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DIFFERENCES BETWEEN ATTITUDES, ABILITY, PHYSICAL WELL-BEING
AND SOCIAL INVOLVEMENT OF PEOPLE WITH PARKINSON'S DISEASE
WHO JOIN THE PARKINSON'S SOCIETY AND THOSE WHO DO NOT JOIN.

A thesis presented in partial fulfilment of
the requirements for the degree of Master of
Arts in Psychology at Massey University.

Sharon Mary Humphries

1992

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This study is dedicated to James Sydney Henney, late of Atawhai Hospital, Napier, my first Parkinson's patient.

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ABSTRACT

An investigation was undertaken to compare demographic, physical disability, and some personality differences between members and non-members of the Parkinson's Disease Society. In addition, the leisure activities of subjects were investigated, and levels of activity before and after onset of illness were compared. Eighty-seven patients were interviewed using a structured interview, while the Psychological Adjustment to Illness Scale was used to measure differences in adjustment to the illness between the member and non-member groups. While few differences were found between members and non-members, a trend in the amount of leisure activities the two groups enjoyed was discovered. Whether these differences were there prior to joining the Society, or whether the Society membership mediated the differences could not be ascertained from a correlational study, and the implications of this are considered. Of the activities provided by the Parkinson's Disease Society, members appreciated the information contained in the newsletter the most.

INTRODUCTION

In 1817 an English physician, James Parkinson, wrote '*An Essay on the Shaking Palsy*' in which he described six patients, each with a slowly progressive physical disease. The description, that the illness was characterised by "involuntary tremulous motion, with lessened muscular power, in parts not in action even when supported, with a propensity to bend the trunk forward and to pass from a walking to a running pace" (Parkinson, 1817, cited in Stern & Lees, 1982) has changed little today. However, while Parkinson was able to speculate at length on the possible causes and treatment of "the shaking palsy", he could offer little more. Today, the pathological changes in the brain that cause the disease can be pinpointed, and treatments that slow down the progress of the disease can be administered. But there is still only speculation as to the cause of the biological changes that result in the devastating illness that today is called Parkinson's disease.

Symptoms

Parkinson's disease produces three main symptoms, present in virtually all patients, though in varying degrees. As well, many other "minor" symptoms are present - minor in that they do not appear in all patients, or all of the time in any one patient.

The three main symptoms of the disorder are tremor, particularly resting tremor, rigidity, or stiffness of the muscles, and bradykinesia, or slowness of movement. In most patients, one symptom will predominate, but while the severity of tremor is variable among cases, it would be unusual to find a patient with no slowing or difficulty with voluntary movement.

Tremor is usually the first symptom that comes to the patient's attention, and causes the first visit to the doctor. In hindsight, though, most patients are able to think of occasions that should have alerted them that something was wrong - inexplicable tiredness, mild muscular aches, lassitude, all perhaps put down to "overwork" or mild depression. The tremor normally appears first in one hand, and perhaps the foot on the same side. In the early stages it may appear only when the patient is fatigued or anxious, typically when the limb is at rest. The patient may be aware of the tremor even when it is too fine to be noticeable to anyone else. However, this awareness will frequently be the beginning of the patient's endeavours to hide the problem - by swinging an arm, always carrying something in the offending hand, or keeping it tightly hidden in a pocket. Unfortunately, emotional upset of any kind will exacerbate the tremor, and while many become adept at disguising their shaking limb, there is always the fear of discovery, and the repercussions that will follow realization of their illness, perhaps by an unsympathetic employer. Naturally, this fear causes the tremor to worsen, provoking a vicious cycle of tremor, worry, worse tremor, and more worry. In many cases this fear is well

founded. Numerous Parkinson's patients, particularly those in positions of responsibility such as doctors, lawyers, accountants or other professionals, fear that their clients have lost confidence in them after noticing the tremor (Dorros, 1981). An Austrian study (Klingler & Tragner, 1986) found a cycle of fear and anticipation that increased tremor, led to avoidance behaviour, and ultimately spelt isolation.

Despite the fact that tremor is the most noticeable symptom of Parkinson's disease, and the most upsetting to the patient, it is also probably the least disabling. The other two symptoms of the triad, rigidity and bradykinesia, cause the most physical life changes for the patient. In 1817 it was not customary to examine patients in detail, and James Parkinson made no reference to the rigidity which causes the patient to complain of a feeling of stiffness, and of a tired, aching awareness, cramps and persistent pain. In fact, rigidity is, technically speaking, an objective sign that can only be measured by a physician examining the patient for evidence of resistance to passive motion, usually around the elbow joint, but also the knee, ankle, spine or wrist. Muscular rigidity undoubtedly slows movement, and for many years it was believed that the tremor and rigidity accounted for all the symptoms of Parkinson's disease. In reality, things are more complicated.

Careful observation shows that slowness of movement (one aspect of bradykinesia) can occur in the limbs with the least rigidity, and that rapid movement can occur even with rigidity.

Bradykinesia also describes the lack of willed movements, delay in initiation of movements, loss of automatic movements, difficulty in performing rapid, repetitive movements, and fatigue.

If bradykinesia is minimal it may be barely noticeable, except to those close to the patient. However, automatic movements are also lost in bradykinesia. The loss of the movements normally made without even being conscious of them, such as blinking, swallowing, swinging of the arms, is most debilitating. Reduced frequency of eye blinks not only gives the face a staring expression, but also reduces their cleansing actions on the eyes, resulting in irritation with the eyelids becoming dry, reddened and crusted. The patient experiences a miserable burning sensation, and the eyes must be washed with artificial tears or an eyewash several times a day.

Diminished frequency of swallowing produces drooling, a problem that does nothing for the self image of the patient. Combine the lack of expression, drooling, and slowness of movement, and the patient gives the distinct impression of low intelligence - and is frequently treated that way. The deficit in arm movement in walking, resulting in an inability to turn properly, reinforces this image (Godwin-Austen, 1979).

Bradykinesia is also apparent in the patient's voluntary actions. There may be a delay in starting to walk, as if both feet are frozen to the ground. Turning over in bed may be a problem, as

might getting up out of a chair or getting dressed. Doing two things at once may be impossible (Vaughan, 1986), and stopping one thing to start another may be equally as difficult. A conscious effort is needed to deal with such chores as shaving, cleaning the teeth, doing up buttons and cufflinks, all of which will soon become impossible for the patient to carry out alone.

If the muscles that determine the tone and clarity of the voice become involved, speech may become slower and muffled. Expression and rhythm are lost. In rare cases, however, the speech becomes faster and more difficult, if not impossible, to comprehend.

Tremor, rigidity and bradykinesia, then, are the triad of major symptoms found in most Parkinson's disease patients. However, the problems do not stop there, there being a host of more minor symptoms.

Aches and pains may not be as severe as in other diseases such as arthritis or cancer, but persistent muscle aches or cramps can still be distressing on top of all the other problems. Thermal parasthesias (unexplained temperature changes causing a hand or foot to become extremely cold or hot) may also cause discomfort. Postural changes are common, with a tendency to bend forwards in many patients, which then aggravates back pain and interferes with balance. Speech is a problem in many ways and often patients are unaware that their speech has become so soft, becoming bewildered when others have trouble hearing them. Many Parkinson's patients are very difficult to understand on the

telephone, the softness of tone being due to diminishing chest movement. A soft voice coupled with reduced facial expression and body movements results in quite serious difficulties with communication.

Difficulty swallowing not only produces drooling, but eating becomes slower and slower until the patient may have difficulty in consuming enough calories for healthy living. This in turn adds to slowing of the bowels, resulting in constipation, often followed by haemorrhoids. Urination is also slowed, and the patient may have difficulty in properly emptying the bladder, thus having to void again after a very short time; frequent night visits to the toilet are a neverending ordeal.

Walking is always severely impaired. Quite early in the disease the step becomes shorter, the foot not being raised to its usual height, and the arm swing lost. Turning is slow and hesitant because the body turns in one piece, rather than the head followed by trunk, then the legs as in an unafflicted person. Later, shuffling occurs followed by the freezing phenomenon, where there is difficulty in starting. Festination (propulsion) also occurs where the patient takes short rapid steps getting faster and faster with an increasing likelihood of pitching forward (Duvoisin, 1978). Responses to an impending fall will be made too late, too slowly, and with movements that are just too small to help. Thus, falls are common.

Micrographia, the tendency to write small, can document a

patient's progress as the disease continues to worsen. Letters may remain perfectly formed, but eventually become so tiny as to be impossible to read. Reading difficulties may also occur, although testing will find the eyes normal. The difficulty with reading is due to the fact that the eyes move in an irregular and jerky manner along the lines. The patient then has difficulty finding the beginning of the next line, making reading hard work.

Seborrhoea, an excessive discharge of the oily secretion of the sebaceous glands of the skin, is a further common occurrence, with the forehead, sides of the nose, and the scalp being particularly affected. These are reasonably common occurrences in persons without Parkinson's disease, when they are termed dandruff (when the condition is confined to the scalp) and seborrhoeic dermatitis. The conditions are irritating for anyone, but an extra aggravation for the Parkinson's sufferer. Excessive sweating in irregular bursts is a further irritation. The disease seems to cause poor control of the sweat glands, and normal stimuli can trigger a highly exaggerated response (Vaughan, 1986).

Depression and dementia are also found in a large number of sufferers. There has been much debate on whether depression is a symptom or a result of Parkinson's disease, or a combination of both (e.g. Dakof & Mendelsohn, 1986). Dementia develops in the later stages of the disease in around 32% of patients (Lieberman, Dziatolowski, Kupersmith, Serby, Goodgold, Korein & Goldstein, 1978).

In the majority of patients with Parkinson's disease the symptoms will be slowly progressive, the rate of progression varying greatly across people. Normally, however, for the first few years that clinical symptoms are present, the rate of progression will be so slow that there will be little interference with normal life.

Biological basis

The plethora of symptoms mentioned above are almost all caused by damage to the area of the brain called the substantia nigra, and the axons leading from the substantia nigra to the basal ganglia, via the nigrostriatal pathway. The major structures in the basal ganglia are the caudate nucleus, the putamen, and the globus pallidus (Figure 1). These subcortical structures receive input from all parts of the cerebral cortex, as well as parts of the thalamus, controlling the direction and amplitude of large body movements.

In Parkinson's disease, for reasons as yet unknown, the neurons making up the substantia nigra and the pathway of dopamine-containing axons between the substantia nigra and the caudate nucleus and putamen (the nigrostriatal bundle) have degenerated. The substantia nigra is the dopamine producing area of the brain, comprised of melanin-containing neurons which show in the brain as a darkened region. Even with the naked eye degeneration can be seen by the loss of colour. Figure 2 shows the area of degeneration. Thus the symptoms of Parkinson's disease are caused

by the deficiency of the neurotransmitter dopamine in these important movement areas.

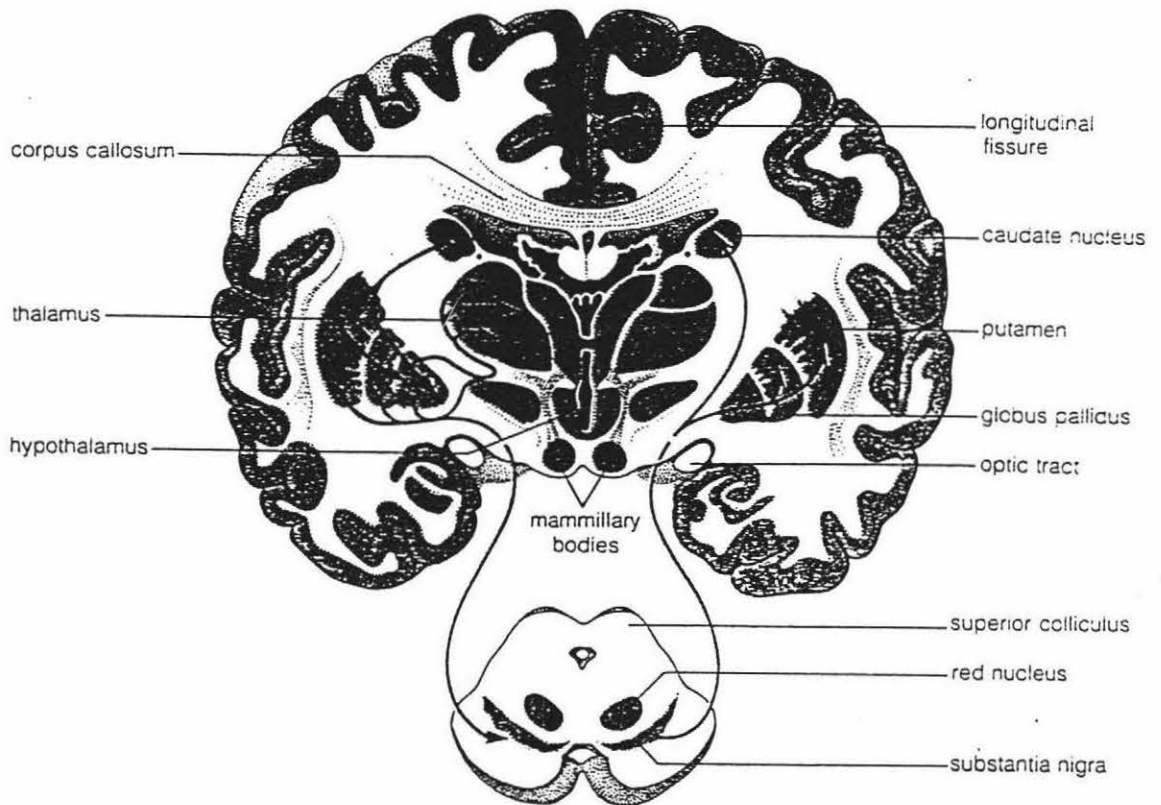


Figure 1: Location of the basal ganglia, consisting of the globus pallidus, the caudate nucleus and putamen. The latter two structures make up the striatum (Graham, 1990).

Degeneration does not seem to occur suddenly. It appears that for many years the brain compensates for the loss of dopamine by increasing its sensitivity to the reduced supply, and by increasing metabolism. Eighty percent of dopamine may be depleted, and compensated for, before even mild symptoms become apparent. A further 10% decrease in the remaining dopamine level causes symptoms to become more marked and the patient moves into the advanced stages of the disease.

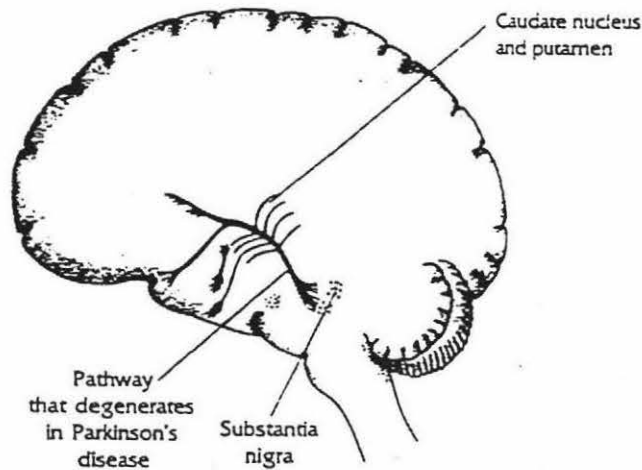


Figure 2: Brain pathways involved in Parkinson's disease. The caudate nucleus and the putamen are two of the major structures of the basal ganglia (Kalat, 1988).

If it is assumed that the loss of dopamine occurs linearly, 20 to 30 years will have elapsed from the beginning of the neuronal degeneration in the substantia nigra to the time when symptoms become apparent (Marttila & Rinne, 1986). The incidence of Parkinson's disease increases rapidly with age, peaking at 70 to 80 years, but after that it declines rapidly (Marttila & Rinne, 1976). Obviously this pattern is not consistent with any disease closely related to aging. Marttila and Rinne suggest that exposure to the cause has also increased then declined, albeit some decades earlier.

Epidemiology

The incidence of Parkinson's disease has been studied world wide by a number of researchers.

According to Marttila and Rinne (1986), whites have a 2.4% risk of developing Parkinson's disease, but in blacks (Chandra, Bharucha, & Schoenberg, 1984) and orientals (Isaacson, 1992) the risk is smaller. These predictions were made by calculating the number of persons affected annually in the surviving part of a cohort aging together from birth. However, roughly half the population die before reaching 75 years, the peak age for developing Parkinson's disease. Many of those that die without overt Parkinson's symptoms may, in fact, have subclinical Parkinson's disease.

This assumption is supported by the fact that Lewy bodies, which are normally found in the dopamine deficient substantia nigra, are found in the substantia nigra of 4% to 7% of the population of persons over 60 years of age, but without clinical Parkinson's disease at death (Forno, 1969). It is assumed that had these people lived long enough they would have developed Parkinson's disease, in which case it would appear that 5% to 10% of the population as a whole have the disorder.

Kessler (1978) reviewed ten epidemiological surveys, covering several states of the United States, and cities in Sweden, Iceland, Australia and New Zealand. In all but the Australian and New Zealand surveys males slightly outnumbered females. Chandra et al. (1984) found that in the U.S. both white and black males outnumbered their female counterparts in deaths from Parkinson's related causes by close to double. Jenkins (1966) found in Australia, however, that females outnumbered males 1.6:1. Several

investigations have also found an earlier onset in males (e.g. Kessler, 1972; Poskanzer, Schwab, & Fraser, 1968). However, Hoehn and Yahr (1967) reported that their women subjects had a mean age of 54.8 years and their male subjects a mean age of 55.6 years. The difference, though, was not significant, and the distribution of ages at onset was the same for both sexes. An interesting point made by these researchers was that during the years 1949 to 1964 there appeared to have been a gradual increase in the average age of patients attending their clinic. This finding is consistent with that of Schwab, Doshay, Garland, Bradshaw, Garvey, and Crawford (1956, cited in Pollock & Hornabrook, 1966) in their earlier research, and with similar trends found by Poskanzer and Schwab (1961).

Race also seems to figure importantly in the likelihood of developing Parkinson's disease. Marttila and Rinne (1981) found that among the white races the prevalence rates of Parkinson's disease were from 66 to 187 per 100,000 population, though without any obvious geographical pattern. However, not only is the disease considerably less common among the blacks of America and Africa, but also among Sardinian people, many of whom have negroid features. Rosati, Granieri, Pinna, Aiello, Tola, Bastiani, Pirini, and Devoto (1980) found a prevalence in Sardinians of just half that of North Europeans, while Lombard and Gelfand (1978) found Parkinson's disease relatively rare in the Black African population. On the basis of such findings Kessler (1972) suggests that the frequency of Parkinson's disease may be affected in some way by body melanin pigments. Yet the

opposite situation occurs in some parts of West New Guinea, where a high incidence is found among certain tribes (Gajdusek, & Salazar, 1982).

In view of these findings, Harada, Nishikawa, and Takahashi (1983) carried out a survey in the city of Yonago, in Western Japan, and found an incidence rate of 80.6 per 100,000 population, a rate very much in line with the findings for the Western world. For example, Garland (1952) found a prevalence of 59 per 100,000 in Leeds (an older survey possibly using less efficient methods); Schwab, England and Peterson (1959) found a rate of 65 per 100,000 in Boston; and Kurland and Darrell (1961) a rate of 112.5 per 100,000 in Carlisle. Closer to home, Pollock and Hornabrook (1966) found a rate of 106 per 100,000 in Wellington, New Zealand.

A 1990 survey of the Manawatu area (Appendix 1) indicated a rate of around 157 per 100,000 persons. An identical study in the Wanganui area (1990) yielded 169 per 100,000. These are higher than most previous estimates, but it is suggested that perhaps patients are attending doctors at an earlier stage nowadays, thus being "counted" sooner. It is also possible that the drugs now available are allowing people to live longer. An Italian team studying Parkinson's disease found a considerable increase in the mortality rate since 1980 for patients older than age 79, but a constant rate for younger patients (Isaacson, 1992). A 1985 Finnish study found about eight patients more per 100,000 population, again in the older age group (Isaacson, 1992).

Thus, although Parkinson's disease is among the most common of the neurological disorders, even now, 175 years after James Parkinson first described it, no definite cause can be given for its development.

Etiology

Over the last century many changes have come about in explanations for the disorder. Dimsdale (1946) describes these changes, starting with paralysis agitans, which at the beginning of the twentieth century appeared to be the predominant form. During the period 1929 to 1930 over two thirds of the cases of Parkinson's disease were attributed to the epidemic of encephalitis lethargica, with a mean onset age of 27.4 (Duvoisin, Yahr, Schweitzer, & Merritt, 1963). When Dimsdale wrote his paper there was little inkling of the drug-induced form of Parkinsonism that was to develop (see p.15), and which has given the medical world the greatest leads in tracing the etiology of the disorder. Today, paralysis agitans has been renamed Idiopathic Parkinson's disease, and it is with this branch of the disorder that this report chiefly deals. However, the other two branches are important because they have played their part in helping to unravel the mysteries of a disorder which projects a healthy individual into a life of dependence and misery.

Von Economo's disease, commonly known as encephalitis lethargica, appeared mainly during the 1919 -1926 period (Duvoisin & Yahr, 1965). The Parkinsonian syndrome appeared in most of the

survivors, often in the second or third decade of life (although it struck children as well). Similar to Idiopathic Parkinsonism in many of the symptoms, post-encephalitic Parkinsonism condemned many people to institutions for life, mask-like faces on unmoving bodies but with minds as able as when they first became ill. However, there were also some differences. Nielson (1936, cited in Aring, 1962) tells of the relief of the syndrome during one 16 year old patient's sleepwalking episodes. There are not many post-encephalitic patients left today, but they played their part in unravelling the mystery behind the disease. For example, immunological research, which led to a theory of possible genetic susceptibility (Elizan, Terasaki, & Yahr, 1980), and the knowledge gained from the use of levodopa by such researchers as Dr Oliver Sacks at Bainbridge Hospital in New York (Sacks, 1991).

The third branch of Parkinsonism is drug-induced Parkinsonism, the first documented case of which appeared in 1976. The patient was a 23 year old student who had successfully concocted his own narcotics for some time, but then began to take short cuts. The narcotic he was attempting to manufacture was MPPP, 1-methyl-4-phenyl-4-propionoxy-piperidine. Unfortunately for the student, the short cuts he took resulted in the manufacture of MPTP, 1-methyl-4-phenyl-1,2,5,6-tetrahydropyridine (Langston, 1984). The student was admitted to hospital after two days use of this designer drug with muteness, severe rigidity, tremor, flat facial expression, little verbal response, and thick saliva filling his mouth. Treatment with sinemet (a combination of levodopa, the precursor to the neurotransmitter dopamine, and carbidopa

monohydrate, used to control side effects) rendered him again mobile. However, he committed suicide two years later. An autopsy revealed that the cells of his substantia nigra were destroyed, just as those in a person with Idiopathic Parkinson's disease are. By checking the student's very detailed notes, it was found that it was indeed MPTP that had done the damage, and the conclusion was drawn that "MPTP, when given systemically to humans, is toxic to the substantia nigra" (Langston, 1984, p.3).

Seven years after the first drug-induced Parkinson patient was examined, studies were published by Langston and Ballard (1983) and Langston, Ballard, Tetrud, and Irwin (1983) describing identical symptoms in four more patients who had injected the substance, which by now had made its way out onto the streets.

In all these cases MPTP was intravenously introduced into the body. However, it was confirmed by Langston and Ballard (1983) that it was possible to develop Parkinson's disease without taking the drug intravenously - a 43 year old chemist working with MPTP had developed the symptoms. By 1985 numerous cases had been reported (e.g. see Ballard, Tetrud, & Langston, 1985). However, the important point was that not only were intravenous drug users developing drug-induced Parkinsonism, but others as well, which suggested that the cause of the disease may be something in the environment containing MPTP.

The environmental toxins most likely to be the culprits are the pyridines. These are similar in structure to MPTP, for example,

4PP (4-phenylpyridine) which exists in many foods and industrial sources (Snyder & D'Amato, 1985), and MPP⁺, occurring in the herbicide paraquat. Figure 3 shows the resemblance in their molecular structures. Barbeau (1985, cited in Snyder & D'Amato, 1985) found that in Montreal, Quebec, those areas that used paraquat the most frequently had rates of Parkinson's disease seven times higher than the areas that used it least.

Fears are held for the future of an estimated 9,000 people in the United States who have been exposed to at least 100 micrograms of paraquat via marijuana, sprayed in Mexico in an unsuccessful attempt to eradicate the plant (Landrigan, Powell, James, & Taylor, 1983, cited in Kalat, 1992).

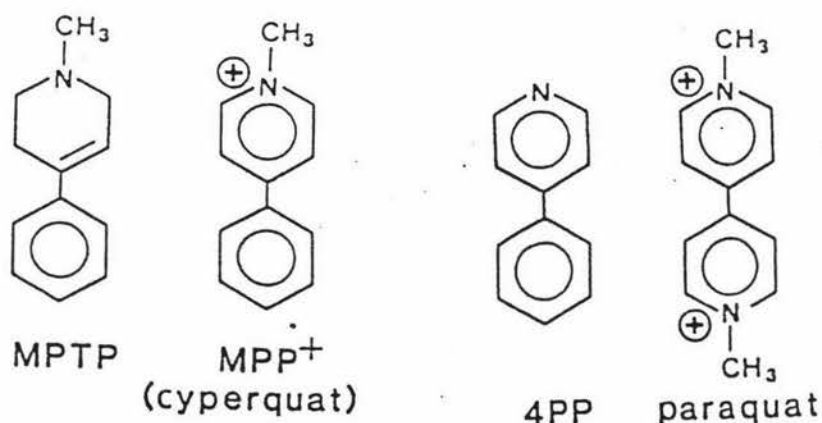


Figure 3: Comparison of MPTP, MPP⁺, 4PP and paraquat (Snyder & D'Amato, 1985).

