A STUDY OF PSYCHOLOGICAL DISTRESS IN CAREGIVERS OF PARKINSON'S DISEASE PATIENTS

Thesis submitted in accordance with the requirements of the University of Liverpool for the degree of Doctor in Philosophy by Rosanna Cousins.

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ABSTRACT

The aim of this PhD was to extend current research on caregiving by investigating outcomes for a large group of caregivers who have been relatively neglected in the caregiving literature. The focus of the research was to identify predictors of psychological distress in caregivers of Parkinson's disease (PD) patients using a longitudinal design and quantitative and qualitative data.

In chapter one, Parkinson's disease is described in sufficient detail to illustrate the demands of PD caregivers. In chapter two, the caregiving literature is reviewed. The major factors in the prediction of caregiver distress are covered and various hypotheses are made with respect to Parkinson's disease caregiving. It was hypothesised that the much greater physical demands placed on those who give care to PD patients would mean that the predictors of negative outcomes may not be the same as the predictors of distress in other caregiving situations.

In chapter three, current models of caregiving are presented and evaluated. As caregiving can be perceived as being a job, theories from the organisational stress literature as well as the caregiving literature were used to conceptualise PD caregiving in a simple model. From the organisational literature, it was hypothesised that the interaction of job demand and discretion would predict distress, and that uncertainty, or lack of knowledge, would be a predictor of distress. A methods section follows in which the choice of measures is discussed. In this research, caregiver distress was not seen as a global concept, but rather it was reduced to six qualitatively distinct components - burden from impact on relationship, burden from impact on social life, emotional burden, depression, poor psychological health and low life satisfaction.

Patients and caregivers were tested on two occasions. The tests and interviews took place approximately fourteen months apart. 83 patients and caregivers took part in phase I; 56 patients and caregivers took part in phase II. The main cause of atrophy was death.

Phase I results are presented in chapter four, and phase II results are presented in chapter five. The main findings were (i) that it was correct to reduce caregiver distress for the predictor variables accounting for the maximum variance were different for each aspect of distress, (ii) patient variables - particularly physical demand and cognitive demand - were found to be important predictors of PD caregiver distress, (iii) caregiver personality and coping style had a major influence on caregiving outcomes, (iv) although there was a measurable progression of PD from phase I to phase II, there was no increase in distress in the same period, (v) there were moderator variables that did not directly predict distress but were nevertheless important to a model of PD caregiving, (vi) contrary to the hypothesis, the more that caregivers knew about PD, the greater their distress. It was suggested that this is a result of having to learn about the illness situation by experience.

Qualitative data is presented in chapter six to describe carers' experiences of Parkinson's disease. Summary statistics and selected case studies are used to illustrate important themes, such as onset, personality change and job demand.

The results are discussed in chapter seven and it is concluded that there are predictors of distress that hold across caregiving situations. These tend to be caregiver variables such as personality and coping style. But there are also predictors of distress that are specific to Parkinson's disease, such as job demand which, unlike in most other caregiving situations, was the biggest predictor of two aspects of distress. It was concluded that a general model of caregiving is not appropriate, and a revised simple model of Parkinson's disease caregiving is presented.

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CHAPTER 1

THE NATURE OF PARKINSON'S DISEASE

1.1 Introduction

This thesis describes the consequences for the primary caregiver of taking on the role of looking after someone who has Parkinson's Disease. The major aim of the research was to extend current models of caregiver distress by undertaking a systematic, theory-based, longitudinal investigation of a large group of caregivers who have been relatively neglected in the caregiving literature.

The approach has been to consider that whilst much of the extant research has indicated that caregiving is "potentially a fertile ground for persistent stress" (Pearlin *et al.*, 1990, p583), that current literature has mainly focused on giving care to demented individuals - particularly people with senile dementia of the Alzheimer's type (SDAT; Williams, 1994). There are, however, many more older adults who receive informal care because they have physical impairments (c.f. Green, 1988). Parkinson's Disease (PD) patients are one such group. In practice the caregiver is most often the patient's spouse, who like the patient, will be elderly.

The thesis explores the degree of distress in those who look after PD patients and examines the potential sources of negative outcomes. The patients studied range from the newly diagnosed to those whose disease is so advanced that those who look after them describe themselves as "24-hour caregivers". It will thus be possible to investigate links between illness and outcomes. A number of Parkinson's patients also presented with dementia. The ability to contrast those who are dementing in addition to having physical impairments with those needing assistance only with activities of daily living makes Parkinson's disease a particularly interesting object of academic study, since it allows investigation of whether the major predictors of negative outcomes for caregivers differ according to the needs of the care recipient. It has been suggested that giving care to SDAT patients provides a special set of problems (Diemling & Bass, 1986; Palmore *et al.*, 1985), although Montgomery *et al.* (1990) reported that "the overwhelming evidence is that the caregiving experience is not terribly different for caregivers of Alzheimer's victims who remain in the community than it is for caregivers of elders with other impairments" (p.157). In contrast, Clipp & George (1993) argued that there are great differences between caring for someone who is cognitively impaired, as compared with someone who is physically impaired. Brown & Powell-Cope (1991), in the context of family caregiving for AIDS patients, suggest that "while there may be challenges common to all caregivers, each subgroup of caregivers face unique psychosocial stressors, often related to the characteristics of the care-recipient" (p. 338). The demonstration of similar levels of distress in distinct groups of caregivers does not necessarily mean that the source of that distress is comparable. The aim of this research is to indicate the predictors of distress in caregivers of Parkinson's patients.

The existing literature provided the methodological basis for examining the consequences of Parkinson's caregiving although the care provided to Parkinson's patients was not assumed to be the same as for other groups of caregivers. For example, the much greater level of physical assistance that is typically demanded of PD caregivers, together with the supervision of often complicated medication regimes may be a predictor of distress for Parkinson's carers, although research studies with other groups have consistently found no relationship between dependents' physical limitations and caregiver distress (e.g. George & Gwyther, 1986; Zarit *et al.*, 1980, 1986).

As this investigation primarily concerns caregiving, the introductory review of the nature of Parkinson's Disease includes material which is relevant to the caregiving role. This introductory chapter, in consequence, includes an outline of the pathology and clinical presentation of PD - to illustrate the physical problems of those receiving care; the prevalence and incidence of PD - to demonstrate the extent of caregiving required; and a review of personality and cognitive changes associated with the disease - to illustrate the psychological characteristics of those receiving care. The chapter serves to enable the reader to appreciate the nature of Parkinson's disease, and to present the scenario faced by those who give care to people with PD.

In Chapter 2, the literature on caregiving is reviewed. As Parkinson's disease is an archetypal disease of old age the focus is on the literature associated with caring for older adults. No attempt is made to include studies which explore caregiving in other settings. It is noted that prevailing theories of caregiver burden and stress have been founded on the study of Alzheimer's patients: findings from the dementia literature may not generalise to those giving informal care to someone who has Parkinson's disease without dementia. For example, if the greater physical demands of PD cargiving do predict negative outcomes for caregivers, then this suggests the source(s) of distress in different carer populations may not be the same.

In chapter 3 models of caregiving are reviewed and consideration is given to their relevance for this investigation. To provide a clear picture of caregiving in Parkinson's disease, caregiving was considered to be a job. In formulating the hypotheses it was necessary to supplement theory from the (essentially SDAT) caregiving literature with findings in the occupational stress literature - particularly the notion of *strain* Karasek (1979), and the concept of uncertainty or inadequate *knowledge*. A simple hypothesised model of PD caregiving is presented. The choice of tests is also discussed in chapter 3, followed by details of the design and procedures.

The quantitative results are presented in chapters 4 and 5. Descriptive statistics, correlational data, analyses of variance and multiple regression techniques are used to analyse the data collected with respect to the hypotheses. In chapter 6 qualitative methods are used to describe the experience of giving care to someone who has Parkinson's disease. From interview data a sample of cases was selected to illustrate the heterogeneity of the caregiving situation according to stage of illness, other life events that encroach upon the caregiving situation, and indeed the characteristics of the patient and the caregiver. This chapter is used to explain that distress is only part of the caregiving experience. Caregivers report positive as well as negative outcomes to taking on the caregiving role. Examples and summary statistics are used to illustrate reasons for caregiving, the most stressful aspects for the participants in this study, and satisfaction that arises from doing the job well.

Chapter 7 provides a discussion of the results of the preceding chapters with respect to the hypotheses and the published literature.

1.2 Parkinson's disease: historical perspective

Parkinson's disease is a clinical syndrome characterised by tremor of the limbs at rest, rigidity, slowness of movement, and disorders of posture. The disease is not new. Ancient books have recorded a variety of types of tremors and paralytic disorders. It was noted by Golbe & Langston (1993) that Galen had described components of the "shaking palsy" almost two thousand years ago. Manyam (1990) reported that a similar disease is mentioned in the Indian Ayurvedic medical text of 1000 BC. But because the disease is largely one that manifests with advancing age, it is likely that few individuals would have been at risk until relatively recently. It is then perhaps not surprising that it was not until after 1817, when James Parkinson published *An Essay on the Shaking Palsy,* that understanding and treatment of the disease that was to bear Parkinson's name improved.

Parkinson's essay is made up of six well illustrated case histories. His acute clinical observations drew attention to the distinctive features of the syndrome, however, his descriptions have since required a little clarification (Stacy & Jankovic, 1992). Parkinson did not mention facial immobility or rigidity. Moreover, he categorically stated that "the senses and intellect (are) uninjured" (Parkinson, 1817). Although this assertion remained unchallenged until the turn of the century, a continuing debate over the frequency and types of cognitive impairments in PD has emerged since then. Further, the introduction of surgical and pharmacological interventions has compounded the controversy because these therapies, by themselves, can be associated with mental aberrations (Goetz, 1992).

1.3 Pathology, clinical presentation and treatment.

1.3.1 Pathology

Parkinson's disease is primarily a disorder of later life. The major manifestation is a progressive disturbance in motor function caused by dopaminergic cell loss in the substantia nigra, which projects to the striatum, with formation of Lewy bodies (Bradshaw & Mattingley, 1995). Lewy bodies - laminated, eosinophilic, cytoplasmic inclusions of 7-20 nm in diameter - are associated with degenerating organelles (Gibb, 1993), and may be a non-specific indicator of cell pathology in various neurodegenerative diseases (Stacy & Jankovic, 1992). Most neuropathologists insist on nigral cell loss of at least 60%, with Lewy bodies in the surviving nerve cells as a prerequisite for the diagnosis of Parkinson's disease (Gibb & Lees, 1994). Hence, strictly speaking, definitive diagnosis can only be made post-mortem.

Calne & Langston (1983) suggest that the preclinical phase of PD arrives from an acute exogenous or endogenous insult to the substantia nigra, which is followed by age-related nigral cell attrition leading to the onset and progression of symptoms, typically after the age of 60. Certainly nigrostriatal degeneration must progress until there is 60% of cell loss before the clinical symptoms of PD appear (Gibb & Lees, 1994). Until then, normal maintenance of extracellular concentrations of dopamine (DA) may be achieved by increased activity and DA output by the surviving neurons, and by reduced activity in the reuptake sites responsible for the removal of DA from the synaptic cleft (Bradshaw & Mattingley, 1995). Further compensation in the form of an increase in the number of postsynaptic receptors may follow until eventually there is failure to compensate for the loss of DA output; the first symptoms of PD then manifest themselves.

In the course of compensation, damage may extend from the nigrostriatal system to many other regions, which probably accounts for the considerable heterogeneity in the symptoms, severity, extent and progression of the illness. Hence it is possible to account for PD presenting primarily with or without tremor and with or without cognitive impairments, depression and dementia (Bradshaw & Mattingley, 1995).

1.3.2 Clinical Features

The classic triad of symptoms of PD is tremor, rigidity and bradykinaesia. Presentation of PD is usually asymmetrical and even when there is bilateral involvement it remains asymmetrical throughout its course. The most common early symptom is a rhythmical shaking of one, or occasionally both hands or arms (Pearce, 1992). Tremor, which occurs in a majority, but not all cases of PD (Marsden, 1994) manifests at rest and disappears when the limb is used and during sleep. Rigidity, which means a resistance to passive movement of equal degree in opposing muscles groups, can be detected in a greater proportion of patients than tremor (Selby, 1990). It typically starts axially, and spreads distally to the limbs (Bradshaw & Mattingley, 1995).

The diagnosis of PD remains entirely clinical (Quinn, 1995). Drawing attention to the high rate of misdiagnosis of idiopathic PD - indicated at autopsy - Quinn (1995) has suggested that upper body akinaesia must be present for an established diagnosis of PD. Akinaesia is a specific disorder of movement that only occurs in PD (Selby, 1990). All the muscles from the face to the toes may be involved, although it may remain confined to a small part of the patient's body for many years. It is the core disabling clinical feature of PD is a symptom complex containing most or all of the following:

1. Loss or reduction of spontaneous movement (hypokinaesia).
2. Difficulty in initiating movement.
3. Slowness of movement (bradykinaesia).
4. Poverty of movement (e.g. facial amimia, impaired arm swing).
5. Progressive fatiguing and diminishing amplitude of repetitive alternating movements.

Akinaesia may additionally be a result of impairments of the programming or motor planning required for more complex movements (Bradshaw & Mattingley, 1995).

Other physical features of the disease may manifest themselves as a direct effect of akinaesia:

1. Mask-like face. Both rigidity and hypokinaesia contribute to the reduction of emotional facial movements. The smile is slow to appear, and there may be a reduced blinking rate.

2. Speech. The loss of volume of the voice, the monotony of tone and slurring dysarthia are a result of hypokinaesia of the muscles which participate in the complex and skilled movements required for articulate speech (Selby, 1990).

3. Abnormalities of posture. Impoverished awareness of the centre of gravity is part of the defective motor programme (Pearce, 1992). The failure of postural reflexes and righting reflexes explains the frequent falls in some patients.

4. Handwriting. Micrographia, a progressive decrease in the size and speed of writing over a couple of lines (Bradshaw & Mattingley, 1995), is an early and almost invariable complaint in Parkinson's patients (Selby, 1990). It is a result of hypokinaesia in the hands affecting the skilled movements required to write legibly.

5. Dexterity. Difficulties with fine movements such as fastening small buttons and shoelaces, using a knife and fork, winding a watch, and cleaning one's teeth appear early (Selby, 1990). Bradykinaesia means that all voluntary movements are slowed, and everything takes longer to do than before.

6. Bladder problems. Urge incontinence, frequency, and a poor stream are common symptoms. Incontinence occurs in 5-10% of male patients (Pearce, 1992).

7. Constipation. Constipation is almost invariable. It is caused by slowing of intestinal peristalsis. This causes much distress to patients, although intestinal obstruction rarely occurs. Purgative abuse is frequently encountered (Pearce, 1992).

8. Sexual disorders. This issue is worse when the affected patient is male. Over half of all PD patients have sexual problems which lead to avoidance of, or infrequent intercourse. Lack of orgasm is common in females and impotence and premature ejaculation are common in men (Brown *et al.,* 1990).

9. Sialorrhoea. The constant dribbling frequently seen in more advanced patients is not due to excessive production of saliva but is a result of immobility of the mouth, tongue,

palate and pharyngeal musculature which stops the normal spontaneous subconscious swallowing movements to dispose of saliva (Selby, 1990).

1.3.3 Rate of progression

> "So slow and nearly imperceptible are the first inroads of this malady, and so extremely slow is its progress, that it rarely happens that the patient can form any recollection of the precise period of its commencement".
>
> Parkinson (1817).

This is a constant and characteristic feature of the disease. Many patients do not consult a doctor for several months or even years because while the earliest symptoms may be a nuisance, they are not disabling. Typically, the first symptoms of PD are only elicited by close questioning.

In the majority of cases progression is slow, but nevertheless, the disease is invariably progressive: remissions do not occur (Selby, 1990). The course and progression of PD has changed in the last 30 years since treatment with levodopa became available in 1967. Most patients improve with levodopa treatment, and a complete lack of response suggests an alternative diagnosis (Gancher, 1992). Not all symptoms, however, improve to an equal degree (Bonnet *et al.,* 1987) and the fact that chronic levodopa therapy is complicated by motor fluctuations (Marsden & Parkes, 1977) indicates that to alter the natural course of the disease meaningfully, significant novel therapeutic approaches must be tested. Indeed, trials abound describing the effects of a wide variety of drugs: most new pharmacological therapies focus on the dopaminergic system (Goetz, 1997). Nevertheless, at present levodopa remains the most effective pharmacological agent available for the relief of Parkinsonian symptoms (Hurtig, 1997).

1.3.3.1 Pre-levodopa era

Before treatment with levodopa became available, prognosis of Parkinson's disease was poor. The prevailing view was that a diagnosis of PD meant inevitable invalidism after seven or eight years (e.g. Mjönes, 1949), until Schwab (1960) presented evidence that this was not necessarily true for all patients. He put forward 40 patients (from a series of 800 patients) who had survived for 25-29 years since the onset of symptoms - one half of which remained independent. Following from this he divided progression into five grades, cautioning that in his work he had found no relationship between age of onset or duration of illness and prognosis or progression of illness (see table 1.3.3.1.1 below).

Table 1.3.3.1.1 Grades of Progression. (Percentage of patients in parentheses).
(from Schwab, 1960).

1. Patients with symptoms so mild that they presented problems in diagnosis. (10%)
2. Where the disease may remain unilateral for many years, slight progression appearing only in the fifth or sixth year. (25%)
3. Symptoms of moderate severity, though the patients remained independent and able to work after 10 years with the disease. (25%)
4. Progression is slow, but tremor and rigidity are bilateral and severe after five years and the patient usually becomes invalided and dependent after 8-10 years. (20%)
5. A rapid progression within the first year after onset, with severe bilateral tremor and rigidity, akinaesia and disorders of gait and balance, so that the patient becomes completely dependent on help and is bedridden within 3-4 years from the onset of the disease. (20%)

Schwab reported that a "benign group", perhaps 10-15% (i.e. Grade 1+) appear to remain without clinical deterioration for 20 years or more, but, as Pearce (1992) pointed out "doubtless their fundamental nigrostriatal dysfunction is of different pathogenesis from the classic type of disease" (p. 35). The diagnosis of Parkinson's disease remains entirely clinical, and a monosymptomatic disorder called *essential tremor* is commonly misdiagnosed as PD (Quinn, 1995). In support of Pearce's assertions that Schwab's sample was contaminated by mistaken diagnoses of PD, two recent studies from Parkinsonian brain banks revealed that 25% of cases which were carrying, at death, a diagnosis of idiopathic Parkinson's disease, did not have the disease (Hughes *et al.*, 1992; Rajput *et al.*, 1991). Certainly, Schwab's staging system, whilst pioneering, has not stood the test of time.

In 1967, Hoehn & Yahr published the best known and most influential publication concerning the onset, progression and mortality of Parkinson's disease and introduced a staging system which is still used to identify the status of Parkinson's patients (see table 1.3.3.1.2 below). They considered the history of 866 patients first seen within two years of onset of PD, then followed up in their clinic during the period 1949-1964 (i.e. before levodopa became available). Of the patients who had first attended their clinic during 1950-1954, 83% were either dead or totally dependent when reviewed 10-14 years later. Of the patients who had first attended their clinic during 1960-1964, 25% were either dead or totally dependent when reviewed in 1966. They reported that the mortality rate of PD patients was three times that of the general population of the same age, sex and colour (Hoehn & Yahr, 1967).

Table 1.3.3.1.2 Hoehn & Yahr Degree of Disability Scale (adapted from Hoehn & Yahr, 1967).

Stage 1. Unilateral, a single extremity tremor and mild rigidity; mild inconvenience, lasting about 3 years.

Stage 2. Asymmetrical bilateral tremor and rigidity, a mildly flexed posture with limb adduction, facial masking, monotonous hypophonic speech, mild gait disturbance and slowness, decreased spontaneous movement, mild fatiguability. About 6 years total.

Stage 3. Disequilibrium, impaired balance, posture, and righting reflexes especially on turning or if pulled backwards; hesitation, freezing, festination. About 7 years total.

Stage 4. Help may now be needed for walking, dressing, feeding, or bathing. Around 9 years total.

Stage 5. Severe disability requiring use of wheelchair or bed; complete invalidism. Death due to the complications of inactivity after a total of about 14 years.

1.3.3.2 Levodopa era

The discovery of levodopa aroused tremendous optimism with respect to the prognosis of Parkinson's disease. The initially spectacular improvements in tremor, rigidity, akinaesia, in the patient's speech and gait appeared to indicate that there was a cure for PD (e.g. Cotzias, 1971). By 1975, however, patients and their doctors realised that this optimism was misplaced. About half of the patients began to deteriorate, at least in some aspects of the disease, after 2-5 years of beginning treatment (Selby, 1990).

By 1976, the mortality rate for PD patients treated with levodopa had dropped from three times to 1.5 times greater than the general population (Yahr, 1976), but a large number of reports appeared at this time confirming the gradual failure of treatment with levodopa in more than half the people who had been taking it for 5-7 years (Selby, 1990). To obtain an accurate assessment of the efficacy of levodopa treatment it is essential to have ongoing assessment and long-term evaluation. For example, Hunter *et al.* (1973) observed that of 178 patients, only 60% maintained their initial improvement two years after start of levodopa treatment (quite apart from emerging complications). A six-year review of the same patients (Shaw *et al.,* 1980) provided a mortality ratio of 1.5:1. Of the total sample, some patients had been unable to tolerate levodopa for longer than 2 years. For these patients the observed to expected deaths were 2.38:1. For those able to tolerate sustained medication life expectancy was normal. However, when this same sample were reviewed after 12 years of therapy, the mortality ratio had risen to 2.59:1. This series of results strongly suggests that the protective effect of levodopa therapy declines with the progression of the illness, and two more recent studies (Ben-Shlomo & Marmot, 1995; Ebmeier *et al.,* 1990) suggest that mortality from PD compared with that of the general population has not altered very much from the prelevodopa days (Hoehn & Yahr, 1967). The latter findings, however, could be because mortality rates have improved for both groups. Certainly, therapy with levodopa modifies the rapidity with which the Hoehn & Yahr stages are reached (see table 1.3.3.1.2 above), but the underlying disease progresses at the same rate (Bradshaw & Mattingly, 1995).

Before the introduction of levodopa medications, anticholinergics were used to control tremor, but not extensively, as these drugs are not efficacious against rigidity, akinaesia or instability. Furthermore, they can have unpleasant side effects (Bradshaw & Mattingly, 1995). Despite the discovery in the late 1950's that there was a depletion of dopamine and its metabolites in the brains of Parkinsonians (Ehringer & Hornykiewicz, 1960), until Cotzias (1967) prepared a crude D-L-isomeric mixture of dopa, it was not possible for patients to ingest dopamine, because it does not cross the blood-brain barrier. Cotzias' pioneering treatment, however, subjected patients to considerable toxicity in the early stages of treatment (Pearce, 1992) until it was refined in favour of the purer levodopa. Levodopa is a precursor of dopamine which is converted in the brain to active dopamine. Levodopa is now usually combined with a carboxylase inhibitor to prevent peripheral breakdown of the drug and to reduce the gastrointestinal side-effects (specifically, nausea and vomiting) which were previously common at the start of treatment (BMA, 1994).

1.3.3.3 Complications associated with Parkinsonian medication

Clinical efficacy, as seen by improvement in motor function, is very variable. Most patients experience a smooth, lasting response to a small dose of levodopa at the start of treatment, but as the underlying disease progresses treatment-related problems arise. Motor fluctuations, which slowly emerge after 3-5 years of sustained therapy, gradually replace the smooth pattern of response and become more frequent, requiring a greater dose for their control (Hurtig, 1997).

The dose of levodopa often has to be reduced to sub-optimal levels because of the appearance of choreic (twitching) or athetoid (writhing) movements called *dyskinaesias* (Selby, 1990). They typically occur 1-3 hours after medication when brain levels of dopamine are at a peak (Pearce, 1992). The drug-induced movements affect the head and limbs and may distort the trunk. In the limbs dyskinaesias range from mild and intermittent choreic movements to severe, bizarre dystonic postures which may last for hours. Painful clawing of the toes and hands are signs of *dystonia*, an involuntary contraction of the muscles, which may occur at peak dose, or when the effects of the dose are wearing off (Pearce, 1992). Critically, the appearance of dyskinaesias can be as disabling as the true symptoms of the disease. They can force patients to sit or lie on the floor to avoid being thrown from a chair. Similarly, for the patient's caregiver, the dyskinaesias can be more trouble than for the patients themselves, as in addition to having to make sure that the patient is in a safe environment at these times, the movements are often embarrassing and unsightly. It is virtually impossible to eat without making a mess when dyskinaesias are present and this tends to restrict social activities.

For about two-thirds of patients on sustained therapy with levodopa for six years, the beneficial effects of the drug wear off 2-3 hours after the last dose and they can feel themselves becoming slower and more akinetic (Shaw *et al.*, 1980). This is called the *wearing-off effect.* This end-dose loss of effect progresses to non-dose-related "on-off" fluctuations (Guridi *et al.*, 1993). During *"on"* periods, patients may be mobile and independent (but often with dyskinaesias); during *"off"* periods they may experience sudden freezing. The feet “stick” to the floor for a short period of time. Some patients become completely immobile (although an injection of Apomorphine can be an effective antidote to this). At this stage, symptom control of Parkinson's disease may be markedly decreased. The transformation from a normally active and mobile person to an akinetic, stooped and shuffling person can be rapid; the end of the "off" period and the re-emergence of relatively normal upright person again takes place in the course of only a few minutes (Selby, 1990). Caregivers of these patients may find that they have similar "on-off" demands. Their care-recipient may be able to look after and do tasks themselves when "on", but the caregiver will be very much in demand when the patient is off. The most difficult thing about "on-off" attacks is their unpredictability (Marsden & Parkes, 1976), which tends to be as troublesome for the caregiver as for the patient.

1.3.3.4 Side-effects of Parkinsonian medication

In addition to the dose-related complications there is a wide variety of side-effects and toxicity associated with levodopa. These include vivid dreams, hallucinations, delusions, confusion, nausea and orthostatic hypotension (Bradshaw & Mattingly, 1995). As treatment of PD consists of medication which, by design, alter the fundamental neurochemistry of the brain, it is not surprising that there are neuropsychiatric side effects (Cummings, 1992). These may affect many systems, as indicated in table 1.3.3.4.1 below. Visual hallucinations are the most common neuropsychiatric side effect (Cummings, 1992) and may result from all classes of Parkinsonian medication (Parkes, 1981). Hallucinations are generally not a problem, however, for patients taking *Apomorphine*, a relatively non-selective dopamine agonist acting at both D_1 and D_2 receptors (Mouradian & Chase, 1994).

Table 1.3.3.4.1 Side-effects of levodopa medication (Adapted from Pearce, 1992 and Cummings, 1992).

Neuropsychiatric:	hallucinations, psychosis, mood disorders, anxiety, sexual alterations, sleep disturbances, delirium
Cardiovascular:	faintness, postural fall in blood pressure, arrhythmia
Gastro-intestinal:	nausea, vomiting, anorexia
Miscellaneous:	increased libido, red urine, rashes

Cummings (1992) reviewed 29 papers reporting the prevalence of hallucinations arising from the treatment of PD: for patients treated with levodopa the average prevalence was 20% (range 6-38%), although he cautions that the actual prevalence is likely to be higher than this because, in the available reports, hallucinations may not have been sought systematically. "They may be under reported by patients who believe them to be a sign of mental illness" (p. 312). Some support for this assertion is provided by a study which ascertained the prevalence of psychotic symptoms in a group of PD patients with dementia. Of the 101 patients that were investigated, 36 patients (i.e. 35.6%) had either hallucinations, delusions or both (Naimark *et al.,* 1996). However, caution must be taken before extrapolating this figure to the whole PD population. While hallucinations occur more frequently in older patients with co-existent cognitive dysfunction (Roos, 1994), they are not exclusive to this population of PD patients.

As reported in Chapter 6, the presence of hallucinations may be very stressful for caregivers, although generally this is not the case for the patients. Some patients are aware that they are hallucinating; others remain convinced that the hallucinations are real, even when faced with contradictory evidence by the caregiver. Hallucinations in PD usually occur in a normal state of consciousness without delirium (Cummings, 1992). They are typically fully formed images of humans or animals and are stereotyped for each patient (Moskovitz, 1978). In a review of 775 PD patients, of whom 257 had hallucinations, Tanner *et al.* (1983) found no relationship between hallucinations and duration of illness, duration of medication, severity of illness, or dyskinaesias. However, the patients with hallucinations were older, and had more often been treated with amantidine (now rarely prescribed) or anticholinergics. This suggests that age and anticholinergic treatment represent risk factors for hallucinosis, although hallucinations produced by domaminergic drugs can be distinguished from those caused by anticholinergic therapy (Goetz *et al.,* 1982).

Antiparkinsonian therapy also causes a variety of other neuropsychiatric alterations including delusions, mania, anxiety, sexual behaviour changes, vivid dreams and nightmares and confusion (Cummings, 1992). A full discussion is beyond the scope of this thesis. Nevertheless, it is worthy of comment that levodopa is the only naturally occurring substance known to have hallucinogenic properties. Moreover, the behavioural properties of levodopa appear to be common to the dopamine receptor agonists also used in the therapy of PD (anticholinergics have also been associated with hallucinations). It is true that a reduction of either anticholinergic or dopaminergic therapy usually reduces hallucinations - although the response may not be immediate (Goetz *et al.*, 1982), but this is not always the case. Most of the current literature considers that hallucinations in PD are a side effect of medication. However, some caution is advised in so far as there are reports of hallucinations and delusions prior to the discovery of levodopa (e.g. Jackson *et al.*, 1923; Mjönes, 1949). Also, levodopa is rarely given to nonparkinsonian patients. If other people had experienced hallucinations from levodopa, then this would provide more substantive evidence that these symptoms can be attributed to the drugs. As far as the evidence presented to date goes, it is hard to conclude that hallucinations are a behavioural side-effect of the medication rather than part of the disease process.

