients to an exercise program and should have either the basic knowledge about the types of movements patients should undertake, or informational brochures the patient can read. Physiotherapy is not always the answer for some patients. Many of the benefits of a group exercise program are not realized in physiotherapy sessions.

- Additional research should be undertaken in this area, especially from a qualitative stand. The patients lived experience has so much value and information that isn't possible to obtain through statistical analysis. Without a research vocabulary, few people can understand the full impact of the statistical implications common to empirical research.

- This program needs more exposure, and to that end, I will attempt to do so now that this thesis is a memory. Maybe more people will surface from hiding and make the effort to attend once they have read this. They will be wondering, I am sure, why they weren't aware that this program existed.

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APPENDIX A

SAMPLE FIELD NOTES

Field Notes - William

August 26, 1991, 10:30a.m.

Residence

Journal entry prior to visit

On my way to interview William. I think this is an exercise in futility and I'm not looking forward to listening to his tireless and dispiriting diatribe about his endless woes. Everyone else in the group seems so determined to weather the daily tempests that are a part of this disease but not William. The more pills he can convince the doctors to prescribe, the happier he seems to be. What is it about drugs that some people have such an adoration for. I know so many people who are like that. I believe that exercise can be the panacea for a good many of the afflictions that beseige some of these hypochondriacs, not that William is imagining Parkinson's...

I have to keep reminding myself that my assumptions should be reeled in from time to time. Let the patients tell me their beliefs and be careful about jumping to conclusions too quickly.

Post Interview

William's wife was flying out the door when I arrived, purse swinging wildly by her side, hair dishevelled, and coat partially buttoned. She muttered a quick greeting and breathlessly noted that William was in the living room. I carefully knocked on the old wooden door and navigated my way inside.

William was sitting at what I presumed was an antique mahogany table. There was such a mountain of clutter in front of him that I couldn't validate my assumptions. I noticed an infinite number of electronic gadgets, pills, books, pills, travel documents, pills, and porcelain ornaments. I remember William's fascination with languages, the music box, and yes the pills, so none of this surprised me. I was somewhat amused by the old photographs that lined most of the walls and tables throughout the living room. It was hard to believe that the handsome young man whose face adorned some of the pictures was actually William. He smiled at the replicas and announced that those were happier days.

We sat at the table for the interview. He was a little curious about the dictaphone and eventually ignored the thing once I positioned it inconspicuously amongst the rubble! He doesn't look at me when we speak, but stares into the empty space somewhere between the top of his eyebrows and the stucco ceiling. His face remains expressionless and his voice is a little too monotone for me. He frets about the necessity of taking his medication on time, noting that I should remind him when it is 11:30. He also reminds me that he is very tired and may not be too good with the conversation.

He surprised me today. Once we got off the topic of the pills, I steered him to a more comfortable topic. When I told him how helpful he was to assist me with my research, the eyes positioned themselves in my direction and his face let a smile escape. He sat straighter and encouraged me to ask him about what ever it was I was doing.

He showed me a few pamphlets that he had scattered on the table that described exercises for the back and then did a short demonstration of some of the movements. He then read some Spanish to me and proudly displayed his ability to ask a senorita for a dance. I thought, "William is a little sly and a little more adventurous then one might believe!"

He escorted me to the door, and I truly believe that his spirits were higher then when I arrived. He enjoyed having someone to talk to and show off some of his talents. I get the feeling that he is very lonely and truly thinks that no one cares. It is not surprising then that he thinks the class is good for him because he gets to talk with others in similar predicaments.

APPENDIX B

SAMPLE INTERVIEW

Interview Number 3

Annette - September 16, 1991, 2:30p.m.

Residence

P. I'm studying the role of exercise and recreation in the management of Parkinson's disease and from talking to everybody I get the impression that the most important thing in this management are the pills, the restructuring of the house, support from family... and I'm starting to wonder if recreation has a big role to play at all. What do you think?

A. Well recreation... that recreation is such a general term, I'm going to change it to exercise and exercise has a vital role and it's not that understood and not that well thought of but you see, the pills give you the ability to move. If you sit in your chair you just lose your muscles anyway. You just make sure you take the pills because if you don't use it you lose it, that old statement, and so that's why an active life is pretty good. You know you take the pills and you do what you can, you have your hobbies and quite frankly I'm a lazy pig at exercise. I don't do as much as I should but I know the theory of it and what Parkinson's does is that it tightens up certain muscles. It shortens them and so the others get longer, and flabbier and weaker so what you have to do constantly is work against the effects of the disease and therefore you have so much exercise that you really can't do at all unless you're devoted to it entirely and have a devoted spouse who will get you going. It's very hard to get going but you have to, every day, do your breathing exercises for example and your posture because if you don't you'll get like Gordon Ash and you have to work against it - like working against gravity. You have to struggle and you have to pick a time. It's hopeless to do it when you're not functional. You have to pick a time and you have to do this (demonstrates by putting arm high in the air) all the time. Stretch and then your deep breathing because if you don't keep those muscles as flexible as you can, fight the tightening - you see the tightening is going on 24 hours a day - and so therefore and the weakness that's going on, I think you can sit for a week and you know how hard it is to get about, so that's what you're like everyday so you have to fight it and I'm going to talk about that.