With the advent of positron emission tomography (PET), damage can

be seen in a living patient (perhaps before the symptoms of Parkinson's even appear). Figure 4 shows PET scans from a normal subject, and those of a subject with no clinical defects, but exposed to MPTP. The activity is intermediate between normality and Parkinson's disease (Calne, Langston, Martin, Stoessl, Ruth, Adam, Pate, & Schulzer, 1985). However, the ethical implications of such predictions are a cause for concern.

There is further direct evidence that environmental toxins may cause different types of Parkinson's disease. For instance, manganese miners in South America are at risk (Politis, Schaumburg, & Spencer, 1980) and in 1982 Gajdusek and Salazar found differences in the incidence of another form of Parkinsonism in villages separated by only a few miles in West New Guinea. The only apparent correlation involved varying levels of minerals in the drinking water.

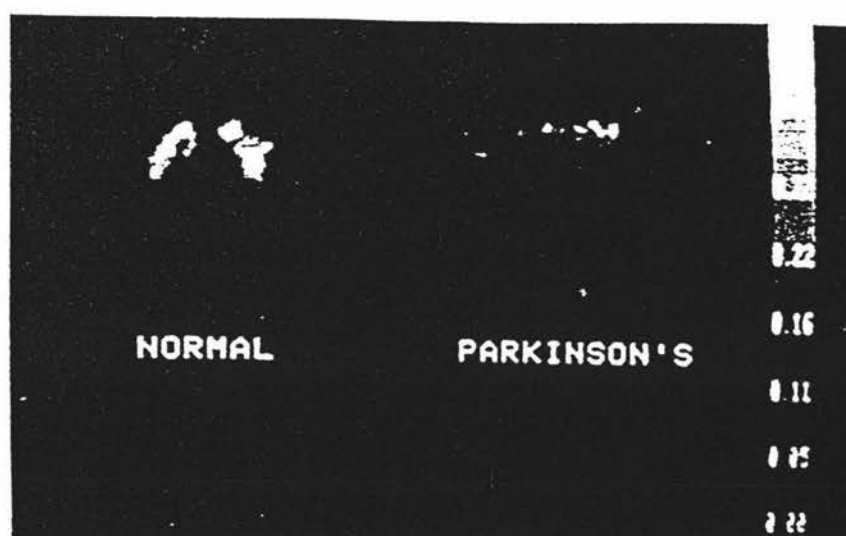


Figure 4: Comparison of a normal human brain, and one exposed to MPTP. (Calne et al., 1985). It can be seen that there is very little left of the dopamine producing area in the Parkinson's brain.

Another well documented case involving a different chemical was an otherwise healthy 23 year old male who injected himself with a meperidine congener, resulting in Parkinsonism (Davis, Williams, Markey, Ebert, Caine, Reichert, & Kopin, 1979). Lastly, acute carbon monoxide intoxication is reported to have produced the syndrome in a 50 year old woman (Klawans, Stein, Tanner, & Goetz, 1982), and Rosenberg, Myers and Martin (1989) report a case of Parkinsonism developing after a suicide attempt resulting in cyanide intoxication.

Thus the role of environmental toxins is currently a big issue in research into the etiology of Parkinson's disease. More recently Tanner and Chen (1989, cited in Sack, 1989) found that occupational or residential exposure to industrial chemical plants and printing plants led to an increased risk factor for Parkinson's disease, this research being carried out in China which is much less industrialized, and with a relatively stable geographic population. In Japan the toxic substance TIQ (tetrahydroisoquinoline) is currently under observation, having been found in greater concentrations in the brains of Parkinson's patients than in controls (Ohta & Itakura, 1989, cited in Sack, 1989).

In 1990, Koller, Vetere-Overfield, Gray, Alexander, Chin, Dolezal, Hassanein, and Tanner found a statistically significant difference in Parkinson's rates in persons who had lived for many years in a rural environment compared to urban dwellers. Moreover, the mean number of years of drinking well water was

significantly greater in the patients. But not everyone who lives in these areas develops Parkinson's disease, and it would seem that all people do not process and remove chemical toxins in the same manner. Williams (1990, cited in Sack, 1989) suggests that some people have a subtle abnormality which leads to a dysfunction in the liver enzyme thiomethyltransferase, impairing the ability to break down certain chemicals. Certainly this seems to be the most likely line of attack at present. If this distinction between people is inbuilt one must look to the role of genetics in Parkinson's disease.

There has always been controversy over whether Parkinson's disease contains a genetic component. Early reports, for example, Allan and Charlotte (1935); Martin, Young, and Anderson (1973) and more recently Barbeau and Pourcher (1982), Roy, Boyer, and Barbeau (1983), and Barbeau and Roy (1984), seemed to indicate a strong genetic link. A report on identical twins with familial fatal Parkinsonism with alveolar hypoventilation and mental depression by Purdy, Hahn, Barnett, Bratty, Ahmad, Lloyd, McGeer, and Perry (1978) certainly supported the position.

However, other researchers have felt, particularly with the apparent evidence of environmental toxins being at fault, that genetics do not come into it (e.g. Duvoisin, 1984; Duvoisin, Eldridge, Williams, Nutt, & Calne, 1981). A study of discordant identical twins by Pembrey (1972) supported the environmentalists' stand. However, today's researchers are more likely to look to a multifactorial cause for the disorder. Kondo,

Kurland, and Schull (1973) investigated how genetic disposition acts with different environmental factors, fitting in well with the research of Williams (1990, cited in Sack, 1990), mentioned above. Nevertheless, the latest on genetics in Parkinson's disease comes from the Robert Wood Johnson Medical School, New York (1990, in Sack, 1990) and concludes that the disorder is probably caused in part by a single gene. This conclusion was based on research by Golbe, Di Iorio, Bonavita, Miller, and Duvoisin (1990) on large families from Italy, with considerably more members with Parkinson's than is the norm.

One last etiological factor, rarely investigated today but of historical interest, is the Parkinsonian personality. The original proponent of this theory was Booth (1948) who studied Parkinson's disease from the psychodynamic point of view, and found a specific personality type. It is characterised by an urge towards action, expressed through motor activity and through industriousness. The premorbid patient strived for independence, authority, and success within a rigid, usually moralistic, behaviour pattern. The disease symptoms were said to appear when this "personality attitude" could not be carried on successfully, satisfying the dominant needs of the Parkinsonian on a symbolic level - compulsive activity of the motor system and rigid behaviour. Crown (1971) followed up on the earlier research by considering the relationship between the basal ganglia and personality.

Incredible though this may seem today, still other attempts were

made to find the Parkinsonian personality. For example, a number of studies (e.g. Marttila & Rinne, 1980; Godwin-Austen, Lee, Marmot, & Stern, 1982; Rajput, 1984) have found that people that smoke tend to have a lower incidence of Parkinson's disease. The suggestion has been made that there is a personality difference between the smokers and the non-smokers, rather than the smoking being a preventative measure against Parkinson's disease. Alcohol consumption may also differ between personalities; however, it seems that there is no difference in alcohol consumption between the Parkinson's patients and controls (Lang, Marsden, Obeso, & Parkes, 1981). The most recent attempt to find the Parkinsonian personality appears to be from Kondo (1984) who speaks of Parkinson's patients as "introversive, anancastic, excessively responsible, urged towards perfect fulfilment of tasks, and keeping an exact schedule for daily activities" (p.347).

In summary, the basic cause of Parkinson's disease is still unknown, but enough has been learnt, through research and good fortune, to at least treat the symptoms via the biological basis.

Treatment

There is no cure for Parkinson's disease. In the majority of cases, the symptoms are slowly progressive, although the rate of progression does vary from person to person.

The symptoms of Parkinson's disease are not all equally responsive to drug treatment. Some of the symptoms will respond

quite readily, other slightly, some not at all, and others may be exacerbated by the drugs. Constipation, for example, a problem already in Parkinson's disease, is actually increased by most of the anti-Parkinson drugs (Duvoisin, 1978).

One of the goals of medical treatment is the re-establishment of the equilibrium between dopaminergic and cholinergic activity in the striatum, part of the basal ganglia. The first drugs to be used, and which are still in use today, were the anticholinergics. Introduced by Professor Charcot and his colleagues while working in the Salpêtrière, a large asylum for incurables (Stern & Lees, 1982), these drugs work by blocking the chemical neurotransmitter acetylcholine. In Parkinson's disease, with its deficiency of dopamine, a relative predominance of acetylcholine exists. Anticholinergic drugs are given to redress the balance between the two transmitters. The anticholinergics have a major effect on rigidity, with only slight effects on tremor and bradykinesia. Regrettably, however, the blocking of acetylcholine also has a number of undesirable side effects. The commonest are dryness of the mouth, blurring of near vision, constipation and weakness of the bladder. In addition there are several mental effects - the first and least obtrusive being the loss of short term memory. This may be followed by mild confusion, visual illusions, such as a pattern on a floor being mistaken for worms (Duvoisin, 1978), and hallucinations. The unfortunate patient may at first be afraid to mention these because of the fear of being labelled crazy. In such cases the drug must be reduced or even discontinued.

Imipramine has also been used to combat particularly the akinesia of Parkinson's disease, with some success in the under 50 age group (Rossi, 1965).

Anticholinergics are not used alone nowadays, and the potentiation of the dopamine system must be achieved in other ways. For instance, replacement of missing dopamine by administration of one of its precursors that readily passes the blood-brain barrier (levodopa), inhibition of the breakdown and reuptake of dopamine (amantadine), inhibition of dopamine breakdown by a monoamine oxidase inhibitor (deprenyl), and direct stimulation of dopamine receptors by dopamine agonists (bromocriptine).

Amantadine (Symmetrel) has some effect on some people. Unfortunately, like many of the Parkinson drugs, the effects may wear off after several months. It has two unusual side effects - livido reticularis, a purplish mottling of the skin of the legs and forearms, and edema, the swelling of the feet and ankles due to the accumulation of water in the soft tissues. However, many patients feel that the benefit they gain from the drug outweighs its problems, and it is still prescribed, if somewhat infrequently.

Bromocriptine (Parlodel), a direct-acting dopamine agonist used as an adjunct to levodopa, helps deal with some of the major problems associated with the latter. It allows the levodopa to be administered in lower doses than when administered alone, with

corresponding lower rates of the adverse reactions normally found - dystonia, dyskinesias, end-of-dose deterioration, and the "on-off" phenomenon (Stern & Lees, 1982). A number of researchers (e.g. Olanow, Alberts, Stajich, & Burch, 1987; Rinne, 1987; Riopelle, Gawel, Libman, King, McLean, Paulseth, Raphy, & Bouchard, 1987; Morris, Hely, Genge, O'Sullivan, Williamson, Rail, & Broe, 1987) have found that there is a reduced incidence of adverse reaction when therapy is initiated with bromocriptine rather than levodopa. Morris et al. (1987) report that the drug offers comparable efficiency to levodopa for at least the first six months of therapy. This is important, as levodopa is best avoided for as long as possible to escape the larger and larger doses that become necessary, with their eventually disabling side effects. A synthetic analogue of the alkaloid agent ergotamine, bromocriptine was found in laboratory experiments to imitate the action of dopamine. Unfortunately, though, it does produce some of the same side effects as levodopa, and may be even worse in producing confusion (Teychenne, Calne, Leigh, Greenacre, Reid, & Petrie, 1975). Like so many of the Parkinson drugs, at first hailed as miracle drugs, it is now relegated to its proper place of helping some, for a while at least, and being a complete failure with other patients.

Levodopa, the best known of all the Parkinson's drugs, is still the most effective substance currently available for the treatment of Parkinson's disease.

The first studies with levodopa were carried out in Montreal in

the early 1960s, but world supplies initially were very low, and only small doses for short periods could be given. Nevertheless, the effects in some patients were startling. In 1967, Cotzias (cited in Kety, 1979) gave larger amounts to his patients, and the true potential of the drug was realised.

Levodopa (L-3,4-dihydroxyphenylalanine) is a chemical substance occurring in nature in both animals and plants. It is an amino acid found in the plant kingdom in many legumes, and in the animal world where it plays the role of an intermediate substance in the metabolism of adrenalin. The adrenal gland makes adrenaline in a series of chemical reactions that begin with the amino acid tyrosine, eaten daily in our protein. Most of the tyrosine is used to build new protein, but a small proportion is taken up from the circulation by the cells of the adrenal gland. Here it is quickly converted by a single molecular arrangement into levodopa, which is immediately changed to dopamine (Stryer, 1988). (The importance of the production of dopamine by the adrenal glands will be seen in a later section on brain tissue transplants.) In turn, this dopamine is converted into noradrenaline and then to adrenaline. The same sequence of reactions occurs in the substantia nigra of the brain, but here the process stops after the production of dopamine (Wade, 1978).

The step from tyrosine to levodopa in the adrenal gland is termed "rate-limiting", in that it is strictly controlled. That is, feeding a patient large amounts of tyrosine does not result in the formation of large amounts of dopamine. However, the step

from levodopa to dopamine is not controlled in this way, so it is possible to increase the amount of dopamine by introducing large amounts of levodopa. This is the principle by which the administration of levodopa to Parkinson's patients works. Levodopa taken by mouth is absorbed by the upper small intestine and carried round the body. Ultimately about one percent reaches the brain. The process takes several hours, with the peak value approximately two to three hours after a dose is taken by mouth. What is in the stomach at the time of taking the drug is most important, as is the time of day. Solid food delays absorption, as does an acid stomach. It is now well known that a low protein diet taken during the day will allow lower doses of levodopa to work effectively (Kurlan, 1987), partly due to ease of absorption, and partly due to less competition between the levodopa and diet-derived amino acids for transport across the blood brain barrier.

The newly formed dopamine is indistinguishable from that dopamine which has been formed in the normal manner, thus replenishing brain stores, and diminishing the symptoms of Parkinson's disease. Unfortunately, levodopa treatment is not a cure; it merely adds to the supply of dopamine available in the striatum.

Dopamine replacement therapy does not always work, and when it does, there are many side effects. As well, even if it does work initially, after a few years, the benefit may have worn off, and the patient may be left in very poor shape.

However, when levodopa is first administered improvement is often impressive. For around the first three years, the patient may (almost) be able to forget the presence of Parkinson's disease. But gradually increasing disability is accompanied by side effects related to long term therapy, side effects which will strike the majority of patients within five years of the commencement of the levodopa regime (Schindler, 1986).

The problems created by side effects fall into five main areas - dyskinesia, daily fluctuations in the level of function, dementia and drug-induced confusion, progressive drug failure and postural defects (Grimes, 1986).

It has been judged that eventually 80% of patients on long-term levodopa therapy develop dyskinesias (involuntary movements). They may be twitches, jerks, nods, gestures, twisting or writhing movements, restlessness, or painful dystonic cramping movements. They may be severe enough to be tiring and may cause clumsiness and falls. Most common one to two hours after a dose, they signify an excess of the drug, and are the single, most common dose-limiting factor.

There are three types of fluctuation in the level of function; end-of-dose deterioration; freezing episodes; and the on-off phenomenon.

After around five years of levodopa therapy, at least 60% of patients report a dose-related "wearing off" effect (Grimes,

1986), at which stage a single dose may relieve Parkinsonism for only two or three hours. After this there may be a sudden return of bradykinesia or tremor, or in others the complete loss of the ability to walk. Vaughan (1986) vividly tells of his ability to go for runs at certain times of the day, followed by total dependence at others. Relief comes only with the next dose of levodopa, and even then the "good" phase of the day's treatment may be marred by the levodopa-induced dyskinesia. The problem becomes worse over time as the "bad" patches become increasingly more severe. Patients can attempt to control at least what they achieve during these phases by taking their medications so that the "good" times coincide with the things they want or need to do. It has been suggested by Lesser, Fahn, Snider, Cote, Isgreen, and Barrett (1979) that the effect may be caused by levodopa-induced cerebral changes that are cumulative over time. There is a tendency for the phenomenon to be more severe in patients who were younger when they began levodopa therapy.

Freezing episodes, sudden spells of immobility lasting a few seconds to a minute, may occur when movement is initiated, or may arrest ongoing movement. Associated with end-of-dose deterioration, this phenomenon causes frequent falls, for example when freezing occurs as a patient is trying to change direction during walking.

The "on-off" phenomenon, the most severe type of fluctuation and also correlated with the cumulative dose of levodopa (Calne, Kebabian, Silbergeld, & Evarts, 1979), affects 10% of patients

on long term levodopa therapy. Unpredictable swings from mobility to extreme bradykinesia, with no apparent relationship to levodopa intake can cause havoc in the patient's life. The mobile phase is normally accompanied by paroxysmal dyskinesias, wild ballistic limb movements.

The third set of problems caused by levodopa is dementia and drug-induced confusion. Dementia will be dealt with in depth in a later section, but it is important to realise that drug-induced confusion is a major treatment-limiting factor, as although mobility can be maintained, the drugs must sometimes be withdrawn because the confusion has made management so difficult.

Progressive drug failure and postural defects demonstrate how the pathological process of Parkinson's disease continues during treatment. Increasing basal ganglia pathology displays itself in unresponsiveness to drugs and in postural defects and falls. Hip fractures become common at this stage.

Figure 5 illustrates the progressive response of Parkinson's patients to levodopa. While 85% show an initial big improvement, two thirds of these deteriorate after three years. For 15% there is no relief at all.

Although deprenyl (selegeline hydrochloride) has been around for some decades, it is only recently that it has made a reappearance on the Parkinson's scene and is being hailed by a few people as the latest "wonder drug".

Synthesised first in Hungary in the 1960s, it belongs to the class of drugs called monoamine oxidase inhibitors. Monoamine oxidase is an enzyme present in many parts of the body that destroys excessive amounts of the monoamines, including dopamine. By blocking this enzyme, more dopamine is left in the system. Deprenyl is extraordinary in that it blocks **only** the enzyme that destroys dopamine, allowing the normal degradation of other monoamines to continue. Although when given alone, deprenyl has only slight effects on Parkinsonian symptoms, given with levodopa it seems to increase the duration of benefit, due to the slower breakdown of levodopa (McGoan, 1990).

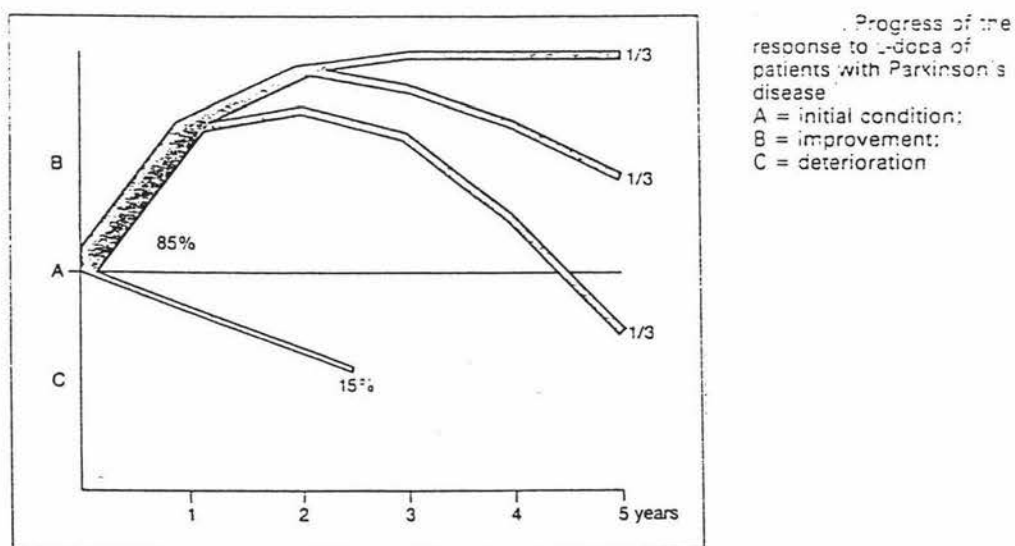


Figure 5: Decreasing response to levodopa over five years (Schindler, 1986).

Most recently, it has been found that putting patients on to deprenyl early has practically doubled the amount of time they were able to stay free of the need to take levodopa (Cotton, 1990). That is, it seems to slow down the progression of the

disease.

Other drugs are used in the treatment of Parkinson's disease, though most are less well known. Imipramine (normally used as an antidepressant) was found to be useful in patients under the age of 50, with short histories of the disease, and less incapacitation (Strang, 1965). Ro 4-4602, an inhibitor of peripheral dopa-decarboxylase, was first described in 1963 by Pletscher and Gay (cited in Barbeau, 1970), and has since been used with some success. For example, Barbeau (1970) found less of the peripheral side effects that other drugs produce, particularly less nausea. More recently a new drug, ropinirole, appears to act directly by stimulating the post-synaptic dopamine receptors in the brain (Boothman & Spokes, 1990). It is hoped that this drug may even help those who have lost a significant number of dopaminergic neurons, that is, the advanced patients. While most researchers are using it in conjunction with levodopa, Vidailhet, Bonnet, Belal, Dubois, Marle, and Agid (1990) are studying it for use as a monotherapy. Testing for many new drugs continues on a world wide scale.

Recently, surgery has reappeared on the scene of Parkinson's disease treatments. Most research into the surgical control of Parkinson's disease has of necessity been performed on animals. For example, Bergman, Wichmann, and DeLong (1990) attempted reversal by lesions of the subthalamic nucleus in monkeys. Surgical treatment of Parkinson's disease however, has been used for many years, although numbers dropped greatly with the advent

of levodopa. The operation reduces tremor and rigidity, but unfortunately only on one side of the body at a time, so the operation must normally be done twice. The second is often not as successful as the first. Nevertheless, in younger patients with tremor mainly in one side, the operation is still occasionally performed. Fears were expressed initially that such a drastic "brain" operation might cause psychological or behavioural changes. However, research by Asso, Crown, Russell, and Logue (1969) contraindicates this.

Today the surgery emphasis is on tissue transplant for producing extra dopamine in the brain, either using adrenal cells, or the controversial fetal ventral mesencephalon tissue. While results from the former at first appeared spectacular, by 1988 it was commented that the improvements only occurred in young patients, and were only 10% to 15%, not the 50% originally cited (Nausieda, 1988, cited in Sack, 1988). It seems that while improvement may occur at first, it is temporary, and may even leave the patient worse than before the surgery.

The human fetal tissue transplants may be more successful. Previously, the controversy surrounding the use of aborted fetuses had overridden any further research, but the Clinton administration has opened the way once again. In late 1988 a 52 year old man with a 20 year history of Parkinson's disease received the first American brain human fetal tissue cells (Sack, 1989). At the time of writing the man was still improving, able to walk 50% faster, and take less levodopa. However, the Bush

administration has placed a ban on this work, and federal funds cannot be used for research. The medical profession is still attempting to overthrow this ruling, which it claims has slowed research not only on Parkinson's disease, but other disorders as well (Hilts, 1991). Nevertheless, whatever the outcome, it will probably be a long time before New Zealanders are able to benefit from this kind of operation.

Treatment for Parkinson's disease ranges from drugs of various kinds to surgery, but while advances continue to be made, there is still no cure. It is therefore not surprising that psychological disturbance in patients is common.

Psychological effects of the disorder

Machover (1957, p.333) stated *"Illness, particularly chronic illness which alters structure, distorts or limits function, must produce corresponding changes in self-concept. Old ways of perceiving and behaving become inappropriate, as new ways gain relevance to the expressive requirements of the altered condition and the altered self-concept."*

A large number of psychological and social impairments are associated with Parkinson's disease, among them depression, loss of self-confidence, anxiety, apathy, irritability, agitation, resignation, feelings of helplessness, social isolation, and hallucinations (Dakof & Mendelsohn, 1986). Whether these are a reaction to the debilitating illness, or a further manifestation

of the basal ganglia degeneration is debatable. The original view was that it was a reaction, depression being the most common functional psychiatric disorder amongst the elderly (Mintz, Steuer, & Jarvik, 1981). Mintz et al. found that psychotherapy with these patients was, in fact, beneficial. Nevertheless, researchers today consider it to be a part of the biological effects of the disorder (e.g. Brown & Wilson, 1972; Mayeux, Stern, Cote, & Williams, 1984; Hoehn, Crowley, & Rutledge, 1976; Yudofsky, 1979; Schultz, 1984).

Some researchers have used electroconvulsive therapy (ECT) successfully to alleviate the depression (e.g. Asnis, 1977) indicating a biological basis, while others have compared effects of medication on both the depression and the Parkinsonian symptoms (e.g. Jouvent, Abensour, Bonnet, Widlocher, Agid, & Lhermitte, 1983). Jouvent et al. conclude that central dopaminergic deficiency may play a role in the incidence of depression in Parkinson patients.

However, other groups consider that depression in Parkinson's disease is of both reactive and endogenous origin. For example, Andersen, Aabro, Gulmann, Hjelmsted, and Pedersen (1980) found that various tricyclics (antidepressants) had an effect on the neurological as well as the depressive symptoms in patients with Parkinson's disease.

Schiffer, Kurlan, Rubin, and Boer (1988) have made further observations regarding depression in a number of their patients.

Following up on the research by Mayeux et al. (1984) who found that affective disorder is not consistently related to severity of motor disturbance, or to duration of neurologic disease, they found that there were several atypical features of panic and anxiety episodes among depressed Parkinson's patients. They pointed out that such episodes were not observed among patients with multiple sclerosis, who experience a risk for affective disturbance during the course of the disease in the range of 40% to 60% (Schiffer, 1987). They hypothesised, therefore, that depressive episodes in Parkinson's disease may be qualitatively different from depressive episodes in multiple sclerosis.