1.3.4 Summary

This overview of the literature concerning the pathology, clinical presentation and treatment indicates that demands are made on PD caregivers not only from the clinical presentation of the illness, but from dose-related fluctuations and side-effects of medication. While levodopa therapy leads to a great improvement in mobility for the patient to start with - and hence reduces demands on the caregiver - this "honeymoon period", as it has become known, does not continue indefinitely. In the early stage of PD, a patient who is medicated effectively will require only minimal assistance with activities of daily living, and the lifestyle of the patient and caregiver will not be particularly disrupted. However, the medication dosage has to be raised as the disease progresses, as its effectiveness is reduced in the face of further loss of dopamine producing cells. Ultimately the mobility of the PD patient is impaired. The price of maintaining maximum mobility after a period of time is a combination of dyskinaesias, dystonia and freezing spells for many patients, alongside the increasing akinaesia. There are also neuropsychiatric, cardiovascular and gastro-intestinal side-effects of levodopa medication. It was mentioned that experience of visual hallucinations can actually be more distressing for the caregiver than for the patient. Although Parkinson's disease is heterogenous in presentation, what is true for all caregivers, is that as the patient's disease progresses, so the demands put upon them increase.

1.4 Epidemiology

A detailed study in Northampton, England, in 1992, estimated that prevalence of idiopathic PD was 121 per 100,000 (Sutcliffe and Meara, 1995). This represented an increase of 13 per 100,000 on the prevalence found in the same district ten years earlier (Sutcliffe *et al.*, 1985). According to Sutcliffe & Meara, this increase was predictable simply because awareness of PD has increased in that time and many GPs now have a PD register.

Sutcliffe & Meara's English prevalence rates are in between the prevalence of PD of 164 per 100,000 in Aberdeen, Scotland in 1984 (Mutch *et al.*, 1984), and 102 per 100,000 in Rogaland, Norway in 1993 (Tandberg *et al.*, 1995). When prevalence studies from many countries are compared, PD prevalence is generally higher where Caucasians constitute the majority of the population (Kurland, 1958, Marttila &

Rinne, 1976a; Mutch *et al.*, 1986; Rajput *et al.*, 1984a; Sutcliffe & Meara, 1995; Tandberg, 1995) and lower where other racial groups predominate (Harada *et al.*, 1983; Li *et al.*, 1985; Schoenberg, 1988). No geographical region or racial group is entirely free of the disease (La Rue, 1992). In all epidemiological studies, prevalence increases with an increase in age, as illustrated in table 1.4.1 below.

Parkinson's disease is primarily a disease of late middle age and beyond. The average age of onset reported by Hoehn & Yahr in 1967 was 55.3 years. However more recent population-based studies (which represent the demographic characteristics more accurately than the hospital sample of Hoehn & Yahr) have indicated that average age of onset is now up to ten years later, ranging between 61.6 and 65.3 years (Dupont, 1977; Harada *et al.*, 1983; Kessler, 1972; Marttila & Rinne, 1976a; Mutch *et al.*, 1986). This increase can probably be accounted for when one considers that prevalence increases continuously with age, and that (as detailed in Chapter 2) the population is now living longer. There has, however, also been a decrease in the incidence of PD in young age groups which has been attributed to a decrease in environmental exposures (Treves & de Pedro-Cuesta, 1991).

Table 1.4.1 Age-specific prevalence of Parkinson's disease per 100,000 in different studies.
(Adapted from McKeigue & Marmot, 1990)

	Age (years)				
	40-49	50-59	60-69	70-79	Reference
Europe					
Aberdeen 1984	47	78	254	832	Mutch *et al.* (1986)
Carlisle 1961	145	162	315	614	Brewis *et al.* (1966)
Iceland 1963	61	163	936	1581	Gudmundsson (1967)
Northampton 1982	15	64	277	702	Sutcliffe *et al.* (1985)
Northampton 1992	14	187	502	1520	Sutcliffe & Meara (1995)
Sardinia 1972	39	205	342	311	Rosati *et al.* (1980)
Turku 1971	28	136	504	736	Marttila & Rinne (1976a)
Asia					
Yonago 1980	40	86	245	698	Harada *et al.* (1983)
Chinese Cities 1983	92	145	615		Li *et al.* (1985)
North America					
Rochester 1955	5	239	758		Kurland (1958)
Australia					
Victoria 1965	28	166	297		Jenkins (1966)

Of the 802 PD patients seen by Hoehn & Yahr between 1949 and 1964, 404 were men, and 268 were women (Hoehn & Yahr, 1967). Recent studies also support an excess of male to female cases (Ben-Shlomo, 1996), and, with the exception of the door-to-door study conducted in China (Li *et al.*, 1985), where the male to female ratio was 3.7:1, the difference is similar to the 1.5:1 ratio reported by Hoehn & Yahr. Considering the global occurrence of PD, Zhang & Roman (1993) found that the average ratio of males to females is 1.35:1 in prevalence studies and 1.31:1 in incidence studies, although the range was wide. Most recently Tandberg *et al.* (1995) reported that the total age-adjusted prevalence in Norway was calculated to be 120.9 per 100,000 men and 89.8 per 100,000 women.

There is no indication that Parkinson's disease is decreasing in prevalence. In fact, it is increasingly common in the elderly (Mutch *et al.,* 1986). Pearce (1992) estimated that about 100,000 patients are affected in the UK at any one time. Prevalence increases with age in both sexes, but on the weight of evidence, there appears to be a distinct preponderance of PD in men despite the female preponderance in the elderly general population. This is difficult to explain as the ultimate cause(s) of PD are still not known. Hypotheses involving genetic factors, environmental toxins, viruses, protective effects of smoking, personality, head trauma, rural residence, well water, and dietary factors have all turned out to be inconclusive (c.f. Ben-Shlomo, 1996).

1.5 Cognitive aspects of PD

Parkinson's disease is primarily considered as a motor disorder, but cognitive deficits are commonly associated with the illness (Mahurin *et al.,* 1993). Although James Parkinson (1817) had unequivocally declared that the intellect was not affected, careful reading of his original essay does indicate an abnormal mental status, specifically depression, in at least one of the six patients he described (Mayeux *et al.*, 1981). This assertion remained unchallenged for almost half a century until Charcot & Vulpian (1861, 1862; cited in Dubois *et al.*, 1991) stated that "in general, psychic faculties are definitely impaired". Lewy (1923) went further and suggested that mental derangement and particularly dementia was an almost invariable feature of the advanced stages of PD. Since then, a continuing controversy over the types and frequency of cognitive impairments has materialised (Goetz, 1992).

There has been a surge in the number of PD patients reported to have cognitive impairments in recent years (Dubois *et al.*, 1990). The degree of cognitive change ranges from minimal generalised deficits to dementia (Mohr *et al.,* 1990; Taylor *et al.* 1988). The increase may be a result of (a) clinicians' greater awareness of cognitive deficits, (b) an effect of levodopa administration, or, more likely, (c) that patients are living longer and are therefore more likely to manifest cognitive changes. Certainly aging does seem to be implicated in so far as there is a positive correlation between age of onset and cognitive impairment (Dubois *et al.*, 1990; Garron *et al.*, 1972; Lichter *et al.*, 1988). Younger PD patients have little difficulty in learning, understanding, remembering or perceiving, and many continue in intellectually demanding jobs despite considerable physical handicaps (Lees, 1990). Nevertheless, even in this group, subtle changes may lead their caregiver, family and friends to notice that their behaviour is not as it was. As Lees described, quite early in the disease all patients tend to manifest "a lack of spontaneity, a blunting of emotions, an increasing poverty of imagination and a tendency to repetition [which] may lead to difficulties in sustaining repartee. Other early complaints are increasing apathy, lack of initiative and mild word-finding difficulties during conversation" (p. 389). It is easy to speculate that such changes are likely cause some concern to caregivers - especially if these symptoms begin to emerge before diagnosis, or if the carer is not aware that the disease is associated with such changes.

1.5.1 Dementia

Dementia refers to an acquired and persistent impairment of cognitive function that represents a departure from the previous level of function (Cummings & Benson, 1983). To meet Cummings & Benson's criteria for dementia in Parkinson's disease, there must be impairment in at least three of the five neurobehavioural areas shown in table 1.5.1.1, below.

Table 1.5.1.1. Cummings & Benson's (1983) criteria for dementia in PD

Significant impairment in at least three of these areas is required:

1. Language
2. Memory
3. Visuospatial function
4. Personality / mood
5. Cognition (executive function)

While there is some consensus in the literature that in an unselected population of PD patients, the prevalence of dementia is greater than in age matched controls, there is extreme variability of the frequency of dementia according to source. At one end of the spectrum Patrick & Levy (1922), using clinical examination, found that just 4% of their PD sample were demented; in contrast Pirozzolo *et al.* (1982), using psychological tests, declared that 93% of their PD patients were demented. Whilst the method of determining the association between PD and dementia was different in these two studies, table 1.5.1.2 below reveals that both high and low estimates of dementia in PD are present with both methods of assessment.

Table 1.5.1.2 Reference, method, number and percentage of demented patients in studies that found an association between PD and dementia. (Adapted from Dubois *et al.*, 1991).

Reference	Method	*(n)*	%
Patrick & Levy (1922)	Clinical Examination	(146)	4%
Lewy (1923)	Clinical Examination	(70)	63%
Mjönes (1949)	Psychological Tests	(194)	40%
Pollock *et al.* (1966)	Clinical Examination	(84)	20%
Hoehn & Yahr (1967)	Clinical Examination	(802)	14%
Christensen *et al.* (1970)	Psychological Tests	(41)	15%
Mindham (1970)	Clinical Examination	(36)	33%
Celesia *et al.* (1972)	Psychological Tests	(153)	40%
Garron *et al.* (1972)	Psychological Tests	(30)	45%
Loranger *et al.* (1972)	Psychological Tests	(63)	37%
Sacks *et al.* (1972)	Clinical Examination	(72)	21%
Martin *et al.* (1973)	Psychological Tests	(100)	81%
Rajput & Rozdilsky (1975)	Clinical Examination	(125)	28%
Marttila & Rinne (1976b)	Psychological Tests	(444)	29%
Sweet *et al.* (1976)	Clinical Examination	(100)	56%
Lieberman *et al.* (1979)	Clinical Examination	(520)	32%
Hakim & Mathieson (1979)	Clinical Examination	(34)	56%
Lesser *et al.* (1979)	Clinical Examination	(131)	31%
Boller *et al.* (1980)	Clinical Examination	(36)	55%
Sroka *et al.* (1981)	Clinical Examination	(71)	15%
De Smet *et al.* (1982)	Clinical Examination	(75)	36%
Mindham *et al.* (1982)	Psychological Tests	(40)	20%
Pirozzolo *et al.* (1982)	Psychological Tests	(60)	93%
Hershey (1982)	Psychological Tests	(22)	45%
Piccirilli *et al.* (1984)	Psychological Tests	(70)	33%
Portin & Rinne (1984)	Psychological Tests	(79)	42%
Rajput *et al.* (1984b)	Clinical Examination	(138)	9%
Lees (1985)	Clinical Examination	(48)	15%
Taylor *et al.* (1985)	Psychological Tests	(100)	8%
Zetuski *et al.* (1985)	Clinical Examination	(203)	29%
Huber *et al.* (1986)	Psychological Tests	(48)	33%
Oyebode *et al.* (1986)	Psychological Tests	(43)	72%
Girotti *et al.* (1988)	Clinical Examination	(147)	14%
Mayeux *et al.* (1988)	Clinical Examination	(339)	11%
Reid *et al.* (1990)	Psychological Tests	(107)	8-83%
Pillon *et al.* (1991)	Psychological Tests	(164)	18%

A longitudinal study of newly diagnosed patients by Reid *et al.* (1990) provides some insight to the wide discrepancies. Reid *et al.* administered a battery of neuropsychological tests to separate groups of early-onset (<70 years) and late-onset (>70 years) patients. They classified just 8% of the under 70s as demented, as compared to 32% of the over 70s. When the sample was re-tested three years later, 18% of the early onset group and 83% of the late onset group were now classified as demented. These findings strongly suggest that the risk increases with increasing age, and differences in the composition of Parkinsonian patients in epidemiology studies of dementia may account for some of the discrepancies. On that same point, Marder *et al.* (1991) pointed out it is difficult to get a true estimate of the prevalence of dementia in PD because of the shorter life expectancy of demented patients, and probably more critically, Lees (1990) implied that the definition of dementia according to DSM III (American Psychiatric Association, 1987) was not strictly adhered to in many prevalence studies. Moreover, he considered that in most reports, no attempt had been made to separate "the relative contribution of depression, medical and surgical treatment, co-existing cerebrovascular disease and aging effects" from the disease process (p404). If one adopts Lees more stringent recommendation of only counting those patients with "unequivocal moderately severe dementia" (p.405) in hospital-based clinical studies, then about 10% of the PD population will be demented at the mean age of 65 years (Lees, 1990).

When contemplating the wide range of estimates of the risk of dementia in PD, it is useful to consider that dementia in PD is not clearly defined. DSM IV criteria (American Psychiatric Association, 1994) are well adapted for the diagnosis of dementia in Alzheimer's disease, but less appropriate for Parkinson's disease, where the motor impairments may intervene in the autonomy of the patient (Dubois

& Pillon, 1997). In DSM IV (American Psychiatric Association, 1994), dementia in Parkinson's disease is described as a progressive dysexecutive syndrome with memory deficits, in the absence of aphasia, apraxia or agnosia. However, current test batteries do not include the assessment of executive functions (Pillon *et al.* 1996). Moreover, circadian variations may interfere with the evaluation of cognitive functions. Specifically, when "off", patients can be severely akinetic, with hypophonic and slurred speech and anxiety - all of which will have an effect on performance. When at peak dose, patients may be inattentive, distracted by dyskinaesias (Dubois & Pillon, 1997). It has also been argued that the anticholinergic medication frequently prescribed to augment levodopa treatment may provoke an acute confusional state (De Smet *et al.,* 1982), and even lead to permanent cognitive changes, especially when patients are old and present memory problems (Dubois *et al.*, 1990).

A deficit in learning new information, considered to be the hallmark for the diagnosis of dementia (Dubois & Pillon, 1997), has been reported in demented PD patients using the Wechsler Memory Scale or word list learning. On these tests, however, PD patients do not perform as badly as SDAT patients (Helkala *et al.*, 1988; Pillon *et al.,* 1993; Stern *et al.,* 1993). Interestingly, Pillon *et al.* (1993) found that although demented PD patients were severely impaired in free recall, their performance could be dramatically improved by semantic cueing, which triggered efficient retrieval processes. This finding strongly suggests that the recall impairment was not simply a result of memory problems, because the ability to register, store and consolidate information was demonstrated. It seems that the demented PD patients had difficulties in activating the processes involved in the functional use of memory stores. Moreover, a correlation analysis showed that PD patients' performance on this task was strongly related to their scores on tests of executive function. This implicates the frontal lobes in the defective activation of memory processes and supports previous assertions of a dysexecutive syndrome in PD patients with dementia (Litvan *et al.,* 1991; Pillon *et al.,* 1991).

If a dysexecutive syndrome is the main characteristic of dementia in PD (Dubois & Pillon, 1997), it may be that the severe cognitive impairments seen in demented PD patients are the result of lesions of subcortical, or frontal, origin, and that cortical cognitive processes are not necessarily damaged, but deactivated. That is, dementia occurs when the damage to ascending neuronal pathways exceeds a threshold (Agid *et al.,* 1987). Dementia has been reported in PD patients who have no apparent cortical lesions (Xuerub *et al.,* 1990). However, there is also evidence that cortical neuronal loss, Alzheimer's-like histological changes, and Lewy bodies in neurons of the cerebral cortex may also play a role in dementia in Parkinson's patients (Hakim & Mathieson, 1979; Boller *et al.,* 1980; Jellinger & Grissold, 1982). But there is also a high frequency of Alzheimer's-like histological changes in the cerebral cortex of PD patients that are not demented (Ball, 1984; Paulus *et al.,* 1991).

It follows from this short discussion that dementia can occur in PD, but there is very little agreement about its incidence, nature or severity. The extreme divergence in estimates of prevalence of dementia in PD is primarily caused by the absence of standardised criteria of definition and variation in the methodologies used to assess it (Huber & Bornstein, 1992). The respective roles of cortical and subcortical lesions in dementia in PD are not clear. There is a convincing argument, however, that subcortical lesions have the potential to be solely responsible for the dysexecutive syndrome typical of demented Parkinson's patients.

1.5.2 Depression

Depression is a serious and frequent problem for Parkinson's patients. The range of severity of affective disturbance is broad, with both transient moods swings and major depression (Sano & Mayeux, 1992). In most patients, however, depression is relatively mild, and psychotic depression occurs in less than 10% of cases (Lees, 1990). Estimates of the frequency of depression range from 12% (Rondot *et al.*, 1984) to 70% (Mahurin *et al.*, 1993). Several prospective studies have reported the prevalence of depression to be about 40%, and there is no association of depression and age, gender or severity of motor symptoms (Celesia & Wanamaker, 1972; Mindham *et al.*, 1976; Mayeux *et al*, 1984; Gotham *et al.*, 1986). Lees (1990), however, cautions that some symptoms of PD, for example, the flat, emotionless speech, the mask-like, emotionless face, the languid posture, the diminution in alertness and motivation, and the occurrence of constipation and weight loss, provide opportunity for a misdiagnosis of depression.

Depression has been found to antedate the onset of PD, and to parallel the severity of cognitive symptoms (Mayeux *et al.*, 1981; Mindham, 1970; Shaw *et al.*, 1980). This supports the notion that depression is integral to the illness, rather than simply a reaction to a chronic incapacitating physical illness. Certainly PD patients are more depressed than healthy controls (Horn, 1974; Mayeux *et al.*, 1981), and depression has frequently been found in patients of many chronic diseases (Dakof & Mendelsohn, 1986), which lends some support to the reaction to disability position. However, a comparison of Parkinson's patients and people with severe physical disabilities from stroke, spinal disease and rheumatological causes found that the PD patients were significantly more depressed, as measured by the Hamilton Rating Scale (Robins, 1976). This finding supports the view that depression in PD is biochemically based. A similar study by Horn (1974) however, found PD patients and paraplegics had comparable levels of depression, as measured using 30 items from the MMPI scale. Differences in the control patients and the measures used in the two studies may explain the discrepant findings, but that is not particularly helpful in resolving the status of depression in PD. Additional support for the view that depression should be considered as an integral component of the Parkinsonian symptom-complex is provided by a more recent study by Ehmann *et al.* (1990). These researchers assessed the depressive symptomatology of 45 PD patients and 24 disabled controls of mixed aetiology who were matched for functional disability. The PD patients obtained significantly higher scores on the Beck Depression Inventory.

The evidence presented does not present a clear answer to the status of depression in PD. Whilst there is strong evidence to suggest that depression is caused by neurotransmitter dysfunction, it is likely that some PD patients may experience depressive symptomatology that relates to their physical condition (Sano & Mayeux, 1992). These symptoms are less persistent. Certainly not all Parkinsonians are depressed, but there is some consensus that about 40% of patients are depressed during the course of the illness.

1.5.3 Bradyphrenia

The term *bradyphrenia* was introduced by the French neurologist Naville (1922), to describe what he believed to be a new psychiatric syndrome produced by the epidemic of Von Economo's encephalitis lethargica sweeping across Europe. Naville noticed that patients manifested a diminution of attention, a lack of spontaneous interest, apathy, impaired capacity for sustained effort and mild amnesia. He considered bradyphrenia - slowness of the thinking process - to be associated with attentional difficulties and intellectual inertia.

Some 40 years previous to this, Ball (1882) had made a similar observation with respect to Parkinson's patients:

> "an invisible weight seems to crush the intellect and slow down perception, movement and ideas...The present case is obviously one of paralysis agitans with dementia, but one cannot help, on seeing these symptoms think of certain cases of melancholic stupor, such as seen in our mental asylums."
>
> Ball (1882); translation as cited in Rogers (1992).

Ball compared the slowness of thought to the psychomotor retardation of depressive illness. Similarly, Naville (1922) included motor impairments in his definition of bradyphrenia. Specifically, he thought that although peripheral execution of movement could be slow, and there could be a delay between the impulse for movement and its initiation, the actual impulse for movement was especially slow. So essentially, it was indistinguishable from bradykinaesia - slowness of movement.

Both bradykinaesia and bradyphrenia were considered a psychiatric syndrome until the discovery in the late 1950's of the biochemical processes that underlie the behavioural manifestations of PD (Dakof & Mendelsohn, 1986). As the psychiatric interpretations of the symptoms of PD (e.g. Booth, 1948; Jackson *et al.*, 1923; Shaskan *et al.*, 1942) disappeared, akinaesia became established, and bradyphrenia became regarded as its mental corollary (Rogers, 1992).

Bradyphrenia has been interpreted in two ways. Some researchers regard it as a purely clinical entity that includes symptoms typically present in PD: apathy, intellectual inertia and impairments to attention. In this sense, bradyphrenia has been equated to the concept of subcortical dementia (Rogers, 1986). Proponents of this view therefore consider bradyphrenia to be an ill-defined syndrome to be evaluated subjectively. In contrast, some researchers consider that bradyphrenia is a symptom defined as a measurable lengthening of normal information-processing time. That is, it is physiological parameter that can be measured experimentally (Dubois *et al.*, 1991)

The concept of slowing of cognition is crucial to the notion of bradyphrenia. There is not, however, very much supportive data (Lees, 1990). A problem often encountered in the clinical evaluation of cognitive slowing concerns its differentiation from the depression and motor slowing that are commonly seen in PD. Bradyphrenic patients are often the most kinetic, the most depressed, or both (Dubois *et al.,* 1991). Similarly, motor slowing can affect the clinical evaluation of motor slowing: most mental operations require a motor response. While Evarts *et al.* (1981), found that both movement times and reaction times were prolonged in 29 PD patients, as compared to 44 controls, there was no reliable difference between delays in reaction time and delays in movement time, making it difficult to ascertain the cognitive component of response time slowing. Noting the frequent association of cognitive and motor slowing, some authors prefer the use of the clinical concept "psychomotor slowing" (e.g. Lees, 1992; Mortimer *et al.,* 1982; Rogers *et al.,* 1987). Specifically, Lees (1992) suggests that impairment of a cerebral system common to both depression and PD is likely to be responsible for psychomotor slowing.

As a clear-cut dissociation where intellectual slowing is present in the absence of motor slowing is rarely seen in PD, the reaction time (RT) paradigm has been used to compare the performance of PD patients and matched controls in tasks of different levels of cognitive complexity, but with the same motor response. The notion is that if longer response times as a function of task complexity are seen, then there must be differences in central processing associated with the identification of stimulus inputs and the selection of response outputs. Most of the early experiments using this procedure, however, failed to show a selective impairment for the more complex tasks (see table 1.5.3.1. below).

Table 1.5.3.1 Studies assessing central processing time with choice reaction time procedures. (Adapted from Dubois *et al.* 1991).

Reference	Test	Result
Evarts *et al.* (1981)	Choice RT vs. simple visual kinaesthetic RT	Normal
Bloxham *et al.* (1984)	Uncued vs. cued visual RT	Decreased
Girotti *et al.* (1986)	Unpredicted vs. predicted visual RT	Normal
Heitanen *et al.* (1986)	Visual choice RT vs. visual simple RT	Normal
Mayeux *et al.* (1987)	Choice RT vs simple RT	Normal
Dubois *et al.* (1988)	Unpredicted vs. predicted visual RT	Normal
Pullman *et al.* (1988)	Visual choice RT vs. visual simple RT	Decreased
Rogers & Chan (1988)	Choice RT vs. simple ballistic and tracking RT	Increased

Dubois *et al.* (1991) suggested that the unexpected failure of these choice RT tests to reveal selective impairment in central processing for the more complex tasks was because the tests made low cognitive demands. They asserted that slowing of thought processes can be better investigated using more complex tests with higher cognitive demands. Certainly cognitive slowing has only been clearly demonstrated on test that require a high level of processing. A significant increase in response time in PD patients, as compared to normal controls was demonstrated using a computerised version of the Tower of London task (Morris *et al.,* 1988); on the Stroop Test (Brown & Marsden, 1988), and on the 15-Objects test (Pillon *et al.* 1989). The 15-Objects test is a visual discrimination task of 15 superimposed images of well-known objects. 70 PD patients took significantly longer to identify twelve of the fifteen objects than 20 normal controls - both off and on levodopa medication. As there was no difference between the two groups in identifying the objects when they were not superimposed, Pillon *et al.* attributed the test results to cognitive slowing probably caused by nondopaminergic neuronal systems. The results could, however, alternately interpreted to suggest that the PD patients had problems resisting visual closure. Indeed, in all these more complex tasks, the greater time PD patients spent doing the tests may indicate a defective cognitive <u>strategy</u>, rather than bradyphrenia. For instance, on the 15-Objects Test the performance slowing increased from the first to the twelfth object identified, as the task became more difficult. This is not what would be expected considering the <u>constant</u> psychomotor slowing in RT tests (c.f. Brown & Marsden, 1986). Further, the slowest patients identified objects in a random, rather than a systematic fashion, and repeated previously named objects, suggesting inappropriate maintenance of a category of activity. Even Pillon *et al.* (1989) commented that the slowing of cognitive processing demonstrated may be an emergent property of frontal-lobe dysfunction. Moreover, the picture is muddied further when one considers that Pillon's findings were not replicated by Dewick (1991). In her late-onset sample, both Parkinsonian and control groups performed at a similar speed on the 15-objects Test.

Bradyphrenia is a valid and useful concept from a clinical standpoint - but does it exist? To date bradyphrenia remains a controversial finding for a number of reasons. Crucially, it is not found in all patients and it has not been found in all studies. Its relationship to motor slowing is clouded by differing views of what is mental and what is motor. Moreover, the cerebral localisations suggested for both bradykinaesia and bradyphrenia are indistinguishable (Rogers, 1992). That is, the clear distinction between motor and mental slowing may be more apparent than real.

Evidence of cognitive slowing has only been found on complex tasks which involve the participation of executive function: The Tower of London (Morris *et al.*, 1988) requires planning ability and the 15-Objects Test (Pillon *et al.*, 1989) demands self-elaboration of strategy. The weight of evidence leads to the conclusion that bradyphrenia in PD, defined as a non-specific lengthening of information-processing time, has not been clearly demonstrated. However, a cognitive slowing may result from executive function impairments (Dubois *et al.* 1991).

1.5.4 Specific Cognitive Changes

Despite the controversy concerning global cognitive slowing, specific cognitive deficits can be seen in non-demented patients with PD, even at very early stages of the disease, if appropriate neuropsychological tests are used. Lees & Smith (1983), for example, compared 30 people under the age of 65 years, newly diagnosed with PD (mean duration of illness from first symptoms = 2.4 years) and not receiving Parkinson's medication, with 30 matched hospital controls. Whilst there was no difference in the two groups on the Wechsler Adult Intelligence Scale (WAIS) or on Warrington's Recognition Memory Test (WRM) for words or faces, PD patients made more perseverative errors, and tended to identify fewer categories on a modified version of the Wisconsin Card Sort Test (WCST) and on a test of verbal fluency (VF), although there was no difference in the number of errors (WCST) or number of words correct between the two groups.

Similarly, a study of untreated *de novo* PD patients by Hietanen & Teravainen (1986) found large differences between Parkinsonians and controls on psychomotor tasks: Purdue pegboard scores were reduced by approximately 20%, and on the Trail Making and Stroop tests, PD patients were 30% and 36%

respectively slower than the controls. Mild impairments were also seen on the Logical Memory, Associate Learning and Visual Reproduction subtests from the Wechsler Memory Scale.

Weingartner *et al.* (1984) reported that mild to moderate untreated PD patients are efficient at accessing previously acquired knowledge. The six patients performed similarly to eight healthy matched controls in terms of semantic memory processes (verbal fluency, recognising degraded pictures) and "automatic" memory processes (frequency monitoring, recall of input modality) which require little cognitive capacity. However, on effortful memory tasks (free recall of pictures and words, serial list learning), the PD patients were consistently impaired relative to the controls.

Collectively, these studies suggest that in early PD cognitive deficits are likely to be confined to three areas:

1. Psychomotor slowing
2. Loss of flexibility of thought
3. Mildly impaired learning and recall.

Changes in cognitive flexibility in PD are reminiscent of problems resulting from frontal lobe damage (La Rue, 1992; Taylor *et al.,* 1986). Also, it has been observed that everyday behaviour of early PD patients may include subtle signs of frontal impairment (Lees, 1990). Together this evidence supports the view that early cognitive changes in PD are mediated by changes in subcortical systems that influence the frontal lobes (e.g. Cummings & Benson, 1988; Dubois *et al.,* 1991). Frontal-type impairments are found in early, and generally intellectually intact patients, but are not universal. Canavan *et al.* (1989), for instance, found that only a third of their sample was impaired. A similar figure was reported by Piccirilli *et al.*

(1989). An important aspect of the latter study was that Piccirilli *et al.* followed up their patients four years later. They found that those patients who had shown a relatively specific frontal-type deficit at the initial testing had progressed such that they had developed a more generalised impairment at follow-up. From this, Piccirilli *et al.* suggested that early frontal-type cognitive deficits in Parkinson's disease may be predictive of subsequent dementia.

PD is a complex, multi-system disease and as with the clinical symptoms, there is a degree of heterogeneity with respect to cognitive deficits. Although impairments vary between patients - even within the same patient at different times of the day, as a function of medical status (Dubois *et al.*, 1991), there is a slow progressive decline in some aspects of mental functioning alongside the decline in motor functioning. Indeed, there is a distinct relationship between cognitive dysfunction and the diagnostic physical symptoms in PD (Iwasaki *et al.*, 1989). It is therefore not surprising that patients who have had treatment for PD for several years often have more substantial neuropsychological impairments (La Rue, 1992). As previously mentioned, Pirozzolo *et al.* (1982) found cognitive deficits in 93% of his sample of 60 PD patients (mean age = 63 years, mean duration of illness = 9 years) compared with 60 matched controls. A comprehensive range of tests given, as shown in Table 1.5.4.1 below.

Table 1.5.4.1 Test Performance in Moderate to Severe Parkinson's Disease Patients as compared to Normal Ageing. (Adapted from Pirozzolo *et al.*, 1982).