Now I'm going to show you my arm. See that? Now that's what they call contracture. It won't stay relaxed. Now it's pretty good. It's been worse than that. Its been stiff, like this (contracts the arm). Now this one move quite well so you see you have to work against the contractures all the time or you'll get ahead of you. It's impossible to move so that's why exercise is vitally important and twice daily exercise is really benefit to the parkinsonian. So that's part of it. The other reason why it is that most people, the symptoms can relieve themselves with exercise. Now it's awfully hard to do it yourself but the exercise group, you watched us and now we walk better at the end, and we are smoother with our walk after exercises, and that is a little known effect. With all the exercises I've gone to, people become a little more flexible and normal with their posture and movements back in twenty minutes or so of exercising. When you start the best time to do exercises is when you're stiff because you can work it out but you see you can get your arm up to about there at first (demo) and there after you've done it for a while, your reach is way higher and that is one of the things that you do feel better. You're more functional and you feel better. Now that's my twenty minute dissertation.

P. That's what I need. So you think it's body and mind together?

A. It is body and mind and the pousy wousyness of our Toronto group, now they were a lovely group. An older lady whose husband had Parkinson's, she was the leader, and she kept him going for years. She exercised us in the nicest way and she was funny too. She started this class in 1980 when her husband was first diagnosed. He died in 1988. He had Parkinson's for 10 years or so. She had it too so you had to keep the muscles flexible and moveable and you need the companionship and when you exercise you do the Parkinson's symptoms do seem to release. Your stiffness releases and you feel a lot better. I'll show you some pictures.

P. Okey

A. Now this is Ted and his wife had Parkinson's. He was great. He use to say "now this is a democracy and I run it." Anyway I talked to Ted and when I went to the class I got to the door and I turned tail and left and went home again. I was too nervous to go so Ted phoned me and said "we missed you" and I felt embarrassed and I said "well, I'd gotten involved. I'll be there next week" so I went and they welcomed me - just like our real pousy wousy group and this will show you that it's not that different. (Shows all the pictures)

The real business of the exercise is that you got something that is working to slow you down and tighten you up and to weaken you and you really have to work against it and really some exercises are not that helpful because they work on strengthen and tightening these muscles (points) that don't need it because they work. You see getting in and out of bed and it is incredibly difficult and unless you keep yourself toned up you won't be able to get out of bed. Now once you can't get out of bed by yourself, you can't live alone.

P. That's right.

A. By strengthening your muscles, you can get into bed and move in bed and get out of bed then you can put off the day and be independent.

P. We need to know what each person needs, like an individual program.

A. Now that would be the absolute ideal but it is fun, speaking as a participant, to participate in a group and do the exercises in a pousey wousey way. Really, the ideal world of a situation they are doing in England, where they are assessing people, when they are first diagnosed, and they are designing an individual program for them, and they are reviewing them once a year.

P. Good idea.

A. I think you need a meeting place. People with Alzheimers disease get very ratty when the scenery is changed but people with Parkinson's get much improved when the scenery is changed. Jason, my husband, says that they trot about, and they try and look after each other, and they do, and it makes them feel good to be a part of something because you see mine isn't usually badly affected.

At the beginning you get a bit of depression. One of the ways to cope is to take hold of your life and take control and by going to an exercise program and being at home, you are talking control - doing something and not just sitting around. What we need, is a place to lie down and another thing is don't worry about too much progress because it's just so super to get out and do the exercises. What would be lovely though is water exercises.

P. We are going to try that some time.

A. It's terribly frightening and you need a lot of volunteers.

You need to warm people to wear their bathing suits under their clothes because dressing and undressing is just so awful. It's one of the reasons I buy clothes when my daughters are here because you see I can't get undressed in the dressing rooms. Parkinson's negatively impinges on so many aspects of life that it's really rotten.

P. How long do the effects of exercise last?

A. Several hours. You feel very tired after a good workout. For example, I used to drive to the Toronto exercise group and quite often I would have difficulty with my driving on the way up but I knew that after the exercises was done, I was much more supple and flexible and I could move much more freely.