The results of a comparative study confirmed the hypothesis (Schiffer et al., 1988). They suggest that the relatively late onset of panic and anxiety among the patients with Parkinson's disease implies a pathophysiologic relation between the neurologic disease or its treatment with dopamine agonists, and the psychiatric symptoms. Three patients consistently experienced panic attacks during off periods, suggesting a possible relationship between panic and anxiety and falling levels of central nervous system (CNS) dopamine.

The relationship between levodopa and depression must be considered. Goodwin (1971) reviewed studies of the psychiatric side effects of the drug, and found that confusion and delirium are the most common, occurring in 4.4% of patients taking the drug, with depression not far behind (4.2% of patients). Overactivity, restlessness and agitation were found in 3.6%,

psychosis, delusions and paranoia in 3.6%, hypomania in 1.5%, and hypersexual behaviour in 0.9%. Thus although the majority of patients actually experience an improvement in mood while on levodopa therapy (Damasio, Antunes, & Macedo, 1970; Celesia & Wanamaker, 1972), there are still many whose problems are aggravated. Damasio, Antunes, and Macedo (1971) considered an antidepressant action of levodopa most improbable, and felt that the improvement was in patients with reactive depression, attributing it to neurological improvement.

So although no definite conclusions have been reached, it would appear that depression is in fact part and parcel of Parkinson's disease itself, a further result of neuronal impairment.

Some very specific impairments of cognitive functioning in otherwise normal Parkinson patients suggest basal ganglia impairment. Wilson, Kasniak, and Fox (1980, in Lezak, 1983) found slowed scanning on a visual recognition task, Bowen (1976, cited in Lezak, 1983) found diminished conceptual flexibility, and several researchers found slowing on motor tasks that they felt might reflect both bradykinesia and a central defect of motor programming (e.g. Bowen, 1976; Matthews & Haaland, 1979, cited in Lezak, 1983). In a further study Parkinson patients also performed significantly less well than their spouses (the control group) and showed significant deficits on a number of tests that are sensitive to frontal-lobe damage (Kolb & Whishaw, 1985).

Irritability, suspiciousness and egocentricity also appear often

enough to suggest that they may be characteristic of the disorder (Lishman, 1978). However, data on memory are contradictory. Bowen (1976, cited in Lezak, 1983) and Pirozzolo, Hansch, Mortimer, Webster, and Kuskowski (1982, cited in Kolb & Whishaw, 1985) both describe short-term memory deficits, while a group studied by Gainotti, Cianchetti, and Tiacchi (1972, cited in Kolb & Whishaw, 1985) performed slightly above average. Other discrepancies in the Gainotti et al. findings, however, suggest that they were a particularly well preserved group (Kolb & Whishaw, 1985).

Doctors have tended to downplay the incidence of dementia found in Parkinson's disease patients. But over the last 20 years or so it has become increasingly obvious that there is a considerably higher rate (ten times, according to Lieberman et al., 1978) of dementia among Parkinson's patients than among others of the same age in the population.

It would appear that the dementia in Parkinson's patients may be related to a deficit of acetylcholine in the brain (Agid, 1985). This hypothesis has been given indirect support by the finding that Parkinson's patients have a deficiency of acetylcholine in the frontal cortex similar to that found in Alzheimer's patients. Moreover, in animal studies, specific lesions of the cerebral cholinergic system are followed by disturbances of memory, behaviour and learning ability.

Figures quoted for the prevalence of dementia in Parkinson's patients vary widely. Lieberman et al. (1978) had a 32% rate,

while other estimates range from as low as 14.2% to a high of 68% (Dakof & Mendelsohn, 1986). The certainty is that the likelihood of dementia increases as the disease progresses. Figure 6 shows the incidence of dementia in Parkinsonian patients in relation to the stage of the disease.

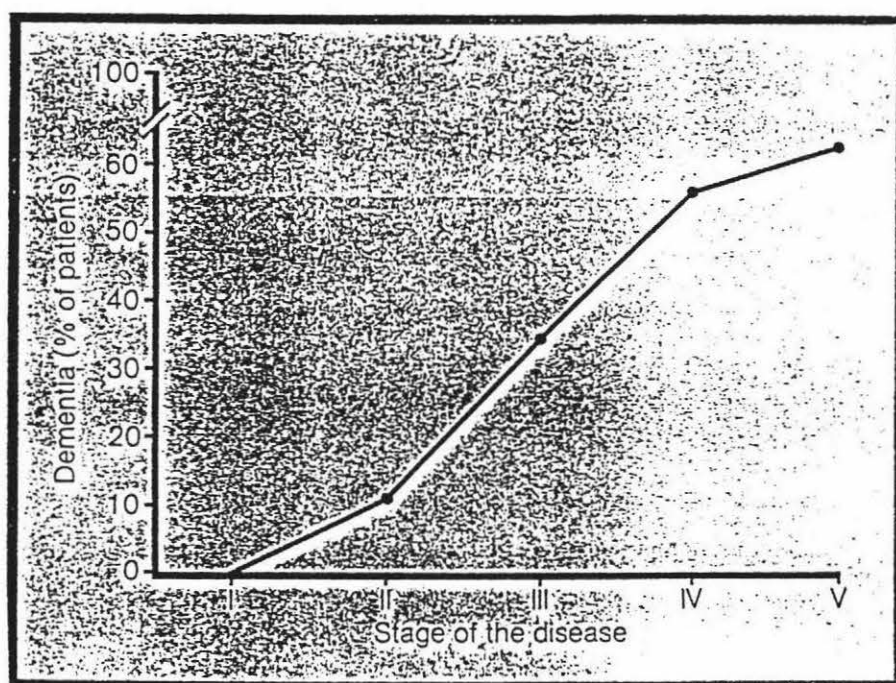


Figure 6: The incidence of dementia in relation to the stage of Parkinson's disease (Agid, 1985).

Hoehn and Yahr (1967) have divided Parkinson's disease into five stages which are used widely by doctors and researchers alike. At stage I there is unilateral involvement only, usually with minimal or no functional impairment. At stage II, there is bilateral or midline involvement, without impairment of balance. At stage III, there is unsteadiness on turning, or when standing with feet together or eyes closed. Functionally the patient will be somewhat restricted in activities, but will be physically capable of leading an independent life, and disability is mild to moderate. At stage IV, the disease has fully developed and has become severely disabling. The patient is still able to walk and stand unassisted, but is markedly incapacitated. By stage V the patient is confined to bed or wheelchair unless aided. At this stage dementia may be present in more than 60% of patients.

Lieberman et al. (1978) found that the demented patients were in the main older than the non-demented patients, had developed Parkinson's disease later, and had had the disease for a shorter duration. There was no difference in the incidence of dementia among the patients treated with levodopa and those who were not, an interesting finding. Non-demented patients showed less regression during treatment, however, but involuntary movements and on-off phenomena were more prominent in the non-demented patients.

Nonetheless, Danielczyk (1983) stated that permanent dementia is not characteristic of patients with typical idiopathic Parkinson's disease. Even when demented, their mental ability

tends to be relatively good in comparison to those with other types of dementia - primary degenerative senile dementia, or multiple infarction dementia.

The symptoms outlined above, the treatments that can help only to a certain extent, and the degree of incapacity that Parkinson's disease can result in mean that the lives of sufferers, and of their families, will be severely affected by the disease.

Parkinson's disease is generally a long-term chronic illness with many attendant psychological and social problems. As in any chronic illness, the whole way of life must be adapted in order to survive, albeit with less quality of life than before the illness.

Chronic Illness

Chronic illness is the major health problem in Western countries, where degenerative diseases are the primary cause of mortality and morbidity (Hardiker & Tod, 1982). People are living longer due to improvements in public health and living standards, along with the introduction of antibiotics. Average life expectancy has increased, and although chronic illness affects people in all age and socio-economic groups, older people are much more likely to be affected.

Because of the expectation that older people are starting to

disengage from life, their problems are often seen as less distressing than a chronic illness in a younger person. Certainly better mental health scores were found in the older groups of patients studied, where various age groups each with a particular chronic disease were tested (e.g. cancer, diabetes, renal disease, arthritis, and dermatologic disorders) (Cassileth, Lusk, Strouse, Miller, Brown, Cross, & Tenaglia, 1984). Cassileth et al. found that psychological adaptation among patients with chronic illness was mostly very effective, but that the older people did indeed have less expectations than the younger ones, and a perspective that in fact aided adaptation.

Nevertheless, it must be remembered that firstly, Parkinson's patients may not necessarily be elderly, and secondly, that even if they are, they are still suffering not only the physical pain of the disorder, but the loss of self esteem that comes as their former self images "crumble away without simultaneous development of equally valued new ones" (Charmaz, 1981, p. 169).

According to Charmaz (1981) the chronically ill person suffers from leading a restricted life, experiencing social isolation, being discredited, and being a burden to others. Additionally the patient has lost many roles in life. According to Parsons (1958, cited in English, 1974) illness or disability disrupts established role patterns and leads to a reorganisation of roles. Unfortunately for ill people, this reorganisation may not cast them in a role they wish to be in.

How a person deals with these problems will depend largely on coping strategies learned in the past, the information a person has relating to the disability, attitudes towards the disability (resulting from prior experience with it), and stereotypes and attitudes formed over the person's lifetime. Lastly, the individual's view of the purpose of his or her body, and the relationship this view has with the type and extent of disability will affect his or her perception of the illness (Cull, 1972).

Felton and Revenson (1984) studied coping strategies, and found that the strategy of information seeking was strongly linked to reduced negative affect. Their results also suggested that it was the information seeking that reduces the negative affect, not reduced negative affect that prompts information seeking. (This is most relevant when examining the function of the Parkinsonism Society.)

Parkinson's disease is a chronic disabling illness, with all the problems of other chronic illnesses, plus a few peculiar to the disease itself. For example, most symptoms involve motor behaviour and coordination often resulting in potential embarrassment for the patient in social situations. Thus the disease has important social implications.

Social implications of Parkinson's disease

The symptoms of Parkinson's disease appear slowly. Often the patient will have spent some months trying to deny these

symptoms, or trying to compensate for them before diagnosis is made. The famous photographer, Margaret Bourke-White, describes how she covered up for the imbalance caused by the initial stiffness in her leg:

"I was highly embarrassed by these staggers and thought up little concealing devices such as dropping my gloves and retrieving them; with the smallest delaying action, I could walk." (Bourke-White, 1963, cited in Esibill, 1983, p. 121).

These physical signs frequently worsen when the person is under stress, or even when the social situation appears to be anything but stressful. Essex (1983) relates how one patient told him that if he and his wife stopped to chat with a friend in the street, after a short time he would often have a feeling of panic, and feel that he must get home as soon as possible, upsetting for everyone. A consequence of these sorts of reactions is that patients may be judged bored or depressed because they lack facial expression, are highly nervous because of their tremor, and uncomfortable in social situations because of their slow verbal responses. As they sense others' discomfort with them, they begin to withdraw from social situations, suffer decreased self esteem, and become more and more dependent on family members for support.

The on/off phenomenon is confusing to outsiders to say the least. Todes (1983) states:

"There can be no other condition in which the body can be so rapidly and completely transformed as if the gods were breathing fire into it. The contrast when off, and the feebleness of mind and body, is a perpetual reminder of one's decline" (p. 978).

Todes, a psychotherapist and a Parkinson's sufferer, points out that he had to be "on" to write, and that after 12 years of the illness, there are normally only about three to four "good" hours in the day. He points out that on/off symptoms play havoc with the predictability of life, eroding continuity and confidence. Todes was just 39 when he was diagnosed.

Singer (1974) sees Parkinson's disease as resulting in premature social aging, in the sense that activity levels of Parkinson's patients correspond to those of persons chronologically much older. Singer found that in all current roles Parkinson's patients showed the effects of the illness. The patients were much less likely to be working, participating in household management, or to be enjoying a circle of close friends than other people of comparable age.

In the case of older people, the shrinking circle of friends may be due partly to the deaths of many, but for younger patients, their withdrawal from others, and the withdrawal of others from them, is more likely to be the main factor.

The effect of these factors is that Parkinson's patients are more likely than others to be isolated from interpersonal contacts.

Parkinson's patients have been found to spend a much greater proportion of their day in "napping and idleness" (Singer, 1973, p. 251), and watch more television than other persons of comparable age.

Singer (1973) also found participation in social activities is low, with the proportion of those reporting no organisational membership actually higher in the younger age groups. Forty five percent of those under 65, compared with 36% of those 65 and over, belonged to no church, social, or labour group at all. Consequently, Parkinson's patients were more likely than others of comparable age to experience loneliness and boredom (Singer, 1974), with the differences between patients and others again being greatest for the youngest group, declining steadily with age.

What happens to the self-concept of the Parkinson's patient? MacCarthy and Brown (1989) demonstrated that self-esteem in Parkinson's patients did not necessarily reflect levels of impairment or disability. Instead, self-esteem and coping behaviour helped to explain individuals' ability to remain cheerful and to adapt to changes imposed by their illness, independent of their physical state. But self esteem cannot help but be buffeted by this attack on self-integrity. Well people predicate their life on the notion of an orderly, predictable and inherently stable world, a situation largely unknown to the Parkinson's patient.

"Plans are made in the reasonably confident expectation of their materializing. This is essentially a survival device, protecting us from experiencing the world as intolerably anarchic" (Pinder, 1988, p.69).

But the person with Parkinson's disease cannot make plans with any confidence of their materializing. Predictability cannot be assumed, because there is no guarantee that the effects of the disease will remain the same, or that the effects of the drugs taken to combat the disease will remain the same.

Being discredited is a powerful attack on the self image. Discrediting definitions of self can arise from interactions with others, or develop out of the un-met expectations of the ill person (Charmaz, 1981). They can occur during public mortification experienced by the patient. The shuffling gait of Parkinson's patients, their tendency to spill and drop things, to fall, to drool - the list is endless. An embarrassing public episode may send the patient into hibernation for months - or forever.

Lohr, Lohr, Wasli, Hilliard, Larson, Vardiman, Wade, and Jeste (1987) discovered that 89% of the patients with Parkinson's disease they studied were aware of their movement disorders, and that this awareness correlated with depression scores. No one wants to appear "strange" in public, and one result would seem to be depression, perhaps exacerbated by lack of contact with other people, due to the fear of appearing odd. An unhappy cycle

results.

When patients can no longer take for granted some valued attribute or function which they viewed as fundamental for a positive self-image, self-discreditation begins. It continues as it is realised that attempts to return to the normal world are failing, and a feeling of deep disappointment and grief for their lost self image emerges. As discrediting events recur, the patients see themselves as permanent failures, and as a burden to others. Eventually, they accept the discredited self.

Within the family, role reversal may occur, particularly if the patient is a man. Vaughan (1986) poignantly describes the efforts of his teenage daughter to feed him. The effects on the family of the younger patient will be greater, for example, on children whose father has suddenly become "too old" to play with them, may have become irritable, and unable or unwilling to attend functions and the like.

Essex (1983), a University lecturer in social work, must have developed the disease at an unusually young age, as he spoke of his earliest difficulties in the manipulation of a nappy pin, and his GP insisting that he was too young to have the disorder. He finds meeting new people difficult, and even phoning students a hurdle. Not knowing what causes a good and bad day, and hence being unable to develop a social or work calendar makes planning next to impossible, and although he still lectures, confidence has diminished, as his voice can dry up, breathing can become

difficult, and tremor can return in full force.

Sexual function will be affected for a number of reasons. Muscle rigidity and tremors can contribute to difficulties in actual performance of sexual activities, causing increased physical discomfort. As the disease progresses, the ill partner becomes progressively more dependent on the well, and feelings of resentment and preoccupation with daily medical care may take up the energy of both partners.

Levodopa can produce physiological changes in both males and females. Postmenopausal women may experience uterine bleeding and an increase in vaginal secretions, while males may experience an increase in ejaculatory volume and a thickening of the seminal fluid (Bianchine, Turkall, & Rinaldi, 1979, cited in Esibill, 1983).

In a study of Parkinson's disease patients and their partners Brown, Jahanshahi, Quinn, and Marsden (1990) found that all couples studied reported problems in the area of sexual activity. However, it was in the younger couples that the most dissatisfaction was reported. This could indicate either that older persons may have accepted the stereotype that sexual activity is not a necessary part of the life of the aged person, or perhaps that younger couples are more sexually active, therefore finding more opportunities for frustration. Older couples could, however, have adopted this attitude as a strategy to minimize the impact of the problem, so that it does not lead

to further dissatisfaction in their lives. The implications of the loss of a sexual aspect are high. Socially, a whole area of life has gone.

Work becomes a problem because of the unpredictability of whether or not one will be able to perform one's job. Because Parkinson's disease does affect mainly older people, its interference with work will be less than that of some other chronic diseases. However, Oxtoby (1982) found that 38% of her sample of 261 patients had finished work because of their Parkinson's disease. This cannot fail to affect financial security, may invalidate long planned superannuation schemes, and could result in the usual problems of an early retirement - or early onset of the problems that go with any retirement at all. Work is important for a person's social contact with the world, and with loss of work a whole network of acquaintances may be lost.

Social life, too, becomes limited because of the unpredictability that goes with the disorder.

Pentland, Gray, Riddle, and Pitcairn (1988) examined the effects that reduced non-verbal communication had on other people. It was found that Parkinson's patients appeared more anxious, hostile, suspicious, depressed, bored and tense than controls, appearing to relate less well to the interviewer, and to be more introverted and passive. While the reduction in facial expression and spontaneous body movements accentuate this appearance of unfeeling coldness, if others in society do not recognise this,

their reactions will cause the sufferer to feel even more rejected, exacerbating symptoms, and leading to further isolation.

In Oxtoby's (1982) research, 15% of the sample advised that they had no outside activities whatsoever. However, a comparison with a sample of elderly persons without Parkinson's would be needed to evaluate the validity of this finding. Nevertheless, many patients did state that before their illness they spent their time mainly with others. Parkinson's disease cannot fail to make communication with the outside world more difficult.

Patients who develop Parkinson's disease may lose their jobs, many or most of their life roles, and certainly their sense of predictability. Communication, verbal and physical, becomes difficult. Parkinson's patients may withdraw into themselves, and hope that the world will go away. Others may look for patients like themselves, aware that if they have something in common with anyone else in this world, it will be with another person with Parkinson's disease. This is where the self-help group comes in.

Social Support - the self-help group

The problems faced by Parkinson's patients are many. Their coping strategies will affect the way they adapt to their illness, but much of the support gained will also come from outside. One area from which many people receive support and encouragement is the self-help group. The literature on self-helps groups covers

several decades. An early article by Katz (1963) relates that in the United States there were at that time at least 40 national voluntary organisations. An article from 1989 (Jacobs & Goodman) predicts a 6.78 million membership for 1990, doubtless covering rather more than 40 organisations!

In Britain, a concentrated effort has been made to reduce institutionalized care for the elderly. Attempts have been made to substitute care at home since the early 1960s (Katz, 1965), with the subsequent increase in day care programs for the elderly, which often function as quasi-family for the old, lonely person. Unfortunately New Zealand is lagging behind in this area, but these types of activities alone could counteract some of the inactivity of the Parkinson's patient. Thus, there is an important place in New Zealand for the self-help group.

Katz (1970) suggests eight essential features that characterize the self-help group:

1. Self-help organisations share the properties of small groups - the participants belong because they can achieve certain satisfactions from the organisation which would not be so readily possible for them through any other device.
2. Self-help groups are problem centred, organised with reference to a specific problem or problems.

3. Members of such groups tend to be peers.
4. Self-help groups hold common goals.
5. Action is group action.
6. Helping others is an expressed norm of the group.
7. The role of the "professional" is not clear-cut, if it exists at all, in the self-help group.
8. Power and leadership in self-help groups is on a peer or horizontal basis.

Coyte (1990) lists a number of reasons for the growth of self-help groups. Several of them are quite relevant to the Parkinson's groups:

1. Erosion of the traditional family format has reduced the available supply of traditional social support. With the heightened geographical movement of populations, many old people are indeed left without the family support that they could have once enjoyed. Even the younger patient is likely to have his family spread over many miles, or even countries.
2. Dramatic advances in medical science have increased the proportion of people who live to old age, who are struggling with chronic medical problems, and with the psychological

concomitants.

3. While New Zealand was once a leading country in regard to health care, public confidence in the major institutions of the country, including the medical establishment, has been seriously weakened. Also various civil and consumer rights movements have stimulated an increased sense of personal entitlement and empowerment. One result is that people want a measure of personal control over their own health. Many members in the Parkinson's groups state that disillusionment with the medical profession encouraged their joining. They are just not getting the satisfaction they expect.

4. Most countries suffer an unavailability of needed mental health services. The traditional mental health delivery system has failed adequately to address a wide range of psychological problems experienced by various minorities, lower income groups, and those coping with major disrupting diseases. These problems have been exacerbated by budget cuts.

5. An obsession with cost containment in all phases of health care delivery continues to stimulate the search by government, health care providers, and insurance companies (rather more relevant in the U.S.) for alternate treatment models and strategies for promoting wellness.

6. In recent years there has been a greater acceptance of social support and experientially gained knowledge as useful

commodities in maintaining health.

7. Many television programmes depict people coping with many problems - incest, spouse battering, cancer, Alzheimer's disease, abuse of the elderly. According to Coyte (1990), almost all of the scripts involve a successful self-help group as part of the plot!

Moreover, in small communities many helping activities occur that cannot be duplicated in a big city - by anyone! Patterson and Twente (1971) studied the helping activities of persons over 60 years of age in a rural Kansas county. A Parkinson's patient in a community of this sort would be part of a pattern of community help - and probably be helping someone else in turn. Our highly urbanised lifestyle of today renders the small self-help group essential where the traditional helping systems have, of necessity, broken down.

One further point in support of the self-help group is expressed by Barish (1971, cited in Killilea, 1976) when he suggests that

"...one of the major purposes of a self-help group is to counteract the isolation and alienation that result from being 'different', by creating a place where a member can belong. Most self-help groups emphasize that they provide a 'world within a world' where the 'deviant' is given a voice that can be heard and accepted as part of the collective. In this he has the security of finally being one of a majority and a movement, rather than

individual and alone" (p. 1165).

Essex's (1983) description of his feelings as a Parkinson's patient support Barish's:

"Who does one share such wearying thoughts with? I suppose for the most part they are not shared at all. I rarely tell anyone how I feel at that moment for a variety of reasons. I suppose I don't want to upset them, I don't feel that they really want to know, and in any case I may feel better in a little while, and, I try to be as normal and self-sufficient as possible.....I find that I can share some of these feelings with other members of the Parkinson's disease Society, and they can ask very direct questions, for example 'Do your legs ever feel like lead in the mornings?'. They do." (p. 171). Who else could one share worries of this kind with?

In coping also with stigma, it may be more encouraging to join others suffering the same stigma. Drooling, for example, a problem shared by more than 40% of sufferers according to Oxtoby (1982). The problem is shared, helping where:

" The sense of isolation created by social or medical problems often makes a difficult situation unbearable. Normal relationships with others are severed or impaired so that afflicted persons are denied help or encouragement when they need them most." (Ashley, 1975, cited in Robinson & Henry, 1977, p.90).

Only the words of the sufferers themselves can express what they gain from the support and company of others, and the feeling of no longer being alone. Therefore for the Parkinson's disease sufferer, with his or her own special set of symptoms, the existence of a group where each person is in the same position would appear to be a much needed lifeline.

The Parkinson's Disease Society

One hundred and fifty years after Parkinson published his essay, an advertisement appeared in *The Times* and other newspapers that read 'Parkinson's Disease: Those concerned are invited to send their views (not money) on need for a Society devoted to mutual help and promotion of research.' Within a couple of years, in 1969 (Kilmister, 1981), the Parkinson's Disease Society was formed in England, and in 1981 Jewell stated that there were 15,000 names on the mailing lists, and 50 branches throughout the country. But in 1981 there were believed to be more than 60,000 Parkinson's disease patients in the U.K.

Those who have become members feel that they have gained much from membership. One member wrote after receiving the Society's booklets:

"I found the booklets most interesting and very helpful. What a pity I did not have them sooner. Much sadness could have been saved..." (Jewell, 1981, p.215).

Kilmister (1981) has stated that Parkinsonians are often referred to as "tortoise people" with their odd, slow walk, inability to hurry, and the tendency to 'draw into their shells' if treated roughly. Kilmister believes that one of the jobs of the Society is to coax them out of their shells and restore their confidence.

In addition to sponsoring research, the Society aims to collect and disseminate information on Parkinson's disease, and to help patients and their relatives with problems arising from the disease.

A frequent criticism encountered by branch members is that general practitioners often do not appear to know much about Parkinson's disease or its treatment, and do not bother to find out (Essex, 1983). As many doctors may have only occasional contact with the disorder, this is to be understood, but is nevertheless devastating to a patient's morale when the doctor's apparent lack of understanding is obvious. The Society can fill this need by keeping up to date on treatment progress and research as well as offering the badly needed support.

Therefore, the question arises as to why a large number of Parkinson's patients do not join a Society, even when they have one in close proximity to where they live. If one is immobile and housebound, then a meeting two doors away is too far to go, and even reading a newsletter may be impossible. But what of those who are quite mobile and have transport? What causes them to prefer to stay independent? Are the factors involved generally

of a personal nature? Kaplan De-Nour and Czaczkes (1976) found that their dialysis patients' personalities greatly influenced their reactions and attitudes to their illness. Or are situational factors the cause of some people joining the Society, and others preferring to remain detached?