Measure	PD patients	Healthy Controls
WAIS (age-scaled scores)		
Vocabulary	11.17 (2.79)	11.78 (2.04)
Information	11.58 (2.49)	12.33 (2.03)
Digit Span	11.35 (2.64)	12.92 (2.80)
Digit Symbol**	8.23 (3.05)	13.08 (2.45)
Block Design**	9.48 (3.35)	13.67 (3.05)
WMS		
Logical Memory (immediate)		
Paragraph I**	6.87 (4.26)	10.77 (3.80)
Paragraph II**	5.21 (3.31)	8.45 (3.11)
Logical Memory (delayed)		
Paragraph I**	4.65 (4.28)	8.30 (4.04)
Paragraph II**	3.00 (3.23)	6.45 (3.64)
Associate Learning (immediate)		
Easy pairs**	5.43 (0.91)	5.98 (0.13)
Hard pairs**	1.33 (1.32)	2.83 (1.17)
Associate Learning (delayed)		
Easy pairs**	5.29 (1.09)	5.91 (0.33)
Hard pairs**	0.98 (1.21)	2.23 (1.32)
Bender Gestalt (recall)**	3.36 (1.97)	5.12 (1.36)
Spatial Orientation**	10.80 (3.81)	14.82 (2.79)
Visual Discrimination**	16.48 (2.89)	19.25 (1.16)
Finger tapping		
Right**	30.27 (13.76)	50.07 (8.75)
Left**	30.13 (11.64)	46.73 (8.43)
Digit Cancellation (secs.)**	80.25 (42.03)	51.50 (15.59)
Trail Making Test		
Part A**	118.31 (81.72)	56.27 (19.69)
Part B**	291.43 (175.54)	121.85 (92.69)
Object Naming	17.95 (0.22)	18.00
Apraxia Test	4.98 (0.16)	5.00
Depression (self-rated)**	51.45 (10.30)	38.66 (7.43)

Table values are mean scores with standard deviations in parentheses. **$p < .001$

Differences between Parkinson's patients and the healthy controls were negligible with respect to verbal intelligence, confrontation naming and on brief tests of apraxia. Digit Span scores were tended to be lower for the PD group, but they were well within the normal range for age. However, on all the other tests, which included measures of psychomotor speed, visuospatial ability, and learning and recall, the performance of the PD patients was significantly impaired in comparison to that of the controls. Interestingly, Pirozzolo *et al.* drew attention to the fact that the cognitive decline in PD could be likened to an accelerated aging process: crystallised verbal intelligence remained relatively intact whereas fluid intellectual processes were grossly diminished.

There is considerable evidence of visuospatial dysfunction in PD, even when intellectual efficiency is preserved and the tests require little motor input (Boller *et al.*, 1984; Bowen *et al.*, 1972; Hovestadt *et al.*, 1987). Although some authors continue to assert that there is a genuine visuospatial deficit in PD, the general consensus now is that the impaired performance is due to the high cognitive demand required by the tests used (Dubois & Pillon, 1997). This was clearly demonstrated in a study which required PD patients to do both visuospatial and confirmed frontal tasks. When performance on the frontal tasks was statistically covaried, the visuospatial deficits disappeared (Bondi *et al.*, 1993).

Several memory functions are impaired in PD. Briefly, it has been demonstrated that working memory capacity is decreased (Cooper *et al.*, 1992; Marié *et al.*, 1995; Owen *et al.*, 1993) and explicit memory is decreased as demonstrated by tasks which require organization of the to-be-remembered material (Taylor *et al.*, 1986, 1990), temporal ordering (Sagar *et al.*, 1988; Vriezen & Moscovitch, 1990), or conditional associative learning (Sprengelmeyer *et al.*, 1995). Long-term memory may be impaired as well, depending on the nature of the task and the processes that are required (Dubois & Pillon, 1997), although there is evidence that the storing and consolidating processes that are under the control of the temporal lobes tend to be preserved in PD (Pillon *et al.*, 1996).

Deficits have also been reported in attention and information processing, procedural learning, praxis, perceptual function, language and executive control (e.g. Mahurin, 1993). In fact, it appears that very few areas of cognition are immune to dysfunction, in some form, from the effects of PD (Brown, 1994). This raises an important question - are the multiple cognitive impairments seen in PD the result of a single underlying dysfunction, or do they really represent specific, independent deficits?

There is a trend towards considering that the diversity of cognitive disorders may arise from some fundamental impairment, the nature of which remains unclear (Brown, 1994; Dubois & Pillon, 1997). Certainly many of the hypotheses that have been presented implicate processes that are under frontal lobe control (c.f. Dubois *et al.*, 1994). The question remains as to whether a frontal-type impairment is generally characteristic of PD; or whether it is only a concomitant of a more general intellectual decline, albeit one in which such frontal impairment is an important aspect. What is not in doubt, however, is that cognitive deficits are increasingly recognised as an important manifestation of Parkinson's disease. Whilst the number of people said to be affected on a particular task varies enormously, it appears that a large number of PD patients experience relatively specific cognitive impairments without dementia. Probably a small minority of patients show no cognitive change even when carefully assessed and in a more sizeable percentage the cognitive changes reach such a magnitude that these patients are considered to be demented.

1.6 Personality

Personality is the sum of characteristics that make an individual a unique self (Stuss *et al.,* 1992). Usually, these characteristics are observed as stable and predictable behavioural response patterns of a person interacting with his or her environment. It is known, however, that after damage to frontal systems, changes in emotional response and personality can occur. The most striking, and most extreme, example of altered personality following damage to the frontal lobes, is that of Phineas Gage (Harlow, 1868). Although Gage made a good physical recovery with many preserved cognitive abilities after an iron tamping bar was propelled by an explosion upward through the midfrontal regions of his brain, his personality was so significantly changed that his friends stated that he was a different person.

As outlined above, the nature of the cognitive deficits seen in Parkinson's disease suggests that there is dysfunction in frontal systems in PD patients. If, as suggested by the Gage case, damage to the frontal lobes changes personality, then there may be personality changes associated with PD. A problem for testing this hypothesis is the fact that PD has a very insidious onset which makes it difficult to distinguish premorbid from morbid personality. Moreover, when PD was considered a psychiatric disorder it was thought that there was a specific Parkinsonian personality that could <u>cause</u> the onset of the disease. Patrick & Levy (1922), for instance, proposed that recognisable and significant psychological factors may play a causal role in the disease. Similarly, Jackson *et al.* (1923) argued that psychological problems precede neurological symptoms and predisposed an individual to the disease. When the psychiatric interpretation of PD was at its most influential Jelliffe (1940), comparing those who had developed post-encephalitic parkinsonism to those who had not, declared that the characteristic motor symptoms should be viewed as physical manifestations of a defence against unconscious hostility. He supported his argument by noting the similarity between the Parkinsonian stooped posture, and the stance of a boxer facing an opponent.

Despite dubious methodology (Stern, 1994), the search for personality factors that would identify people who were at risk of PD continued for many years. Prick (1966) described people with PD as mentally rigid with difficulties in coping with emotional stress - although they were also seen as polite, honest and conscientious. Lit (1968) found the pre-morbid personality of Parkinsonians to include limited emotional expression, mental rigidity, and a tendency to introversion. Sceptics of this approach were, however beginning to appear. Riklan *et al.* (1959) conducted a detailed study of the psychosocial factors that were hypothesised to be associated with the onset of PD. They came to the conclusion that there was no typical personality in the 108 PD patients they investigated. The previous year, Machover (1958) had published a study in which he had used the Rorschach technique to measure Parkinsonian personality. He found that no distinctive features could be discerned in recently diagnosed patients, but in those with more advanced PD, mental rigidity and inertia were evident. However, he suggested this could be attributed to the problems of living with a progressively disabling illness as much as being an integral part of Parkinson's disease.

Probably because the aetiology of PD remains obscure the interest in pre-morbid personality persisted. Even much more recent post-levodopa literature has asserted that the premorbid personality of PD patients is characterised by traits of introversion, depression, moral rigidity and inflexibility (Eatough *et al.*, 1990; Poewe *et al.*, 1983; Todes & Lees, 1985). Kessler & Diamond (1971) speculated that these personality traits, along with a decreased tendency to smoke, may be early expressions of the underlying neurochemical changes in the dopamine system associated with PD (Duvoisin *et al.*, 1981; Menza *et al.*, 1990, 1995). Todes & Lees (1985), summarising the recurring themes in the now voluminous literature, reported that PD patients have repeatedly been described as emotionally inflexible, attitudinally inflexible, having a lack of affect, having a tendency to be depressive, introspective, and over-controlled. But they concluded that it was unclear whether PD patients exhibit this distinct personality profile before developing motor symptoms.

In 1991, Paulson & Dadmehr undertook a comprehensive review of the literature from 1913 to date in order to find support for the Parkinsonian personality, as described above. They concluded that the limited quantitative data tended to be confirmatory but commented that the vast majority of the literature was anecdotal and abounding in unprovable psychodynamic postulates.

Poewe *et al.* (1990) compared actual and premorbid personality traits of a group of 38 PD patients and compared them to those of patients with essential tremor and healthy controls using Cattell's 16PF personality inventory and a semi-standardised structured interview with both the patient, and (separately) a close relative. Of interest to this discussion, they found the premorbid and morbid personality of PD patients to be characterised by traits of introversion, rigidity and inflexibility - in agreement with the previous literature, but a very similar actual and premorbid personality profile was found in patients with essential tremor.

Poewe *et al.* suggest that one interpretation of the similar personality characteristics could be the postulated psychological links between the two diseases (Geraghty *et al.*, 1985), although these commonalities have been disputed (Larsson & Sjögren, 1960; Rautakorpi *et al.*, 1982). Alternatively, the failure to detect differences between the two patient groups could simply be because previous findings which describe the premorbid Parkinsonian personality may reflect patterns of depression and introversion common to many disabling illnesses.

A similar study by Glosser *et al.* (1995) compared Parkinson's patients with people with probable Alzheimer's disease and medical controls using the NEO personality inventory (Costa & McCrae, 1985). They found that in terms of relatives' perceptions of premorbid personality and morbid personality, PD patients were very similar to SDAT patients. This supports the proposition that personality changes in PD may be common to all who succumb to chronic illness (Poewe *et al.,* 1990). However, Glosser *et al.* (1995) also found that although the PD patients did not differ from the medical controls premorbidly, and there was "no evidence for a specific personality profile for the PD patients either premorbidly or following development of motor symptoms" (p. 205). Nevertheless, they reported that after developing symptoms, PD patients and SDAT patients were "less extroverted, less exploratory, less curious, less organised, less goal directed, less disciplined and less well-adjusted emotionally" (p. 205). All of which does go some way to suggest that changes to personality, although perhaps only subtle, are associated with progression of these neurological illnesses. It is feasible that individuals with various kinds of neurological impairment might exhibit a common pattern of behavioural adaptation. Critically, this study can be interpreted as providing some support for the idea that progressive frontal dysfunction such as that reported in PD may lead to subtle, but indisputable personality changes during the course of the illness.

Data supporting the hypothesis that personality changes are seen during the course of PD have been published by Mendelsohn *et al.* (1995). Using the Adjectives Check List, 41 PD patients were described by themselves and their spouses in terms of their current and premorbid personality. The descriptions of the patients and spouses were similar; both reported clear, uniform changes on all of the "Big Five" dimensions of personality. Equivalent self and spouse descriptions were obtained from a matched community sample (*n* = 96). There were also personality changes in the control sample, but these were much less than those found in the PD sample. From this, Mendelsohn *et al.* concluded that their results indicated that the personality changes in PD patients were primarily associated with the disease, rather than aging. They argued that the similar pattern of changes in the control population, albeit of a much lower degree, suggests that PD accelerates and intensifies changes normally expected in later life.

This review has found little strong evidence to support the notion that there is a specific premorbid Parkinsonian personality which leaves an individual vulnerable to the disease. Although there is a wealth of early studies which have suggested that this might be the case, they are methodologically weak, and their concept of "a pre-morbid Parkinsonian personality should be regarded as untenable and be delegated to the realm of neuromythology" (Stern, 1994, p.103). However, there is some suggestion from recent studies that personality changes may accompany the progression of the disease. It is not clear whether these personality changes, subtle and overt, are specific to PD. Mendelsohn *et al.* (1995) suggests that PD accelerates and intensifies changes normally seen in later life.

Of critical importance to this research is the consideration of the role patient personality changes may have on the caregiver. Those who knew Phineas Gage well declared that he was no longer the same person: "No longer Gage" (Stuss *et al.* 1992). It is likely that if caregivers perceive personality changes in the PD patient they are giving care to, they may come to a similar conclusion "This is no longer the man / woman I married". This gives rise to the question of whether morbid personality changes in the patient affect caregiving outcomes. The null hypothesis that changes in patient personality will not influence caregiving outcomes will be tested.

1.7 Summary

In this chapter the nature of Parkinson's disease in terms of its epidemiology, clinical presentation, psychological presentation and treatment have been outlined. Evidence has been presented to show that PD affects both men and women, and it is found all over the world. PD is primarily a disorder of later life with an average age of onset being around 65 years. Its incidence increases with age; its prevalence is about one in a thousand overall, although this increases to about one in every hundred of those in their seventies. Pearce (1992) estimated that about 100,000 people in the UK have PD at any one time.

The detail given with respect to the presentation of the disease should clearly indicate that PD patients have a need for assistance with activities of daily living. Moreover, it should be clear that there are other factors associated with the illness besides the motor impairments required for a diagnosis of PD. The literature strongly suggests that a large majority of patients also present with psychological change - that is, cognitive changes and personality changes, which both seem to arise from biochemical changes in the frontal lobes which leads to an acceleration of the aging process. Together, the physical demands and the demands that arise from psychological change provide a challenging job for those who care for Parkinsonian patients.

PD affects a substantial number of the elderly population, but its aetiology remains unknown. Current medical treatment is effective in ameliorating physical disability, but progression of the disease continues. For the caregiver, as well as the patient, there is no remission following diagnosis. Moreover, in addition to physical and psychological deterioration with time, the treatment itself is associated with further problems, both physical and psychological. Continued therapy for five years or more leads to the smooth pattern of response being replaced by motor fluctuations and the appearance of dykinaesias, dystonia, and wearing off effects. These increase the patient's dependency on their caregiver. The medication is also known to have neuropsychiatric (e.g. hallucinations), cardiovascular (e.g. postural fall in blood pressure which increases the risk of falling) and gastro-intestinal (e.g. vomiting) side effects. Again, the effect these concomitants of the disease have on the caregiver is considerable.

Parkinson's disease is both a motor disease and a neurological disease. Because PD is a motor disease, considerable physical demands are put upon the caregivers. For example, patients may continually be at risk of falling. This means they have to be supported whenever they want to move from one place to another - even in the house, even in the night. If they do fall, they have to be helped up. The potential burden placed on an elderly woman who needs to pick up a full-grown but immobile man - repeatedly - has not been recognized in the caregiving literature. More detailed consideration of the experience of looking after someone with PD is presented qualitatively in Chapter 6. Suffice it to say that the caregiving literature, to date, has not given due consideration to the substantial population of carers who may be distressed by the physical demands of their job.

Parkinson's disease is also a neurological disease. There is now a considerable amount of evidence to show that there are cognitive and behavioural changes even in the early stages of PD. Mental changes and personality changes may dramatically alter the relationship between patient and caregiver over the course of the illness. There is much evidence to support this from the example of Alzheimer's disease, on which most of the work on caregiving has been concentrated. The much greater cognitive changes in SDAT have been associated with negative outcomes for caregivers.

PD is therefore an important and special disease. Diagnosis is dependent on a clinical syndrome based on slowness of movement, rigidity and resting tremor, (and a positive response to levodopa), and as such the primary reason for a caregiver is to assist with the physical needs of their care-recipient. Whilst there are also personality and cognitive changes associated with the disease, and an increased risk of dementia, only a relatively small proportion of Parkinson's caregivers have the problems documented in the Alzheimer's literature, but these are in addition to the considerable physical demands. But nevertheless, there are subtle and overt psychological changes in this patient population, and as such, a secondary need for a caregiver is to assist with their psychological demands.

The current caregiving models have concentrated on the (negative) outcomes of caring for those with mental impairments and have neglected populations of caregivers who are caring for those with physical impairments. This research was conducted to redress the balance, and to provide a model of caregiving in Parkinson's disease, a disease in which there is both physical and psychological change.

CHAPTER 2

THE NATURE OF CAREGIVING

2.1 Introduction

For the last forty years it has been government policy to care for the sick and disabled in the community, rather than in institutions, unless institutional care is unavoidable. This view is generally shared by the people concerned and their relatives. When the policy was introduced, it was thought that the savings made from not having to provide institutional care would be sufficient to develop a comprehensive health and welfare service in the community. To some extent this has happened, but it is apparent that the main support for dependent people in the community is provided by their families (Qureshi, 1990). A government White Paper on the issue of *Growing Older* implies that this should be the case:

> "whatever level of public expenditure proves practicable and however it is distributed, the primary sources of support and care for elderly people are informal and voluntary. These spring from the personal ties of kinship, friendship and neighbourhood. They are irreplaceable. It is the role of the public authorities to sustain and, where necessary, develop, but never to displace such support and care."
>
> (DHSS, 1981).

The number of people in need of care has increased, and this trend is likely to continue. This course, however, is much more a result of developments in medical treatment than the care in the community policy. The death rate for older people has been falling steadily for over 50 years. Figures from the United States show that the age-adjusted death rate for the over 65s fell by 29% between 1950 and 1982 (Biegel & Blum, 1990). During this period the death rate from cerebrovascular incidents decreased by 56%, and from heart disease by 34% (Waldo & Lazenby, 1984). In Great Britain, between 1981 and 1989 the number of people aged between 75 and 84 rose by 16%, and the number of people over the age of 85 rose by over 39% (Grimley Evans, 1991). A consequence of the fall in the death rate is that the size of the elderly population has been steadily increasing. Average life expectancy at birth is now about 78 years for women and 71 years for men (La Rue, 1992). The number of people who live to be 75 or more is projected to increase by 25% for the 15 years between 1985 and 2001 (OPCS, 1986), although there has been a deceleration in the rate of increase of older adults in countries where there has been a considerable reduction in mortality rates (Nusselder & Mackenbach, 1996). These include Great Britain, Australia and the United States.

The decreases in mortality of stroke and heart disease, however, have been coupled with increases in the number of older adults with functional disabilities, chronic impairments, and diseases such as Parkinson’s disease (PD) where age is a positive risk factor. Figures from the General Household Survey (GHS; Green, 1988) indicate that almost 60% of disabled people in Britain are over the age of 65 years. Age associated disease and disability is a major cause for concern by any standard (Grimley Evans, 1991). (Uhlenberg, 1996, however, optimistically reasons that it is not necessarily the case that aging in the future will replicate the present pattern of aging.).

As the number of people needing care increases, it seems likely that the number of people who are able to provide it will decrease. Family size is decreasing, there is greater migration of children away from their elderly parents (Hermanova, 1995) and there is a higher proportion of married women in paid employment than previously (Green, 1988). This means that more women - and it is women who provide the majority of informal care to the elderly (Dwyer *et al.,* 1994) - now have commitments during the day which do not leave them available for giving assistance to elderly relatives, as has historically been the case (Dwyer, 1995). Following from this, the early literature on caregiving was concerned with the support of older people, and the differential burden borne by daughters.

2.1.1 What is the definition of a caregiver?

The descriptive words “carer”, and “caregiver”, are used interchangeably and first appeared in the academic literature in the 1970’s and became common in the 1980’s as research interest into the caregiving process increased. In 1990, the word “carer” appeared for the first time in statute in the NHS and Community Care Act (Twigg, 1994). This Act defines a “private carer” as “a person who is not employed to provide the care in question” (NHS and Community Care Act 1990, section 46). (The “care in question” is not itself defined).

Ungerson (1987) acknowledges that the definitional problems arise out of the concept of “caring”, and the difficulty of specifying what a caregiver actually does. She raises the question of whether someone should be defined as a carer only if they do intimate caring tasks for a highly dependent person, or whether someone who does a lot of housework, but no intimate tasks should also be regarded as a carer. Whilst Ungerson does not specifically take a line on this issue, she appears to support the view that one does not need to be providing assistance with intimate tasks to be regarded as a caregiver. Her sample of nineteen includes three carers whose only work at that time was housework.

Similarly, Green (1988) noted that there was not a widely accepted definition of caregiving and that few of the published studies to date had included the criteria by which they had identified those who were described as carers. In her own research for the General Household Survey of 1985, she defined carers as those who, when asked, agreed that they provided either “extra family responsibilities because they look after someone who is sick, handicapped or elderly” or “some regular service or help” for someone not living with them (p6).

Another more recent population study of people providing care to an elderly person in Dundee, Scotland, was carried out by Orbell *et al.* (1992), with the aim of collecting data from carers who represent the full range of care experience from occasional assistance to full time assistance. As they point out, a major problem in the caregiving literature is the tendency to use carers who attend support groups or carers who are already known to the health and social services. To establish a representative sample Orbell *et al.* used a screening survey to identify their caregiver sample (See Table 2.1.1.1 below). The screening survey was sent to all adults who were registered with one Dundee general practice. Respondents were described as carers if they reported that they were providing at least one of the eighteen specified forms of assistance to an elderly person.

Table 2.1.1.1 Definition of Carer (Screening Survey)
(from Orbell *et al.,* 1992).

Do you currently provide unpaid assistance to an elderly person in any of the following ways?

Shopping
Transportation
Financial matters
Washing clothes / bedding
Legal matters
Housework
Preparing meals
Nursing tasks
Dressing / undressing
Bathing / washing
Toileting
Going to bed / getting up
Eating / feeding
Household repairs
Gardening
Decorating
Dog walking
Companionship

This method, however, has its problems. Orbell *et al.*'s criteria, in focusing on the provision of assistance, do not consider whether the person providing the assistance regards him or herself as a carer. It seems likely that some spouse and child caregivers look upon the assistance given as being within their usual role whilst others might not. Moreover, the classification does not take into account the extent of assistance provided. The range of care given to dependents is great. In the two population studies mentioned above, people were identified as giving informal care if they regularly collected library books, or if they did the shopping for someone who could not do these tasks themselves, in the same way as someone was identified as a caregiver if they were providing 24-hour care.

Braithwaite (1990) pointed out that most people are caregivers to some degree if we accept that to care means showing concern for another's well-being and ensuring that essential services are provided. She considers that it is important to differentiate between care which is out of the ordinary from care which falls into the bounds of everyday life. She argues that caregivers are "people who assume the major responsibility for providing or organising services on a regular basis to someone who is incapable of providing for her or himself" (pp. 35-36). This definition acknowledges the acceptance of responsibility for providing a service. This aspect of caregiving was not required to be identified as a carer in the population study of Green (1988), or Orbell *et al.* (1992). Braithwaite's definition was adopted for recruitment of caregivers to this study. Recruitment to this study was achieved by inviting consecutive patients who attended PD clinics in Merseyside who had an identifiable primary caregiver, someone who acknowledged that they would be responsible for the needs of the PD patient, to participate in the research project. Because of the progressive nature of Parkinson's disease, a consultant will seek to identify a caregiver who accepts responsibility for the welfare of the patient at an early stage. Therefore, although minimal demands may initially be required of a PD caregiver of a recently diagnosed patient, all the caregivers in this study accepted that they were responsible for the welfare of the PD patient.

2.1.2 Definitions of caregiving.

Hall (1990) suggested that there are a number of different forms of care. He distinguishes between: (i) “having regard or affection or concern for” - and he notes that since care is most typically given by relatives, there is likely to be a pre-existing attachment bond between caregiver and care-recipient; (ii) “to provide for physical needs” - considering caregiving as a job to be done; and (iii) “protective or supervisory control or oversight”. Hall’s main concern on the latter point is supervision of the caregiver, as advocated by the DHSS (1981). It should be emphasised however, that this definition of care can be applied to those caregivers who consider that their main role is to oversee their care-recipients behaviour, in order to protect because of the *potential* for them to come to harm. This can lead to the view that the caregiver is not actually *doing* a caregiving act, but nevertheless it can be argued that they are assuming the responsibility of caring.

As has already been mentioned, some people who give very little assistance to an older adult identify themselves as carers, whilst others who provide regular assistance do not regard themselves as caregivers. Following from this, Blum *et al.* (1989) pointed out that different people may be considered as carers according to whether caregiving is defined simply by asking people to identify themselves as carers, or by using an operational definition of caregiving, for example, by defining caregiving as providing help on a regular basis with at least one activity of daily living.

Zarit & Edwards (1996) defined caregiving as "interactions in which one family member is helping another on a regular (i.e. daily or nearly so) basis with tasks which are necessary for independent living" (p. 334). They list tasks considered to be necessary for independent living. These include instrumental tasks such as shopping and transportation, as well as intimate tasks such as bathing and toileting. They also acknowledge the necessity for ongoing supervision in the case of disabilities involving dementia. Zarit & Edwards would include most of the tasks which Orbell *et al.* (1992) used to define a carer (with the probable exception of *dog walking,* and *companionship).* The key difference between their operational definition and that of Orbell *et al.* and Green (1988) is that the word *regular* is clearly defined: the unpaid assistance should be provided on a virtually daily basis.

Zarit & Edwards also specified that "a relationship develops into caregiving when an older person becomes dependent on another's help" (my emphasis). That is, the recipient actually needs the help given, which is not necessarily the case. This essentially means that caregiving constitutes a change in the dyadic relationship in response to the needs of the care-recipient.

In this study, the care-recipients were Parkinson's patients. Most of the patients were dependent on their carer for a wide range of tasks on a daily basis - indeed some could do very little for themselves. However, a small number of newly diagnosed patients who were essentially relieved of symptoms by medication and who therefore did not require instrumental help on a daily basis were also included. This was because (a) the longitudinal nature of the study meant that it was likely that there would a change in these patients' dependency over the twelve-month period.

and (b) the diagnosis and the events leading to diagnosis were likely to have initiated some alteration in the ongoing patterns of exchange between the two people. The spouse of a PD patient may introduce “protective or supervisory control or oversight” (Hall, 1990) in order to protect because of the *potential* for them to come to harm. That is, for the purposes of this research it was considered that the relationship develops into caregiving very early in Parkinson’s disease.

2.1.3 Who is caregiving?

The most comprehensive reference for determining who is providing informal care is the 1985 General Household Survey (GHS; Green, 1988). The survey was carried out in order to determine the proportion of people in Great Britain who are caregivers. Whilst it is acknowledged that it is nearly a decade since the publication of her findings, these figures remain as the reference point for British research to date.

Green’s survey was based on a large sample of 10,000 private households in Great Britain. The aims were to provide national estimates of the number of people providing informal care and to describe the characteristics of the carers. Information with respect to age and type of disability (i.e. physical and/or mental) was provided, although the characteristics of the caregiver were not broken down by reason for the need to take on the caregiving role (i.e. health status). If this information had been included, it would have been useful for ascertaining the representativeness of a specific sample of caregivers. It is not expected that the relationship of caregiver and care-recipient should be similar in cases where the characteristics of the dependent are quite different. For example, one would expect a high proportion of caregivers of Down’s Syndrome children to be parents, whilst one finds that, in practice, a high proportion of caregivers of people with Parkinson's disease are spouses (Miller *et al.*, 1996).

A second, more recent, but much smaller survey of people providing care to the elderly in Dundee (Orbell *et al.*, 1992) provides another important reference for determining who is providing care.

Green (1988) reported that one adult in seven had effectively identified themselves as caregivers by affirming they had either (i) extra family responsibilities because they looked after someone at home, or (ii) they regularly looked after someone who was not living with them. If the sample figures are extrapolated using 1986 OPCS population figures, there are approximately 6 million caregivers in Great Britain: 3.5 million women and 2.5 million men. This amounts to 15% of women and 12% of men in that sample are caregiving. The survey also indicated that 3% of all adults in Great Britain devote at least 20 hours a week to caregiving.

Considering caregivers with a dependent in the same household, Green found that although the proportions of men and women who were devoting at least 20 hours a week to caregiving were similar, a discrepancy arose when the caregiving time increased. 51% of women, compared with 39% of men, reported that they provided over 50 hours of care. This supports Nissel & Bonnerjea's (1982) detailed diary study findings which revealed that wife and husband caregivers spent an average of over 2 hours a day and eight minutes a day respectively.

In contrast to these findings, Stone *et al.* (1989) found that male spouses reported that they spent more time involved with caregiving each day than female spouses, although this time was less that that spent by females giving care to parents or friends. Similarly, Dwyer & Seccombe (1991) found that husband carers reported that they did more tasks and spent more time caregiving than wives. Sons and daughters, however, gave reports that were quite similar. They argue that these counterintuitive findings can be explained when one takes into account the fact that men and women define caregiving as a job in a different way. Many tasks associated with caregiving have traditionally been done by women (e.g. cooking, cleaning, washing). Therefore, when a caregiver is asked what they do as a result of their care-recipient's incapacity, a husband will list these things, whereas a wife will tend not to. This is because a wife is not doing anything in addition to what she did before her husband's disability. Overall, it must be concluded that attempts to define the amount of care given by men and women have not provided consistent results (Orbell, 1996).