P. In addition to the exercise class do you think the idea of being in a support group helps them?

A. Well, I know that most of us feel... like I do feel for the other people there and you try and cheer them up. You try and put on a happy face for them and you know, "my don't you look good today" and all that sort of thing, and you can't keep on feeling miserable because other people do that for you, and it's good things they say, "we missed you" and "it's good to see you back" and it does good things to your spirit to have to be wanted. (Change tape) .. To have people there and have a chance to chat with the other people. It's very good for keeping your spirits up and you know it really helps when you walk into a place and people say "Hi, how are you, nice to see you again" and all that kind of stuff and it changes your outlook on life very seriously and very quickly and also it's more interesting.

Parkinson's is awfully boring because you can't do half as much as you'd like. You sit there and you mind goes round and round like your locked in a cage. But if you go out and your stimulated you've got something to look forward to all week. Sometimes the only thing... Remember that nice Mrs. Kean? She said "it was something to look forward to" and she didn't participate all that much but she liked coming and having fun. You see, you lose yourself as a person with this disease because you can't do anything for yourself but you know if you have a bunch of buddies, and you have a place to go every week, and they're interested, and they know you're feeling miserable, and so you really have a good thing going for you so that is one thing and it's not to underestimate the power of feeling in a group like that.

Remember the educational group? We went to the review of that and I'm very glad that I went because I was able to tell them that we that they had some of the patients drop out and quite frankly, we resented it in a way. You guys making off with our buddies on the same day that we have exercises. We wanted them there and I said you know, "we're a real group and you know you people took half of our group away and that." And we were talking about Kevin. He didn't stay with that group, he came back to ours. We didn't like missing our friends. There was quite a lot of irritation about that by different people and I said we also didn't like our friends getting something that we were not. So they were quite surprised and I said "it's a gang, a real gang."

P. Everyone is close.

A. Yeah, although we don't see each other outside.

P. Everyone is always concerned about each other.

A. And show and tell before the class, and I'd say that's a very big part of it, and that's what you ran into with it. The physiotherapist in that program - I don't think that she was able to adapt her service to the program, to their needs, because I was quite firm with her. 20 minutes twice a day was better for people with Parkinson's then trying to make them go for a longer time.

P. Yes. The participants point of view is important.

A. See my muscle here now? You can't really loosen it up because even when I stretch it up, the lumps are still there. It cramps up. You do get cramps sometimes. Kim can give you the really technical stuff. When I'm really bad this muscle pulls the toe up (demo) and this muscle pulls the other toes down.

P. Really?

A. These toes cramp down like claws and these stick in the air.

P. It all has to do with the muscles?

A. Yeah.

P. Working the outside of the muscles is very good for that I hear.

A. Keep the joint flexible for the whole day because if you don't do it, you just feel uncomfortable because everything gets all stiff and cranky. There isn't much written on the aspect that you're working on because there isn't much studied. That's one of the problems I think.

P. I found some things in the books that you gave me about that.

A. That new book that you have is wonderful.

P. Yes

A. She pinched my title. I think that activity is different than exercise. Activity is very very important, and you have to do it, but it doesn't put you through the full range of motion which you should do but activity is quite important. Activity that isn't accomplished is no point in being flagellating yourself because you want to do something really big. It's enough activity for me to go out in the garden and pull up a couple of weeds or tell somebody else to dig a hole, and you're walking about in the garden is activity for you.

So you know it just frustrates me so I get out and do something so you have to tune your activity to your fitness level.

P. What do you think that I should talk about?

A. I think that you should talk about the importance of physical activity and the importance of socialization and stuff like that. Results are there in a fitness program because activity means you're going out. You got a plan; you've got a deadline, you got to get there by class time. Well if you don't have any deadlines during the week, life must be very very... nothing, no need to get ready to do anything.

You just get awful saggy I think. So if you tighten in on exercise then you could show that exercise gives people the activity...

P. Yes exercise opens the world to activity.

A. Yes. Did you know that George Thompson, when he first came to the group, didn't realize that he was suppose to be able to walk? Rachel Thompson, his wife, is a very supportive generous and loving and caring person and she pleaded to his every need, but he didn't know any other parkinsonians and he was almost going everywhere in his wheel chair because his muscles were very weak and it is a bit easier for her to take him in a wheel chair, but he started to coming to our meetings and he'd come in his wheel chair and use the wheel chair elevator and now he comes without it.

There he is. He's got his pills organized and they are working better and he didn't realize that he was suppose to be able to walk. At least I don't think so.

P. His technique needs a little work I think.

A. Well he didn't know that, he just sat in his chair when he felt weak and he didn't push himself so the muscles get weaker. That's the problem with most men. They get caudelled a lot and they get more fragile and more weaker faster. People like Geraldine and Charlotte are very special people. They are very athletic - so fit.

P. Yes, some people really resign themselves to their chair...

A. Yes. Daniel needs a physiotherapist. They need someone to come to their house once a week. He could sit like me and do the exercises.