A summary:

The biological basis of Parkinson's disease, the epidemiology, the treatments, the psychological effects of the disorder, and what can be done to soften the effects of Parkinson's disease for patients and their families have all been discussed in depth. This has been done in order to present a full and complete picture of the plight of the Parkinson's sufferer. Parkinson's disease is a devastating, chronic and progressive disorder which affects sufferers and caregivers in all aspects of their lives. There is no let-up, and no prospect of improvement. Only a downhill spiral of degeneration, mention of which is usually avoided or sidestepped by well-meaning doctors, and often relations also. The importance of the issues in question cannot be realised without full understanding of the havoc caused by the illness.

The aims of this study:

The aims of this study were to learn just how much life change Parkinson's disease results in for a sufferer, and secondly, why the services offered by the Society are not taken up by almost

half of the Parkinson's patients. Members are positive about the gains made from their participation, yet a large proportion, despite the obvious major changes the disease has caused in their lives, decline the opportunity to join fellow sufferers, and to learn more about their disorder. What are the differences between these two groups? A comparison of activities, PAIS (Psychological Adjustment to Illness Scale) scores, and sufferers' feelings about membership were analyzed with these questions in mind.

There has been no record made of the number of people in New Zealand with Parkinson's disease. However, the 1990 population of the country was 3.4 million (MacMillan, 1990). On average 150 of every 100,000 people have Parkinson's disease (McGoon, 1990). Therefore there must be approximately 5,100 sufferers in New Zealand. Of these, more than 90% live at home with their families (Schwab & Doshay, 1986). At this stage, it would appear that little or no research has been done in New Zealand to investigate the impact of the disease on the patients or their families. It was the aim of this study to try to redress this imbalance in a number of ways:

- a) The way in which the Parkinson's patient adjusts to his or her illness was investigated. Adjustment was measured using the PAIS, which has been designed to measure adjustment in seven areas: health care orientation; vocational environment; domestic environment; sexual relationships; extended family relationships; social environment; and psychological distress (Derogatis & Derogatis, 1990). The

PAIS works on the principal that "the functional efficiencies of an individual's role behaviours (e.g. spouse, parent, professional) tend to be highly correlated with judgments concerning his or her levels of psychosocial adjustment" (Derogatis & Derogatis, 1990, p. 2). As Parkinson's disease undoubtedly affects patients' ability to carry out their role tasks, how this affects adjustment to illness is clearly of interest.

- b) The changes in the activities of the patients since their illness was investigated by measuring the amount of time spent on various activities - leisure, social, group, for example - before the onset of the illness, and now. The size of the differences was also investigated. It was expected that where the differences were greatest, adjustment to the illness would be most difficult to make.
- c) What situational and personal factors impact on membership in the Society? Members' impressions and feelings about the Society they belong to were investigated, as well as details regarding which activities of the Society are the most popular. Non-members were also asked for their opinions regarding the Society, in an attempt to find out why they feel membership is not for them.

Prior research (e.g. Singer, 1973, 1974; Esibill, 1983; Pinder, 1988) suggests massive social costs to sufferers, particularly those in the younger age group. But older people also have their plans foiled and their roles taken away from them prematurely. That Society membership can soften the impact is firmly believed

by members overseas (e.g. Essex, 1983; Kilmister, 1981). Within New Zealand, although no official data exist, it is this writer's experience (admittedly based on a somewhat limited sample) that members here express the same sentiments. But would the non-members benefit in the same way if they were convinced to join? Or are they inherently different people, who would receive no comfort from communication with others in the same position as themselves? It was the aim of this study to attempt to answer these questions, with the hope that the information obtained might bring some help to the more than 5,000 sufferers in New Zealand, via the Parkinson's Society.

METHOD

Recruitment of Subjects:

Subjects were recruited chiefly through the area's general practitioners, the area geriatrician, local support groups, and through word of mouth. All general practitioners in the Wanganui, Levin, and Palmerston North areas had earlier been contacted by mail requesting the number of Parkinson's patients that each had on his/her books. Those who did have Parkinson's patients were later contacted, again by mail, and a request made for them to ask their patients if they would be interested in participating in a study regarding the social implications of Parkinson's disease. The geriatrician requested information sheets for him to give to his patients, and these were dispatched. While most participants were recruited in this manner, a number whose doctors had declined to participate were obtained through personal appeals made at support group meetings by the investigator. Lastly a number were recruited through friends with Parkinson's, several actually ringing the investigator and asking if they could participate.

The 87 subjects ranged from 28 years of age to 92, with a mean of 69.4 years (S.D.= 10), and a mode of 70 years. Originally there were 89 subjects. However, one died shortly before his interview, and the other, unfortunately the only non-European subject, refused to answer his door at the arranged interview

time, having apparently had last minute qualms about answering the questions. Appointments were made by phone, during which conversation the study was explained and any questions answered. The night before each appointment a reminder call was made, and the subject given the opportunity to ask any further questions.

Before each interview commenced, subjects were reminded that their participation in the study was completely voluntary, that they were free to withdraw at any time, and that if there was anything that they did not wish to discuss, then they should refuse to do so. They were again assured of the confidentiality of their replies, and the system for this described - that is, that they would be identified only by a numeric code, shown to each subject on both the questionnaire forms, and that the list of associated names would be held only by the investigator in a safe place. They were also assured that the need for any identification at all was to ensure that the data from the two separate questionnaires would be associated correctly, and that even the investigator was unlikely to associate numbers with data to any great degree (with the exception of the gentleman who insisted on being numbered as 007!)

Description of subjects:

Of the 87 subjects, 55 were males, 32 females. Sixty were married, 16 widowed, 8 single, and 3 divorced. On the whole, those in their own homes appeared comfortably off, although no questions were asked regarding income. Subjects were asked only

whether or not the illness had affected their financial situation. Of the 87, nine had been agricultural workers of one sort or another, three had held managerial positions, 42 had been white collar or professional workers and 23 blue collar workers, and 10 had always been housewives. Currently 2 were still working for more than 30 hours per week, 2 part time (between 2 and 20 hours), 8 were permanently on disability payments, 69 were retired, and 6 classified themselves still as housewives. Of those that were retired, 34 had finished work because of the Parkinson's disease. Fifty-five of the patients had at least one other illness or disorder in addition to Parkinson's disease, several as many as four or five further disorders. Of the 87, 84 were on medication for Parkinson's disease, often three or four different types.

Sixty percent of the males, and 66% of the females were members of the Parkinson's disease support group in their area.

Fifty subjects lived in a city, either Wanganui or Palmerston North, 30 in a town, either Levin, Feilding, Ashurst, Taihape, Hunterville, Marton, Otaki, or Ohakune, and the remaining 7 in the country surrounding one of the prior areas.

Data collection:

Each participant was interviewed in his or her own home by the investigator. Although participants had been advised that the investigator could return later to complete interviews if the

subject became tired, all interviews were in fact completed in one sitting, lasting from one and a quarter hours to two hours. Longer sessions often occurred where subjects or their caregivers had themselves questions to ask about the disorder.

Where the subject had difficulty speaking, the spouse was invited to assist, and in several cases where writing had become impossible the spouse signed the consent form on the subject's behalf.

Two questionnaires were used for each subject. The first questionnaire (Appendix 2) sought information on demographics, the subject's health and handicap status, transport opportunities, leisure time activities, and membership or otherwise of the Parkinson's Society. The latter questions also examined those areas which Parkinson's patients find most important and helpful in the Society. Although the interview was highly structured, points were noted throughout on impressions received, special circumstances, and the like. The general outline of the questionnaire was based on that of Oxtoby (1982).

The second questionnaire (Appendix 3), the PAIS (Derogatis & Derogatis, 1990) is a semi-structured interview scale which has been designed to assess patients' psychological adjustment to their current medical illness (Derogatis, 1986). It examines seven areas in which adjustment is measured: Health Care Orientation; Vocational Environment; Domestic Environment; Sexual Relationships; Extended Family Relationships; Social Environment;

and Psychological Distress. While reliability for the scale has not previously been ascertained with Parkinson's patients, it has been ascertained for a number of other groups. For example, Hodgkin's disease yielded $r = 0.33$ to $r = 0.83$ on subtests, the 0.33 (the extended family subtest), being considerably lower than the next at 0.52, and the reliability over the total score equalling 0.83 (Morrow, Chiarello, & Derogatis, 1978). Breast cancer-produced reliability coefficients ranging from $r = 0.56$ (again the extended family subset) to $r = 0.86$, with reliability over the total PAIS score of 0.86. Renal dialysis coefficients ranged from $r = 0.63$ to $r = 0.81$ and cardiac patients $r = 0.47$ to $r = 0.85$. In the latter, the 0.47 was considerably lower than the next subtest coefficient of 0.62 (Derogatis & Derogatis, 1990).

In relation to validity, a number of investigators (e.g. Derogatis, Abeloff, & Melisaratos, 1979; Morrow et al., 1978) have found high correlations between the PAIS Total Adjustment Score and other scores of psychological distress. For example, with the GAIS (Global Adjustment to Illness scale), $r = 0.81$. And with the ABS (Affect Balance Scale), $r = .69$. Morrow et al. also found that the seven subtests were relatively independent from one another while still contributing to the total score, thus supporting the construct validity of the instrument. Regarding criterion validity, the different sections each correlated positively with other valid measures. For example, the health care orientation section correlated positively with questionnaire items assessing level of satisfaction with health care ($r = 0.27$,

$p < 0.05$), domestic environment scores correlated positively with an appraisal of how greatly the disease had affected family relationships ($r = 0.44$, $p < 0.001$), and the psychological distress subtest correlated significantly with both patients' self assessment, and observer ratings of anxiety and depression. (Patients' self-ratings were on the State-Trait Anxiety Inventory - $r = 0.51$, $p < 0.001$; observers on the Symptom Check List 90 Analogue Scale - $r = 0.47$, $p < 0.001$).

A slight weakness has been found by Morrow et al. (1978) in the extended family relationships subtest, where inter-rater reliability reached only a 0.33 coefficient of agreement, and was not statistically significant. However, Kaplan De-Nour (1982) found high agreement between haemodialysis patients' total scores of adjustment, and physicians' assessment of the patients' adjustment. Despite the question mark over the PAIS inter-rater reliability its mainly high reliability and validity ratings have seen it utilized in health studies relating to a wide range of illnesses.

Subjects were reminded again before this section of the interview that they must not feel compelled to answer the more personal questions if they felt uncomfortable. However, by this time rapport was excellent in most cases, and at no time were any problems encountered, with many of the more personal questions opening up avenues which the participants obviously were glad finally to be able to discuss.

At the end of the interview participants were given the opportunity to ask any questions they wished, about either the study or about Parkinson's disease itself. In a large number of cases this opportunity was taken gladly, indicating how deficient is much of the information available to people with this disorder, particularly to those who have chosen not to, or have been unable to, join a Parkinson's Society group. Subjects were advised that an abbreviated form of the results would be mailed to them when the report had been written up.

Analysis:

Analysis was carried out with one aim being to determine why some people join a Parkinson's Society, and why others do not. The differences between these two groups were looked for by comparing the descriptive differences between them, and the means of all measures - transport availability, leisure time activities, handicap, and the PAIS scores. Another aim was to investigate the differences in lifestyle before and after the illness, and again the members and non-members were compared in their leisure and social activities. It was realised, however, that even if differences were found between the Society members and non-members that these differences were not necessarily the reason for joining the Society *per se*, but could in fact be a result of membership.

RESULTS

The presentation of results is divided into three sections. In the first instance, characteristics of the sample are described, the sample being divided into members and non-members of the Parkinson's Society. The differences in time spent on particular activities before and since the onset of Parkinson's disease, both social and hobby, are next presented. Finally, the data relating what attracts members to the Parkinson's Society, and discourages non-members from joining, are examined. The results of the PAIS are presented, both in terms of members and non-members, as an integral part of these three sections.

Statistics have been determined using parametric measurements wherever possible, as is the norm in psychological research for the kind of data obtained in this investigation. However, results were also calculated using the less powerful non-parametric statistics, with almost identical results.

Characteristics of the sample

Age and Sex

At the extremes of the distribution, as seen in Table 1, were one male aged 28 years, and another aged 92. Mean age for males was 68.27, for females 71.34. It is interesting to note the apparent difference in the 70 to 79 age group, where 55% of men are non-

members, and only 27% of women, yet at the 80 plus age level, 27% of women are non-members, and only 9% of men. It should be noted, though, that numbers are very small for comparison. However, there was no significant difference between the sexes and membership of the Parkinson's Disease Society when collapsed over age categories, Chi Square (1, $N = 87$) = 0.27, $df = 1$, $p = 0.6$.

Also, an ANOVA showed that there was no significant difference between the age of members and non-members of the Parkinson's Society, $F (1, 86) = 1.29$, $p = 0.26$.

Table 1: Age and sex of sample, comparing members and non-members.

	Men		Women		Total	
	Mem.	Non.	Mem.	Non.	Mem.	Non
Under 60	6 (18)	1 (5)	1 (5)	1 (9)	7 (13)	2 (6)
60 - 69	9 (27)	7 (32)	6 (29)	4 (36)	15 (28)	11 (33)
70 - 79	15 (45)	12 (55)	11 (52)	3 (27)	26 (48)	15 (45)
80 and over	3 (9)	2 (9)	3 (14)	3 (27)	6 (11)	5 (15)
	33	22	21	11	54	33

Note. Figures in parentheses in tables are always percentages unless otherwise stated. Mem = members; Non = non-members.

Marital status and household composition

Table 2: Marital status and sex of sample, comparing members and non-members.

	Men		Women		Total	
	Mem.	Non.	Mem.	Non.	Mem.	Non.
Single	3 (9)	3 (14)	1 (5)	1 (9)	4 (7)	4 (12)
Married	26 (79)	17 (77)	12 (57)	5 (45)	38 (70)	22 (67)
Divorced/ separated	1 (3)	0 (0)	1 (5)	1 (9)	2 (4)	1 (3)
Widowed	3 (9)	2 (9)	7 (33)	4 (36)	10 (19)	6 (18)
	33	22	21	11	54	33

Table 2 demonstrates that 69% of the sample were married, 18% widowed, 9% single, and the remaining 3% either divorced or separated. (The greater likelihood of a woman becoming a widow is clearly illustrated here.) Separating members and non-members, 50% of single males are members, as are 50% of single females. Of the married men 60.5% are members, and 70.6% of married women. The sample size of divorced and separated persons is too small to be analyzed, but for the widowed, 60% of men are members, and 63.6% of women. These data clearly showed that marital status

(collapsed over sex) was not a determinant of membership, Chi Square (3, $N = 87$) = 0.56, $p = 0.9$.

Table 3: Household composition of subjects, comparing members and non-members.

	Men		Women		Total	
Living Arrangements	Mem.	Non.	Mem.	Non.	Mem.	Non.
Living alone	2 (6)	4 (18)	3 (14)	4 (36)	5 (9)	8 (24)
With spouse	22 (67)	15 (68)	11 (52)	3 (27)	33 (61)	18 (55)
With siblings	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)
With son/ daughter	0 (0)	0 (0)	1 (5)	1 (9)	1 (2)	1 (3)
Residential	5 (15)	2 (9)	4 (19)	2 (18)	9 (17)	4 (12)
Other	4 (12)	1 (5)	2 (9)	1 (9)	6 (11)	2 (6)
	33	22	21	11	54	33

Table 3 shows that in the present sample 59% of all subjects were living with their spouse. Comparing Tables 2 and 3 it can be seen that the illness has necessitated residential care for nine of the partners who are still married. Sixty-two point five percent of single people are society members (the sexes have been combined here, as subject numbers are low). For married people, 59.5% of men are members, and 78.6% of women. For those in residential care, 69.2% are members (once more, sexes have been combined).

Again, there was no significant difference between members and non-members, this time with regard to household composition, Chi Square (5, $N = 87$) = 4.4, $p = 0.38$.

Work status

Table 4: Current work status of sample

	No. subjects	Average age
Full time job > 30 hrs week	2 (2)	46
Part-time job	2 (2)	69
Permanently disabled	8 (9)	52
Retired	69 (79)	72
Unemployed	0 (0)	-
Housewife	6 (7)	69
	87	

Table 4 shows that in the older age group, subjects tend to see themselves as retired rather than disabled. However, those who see themselves as permanently disabled rather than retired average only 52 years, as against the 72 years of those who described themselves as retired. Just two of the subjects were still able to work full time at the time of writing, both of these in their forties but with the older participant (48 years) making plans to give up his business shortly. The younger participant (44 years) was a single farm worker who is still able

to find work with family and friends, but feels that in a different position, he would be unable to do so.

Table 4 has not been divided between member and non-membership as numbers become too small to be valid. However, both full time workers were members of the Society. Further analysis revealed no significant difference in membership status between the work status groups, Chi Square (5, $N = 87$) = 7.1, $p = 0.13$.

Table 5: Main occupation of participants, comparing members and non-members.

	Number of subjects	
	Mem.	Non.
Agricultural	4 (7)	5 (15)
Managerial	3 (6)	0 (0)
White collar/ professional	30 (55)	12 (37)
Blue collar	14 (26)	9 (27)
Housewife	3 (6)	7 (21)
	54	33

Forty-four percent of agricultural workers join the Parkinson's Society, 100% of managers (albeit based on a very small sample), 71.4% of white collar workers and professionals, 60.9% of blue collar workers, and only 30% of housewives. A Chi Square analysis revealed a close to significant difference between the occupation

groups in their membership or non-membership status, Chi Square (4, $N = 87$) = 8.97, $p = 0.06$. Much of this difference occurs as a result of most white collar workers (66%) and professionals (100%) belonging to the Society.

Table 6: Influence of Parkinson's disease on the decision to finish work for both members and non-members.

	Number	
	Mem.	Non.
Influenced stopping work	25 (46)	15 (45)
No influence	24 (44)	10 (30)
Still working	2 (4)	1 (3)
Housewife	3 (6)	7 (21)
	54	33

Sixty-two point five percent of those who were forced to finish work due to Parkinson's disease became Society members, whereas 70% of those whose Parkinson's had no influence on their decision to finish work joined the Society. There was no significant difference between the membership and non-membership groups as to whether or not Parkinson's disease had forced them to finish work, Chi Square (1, $N = 87$) = 0.54, $p = 0.46$. Scores on the PAIS showed means of 45.6 for those whose Parkinson's disease had influenced their decision to finish work, and 39.7 for those whose decision had not been influenced by the disorder, but this difference was not significant using a t -test. However, as

expected, there was a significant relationship between the number of years since finishing work and the PAIS score, $r(87) = .31$, $p < .01$. That is, the PAIS score, measuring adjustment to illness, increases as the length of time since finishing work increases, an increased score showing greater distress in relation to the illness.

Health and handicap

Table 7: Frequency of other types of illness in Parkinson's disease patients.

	Female	Male	Total
Arthritis	3	1	4
Coronary heart disease	1	3	4
Diabetes	0	1	1
Prostate problems	0	1	1
Hip replacement/joint (Orthopaedic)	3	7	10
Stroke	0	1	1
Multiple	11	15	26
Other	3	4	7
Not applicable (no other illnesses)	11	22	33
	32	55	87

Note: Multiple refers to more than one of the prior-mentioned illnesses

Table 7 shows other disorders that Parkinson's patients in the present sample suffered from. Only 38% did not suffer at least one other disorder, the most common being an orthopaedic problem.

The figure for prostate gland problems shows as relatively low. However, a number of the male subjects had had the prostate operation, and assured me that while this was no longer a disabling problem to them, it had been in the past. The one patient who still suffered from the problem had had an unsuccessful operation, and found the prostate symptoms as disabling, if not more so, than his Parkinson's symptoms.

There was no significant difference between the number of members suffering from other illnesses (64.89%) and non-members (60.6%), Chi Square (1, $N = 87$) = 0.19, $p = 0.69$.

Other disabilities

Because Parkinson's disease symptoms vary immensely not only from one patient to the next, but within the one patient on a day to day, or even hour to hour, basis, the disability section of the questionnaire - tremor, walking and speech - was scored for the worst times plus the best times, giving an overall disability score. The very wide variation in symptom magnitude within a subject made it impossible to develop a totally satisfactory assessment method. However, the subject's perceptions of the degree of disablement was of greatest interest for the present research. Great differences exist in what one patient finds

disabling compared to another, and how the patient perceives it decides how disabled that patient sees him- or herself.

Tremor

Tremor scores could range from 2 (where tremor is no problem even at the worst times of the day) to 18 (which would constitute an inability to do most things at even the best times due to bad tremor). The ability to complete tasks such as doing up or undoing buttons and fasteners, holding a cup, and writing were used to assess the degree of tremor.

Scores ranged from 2 to 18, with a mean of 9.49, S.D. = 3.86.

Table 8 shows the distribution of scores as a function of Parkinson's Society membership.

Table 8: Distribution of tremor scores for members and non-members. A score of less than 4 represents no disability, and of more than 12, severe disability

	Number of subjects	
	Mem.	Non.
Scores 1 - 4	6 (11)	2 (6)
Scores 5 - 8	22 (40)	7 (21)
Scores 9 - 12	18 (33)	12 (36)
Scores > 12	8 (15)	12 (36)
Total	54	33

It should be noted that the division of scores was made arbitrarily, merely by dividing them into ranges of four points over the first 12 points of the range. The remainder of the scores (13 - 18) were used to make up a single category because at this level disability is very severe. Table 8 shows that 96% of subjects suffer a moderate to severe (scores 5 to 8) perceived level of disability from their tremor.

There was a statistically significant difference in tremor between members (mean 8.65, S.D. 3.43) and non-members (mean 10.88, S.D. 4.18) of the Parkinson's Society, $F(1, 86) = 7.3$, $p = .005$. That is, tremor appeared less disabling for the members than the non-members.

A correlation between tremor severity and PAIS scores of $r(87) = .46$, $p < .001$ indicated that the more severe the tremor, the harder it tends to be to adjust to the illness.

Walking

Walking scores could range from 2 (no mobility problems at all) to 34 (mobility problems at not only the worst times, but at the best times as well). Walking was assessed by the distance that could be walked, help needed, negotiation of various household areas, and standing up from a sitting position (full details appear in Appendix 2). Scores ranged from 3 to 34, with a mean of 15.26, and a relatively large S.D. of 7.99.

Table 9 shows the distribution of walking disability scores for

both members and non-members. As with the tremor scores, the walking score divisions are arbitrary, dividing them into ranges of 8 points over the first 24 (2 was the minimum score possible) and keeping the last 10 scores as a single category due to the severity of handicap at this level. No significant difference was found between walking scores for members (mean 14.65, S.D. 7.39) and non-members (mean 16.27, S.D. 8.92) of the Society, $F(1, 86) = .85$, $p = 0.361$.

Table 9: Distribution of walking disability scores for both members and non-members. A low score means little or no disability ranging to severe disability at the higher scores.

	No. of subjects	
	Mem.	Non.
Score 2 - 8	12 (22)	7 (21)
Score 9 - 16	24 (44)	14 (42)
Score 17 - 24	12 (22)	4 (12)
Score 25 - 34	6 (11)	8 (24)
	54	33

As for tremor, there was a significant difference between the PAIS scores of subjects with different walking abilities, with a correlation of $r(87) = .55$, $p < .001$. Again it seems that increasing severity of the disability often results in a less

satisfactory adjustment to the illness, as would be expected.

Speech and mouth related problems

Speech scores were able to range from 2 (no speech or mouth problems at all) to 12 (poor speech and swallowing, dribbling, and dry mouth problems much of the time). Speech scores were obtained from questions on how easy it was to understand what the Parkinson's patient was saying, whether the patient had difficulty with swallowing or a dry mouth, and whether dribbling was a problem. Table 10 shows the spread of the scores over the member and non-member groups.

Table 10: Distribution of speech difficulties for members and non-members. The higher the score the greater the difficulty.

	Number of subjects	
	Mem.	Non.
Score 2 - 4	16 (30)	7 (21)
Score 5 - 8	33 (61)	19 (58)
Score 9 - 12	5 (9)	7 (21)
	54	33

In fact the speech scores did cover the complete range (2 to 12), with a mean of 6.02, S.D. = 2.26. However, there was no significant difference between the speech difficulties of the member (mean, 5.83, S.D. 2.11) and non-member (mean, 6.33, S.D.

2.50) groups, $F(1, 86) = 1.001$, $p = 0.32$. Again, there was a significant correlation between the PAIS and speech scores of subjects, $r(87) = .53$, $p < .001$.

Dribbling

Dribbling is an embarrassing and uncomfortable symptom found commonly in Parkinson's disease, and was therefore examined separately, although it also constitutes part of the speech total (a maximum of two points). Because it is such a "socially unacceptable" symptom, it was felt that it could be a critical factor in distinguishing likelihood of membership in the Society.

In Table 11 a score of 0 constitutes no dribbling problem, a score of 1 a problem only at the worst times, and a score of 2 constitutes an ongoing problem, at all times.

Table 11: Dribbling scores comparing members and non-members. A score of 0 represents no problem, ranging up to A score of 2 which indicates a severe and permanent problem.