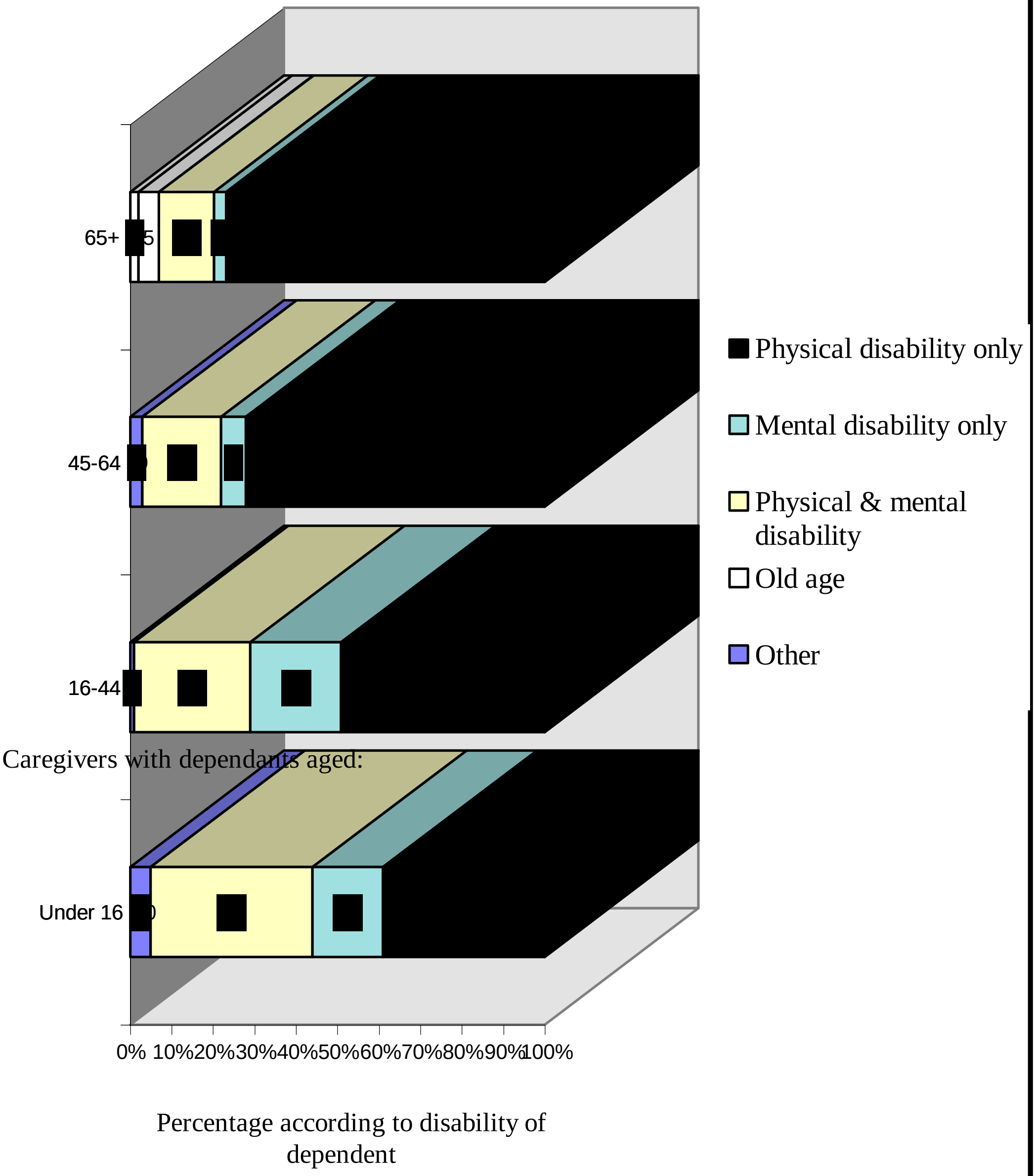
Table 2.1.3.1, below, shows the demographic composition of the Green's sample of caregivers. This enables one to see the difference in the range of caregiving in the total population in relation to the total number of caregivers involved. The highest age-specific participation in all forms of informal care is in the 45 - 64 years age range. This was also the case in Orbell *et al's* (1992) Scottish sample. There are more female than male caregivers which is consistent with other studies which have used a representative population sample (Cantor, 1983; Jones & Vetter, 1984; Orbell *et al.,* 1992; Stone *et al.,* 1987; and Tennestedt *et al.,* 1989).

Table 2.1.3.1 Caregivers: age, sex and marital status (from Green, 1988)

Sex, age and marital status	Carers with a dependent in the same household	Carers with a dependent in another private household only	Main carers	Carers devoting at least 20 hours per week to caring	All carers	All adults
	%	%	%	%	%	%
Sex						
Men	45	38	35	36	40	46
Women	55	62	65	64	60	54
Age	%	%	%	%	%	%
16-29	12	12	7	8	12	25
30-44	20	31	25	23	28	27
45-64	43	42	47	43	42	29
65+	25	15	20	26	18	19
Marital status	%	%	%	%	%	%
Married	71	75	76	74	74	65
Single	20	10	10	14	13	20
Widowed, divorced or separated	9	14	13	12	13	15

There are many different categories of people who have a need for informal care (see Fig. 2.1.3.1 below). Green reported that for those with dependents over the age of 45 years, over three quarters of caregiving is a consequence of physical disability. This finding is surprising in view of the concentration of the research literature on outcomes of caregiving in dementia of the Alzheimer type (SDAT). This is likely to be because studies that have used a heterogeneous sample of caregivers of older adults have found that the principal determinant of demands on caregivers is behavioural problems, which are a hallmark of SDAT.

Fig 2.1.3.1 Disability of dependent by age of dependent; Great Britain, 1985. (from Green, 1988)



However, there are differences in the care-receiving population as a direct result of disability and age. It follows that a generalisation of the outcomes of the caregiving task across the type of care required is inappropriate. Similarly, consideration of specific patient populations cannot be expected to follow the general pattern depicted in Green's population study.

2.2 Why do people become caregivers?

2.2.1. There is a need.

Although there is now a substantial amount of information outlining the demographic characteristics of those who give care, relatively little is known about the reasons for people taking on the caregiving role. Obviously, caregiving will only arise if there are people in society who need care. But there have always been people who need care.

There is a need for caregiving at different times in a system of treatment (Hall, 1990). Informal care may precede any formal intervention, and it may prevent the need for further intervention; caregiving may occur in parallel to medical treatment, and it may be the consequence of medical or surgical treatment. Informal caregiving may be the only answer for those close to death. But need *per se* does not address the issue of why one person rather than another gives the required care.

2.2.2 Hierarchy

In western society, the probability of becoming a caregiver follows a hierarchical pattern with respect to the relationship of the caregiver to the care-recipient (Qureshi & Walker, 1989; Shanas, 1979a, 1979b). If a spouse is available and able then the spouse will be the primary caregiver. In the absence of a spouse, children will assume the caregiving role, followed by siblings, and other family members. Within type of relationship, wives are caregivers more often than husbands (Tennstedt *et al.*, 1989). This is because women live longer than men and tend to marry men older than themselves. It is three times more probable that a daughter will take on the caregiving role than a son, when other factors that affect caregiving behaviour are controlled (Braithwaite, 1990; Dwyer & Coward, 1991). Similarly, sisters are more likely than brothers to provide care (Matthews & Rosner, 1988). Certainly gender is the major predictor of who will give care when there is no spousal support (Braithwaite, 1990; Jones & Vetter, 1984; Stephens & Christianson, 1986).

Population studies generally indicate that spouse caregivers account for approximately one third of the total sample (Cantor, 1983; Green, 1988; Jones & Vetter, 1984; Stone *et al.*, 1987; Tennstedt *et al.* 1989). The 1986 US census found that spouses constituted 44% of those giving care to someone over the age of 65 years (US Bureau of the Census, 1990). In Orbell *et al.*'s (1992) study, however, only 6% of the caregivers identified by their screening survey (see table 2.1.1.1 p.4) were spouses. This is probably a recruitment problem where spouses did not identify themselves as carers (Orbell, 1996). Some support for this position can be derived from Dywer & Seccombe (1991) in that wives may not identify themselves as caregivers if they are not doing any additional tasks in the home, but the position is more difficult to explain with respect to husbands. There is evidence that even though husbands and wives spend similar amounts of time giving care to their brain-injured spouse, husbands receive more help from other informal sources than wives (Enright, 1991).

Intuitively, one might have expected the rates of spousal support to be higher than one third, but the fact that marriage rates decrease with increasing age has to be taken into account. The General Health Survey of 1980 (OPCS, 1982) indicated that

52% of those over 65 years are married, and just 35% of elderly people over 74 years are married (Qureshi & Walker, 1989). In view of these figures, studies which include higher rates of spousal support are likely to have sampling biased in favour of married couples (Orbell, 1996). However, this is probably unavoidable for studies investigating samples of carers providing a considerable amount of care where the absence of a residential caregiver would lead to institutionalisation of the care-recipient, as is typically the case for PD patients.

2.2.3 Individual motives

Matthews & Rosner (1988) point out that although one has no choice in belonging to a family, taking part in family caregiving is “voluntary”. Whilst there is much evidence to support the notion of a hierarchy in family caregiving, this is not sufficient to explain who takes on the caregiving role. Although there is much evidence supporting the notion that the marital bond makes the strongest claim on who will provide care, Braithwaite (1990) found that in her sample of 144 caregivers, 13% were daughters-in-law. In all these cases their husbands, the sons, were alive and well. It was paid employment by the men but not by the women which explained the caring arrangements for six of the 11 families. In the remaining five families the daughter-in-law was also working. Braithwaite suggested that these women took on the caregiving role as an extension of their nurturing role within the family.

It must also be noted that the daughters-in-law were not caregiving as a result of there being no other brothers or sisters in the family. Six of the care-receivers had other children - four of them having daughters. Where a daughter was available, differences in employment status did not explain why the daughters-in-law took on the caregiving role. This suggests that there must be some other factor influencing the caregiving situation. Indeed, further analysis of Braithwaite's sample revealed that for 77% of the non-spouse caregivers, there were other people who were as closely related to the dependent who could have taken on the role.

Participation in caregiving by different members of the social hierarchy has been explained with reference to socially normative expectations and obligations. Models which are based on this approach assume that an individual is unable to avoid giving care if they fulfil socially created normative expectations. One such model is the social psychological approach which focuses on personal beliefs pertaining to self and others and the role that they play in care participation. Notably, Albert (1992), characterised two components of a belief system that are relevant to giving care to elderly parents. These are *communal orientation* and *infantalisation*.

Infantalisation is characterised by endorsing the sentiments "I am like a parent to my own parent" and "my parent is like a child", Albert (1992). This reconceptualises the caregiver-dependent relationship in terms of role reversal, and Albert found that scores on his infantalisation scale were associated with a sense or feeling of being trapped in the caregiving situation. In contrast, it is presumed that in communal relationships individuals feel responsible for another's welfare.

The notion that a communal orientation prevails in some relationships, but not others, comes from a programme of research focusing on the difference between communal and exchange relationships (Clark & Mills, 1979; Mills & Clark, 1982). Communal relationships are exemplified by relationships with family members, friends and romantic partners, in contrast to exchange relationships which are typically between strangers or people who do business with one another. In communal relationships, people feel responsible for the other's welfare. "They desire and/or feel obligated to benefit the other person when he or she has a need" (Clark *et* *al.*, 1987, p. 94). In contrast, in exchange relationships people do not feel responsible for the other person; they give in response to benefits received in the past, with the expectation of receiving benefits in the future. Clark and her colleagues regard communal orientation to be a dispositional trait. People high in communal orientation are expected to help others more than people low in communal orientation. Following from this, it can be argued that the reason why some people provide care is because they are dispositionally high in communal orientation. Albert's (1992) cross-sectional data indicated that communal orientation was positively associated with caregiver satisfaction providing support for this view. The association between communal orientation and caregiving outcomes will be tested in this research which mainly consists of caring for a spouse, rather than a parent.

To summarise, Albert's findings suggest that accepting filial responsibility is associated with willingness to assume the caregiving role whilst perceiving the situation as a loss of the normal relationship is associated with a wish to escape from the caregiving situation.

There are also accounts of caregiving which emphasise self-identity concerns, particularly with respect to the gender differences in caregiving. It has been suggested that caregiving is consistent with female identity. Eagly (1987) argued that males and females are assigned different roles in the hierarchical social structure from birth. This leads to different concerns and commitments in later life. Similarly, Graham (1983) proposed that the way girls are typically reared means that they obtain and maintain their self-esteem through social ties and nurturant behaviours. Orbell (1996) discusses various studies on this issue and concludes that the gender inequality in care participation is likely to be an outcome of childhood socialisation such that social acts are less important to the self-concept of men, and as a consequence they may not experience any obligations or guilt with respect to caregiving. In contrast, women learn that being socially responsive and nurturant enhances their self-esteem.

The gender differences in caregiving have also been explained by reference to differences in economic resources. Ungerson (1983) considered earnings differentials between men and women. She argued that because social conditions in general restrict women's employment opportunities, there is a widespread income discrepancy, such that husbands earn more than wives. Using data from Nissel & Bonnerjea's (1982) diary study, she pointed out that whenever the wife had given up work to care for a dependent relative, her earnings would have been lower than those paid to a man. This is not inconsistent with Braithwaite's findings, although Braithwaite does not provide the detailed information required to directly support this view. The involvement of family income in the daughter's decision making was not demonstrated. Orbell (1996), however, cautions that it may be simplistic to suggest that income of family members predicts involvement in caregiving without paying attention to psychological processes, explicit or implicit, which result in more women accepting caring responsibilities.

It is also relevant to consider attempts that have been made to characterise general reasons for helping others. Egoistic explanations assert that helping is motivated by the anticipation of reward for helping or punishment for not helping. People may help because of the prospect of payment, gaining social approval, increasing self-esteem, avoiding censure, and / or avoiding guilt (Schulz, 1990). Brody *et al.* (1978) argued that taking on the caregiving role to prevent institutionalisation can be seen as avoiding criticism, as seeing oneself as doing something worthy, as well as complying with social norms. Institutionalisation could also cause financial hardship which can be a motivating factor in many different ways.

Those who provide care for a parent often refer to their actions as a reciprocation of care that they have already received (Schulz, 1990). Greenberg (1980) suggested that indebtedness can be seen as a reason for helping others. Strong feelings of indebtedness may arise if a person perceives that help was given to them altruistically, if help was given in response to their own request for help, or if the helper incurred costs during the course of providing the help. The stronger the feelings of indebtedness, the greater the cognitive arousal and discomfort, and the greater the attempts to relieve such feelings. These are factors that apply to spousal and parent-child relationships and are likely to be important in understanding the magnitude of costs that a caregiver is willing to incur during the course of providing care (Schulz, 1990).

There is also a theory of helping that is based on purely altruistic motivation. People are willing to help others as a result of being able to empathise with another's situation. As the primary goal of empathically provoked altruistic helping is to benefit another and not oneself, it seems reasonable to assume that the ability to empathise may be a function of relationship, similarity, prior interaction, attachment, or some combination of these variables, all of which are pertinent to family caregiving (Schulz, 1990).

There is much support for the premise that relationship hierarchy is a primary contributor to who takes on the caregiving role. However, it is likely that the motivation for an individual taking on the caregiving role is derived from more than one source. It must also be recognised that there is a small population of caregivers who perceive their circumstances to be undesirable. Whatever the reason for their taking on the caregiving, they get to a stage where they feel trapped in the situation.

2.2.4 Summary

There is substantial evidence which indicates that if a spouse is alive and well, there is little ambiguity as to who will provide care (Qureshi & Walker, 1989). Spouses are more likely than adult children to provide care at home (Enright, 1991). A variety of reasons have been put forward to explain why one person, rather than another accepts the responsibility for care when no spouse is available, as illustrated in figure 2.2.4.1 below.

Fig.2.2.4.1. Reasons for Caregiving.

1. SPOUSE
2. INDIVIDUAL MOTIVES
    * relationship hierarchy / social norms
    * female identity
    * high in dispositional communal orientation
    * economic considerations
    * anticipation of reward
    * reciprocation of care / indebtedness
    * altruism
    * to prevent institutionalisation

2.3 Caregiver Burden

Grad & Sainsbury (1963) were the first to report that those who care for mentally ill relatives could experience significant distress as a result of the cost to the family of taking care of them. Zarit *et al.* (1980) were the first to study burden in caregivers of demented relatives. They developed the *Burden Interview* for use in their research, and it has been used in many subsequent studies. Indeed, since that study the interest in caregiver burden has mushroomed to the extent that it is now a socially recognised phenomenon.

The concept of burden in caregiving research is important because the potentials of providing informal care are related to the possibility of institutionalisation (Aneshensel *et al.,* 1993; Cohen *et al.,* 1993; Colerick & George, 1986; George & Maddox, 1989; Gerritsen & van der Ende, 1994; Morycz, 1985). Nursing home placement is an alternative to informal caregiving, and many of those looking after elders with chronic disabilities consider placement at some point in the course of their caregiving (Zarit & Edwards, 1996). However, informal caregiving continues, in many instances, until the death of the dependent. Whilst some retrospective studies suggest that the care-recipient's behaviour is the main factor in determining institutionalisation, prospective studies indicate that caregiver distress is as important as the functional impairments or behaviour of the elder (Aneshensel *et al.,* 1993; Zarit *et al.,* 1986). As early as 1972, Isaacs *et al.* observed that when institutionalisation does occur, it is usually because of a breakdown in caregivers' health. In line with this, the concept of burden focuses on the negative impact of caregiving on those who assume this role.

An understanding in the caregiving literature is that taking on a commitment to care for someone who is impaired in some capacity can have a significant effect on the carer's own well-being (see Figure 2.3.1 below). Pearlin *et al.*(1990) described caregiving as a "potentially a fertile ground for persistent stress" (p583). It follows from this that the central feature of the vast majority of caregiving studies is the measurement of burden.

Fig.2.3.1 Problems of Caregiving Relatives.
(Adapted from Sykes, 1994).

PHYSICAL	* Fatigue
	* 20% develop physical illness
EMOTIONAL	* Change in patients' personality
	* Helpless/fear in face of distressing symptoms
	* Difficulties in obtaining information
	* Apprehension relating to dependent's illness
	* Impending loss of patient
SOCIAL	* Change in roles
	* Isolation
	* Loss of financial security
	* Domination by professionals
	* Sexual needs
SPIRITUAL	* Guilt
	* Why me? - why us?

One property of the caregiving literature is its emphasis on defining the caregivers in terms of the disability of the dependent. Poulshock & Deimling (1984), however, advocated that burden should be viewed as a multidimensional concept in which specific burdens are linked to specific types of impairment. Much of the published research, however, focuses on just one illness: Alzheimer's disease (SDAT; Williams, 1994). This is probably a consequence of the results from early studies which strongly suggested that caring for mentally impaired people causes more problems and strains than caring for older adults with physical impairments (Isaacs *et al.,* 1972; Grad & Sainsbury 1963, 1965). There is very little information currently available on distress associated with caring for someone with Parkinson's disease. Calder *et al.* (1991) considered which characteristics of PD patients are associated with stress for their relatives. They found that the stress scores of relatives were within the range of those of relatives of demented patients and higher than those found in relatives of elderly controls. Crucially, they found that stress scores were still related to Parkinsonism (i.e. motor impairments) after cognitive impairment had been accounted for, but that the reverse was not the case. Calder *et al.* caution that as there was a significant association between cognitive and motor impairments. It might not be justified to claim that motor impairments cause more stress to relatives than cognitive impairments, "but motor impairment has to be seen as an important contributor to relatives' stress" (p. 741).

Speer (1993), using longitudinal methodology, investigated how older adults adapt to Parkinson's disease afflicting them or a family member. He found that PD caregiver adjustment was more strongly related to patient functioning than patient adjustment, which gives some support to the findings of Calder and her colleagues.

O'Reilly *et al.* (1996) examined whether caring for a partner with PD is associated with a compromised social, psychological and physical well-being, as compared to controls whose partner does not have PD. In line with other groups of caregivers, they found that overall, carer spouses did have slightly worse social, psychological and physical status than their case controls.

Miller *et al.* (1996) noted that there was no previous work considering the factors that contribute to distress in carers of PD patients. They recruited 54 spouse caregivers and 36 married control subjects where both partners were in good health. Measures used to assess the level of psychological strain were the General Health Questionnaire (GHQ), the Geriatric Depression Scale (GDS), the Beck Depression Inventory (BDI), and the Machin Strain Scale (MSS; Beck *et al.*, 1961; Gilleard, 1987; Goldberg, 1978; Yesavage *et al.*, 1983). Briefly, they found that spouse caregivers of PD patients do have raised levels of distress compared to controls, as measured by the GHQ and the two depression scales. Using multiple regression analyses, Miller *et al.* found that patient GDS scores made a significant contribution to the prediction of distress, whereas physical impairment, as measured by the Karnofsky Performance Status Scale (PSS) did not (Karnofsky *et al.*, 1951). The PSS was a significant predictor only for the Machin Strain Scale. As this scale is essentially a measure of objective burden, this finding is probably not surprising. Of interest to this research is the fact that in the Miller study severity of motor impairments did not make a significant contribution to the prediction of carer distress. This is in contrast to the findings of Calder *et al*. and Speer.

One possible reason for the discrepancy between the studies is a measurement issue. The two studies used completely different measures. To measure distress Calder *et al.* used the Relatives Stress Scale (RSS; Greene *et al.*, 1982), whereas Miller *et al.* used the GHQ, BDI, GDS and MSS. To measure Parkinsonian disability Calder *et al.* used the Hoehn & Yahr scale (Hoehn & Yahr, 1967), whereas Miller *et al.* used the PSS, a measure concerned with motor symptomatology, but not specific to PD. Miller *et al.* also used several cognitive tests. The measures of cognitive functioning "showed little relationship to any of the other variables" (p.265), and no further mention of these variables was mentioned. Unfortunately, the MMSE was not used, and the cognitive status of the patients was not determined and the IQ level of the PD at 108, was lower than the control IQ level of 114. Crucially, this paper indicates that it is patient depression which predicts distress in those caring for someone with PD, but it is not possible to determine whether patient dementia - which is an important consideration in PD - has any effect on caregiver distress. Moreover, in contrast to Calder *et al.* (1991) and Speer (1993), and in line with the

SDAT literature, the severity of illness was not found to predict caregiver distress. This issue will be addressed in this research.

It is possible that the type of impairment in the patient is relatively unimportant in the evolution of caregiver distress (Draper *et al.* 1995), however it is likely that caregivers of PD patients - and indeed caregivers of other neurological illnesses - will have different stressors to those experienced by those caring for people with Alzheimer's disease, because the different underlying pathology gives rise to different demands on the caregivers. A comparison of caregivers of SDAT and stroke patients by Reese *et al.*(1994), for instance, indicated that the two groups of carers were different in terms of psychological distress. In contrast, Draper *et al.* (1992), did a separate comparison study with the same two types of patient and found that caregivers experienced similar degrees of burden. Differences in the methods of measuring outcomes may account for the discrepancy.

The Draper *et al.* study reported high levels of psychological morbidity in both groups of caregivers, so it is possible that the measures they used (GHQ, RSS, Behaviour and Mood Disturbance Questionnaire, Barthel Index for Physical Disability, Quality of Life Questionnaire; Goldberg, 1972; Greene *et al.,* 1982; Mahoney & Barthel, 1965; Wells & Jorm, 1987) were not sensitive enough to distinguish between the two groups. Nevertheless, both studies demonstrated a significant difference between caregivers and noncaregivers.

The importance of the choice of measures used in a research project is clear when one considers that Reese *et al.* also compared the two groups of caregivers and a control group of noncaregivers on several indices of immunologic function. They found that there were no differences between the three groups on these measures. The issue of choice of measures will be elaborated upon in chapter 3.

2.3.1 Definitions of Burden

Dictionary definitions refer to burden as (i) a load, especially a heavy one; (ii) an oppressive duty, obligation, expense, emotion, etc. (The Concise Oxford dictionary). Applied to caregiving, “a load” can be translated to the time and effort needed to attend to the needs of a dependent (Montgomery *et al.* 1985). Schulz (1990) notes that this literal definition simply gives an objective measure of burden because it essentially reflects the amount of time spent caregiving, the type of jobs demanded in the course of caregiving, and financial resources consumed in the course of caregiving. This, however, is substantially insufficient as an operational definition. Most researchers recognise that burden includes a subjective state reflecting the perceptions and reactions of the caregiver.

To distinguish what are presumed to be negative events and activities from caregivers’ feelings and evaluations, Hoenig & Hamilton (1967) coined the terms “objective burden” and “subjective burden” respectively. However, in spite of there being only a weak correlation between objective events and subjective feelings the general term “caregiver burden” remains in the literature to describe both the caregiving situation and the carers’ reactions. Montgomery *et al.* (1985) and Vitaliano *et al.* (1991) have drawn attention to the fact that the distinction between the two types of burden has often been completely disregarded, particularly at the measurement level.

Poulshock & Deimling (1984), focusing on subjective experience, defined caregiver burden in terms of the distress arising from dealing with care-receivers’ debility and behaviour. Likewise, Lawton *et al.* (1989) declared that burden is assumed to be comprised of worry, anxiety, frustration, depression, fatigue, poor health, guilt and resentment. George & Gwyther (1986), however, included both types in their description of burden as “the physical, psychological or emotional, social, and financial problems that can be experienced by family members caring for impaired older adults” (p. 253). Zarit *et al.* (1980), like many subsequent studies, do not attempt to define what they mean by burden at all. Other researchers simply give vague indications of the meaning of burden: “caregiver outcomes refer to physical and emotional health” (Young, 1994), “a sense of strain” (Hadjistavropoulos *et al.*, 1994).

2.4 Predictors of Caregiving Burden

Whilst there have been some attempts to describe the constituents of (subjective) burden (e.g. Orbell *et al.* 1993), and burden has been used as a predictor of other outcomes (e.g. depression and institutionalisation), most research in this field has considered burden as a main outcome measure, and an attempt has been made to describe its antecedents. Following from this, it is assumed that it will be possible to identify patient and caregiver characteristics which tend to be associated with caregiver distress.

2.4.1 Dependant’s Impairment

The available evidence consistently suggests that the stressors associated with giving care to a demented relative take their toll. SDAT caregivers score more poorly than their noncaregiving controls on a variety of burden measures (Hodgson & Cutler, 1994). It is often assumed that this generalises to caregivers of other types of patients. However, Clipp & George (1993) pointed out that cancer and dementia patients may have similar ADL limitations depending on illness stage, but their measurement outcomes suggest that there are great dissimilarities between providing care for a spouse with a cognitive impairment as compared to one who is physically ill, but lucid. Specifically, Clipp & George used 19 measures of well-being in the areas of physical health, substance use, emotional health, social life and financial status. On 16 of the 19 measures there were significant differences between the two groups, and without exception, the SDAT caregivers were more adversely affected.

As Clipp & George point out, the most obvious explanation for the difference is that type of illness creates different caregiving scenarios. Here dementia seems to have more adverse consequences for the caregiver than cancer. It has been claimed that cognitive impairment represents a distinct type of limitation for caregivers (Palmore *et al.,* 1985). This is supported by Clipp & George in view of the fact that cancer and dementia patients were matched in terms of functional limitations in activities of daily living, but the additional difficulty of dealing with cognitive and behavioural changes appears to put dementia caregivers at greater risk of poor outcomes.

This is important for understanding the impact of caregiving to patients with PD - particularly with respect to the fact that there are cognitive impairments associated with the disease, but that they are not a diagnostic pre-requisite. An important question to be addressed is *do PD caregivers find it less stressful to look after someone who is immobile but rational, rather than someone who is not fully cognisant*? Interestingly, a preliminary assessment of giving care to someone with dementia found that there was no difference in caregiving outcomes according to whether the dementia was caused by Alzheimer's disease or Parkinson's disease (Dura *et al.,* 1990). The outcome measures in this study were the Hamilton Depression Rating Scale, the short form of the Beck Depression Inventory and the Brief Symptom Inventory depression subscale (Beck & Beck, 1972; Derogatis &

Spencer, 1982; Guy, 1976). Essentially all three scales measure caregiver depression. Dura *et al.* did not include a specific burden measure. Both groups of caregivers showed were more depressed than matched controls.

Dura *et al.* found that the SDAT caregivers spent significantly more time caregiving than the PD caregivers although there was no difference in duration of caregiving. When the two caregiving groups were compared on patient impairment measures (the Global Deterioration Scale, the Memory and Behavioural Problem Checklist frequency score, and the Blessed Dementia Scale (Blessed *et al.,* 1968; Reisberg *et al.,* 1982; Zarit *et al.,* 1980) the PD patients were found to be significantly less impaired on all three measures. When the level of patient impairment was controlled for, in contrast to their predictions, there was no difference in the caregiver outcomes between carers of SDAT patients and carers of PD patients with dementia. The results indicate that caring for a family member with dementia is associated with similar degrees of depression regardless of the specific subtype of dementia.

Many research studies have found weak or nonsignificant correlations between measures of cognitive impairment and caregiver burden (e.g. Eagles *et al.*, 1987; Gilhooly, 1984; Gilleard, 1982, 1984; Moritz *et al.*, 1989; Zarit *et al.*, 1980, 1986) which has led to the view that cognitive impairments which may be distressing to caregivers do not increase in line with the patients' decline (Pruchno & Resch, 1989a; Zarit *et al.*, 1986). In the case of SDAT, this may be because the patient is more active, and thus presents more of a potential risk to themselves and others, when intellectual impairment is moderate. However, when intellectual impairment becomes advanced, the patient is more passive, and hence demands less attention from a caregiver. Vitaliano *et al.* (1991) similarly noted that there is disagreement in the literature with respect to the relationship between degree of impairment of the patient and caregiver burden. They suggested that this relationship may vary over time as the functional and behavioural concomitants of a particular disease alter course. For example, in the period following diagnosis of a neurological illness, such as Parkinson’s disease or Alzheimer’s disease, or a potentially terminal illness such as AIDS or cancer, the impending stressor may be the loss of a loved one. In the later stages of such illnesses, the primary stressors will probably include the sheer physical demands of providing care to an extremely disabled patient (Schulz, 1990). Consistent with this explanation, Haley & Pardo (1989) found that behavioural problems do decrease in line with the progression of dementia.

Although this has yet to be tested, one would predict that a similar U-shaped function of caregiver distress accompanies cognitive decline in Parkinson’s disease, however in PD, unlike AD, it is likely that physical demands will increase with progression of the disease. Research has consistently shown that there are weak or nonsignificant relationships between measures of elderly dependents’ physical limitations and caregiver burden (Drinka *et al.,* 1987; George & Gwyther, 1986; Gilhooly, 1984; Haley *et al.,* 1987; Hooker *et al.,* 1992; Montgomery *et al.,* 1985a; Pruchno & Resch, 1989a; Zarit *et al.,* 1980). However these studies do not consider the much greater physical limitations that are associated with PD. Certainly physical impairments might be important in causing distress for those providing day-to-day care for PD patients (Calder *et al.,* 1991).