P. Yes. Well, I think that's great for now.

APPENDIX C

PROGRAM DESCRIPTION

Program Description

Class begins with participants sitting in chairs evenly spaced in a circle. The first five or ten minutes are open to conversation about the latest happenings in each of the patients lives. Announcements are also aired at this time as some people have other commitments following the class.

The instructor puts the exercise tape in the music box, then positions herself in the middle of the group. The first 8 minutes of exercise are aimed at warming up the muscles by using a combination of upper and lower body locomotor movements followed by static stretching. Following are some of the moves that are employed in the warm-up:

Warm-up (approximately 8 minutes and executed at half time)

Straight arm raises to the front:

4 with the right arm, 4 with the left, alternating left arm with right arm for 8, then both arms together for 4.

Shoulder shrugs:

Shrug right shoulder then left for 8, roll right shoulder back, then left for 8, shrug both shoulders together for 8

Note: Avoid rolling shoulders to the front, as this type of movement causes patients to slouch. Aim is to stretch the chest and contract the upper back.

Lateral arm raises:

With arms bent at the elbow, lift right arm then left arm to the side for 8, then do both together.

Repeat this pattern with both arms straight.

Arms to the rear:

Arms by the side, reach behind the chair and touch the finger tips. Repeat for 8.

Shoulder press:

Hands at shoulder height, extend right hand to the ceiling and slightly over the front of the head, then the left. Repeat for 8.

Toe taps (heel stays on the floor):

Tap right toe for 8, then left for 8, alternate for 16, then both together for 8. Follow this up with toe taps at 10:00 and 2:00. Best exercise for lower leg.

Heel raises (ball of foot stays on the floor):

Lift both heels off of the floor for 8.

Knee lifts and leg lifts:

Raise right knee then left knee for 8, then repeat with leg extended to the front for 8.

Abduction and adduction of leg at the hip:

Reach to the side with the right leg and repeat for 8, then the left for 8, then alternate for 8. Roll back and forth on the buttocks, lifting the leg to the side as you do so.

Leg kicks to the rear:

Extend lower leg to a point between the legs of the chair. Alternate legs for 8, then right leg for 8, followed by left leg for 8.

Stretching (hold stretches for 8 seconds and repeat sequence again)

Bring ear to right shoulder then left

Clasp hands behind back

Turn upper body to look over opposite shoulder

Extend both arms high in the air, holding thumb, then lean to the right and then to the left

Lift right hip off of the chair then left.

Hands under thigh, lift right leg, then left.

Bend over to touch ankles

Flex toes in the air in front of the body

Locomotor (participants stand, chairs may be positioned in front of them for support if needed. Approximate length is 5 songs or 15 minutes).

Song 1	Lower body muscular conditioning cardiovascular improvement. types of movement include stationary marching, heel touches to the front, side and rear, knee lifts to the front and side, and heel raises to the rear.
Song 2	Upper body conditioning. Similar muscles that were worked in the warm-up, perhaps a little quicker and more repetitions.
Song 3	Lower body mobility. Patients travel to the centre of the circle and back, sideways, around the chair, some marching and other movements used in the first song.
Song 4	Upper body conditioning. Similar to song 2, but different upper body exercises.
Song 5	Walk. Participants walk about the room, down a hall, or a short stroll outside if weather permits. This is a great opportunity for conversation, out of wheelchair travel, and away from the

feelings of being cramped in a small space. Members are encouraged to concentrate on arm swing, lifting the heels when they walk and turning corners whenever possible.

Chair Exercise - 15 minutes, or 3 songs

Song 1 Marching with the feet, knee lifts, leg kicks in all directions, and if special equipment is bought in (wands, tubing, towels, etc.) This is a great spot for using equipment to condition upper body muscles.

Song 2 Facial exercises:

Wrinkle forehead, open mouth wide, puff up cheeks and move the air around, wrinkle nose, stick out tongue, move jaw to the right and left, puff up lower lip, twist mouth, close right eye then left, close both eyes, run tongue around teeth, try to touch nose with tongue, say the vowels, whistle, say a tongue twister, wink at a friend...

Song 3 Hand exercises (sponges are great if you have them)

Open and close fist, rotate palms up to the ceiling then down to the floor, wiggle the fingers, touch each finger individually off of the thumb, spread the fingers as wide as possible, flex and extend the hands at the wrist, pretend to ring out a towel, or open a jar...

Relaxation 2-3 minutes

Soothing instrumental music where patients are encouraged to relax and think about pleasant things. Instructor encourages them to tense and relax certain muscles. Breathing exercises might also be incorporated.

The finale - Juice and cookies and friendly conversation as well as attendance check, done by a different member each week.