Score = 0	Score = 1	Score = 2
Mem. Non.	Mem. Non.	Mem. Non.
26(48) 10(30)	21(39) 15(45)	7(13) 8(24)

From Table 11 it can be seen that 59% of all Parkinson's patients

suffer a dribbling problem, 17% of them all the time. The relationship between this problem and their level of social interaction will be examined in the section on social interactions. However, although Table 11 suggests that there might be a difference between members and non-members, in regard to the severity of the dribbling problem and the likelihood of Society membership, none was found, Chi Square (1, $N = 87$) = 3.30, $p = .19$

Overall handicap

The scores from the sections of the questionnaire on tremor, walking, and speech were totalled, and five further scores added to them, to form a total handicap score. The five further problems, all common in persons with Parkinson's disease, scored one point each if the problem was present, giving a maximum total handicap score of 69. The five problems were severe fatigue, poor eyesight, loss of hearing, constipation, and incontinence.

It was found that 55% of subjects suffered from severe fatigue, 53% from failing eyesight, 37% from hearing problems, 60% from constipation, and 30% from incontinence.

While still looking at the characteristics of the sample, the relationship between the individual's handicaps, and his or her age, time spent pursuing hobbies, time spent in social activities, and the difference in time spent in social activities now as opposed to before the illness occurred was investigated. The relationship between the total PAIS score and these variables

is also shown, as is the relationship between the PAIS section on psychological distress and the same variables.

The PAIS is designed to assess the quality of the patient's psychosocial adjustment to his or her illness, while the subscore relating to psychological distress goes a little further in that it is designed to measure the dysphoric thoughts and feelings that accompany the patient's disorder. As well as anxiety, depression, guilt and hostility, it also measures reduced self-esteem and body image problems, which relate directly to the symptoms of tremor, walking and speech disorders. A relationship between the amount of time spent on hobbies and social activities and the PAIS score was considered as in any people a measure of their involvement in both is often a measure of their adjustment to the world. The difference in social activities was taken, rather than just looking at the "before and after illness" scores, because it was felt that this difference was the relevant figure to peruse. The person who does not socialise at all now may be of one of two categories. He or she may have once socialised a great deal, and have been forced by the illness to curtail this activity. In this case there is a large difference, and one may expect that person to be feeling that difference greatly. If the person never enjoyed socialising, there will be little difference between the scores, and, it was surmised, this person will be less affected by loss of social activity, and therefore will adjust more successfully to his or her enforced relative solitude. The hobbies relate to activities a person indulges in at home, and it was felt that the level of

handicap may well affect this aspect of life.

The "Social now" score (the points gained on the amount of social interaction the subject was involved in at this time) was scored out of a total of 98 points. The greater the time spent socializing, the greater the score. The "social diff" (difference) score was calculated by deducting the amount of socialising done now from the amount carried out before the illness. Hobbies were calculated the same way as the "social now" score (hobbies involved in now), with a possible total of 56 points. The questionnaire in Appendix 2 shows full details of areas covered.

Table 12: Relationship of all handicaps to age, PAIS scores, and selected activities for all subjects.

	Age	Social now	Social diff	Hobbies	Total PAIS	Psych dist.
Tremor	.30*	-.34**	.50**	-.34**	.46**	.36**
Walking	.24	-.49**	.48**	-.44**	.55**	.34**
Speech	.28*	-.29*	.30*	-.41**	.53**	.33**
Total handicap	.31*	-.47**	.52**	-.48**	.62**	.41**

Note. * $p < .01$; ** $p < .001$. Social now = Social activities involved in at this time. Social diff. = the difference in score between social activities involved in before the illness, and now. Hobbies = hobbies involved in at this time. PAIS = the full PAIS score. Psych. dist = the score for section 7 only of the PAIS.

Table 12 displays significant correlations between the degree of handicap, and the amount of time spent pursuing leisure activities, and the score on the PAIS. The lower correlations of age with the individual and total handicaps would indicate that, although there is some correlation between age and degree of handicap, age *per se* does not account for the greater handicap of some Parkinson's patients.

As might be expected there is a strong negative relationship between disability (the degree of handicap) that a patient suffers, and the amount of socialising he or she is able to do and hobby activities that he or she can take part in. There is an even stronger relationship between the disability and the difference between what was enjoyed before the illness and what is enjoyed now. Consistent with these results is the finding that psychological distress and disability are strongly correlated. Tables 13 and 14 present a breakdown of the data in Table 12 in terms of Society membership.

The correlations in Tables 13 and 14 were compared using Fisher's Z transformation. No significant differences were found between members and non-members in regard to the relationship between their social activities now, the difference before and after illness in their social activities, their hobbies, or their PAIS scores, when compared to their handicaps. However, perusal of Tables 13 and 14 shows that there is a definite trend, in that for the Society members the negative correlations between social activities being carried out since the illness and each of the

disability categories (tremor, walking, speech, and total handicap) are less than half those for the non-members. Likewise, the correlation between social activities carried out prior to the illness and now and the disability scores is much smaller for Society members compared to non-members. The negative correlation between handicap and hobbies is much smaller for Society members, in fact, less than one third in all cases bar tremor. The correlations between the overall PAIS scores and the subsection of the PAIS on psychological distress, and the four disability scores as shown in Tables 13 and 14 are much higher for non-members. In fact, taking the sign of the correlation into account, all bar one of the correlations are greater for non-members.

Table 13: Relationship of all handicaps to age, PAIS scores, and selected activities for all Parkinson's Society members.

	Age	Social now	Social diff.	Hobbies	Total PAIS	Psych dist.
Tremor	.24	-.27	.42	-.22	.36*	.22
Walking	.17	-.32	.33*	-.17	.38*	.22
Speech	.29	-.15	.12	-.23	.43**	.23
Total Handicap	.26	-.33*	.38*	-.27	.49**	.29

Note. $p < .01$; ** $p < .001$.

Table 14: Relationship of all handicaps to age, PAIS scores, and selected activities for all non-members.

	Age	Social now	Social diff.	Hobbies	Total PAIS	Psych dist.
Tremor	.37	-.37	.58**	-.46*	.56**	.53**
Walking	.36	-.70**	.65**	-.71**	.75**	.51*
Speech	.25	-.44*	.51*	-.59**	.64**	.45*
Total handicap	.38	-.62**	.66**	-.68**	.75**	.56**

Note. * $p < .01$; ** $p < .001$.

It would appear, therefore, that members do not suffer quite the same difficulty in adjusting to their illness, and do not lose quite as much of their leisure time activity, be it in hobbies or socializing, as the non-member.

Transport

The questionnaire section on transport examined where the subjects live - that is, in a city, a town, or the country, and how mobile they were. Whether subjects were able to use various forms of public transport was examined, and whether they had access to a car, and if so, how easy it was for them to use that car. By analyzing data in terms of locality and mobility, it was contemplated that a picture of membership might emerge being related simply to the ease with which a patient could attend

meetings and functions - that is, how far from Parkinson's groups the patient lived, and whether or not the patient had access to a vehicle.

Table 15 looks at the locations of the subjects' homes. It should be noted that in New Zealand a town becomes a city when it reaches a population of over 20,000.

Table 15: Location of subjects' homes.

	city		town		country	
	Mem. Non.		Mem. Non.		Mem. Non.	
Number of subjects	32	18	20	10	2	5
	(59)	(55)	(37)	(30)	(4)	(15)

Of the total subjects included in the present study, 57.5% live in the city, 34.5% in towns, and 8% in the country.

There was a close to significant difference between members and non-members in regard to the locations of their homes, Chi Square (1, $N = 87$) = 3.63, $p = 0.056$. While 64% of city sufferers were members, and 66% of those living in towns, only 28% of country dwellers were members of the society. The very small sample sizes in each category, however, must be noted here.

Whether a person has easy access to transport is an important

factor in one's wellbeing. Of the 87 subjects:

- 33 owned a car and were still able to drive, at least at their best times;
- 32 had a car in the household, could not drive, but were taken out;
- 14 had no vehicle or driver in the household but could usually get a lift;
- 6 had no driver or car in the household and had trouble getting lifts;
- 2 were housebound through their disability, and unable to go out whether there was a car available or not.

A difference in PAIS scores emerged between those who were still driving (mean = 31.4) and those who were not, and had difficulty finding a lift when it was required (mean = 53.00). The difference was found to be significant $F(1, 86) = 8.04, p < .001$.

Difficulty in using a car was rated on a scale of 1 (no difficulty) to 10 (impossible). This degree of difficulty was compared with the total PAIS score, and a correlation of $r = 0.55, p < .001$ was found. That is, the greater the difficulty in using a car, the less successful the adjustment to the illness. While this could relate to the degree of handicap, remembering that a strong relationship has already been found between the degree of handicap and the PAIS, it could also relate to the lack of socialising that difficulty in using a car produces. Other forms of transport were also rated, but these were so rarely used that the results will not be included.

Summary

While no significant difference was found between members and non-members in relation to age, sex, marital status, living arrangements, work status, decision to finish work, or other illnesses, a significant difference was found in the degree of tremor suffered by members and non-members. However, tremor appeared to be an exception, because mobility, speech, and dribbling problems revealed no further differences. But studying how handicaps affected adjustment and leisure activities revealed a considerably higher correlation between the different handicaps and the PAIS scores, indicating that non-members were coping less well with their illness and its accompanying disabilities. Also, a much higher negative correlation was found between disability and leisure activity in non-members than members, an indication that non-members had curtailed activities considerably more than had members.

Leisure Activities.

The questionnaire (Appendix 2) included a large section on leisure activities, which were examined in three sections - hobbies and pastimes at home; hobbies and pastimes away from home; and group involvement. For example, in the first section, hobbies and pastimes at home, questions were asked on the amount of reading that a patient did these days, compared with the amount of reading he or she had enjoyed before the illness. Other items in this category looked at television viewing, gardening.

handicrafts, music, and jigsaws and crosswords. The second part of the section, activities carried out away from ones own home, compared the amount of time spent visiting friends and relations before and after the illness, the number of car trips, walks, visits to the theatre, time spent playing sports, travelling, and shopping. Group activities looked at church attendance, and attendance at a number of social or hobby related groups, comparing the before and after illness scores as in the two previous parts of the section. Total scores were developed for the activities at home (called total hobbies); activities away from home; group activities, and the second two sections (activities away from home and group activities) combined (called social activities). Three scores were developed for each individual item of the LEISURE section of Questionnaire One, as well as for the total items outlined above. These three scores were the time spent on the activity now; the time spent on the activity before the illness; and the difference between the two. Again, it was felt that the changes over time in any activity may well account for more distress, and give a clearer picture, than merely looking at the time spent on the activity before and after the illness.

Table 16 shows the means of the computed totals for hobbies and social activities, and their correlation with the PAIS total score.

From Table 16 it would seem that the more time spent on socializing and hobbies (i.e. leisure activities) the lower is

the PAIS score. It can also be seen that the greater the difference between the time put into these activities before the illness, and the time put in now, the greater is the PAIS score. These differences are highly significant ($p < .001$).

Table 16: Correlation of the total PAIS scores with current leisure time activities, and with the difference between time spent prior to illness and now for members and non-members.

Lower scores mean lower levels of activity.

	Score (mean)		Correlation with PAIS	
	Mem.	Non	Mem.	Non.
Social activities now	19.20	15.5	-.44**	-.70**
Social activities before	28.91	28.45	.07	.06
The difference	9.70	12.91	.43**	.60**
Hobbies now	21.28	20.70	-.30	-.62**
Hobbies before	27.20	27.55	.07	-.06
The difference	5.93	6.85	-.49**	-.55**

Note. * $p < .01$; ** $p < .001$.

The leisure activities were next tabulated as the original individual items, to see in which activities the greatest loss or increase in time spent on them had occurred. Results are shown in Table 17. Note that the before and after scores have been retained, rather than the differences calculated, to give a

clearer picture of the direction in which the changes have occurred. Student *t*-tests were conducted on the now and before means, a separate test for each activity. The *t* values and significance levels are shown in Table 17.

Table 17: Individual leisure activities before and after illness for members and non-members combined. Lower scores mean lower activity.

	Now	Before	<i>t</i> value	signif.
Reading	4.37	5.49	-4.07	$p < .01$
TV	6.23	5.68	3.22	$p < .01$
Garden	2.53	5.01	-8.41	$p < .01$
Crafts	0.94	3.07	-6.61	$p < .01$
Music	3.24	3.00	1.02	NS
Cards etc	1.60	2.10	-1.83	NS
Crosswords	1.48	2.03	-3.31	$p < .01$
Other act.	0.67	0.95	-1.48	NS

In Tables 18 and 19, the data have been divided up between members and non-members, to investigate any differences between the two groups in their leisure activities.

Tables 17 to 19 demonstrate that almost all home-based activities decrease, on the average, when a person develops Parkinson's disease, even such passive activities as reading. The reason for this is often due to lack of concentration or failing eyesight. The two activities that do not decrease are television viewing and listening to music. Both of these increased for the overall group (members and non-members combined) and for the non-member group. For the members there was a significant increase in TV

watching (see Table 18), although not for the non-members. There was no change at all in the amount of music enjoyed by the members. In all, Tables 18 and 19 suggest that there are few, if any, consistent differences between members and non-members with respect to individual leisure activities.

Table 18: Individual leisure activities before and after illness for Parkinson's Society members.

	Now	Before	t value	Signif.
Reading	4.56	5.24	-2.20	NS
TV	6.41	5.74	3.85	$p < .01$
Garden	2.57	5.19	-6.71	$p < .01$
Crafts	1.09	2.91	-4.81	$p < .01$
Music	3.13	3.13	0.00	NS
Cards etc.	1.44	2.04	-1.73	$p < .01$
Crosswords	1.35	1.91	-2.92	$p < .01$
Other act.	0.72	1.06	-1.90	$p < .05$

Table 19: Individual leisure activities before and after illness for Parkinson's Society non-members.

	Now	Before	t value	signif.
Reading	4.86	5.91	-3.67	$p < .01$
TV	5.94	5.58	1.03	NS
Garden	2.45	4.73	-5.02	$p < .01$
Crafts	0.70	3.33	-4.57	$p < .01$
Music	3.42	2.79	1.63	NS
Cards etc.	1.85	2.21	-0.77	NS
Crosswords	1.70	2.21	-1.71	NS
Other act.	0.58	0.79	-0.50	NS

Shifting now to outside activities, Tables 20 to 22 present the scores on both active and passive social activities out of the

home setting, before and after the illness, for both members and non-members combined (Table 20) and for the two groups separately (Tables 21 and 22).

Table 20: Activities outside the home both before and after illness for all subjects. A lower scores means less activity.

	Now	Before	t value	Signif.
Visiting	3.49	4.44	-4.28	$p < .01$
Car rides	1.83	2.69	-3.01	$p < .01$
Walks	2.19	2.69	-3.51	$p < .01$
Theatre	0.71	1.63	-4.91	$p < .01$
Sport	0.90	2.76	-6.36	$p < .01$
Shopping	2.37	3.30	-3.26	$p < .01$
Travel	2.37	4.87	-6.45	$p < .01$
Other	0.25	0.40	-1.16	NS

Table 21: Activities outside the home both before and after illness for Society members.

	Now	Before	t value	Signif.
Visiting	3.72	4.39	-2.34	$p < .05$
Car rides	1.89	2.50	-1.76	NS
Walks	2.30	2.96	-1.52	NS
Theatre	0.74	1.74	-4.26	$p < .01$
Sport	1.07	2.78	-4.51	$p < .01$
Shopping	2.37	3.31	-2.47	$p < .05$
Travel	2.56	4.22	-4.69	$p < .01$
Other	0.22	0.57	-2.05	NS

Significant differences in the amount of time spent in these activities before and after the onset of illness were found in

all categories except the "other activities" (in which numbers were very small) when members and non-members were combined Table 20). Exactly the same set of results were obtained when non-members were considered alone (Table 22). However, as shown in Table 21, the before and after activity levels of members shows a significant difference in just five of the categories, with the difference in the amount of time spent walking and taking rides in the car not showing a significant change.

Table 22: Activities outside the home both before and after illness for Society non-members.

	Now	Before	t value	Signif.
Visiting	3.09	4.52	-4.09	$p < .01$
Car rides	1.73	3.00	-2.56	$p < .01$
Walks	2.00	4.06	-4.02	$p < .01$
Theatre	0.67	1.45	-2.52	$p < .05$
Sport	0.61	2.73	-4.57	$p < .01$
Shopping	2.36	3.27	-2.14	$p < .05$
Travel	2.06	3.76	-4.58	$p < .01$
Other	0.30	0.12	1.00	NS

Finally in this section, data relating to group activities which subjects engaged in both before and after their illness are presented. Data for all subjects appear in Table 23 while Tables 24 and 25 show the data for Society members and non-members respectively. Measurements were taken of the estimated number of attendances each week, and the average length of each attendance. "Church" refers to church attendance itself, as well as

attendance at church groups. "Senior citizens" refers to attendance at senior citizens clubs; "Volunteer" to any volunteer group in which the patient participated (e.g. meals on wheels, grandparent schemes); "Day centre" to day care centres for the elderly; "Hobby groups" to such groups as craft groups, poetry group in one case, even repertory; "Other" refers to any other group which was omitted from the prior five categories, and in which lodges came up frequently.

Table 23: Group activities now and before the illness for all subjects.

	Now	Before	t value	signif.
Church	1.39	2.44	-5.28	$p < .01$
Senior Citizens	0.15	0.45	-2.20	$p < .05$
Volunteer	0.75	1.83	-4.21	$p < .01$
Day centre	0.54	0.15	2.35	$p < .05$
Hobby groups	0.40	1.26	-3.65	$p < .01$
Other	0.49	0.67	-1.08	NS

Table 24: Group activities now and before the illness for Parkinson's Society members.

	Now	Before	t value	signif.
Church	1.67	2.69	-4.17	$p < .01$
Senior Citizens	0.17	0.43	-1.85	NS
Volunteer	0.81	1.72	-3.35	$p < .01$
Day Centre	0.50	0.19	1.42	NS
Hobby Groups	0.65	1.41	-2.45	$p < .05$
Other	0.54	0.80	-1.23	NS

Table 25: Group activities now and before the illness
for Parkinson's Society non-members.

	Now	Before	t value	signif.
Church	0.94	2.03	-3.20	$p < .01$
Senior Citizens	0.12	0.48	-1.31	NS
Volunteer	0.64	2.00	-2.66	$p < .01$
Day centres	0.61	0.00	1.95	NS
Hobby Groups	0.00	1.03	-2.84	$p < .05$
Other	0.42	0.48	-0.21	NS

All group activity, with the exception of day care centre attendance, decreases with Parkinson's disease, all significantly so with the exception of the "Other groups" category. The day care centre attendance increases significantly when both groups are taken into account, as those who could once look after themselves during the day must now be cared for. However, the significant difference in day care centre attendance disappears when the groups are divided into members and non-members (Tables 24 & 25), with the now smaller samples. The same occurs with the senior citizens centre attendance. Despite this, however, there can still be seen a difference between the members and the non-members. Church attendance has dropped more for non-members than members, as has voluntary work. It is particularly interesting to note that not only is there a bigger difference between the amount of time spent in hobby groups for the non-members than the members, but the non-members actually spend no time at all attending hobby groups nowadays. A further point of interest is that the members actually spent more time in church activities

and hobby groups than their non-member counterparts before their illness, though they spent less time in voluntary work.

Summary

When leisure activities were studied for the member and non-member groups, few differences were found relating to the leisure activities carried out within the homes of members and non-members, although for both groups there were significant differences in the amount of time spent on these activities before and after the illness. Much more time was spent watching television, while pastimes such as reading or gardening had lessened. However, when it came to activities outside the home, it was found that although members still participated less since their illness than they had before, the change was not as major as it was for the non-members. The same effect was found in relation to group activities. Clearly, there is a difference between the members of the Society and the non-members in this area of their lives.

The Parkinson's Society

It will be recalled that data were collected on the views and feelings of members and non-members in regard to the Parkinson's Society. The purpose of this was to find out what aspects of the Society the members enjoyed most, gained the most help and information from, and why the non-members did not wish to join.

First, details of those who are members is given, followed by information on what members enjoy most about the Society and what

they expect from it. Finally, the differences between members and non-members are presented.

Of the 87 subjects, 54 are members of their local Parkinson's Disease Society; of these 33 are males and 21 females. Sixty percent of the male subjects are members, and 66% of the females. Regarding marital status, 50% of single subjects are members, 63% of married subjects, 66% of divorced subjects, and 62.5% of widowed subjects. Therefore, neither gender nor marital status appear to affect membership.

The average length of time after diagnosis that a member joined was 4.76 years. However, this high figure is partly a function of the fact that the Central North Island Societies have not been running for too many years, particularly in some areas. The majority of members (89%) joined the Society straight after hearing about it.

It is important for the Society to know from where it gains most members, and subjects were asked from what source (e.g. newspaper, poster, doctor) they had learnt about the Society. These data are given in Table 26. It can be seen that 39% of members got information from a newspaper or magazine, by far the largest group, followed by 22% who were told about the Society by their doctor or a hospital staff member.

The Society offers its members six main areas of help, as

outlined in Table 27. The subjects who are members were asked which particular aspects of the Society's activities they found the most helpful. It was thought that how well members had adjusted to their illness might influence responses here, because a well-adjusted person may well be looking for something different in a self-help group than a less well-adjusted person. Therefore, the PAIS scores are presented along with the numbers of subjects finding the various categories helpful.

Table 26: Source from which members learnt about the existence of the Parkinson's Society

Source	Number	Percentage
From another member	6	11
From a friend or relative	6	11
From TV or radio	1	2
From a newspaper or magazine	21	39
From a doctor or hospital worker	12	22
From a poster on a notice board	1	2
Other	4	7
Don't remember	3	6

Table 27: Society activities found most helpful by members, and the PAIS scores of each group.

Activity	<u>N</u>	Mean PAIS score
Information in general	15	35.00
Newsletter	30	37.20
Meetings	18	38.28
Company	12	39.90
Support	7	51.00
Support for the caregiver	11	49.27

Interestingly, there is quite a variation between the PAIS scores across the six activities of the Society that subjects were asked

about. As need for support increases, so does the PAIS score. Where information alone is sought, the PAIS score is lowest.

In general, Parkinson's Society groups meet monthly or bi-monthly (though there are exceptions). Of the 54 members, 25 (46.3%) attended all but one or two meetings in any given year, 10 (18.5%) about 50% of meetings, and 5 (9.3%) just the odd meeting. Fourteen members (25.9%) do not attend meetings at all.

The next question perused was why these people did not attend meetings. Subjects were permitted to give more than one reason. Table 28 shows the number of members providing each of the reasons along with the average PAIS scores for persons giving these reasons.

The most likely reasons that people do not attend meetings appear to be transport problems, the meetings are too depressing, or the meetings are not needed. These three reasons accounted for 62% of the responses. Those not feeling the need for meetings, or who find the meetings depressing appear to be the fitter members who do not wish to be reminded of what may be to come, an observation consistent with their lower PAIS scores. However, it must be first noted that, overall, there are many reasons for non-attendance, and second that the sample size, divided over reasons, is very small. Only 14 members did not attend at all, and the total of 21 reasons was given by this small number.

Table 28: Reasons for non-attendance of Parkinson's Society meetings by members. Mean PAIS scores for the members who gave each reason are also shown.

	Number giving this reason	PAIS score (mean)
transport problem	6	41.8
Distance	1	56.00
Time of meetings	1	18.00
Health	3	51.67
Need an escort	1	53.00
Feel don't need meetings	3	31.00
Shy, afraid	2	52.00
Find them depressing	4	28.00

Turning now to the responses of the non-members regarding Society membership, of the 33 non-members 5 had not heard of the Parkinson's Society. Only 12 had made any attempt to contact any other person with the disorder, and only nine were interested in joining the Society. This leaves 24 Parkinson's disease sufferers who had no wish to join any Parkinson's Society.

Table 29 lists the wide range of reasons given by non-members for not wishing to join the Society. Most common was that the medical condition of the subject prevented joining (24%), followed by travelling problems, and simply not being group joiners (18% each). The most important point to take from these data is that there is no one particular reason for not wishing to join the Society. However, it is possible that there may be

some relationship between the reasons for not wishing to join, and the psychological differences between those who join and those who do not. Therefore, the scores for each section of the PAIS were compared for members and non-members (Table 30).

Table 29: Reasons given by non-members of the Parkinson's Society for not wishing to join the Society.

Reason for not wishing to join	Number
Able/wish to lead a normal life	5
Too busy with other things	2
Prefer to avoid others with it	4
Don't join groups	6
Medical condition prevents it	8
Too remote, travelling problems	6
Can't really give a reason	2

As shown by ANOVA there were no significant differences between the individual sub-sections of the PAIS. Neither did the total PAIS scores of members and non-members of the Parkinson's Society differ, $F(1,86) = .80, p = .37$.

Summary

Clearly the majority of Parkinson's Society members learnt of the Society from a newspaper or magazine, in most cases probably from the local "freebie" - this was mentioned by a large number of the members. Members join looking for information about their disorder, received through the newsletter and meetings. Thirty-three percent found the meetings the most important aspect for them, and gained most comfort from this aspect of the group. The

reasons why people do not join are varied, ranging from lack of transport to not wishing to attend a meeting the patient finds depressing.

Table 30: Mean scores for each major subsection of the PAIS presented as a function of Parkinson's Society membership.

	Members	Non-members
Health care orientation	7.57	8.67
Vocational environment	7.46	7.42
Domestic environment	6.67	7.06
Sexual relationships	3.11	3.12
Extended family relationships	1.81	2.39
Social environment	6.85	7.58
Psychological distress	6.80	7.55
Total PAIS	40.28	43.79

DISCUSSION

As this was an exploratory study, there were no formal hypotheses posited. Nevertheless it was expected that somewhere a difference would show between those people who had joined the Parkinson's Society, and those who had not, be it a demographic variable or a psychological variable. Considering the results as a whole, there were surprisingly few differences between members and non-members. Moreover, there appears to be no easy way of characterising those differences that were found.