Orbell & Gillies (1993) provide a point of caution on this issue. As mentioned earlier, physical demands are typically assessed by standard ADL instruments which measure dependents’ functional impairment. The critical point though, is that this does not mean that they measure the demands put on the caregiver, although this relationship is often assumed. Many caregivers are not the only source of support for the patient. Certainly in advanced cases of PD the caregiver almost always has some formal care assistance, because it is only by using such services that the need for institutionalisation is avoided. There are also instances where the care-recipient may be minimally impaired, but the caregiver is unable to provide a specific service for them. For example, the PD patient may not be able to take a bath without assistance but is too heavy for the caregiver to assist in this way on her own. Therefore, she may need additional assistance to fulfil this demand - which may actually provide extra demand by way of organising the assistance. Alternatively, the patient may just not get bathed - which means the caregiver has no demand arising from that functional impairment. Orbell & Gillies (1993) concluded that task-related effort did not make a contribution to caregiver strain in a population sample of elderly people requiring assistance with any of eleven forms of basic assistance. However, the study did not address the issue of whether physical demands do have an effect on caregiver distress when the demands exceed a critical point - as is potentially the case in PD. This issue will be addressed in this research.

Figure 2.4.1 Predictors of caregiving burden (adapted from Braithwaite, 1990, p19).

WORKLOAD	* Task-oriented demands * Social-emotional demands
RESOURCES	* Personality * Coping strategies * Social Support * Health * Financial
CRISES OF DECLINE	* Awareness of progression of illness * Unpredictability * Dyadic relationship * Discretion * Time constraints

There are great individual differences in the way that caregivers deal with what would seem to be objectively similar situations (Haley *et al.,* 1987). As mentioned above, there is no strong evidence that the level of a dependant's impairment is related to caregiver outcomes. This strongly suggests that characteristics of the caregiver are more important for predicting caregiver distress than care-recipients' level of functioning (Hooker *et al.* 1992). These include the personality of the caregiver (Hooker *et al.,* 1992; Reis *et al.,* 1994; Monahan & Hooker, 1995; Wellaford *et al.,* 1995), coping skills (Haley *et al.,* 1987; Pruchno & Resch, 1989b; Stephens *et al.,* 1988), and social support (Clipp & George, 1990; Monahan & Hooker, 1995; Schulz & Williamson, 1991).

2.4.2 Caregiver Personality

The bi-polar dimensions *neuroticism-emotional adjustment* and *extraversion-introversion* feature as central constructs in all the major trait theories of personality and have been linked both theoretically and empirically to affect and well-being (Costa & McCrae, 1980; Hotard *et al.,* 1980), notably in stressful situations (Bolger & Eckenrode, 1991; Ormel & Wohlfarth, 1991). Of the five dimensions that seem to adequately depict the major domains of personality, neuroticism is the domain most strongly associated with negative affective states (Carson, 1989).

According to the trait theory of personality, age is not associated with changes in personality. That is, personality in adulthood should remain relatively stable (Costa & McCrae, 1988). It has been found that personality characteristics have an influence on vulnerability to certain illnesses, for example, the *type A* personality and the increased risk of heart attack (Williams *et al.,* 1988). Similarly, *hostility* has been shown to be predictive of coronary heart disease and disease in general (Barefoot *et al.,* 1983, Friedman & Booth-Kewley, 1987). In contrast, there are personality characteristics that have been shown to enhance health, such as personal hardiness (Kobasa *et al.,* 1982) and dispositional optimism (Reker & Wong, 1985; Scheier & Carver, 1987). It follows from this that the personality of the caregiver may serve to potentiate outcomes.

A study by Hooker *et al.* (1992), which claimed to be the first study to systematically examine the personality of caregivers used a sample of 51 spouse caregivers of SDAT patients. Hooker *et al.* considered the extent to which two personality dimensions - neuroticism and dispositional optimism - contribute to perceived stress and caregiver mental and physical health. It was hypothesised that caregivers who are high in neuroticism, or low in dispositional optimism will perceive daily events as more stressful and will have poorer physical and mental health outcomes than those who are low in neuroticism or high in dispositional optimism.

Neuroticism was found to have a direct effect, in the hypothesised direction, on perceived stress and all of the health outcome measures. Path analyses also indicated that neuroticism had a direct effect on all of the health outcome measures, independently of perceived stress, and indirect effects on mental health because of the association of neuroticism and perceived stress.

Optimism was significantly correlated, in the expected direction, with perceived stress and mental health variables but not with physical health outcomes. Path analyses revealed that optimism was related to mental health outcomes only through its relationship with perceived stress. It may be noted here that significant correlations have been found between the LOT optimism measure (Scheier & Carver, 1985) and neuroticism (Smith *et al.* 1989; Williams, 1992). Indeed Smith *et* *al.* declared that the optimism measure is “virtually indistinguishable from measures of neuroticism” (p. 640). The findings of Hooker *et al.* (1992), however, suggest that this is not quite the case.

Hooker *et al.*’s results suggest that an individual who is high in neuroticism who takes on the role of caring for their demented spouse may be badly prepared for successfully adapting to the demands of the job and therefore at risk of distress and negative outcomes.

Reis *et al.* (1994) also noted that researchers have not examined the influence of caregiver personality on outcomes. They gave 213 caregivers of SDAT patients 32 items from the *neuroticism* and *extraversion* subscales of the NEO-Personality Inventory. They found that neuroticism scales correlated negatively with extent and satisfaction with caregivers’ social support and self-appraised good health, and positively with burden. Neuroticism was the single largest predictor of health complaints and it exerted a significant effect on global feelings of burden. In contrast, extraversion appeared to have no influence on the outcomes of caregiving although high scores were associated with lower levels of neuroticism and better health. The results from this considerably larger sample, again suggest that caregivers of SDAT patients who have high scores on the neuroticism dimension are more vulnerable to caregiver distress.

An earlier study than those mentioned above used the General Health Questionnaire (GHQ; Goldberg & Hillier, 1979) as a screen for emotional disorders in caregivers of people with dementia and people with cancer (Rabins *et al.*, 1990). The results from this study indicated that only caregiver personality factors - specifically, neuroticism and openness to experience - predicted emotional distress in both caregiver groups. Following from this, Rabins *et al.* suggest that neurotic personality traits in the caregiver are risk factors for the development of negative emotional outcomes.

Wellaford *et al.* (1995) used all five dimensions of the NEO-PI (Costa & McCrae, 1985) to determine the relationship of caregiver personality and caregiver distress in caregivers of individuals with mild to moderate SDAT. Caregiver burden was assessed using the Screen for Caregiver Burden (SCB; Vitaliano *et al.*, 1991a) which differentiates between objective and subjective burden. In line with other findings, they found that there were significant correlations between objective burden and subjective burden and neuroticism. Other caregiver personality domains were not related to the two burden scales.

Braithwaite (1990) considered that caregivers who have high self-esteem and a sense of mastery may be less likely to perceive caregiving as a threat because both these characteristics have been associated with successful adaptation to life's problems. Crossman *et al.* (1981) reported that caregivers with low self-esteem blamed themselves for the problems they experienced, rather than seeing the situation as difficult. Similarly, Pagel *et al.* (1985) argued that self-blame is destructive to well-being. Mastery refers to the belief that one is in control of their own destiny, and capable of making the necessary decisions to overcome difficulties. Levine (1983) suggested that a sense of mastery is beneficial for good caregiver outcomes. Braithwaite (1990), however, points out that not all aspects of caring are within the control of the caregiver. Mistakenly appraising an uncontrollable situation as controllable may mean using inappropriate coping strategies, which can lead to frustration (Folkman, 1984). It follows from this that mastery may only be beneficial to caregivers when combined with an appreciation of the limits of a given situation.

Braithwaite (1990) also considered that personality characteristics may directly predict burden. Greater burden was hypothesised to be associated with caregivers who are “easily frightened, angered or upset, characteristics which some have labelled as neuroticism, but will be referred to here as emotionality” (p. 24). Braithwaite tested her hypotheses using a self-completion, 48-item, 6-dimension “personality scale”. Essentially this was a series of statements to which 144 caregivers of older adults responded on a 5-point scale.

Using this scale Braithwaite found that high burden was linked to low self-esteem, little sense of mastery, and being highly emotional (i.e. neurotic). When the personality variables were entered into a stepwise multiple linear regression analysis, two significant predictors of burden were found: self-esteem and emotionality (neuroticism).

Emotionality, together with mastery, emerged as significant predictors of minor psychiatric symptoms. Braithwaite pointed out that emotionality is a stable trait, whereas psychiatric symptoms (feeling depressed, anxious) are a more transient response to a situation (i.e. a state). This distinction is supported by a longitudinal study by Cramer (1994). Braithwaite asserts that in the caregiving situation, trait-state distinctions may not be clear because caregiving may persist for a considerable period of time. She suggests that personality measures could be influenced by the caregiver’s levels of anxiety and depression.

To examine whether anxiety and depression could be separated from the enduring personality characteristics of emotionality, self-esteem and mastery, Braithwaite performed hierarchical multiple regression to consider whether the trait measures would add variance to the prediction of burden after psychiatric symptoms had been entered into the equation. In support of her assertions, they did not.

Braithwaite’s study of caregivers of older adults living in the community did not provide conclusive evidence that personality has a significant influence on caregiver burden. Whilst emotionality, self-esteem and mastery were associated with burden, these, she points out, could not be satisfactorily disentangled from psychiatric symptoms. Assuming the goal of Braithwaite’s research was to identify predictors of burden, the data from this study indicate that minor psychiatric symptoms (i.e. anxiety and depression) were better predictors of caregiver burden than personality characteristics.

In summary, Braithwaite’s (1991) study was at odds with other published studies in that which she did not find that caregiver personality was a predictor of burden. How did the studies differ? There were two major factors: the first being that Braithwaite’s study was rather idiosyncratic in that she chose to use her own measure, (c.f. Braithwaite, 1991, pp. 152-153) in contrast to the other published studies (Hooker *et al.,* 1992; Reis *et al.,* 1994; Wellaford *et al.,* 1995) where well-validated scales, such as the NEO, were used. The second obvious difference was that she did not use caregivers of SDAT patients. Further, the statistical techniques she used, were more sophisticated than those used in the other studies.

The collective results from research supporting the hypothesis that caregiver personality makes a significant contribution to the prediction of caregiver distress, indicates that the position of the caregiver on the neuroticism-adjustment dimension is of particular importance. To reiterate, the work in this area centres on caregivers of individuals with Alzheimer’s disease, but Braithwaite’s work suggests that the contribution of personality to caregiving outcomes may not generalise across populations of caregivers. Accepting the fact that the caregiving role is different for caregiver’s of SDAT and PD patients, it is important to replicate this work with a PD population if one is to describe predictors of burden in caregivers of PD patients. It appears that there are still many questions with respect to the strength of neuroticism as a predictor, and it would be useful to consider the role other aspects of personality play on caregiver outcomes. For instance, dispositional optimism has been associated with perceived stress (Hooker *et al.,* 1992). There is also evidence that dispositional resilience (or hardiness) serves as a modulator of the deleterious impact of stress and illness (Bartone *et al.,* 1989). This needs to be considered with respect to the caregiving process. These points are addressed in this research project.

2.4.3 Coping Strategies

Coping strategies are the responses people make to stressors to try to avoid potentially harmful consequences (Pearlin & Schooler, 1978). Pruchno & Resch (1989b) proposed that people committed to long-term caring for an impaired spouse at home have to develop a repertoire of both behavioural and cognitive strategies in order to protect themselves against despair, and to adequately respond to the demands of the job. The coping strategies of caregivers have been examined because they provide a means of explaining the individual differences in outcomes between caregivers.

Lazarus & Folkman (1984) distinguished between problem-focused coping - taking action to manage or change the problem to get it under control, and emotion-focused coping which involves taking steps to regulate the emotional distress produced by the stressful situation. Although most stressors elicit both types of coping, a problem-focused approach will prevail when an individual perceives that something helpful can be done, whereas emotion-focused coping tends to predominate when an individual considers that the stressor is something that must be endured (Folkman & Lazarus, 1980).

The results of many studies indicate that effective strategies more often fall into the problem-focused category, and that emotion-focused strategies are more often associated with negative outcomes (e.g. Felton *et al.,* 1984; Kahana *et al.,* 1987; Mitchell & Hodson, 1983). Studies of the relationship between coping strategies and caregiver burden have achieved results that are consistent with this pattern (Haley *et al.,* 1987; Harvis & Rabins, 1989; Killen, 1990; Pratt *et al.,* 1985; Pruchno & Resch, 1989a, 1989b; Vitaliano *et al.,* 1985). However, there is no clear consensus with respect to which coping strategy is most effective for maintaining good health (Aldwin & Reverson, 1987).

An issue in the coping literature is whether individuals are consistent in their coping responses across various situations, or whether coping is situation-specific. Research addressing how caregivers behave in stressful situations associated with caregiving should ask subjects to respond in the context of caregiving, rather than how they cope in general. Coping in the caregiving situation is different to coping with other stressful events, due to the interpersonal nature of the job (DeLongis & O'Brien, 1990; Kramer, 1993). Certainly interactional models of coping argue that the use of particular coping strategies is at least a partial function of situational demands (Anshel & Kaissidis, 1997).

Felton *et al.* (1984) asserted that the consequences for employing specific coping strategies may differ according to the type of stressor experienced. That is, different strategies may prove to be most effective according to the situation. Although emotion-focused coping is generally associated with negative outcomes, Pearlin & Schooler (1978) found that emotion-focused strategies were most effective in situations that were not open to personal control. Similarly, Mullen & Suls (1982) have argued that avoidance strategies - i.e. not thinking about and not doing anything with respect to the problem situation - may be helpful in acute stress situations where one has little control over the event, or where there are no short-term effects.

Pruchno & Resch (1989b) found that the majority of coping efforts made by spouses of SDAT patients were emotion-focused. In line with the ideas of Strong (1984), they reason that because SDAT is essentially an incurable degenerative disease and there is little one can do but accept it, strategies that are concerned with minimising emotional distress are the coping strategies of choice. Nevertheless, in this study, emotion-focused coping was related to poorer mental health outcomes.

Saad *et al.* (1995) found that both active practical and psychological strategies were negatively related to depression amongst carers living with dementia sufferers. They suggested that Rotter's (1966) ideas of *locus of control*, which consider how much a person feels at the mercy of circumstances and therefore helpless, may be useful towards understanding why certain coping strategies are associated with increased depression. For when discretion was also taken into account, the associations of coping strategy with outcomes became more apparent. Discretion *per se* however, was not associated with depression. Saad *et al.* therefore proposed that coping strategies are important mediators of depression in caregivers.

Intieri & Rapp (1994) suggested that cognitive and behavioural strategies, like systematic problem solving, may be associated with improved caregiving outcomes because of their ability to modulate emotions and cognitions - and hence behaviour - during stressful situations associated with caregiving. Parkes (1994) also regards coping as a moderator variable in work stress process. Pruchno & Resch (1989b) however, argued that coping styles can have either direct effects on mental health outcomes, or effects that mediate the relationship between stressor and outcome, but that coping style is not a moderator of the stressor-outcome relationship (Pruchno & Resch, 1989b). This is obviously contradictory. As mentioned above, Saad *et al.* (1995) support the mediator view, as does Braithwaite (1990) who commented "coping strategies do not prevent perceptions of burden. Instead, they appear to be a response to burden" (p. 97). Indeed, she concluded from her consistent pattern of positive correlations between coping strategies and caregiver burden that as burden increases, caregivers are prepared to try any strategy for dealing with the situation. This supports Pearlin & Schooler's (1978) model. That is, the coping strategies an individual chooses will be employed after a threat is recognised, and thus coping has a direct effect on whether a stress reaction is averted or provoked. Following from this, it is apparent that coping strategies should be viewed as predictors of burden as well as mediators between burden and mental well-being.

To summarize the above discussion, there is evidence that in situations not amenable to personal control, emotion-focused or avoidant strategies may be effective for caregivers. However, if some degree of discretion exists, then the use of problem-focused strategies appears to play a major role in successfully adapting to the situation.

2.4.4 Social Support

Social support has consistently been found to be a powerful mediator in stressful situations, including those associated with caregiving (Pearlin *et al.,* 1990). Zarit *et al.* (1980) found that there was a significant negative association between frequency of visits from family members and caregiver burden, and that this was the best predictor of burden in their study. There is also evidence from prospective studies which suggests that social support is predictive of mental health (James & Davies, 1987). Social support has been defined as “the presence of others, or the resources provided by them, prior to, during, and following a stressful event” (Ganster & Victor, 1988, p. 17). Broadly speaking, this refers to the supply and acceptance of tangible and intangible goods, services and benefits in the context of informal relationships (George, 1989). Examples of tangible services include assistance with housekeeping, transportation, running errands. Examples of intangible forms of social support include friendship, advice, and feedback promoting high self-esteem.

Conceptualisations of social support include both positive social connections, which are characterised by practical and emotional helpfulness, and negative social ties, which include elements of interpersonal conflict (Finch *et al.*, 1989). There is a general agreement that social support is multidimensional and that various dimensions of support may be differentially important according to the type of stress one is confronted with. That is, practical assistance is most important for coping with inability to do particular tasks, whereas emotional support may be more important when faced with the decision to institutionalise.

Lyons *et al.* (1995) considered the effects of chronic illness on social networks. To summarise, they found a tendency towards the following changes:

1. Social network size is reduced (Janssen *et al.*, 1990; Lyons, 1991).
2. There is a reduction in the frequency of social contact (Berkman & Syme, 1979; Morgan *et al.*, 1984).
3. There are changes in social space; more companionate activities take place in the home and neighbourhood (Brent, 1982; Lyons, 1986; Morgan *et al.*, 1984).
4. There is a decrease in the range of interaction (Guay, 1982; Lyons, 1986).

5. There is an increase in frequency of contacts at the onset of illness and at times of hospitalisation, and then a reduction or avoidance of contacts (Dunkel-Schetter & Wortman, 1982).
6. A reduction in social contact is initiated by the person with a disability in the early stages of psychological adjustment (Strauss *et al.,* 1984).
7. Social networks are restructured to include people with similar disabilities and health professionals (Binger *et al.,* 1969; Bozeman *et al.,* 1955; Dunkel-Schetter & Wortman, 1982; Lyons, 1986; Morgan *et al.,* 1984; Wright, 1983).
8. There is reduced support for the caregiver within the relationship because reciprocity is diminished and the care-receiver no longer provides support at previous levels (Lyons *et al.,* 1995).

Social support is commonly viewed as a buffer to stressful life events, i.e. it moderates the effects of stress that follows from the presence of a life event. The buffer view (Dean & Lin, 1977; Rook & Dooley, 1985), asserts that a lack of social support during stressful periods results in somatic and psychiatric illnesses. According to Gesten & Jason (1987), the extent of the caregiver's social support network of relations and friends, and particularly the satisfaction they feel with the quality of the support they receive, reduces the negative effects of caregiving. However, Krause (1986b, 1987a), considering depression as an outcome, found that stress-buffering effects are found for some, but not all dimensions of social support; for some, but not all kinds of stressors; and for some, but not all dimensions of depressed affect. Jacobsen (1986) reasoned that social support may have direct effects on depression, (e.g. by promoting self-esteem or perceptions of control), and a buffering effect that is particularly important at times of crisis.

One line of reasoning, with respect to understanding how assistance provided by others helps people to cope effectively with stressful events, suggests that stress affects well-being indirectly by eroding feelings of personal control and self-worth (Pearlin *et al.,* 1981); social support may counterbalance these negative effects by replenishing the very resources (i.e. control and self-esteem) that have been diminished by stressful experiences (Krause, 1987b, 1987c). Krause (1987d) suggested that there is a non-linear relationship between social support and well-being. Specifically, he hypothesised that if older adults become over-dependent on significant others then the social support they receive tends to diminish rather than to increase their feelings of control. That is, social support may generally serve to promote feelings of control, but there is a threshold beyond which continued support leads to dependence.

Drawing on recent developments in identity theory, Thoits (1991) and Burke (1991) suggested that if stressors arise in social roles that are more highly valued than others, then the impact will be more deleterious. That is, the impact of a stressor will depend on which role is threatened. Accepting that individuals occupy a number of roles (e.g. mother, wife, friend, neighbour, colleague) and that there is a separate identity associated with the different social positions, stressors arising in highly valued roles should have a more negative impact than stressors which arise in roles that are less valued.

Krause & Borawski-Clark (1994) tested this, using a large sample of older adults. Noting that the dimensions of received support are highly intercorrelated (House & Kahn, 1985; James & Davies, 1987) and that emotional support is particularly important for rebuilding feelings of control and self-worth (Hobfoll & Vaux, 1993), they elected to examine only emotional social support, using the four items previously used by Krause & Markides (1990). There is some support for this position as even task specific support from significant others is believed to imply emotional support, which is not assumed to be part of the formal care system. Krause & Borawski-Clark (1994) hypothesised that emotional social support will reduce the deleterious effects of salient role stressors by (i) bolstering feelings of personal control and (ii) enhancing feelings of self-worth. In contrast, assistance from others will be less effective in reducing the impact of stressors that arise in roles that are valued less highly.

Their results indicated that stressors arising in salient social roles significantly eroded feelings of control, and role specific feelings of self-esteem, whereas stressors that emerged in roles that were not valued as highly failed to exert an effect. In support of their hypotheses, they found that irrespective of the amount of stress present, greater emotional support was associated with increased feelings of control and increased self-esteem. Interestingly though, their results indicate that social support is an efficacious coping resource for resisting salient role stressors, but not for stressful events that arise in less highly valued roles. To summarize, the findings support the notion that supportive social relations operate by replenishing self-esteem and feelings of control, but these effects are only evident when the life events are associated with salient identity roles.

With respect to caregiver burden, one might conclude from this short discussion that measures of social support can serve as direct predictors of burden: effective social support can serve to reduce the significance of stress. In addition, social support can moderate, or buffer, the effects of stress. Certainly, Redinbaugh *et al.* (1995) using sophisticated structural equation modelling techniques on longitudinal data, found that caregivers with persistently low levels of social support experienced the most stress and depression, however, there was an absence of a significant direct influence of unwanted social support upsetting the caregiver.

Indices of the perceived availability of support (e.g. James *et al.* 1986) attempt to gauge the amount of support that a person perceives to be available to them, should the need arise. This approach appears to be validated by the arguments of Wethington & Kessler (1986) who assert that the expectation of support is a more potent stress-reduction factor than the amount of support actually provided. Krause (1989) however, cautions that for individuals who incorrectly assume that support will be forthcoming, such perceptions serve to actually heighten the effects of stress.

If one accepts that social support serves as a moderator of stressor outcomes, then it is appropriate to use a measure of the perceived availability of support with caregivers to investigate its contribution to burden, because changes in perceived support do not have to be linked with life events. (This would be required by suppressor models which assume that as stress increases, individuals mobilise support from significant others. That is, the level of support is dependent on the amount of stress that is present. c.f. Alloway & Bebbington, 1987). Instead, it can be assumed that perceptions of perceived support are stable, and independent of life events.

As the research of the contribution of social support to the manifestation of stress evolved, it became evident that people do not use the same amounts or sources of support (Ward, 1985). To deal with this, researchers began to ask whether subjects were satisfied with the support they had received in order to consider differences in the need for social support (Krause, 1989). Although it has been argued that there are problems involved with measuring qualitative aspects of social relations because of the potential for influence by the psychological state of the respondent (Arling, 1987;

Dohrenwend *et al.*, 1984), Krause *et al.* (1989) found evidence that qualitative evaluations of support are not contaminated by psychological distress and that changes in satisfaction with social support appear <u>before</u> changes in depressive symptoms. It follows from this a measure of perceived social support, and a measure of satisfaction with that level of support will be required to assess the role of social support on burden levels of caregivers of people with Parkinson's disease.

Miller *et al.* (1996), in their investigation of factors that contribute to distress in PD caregivers found that Parkinsonian couples had smaller social networks and a more restricted range of social contacts than controls couples matched for age. Despite this, and in contrast to other caregiving studies (e.g. Zarit *et al.*, 1980), they found that size of social network was not related to caregiver distress, although clear evidence was obtained that spouse caregivers of PD patients do have raised levels of distress. Miller *et al.* (1996) acknowledged that this result was unexpected in light of previous findings with other disorders that social support is an important predictor of caregiver outcomes. They suggest that their result "may reflect the inadequate nature of the measure that was employed" (p.267). They had simply counted the number of people outside the carer's immediate household that the carer had been in contact with during the previous two weeks. These would include visits from friends and neighbours as well as "chatting to the milkman" (p. 264). It is therefore essential that the question of whether social support affects outcomes for PD caregivers is investigated using a much better measure. This issue will be addressed in this study.

2.4.5 Dyadic Relationship

The pre-morbid relationship between care-receiver and caregiver may have a profound impact on the caregiver's adjustment (Coyne & Fiske, 1992; Kramer, 1993a; Revenson, 1994; Thompson & Pitts, 1992). This is especially the case for married dyads, as the marital relationship is likely to be the primary social relationship (Coyne & DeLongis, 1986). Investigations of the relationship between patient and caregiver have focused on closeness between family members prior to the onset of dementia (Majerovitz, 1995). Specifically, spouses who reported that they had a close relationship with their partner prior to the onset of dementia experienced less caregiver distress than those spouses who reported more a more distant relationship with the patient (Horowitz & Shindelman, 1983; Kramer, 1993b; Morris *et al.*, 1988; Robinson, 1990).

Morris *et al.* (1988) suggest that a poor pre-morbid relationship or a marked change in intimacy serves as a vulnerability factor with respect to caregiver depression. Similarly, Williamson & Schulz (1990) found that a close pre-morbid relationship between spouse and adult-child caregivers and a patient with dementia was related to lower levels of burden, although there was no relationship between pre-morbid relationship and caregiver depression. From empirical evidence, Draper *et al.* (1995) summarised that caregivers who report a worsening in their relationship following the onset of illness were at risk of higher levels of burden.

In 1984, Gilleard *et al.* reported that caregivers' ratings of their past relationship with their mentally infirm dependent was strongly associated with caregiver distress, as measured by the GHQ. In contrast, Gilhooly (1984) reported that the quality of the dyadic relationship prior to the onset of senile dementia was not significantly related to caregiver well-being. Gilleard *et al.* (1984) used caregivers' ratings, whereas Gilhooly used interview data in order to make an interviewer rating of the quality of the premorbid relationship. It seems likely that these two methods have not achieved the same measure of the quality of premorbid dyadic relationships and may explain the different results of the two studies. Certainly, most of the research in this area suggests that the quality of the pre-morbid relationship between dementia sufferers and their carers is associated with caregiving outcomes.

Townsend & Franks (1995) investigated the quality of caregivers' present relationship with non-institutionalised parents who needed assistance with at least one of a variety of activities of daily living and the effect this had on caregivers' well-being. The underlying reason for the functional impairments were classed as cognitive or functional. Of interest here, they found that although both emotional closeness and conflict between caregivers and dependants were important in determining the impact of parents' impairment on caregivers' well-being, outcomes differed according to whether the dependent had a cognitive impairment or not. Cognitive impairment was related more consistently than functional impairment to the quality of the dyadic relationship which was, in turn, related to caregivers' well-being. This finding, they argue, supports previous research that when cognitive impairment is present, caregivers are forced to re-evaluate their affective bonds with care-recipients, and suggests that it is not caregiving *per se* which affects caregiving dyadic relationships, but rather it is the nature of the caregiving that matters.

Townsend & Frank's findings imply that the importance of dyadic relationship quality as a predictor of burden for caregivers of Parkinson's patients may differ according to whether the physical impairments of the disease are accompanied by overt cognitive impairments. As discussed in Chapter One, this is the case for some, but not all of the Parkinson's population. If affective relationship quality only serves as a predictor of burden when the nature of care-recipients' impairment is cognitive, then it would be expected that relationship quality is immaterial to caregiving outcomes, except in the presence of dementia. This hypothesis will be tested in the current research.

2.5 Caregiver Satisfaction

While much of the caregiving literature focuses on burden and distress, the satisfaction, rewards and accomplishments of caring are receiving some attention (Given *et al.*, 1990). If caregivers are not overburdened, caregiving can be viewed as containing a special set of rewards such as caring for a loved one, and / or seeing the caregiving role as an "occupation" where one develops a high level of skill and expertise in understanding an illness and dealing with its symptoms (Mingo, 1993; Toseland *et al.*, 1989). Stone *et al.* (1987) found that almost three-quarters of their sample of caregivers reported that the job makes them feel useful. It is therefore not appropriate to consider only the negative effects of caregiving in a model that seeks to explain caregiver distress. This is an overlooked variable in research (Cohen *et al.*, 1994). Cohen and her colleagues developed a simple measure of enjoyable aspects of caregiving for use in a longitudinal study of dementia care in the Canadian community. They reported that enjoyment of caregiving was significantly positively correlated with caregiver health, negatively correlated with caregiver burden, and the measure predicted caregiver desire to institutionalise their dependent. Similarly, Bull (1995) noting that many caregivers perceive their health as quite good and report that they are satisfied with life, calls for further research examining caregiver's satisfaction with the caregiving role.

2.6 Summary

As the population has aged, the number of people in need of care has increased. The main support for older adults who have a chronic need for assistance in activities of daily living comes from informal sources. Family caregivers play a critical role in meeting the needs of members who have a chronic illness.

Three quarters of those with dependents over the age of 45 years give care as a consequence of physical disability. Much of the caregiving literature, however, focuses on mental disability. Notably, the outcomes of caregiving for people giving care to Parkinson's disease patients - who comprise a substantial number of the caregiving population - have aroused little interest to date.

In this chapter demographics of caregiving have been presented, followed by a discussion of why people take on the caregiving role. The probability of becoming a caregiver appears to follow a hierarchical pattern. If a person in need of care has a spouse then the spouse will be the primary caregiver. Individual motives for taking on the caregiving role when no spouse is available are considered. Family hierarchy provides a strong reason, but anomalies in caregiving samples suggest that there are also other reasons for giving care. These include having a dispositional communal orientation, childhood socialisation, indebtedness and economic considerations.

Studies with SDAT and the frail elderly have indicated that caregiving is often stressful. The ability of caregivers to effectively cope and mobilise resources to assist with the demands and strains of the caregiving situation ultimately may affect their own personal health and life satisfaction. Following from this, the concept of burden is a central variable in the caregiving literature. The aim being to measure burden and to identify predictors of burden and other negative (e.g. depression) and positive (e.g. life satisfaction) outcomes for the carer.

In this chapter, variables that have been associated with caregiver burden have been discussed. These include the care-recipient's impairment, caregiver personality, coping strategies, social support, and dyadic relationship. It has been claimed that caregivers of demented relatives are more adversely affected than other groups of caregivers leading to the wealth of research in this area which examines SDAT caregiving. However, studies are beginning to emerge which suggest that whilst there may be aspects of the caregiving process which are common to all caregivers, characteristics of the dependent may represent specific predictors of distress according to patient group. Reasons are presented for not accepting that the model of caregiving in Alzheimer's may generalise to describe the caregiving situation for Parkinson's caregivers.

CHAPTER 3

THE CONCEPTUALISATION OF CAREGIVER DISTRESS

3.1 Introduction

Models have great explanatory value in elucidating the processes affecting individuals in stressful situations and their outcomes (Lazarus & Folkman, 1984). In this chapter, current models of caregiving are critically reviewed, and then a simple model is presented which outlines the conceptual framework of this investigation of caregiving in Parkinson's disease. Following from that, the specific hypotheses that were tested are defined, together with the methodology that was used to examine them.

To reiterate, this thesis is primarily concerned with describing the outcomes for caregivers of a specific illness situation - Parkinson's Disease. However, it is acknowledged that an important reason for investigating caregiver outcomes, besides the concern for the welfare of caregivers *per se,* is because caregiving outcomes directly affect the well-being of the care-recipient (Young, 1983). It has already been mentioned that if a caregiver is distressed to a point where their health breaks down, then institutionalisation of the patient becomes a strong possibility. This has an extreme effect on the patient, but interim to that, caregiver distress can mean that the care-recipient does not get optimal care, which can perpetuate the illness situation.

Following from this, it is useful to first consider a comparatively simple model of late life illness proposed by Young (1994), whilst bearing in mind that only a part of it is directly relevant to this research. Nevertheless, the Young model serves to put this research into a wider perspective (see fig. 3.1.1, below)

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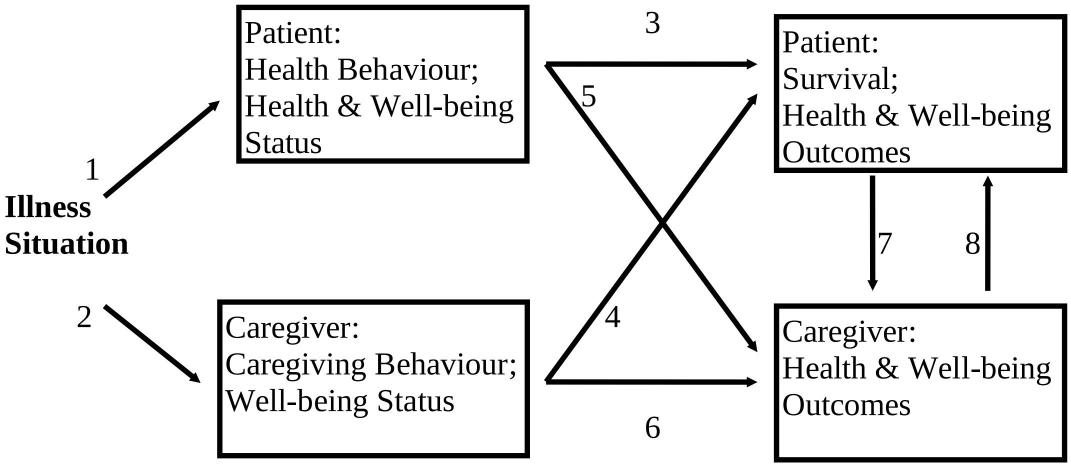
Figure 3.1.1 Late Life Family Illness: Patient-Caregiver Interaction Model.
(From Young, 1994).



Young (1994) argues that the consequences of illness in the family should be conceptualised as a mutual encounter - both the patient response and the caregiving response to the illness situation, in turn, effects the situation. Her model shows that late life family illness has a separate impact on the patient and the caregiver, but then their respective ensuing behaviour affects each other and influences outcomes.

One of the model’s strengths is that in simplicity there is generality. As indicated by arrow one, the illness constitutes a basic threat to life, quality of life and emotional well-being for the sufferer. This is as true for Parkinson’s disease, as for myocardial infarction (MI), the illness situation Young uses to state her case. Hickey (1980) notes that there is an important physical-mental interface at late-life because disease states reduce physical capacity and increase the need for assistance. Actually, the fears of dependency that follow the reduction of physical capacity associated with PD are probably not confined to those of advanced years, but the point is a relevant one. Fears of dependency have been associated with depression and anxiety (Hackett & Cassem, 1975; Krantz & Deckel, 1983).

As indicated by arrow two, caregiving begins when a family member has a decline in health (Miller *et al.*, 1991). Caregivers bring to the caregiving situation their own health and well-being, and their personal characteristics. Indeed, caregiving is characterised by a great deal of individual variation, and perhaps the most critical point to emerge from research on family caregiving is that carers behave quite differently even in essentially similar situations (Zarit & Edwards, 1996).

Arrows 3-8 address the responses of patients and caregivers to the demands of illness. Briefly, arrow three points out that the behaviour of the patients themselves influences patient outcomes; arrow four shows that the carer's actions are critical to patient well-being; arrows seven and eight show the relationship between patient and caregiver outcomes are connected: the patients' outcomes affect the caregiver, and the caregiver's outcomes affect the patient. Nothing more will be said on these four links as further discussion is beyond the scope of this research. The chapter now remains focused on caregiving outcomes.

Arrow five shows that the patient's behaviour and attitudes directly affect caregiver outcomes. Caring for people who require a considerable amount of assistance, or have many needs is stressful (Miller *et al.*, 1991). Caring for people with Parkinson's disease has been associated with negative outcomes for carers (Calder *et al.*, 1991; Miller *et al.*, 1996; O'Reilly *et al.,* 1996). Arrow six indicates that caregivers may exert considerable influence over their own outcomes - certainly coping strategies can be effective mediators of caregiver distress (Pearlin *et al.,* 1990).

To summarise, the Young model illustrates that there are multiple aspects of the patient-caregiver interface. When an older adult is affected by illness, so is his or her family. Patient and caregiver become ensconced in the illness situation in ways that affect each other and can influence the outcomes for each other. This research is concerned with defining more elaborately the nature of links five and six in the model. Taking Parkinson's disease as the illness situation, the question is *which aspects of patient health status and behaviour, and which aspects of caregiver characteristics and behaviour are most pertinent to caregiver health and well-being outcomes?* There have been some attempts to model these pathways where the illness situation has been either Alzheimer's disease, or late-life frailty in general. These will be discussed in the next section.

3.2 Models of Caregiving Stress

The concept of burden is shared by diverse caregivers to diverse groups of older adults (Kahana & Young, 1990). Outcomes for carers vary enormously even in similar caregiving situations (Zarit & Edwards, 1996). To explore individual differences in caregiving outcomes, theories of stress and adaptation (e.g. Lazarus & Folkman, 1984; Pearlin *et al.* 1981) have been used as a framework within which to operationalise the important constructs.

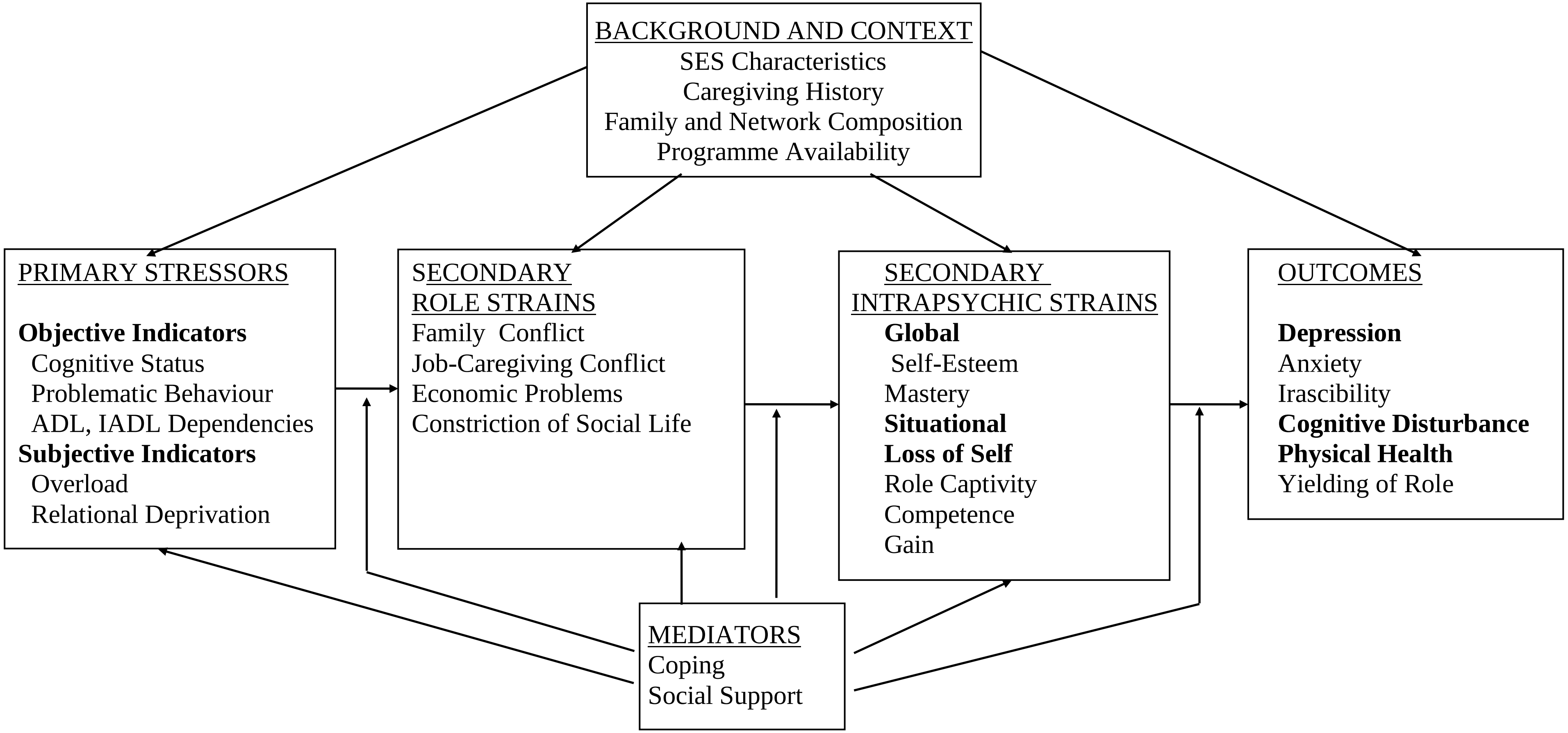
Models of stress maintain that stress is a process, that is, stress is not static, but dynamic. Changes in one part of the model will result in changes in other parts of the model. Lazarus & Folkman (1984) conceptualised the stress process as an ongoing series of interactions between objective events in the environment, individuals' perceptions of these events, attempts to cope with appraisals of the events, and behavioural and psychosocial outcomes. Central to the conceptualisation of the stress process is the assumption that major life events, such as illness and disability, exert their effect through a wider context of ongoing strains. Pearlin *et al.*

described the stress process as involving three domains: stressors (objective and subjective), mediators (coping and social support), and outcomes.

In 1990, Pearlin *et al.* published an adaptation of the stress process model as a conceptualisation of the potential distress that accompanies giving care to SDAT patients. In this model the stress process is made up of four domains: the background and context of stress; the stressors, the mediators of stress; and the outcomes or manifestations of stress (See figure 3.2.1 below).

The illness situation is essentially the context of stress, and the overall experience of stress experienced by carers is potentially influenced by social and economic characteristics of the caregiver. Primary stressors are viewed as stemming directly from patient needs and the extent of care demanded by these needs. Secondary strains are other stressors that are generated from primary stressors (e.g. constriction of social life). The constellations of primary and secondary stressors gives rise to the manifestation of stress experienced by caregivers defined by their physical and mental health, and their ability to sustain their social roles. Coping and social support are theorised to be the principal mediators of the stress process and are thought to exert their action by reducing the intensity of stressors and buffering outcomes. There is also provision for mediators limiting the proliferation of secondary stressors.

Figure 3.2.1 Conceptual model of Alzheimer's caregivers' stress. (From Pearlin *et al.*,1990).

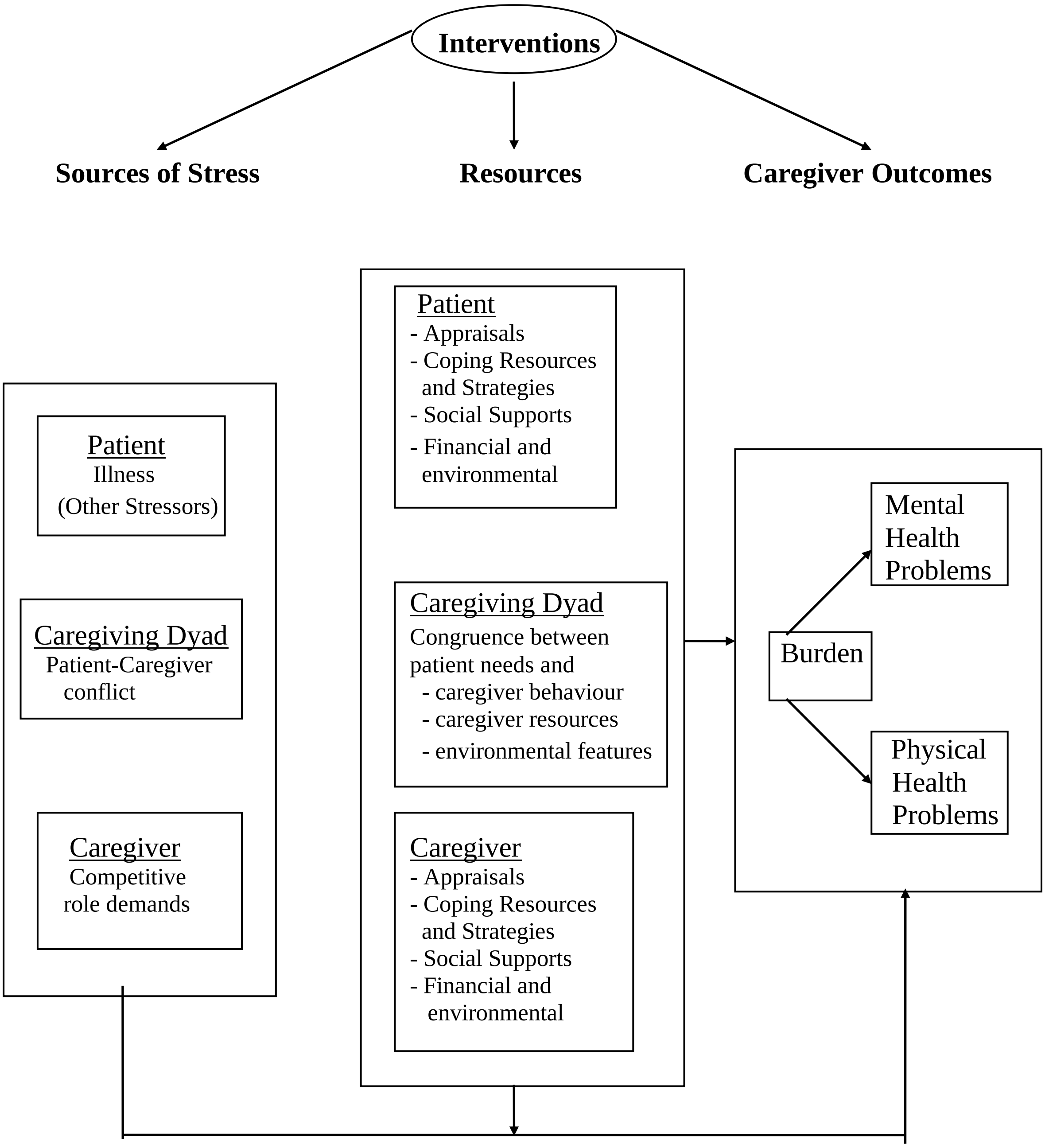


Pearlin *et al.*(1990) emphasised that the constructs that are included in their conceptual model, and the hypothesised relationships among them, should be regarded as a heuristic device for future research. The model has been endorsed as a useful approach to guide findings from the caregiving literature (Zarit & Edwards, 1996). However, it has been recognized that the constructs presented in the Pearlin *et al.* model are not sufficient. For instance, it has been documented that both care-recipient and caregiver characteristics, and the dyadic relationship between carer and dependent have an influence on caregiver outcomes (Hooker *et al.,* 1992; Kahana & Kinney, 1991; Kahana & Young, 1990; Morris *et al.,* 1988; Young & Kahana, 1987). These are not emphatically mentioned in the Pearlin *et al.* (1990) model.

Kahana & Kinney (1991) argued that theories of caregiver stress are needed before it is possible to design interventions to help carers reduce or eliminate the negative aspects and consequences of caregiving. They put forward a conceptual model of caregiver stress that, they suggest, will enable caregiving intervention in terms of the components of the stress model they affect.

In Kahana & Kinney's model (see figure 3.2.2 below), the stress process consists of three major components: sources of stress, resources, and outcomes. In specifying sources and resources, they consider those attributable to patient, carer, and dyadic relationship separately. The first source of stress arises from the care-recipient's illness/disease (i.e. degree of impairment, the amount of care required in activities of daily living). These are the primary stressors of Pearlin *et al.'s* (1991) model. Pearlin *et al.* also proposed secondary stressors which are based on the carer's perceptions of primary stressors. Kahana & Kinney, however, include appraisals under resources, rather than considering them as stressors. They argue that it is more appropriate to consider appraisals of the patient's illness as representing coping with the objective stress. That is, "negative appraisals may constitute secondary stress, [and] positive appraisals may represent a resource" (p. 126).

Figure 3.2.2 Conceptual Model of Interventions Relevant to Caregiver Stress. (from Kahana & Kinney, 1991).



Additional stressors in this model are the objective demands made on the caregiver that encroach upon other areas of the caregiver's life (e.g. responsibilities to others, restriction in own social life), and aspects of the dyadic relationship that present problems. Possible resources include personal, social and environmental resources that are available to the caregiver, and/or the care-recipient. In agreement with other models, Kahana & Kinney propose that the influence of stressors on outcomes is buffered by resources. If there is a mismatch between demands and resources, then caregivers will feel burdened, and mental and physical distress will ensue. Burden is an outcome variable in this model, "to reinforce our belief that caregivers' perceptions of and evaluations of their situation determine which caregivers will experience difficulty in their role as a caregiver" (p.127). Observable health or mental problems are considered to be a consequence of caregiver burden.

This model was specifically presented as a framework for planning interventions (although one would hope that this is the ultimate use of all caregiving research). There follows a discussion of the model with respect to providing intervention. Kahana & Kinney argue that mediators of the stress process are most amenable to successful intervention. It follows from this that they consider mediators to be important predictors of caregiver distress. This naturally begs the questions: *what are mediators?* and *which mediators in particular?*

According to Kahana & Kinney's model, mediators of outcomes are "resources". (Hence the interventions should be targeted to provide the caregiver with increased personal, social and environmental resources.) Unfortunately, they do not present any data to support their assertions beyond referring to the work of Gallagher (1990) and Pearlin *et al.* (1989).

Nevertheless, there is some support for the assertion that a significant contribution to negatives outcomes - burden, psychological and physical health problems - comes from the mediators. Emotion-focused coping is generally associated with negative outcomes for carers (Pruchno & Resch, 1989b; Saad *et al.,* 1995), and social support is related to caregiver distress (Gold *et al.,* 1995, Pearlin *et al.,* 1990; Redinbaugh *et al.,* 1995; Zarit, 1980). In the Alzheimer's literature several studies have found only weak associations between patients' memory and behaviour problems and negative outcomes for carers (e.g. Eagles *et al.,* 1987; Gilhooley *et al.,* 1984; Pagel *et al.,* 1985; Zarit *et al.,* 1980). But this is equivocal. Against the view that a significant contribution to carer distress comes from the mediators is the argument that it is SDAT patients' memory and behaviour problems (i.e. a source of stress) that put their caregivers at additional risk for poor outcomes, as compared with other caregiving groups (Palmore *et al.,* 1985; Clipp & George, 1993). Also, it has been found that past relationship (in this model a source of stress) is associated with carer burden and depression (Gold *et al.,* 1995; Morris *et al.,* 1988).

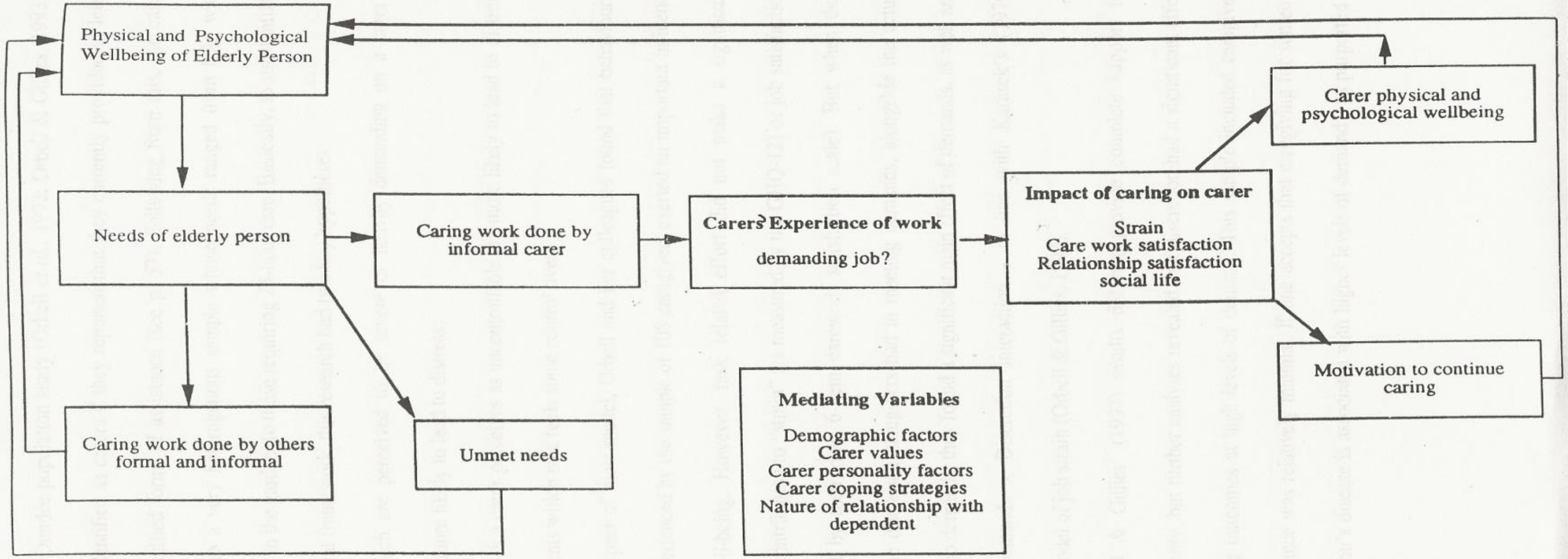
With respect to Parkinson's disease, there is some evidence that motor impairment (a source) is an important contributor to relatives' distress (Calder *et al.,* 1991). Moreover, Miller *et al.* (1996) found that patient depression (a source) was the best predictor of distress in PD caregivers, and that social support (a mediator) did not predict carer distress. Although these results currently stand in isolation simply because of the dearth of PD caregiving research, together they suggest that Kahana & Kinney's reasoning may not generalise to provide efficient intervention strategies for PD carers, and hence for modelling PD caregiving.

While Kahana & Kinney (1991) focused on the role of mediators in their model of family caregiving, Orbell and her colleagues concentrated on carers' experience of the caregiving job - that is the demands of the job, and the discretion caregivers perceived they had in fulfilling these demands. In their model of providing care to an elderly person (Orbell *et al.*, 1992) the role of mediators were effectively marginalised (see fig. 3.2.3 below).

To consider "What's stressful about caring?" (Orbell & Gillies, 1993), Orbell and her colleagues conceptualised caring as an occupational stressor. That is, they considered caregiving as work, as a job. They used the job strain model of Karasek (Karasek, 1979; Karasek & Theorell, 1990) to provide the theoretical framework for the study. Briefly, Karasek's demand-discretion model of job strain combines two major dimensions of the work environment, demand (particularly quantitative workload) and discretion (opportunities for control, and decision-making). Karasek proposed that psychological health is determined by the joint effects of the demands of the work situation and the degree of discretion available to the individual facing those demands. Critically, his model predicts an interaction between demand and discretion such that low levels of demand and high discretion is not stressful, but worker strain and dissatisfaction are high if high levels of demand are combined with low levels of discretion.

The application of Karasek's occupational framework to the illness situation requires consideration of the components of demands placed on caregivers. Orbell & Gillies (1993) conceded that there are two broad bands of demand in the caregiving context: the first arises from the care-recipient's need for assistance with activities of daily living (ADL), and the second comes from impairments in cognitive functioning. "Each of these variables may contribute to psychological stress" (p. 274).

Figure 3.2.3 Model of Impact of Caring (From Orbell *et al.* 1992).



In the Dundee population study (Orbell *et al.*, 1992; Orbell & Gillies, 1993), adults were identified as carers if they reported that they currently provided at least one of 18 specified forms of assistance (see p. 53). Following from this, the care-recipients were a very heterogenous sample whose needs ranged from help with decorating, or in the garden, to those requiring 24-hour care. Basically, to substantiate their conceptual framework, this research had two key hypotheses:

1. Events which are perceived to be severe or heavily demanding on a carer's resources are more likely to lead to distress
2. Events which a carer perceives as uncontrollable are more likely to lead to distress than those events which s/he feels some control over.

In support of their model, Orbell and her colleagues found that behavioural problems experienced by the sample of 108 caregivers exerted an important influence on carer well-being. However, task related effort did not make a significant independent contribution to "strain" (as measured by the GHQ-12) or job satisfaction (as measured by their own 6-item care work satisfaction scale). But when they considered the discretion caregivers had in meeting demands, alongside the actual (perceived) job demands, they found a significant main effect of demands, as well as a significant Demands x Discretion interaction - in line with Karasek's (1979) theoretical model of job strain (Orbell & Gillies, 1993).

Orbell & Gillies' (1993) results did not provide complete support for Karasek's theory, but further analyses revealed that discretion had a significant effect on caregiving outcomes at high levels of demand. This sample included caregivers whose assistance was relatively minimal. If one accepts that caregiving for someone with Parkinson's disease is associated with higher levels of demand - as purported in

Chapter 1, then this suggests that caregiver discretion is an important variable in modelling caregiving in Parkinson's disease. Certainly, Orbell & Gillies propose that an approach to effective support for carers should focus on increasing discretion in relation to care work.

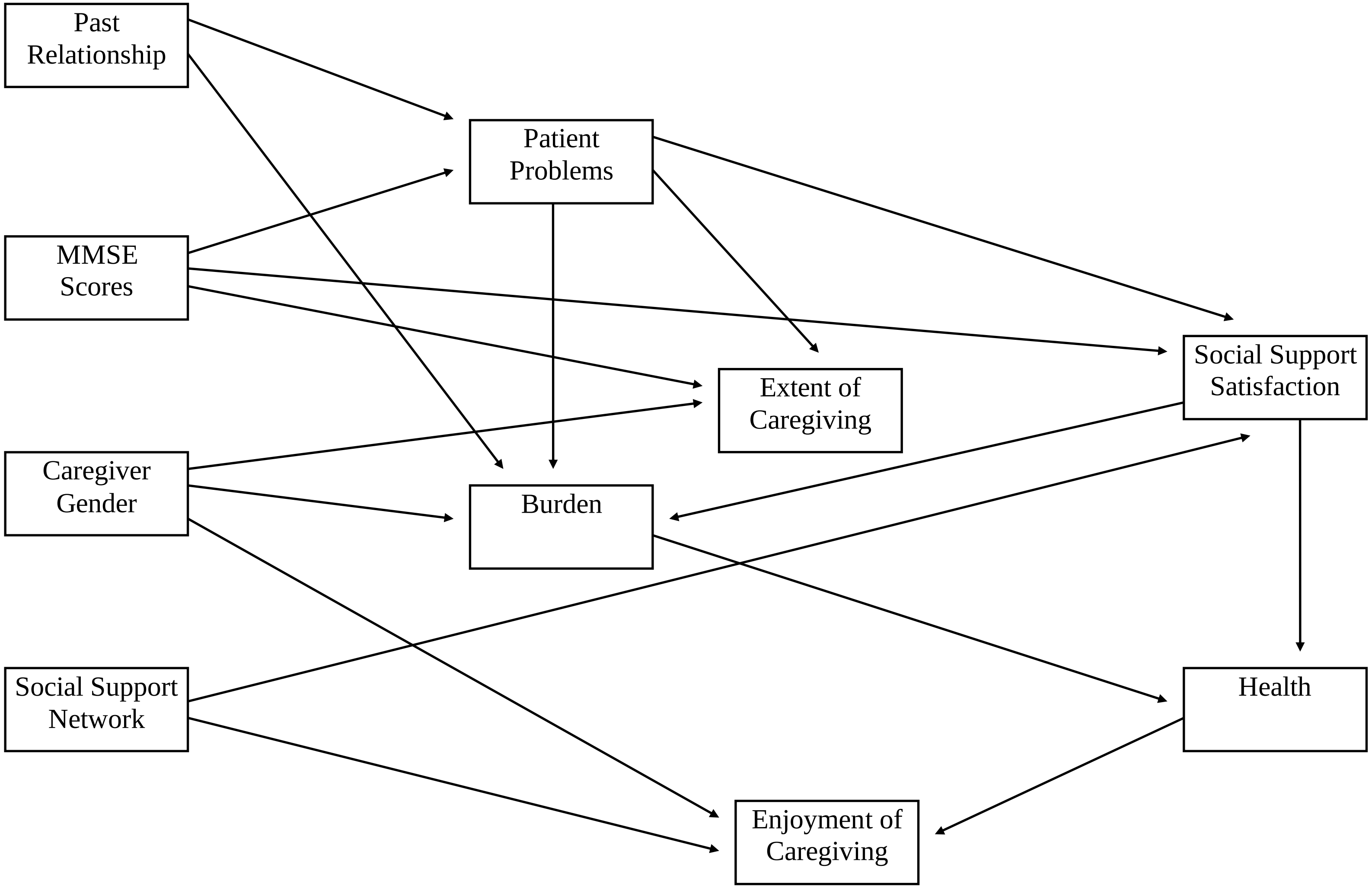
Lawton *et al.* (1991) presented a conceptual model confined to considering SDAT patient's symptoms, caregiver's social resources, and caregiver's appraisals of caregiving - operationalised as satisfaction and burden - with a view to determining how they affected positive affect and depression. Specifically, they proposed that caregiving activity can simultaneously enhance caregiver satisfaction, and increase carer burden, and they expected the two types of caregiver appraisal (satisfaction and burden) to be (separately) linked to two types of psychological well-being (positive affect and depression). However, their data did not fully uphold the hypothesised view of separate causal paths that link outcomes. Considering spouse and adult child caregivers separately, Lawton *et al.* found that, for spouse carers, satisfaction led to positive affect and burden to depression. However, they were unable to determine the source of satisfaction for spouse caregivers. "It is easy to speculate that the long-term and present quality of the marital relationship would be such a determinant of satisfaction with caregiving" (p. P187). However, it was not considered in the model.