Characteristics of sample

Neither age nor sex appeared to relate to whether or not a patient joined the Parkinson's Disease Society in the present study. Oxtoby (1982), however, found that subjects were less likely to join the Society with increasing age. Oxtoby's is an English survey, and there may have been major differences in transport facilities, accessibility to Societies, or other reasons for these differences between the present study and hers. What the present results show in relation to Oxtoby's is that it may be unwise to generalise the findings of one sample of patients too far.

Perhaps surprisingly, in view of the help that a partner may offer in getting around, marital status did not figure as a difference between member and non-members in either the present study or Oxtoby's (1982) survey. During the interviews, the

impression was gained that the married men who had Parkinson's disease were getting more help and assistance in the social sphere from their wives than the married women patients from their husbands. Indeed, the data from both studies show that many more married men than women are members. However, closer examination shows that many more married men than married women are non-members also. (See Table 2, p. 72.) The disparity, of course, is that there are many more married men than married women around in the older age groups, along with many more widowed women than widowed men among both members and non-members.

More suggestive were the data on household composition. While the difference was not significant, more than twice as many non-members as members, for both men and women, lived alone. From the present data it is impossible to say whether non-membership was due to their living alone (e.g. no transport, little support), or whether both their living alone and their non-membership were due to the same factor - a preference for isolation perhaps, or a personality idiosyncrasy which rendered this lifestyle more suitable for them. The degree of isolation in households is an area that should be pursued in future research.

Figures presented by Oxtoby (1982) support those of the present study in regard to numbers living with spouse, and living alone. However, there was a major difference in the category "Living with son/daughter". While only 2% of all the subjects in the present study lived with their daughter or son (in fact, they

were both women, one with her unmarried son, and one with her married daughter, but with her own granny flat), 18% of women and 20% of men lived with their son or daughter in the 1982 Oxtoby study. The difference could be due to a variety of reasons: the lower mobility of families in many parts of Britain compared to New Zealand (the Oxtoby survey was a postal survey which covered the whole of Britain); better facilities in New Zealand for home care; or a different attitude in the English towards residential care. For while the Oxtoby survey indicated that only 4% of men and 7% of women were in residential care, the present study found 17% of members and 12% of non-members in residential care. Whatever the reason, the data once again suggest that there might be marked differences between samples of Parkinson's patients. In New Zealand (Dpt. of Statistics, 1990) 55.8% of persons over 65 lived as married couples, 32.1% alone, 10% with other family members, and 2.8% in residential homes. Comparing this with the figures for the Parkinson's patients in the present study, whereas the figures for those living as married couples showed little difference, there are considerably more people with Parkinson's disease in rest homes than there are from the general population. There was no breakdown of men and women to be found in regard to household composition for New Zealand (i.e. the elderly were not divided by sex in the Department of Statistics study), but the present study, and that of Oxtoby (1982) and Singer (1973) emphasise that a greater number of women live alone. Because of their higher life expectancy, women living alone have been a common phenomenon for many centuries. Indeed, their problems may have diminished with time (in the late middle

ages they were the prime candidates for burning as witches), but the elderly unwell woman still needs a great deal of support. The Parkinson's Society is an area that could offer this support - yet these women do not seem to join as often as their married sisters or those in residential care.

Only 2% of the subjects in the present study were working full-time, and 2% part-time. All of these subjects were members of the Society. This is a very different result from Oxtoby's (1982) study where 14% of members and 15% of non-members were working full-time (though only 2% and 3% respectively part-time). Conversely, this present study found 9% describing themselves as permanently disabled, rather than retired, in contrast with Oxtoby's 23%. Those describing themselves as permanently disabled tended to be the younger subjects (i.e. in their 40s and 50s). This relationship was also found by Singer (1974). Presumably the large proportion still working in the English study is also the younger age group. One can only speculate about what caused the difference between the two studies. It has been found in previous studies (e.g. Singer, 1973) that about one third of professionals, managers, proprietors, clericals, and sales workers remain in work for several years after diagnosis, compared with about 20% of craftsmen, operatives, and service workers. As it has also been found that in England at least, membership of the Parkinson's Society is known to be over-represented among the non-manual classes (Pinder, 1988), the immediate assumption was that this explained the higher employment rates in the English study. However, further perusal

of Oxtoby's (1982) data show that 15% of non-members also worked full-time. Thus, the reasons for this discrepancy are not clear.

However, the relationship between the subject's main occupation during working life and membership was close to significant, although it must be born in mind that sample sizes were small. One hundred percent of managers had become members, and 57% of all members questioned were white collar workers (only 3% of white collar workers were not members). The percentage of members and non-members for blue collar workers was virtually the same. It appears then, that in New Zealand, as well as in England, the white collar worker and the professional are more likely to join the Society. It is possible that knowledge of the Society is not reaching working class patients as often - perhaps through doctors not giving it out, perhaps through less investigation of the illness by the patient him/herself. However, it is more likely that the working class patient is less keen to become involved, feels less need of the support, or does not understand the role of the Society. It is probable that level of education is also a factor, and this component is another which could be involved in further research.

Parkinson's disease frequently results in early retirement, and for the person who is very young, for example, in their forties, the financial effects can be catastrophic. This is especially so for blue collar workers who are likely to have accumulated few resources and capital. The present sample included several subjects in their forties, including a man and a woman both 43

years old, and both of whom had had the disease since their late thirties. The male subject had been the company director of a large transport firm, and his wife is a nurse. The woman was a housewife at the onset of her illness (though originally an obstetrics nurse), her husband a farm worker. Both families have teenage children, the former two, the latter four. In both families, the youngest child was pre-teen when the illness struck. Today the former company director still lives in their extremely comfortable home, and although his wife has returned to work, the material aspects of their life have not changed a great deal. However, for the woman patient, life has become quite different. She has been forced to move to shoddy rental accommodation in very poor repair, as the husband was forced to give up his job to look after her and the family. It was also necessary for them to move into town, both due to his job loss, and for her medical care. Their car has been sold, and although the patient is able to walk to town sometimes, there are no guarantees that she will make it back. There are no "mod-cons" to make life easier for her. In fact, the age and condition of their "new" home makes life harder. Singer (1973) likewise found that those over 65 suffered less income loss than the younger individuals. However, she also found that the material deficit was worse among the unmarried younger patients. As there were only two subjects in this category in this present study (males, aged 28 and 44), and both were living at home with their parents, this paucity was not readily apparent. Nevertheless, the destitution of a young patient with no supportive family can be imagined.

Still on the subject of work, considering that most patients were past retirement age, were they in fact influenced by their Parkinson's disease in their decision to finish work? Oxtoby (1982) found that 38% of her subjects had been forced to finish work because of their Parkinson's disease, and in the present study a not too dissimilar 46% of members and 45% of non-members had been influenced by the disorder.

There was no difference between members and non-members regarding the influence of their disease on their finishing work. Nonetheless, it was interesting to note (although the effect was not statistically significant) that the mean PAIS score for those who had finished work of their own accord was lower, indicating a possible trend towards a healthier adjustment to their illness, than the mean PAIS score for those who had been forced to stop work because of their illness.

There was a significant correlation between the PAIS score and the number of years since finishing work. As the period of time since finishing work increased, Parkinson's disease sufferers showed an increasingly poor adjustment to their disorder. This correlation could be a function of many factors - age, increasing disability with the years, or a dissatisfaction with lack of productivity. Many of the older men interviewed appeared to have become more bitter over the years regarding their early retirements, although according to some researchers (e.g. Cassileth et al., 1984) better mental-health scores are found in the older age groups of patients studied. However, the male

subjects who come to mind who are still feeling bitter about their enforced retirement had been in the main active, mobile men - two builders and two other men of other occupations, but who built their own homes; a bushman and a physical education teacher. Cull (1972) talks about the human body as falling somewhere along a continuum, with the body as an active tool with which to accomplish work at one end, and as an aesthetic stimulus for others to enjoy at the other end. For the active outdoor person, banishment to a life of television and sedentary activities probably has a much greater impact than on the person who spent a great deal of time reading or listening to music anyway. For example, one elderly subject revelled in the time that she now had to read, study drama, listen to music, and write poetry, although she harboured a great fear of becoming helpless and developing the Parkinsonian mask. Therefore there is likely to be more than one reason for the increasingly poor adjustment to the disease with time.

As the majority of Parkinson's patients are elderly, it is not unreasonable to expect that there will be other disorders present in addition to the Parkinson's disease. The present study found 38% suffered no other disorders, whereas Oxtoby (1982) found that 48% of her subjects had no other disorders. In as much as the difference here is real, it might be due to the fact that the Oxtoby study was conducted by mail. The present data were collected by personal interviews where it was seen that, often, subjects forgot about their other disorders until they came up in conversation on other topics, such as medication or leisure

activities. For example, there was an 82 year old who assured the investigator that she had only Parkinson's disease, then when the question on walking later came up produced bottles of pills for everything from heart disease to kidney failure. Others also remembered their angina only when asked about their walking or sports activities. Observation of excess bottles of pills in the houses of people who lived alone, and comments by spouses, caused the present investigator to be wary of the 38% figure given by Oxtoby. It is possible that the result is an artifact of the collection method, but one which Dr. Oxtoby would not have considered, not having had the experience of collecting the data in person.

The English sample indicated a much higher rate of arthritis than was found in the New Zealand sample, but a lower percentage (12% as opposed to 30%) with two or more conditions in addition to Parkinson's disease. Again, the possibility of this being a function of data collection method is posited. Other subjects were almost indignant that someone might think that they might have some other disorder as well (although the men who had suffered prostate trouble were largely keen to talk about it). The point being made here is that survey results may be partly dependent upon the method of data collection. It is suggested that data collected by interview may yield more accurate results than that collected by post. Further research is required.

The on/off syndrome, peculiar to Parkinson's disease in the advanced stages and described so eloquently by Todes (1983),

causes enough problems of its own. Todes described the transformation of the body from "off" to "on" " ...as if the gods were breathing fire into it..." (1983, p.978). Diagnosed as having Parkinson's disease 12 years before he wrote these words at the age of 39, Todes, a psychotherapist, considers the on/off syndrome central to patients with chronic Parkinsonism. It is for this reason that a score of disability was constructed taking into account both the good and the bad (on or off) times for a patient. During the good (on) times the patient might be quite capable of running, driving or even playing tennis for example, but at the bad (off) times, quite incapable of feeding or going to the toilet unaided, or even speaking. Pinder's (1988) in depth interviews with 10 Parkinson's patients highlight this problem. One of Pinder's subjects could go from total frozen immobility, with total dependence on his wife, to running up and down the stairs to his flat, all within an hour. He described it as the "Lazarus" effect, and stated:

"I cram into the periods when I'm flexible all the things I would have liked to have done the rest of the day. It doesn't always work that way though. One day I may be nine-tenths of the day free, although that's very rare, and another much less. There's nothing I can do about it." (From Pinder, 1988, p. 79).

Therefore, in examining disability one must look at both good and bad times. That is, the good and the bad times from the patient's perceptions and perspective. As previously mentioned, the person used to using the body as a tool sees immobility as a terrible

disability. On the other hand the more sedentary person may consider a slight degree of blindness or deafness the greater disability. The musician may have the perception of severe disability when his or her fingers will no longer play an arpeggio, while the (objectively) equally physically disabled farmer has not even considered the possibility. These perceptual differences were observed many times during interviews. For instance, the 92 year old patient who stated that he walked only limited distances was found to in fact wander all over the large Horowhenua Hospital grounds. However, the distances were limited in relation to what he had managed only a year or two before - that is, when he marched the one kilometre into town quite regularly. Conversely, a woman patient who advised that she walked quite normally ("perhaps a little slowly") but in later discussion was found to have difficulty making it to the letter box. But it had been a long time since she had wanted to walk anywhere, being something of a recluse. It is important to take these self perceptions into account.

The first disability considered was tremor. This was possibly more straightforward for the patient to describe, and less subjective, than walking and speech. Often, over a cup of tea, the extent of tremor was demonstrated to the investigator, and most subjects seemed accurate in their description of their tremor.

There was a statistically significant difference between the tremor scores of members and non-members. Non-members had

clearly higher mean tremor scores than members (see Table 8). As tremor is one of the most upsetting of the Parkinson's symptoms (although it actually causes less problems than does the inability to walk, or the rigidity), the embarrassment of uncontrollable tremor may well be a reason for not wishing to become involved in a Society. Interestingly, however, the sample surveyed by Oxtoby (1982) showed the opposite relationship. According to Oxtoby a higher proportion of the non-member group were able to hold a cup normally than of the member group. It must be remembered, however, that again these data could be biased by the self-report of the postal survey. Also, the present survey used a more comprehensive measure of tremor than just holding a cup, with difficulty in such activities as aspects of dressing, using switches and handles also being considered. As might be expected the greater the tremor score, the higher the PAIS score, indicating a less satisfactory adjustment to the illness. Clearly, tremor has a devastating effect on the self esteem, and the confidence with which one conducts one's life.

The questions on walking and mobility covered such areas as: distance that could be covered, difficulty in starting to walk, negotiating doorways and stairs, difficulty in getting to the toilet, in getting into and out of bed, out of chairs, and turning over in bed. There was no overall significant difference between walking scores for members and non-members, although Table 9 shows that at the highest level of disability there was more than twice the percentage of non-members as opposed to members suffering from gross immobility.

Again, there was a significant correlation between walking and PAIS scores. The immobile person appears to find it harder to adjust to his/her illness. Withdrawal due to immobility exacerbates the difficulties of adjustment. This result is not surprising because as Parkinson's disease becomes more advanced, adjustment becomes much more difficult.

Speech ranged from the total inability to speak at all, found in several patients, to no speech problems. There were no differences between members and non-members with respect to speech problems. However, most subjects had at least some problem with speech, if only at the worst times of the day, either in volume, inability to produce words, or inability to think of the words wanted quickly. Oxtoby (1982) advises that the speech part of her questionnaire was the section most commonly left incomplete, and suggests that this avoidance may indicate that subjects found speech problems amongst the most difficult to deal with.

While dribbling formed part of the total speech score, it was decided to examine it in its own right. The reason for this was that it is a most embarrassing symptom, being seen as "socially unacceptable", as well as being uncomfortable and irritating. Seventeen percent of subjects suffer from a dribbling problem all of the time, while another 59% suffer from it at their worst times. However, there was no significant difference between members and non-members in their dribbling scores. But, as for the walking disabilities, there was a trend for less likelihood

of membership when the problem was severe (13% vs 24%) and more likelihood of membership when least severe (48% vs 30%).

A total handicap score was formed from the tremor, walking, and speech scores, with the additional variables of severe fatigue, failing eyesight and hearing, incontinence and constipation. Oxtoby (1982), looking at members only, found severe fatigue in 47.1% of subjects (the present study found it in 55%), and constipation in 53.3% (60% for the present study), which does not show a great deal of variation between the two studies. It would have been useful to compare a measure of incontinence (admitted in 30% of the subjects in the present study). The expressions and denials suggested that this was something they did not always wish to admit to, and one wonders if the true figure may be higher. Incontinence in any disorder breaks down confidence, and will often reduce an otherwise normal individual to the life of a recluse. In three, possibly four, cases, caregivers took the investigator aside and advised that, despite the "no" to the incontinence question, their charge in fact regularly wet the bed. Perhaps it is easier to admit to incontinence on an impersonal sheet of paper. Or perhaps, like the "other disorders", it may have been "forgotten." Had Oxtoby collected incontinence data, the results could have been interesting to compare.

Parkinson's patients are constantly faced with the problems of doing for themselves the things that normal people (and once they themselves) take for granted. Activities such as getting dressed,

shaving, brushing hair, answering the door or the telephone, and signing a cheque. Each of these causes difficulties for many Parkinson's patients to at least some degree. Additionally there is the inability to speak properly, to walk any distance, or to be sure what one's body will, or will not, do. What effect do these handicaps have on the patient's life - on hobbies, on social activities, on home life and sexual relationships?

Oxtoby (1982) found a significant relationship between the years of having had Parkinson's disease and the degree of handicap. The present study also found a significant relationship between total handicap and age. Additionally, a significant relationship was found between handicap plus tremor and handicap plus speech.

However, it is not necessarily age *per se*, or length of illness, which results in the greater handicap. The woman patient who had had Parkinson's disease the longest (40 years) was still walking around, and could be understood reasonably well, while other patients who had had the disease for only a few years were badly disabled. As mentioned earlier, the oldest patient, at 92, was perturbed because he could not get into town by foot as he had a year or two before. There were many occasions during the day when the youngest patient (28) was considerably more disabled than this elderly gentleman. Perhaps some of the unhappiest cases were those males who had been diagnosed in their late fifties, and had gone rapidly downhill to become virtual vegetables in their early sixties. Most of these patients had relatively young wives. In other words, there are no guarantees in Parkinson's

disease. Progress may be slow or rapid, and age may have little to do with it. As well, it is likely that numerous patients have had the disorder for many years before it has become noticeable, or noticeable enough for diagnosis. For example, one woman, now in her sixties, told how as much as 10 years before her diagnosis she had trouble with one arm every time she got on her bicycle. The arm would mysteriously wind its way up her back, before she could bring it back under control. Another remembers feeling her tennis racket had gained in weight the season two years before her diagnosis. Yet another subject repeatedly sent his car back for wheel alignments for some years before diagnosis. But it was he, not the car, causing the sideways movement. It is impossible to put an exact measure on the length of time that Parkinson's disease has been present. However, measures can be taken from the time of positive diagnosis, which is presumably the time when symptoms become severe enough for medical advice to be sought. Nevertheless, with young patients in particular, this is not always the case, as one man in his forties found out. He spent some time in a psychiatric hospital for his "imagined" symptoms of several years duration. It was the psychiatrist there who finally diagnosed Parkinson's disease, and returned him home smartly.

Gradually, however, symptoms which are at first only irritating become a handicap, as patients are unable, or unwilling, to perform the activities they once enjoyed. Strong negative correlations were found between handicap scores and the amount of time spent in socializing and hobbies nowadays, and even

stronger correlations between the handicap scores and the difference between the time spent on socializing and hobbies before the illness and today. The strongest of all correlations were between the total handicap and the PAIS score, and between total handicap and the social difference score. Not surprisingly, these results suggest that the greater the handicap, the greater the loss of leisure and social activities, and the greater the psychological distress (Table 12). Leisure activities will be discussed in depth in the next section. However, suffice it say that the conclusions of Singer (1974) who likened the effects of Parkinson's disease, and other chronic illnesses, to premature social aging, are well supported by the present results for both members of the Parkinson's Society and non-members.

It can be seen from Tables 13 and 14, however, that the effects differ in quantity for members and non-members. Correlations between all categories - social activities nowadays, the difference between social activities nowadays and before illness, hobbies nowadays, PAIS totals, psychological distress, and disability, are almost without exception higher for non-members than for members. That is, the relationships between the disability and loss of time spent on pleasurable activities appear stronger for non-members than members. This finding opens up two possibilities; first that there was originally a difference between the members and non-members, and second, that Society membership somehow mediates between the disability level and the amount of socializing and activity that the patient becomes involved in. The present data cannot be used to make a

reasoned choice between these two possibilities. Indeed, it may be that both possibilities play a part. Further research is urgently required to resolve this issue, because if it is Society activity that helps the patient to maintain a social life, then GPs must be urgently encouraged to recommend membership to their Parkinson's patients.

It will be recalled that data relating to demographic factors were collected to ascertain whether the difference between members lay in something as simple as the location of their homes, and their access to transport.

The difference between number of city and country dwellers who were members or non-members was close to significant. However, the small subject numbers of country dwellers preclude any unequivocal conclusions. Nevertheless, city dwellers have several advantages over country dwellers in belonging to any group. There is less problem in having someone - another member perhaps - pick them up for meetings, the distance is less, therefore less tiring, they are more likely to know people around them, and hence remain more in touch with neighbours. The person in the city has more opportunity to learn about the Society. Most people seemed to learn about the Society from the weekly "freebies" which often do not reach country areas. Posters are less commonly found in the country, and the next door neighbour is further away, and less likely to offer a lift or information about group that her neighbour on the other side told her about. In other words, the country person is more isolated, and the Parkinsonian

condition only adds to that isolation. In fact, the country person may have been more of a loner in the first place. The lifestyle is quite different from that in a big town or city. The main contact for these people must be their doctor, and again it would seem important that GPs and specialists are aware of the probable importance of the Society to sufferers.

Charmaz (1981), in her study of the chronically ill, discusses the loss of freedom of choice that ill people suffer when they lose the ability to drive. Several of her subjects remarked that having a car and retaining their drivers licences allowed them to view themselves as independent, even though they were not always able to exercise this choice.

"Just knowing that the car is in the garage and I can use it if I want to or have to gives me a great deal of comfort. Why, I don't think I have driven it in six months, but knowing it is there helps me to feel independent." (Charmaz, 1981, pp. 172 - 173).

But less than one third of the 87 subjects in the present study owned a car and were able to drive it, at least sometimes. About the same number had a car in the household but were unable to drive it. Sixteen percent had no vehicle or driver in the household, but could normally get a lift. It was the 7% who had no driver or car in the household and had no one to give them a lift, however, that appeared to suffer the worst turmoil. Unlike the 2% who were so disabled that they could not leave the house

anyway, these people would like to have gone out occasionally, but had no one to take them. This was reflected in their PAIS scores, with a significant difference found between those who drove, and those who would like to have gone out, but could not due to lack of transport.

Likewise, there was a significant correlation between the degree of difficulty in using a car, and the PAIS score. If it is difficult to use a car, it is inevitable that the car may begin to be used only when it is absolutely necessary - perhaps for the doctor, and no other time. This means that the social interaction of the patient becomes restricted, and the patient becomes bored and lonely, perhaps even giving up activities that were previously carried out at home, as the positive reinforcement offered by the outside world diminishes and disappears. Admittedly, it has already been found that there is a strong correlation between the total handicap and PAIS score; thus, this later finding may merely be a reflection of the difficulties the more handicapped person has in using the car. However, the cessation of socializing which results from this problem must not be forgotten. These conclusions would seem to emphasise the importance of a transport system for disabled people, not only to be used for their physical needs, but their psychological needs as well. Not one housebound subject mentioned using the disabled transport system available in the area. Clearly more advertising of this facility is necessary - again through the GPs and specialists, who are frequently the only contact for these people.

Leisure activities

As was expected, it was found that almost all leisure activities decreased with the onset of Parkinson's disease, be they "at home" activities, hobbies, socializing, or group activities.

The present results support those of Singer (1973) who found that Parkinson's patients spent around one and a half times more time in "napping and idleness" than a control group, as well as considerably more time watching TV and reading.

Oxtoby (1982) had 15% of her sample write in that they did "nothing" or "no activities". Although this present study found few who were quite so bereft of activities, the Oxtoby questionnaire raises the worry that even if these people do in fact do something with their day, they actually see themselves as doing nothing. Although the answers Oxtoby got were possibly a result of the use of the postal questionnaire, several of the participants of the present study originally saw themselves the same way. But more specific questions established that they did in fact participate in a few activities, even if it was just listening to the radio.

Highly significant differences between what both members and non-members were involved in before their illness, and what they are involved in now, were found. The results showed that there were marked differences between, for example, the time spent on a hobby before the illness and the time spent now, or even the time spent in church activities or reading, supposedly "quiet"

activities. The now and before score differences are very large, suggesting that the changes in these people's lives have been substantial.

For the non-members, the social activities have almost halved, although before their illness their social activity scores were almost identical to those of the members. Hobbies for both groups dropped considerably; however, it should be noted that the odd patient has taken up a new hobby since the illness struck. One subject in his sixties has taken to writing and has written, and had printed, several inspirational booklets. Several who are able have taken to walking as a hobby - but the general trend is that this type of activity wanes and dies. So, although there are exceptions, results clearly show that leisure activities diminish greatly with the progression of the disorder, but the differences between members and non-members remain over almost all of the socially leisure activity categories. The difference remains smaller for the members. The category of "visiting" for example, relating to the amount of time spent visiting friends or relations, showed a much greater change for the non-members, who had in fact spent more time in visiting prior to the illness than the members, but afterwards spent less time in the activity. The results were much the same for walking. Whereas the non-members had spent more time walking before their illness than the members, now they spent less. Members, after the illness, spent more time going for drives, visiting the theatre, playing a sport, shopping, and travelling. In fact, with the exception of playing cards and listening to music a significant decrease in

all activities occurred, the greatest decreases being in gardening and crafts. Oxtoby (1982) did not compare her subjects before and after illness scores. However, 40% of her sample still enjoyed gardening. Oxtoby also included indoor plants under gardening. While indoor plants were mentioned by only two subjects in the present study, gardening for many had been a major part of their lives for many years, and something they had once looked forward to spending even more time on in retirement. The sadness expressed by these people would indicate that some form of gardening suited to their physical capabilities, including indoor plants, is perhaps an area which the Societies, or other helping groups, could look into. Many who had once enjoyed the garden could perhaps be convinced to begin an indoor grove. Research has already been carried out on the psychological impact of having a plant to care for (Langer & Rodin, 1975), and those elderly people who had their own plants to care for increased in their feelings of well-being and their physical health. Small gardens or indoor plants are a cheap and effective way of brightening otherwise sad lives. Further research is needed to investigate the therapeutic benefits of gardening and plants for the Parkinson's patient.