The adult-child caregiving model did not replicate the hypothesised and confirmed model for spouse caregivers. Their positive appraisals (satisfactions) of caregiving did not augment positive affect. That is, for child carers, caregiving satisfaction was not effective in bolstering positive well-being. Interestingly, burden strongly determined both facets of psychological well-being. This was not considered in the spouse model because their hypothesis was supported.

To summarize, the Lawton *et al.* study provided a useful illustration that models of caregiving may not be the same for different groups of caregivers, however, as a model of caregiving that accounts for objective and subjective elements and deals with the complex gains and losses to those who have taken on the caregiver role it is inadequate. In choosing to limit the number of predictors of outcomes, Lawton *et al.* were unable to provide a convincing explanation of their results, and hence its worth as a model of SDAT caregiving is limited.

Gold *et al.* (1995) also presented a model considering the outcomes for informal caregivers of relatives with dementia with a view to specifying causal links among contextual, patient, appraisal, and caregiver outcome variables (see fig. 3.2.4 below). They included three outcome variables: *burden* was measured by the Burden Interview (Zarit *et al.* 1985), psychological *health* was measured by the General Health Questionnaire (GHQ: Goldberg, 1978; Goldberg & Hillier, 1979), and *enjoyment of caregiving* was determined by the response to an open-ended question which was subsequently coded. Independent variables were caregiver gender, social support network, community service use, quality of the past relationship, and patient cognitive function.

Figure 3.2.4 Model of Caregiving Outcomes (From Gold *et al.*, 1995).



Using path analysis, Gold *et al.* (1995), found that the biggest predictor of caregiver *burden* was *problem behaviours*, which was assessed by the Memory and Behaviour Problems Checklist (Zarit *et al.*, 1985). (This measures carers' appraisals of patient functioning). Caregiver gender, satisfaction with social support and quality of the premorbid relationship were also significantly associated with burden. Social support satisfaction was related in the opposite direction to *health*. Social support network and gender were found to be predictors of *enjoyment of caregiving.* In contrast to the hypotheses and to the work of Lawton *et al.* (1991), Gold *et al.* found that the amount of help the caregiver provided to the patient did not affect caregiving outcomes, and neither did patient cognitive functioning.

To measure objective patient cognitive functioning Gold *et al.* (1995) used the Mini-Mental State Examination (MMSE; Folstein *et al.*, 1975). However this was probably inappropriate when a score of below 24/30 (to indicate dementia) was required for inclusion into the study: it is known that the MMSE is susceptible to floor effects in severely demented cases. That is, once patients reach a fairly advanced stage of the disease, they tend to score very few points, and beyond this progression cannot be assessed (Hodges, 1994). The mean MMSE score for the 118 patients who were tested twice was just 13.95, which strongly suggests that some of the sample were severely demented. It is therefore not surprising that MMSE scores were not related to any of the other variables in the model, except extent of caregiving, despite the hypothesis that caring for more cognitively impaired dependents would be associated with greater negative outcomes for caregivers.

The Gold *et al.* study provides some support for a multidimensional model of caregiver distress. The model showed stability when 118 of the original 196 caregivers were re-tested six months later in that consistent relationships were reported for the two occasions. However, as Gold and her colleagues acknowledge, the model does not account for all aspects of the inter-relationships of the variables, as indicated by the goodness of fit indices. They also call for a replication in view of the "unique" relationship between outcomes variables. They found a highly significant relationship between burden and health, and between health and enjoyment of caregiving, which is not unusual, but the relationships between the individual outcome measures and the contextual and appraisal variables lead to a model which presents its outcome variables as being sequential. This is not usual. Whilst Kahana & Kinney (1991) considered that mental and physical health problems resulted from burden, other models portray all caregiving outcomes to be equally affected by the stressors tested (e.g. Orbell *et al.*, 1992; Pearlin *et al.*, 1990; Young, 1994). In these models, outcomes are grouped together in one box. This may not be helpful. Gold *et al.* were able to show that there were four predictors of burden: patient problems, caregiver gender, past relationship, and being dissatisfied with social support. Burden was the best predictor of health, although there is also a direct path leading from social support satisfaction to health. Similarly, health was the biggest predictor of enjoyment of caregiving, with additional variance explained by caregiver gender and social support network, but there is no causal path between burden and enjoyment of caregiving. This seems odd in view of the reported significant relationship between burden and enjoyment of caregiving at both time 1 and time 2, whereas the relationship between health and enjoyment of caregiving at time 1 was not significant. But Gold *et al.* argue that "health is crucial for positive outcomes of caregiving" (p. 194). To reiterate, "health" here, is as measured by the GHQ, which is essentially a measure of psychiatric morbidity (McDowell & Newell, 1996).

In line with the assertions of Kahana & Kinney (1991), the Gold *et al.* (1995) model emphasises the importance of the caregiver's appraisal of the situation they find themselves in. The appraisal of patient symptomatology had the biggest impact on caregiver burden. The model, however, does not take any account of caregiver personality, which have an effect on appraisals (Reis *et al.*, 1994). Similarly, coping styles were not investigated either.

This model is important in that it demonstrates that caregiving is multidimensional. Three outcomes of caregiving were considered separately and found to have different predictors. This represents a step forward from other models which have not differentiated outcomes. The model, however, is incomplete, even for predicting negative and positive outcomes for dementia caregivers in that no consideration was given to the roles played by caregiver personality, dispositional style and coping style.

3.2.2 Summary

By identifying potentially important dimensions of the stress process, a model of caregiving outcomes can guide clinicians in conducting assessments of caregiving families (Zarit & Edwards, 1996). However, there is little consensus in the published models of caregiver distress to date. Orbell *et al.* (1992) emphasised the role of "carers experience of work" (i.e. job demand and discretion) when outlining their conceptual framework of caregiving. In contrast, Kahana & Kinney (1991) focused on the role of mediators. Pearlin *et al.'s* (1990) model, has provided a sound adaptation of the stress process to caregiving, but it has since been recognised that it is insufficient. Research has indicated that additional variables need to be incorporated into their model (such as caregiver characteristics, and dyadic relationship) in order to be comprehensive. Similarly, Gold *et al.* (1995) present a multidimensional model of caregiving, but the contribution of caregiver characteristics is needed to present a fuller picture.

All of the models reviewed have considered the consequences of giving care to someone is elderly. Several of the models focused on dementia caregiving. All of the models have been criticised to some extent, but each has served to direct further experimentation with refinements. This study has built on previous caregiving research to attempt to carry out a comprehensive investigation of caregiver distress in Parkinson's disease. The investigation includes all the variables identified by previous models as being implicated in caregiving outcomes - including carer personality. Also included in this investigation are variables concerned with what carers know about PD. The motives for including variables measuring caregiver's knowledge of Parkinson's disease will be discussed in the following section. The chapter then continues with a summary of the a priori hypotheses that were to be specifically tested in this research project, and the methodology that was used to study Parkinson's disease caregiving.

3.3 Knowledge of Parkinson's Disease

Parkinson's disease is, by definition, a motor disorder. A diagnosis of PD is dependent on the presence of at least two of a triad of physical symptoms (i.e. tremor, rigidity and bradykinaesia) and confirmed with a positive response to levodopa therapy (Quinn, 1995). However, there is a growing awareness among health professionals that PD has cognitive and behavioural symptomatology, as well as being a motor disorder. As illustrated in Chapter 1, there has been considerable academic interest in the cognitive aspects of PD in the last 20 years, and together these studies have indicated that a variety of subtle cognitive changes are concomitant with a diagnosis of PD.

There have been suggestions, however, that the cognitive aspects of PD have been overlooked (Lees, 1990). Practically this neglect is important “because of the need to advise patients and their families on the prognosis of their disease” (Brown & Marsden, 1984). The Parkinson’s Disease Society (PDS) do provide a lot of literature to PD patients and their families, booklets are available free of charge, at hospital clinics and at general practice surgeries, as well as to those who join the society. A content analysis was done on this free literature. This revealed that the PDS provide a wealth of information about the physical aspects of PD, what to expect and how to cope with problems that arise from the physical limitations of the disease. There was, however, a dearth of information regarding behavioural changes in PD. Only the increased risk of depression was acknowledged. Even the increased risk of dementia in PD is dismissed. This suggests that findings concerning the cognitive aspects of PD have not filtered through to PD patients and their caregivers, and led to the hypothesis that patients and carers will know less about the cognitive aspects of PD than they know about the physical aspects of PD.

Stetz (1989) noted that the literature to date on psychological burden associated with cancer identifies uncertainty over the patient’s health as the dominant concern for patients and their families. She went on to show that the (cancer) caregiver’s level of uncertainty was a significant predictor of caregiver health, as measured by the Ware General Health Perceptions Measure (Ware & Karmos, 1976). That is, the greater the uncertainty, the poorer the evaluation of general health. Interestingly, Stetz found that the more disabled the ill spouse, the lower the uncertainty. “This finding may suggest that severe disability is actually a less ambiguous condition, resulting in lower levels of uncertainty in the caregiver" (p. 149). It follows from this, that uncertainty concerning the (cancer) situation, may be resolved through experience.

Similarly, the stress caused by uncertainty has been documented in the AIDS literature. A qualitative study of AIDS family caregiving by Brown & Powell-Cope (1991) identified uncertainty as the basic psychological problem for carers. "Uncertainty for caregivers was related to questioning how the disease would unfold, monitoring the symptoms, determining the meaning of symptoms and illness behaviour..." (Brown & Powell-Cope, 1991; p. 342). If PD caregivers are not in receipt of information concerning important changes that may occur in their care-recipient, then this may be as true for many PD caregivers, as it is for AIDS caregivers. It is true that the early stages of caring for dementing older adults have been associated with uncertainty and unpredictability (Wilson, 1989).

The concept of perceived uncertainty is a key variable in the organizational stress literature (Landy *et al.*, 1994), but as yet it is relatively unexplored in the caregiving literature (Brown & Powell-Cope, 1991). McGrath (1976) suggested that the concept of perceived uncertainty may represent an unifying theme for stress research. Jackson (1989) defined uncertainty from an organizational perspective as inadequate knowledge about an event that requires action or resolution. From a caregiving perspective, it was reasoned that uncertainty may contribute to distress if a caregiver knows little about the illness situation they are in.

3.3.1 Construction of a Knowledge Questionnaire

In order to explore whether inadequate knowledge of PD contributes to carer distress, it was necessary to construct a suitable questionnaire to find out what carers know about PD. On the basis of a thorough literature search, a pilot questionnaire was complied, which consisted of 52 statements - 26 items of physical aspects (PHYS) and 26 items of cognitive aspects (COG) of PD. Subjects were to read each statement and then decide whether it was true or false with respect to PD. Items were counterbalanced to ensure that there were equal numbers of true and false items across the PHYS and COG items.

The 52-item questionnaire was administered individually to 31 PD patients and carers. One thing that was immediately clear during the piloting was that on some items the wording was too complex. A subsequent Flesch analysis confirmed that the document was only suitable for someone with a college education. A reliability analysis was performed to identify those items which were most reliable to be used in a questionnaire of a more manageable length, then the wording was revised, as necessary, on the remaining 28 items.

For some items it actually proved difficult to retain the essence of the meaning of questions without using jargon. An example can be seen in the original statement “Face discrimination is not impaired in Parkinson’s disease”. Some of the pilots had needed clarification on what “face discrimination” actually meant. The question was reworded “Learning to recognise new faces is not impaired in Parkinson’s disease”, but this change was seen to be inadequate. Although there is evidence that some Parkinson’s patients have impairments on face recognition tasks, like many other symptoms of this heterogenous illness, the problems are not found in all patients. To overcome this, the question was again reworded to “Patients find it easy to learn to recognise new faces”. This is false.

Following from this, 77 patients and caregivers from four PDS branches were given the 28-item version of the questionnaire, as a second pilot. Importantly, the results showed that patients and caregivers knew significantly more about physical aspects than cognitive aspects of PD, but a reliability analysis revealed that the questionnaire could be improved upon by reducing the number of items again.

Another consideration was the fact that the construction of the two subscales - PHYS and COG - were essentially based on face validity. A confirmatory factor analysis was needed to verify that the internal structure of the questionnaire did actually yield these two separate factors. For the 28-item version this showed one main factor, which was understood to be *Knowledge of Parkinson's Disease,* but the scree plot could not usefully delineate the subfactors. The logical answer was to increase the specificity of the questionnaire by increasing the number of possible responses. This would also provide a means of differentiating, to an imperfect extent, the degree of certainty from educated guessing.

A third pilot was run using a revised response format. For each item PD patients and carers were required to state whether they thought the answer was *definitely true, probably true, probably false or definitely false.* A score of 2 was given for a correct "definitely" response, and 1 was given for a correct "possibly" response. No score was given for a wrong answer.

The responses from this third pilot (*n* = 153) were analysed using the scale reduction programme on SPSS. Inspection of the separate inter-item correlation matrices for PHYS and COG indicated that a 16-item version of the questionnaire should be used. The crucial point of this exercise was that there should be no negative correlations *between* items on the same scale - to show that there was cohesion within items on each scale. This was true for a version that used eight PHYS items, and eight COG items. Coefficient alphas for this 16-item Knowledge of

Parkinson's Disease (KPD) questionnaire were: total KPD α=.69, PHYS α=.61, COG α=.69.

At this point it was considered critical to demonstrate that the two subscales were distinct and pure, if a test was going to be made comparing knowledge of one subscale to the other, and whether a particular type of lack of knowledge was associated with caregiver distress. The best way to do this was to use the smallest space analysis (SSA) technique (Lingoes, 1973). The results of the SSA are shown in fig. 3.3.1.1, below.

A 16-item KPD questionnaire was therefore prepared to investigate whether a lack of knowledge of PD contributes to PD caregiver distress. It was clear from the SSA that the PHYS and COG subscale were conceptually distinct; the inter-item correlation matrix indicated that there was cohesion within the two subscales, and the reliability of the questionnaire was acceptable.

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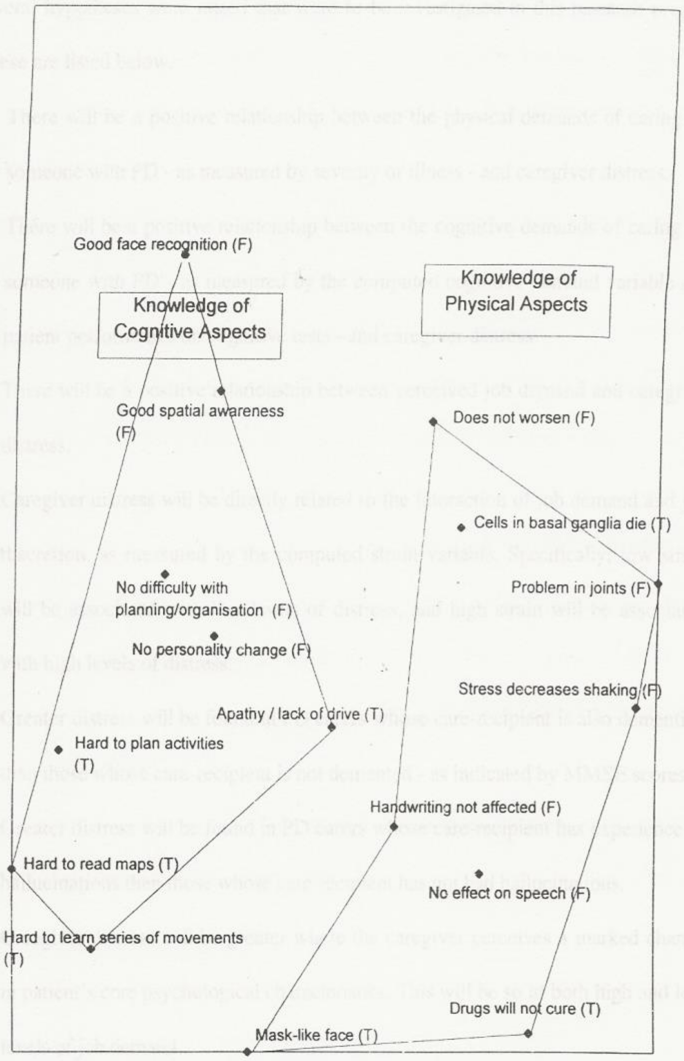
Figure 3.3.1. Smallest Space Analysis of the 16 variable Knowledge of Parkinson's Disease Questionnaire (n=153).



3.4 Summary of the Hypotheses

In the course of reviewing the literature on Parkinson's disease and caregiving, several hypotheses were raised that were to be investigated in this research project. These are listed below.

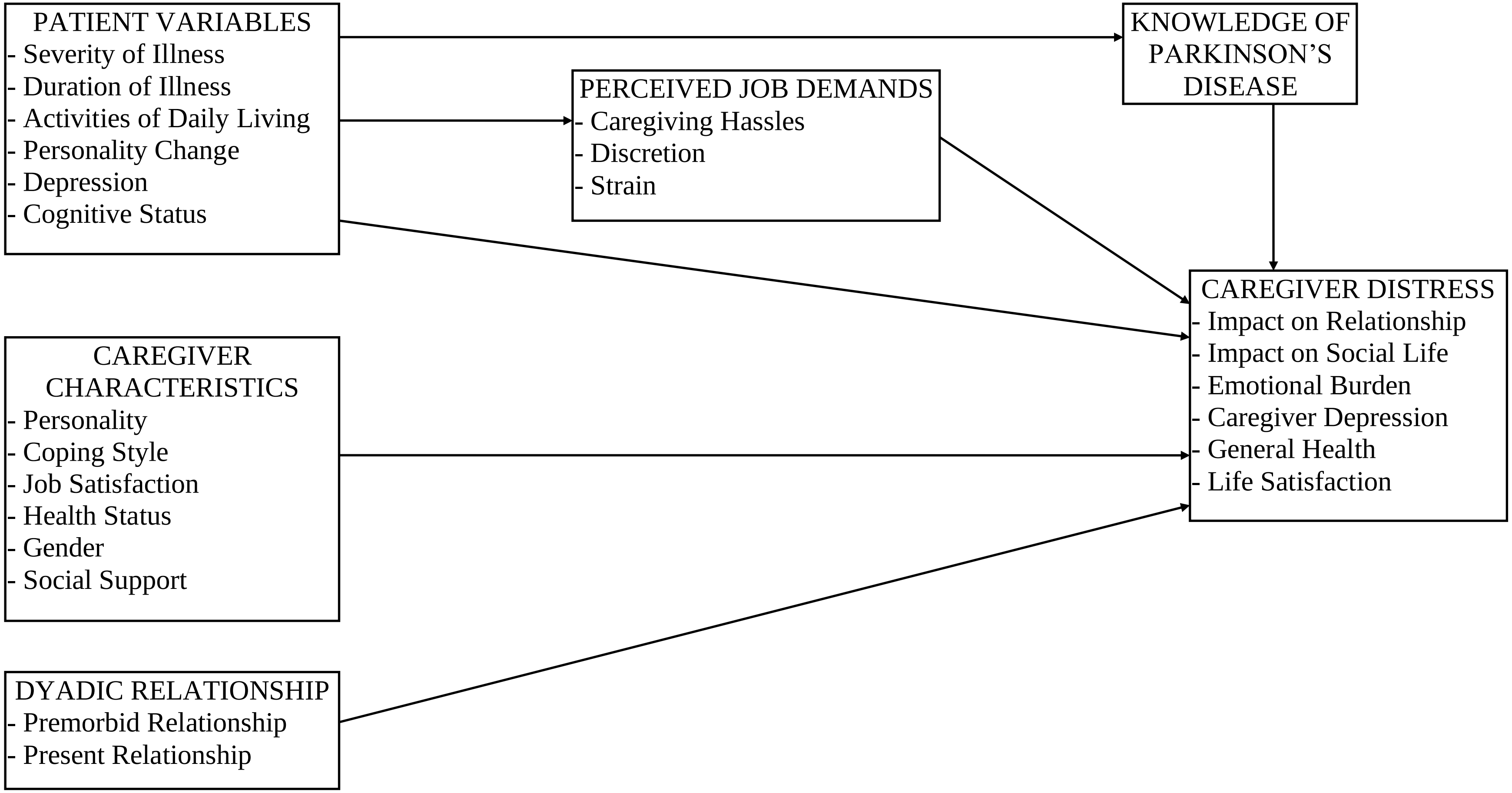
1. There will be a positive relationship between the physical demands of caring for someone with PD - as measured by severity of illness - and caregiver distress.
2. There will be a positive relationship between the cognitive demands of caring for someone with PD - as measured by the computed cognitive demand variable and patient performance on cognitive tests - and caregiver distress.
3. There will be a positive relationship between perceived job demand and caregiver distress.
4. Caregiver distress will be directly related to the interaction of job demand and job discretion, as measured by the computed strain variable. Specifically, low strain will be associated with low levels of distress, and high strain will be associated with high levels of distress.
5. Greater distress will be found in PD carers whose care-recipient is also dementing than those whose care-recipient is not demented - as indicated by MMSE scores.
6. Greater distress will be found in PD carers whose care-recipient has experience of hallucinations then those whose care-recipient has not had hallucinations.
7. Caregiver distress will be greater where the caregiver perceives a marked change in patient's core psychological characteristics. This will be so at both high and low levels of job demand.
8. Caregiver characteristics will have a direct influence on carer outcomes. Specifically, it is hypothesised that caregiver neuroticism will be positively

related to distress and dispositional optimism will be negatively related to distress.

9. The quality of the premorbid relationship will be negatively related to caregiver distress. This will be so both for those caring for both demented and non-demented patients.
10. Caregiver distress will be moderated by carers' gender, social support, coping style, and dispositional style (hardiness and communal orientation).
11. Knowledge of Parkinson's disease (KPD) will be associated with caregiver distress. Specifically, it is hypothesised that (i) patients and caregivers will know more about the physical than the cognitive aspects of PD, even when education level is accounted for; (ii) KPD scores will be similar for patients and caregivers; (iii) duration and severity of illness, and membership of the PDS will influence knowledge of physical, but not cognitive aspects of PD; (iv) there will be a negative relationship between KPD and carer outcomes. Particularly, it is expected that a lack of cognitive knowledge will be associated with greater caregiver distress.
12. Caregiver distress is related to progression of illness, as measured by an increase in burden, depression and general health scores and a decrease in life satisfaction scores from phase I to phase II.

Following from this, a simple model of the expected outcomes of caring for someone with Parkinson's disease is presented in figure 3.4.1, below.

Figure 3.4.1 Hypothesised Model of Parkinson's Disease Caregiving



3.5 Methods

3.5.1 Choice of Measures.

3.5.1.1 Caregiving Outcome Variables

In this investigation of psychological distress in those who care for Parkinson's disease patients, caregiver distress was considered to be derived from a number of variables which were likely to be predicted by different aspects of caregiving. As Greatness & van der Ende (1994) noted, "conceptual sensitivity can be enhanced by accounting for different dimensions within the care-giving burden. A unidimensional definition or representation of caregiving burden obscures its different components. Potentials for interventions will be limited, because specific aspects of burden cannot be distinguished" (p484).

Burden has indeed been conceptualised in a variety of ways. Perusal through the literature leaves an impression that there is no consensus on the best way to measure caregiving burden. This is highlighted by the large variety of measures that have been developed and used (see Table 3.5.1.1.1 below).

Table 3.5.1.1.1 Examples of the variety of measures that have been used to assess caregiving outcomes, including the number of items on the scale.

MEASURE	**ITEMS**
Activities Restrictions (Bass *et al.*, 1994)	6
Affect Balance Scale (Bradburn, 1969)	10
Beck Depression Inventory (Beck & Beck, 1972)	13
Burden 1 (Pruchno & Resch, 1989a)	1
Burden 2 (Pruchno & Resch, 1989a)	17
Burnout Measures (Pines *et al.*, 1981)	21
Caregiver Appraisal Measure (Lawton *et al.*, 1989)	5 dimensions
Caregiver Burden Inventory (Novak & Guest, 1989)	24

MEASURE	ITEMS
Caregiver Burden Scale (Stommel *et al.,* 1990)	31
Caregiver Strain Index (Robinson, 1983)	13
Caregiver Stressors (Williamson & Schulz, 1993): own measure	11
Care-giving Burden Scale (Gerritsen & van der Ende, 1994)	13
Caregiving Burden Screen (Rankin *et al.*, 1994): own measure	11
Care Work Impact Appraisals (Orbell *et al.*, 1993)	31
Center for Epidemiological Studies Depression Scale (Radloff, 1977)	20
Cost of Care Index (Kosberg & Cairl, 1986)	20
Dupuy General Well-Being Index (Dupuy, 1984)	22
Dyadic Relationship Strain (Bass *et al.,* 1994)	6
Frustration Scale (Motenko, 1989): own measure	9
General Health Questionnaire (Goldberg, 1978)	12
Geriatric Depression Scale (Sheik & Yesavage, 1986)	15
Hamilton Depression Rating Scale (Hamilton, 1960)	24
Impact of Caregiving Inventory (Rankin *et al.,* 1992)	9
Impact of Caregiving Scale (Poulshock & Deimling, 1984)	19
Objective Burden Inventory (Montgomery *et al.*, 1985b)	9
Pearlin *et al.* (1990) 15 measures of caregiver stress	94
Perceived Stress Scale (Cohen *et al.*, 1983)	14
Relatives' Stress Scale (Greene *et al.,* 1982)	15
Screen for Caregiver Burden (Vitaliano *et al.*, 1991)	25
Stressors (Pruchno & Kleban, 1993): own measure	12
Structured Interview (Rabins *et al.,* 1982)	52
Structured Burden Questionnaire (Almberg *et al.*, 1997)	7 dimensions
Stull *et al.* (1994): own measure	6 dimensions
Subjective Burden Inventory (Montgomery *et al.*, 1985b)	13
Subjective Caregiver Stress (Townsend *et al.*, 1989)	7
Symptom Checklist-90-R: Depression subscale (Derogatis, 1993)	13
Ware General Health Perceptions Measure (Ware & Karmos, 1976)	32
Zarit Burden Interview (Zarit *et al.*, 1980; Zarit & Zarit, 1987)	29 / 22
Zung Self-rated Depression Scale (Zung, 1965)	20

In some scales, burden has been presented as a global score, without any conceptualisation of the factors contributing to the burden outcome. Montgomery *et al.* (1985a) have defended this approach. They regard burden as an accumulation of stress, rather than a specific set of problems. Essentially though, this is not very satisfactory. The measurement of burden through the generation of a global score obscures specific areas of problems to caregivers and impedes identification of antecedents of any resultant burden (George & Gwyther, 1986). Poulshock & Deimling (1984) suggested that burden is an intervening measure between impairment and other outcomes of the caregiving task. It follows from this that global measures of psychological well-being, physical and emotional health, or depression should not be treated as burden, but as factors affected by burden. Kosberg *et al.* (1990) argued that the measuring caregiver burden with a summated or global score, without consideration of the components of burden, is not useful for gaining an understanding of the concept. Zarit (1989) proposed that the nature of the research question should indicate whether global measures of burden should be used and that domain specific measures should be used when the character and severity of the consequences is of concern. It follows from this that a single measure will not be sufficient to fully assess the outcomes of caregiving.

Consideration of the various measures essentially indicated that there are (at least) three distinct components of burden: emotional burden, burden resulting from the impact on the dyadic relationship, and burden resulting from the impact on the caregiver’s social life. As a response to this, in this investigation of PD caregiving the global measure of burden used in many investigations of caregiving outcomes was displaced in favour of measuring emotional burden, impact on relationship and impact on social life.

Emotional Burden (EB) in PD caregivers was measured using the 17-item *Burden 2* scale compiled by Pruchno & Resch from items used in the caregiver literature (P&R.B2; Pruchno & Resch, 1989a). This scale measures subjective feelings of burden (e.g. isolated and alone; irritable; emotionally drained) without reference to occasion. Caregivers were asked how often (*never, sometimes, often*) during the past month they had experienced each of the 17 specific emotions as a result of caregiving. Scores range from 17 to 51, with higher scores indicating greater burden. Pruchno & Resch gave a reliability coefficient of α=.89[1].

Impact on Relationship (BIR) and *Impact on Social Life* (BIS) were measured using the two subscales of the Impact of Caregiving scale developed by Poulshock & Deimling (1984). BIR consists of eleven items that reflect the negative changes in elder-caregiver (nine items) and caregiver-family (two items) relationships resulting from caregiving. BIS consists of eight items that reflect the restrictions in caregiver activities resulting from caregiving.