Again, a different trend showed between Society members and non-members in relation to time spent on crafts and hobbies. Prior to their illness, the non-members spent a little more time on their crafts than the members (Tables 18 and 19). Yet since the illness, the members spend more time in craft work and non-members. The latter group spend only one fifth of the time spent

previously whereas the members spend more than twice the time spent previously.

Crafts included sewing and knitting, and many a frustrated woman subject had been forced to abandon these. Perhaps the males found their hobbies of wood turning and "fixing things" easier to continue, with less emphasis on tiny holes and thin threads. But for both sexes, the disappointment and loss of esteem resulting from their discontinuation was apparent. Women showed the investigator half-finished jerseys and almost-completed tapestries which they had been forced to abandon.

The data on crafts may give a clue as to why some join the Society and some do not. Crafts can be a social occupation in a group setting, but they can also be very solitary. Were the non-members more solitary people to begin with?

Society members also showed a greater change in television watching, with their viewing being slightly more than that of non-members both before and after their illness. Television watching can also be a solitary occupation, but it also involves the outside world, and can perhaps be more easily enjoyed with the wife or husband than tapestry or wood carving! Other areas in which differences between the two groups showed, even before the illness were in the amount of reading done (non-members read more), the amount of gardening (members spent more time in the garden) and in time spent listening too or making music (again

members spent more time, and in fact this figure did not change at all with the onset of the illness for the members). Members spent less time playing cards and doing crosswords, however, and continued to do so after the illness. Unfortunately the card playing was not divided into social games, and solitary games like patience. However, many subjects did mention patience. This division could be made in future research. The question of differences between members and non-members in time spent on either solitary or group activities is a fascinating area which deserves further investigation, and may shed much light on the question of why some people join the Society and some do not.

Turning now to outside activities - visiting friends, taking car rides, walking, visiting the theatre, sport shopping, and travel - it can be seen that when members and non-members are taken together, all these activities were found to have diminished significantly since the illness's appearance. Singer (1973) also found that Parkinson's patients were more likely than others of comparable age to be isolated from interpersonal contacts, this being particularly so for the younger patients. Whereas the death of close friends may be partly responsible for the shrinking social circle of older people, in the case of the younger patients, their own withdrawal from other people, or the withdrawal of others from them, is a more likely explanation.

Considering Society members and non-members separately (Tables 21 and 22), differences between the two groups are apparent. The changes in visiting were smaller for Society members, and the

changes in the number of car rides and walking not significant. Closer examination showed that in walking, for example, non-members had spent considerably more time indulging in this activity than members - hence the significant change for them when they were suddenly unable to walk as much as they had, while there was no significant change in the walking habits of members. Walking is often a solitary activity. It may be that the people who enjoyed walking prior to their illness walked at the expense of more sociable activities, and when unable to walk as much, cut down further than necessary. The group who previously did not walk as much saw this as something to do that would keep the body moving. They would not have had such a yard stick to attempt to keep up with, thus their time spent walking did not decrease to the same degree.

One might assume that those who were "joiners" before their illness would be the ones most likely to join the Parkinson's Society after their illness. But is this so? Both groups showed a significant decline in the hours spent at church, in performing voluntary activities, and partaking of hobby groups. For each of these activities members showed a slightly higher number of hours spent, both before and after the onset of the illness. A clue to Parkinson's Society membership? The significant drop in group activity supports the findings of other researchers in the area (e.g. Singer, 1974). Parkinson's patients become more and more isolated from interpersonal contacts, and thus less likely to enjoy a circle of close friends, and the kind of support they could use so badly. Worse, it has been found by Singer (1973)

that younger Parkinson's patients are actually less likely to join organisations than are older patients. She found that 45% of her group under 65 did not belong to any organisation, but only 36% of her older group. Perhaps this has a great deal to do with body image. The younger person will be less accepting of his or her prematurely aged body, and may wish to keep it out of sight. It takes a great deal of courage for a shuffling, trembling and drooling forty year old to make a public appearance among active, fit forty year olds. The differences are less apparent in the older person.

Communication problems, both verbal and non-verbal, will discourage group activities. Verbally, the person may not speak loudly enough to be heard. Several subjects gave this as their reason for preferring not to socialize. Others cannot get the words out at any volume, or they speak so slowly that others give up. Of the non-verbal facets - lack of facial expression, nervousness, an appearance of being less than intelligent - none are conducive to relationships. Slowly, the patient withdraws - unless he or she has an active, enthusiastic, and outgoing spouse who literally drags the patient to meetings and other activities. And it is here, the investigator feels, in the personality of the spouse, that one of the differences between members and non-members may lie. Not in marital status *per se*, but in the temperament of the spouse - who has perhaps always been into community, voluntary, and general social activities. Obviously this would be only one of the differences, as many members are not married at all, but it is an area worth following up in

future research.

The Parkinson's Disease Society:

If there is a difference between members and non-members, it is possible that the members are all looking to the Society for the same benefit - something which the non-members would appear not to need, or want. To this end, subjects were asked about where they learned of the Society, what it was that they gained most from membership, and what they felt the Society should be offering.

Most members were found to have learned about the Society from the newspaper, probably the local "freebie" which carries regular advertisements regarding Society functions. Surprisingly, only 12 (22%) members were directed to the Society by their doctors.

The most popular aspects of the Society were the newsletter and the meetings, indicating that information rather than the company might be the important factor. However, the newsletter also talks about real people, reducing the isolated feelings that patients might develop when they feel that they are the only person in the world with the problem. Information seeking has been described as "one of the most universal forms of coping" (Cohen & Lazarus, 1979, cited in Felton & Revenson, 1984, p. 344). The fact that the mean PAIS score of those who listed "information in general" as the aspect of the Society that they found most helpful was 15 points (69%) lower than the mean PAIS

score of those who found "support" the most helpful aspect would appear to be indicative. Cohen (1980) found information seeking to be particularly valuable in recovery and adjustment to illness.

Is this tendency to information seeking among many members a possible reason for the discrepancies found between the leisure activity scores of members and non-members? Information seekers tend to be more outgoing, with a more internalised locus of control regarding their health status (Lefcourt, 1976). They also tend to take more control over the activities they perform that might assist their state of health. In other words, they take responsibility for their health care, and do the best they can.

It is possible, then, that joining the Society is a function of an already information-seeking personality. Then again, by joining the Society, more information has been gained, and the joining itself has made adjustment easier. Again, the question is raised as to whether the differences between members and non-members have been brought about by the Society, or whether they were there to start with. This is a key question which must be examined in future research.

Almost 50% of members attend most meetings, despite the fact that only 33% saw meetings as a most important aspect of membership. Eighteen point five percent attended about half the meetings, 9.3% the odd meeting, and 25.9% none at all. The most common reasons given for nonattendance were transport and health. All

of the patients answering with these two reasons said they would love to come to meetings, but had no one they felt they could ask to take them. Several women in a small town, several miles away from the city of Palmerston North, all voiced the same feeling. If a bus or taxi system would pick them up, so that they were not bothering anyone, they would attend all the meetings, though one woman would have needed an escort to give her the confidence to face the world again. Three of the more active members stated that they did not feel the need of the meetings (but were still very enthusiastic about the information), while four felt they were too depressing. All subjects in these latter two groups admitted that when things got worse, they would no doubt go to meetings - but were not ready for them yet. There was no question of trying to hide from the truth, and this was reflected in low average PAIS scores (31.00 and 28.00).

The reasons given by non-members for not wishing to join the Society were varied. Again, medical conditions and transport problems accounted for 42%. However, these conditions did not stop the members from joining, only from attending meetings. Perhaps more telling were those who "never joined groups" (19%), and those who preferred to avoid others with Parkinson's disease altogether (12%). Incidentally, all five subjects who stated that they were able to live a normal life without joining the Society admitted that they would probably join when things got bad.

Psychological variables

As results indicate that there was clearly a difference in the behaviour of the two groups, members and non-members, it is important to isolate the causes of that difference. While the differences between the two groups before the illness were not major, there was a trend towards some dissimilarity, for example with the amount of time spent on certain activities such as hobbies, television viewing and the other variables discussed in the section on leisure activities. With this in mind the PAIS scores on individual sections of the PAIS were compared for members and non-members. An ANOVA found no significant difference between them. Table 30 does, nevertheless, show that there may be some small differences, particularly in the domestic environment section, the extended family relationships, social environment, and psychological distress section. There are consistently higher scores here for non-members than for members.

The Domestic Environment section examined the relationship of the patient with spouse and family, domestic impairments, communication, dependency on others (and how it is perceived), physical disability, and finances. Scores in this section were sometimes all very high, or all very low. If one relationship crashes under the illness, so will others. Surprisingly, physical disability does not always have a great deal to do with this. If there were problems in the domestic environment, there were sure to be problems in the extended family relationship

environment. Again, sociability, or lack of it, does not necessarily depend on physical problems. One of the most disabled men interviewed was still an interested and valued member of the whole family - a reflection, no doubt, on the characters of both himself and his family. In other families, men and women less disabled were obviously already a burden, to themselves and their caregivers. The investigator admits to being relieved to leave this type of home - the vibes that filled the air were oppressive, most likely because of the quiet desperation of the discredited patient and a family possibly feeling pangs of guilt, rather than being any antagonism towards the interviewer.

The Social Environment section reflects the information gained in the earlier questions on social and leisure activities. However, the change is in the fact that interest is taken into account as well as participation. Even the most disabled patient can still be interested in certain activities, and many were. Again, the average score for Parkinson's Society members was slightly lower than for non-members, though not significantly so.

The last section of the PAIS, examining psychological distress, likewise showed a trend towards greater distress in non-members than in members, although again the difference was not significant. It is possible that this trend was due to personality variables already in place before the illness, which intimated whether or not the patient would join the Society. However, it is also possible that the trend was due to superior coping skills through better knowledge, and greater support

gained by Society membership. Although these differences were not significant, the trend would suggest that future research in the area might be worth pursuing.

Conclusion

A number of the results found in the present study indicate that there are differences between members and non-members of the Parkinson's Society. That the white collar and professional worker is more likely to join a Society is apparent from the present study as well as from research overseas. Tremor is significantly worse in non-members, although there were no differences in walking and speech problems between members and non-members. Tremor may be the symptom that has most effect in causing a patient to avoid going out. There is some suggestion that members are more likely to be city dwellers. In leisure activities, there were large differences in the amount of time members spent on hobbies and socializing in comparison with non-members, despite the fact that in most categories, members and non-members had spent similar amounts of time indulging in hobbies and socializing prior to illness. It was also found that where the differences between the time spent before on an activity, and the time spent now, were biggest, the PAIS score was highest, indicating less successful adjustment.

Putting all of this information together, a picture of a typical Society member begins to emerge. A member of the Society is most likely to be either a white collar or professional worker, probably living in the city, with a tremor, but not a severe

tremor, who is interested in gaining all the information he or she can about the illness and what to expect from it. It is likely that this person will belong to other organisations, but if not, will have a number of other interests in life, having continued with old hobbies, or replaced the old with a new one. If the person is still mobile, it is likely that walking or bowls, or even golf, are an important part of life. It is also likely that if this person is married, the spouse will be an outgoing person, who likes to take the patient out to Society meetings, and no doubt other venues.

However, this study has the limitation that it is essentially correlational in design, and little can be said about causal relationships between the variables. While there appear to be some clear differences between members and non-members, and even a suspicion of differences before the illness, nothing can be said about the reasons for these differences. If the differences were there before the onset of the illness, it is likely that the Society membership was incidental in the obviously greater amount of time spent in leisure activities by the members. If the difference was not there before the illness, then membership of the Society itself must have had a major influence on the activities of patient. If the answer is the latter, then it is imperative that more patients learn of the Society and are encouraged to join. If the answer is the former, however, the question must be asked as to whether Society membership would help the person - if he or she could be convinced to join.

For this reason, future research should bear in mind the implications of membership in the Society. A number of issues have been raised within the present study relating to the differences between members. Clearly members are, on average, dealing with their illness more successfully, are getting out and about more, and coping with the misery that Parkinson's disease can bring, on a more competent level. Future research must look towards, first of all, learning why some people join and others do not. If it is a matter of occupation, and therefore possibly educational level, then it is important that the blue collar workers are located and encouraged to join a Society. Education is needed here. If it is matter of location, something as simple as a taxi bus, as suggested earlier, may solve the problem for some. Further research into these demographic questions is imperative, but it is even more important to look at the differences between the members and non-members now, and ascertain what it is that causes one group, the members, to remain a part of mainstream life more successfully than the non-members. If it is membership *per se*, then a massive membership campaign is in order! But there are almost certainly other factors involved. Extensive research needs to be conducted into the personality factors of the member versus the non-member, and perhaps into the personality of the spouse of the member and non-member. There is, of course, the limitation here that even if a major difference is found, it is not possible to change a person's personality. It is, however, possible, with the right tactics, to encourage most people out into the open, even when suffering from a disabling disease. It is the feeling of this

investigator that even if the differences between members and non-members are found to be part of the personality of the subject, the Parkinson's Society also mediates between the disorder and the world to lessen the impact of the disorder. The reasons for the obvious differences between the members and the non-members are likely to be the combination of these two factors - disposition and Society membership. Therefore, if the non-joiners can be persuaded of the benefits, they too could gain.

The present study was the first in New Zealand, as far as can be ascertained, to look at the differences between those Parkinson's disease sufferers who join a Parkinson's Society and those who do not. It was exploratory in nature, trying to highlight the situational and personal factors that more detailed research can focus on.

Results obtained are generally consistent with previous findings (e.g. Singer, 1973, 1974; Oxtoby, 1982), and point to important directions for future research. The information gained strongly suggests that the Parkinson's Society offers something positive to its members and their families, be it the company or the information. However, the primary focus of immediate future research should be to try to ascertain whether it is the membership itself that brings about the positive differences between the members and non-members, or whether it is only a certain type of personality that joins the Society. This is not clear from the present study.

What is clear though is that Parkinson's patients undoubtedly suffer role loss and isolation, the isolation often still being there when the patient is surrounded by family. Society membership would appear to be one way in which the isolation and suffering can at least be reduced.

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*Incidence of
Parkinson's Disease
in the Manawatu:*

A brief survey.

Sharon Humphries



Incidence of Parkinson's Disease in the Manawatu:

A brief survey.

Survey questionnaires enquiring the number of Parkinson's Disease patients each doctor attended were sent to all doctors in the Manawatu area. Information was also requested as to whether these patients also attended a specialist for their condition. Replies showed that the area contains at least 157 patients with Parkinson's Disease. This information is important for those persons attempting to form support groups or other facilities for persons suffering from the disorder. There was little relationship between the figures received from the doctors, and the area's specialists, indicating that a large number of patients may rely on their family doctor for treatment.

Parkinson's Disease is a slowly progressive condition that occurs when a small area of the brain, the substantia nigra, ceases to produce the neurotransmitter dopamine, plus there is degeneration of the nigrostriatal dopaminergic pathways, which carry the dopamine to the striatum of the basal ganglia. This results in changes to movement, balance and co-ordination, caused by the three main features of tremor, slowness of movement (bradykinesia), and rigidity (Black, 1983).

The illness tends to affect people in their later years but one in seven patients develops the symptoms in their thirties and forties (Stern & Lees, 1982). In the United Kingdom at least one in every thousand of the population will develop Parkinson's Disease, but for the 60 to 70 year age group, approximately one in every hundred (Stern & Lees, 1982). However it is felt that these figures are approximate and may well underestimate the true frequency. Mildly affected individuals may not come to medical attention, and other illnesses may simulate the disorder. In 1966 a detailed study was conducted in the city of Carlisle, showing a prevalence of 113 per 100,000 of the population (Stern & Lees, 1982). Marttila & Rinne (1991) found that among white races, the prevalence rates of Parkinson's Disease ranged from 66 to 187 per 100,000 population, though without any obvious geographical pattern. For Japanese in three cities and a rural area the prevalence ranged from 34.5 to 55.0 per thousand (Kondo, 1984), while for blacks figures are very low (Kondo, 1984; Marttila & Rinne, 1991). Unfortunately no specific figure for blacks could be found.

Pollack and Hornabrook conducted a survey in Wellington, New Zealand, in 1966, when Wellington's population was only 124,000, and found 131 patients with Parkinson's Disease. No more recent or specific figures appear to be available.

The current report looks at the number of patients diagnosed as having Parkinson's disease in the Manawatu region, as per Figure 1. The total population of this district at the 1986 census, as per the Department of Statistics, was 92,495. It was assumed that by 1990, it had reached 100,000 or very close.

A count of those attending a specialist as well as a general practitioner was also taken, and a count of Parkinson's patients attended by the specialists in the area.

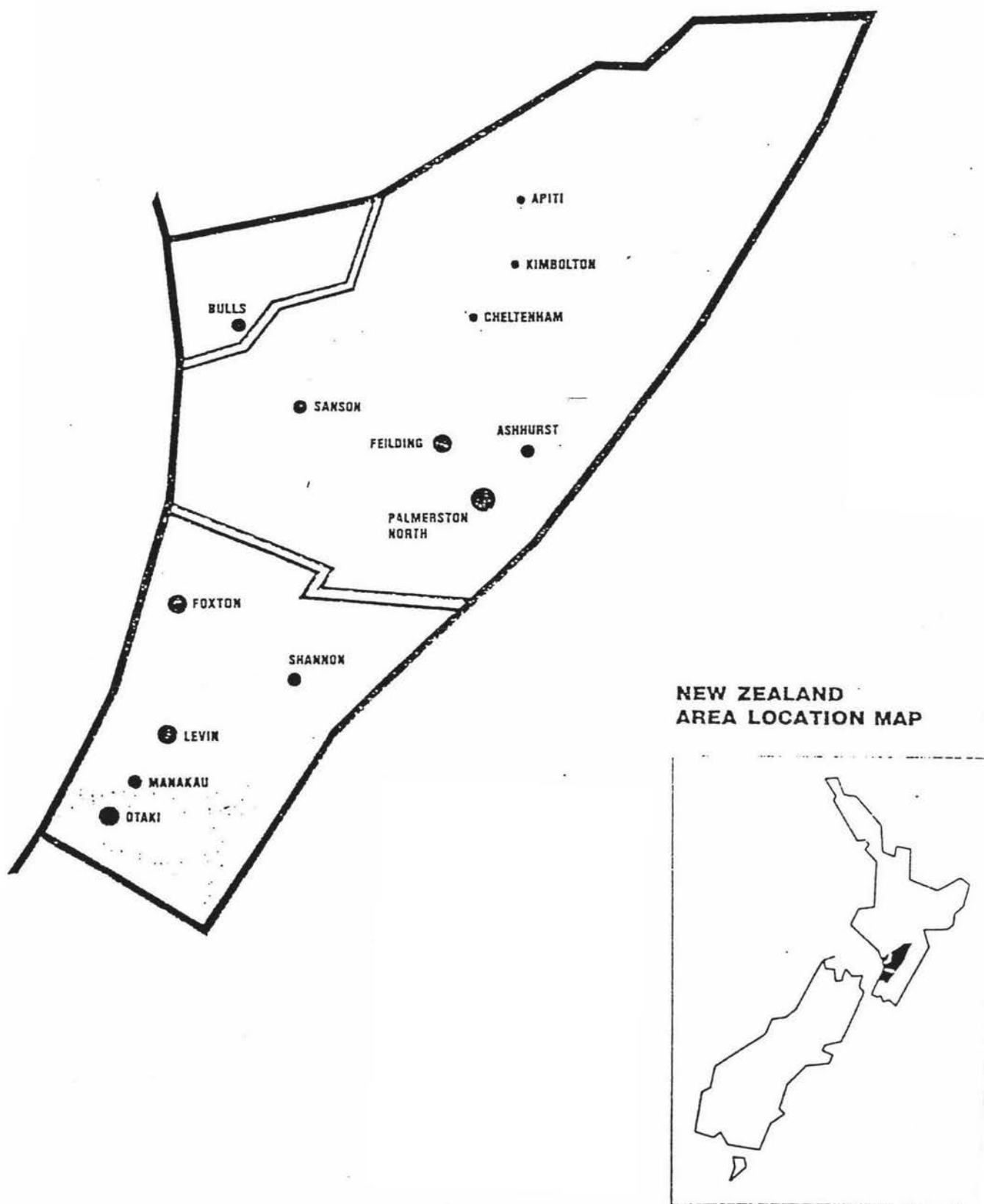


Figure 1: Area covered by survey

Material and Methods

Questionnaires and accompanying letters (Appendices 1 and 2) were sent to every general practitioner in the Manawatu phone book for 1990, and to the three specialists in the area - a geriatrician, and two neurologists. Stamped addressed envelopes were included for the replies.

The information asked for was: How many Parkinson's Disease patients the doctor attended; and in the case of the GPs, how many of these also attended a specialist.

Six weeks later those who had not replied were sent a reminder letter and stamped addresses envelope (Appendix 3).

Results

Of 68 general practitioners, 54 replied by the second posting. Patients being attended to by these practitioners totalled 157.

Of these, according to the general practitioners, 105 also attended specialists.

The specialist's results however were incomplete, as one of the specialists stated that he saw many Parkinson's patients from time to time but that they were "really the G.P.'s patients". The other specialists listed 5 and "approx. 30" respectively.

Discussion

Previous studies showed around one sufferer per thousand population, or in the Wellington Study (Pollack & Hornabrook, 1966) 1.05 per thousand. Of the 14 practitioners who did not reply, one can only guess at their number of Parkinson's patients (if any). Allowing for perhaps another 13 patients in the district attending these practitioners, an estimate of around 1.7 patients per thousand of population can be made.

This estimate is rather higher than previous studies have found, but even using the actual figures, and not allowing for the missing practitioners, a higher figure of 1.57 per thousand is reached. It was stated by Stern and Lees (1982) that they felt that the figures they found might have been rather low. However it is possible that in the intervening years the number of people seeking treatment for the problem may have increased, with patients seeking treatment at an earlier stage, thus raising the number of patients being seen by practitioners.

Of the number of persons known to have Parkinson's Disease in this area, some reside in rest homes, and have reached too degenerated a condition to be able to benefit from support within the community. A further study could be considered to determine this number. Of those still living in the community, 39 persons in the Palmerston North, Fielding, and surrounding areas have joined the Parkinsonism society, which offers information and support. These people benefit greatly from information on progress in treatments, ways of making life easier for the patient and caregiver, mobility aids, and also offer support to the caregiver. For many, it is a rare opportunity to be able to get out and about, as the society offers this service to those otherwise unable to attend meetings.

- This study would appear to indicate that there may be over 100 persons in the community who could benefit from this kind of support, and probably over 100 caregivers. Further studies will attempt to locate many of these people, look at the differences between those who join a society and those who don't, and attempt to ascertain some of the reasons for the differences. e.g. lack of knowledge of the society and what it offers; lack of transport; lack of confidence; other personality factors. Other studies could be made to look at changes made to the present society that might encourage such people to join.

Few conclusions can be drawn regarding the number of persons receiving specialist treatment, however it would appear that unless the specialist who answered so imprecisely has at least 52+ patients, a large number of Parkinson's patients are receiving possibly less than fully up to date care from their busy GP. Medication in the control of Parkinson's Disease is crucial, and close watch must be kept on each individual. Further, and more precise, research in this area could be revealing.

This study is limited by the possible discrepancies between collected and actual numbers, however they can only veer on the low side, and even the low side would appear to show that there are a large number of persons in the community who may welcome support, information, or friendship from others in a similar position. Further investigations will look to these people.

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Dear Dr.

In order to ascertain the number of persons to whom the Manawatu branch of the Parkinsonism Society could be offering their services, it is necessary for us to get a definite idea of the number of cases of Parkinson's Disease in the Manawatu district.

To this end, it would be much appreciated if you would complete the attached short questionnaire, and return to us.

While it is realised that ethically you are unable to supply us with the names and addresses of your Parkinson's patients, it would be appreciated if you could ask your Parkinson's patients to contact us if they are not already in the society. Even if they do not wish to join they can help us greatly with statistics.

We are grateful for your help in this matter.

Yours faithfully,

Sharon Humphries.

Questionnaire for Parkinson's patients

DEMOGRAPHICS

Sex?

Age in years?

Marital status?

Your household:

- Living alone?
- With spouse only?
- With siblings?
- With son/daughter?
- Residential care?
- Other arrangement? Explain.

How old were you when you were told that you had Parkinson's disease?

How long have you had Parkinson's disease?

What Parkinson's medication are you on?

How long have you been on this?

Do you have any other illnesses or conditions which interfere with your activities?

What are they?

At the present time, do you have a paid job or are self-employed?

Yes - full time job (30 hours plus per week)

Yes - part-time job (2 - 29 hours per week)

No - permanently sick or disabled

No - retired

No - unemployed

No - other reason (e.g. housewife)

If you had a full-time job, but are now *no longer working*, how many years since you stopped working?

What has been your main occupation during your working life?

Did your Parkinson's disease have any influence on your decision to finish work?

HEALTH AND HANDICAPS

I would like you to think about various aspects of your health during the last six months. Throughout these questions try to think about when you are feeling *at your worst*, and then *at your best*. I will show you a card on which you will see some descriptions, and I would like you to chose the one which describes you best at those times.

1. *Tremor* - At your worst times:

(Choose one of the following)

a) I can hold a cup normally

b) I have a bit of difficulty holding a cup without spilling anything

c) I have a lot of difficulty holding a cup without spilling anything

Do you have difficulty with any or all of the following:

Doing up buttons and zips

Doing my hair/shaving

Opening bottles, etc.

Writing

Reaching and picking up things

Using switches and handles

Tremor - At your best times:
(Choose one of the following):

- a) I can hold a cup normally
- b) I have a bit of difficulty holding a cup without spilling anything
- c) I have a lot of difficulty holding a cup without spilling anything

Do you have difficulty with any or all of the following:

Doing up buttons and zips
Doing my hair/shaving
Opening bottles, etc.
Writing
Reaching and picking up things
Using switches and handles

2. *Walking* - At your worst times:
(Choose one)

- a) I walk normally
- b) I walk normal distances but a little slowly
- c) I walk only limited distances
- d) I can only take a few steps without help
- e) I can walk only with help
- f) I am unable to walk

Do you have difficulty with any or all of the following:

Starting to walk
'freezing'
Climbing stairs or steps
Negotiating doorways or walking in confined spaces
Answering the door

Getting to the lavatory
Managing alone in the lavatory
Bathing
Sitting down and getting up again
Getting in and out of bed
Turning over in bed

Walking - At your best times:
(Choose one)

- a) I walk normally
- b) I walk normal distances but a little slowly
- c) I walk only limited distances
- d) I can only take a few steps without help
- e) I can walk only with help
- f) I am unable to walk

Do you have difficulty with any or all of the following:

Starting to walk

'freezing'

Climbing stairs or steps

Negotiating doorways or walking in confined spaces

Answering the door

Getting to the lavatory

Managing alone in the lavatory

Bathing

Sitting down and getting up again

Getting in and out of bed

Turning over in bed

3. *Speech* - At your worst times:
(Choose 1)

- a) I have no difficulty with my speech
- b) Strangers have some difficulty in understanding me
- c) Strangers are unable to understand me

Do you also have difficulty with any or all of the following:

Swallowing

Dribbling

Dry mouth

Speech - At your best times:
(Choose 1)

- a) I have no difficulty with my speech
- b) Strangers have some difficulty in understanding me
- c) Strangers are unable to understand me

Do you also have difficulty with any of the following:

Swallowing
Dribbling
Dry mouth

There are some other, more general problems which sometimes affect people with Parkinson's disease. Please tell me which, if any, of those on the card cause you difficulty:

Severe fatigue
Poor eyesight
Loss of hearing
Constipation
Incontinence

TRANSPORT

Getting out and about can be very important. These questions are about your access to and problems with various forms of transport.

Where do you live? Choose one of the following:

Right in a city

In a small town?

If in a small town, how far is your town
from the nearest city?
(____ km)

In the country?

If in the country, how far are you
from the nearest city?
(____ km)

How often do you use the following types of transport? Often, quite often, rarely, never?

Bus

Train

Taxi

Private car

How easy or difficult do you find using each type of transport? On this scale of 1 to 10, where 1 is "easily used" and 10 "impossible", as on this card, rate the difficulty in using the following types of transport:

Bus

Train

Taxi

Private car

Please read through the sentences on this card and tell me the one which best describes your access to a car:

There is a car in the household and I do drive

There is a car in the household: I do not drive, but I get taken out

There is no vehicle or driver in the household, but I can generally get a lift

There is no vehicle or driver in the household and I *cannot* generally get a lift

I am housebound through my disability and unable to get out whether a car is available or not

LEISURE:

The following questions are about hobbies and pastimes.

I am going to look at your chief hobbies and activities in your own house or garden nowadays, and before your illness.

For those activities which you are involved in, I would like you to tell me the number of times each week (on average) that you would be involved in each, and on average the time in hours each session would be. We will look at the time you spend on the activity nowadays first of all, then at the time you would have spent before your illness. This card is to remind you of the times. We aren't going to be absolutely exact, but I would like to know whether you participate in each activity less than once a week, once a week, three to four times a week, or more than this, on average, as is on this card. Then we will look at whether each session would be less than half an hour, an hour, or more than two hours, on average.

Reading nowadays: No. of sessions
Length of sessions

before illness: No. of sessions
Length of sessions

TV, radio nowadays: No. of sessions
Length of sessions

before illness: No. of sessions
Length of sessions

Gardening, indoor plants

nowadays: No. of sessions
Length of sessions

before illness: No. of sessions
Length of sessions

Handicrafts (including, sewing, art, etc)

nowadays: No. of sessions
Length of sessions

before illness: No. of sessions
Length of sessions

Listening to/making music

nowadays: No. of sessions
Length of sessions

before illness: No. of sessions
Length of sessions

Jigsaws, card games, chess, etc.

nowadays: No. of sessions
Length of sessions

before illness: No. of sessions
Length of sessions

Crosswords, other word games

nowadays: No. of sessions
 Length of sessions

before illness:No. of sessions
 Length of sessions

Other activities - you name them

nowadays: No. of sessions
 Length of sessions

before illness:No. of sessions
 Length of sessions

No activities nowadays

 before illness

What things do you most like to do when/if you get out of your own house and garden?

For those activities which you are involved in I'd like you to tell me, just as you did before, the number of times each week (on average) that you would be involved in each activity, and on average the time in hours each session would be, both before and since your illness.

Visiting friends and relatives

nowadays: No. of sessions
 Length of sessions

before illness:No. of sessions
 Length of sessions

Car/coach trips, seeing countryside, etc.

nowadays: No. of sessions
 Length of sessions

before illness:No. of sessions
 Length of sessions

Walking, sitting in park

nowadays: No. of sessions
 Length of sessions

before illness:No. of sessions
 Length of sessions

Visits to theatre, concerts

nowadays: No. of sessions
 Length of sessions

before illness:No. of sessions
 Length of sessions

Sporting activities

nowadays: No. of sessions
 Length of sessions

before illness:No. of sessions
 Length of sessions

Shopping

nowadays: No. of sessions
 Length of sessions

before illness:No. of sessions
 Length of sessions

Travel

nowadays: No. of sessions
 Length of sessions

before illness:No. of sessions
 Length of sessions

Other activities - you name them

nowadays: No. of sessions
 Length of sessions

before illness:No. of sessions
 Length of sessions

No outside activities

Nowadays

Before illness

Do you take part in the activities of any groups, for example church societies, day centres, groups for the elderly and the disabled, and the like?

For those activities which you are (or were) involved in, tell me the number of times each week (on average) that you would be involved in each and on average the time in hours each session would be, just as we did before.

No group activities

Church services and societies

nowadays: No. of sessions
Length of sessions

before illness: No. of sessions
Length of sessions

Senior citizen's clubs

nowadays: No. of sessions
Length of sessions

before illness: No. of sessions
Length of sessions

Country Women's Institute, voluntary societies

nowadays: No. of sessions
Length of sessions

before illness: No. of sessions
Length of sessions

Day centres

nowadays: No. of sessions
Length of sessions

before illness: No. of sessions
Length of sessions

Hobby related groups

nowadays:	No. of sessions
	Length of sessions
before illness:	No. of sessions
	Length of sessions

Other groups

nowadays:	No. of sessions
	Length of sessions
before illness:	No. of sessions
	Length of sessions

THE PARKINSON'S DISEASE SOCIETY

Are you a member of the Parkinson's Disease Society?

If not, have you ever heard of the Parkinson's Disease Society?

THIS SECTION FOR MEMBERS ONLY

As you are a member, I'd like you to please answer these questions

How long have you been a member?

How long after your diagnosis did you become a member?

How long after hearing about the society did you become a member?

How did you learn about the Society?

From another member
 From a friend or relative
 From TV or radio
 From a newspaper or magazine
 From a doctor or hospital worker
 From a social worker
 From a poster on a notice board

Other

Don't remember

In regard to the Parkinson's Disease Society I would like you to read through all the aims given on this card and then tell me the aim you consider *most important* and the aim you consider *next in importance*. Continue in this way until you have rated all the aims - the last will then be the aim which, in your view, is *least important*:

The Parkinson's Society should aim:

To provide an advice and information service to help patients and their relatives with the problems arising from Parkinson's disease

To collect and disseminate information on Parkinson's disease

To press for improvements in health and social services for Parkinson's disease patients

To encourage and provide funds for research into Parkinson's disease

To set up local branches throughout New Zealand for the benefit of patients and their relatives

Which particular aspects of the Society's activities, as written on this card, have you personally found most useful? You can name as many as you like.

Information in general

Newsletter

Meetings

Other members' company

Support for you

Support for your caregiver

Do you ever attend meetings?

If so, how often?

If not, are there any special reasons?

Transport problems
Distance
Time of meetings
Health
Need an escort
Don't feel need them
Shy, afraid of other people
Other

THIS SECTION FOR NON-MEMBERS ONLY

As you are not a member I'd like you to answer these questions:

Have you or your relatives (as far as you know) ever tried to contact other people with Parkinson's disease in your area?

Is there a branch of the society within reasonable travelling distance?

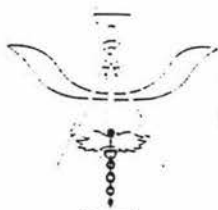
Would you like to belong to a local branch of the Parkinson's Disease Society?

If your answer is no, which of the following reasons, as on this card, best describes your reason for not wishing to join? Note as many as you wish.

- able/wish to lead a normal life
- too busy with other things
- prefer to avoid others with it - too depressing
- don't join groups
- medical condition prevents it
- too remote, travelling problems
- can't really give a reason

PAIS

PSYCHOSOCIAL ADJUSTMENT TO ILLNESS SCALE



CLINICAL PSYCHOMETRIC RESEARCH

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INSTRUCTIONS

The Psychosocial Adjustment to Illness Scale (PAIS) is a semi-structured interview designed to be employed with either medical patients or their relatives to assess the quality of psychological adjustment to a current medical illness.

The scale should be completed by a trained health professional (e.g., physician, psychologist, nurse, social worker, etc.) during and subsequent to a personal interview designed for that purpose. The PAIS interview takes approximately 20-30 minutes to complete, with slight variations in specific instances.

The PAIS approaches psychosocial adjustment to illness via 7 domains of primary relevance. Interview questions are designed to measure adjustment in terms of: I. Health Care Orientation, II. Vocational Environment, III. Domestic Environment, IV. Sexual Relationships, V. Extended Family Relationships, VI. Social Environment, and VII. Psychological Distress.

A total of 46 items concerning the respondent are completed in each PAIS interview. The format is not rigidly fixed; however it is recommended that the interviewer approach the 7 primary domains in the order in which they are presented in the PAIS. Within each adjustment domain, it is further recommended that the items be addressed in their serial order. Suggested questions are provided for each item, and in the section on Psychological Distress, the questions asked of the interviewer are explicitly provided for each item.

In order to adequately conduct the PAIS interview, the interviewer must first ascertain the following information: nature of present illness, occupation of the individual, marital status, household composition, family composition and geographic location, and typical social and leisure activities. For purposes of this interview, the categories of housewife and student are considered as being distinct occupations. When the respondent is a relative of the patient, (e.g. parent, spouse) then questions should be addressed concerning the impact of the patient's illness on the respondent rather than the patient.

The normal time frame for the PAIS interview is 30 days. If the interview is being conducted regarding a hospitalized patient, the referent time should be "the 30 days immediately prior to entering the hospital". If the interview is done in conjunction with an outpatient visit, or at home, the referent should simply be "the past 30 days".

SECTION I - HEALTH CARE ORIENTATION

(1) GENERAL HEALTH CARE ORIENTATION

Could you describe for me your general attitude and approach to taking care of your health?

- [] 0 = very conscientious and attentive to personal health
- [] 1 = reasonably conscientious to health needs - some omissions
- [] 2 = inconsistent about attending to health needs
- [] 3 = clearly inattentive to health needs - minimizes importance

(2) HEALTH CARE - PRESENT DISORDER

Your present condition probably requires some special attention and care on your part; could you tell me about it?

- [] 0 = very conscientious and attentive to present health needs
- [] 1 = reasonably conscientious to present health needs - some omissions
- [] 2 = inconsistent about attending to present health needs
- [] 3 = clearly inattentive to present health needs

(3) GENERAL ATTITUDE TOWARD MEDICINE & PHYSICIANS

Generally speaking, how do you feel about the quality of medical care available and the doctors who provide it?

- [] 0 = very positive with high levels of confidence
- [] 1 = generally positive with some reservations
- [] 2 = somewhat negative with visible cynicism
- [] 3 = clearly negative with a lack of confidence & distrust

(4) ATTITUDE TOWARD PRESENT TREATMENT & DOCTORS

How do you feel about the treatment you have been receiving for your present illness, and the doctors who are treating you?

- [] 0 = very positive with high levels of confidence
- [] 1 = generally positive with some reservations
- [] 2 = somewhat negative with visible cynicism
- [] 3 = clearly negative with a lack of confidence & mistrust

(5) PATIENT EXPECTANCIES - DISORDER

In an illness like yours, everyone has different ideas about their illness and what to expect from it; would you mind telling me about some of your ideas?

- [] 0 = highly realistic expectancies consistent with the facts
- [] 1 = generally realistic expectancies with minor discrepancies
- [] 2 = expectancies somewhat unrealistic, but serving adaptive purposes
- [] 3 = expectancies clearly unrealistic and inappropriate

155 (6) PATIENT INFORMATION - DISORDER

In an illness like yours, different people like to know different amounts of information about what is wrong with them. I wonder if you would mind telling me some of the details about your illness?

- [] 0 = knowledge & understanding accurate and complete
- [] 1 = generally well-informed with some misinformation
- [] 2 = information sparse, with some inaccuracies
- [] 3 = information poor with marked inaccuracies

156 (7) PATIENT EXPECTANCIES - TREATMENT

In an illness like yours, everyone has different ideas about their treatment and what to expect from it; would you mind telling me about some of your ideas?

- [] 0 = highly realistic expectancies consistent with the facts
- [] 1 = generally realistic expectancies with minor discrepancies
- [] 2 = expectancies somewhat unrealistic, but serving adaptive purposes
- [] 3 = expectancies clearly unrealistic and inappropriate

157 (8) PATIENT INFORMATION - TREATMENT

In an illness like yours, different people like to know different amounts of information about their treatment. I wonder if you would mind telling me some of the details about your treatment?

- [] 0 = knowledge & understanding accurate and complete
- [] 1 = generally well-informed with some misinformation
- [] 2 = information sparse, with some inaccuracies
- [] 3 = information poor with marked inaccuracies

SECTION II - VOCATIONAL ENVIRONMENT

(1) VOCATIONAL IMPAIRMENT

Has your illness in any way impaired your ability to do your job? If yes, how, and to what degree?

- [] 0 = no impairment
- [] 1 = mild impairment
- [] 2 = moderate impairment
- [] 3 = marked impairment

(2) PERSONAL PERFORMANCE EVALUATION

How adequately do you do your job now?

- [] 0 = complete adequacy
- [] 1 = slight inadequacy
- [] 2 = moderate inadequacy
- [] 3 = marked inadequacy

(3) TIME LOST ON THE JOB

During the past 30 days, have you lost any time at work due to your illness?

- [] 0 = 3 days or less
- [] 1 = 1 week
- [] 2 = 2 weeks
- [] 3 = greater than 2 weeks

(4) VOCATIONAL INVESTMENT

Is your job as important to you now as it was before your illness?

- [] 0 = equal or greater importance
- [] 1 = only slightly less important than before
- [] 2 = clear loss of investment in job situation
- [] 3 = minimal investment remaining in job

(5) VOCATIONAL GOALS

Have you had to change your basic goals regarding your job as a result of your illness?

- [] 0 = goals unchanged
- [] 1 = slight modification related to illness
- [] 2 = significant reduction in scope & comprehensiveness of goals
- [] 3 = marked modification or shift in goals

(6) INTERPERSONAL CONFLICTS

Have you noticed any increase in arguments, friction, or difficulty in getting along with your coworkers since your illness?

- [] 0 = none
- [] 1 = slight increase in friction
- [] 2 = moderate increase in friction
- [] 3 = marked increase in friction

SECTION III - DOMESTIC ENVIRONMENT(1) QUALITY OF RELATIONSHIP - PRINCIPAL COHABITANT

How would you characterize your relationship with your spouse (boyfriend, parent, etc.)?

- [] 0 = very good
- [] 1 = adequate
- [] 2 = somewhat inadequate
- [] 3 = markedly inadequate

(2) QUALITY OF RELATIONSHIP - ADDITIONAL COHABITANTS

How would you characterize your relationship with the other people you live with (e.g., children, grandparents, etc.)?

- [] 0 = very good
- [] 1 = adequate
- [] 2 = somewhat inadequate
- [] 3 = markedly inadequate

(3) DOMESTIC IMPAIRMENT

To what degree has your illness interfered with your duties and tasks around the house?

- [] 0 = no interference
- [] 1 = slight interference, easily overcome
- [] 2 = substantial impairment of some domestic duties
- [] 3 = marked impairment, affecting all or nearly all tasks

(4) FAMILY ADAPTABILITY

In those areas where you have found your abilities impaired by your illness, has the family shifted roles to take over those duties?

- [] 0 = excellent family adaption
- [] 1 = generally adequate adaption with some flaws
- [] 2 = generally inadequate adaption
- [] 3 = highly inadequate adaption

(5) FAMILY COMMUNICATION

Has your illness resulted in any decrease in communication between yourself and members of your family?

- [] 0 = no decrease in communication
- [] 1 = slight decrease in communication - no withdrawal
- [] 2 = substantial decrease in communication with some withdrawal
- [] 3 = marked reduction in communication with significant withdrawal

(6) DEPENDENCY POSTURE

Many people with an illness such as yours feel they need help from other people in getting things done from day to day; do you feel that you need that kind of help, and is there anyone available to provide it?

- [] 0 = dependency posture consistent with resources
- [] 1 = dependency posture slightly inconsistent but still adaptive
- [] 2 = dependency posture somewhat inconsistent with resources
- [] 3 = dependency posture markedly inconsistent with resources

(7) PHYSICAL DISABILITY

Have you experienced any physical disability associated with your illness?

- [] 0 = no physical disability
- [] 1 = slight physical disability
- [] 2 = moderate physical disability
- [] 3 = marked physical disability

(8) FINANCIAL RESOURCES

An illness such as yours often creates a drain on a family's financial resources; are you having any difficulty meeting the financial demands of your illness?

- [] 0 = no financial drain
- [] 1 = slight financial drain
- [] 2 = substantial financial drain
- [] 3 = marked financial hardship

(1) QUALITY OF INTERPERSONAL SEXUAL RELATIONSHIPS

Sometimes, having an illness can create problems in a close interpersonal relationship; has your illness led to any problems in your relationship with your. _____
(husband, wife, boyfriend, fiancé, etc.)?

- [☒] 0 = no change in investment or intensity of relationship
- [] 1 = slight reduction in intensity of relationship
- [] 2 = significant reduction in intensity or investment
- [] 3 = relationship terminated, with present illness a causal factor

(2) SEXUAL INTEREST

When some people become ill they report a loss of interest in sexual activities; have you experienced a reduction of sexual interest associated with your illness?

- [☒] 0 = none
- [] 1 = slight
- [] 2 = moderate
- [] 3 = significant

(3) FREQUENCY OF SEXUAL ACTIVITY

Has there been a reduction in the frequency of your sexual activities during the past month?

- [☒] 0 = no decrease
- [] 1 = slight decrease
- [] 2 = marked decrease
- [] 3 = no sexual activity

(4) SEXUAL SATISFACTION

Has there been any change in the pleasure or satisfaction you derive from sexual activities?

- [] 0 = no change in sexual satisfaction
- [] 1 = slight reduction in pleasure or satisfaction
- [] 2 = marked reduction in pleasure or satisfaction
- [] 3 = no sexual pleasure or satisfaction

(5) SEXUAL DYSFUNCTION

Do you believe the difficulties that you have been having sexually result from a sexual dysfunction (problem) in either yourself or your partner? (If answer is yes, then ask:) Could you tell me a little more about it?

- [] 0 = no specific sexual dysfunction
- [] 1 = mild & transient dysfunction present
- [] 2 = substantial but intermittent dysfunction present
- [] 3 = substantial and continuous dysfunction present

(6) INTERPERSONAL CONFLICT - SEXUAL

Have any conflicts or arguments developed between you and your partner as a result of any sexual difficulties you have been having?

- [] 0 = no conflicts
- [] 1 = mild conflicts
- [] 2 = moderate conflicts
- [] 3 = marked conflicts

SECTION V - EXTENDED FAMILY RELATIONSHIPS(1) COMMUNICATION

Have you had as much communication with members of your family outside your immediate household since your illness (e.g., called them on the phone, written to them, etc.)?

- [] 0 = communication levels same as previous
- [] 1 = communication reduced slightly
- [] 2 = communication reduced significantly
- [] 3 = communication practically nonexistent

(2) INTEREST IN INTERACTING

Have you remained as interested in interactions or activities with these members of your family as you were prior to your illness?

- [] 0 = same level of interest
- [] 1 = slight reduction in interest
- [] 2 = substantial reduction in interest
- [] 3 = lack of interest in extended family

(3) PHYSICAL DEPENDENCY

Do you depend on these members of your family for support and physical help, particularly since your illness?

- [] 0 = totally independent of extended family
- [] 1 = some dependency, slightly inconsistent with degree of family commitment or capacity
- [] 2 = some dependency, clearly beyond degree of family commitment or capacity
- [] 3 = marked dependency, well beyond the degree of family commitment or capacity

(4) SOCIAL DEPENDENCY

Do you socialize much with these members of your family?
Has your illness reduced your ability to do so?

- [] 0 = no socialization, or absence of negative change
- [] 1 = slight reduction in socialization
- [] 2 = substantial reduction in socialization
- [] 3 = socialization with extended family totally eliminated

(5) QUALITY OF RELATIONSHIP

In general, how well have you been getting along with these members of your family recently?

- [] 0 = same as previously
- [] 1 = slightly less satisfactorily
- [] 2 = significantly less satisfactorily
- [] 3 = very poor compared to previously

SECTION VI - SOCIAL ENVIRONMENT(1) INDIVIDUAL LEISURE INTEREST

Are you still as interested in your leisure time activities and hobbies as you were prior to your illness (i.e., watching T.V., sewing, bicycling, etc.)?

- [] 0 = same level of interest as previously
- [] 1 = slightly less interest than before
- [] 2 = significantly less interest than before
- [] 3 = little or no interest remaining

(2) INDIVIDUAL LEISURE ACTIVITIES

How about actual participation? Are you still actively involved in doing those activities?

- [] 0 = participation remains unchanged
- [] 1 = participation reduced slightly
- [] 2 = participation reduced significantly
- [] 3 = little or no participation at present

(3) FAMILY LEISURE INTEREST

Are you as interested in leisure time activities with your family (i.e., playing cards & games, taking trips, going swimming, etc.) as you were prior to your illness?

- [] 0 = same level of interest as previously
- [] 1 = slightly less interest than before
- [] 2 = significantly less interest than before
- [] 3 = little or no interest remaining

(4) FAMILY LEISURE ACTIVITIES

Do you still participate in those activities to the same degree you once did?

- [] 0 = participation remains unchanged
- [] 1 = participation reduced slightly
- [] 2 = participation reduced significantly
- [] 3 = little or no participation at present

(5) SOCIAL LEISURE INTEREST

Have you maintained your interest in social activities since your illness (e.g., social clubs, church groups, going to the movies, etc.)?

- [] 0 = same level of interest as previously
- [] 1 = slightly less interest than before
- [] 2 = significantly less interest than before
- [] 3 = little or no interest remaining

(6) SOCIAL LEISURE ACTIVITIES

How about participation? Do you still go out with your friends and do those things?

- [] 0 = participation remains unchanged
- [] 1 = participation reduced slightly
- [] 2 = participation reduced significantly
- [] 3 = little or no participation at present

SECTION VII - PSYCHOLOGICAL DISTRESS*

*In this section, the questions to be answered by the interviewer are presented along with suggested questions to the patient, which appear enclosed in parentheses.

(1) ANXIETY

Does the patient manifest signs or complain of symptoms of fear, nervousness, or anxiety?

(Have you been feeling anxious or nervous recently?)

- [] 0 = not at all
- [] 1 = mildly
- [] 2 = moderately
- [] 3 = markedly

(2) DEPRESSION

Does the patient manifest signs or complain of symptoms of sadness, dysphoria, or loss of life interest?

(Have you been feeling sad or depressed at all recently?)

- [] 0 = not at all
- [] 1 = mildly
- [] 2 = moderately
- [] 3 = markedly

(3) HOSTILITY

Does the patient manifest signs or complain of symptoms of anger, hostility, or irritability?

(Have you been more irritable or angry recently?)

- [] 0 = not at all
- [] 1 = mildly
- [] 2 = moderately
- [] 3 = markedly

(4) GUILT

Does the patient manifest signs or complain of symptoms of guilt, blame, or remorse?

(Have you been feeling guilty or like you have let people down lately?)

[]	0 = not at all
[]	1 = mildly
[]	2 = moderately
[]	3 = markedly

(5) WORRY

Does the patient admit to or complain of worrying about his/her condition or other matters?

(Have you been worrying about things more since you became ill?)

[]	0 = not at all
[]	1 = mildly
[]	2 = moderately
[]	3 = markedly

(6) SELF-DEVALUATION

Does the patient behave or speak in a manner that indicates his/her self-esteem and self-evaluation has fallen?

(Have you been feeling down on yourself or feeling inadequate since your illness?)

[]	0 = not at all
[]	1 = mildly
[]	2 = moderately
[]	3 = markedly

(7) BODY-IMAGE DISTORTION

Has the patient experienced a negative body image change as a result of his/her illness?

(Do you think your illness has changed your physical appearance in any way?)

[]	0 = not at all
[]	1 = mildly
[]	2 = moderately
[]	3 = markedly