Both scales use the same self-report 4-point response format. Caregivers were asked to carefully consider each statement (e.g. My relationship with ____ is strained (BIR); I feel like my social life has suffered because of ____ (BIS)), then to select the response that best described how they felt on the point from *Rarely or None of the time, Some or a Little of the time, Occasionally, or a Moderate amount of time, Most or All of the time.*

It is generally considered that caregiving may also have a negative effect on a carer's health and general satisfaction with life. Several researchers have suggested that psychological morbidity and depression are a consequence to burden (Pearlin *et al.* 1990; Kahana & Kinney, 1991; Gold *et al.,* 1995). Poulshock & Deimling (1984), however, reported that caregiver depression can result directly from the nature of the elder impairment, and hence depression can have an important effect on carer's perception of burden. "Whether depression is viewed as an *effect* of caregiving or as

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[1] The questionnaires used in this investigation, and further information concerning the administration

an *antecedent* influence, from the standpoint of measurement, it must be considered. If not, it may confound the interpretation of the relationships between other measures employed in the analysis" (p.235). In the Orbell *et al.* (1992) and Young (1994) studies, caregiver mental health outcomes and depression are modelled as caregiving outcomes alongside burden. In this study, in the first instance, psychological morbidity and caregiver depression will be considered as separate potential outcomes for PD carers. Similarly, life satisfaction, which is a useful indicator of subjective well-being and successful ageing (Neugarten *et al.,* 1961) was included as a sixth outcome measure.

Psychological morbidity was measured by the 12-item version of the *General Health Questionnaire* (GHQ; Goldberg, 1972). The GHQ is a self-administered screening tool designed to detect psychiatric morbidity in the general population. It concentrates on deviation from normal functioning rather than on long-term behaviours. The 12-item version was used to ask caregivers about their general level of happiness, depression, anxiety and sleep disturbance over the past four weeks. Items were scored according to the modified response format 0 = *never/not at all,* to 3 = *always/all the time.* This response format is considered to have greater face validity to those experiencing chronic strain (c.f. Orbell *et al.,* 1993), such as PD caregivers.

Caregiver depression was measured using the *Centre for Epidemiological Studies Depression Scale* (CESD; Radloff, 1977). The CESD is a 20-item, single factor scale which was designed to measure depressive symptoms in community populations. It has been used successfully with caregivers (e.g. Hooker *et al.,* 1992; Lawton *et al.,* 1991; Majerovitz, 1995). The CESD does not diagnose depression

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and scoring can be found in the appendix.

according to clinical criteria, rather it primarily identifies psychological distress, with an emphasis on affective components: both positive and negative. Items refer to the frequency of depressive symptoms in the previous week. Response categories range from 0 *(rarely or none of the time)* to 3 *(most or all of the time).* With a possible range of scores from 0 to 60, scores of 0-15 indicate no depressive symptoms or distress; 16-20 mild distress; 21-30 moderate distress, and more than 30 severe distress (Barnes & Prosen, 1984). The cutting points are somewhat arbitrary, but in wide use (Stommel *et al.,* 1993). Himmelfarb & Murrell (1983) suggested that a cut-off score of 20 was appropriate for older adults. Schulz *et al.* (1990) found that older adults typically score between 8 and 9. Radloff (1977) reported coefficient alphas of .85 for a general population sample, and of .90 for a patient sample.

Life Satisfaction was measured using a six-item *Life Satisfaction Index* (LSI) which came out of the work of Neugarten *et al.* (1961). The construct of life satisfaction essentially has a positive focus, in contrast to the other five outcome variables which seek out negative consequences associated with caregiving. The original 20-item Life Satisfaction Index (Neugarten *et al.,* 1961) has several strengths including reliability and strong correllations with other scales, and as a result of this, it has been extensively used (McDowell & Newell, 1996).

Bigot (1974) argued that a shorter 8-item version, LSI-wellbeing, which was essentially one of the subscales of the original index, was able to distinguish between clinically depressed elderly patients and normal volunteers. James *et al.* (1986) considered the merits of using this shorter scale and found that, whilst six of the items provided a good measure of life satisfaction, two items in Bigot's questionnaire were not reliable. James *et al.* recommended that these items should be eliminated. Following from this, in this investigation we used a six-item version of the LSI, which should be interpreted as a single scale measuring current life satisfaction. As in the original 20-item questionnaire, this 6-item version was scored on a three-point Likert scale: caregivers responded *agree, disagree,* or *uncertain* to each of the six statements according to their opinion. In contrast to the other outcome measures, it is low scores on the LSI that indicate negative well-being.

To summarise, six outcome measures were used in this investigation of caregiving in Parkinson's disease.

1. Emotional Burden (EB)
2. Impact on Relationship (BIR)
3. Impact on Social Life (BIS)
4. Health (GHQ)
5. Depression (CESD)
6. Life Satisfaction (LSI)

It was proposed that these six measures are distinct components of distress, and as such, that different aspects of caregiving will have different effects, according to their salience for the particular construct.

3.5.1.2 Patient Variables

In this investigation of PD caregiving, a considerable amount of information was collected from the patient. It was considered beneficial to collect objective data from both examination by the experimenter and from the patient themselves, whenever it was possible and appropriate. This was because it is known that characteristics of the caregiver can colour appraisals, indeed, numerous empirical investigations have indicated that individuals' perceptions of situations in caregiving, rather than the actual situations *per se,* are the best predictors of caregivers' distress (Haley *et al.,* 1987; Kinney & Stephens, 1989a; Poulshock & Deimling, 1984; Zarit *et al.,* 1980).

3.3.1.2.1 Objective Job Demand

It is clear from this that objective job demand measures made by the experimenter on the patient without contribution from the caregiver are needed to provide strong support for differential contributions from objective demands and caregiver appraisals. Objective demand has frequently been represented by the degree of disability of the person being cared for (Cantor, 1983; Greene *et al.,* 1982; Lawton *et al.,* 1991; Poulshock & Deimling, 1984), but this has typically been a (SDAT) caregiver appraisal of job demand. However, it is possible to record a truly objective measure of physical job demand for the Parkinson's caregiver, by the use of one of the established tests of measuring motor disability. Similarly, cognitive tests can be given to the patient to ascertain the level of cognitive functioning, *without* any input from the caregiver.

Objective job demand, then, was assessed by the use of different measures to consider the contribution of physical demand and cognitive demand to caregiver distress.

3.5.1.2.1.1 Physical Job Demand

PD patient disability status was used as the most important measure of physical job demand. This was measured using the *Unified Parkinson's Disease Rating Scale* (UPD; Fahn *et al.,* 1987). A severity of illness score representing objective job demand was achieved following the experimenter conducting the *motor examination* and parts A and B of the *complications of therapy* sections of the test. The scale was developed to provide a standard format of assessment of PD, with a formulation designed to remove as much ambiguity in scoring as possible; interrater reliability is very high (Lang & Fahn, 1989). The experimenter was trained to administer the UPD by a consultant geriatrician, and several patients from his PD clinic were used as pilots. Scores from this test were also used to categorise patients as having *mild* PD (scoring less than 10), *moderate* PD (scoring between 10-24), or *advanced* PD (scoring 25 or more).

In addition to measuring severity of illness using the UPD, patients were also assigned a disease stage according to the *Hoehn & Yahr* criteria. (see page 12).

The Modified Barthel Activities of Daily Living Index (ADL; Collin *et al.*, 1988) was also used as a measure of patient functional independence in personal care and mobility. There are several ADL scales in the literature; generally they document the same basic functional skills although the number of items included differs. The use of the Barthel Index provides several advantages: continuing widespread use, clarity of scoring system, and completeness (Gresham *et al.*, 1980). Many modifications have been made to the original Barthel Index (Mahoney & Barthel, 1965). In this investigation a 10-item version (Collin *et al.*, 1988) which re-ordered the original ten items, and simplified the scoring was used as an objective measure of the patients' functional ability. The measure is a record of what the patient actually does, as can be established by the best evidence available, (i.e. asking the patient and caregiver) rather than what the patient could do.

3.5.1.2.1.2 Cognitive Job Demand

The *Mini-Mental State Examination* (MMSE; Folstein *et al.*, 1975) was used both as a screening test to identify those patients who were dementing, and to make a general assessment of global cognitive function. The test is useful for the detection of severe and generalised cognitive deficits (McDowell & Newell, 1996). Traditionally, a score of less than 24 out of a maximum of 30 indicates cognitive impairment that is severe enough to meet Cummings & Benson's (1983) criteria for dementia. On this basis the test was also used to classify patients as not demented (i.e. MMSE score = 24+) or demented (MMSE score < 24).

The *National Adult Reading Test* (NART; Nelson, 1982) was used to estimate patient pre-morbid IQ. The test consists of a list of 50 irregular words which the subject reads aloud: single word reading is a relatively preserved function even in dementia.

Present cognitive functioning - and by inference evidence of subtle cognitive change - was measured by the following tests:

1. *Mill Hill Vocabulary Scale* (MH; Raven, 1943). This is a measure of present verbal intelligence. It was appropriate to use this test with an elderly sample as it is not age sensitive. Non-dementing old people preserve their performance until their 80s (Heron & Chown, 1967). The version used (MH version B2) was one of two half-length versions of the original MH scale used in a study by Binks & Davies (1984).
2. *Raven's Progressive Matrices* (RPM; Raven, 1960). Raven's Standard Progressive Matrices consists of 60 matrices grouped into five sets of 12. Each item represents a perceptual analogy in the form of a matrix. There is a valid relationship that connects items in each row and each column of the matrix. Each matrix is presented with a piece from the lower right-hand corner missing. The task is to identify the piece that best completes the matrix from the six or eight alternatives presented. One mark was given for each correct answer (max. = 60).

The test has a low floor and fairly high ceiling, which makes it appropriate for most ability levels (Murphy & Davidshofer, 1991).

3. *Raven's Coloured Progressive Matrices* (RCPM; Raven *et al.,* 1956). A simplified 36-item version of the standard RPM which was designed for use with young children and old people. One mark was given for each correct answer (max=36).
4. *Warrington Recognition Memory Test* (Warrington, 1984). This is a test of long-term recognition memory for words and unfamiliar faces. Subjects are pre-exposed to the target material, then by means of a forced-choice paradigm, are required to identify it from a distracter. First a series of 50 high-frequency words is presented to the subject, one at a time, for 3 seconds each. The subject is required to judge whether they find the word pleasant or unpleasant. Testing immediately follows the presentation of the words. Subjects are required to choose which of a pair of randomly presented pairs of words they have previously been exposed to. The number of correctly identified items is noted. An identical procedure follows when 50 black & white photographs of white men are the target material. (Max score for each part = 50).
5. *Word Reaction Time.* A simple measure of the time taken by patients to read aloud 12 common nouns.

In addition to taking these the above measures, it was considered that a measure of *cognitive demand* that would be an indication of cognitive status would be beneficial. The MMSE, which measures eight of the eleven main aspects of cognitive status (Foreman, 1987) could have been used on its own as such a measure, if one assumes that anyone who has no mental impairment would score the maximum of 30. But besides the fact that there is a relatively small range of scores, the test, as a screen for dementia, is not very demanding and it may miss mild impairments and cognitive changes resulting from right hemisphere lesions (Naugle & Kawczak, 1989). Raven's Progressive Matrices (RPM) were developed as a culture-fair test of general intellectual inability. Although it is now accepted that education does have an effect on normal subjects' performance (Hodges, 1994), the test appears to measure abstract reasoning ability independently of a subject's factual knowledge or prior experience (Murphy & Davidshofer, 1991). The test is sensitive to brain damage in fairly widely distributed areas, since normal performance depends on intact visuo-perceptual, attentional, and problem-solving skills (Hodges, 1994). Chapter 1 contains details of the extent of subtle cognitive impairments that may be found in PD. It was therefore reasoned that scores from the RPM (for range) together with scores from the MMSE (for diversity) may provide a suitable measure of cognitive demand.

The variable COGDEM was created by using error scores from the two tests, then standardising them (for easier interpretation), then multiplying them together. Because a number of patients did not make any errors on the MMSE, a score of 1 was added to each error score. To summarise:

COGDEM = (standardised MMSE error score +1) x (standardised RPM error score)

3.5.1.2.2 Patient Personality

The experimenter administered the *NEO-Five Factor Inventory* (NEO-FFI; Costa & McCrae, 1992), a well-established measure of personality, to patients to measure their current personality with respect to the five subscales of the questionnaire: *Neuroticism, Extraversion, Openness, Agreeableness, Conscientiousness.* Although there has been much interest and controversy in the literature with respect to whether there is such a thing as a particular Parkinsonian personality, outlined in Chapter 1, the main point of collecting this information in this investigation was to assess whether:

1. there is a change in patient personality, on one or more dimensions, with the progression of the disease;
2. Parkinson's patients are not in the normal range on any dimension of personality;
3. patient self-appraisals differ from caregiver appraisals of patient personality;
4. patient personality plays a role in caregiver outcomes.

3.5.1.2.3 Patient Depression

Another aspect of patient characteristics is *depression*. Depression is a common feature of Parkinson's patients, and as such it should be considered as a predictor variable for caregiver distress. In this experiment patient depression was measured using the *Geriatric Depression Scale* (GDS; Brink *et al*, 1982, Yesavage *et al*, 1983) which was specifically developed for screening elderly people for depression (Yesavage *et al.* 1983). Brink *et al.*, (1982) argued that many existing depression scales were inappropriate for use with the elderly, as symptoms of depression in young people (e.g. reduced appetite, sleep disturbance) can be normal effects of ageing. Importantly, the GDS concentrates on psychological aspects of depression, and excludes somatic aspects of depression. This is also particularly important when assessing people with a physical disability as was the case in this research. As the patient sample was mainly elderly <u>and</u> physically handicapped, the GDS was considered the most appropriate measure of depression to use.

3.5.1.3 Caregiver Variables

3.5.1.3.1 Job Demand

Besides using an objective measure of job demand, it was appropriate to use a subjective measure of job demand, as this may be more important in the prediction of carer distress. *The Caregiver Hassles Scale* (CHS; Kinney & Stephens, 1989) was administered to PD caregivers to measure their subjective job demand. The CHS is a 42-item, 5-dimension questionnaire. It was developed to measure the day-to-day demands of caregiving to Alzheimer’s disease patients. It has been widely used and it has good reliability (α=.91). The CHS can be seen as an objective measure in so far as recording the presence of a hassle (did it happen?) does not necessarily imply burden or distress (Vitaliano *et al.*, 1991). The subsequent rating of the hassles that have occurred, however, is subjective. Separate records were therefore taken of the number of hassles that occurred, and of caregiver effort carrying out the hassles, both in total, and for each of the five subscales. According to Kinney & Stephens (1989) hassles, individually, only exert a weak threat to caregiver health, but an accumulation can have a major impact.

3.5.1.3.2 Caregiver discretion.

Discretion was conceptualised as the extent to which caregivers perceived that they had control over various aspects of caregiving. Discretion was measured by using an 18-item *Job Discretion Scale* (JDS) which was adapted by the experimenter from the 22-item *Control Scale* of Dwyer & Ganster (1991). Examples of items are:

- How much discretion do you have over when you can leave ____ and go out?
- How much leeway do you have regarding when and how much you interact with others?

Caregiver choose their response from five alternatives: *very little, little, a moderate amount, much* and *very much.*

The original scale was designed for use with paid employees which made four items unsuitable for unpaid caregivers: these were omitted. The wording was altered on some items to make the questions specific to caregiving, without changing the essence of the item. To score, Dwyer & Ganster averaged responses to the 22 items they used to provide an overall index of how much control the worker experienced over the work environment. This method of scoring was used with this 18-item adaptation to give an overall index of caregiver discretion.

3.5.1.3.3 Job Strain

The Karasek (1979) theory argues that *strain* should predict outcomes, rather than (subjective) job demand or discretion. According to a previously formulated practice (Theorell *et al.,* 1988, 1991) job strain was computed as the ratio between subjective job demand and discretion. That is, a strain score was calculated for each subject using the equation:

$$\text{strain} = \frac{\text{demand}}{\text{discretion}}$$

This method has distinct advantages over the method used by Orbell & Gillies (1993). They used median values to determine high and low demand, and high and low discretion. Carers were then assigned to one of four groups according to whether they had: (a) high demand/low discretion, (b) high demand/high discretion, (c) low demand/low discretion or (d) low demand/high discretion. Firstly, using this method makes meaningful comparisons between studies difficult as, particularly with respect to demand, the median (and the range of) scores are likely to differ according to the (caregiver) sample used. Secondly, cell sizes are likely to be unbalanced. In the

Orbell & Gillies studies cell sizes were (a) 16, (b) 35, (c) 35, (d) 18. If this method had been used in this investigation, cell sizes would have been (a) 21, (b) 6, (c) 3, (d) 18. These figures make it clear that a strain score for each individual carer is far more sensible statistically.

3.5.1.3.4 Personality

3.5.1.3.4.1 Caregiver Personality

Carer personality, a variable which has been often overlooked in caregiving research, was measured in a number of ways. *Neuroticism, Extraversion, Openness, Agreeableness and Conscientiousness* were all measured using the NEO-FFI (Costa & McCrae, 1992).

Optimism was assessed using the *Life Optimism Test* (LOT; Scheier & Carver, 1985). This is a 12-item questionnaire in which eight items are directly concerned with caregiver optimism, and four items are fillers. Subjects respond to statements such as “In uncertain times, I usually expect the best” according to whether they *strongly agree, agree,* are *neutral, disagree,* or *strongly disagree.* Scheier & Carver (1985) reported a reliability coefficient α=.76 for this test.

Research indicates that subjects high in communal orientation help others significantly more than subjects low in communal orientation (Clark *et al.,* 1987; Williamson & Schulz, 1990). To take this into account caregivers were asked to do the 14-item *Communal Orientation Scale* (COS; Clark *et al.,* 1987). This involves rating items such as “When I am making a decision, I take other people’s needs and feelings into account”, on a 5-point scale, according to whether caregivers consider that the statements were characteristic, or uncharacteristic of themselves. Clarke *et al.* reported a reliability coefficient α=.78 for this scale.

Bartone *et al.* (1989) presented evidence that hardiness, or dispositional resilience, is an important modulator of stress. To take this into account, carer were asked to do the *Hardiness Questionnaire* (Bartone *et al*., 1989). Questionnaire items are statements about life, and subjects are required to give their opinion as to how much each one is true in general on a 4-point scale ranging from *not at all true* to *completely true.* The questionnaire consists of three subscales, each comprising 10 items, corresponding to *commitment* (CM), *control* (CO), and *challenge* (CH). Bartone *et al.* reported reliability coefficients as: CM α=.82, CO α=.66, CH α=.62.

3.5.1.3.4.2 Caregiver Appraisals of Patient Personality

To assess caregiver's perceptions of patient personality caregiver were given two adaptations of the NEO-FFI (Costa & McCrae, 1992). The first was a simple conversion of the 60-item questionnaire to the third person (from the first person). The second adaptation was to assess carers' perception of *change* in their care-recipient's personality since the diagnosis of PD. Although this is a retrospective measure, and there are drawbacks to this, the fact remains that this is the only way to get this sort of information. Again, all 60 items on the NEO were used as this questionnaire was given in conjunction with assessing patient's personality. For example, E: "Is it true that _____ is not a worrier?" <response> E: Has _____ always/never been a worrier?" <yes/no> (This is confirmed E: "So there has been a change?" or "So there has been no change?") If the caregiver reported that there had been a change, then the extent of change was determined by the use of a 4-point Likert scale: *very much, quite a lot, in some way, a little.*

The *Identity Test* (Brooks & McKinlay, 1983) was used as a second means of assessing caregiver's perception of change in patient personality. The test sheet consists of 20 bi-polar dimensions (e.g. emotional-stable; co-operative-dependent) on opposite sides with seven hash marks along a line linking the two pole of the dimension. Scoring was from one to seven on a Likert scale where higher scores are associated with the more positive pole of the dimension according to the hash mark crossed by the carer to mark their care-recipient position on that dimension. The test was done twice: the first time the caregiver was required to consider how ______ was before PD (i.e. to obtain a measure of pre-morbid personality), then how they perceived their care-recipient to be at time of testing. A change score for each of the 20 dimensions was achieved by subtracting the "now" scores from the "premorbid scores".

3.5.1.3.5 Coping Style

Caregivers' coping style was investigated using the *Coping Inventory for Stressful Situations* (CISS; Endler & Parker, 1990). This is a 48-item inventory with 16 items for each of three subscales: *task-oriented coping, emotion-oriented coping,* and *avoidance-oriented coping.* The CISS consists of a list of 48 ways in which people may behave in when in a stressful situation, according to their coping style. Carers were asked to consider these 48 behaviours, and then to respond according to whether they would typically engage in such behaviour. The CISS has a 5-point Likert scale response format for each item where 1=*not at all,* and 5=*very much.* Endler & Parker (1990) reported reliability coefficients of: task α = .90, emotion α = .88 and avoidance α = .85.

3.5.1.3.6 Job Satisfaction

To examine satisfaction with their caregiving role, carers were asked to read 12 statements adapted from the 15-item *Job Satisfaction Subscale* (JSS) of Warr & Routledge (1969). The adaptation was a simple replacement of “My Job” for “Caregiving”. The title was not changed, and carers were instructed to consider that their caregiving could be likened to having a job. The change was made after pilot work indicated that being explicit made the questionnaire more acceptable. Three items were omitted from the adaptation because they addressed autonomy rather than satisfaction. Carers were asked whether they *agree, disagree,* or *uncertain* that items such as “caregiving is frustrating” and “caregiving is satisfying” were true for them.

There are several scales of job satisfaction in the literature, however many are unsuitable for use with caregivers because of the unpaid, and typically unchosen nature of the work. This scale does not contain such references, making it the most suitable to use with a sample of caregivers.

3.5.1.3.7 Caregiver Health Status

Caregivers were questioned with respect to their own health status during interview. From the responses, *health* was coded as:

good - no existing illness / acute problems (e.g. colds) only in the previous 12 months.

fair - controlled persistent problem that is not disabling (e.g. angina, diabetes).

poor - chronic disabling health problem (e.g. arthritis, cancer, emphysema).

3.5.1.3.8 Social Support

Caregivers' perceptions of their social support were measured using the *Index of Social Support* (ISS; James & Davies, 1987). The 10-item ISS was constructed to quantify the availability of, and satisfaction with, social support. Caregivers were asked to identify those they could depend upon for support in eight specified instances, and whether they were satisfied with the level of support they had. Two further items refer to others who require help from them on a regular basis. This gives rise to separate measures for caregivers' perceived availability of support - this is calculated by summing the number of supporters mentioned, whilst disregarding those who also required help, and their satisfaction with that support (yes/no; range 0 - 8).

3.5.1.3.9 Knowledge of Parkinson's Disease

A 16-item questionnaire was specifically constructed for use in this research project with the aim of investigating (a) whether patients and caregivers know as much about the cognitive aspects of PD, as they know about the more extensively documented physical aspects of the disease, and (b) whether a lack of knowledge of PD is associated with carer distress. The questionnaire consists of eight questions for each of the two aspects of the disease. The participant was required to state whether, in their opinion, the question was *definitely true, probably true*, *probably false,* or *definitely false.* "Definitely" correct responses scored 2, "probably" correct answers scored 1, and incorrect answers scored 0. Three scores were taken for each subject: their *total* score (max=32), *phys*ical aspects (max=16), and *cog*nitive aspects (max=16).

3.5.1.4 Dyadic Relationship

The quality of the pre-morbid dyadic relationship, and the current dyadic relationship were assessed using the *Short Dyadic Adjustment Scale* (DAS: Spanier, 1976; Sharpley & Cross, 1982). The Dyadic Adjustment Scale (Spanier, 1976) is a 32-item scale designed for assessing the quality of marriage or other similar dyads. Sharpley & Cross (1982), however, argued that researchers can obtain almost as confident a classification using only six of the original items. This shorter scale yields one overall *dyadic adjustment* factor. Following from this, a 6-item dyadic adjustment scale was administered to caregivers to consider their perceptions of the dyadic relationship.

Sharpley and Cross (1982) also pointed out that a seventh item from Spanier’s (1976) scale was suitable for a quick global self-rating of the relationship. This question, considering current *happiness* in the dyadic relationship, was also administered to caregivers as a separate item.

Caregivers were also given *The Family Assessment Measure: Dyadic Relationships Scale* (FAMIII; Skinner, Steinhauer & Santa-Barbara, 1995). This is a self-report instrument that provides quantitative indices of dyadic strengths and weaknesses. There are 6 items for each of seven subscales: *Task Accomplishment, Role Performance, Communication, Affective Expression, Involvement, Control* and *Values & Norms.* Caregivers were asked to read the 42 statements that make up the FAMIII, then to answer *strongly agree, agree, disagree* or *strongly disagree,* as appropriate. Raw scores were converted to separate T-scores for each of the subscales. A subscale T-score of less than 40 indicates dyadic strength, whereas a T-score of more than 60 points to dyadic problems.

3.5.2 Design

This research project had a longitudinal design with two phases of testing - the second phase being approximately 12 months after the first phase. Each phase consisted of two visits to each dyad, in their own home. Much of the second phase of testing was a replication of the first phase of testing.

The first of the two visits of each phase concentrated on collecting data from the patient. A diary and a pack of questionnaires was left with the caregiver to do during the week ahead. The second visits consisted of interviewing the caregiver and administering other established psychometric measures, in order to investigate caregiver distress at two periods of time, approximately 12 months apart.

3.5.3 Ethical Considerations

In this study, patients and their caregivers had the right to decide about participation. Each patient and caregiver signed a consent form to say that they had read the information sheet and had had the chance to ask further questions and that they fully understood that they could discontinue any interview without pressure or sanctions.

The data were treated confidentially. Interview data was transcribed and the tapes re-used. Ethical approval for the research design was received from the relevant health authorities: Liverpool, South Sefton, and Wirral.

3.5.4 Subjects

The participants were 83 individuals diagnosed as suffering from idiopathic Parkinson’s disease and their caregivers. The patient-caregiver dyads were recruited from the PD clinics of three consultants at separate hospitals in Merseyside. Participation was dependent upon the Parkinson’s patient fulfilling predetermined inclusion and exclusion criteria:

Inclusion Criteria:

1. The patient should have a primary diagnosis of idiopathic Parkinson's disease.
2. The patient should have an identifiable primary caregiver.
3. The patient should be living at home and receiving some informal care, rather than be totally dependent on formal care.

Exclusion Criteria:

1. Patients who also have some history of brain injury or another neurological illness.
2. Patients whose health status is such that they cannot reasonably be expected to survive to complete a follow-up test session a year later.
3. Patients whose caregiver's health status is such that they cannot reasonably be expected to survive to undertake a second interview a year after the first.

Consecutive patients who attended PD clinics at Arrowe Park Hospitals, Wirral, Clatterbridge Hospital, Wirral, and the Royal Liverpool University Hospital during the recruitment period who satisfied the criteria for participation, were invited to join a research project called "Perceived psychological change in Parkinson's disease and its effect on caregiver distress". There was no payment made for participation. The large majority of potential participants agreed to join the study. It was estimated that less than 10% of potential participants refused to take part at this stage.

3.5.4.1 Parkinson's Disease Patients.

The sample of 83 patients consisted of 55 males and 28 females. At the first stage of testing the mean duration of illness was 8.22 years (SD = 5.22; range = 1-22 years), the mean age of patients was 74.80 (SD = 8.08; range 48-95 years) with an average age of onset of 66.55 years (SD = 9.77; range 36-84 years). 17% were early-onset patients diagnosed before the age of 60 years; 40% were late-onset patients who were diagnosed after the age of 70 years (see table 3.5.4.1.1, below).

Table 3.5.4.1.1 Demographic data on PD patients

		Duration (years)	
Gender (*n*)		Mean (SD)	8.22 (5.11)
Female	28	Range	1-22
Male	55	MMSE score	
Age (years)		Mean (SD)	27.55 (3.26)
Mean (SD)	74.80 (8.08)	Range	17-30
Range	48-95	Demented	10
Age of Onset (years)		Without dementia	73
Mean (SD)	66.55 (9.77)	Medication (*n*)	
Range	36-84	Sinemet	44
Early Onset (<60)	14	Madopar	31
Typical Onset (60-70)	36	Benzhexol	2
Late Onset (>70)	33	Anticholinergics only	3
Severity of Illness (UPD)		Apomorphine	4
Mean (SD)	22.49 (11.30)	None	3
Mild (<10)	11	Education (*n*)	
Moderate (10-24)	36	Primary	39
Advanced (25+)	36	Secondary	30
Hoehn & Yahr Stage (*n*)		Higher	17
Stage I	14	Premorbid IQ (NART)	
Stage II	14	Mean	107
Stage III	38	Current Employment (*n*)	
Stage IV	13	Retired / disability	82
Stage V	4	Employed	1

Severity of illness was assessed by the Unified Parkinson's Disease Rating Scale (UPD: Fahn *et al.,* 1987). Phase I UPD scores indicated that 11 subjects had *mild* PD (<10), 36 patients had *moderate* PD (10-24), and 36 patients had *advanced* PD (25+). Patients were also assigned a disease stage according to the Hoehn & Yahr disability scale (Hoehn & Yahr, 1967): stage I = 14, stage II = 14, stage III = 38, stage IV = 13, stage V = 4. Ten PD patients (12%) were also dementing, as indicated by a MMSE score below 24. Mean MMSE score was 27.55 (SD = 3.26).80 patients were taking anti-Parkinsonian medication. Of the three patients who were not medicated at time of testing, one was newly diagnosed, and L-dopa treatment was being delayed; one patient was not compliant, and one was temporarily withdrawn from treatment because of the unacceptable degree of dyskinaesias.

47% of patients had a primary education, 36% had received secondary education, and 17% had higher education. The mean pre-morbid IQ was 107.

Fifteen of the 83 patients (18%) were in employment at the onset of Parkinson's disease. Whilst medication enabled all these patients to continue working for a period of time, at time of testing all of this group, except one, had stopped working. (Range of continuing to work post-diagnosis 1-11 years).

3.5.4.2 Caregivers

Of the 83 caregivers, 62 were female and 21 were male. 72 were married to the patient, eight were adult children, one a daughter-in-law, and two were female friends of the patient. With the exception of two of the daughters and the daughter-in-law, all of the caregivers lived with the patient (see table 3.5.4.2.1, below).

The mean age of the caregivers was 69.10 years (SD = 10.35; range 36-89 years). With the exception of one son who had taken on the caregiving role after his father's death, the duration of caregiving was the same as duration of illness. Caregiver's own health status was determined objectively using the existence of defined illnesses. Thus, the health status of 39 carers was *good* (no existing problems), 24 were *fair* (mild or acute conditions, e.g. problem with knee, irritable bowel syndrome) and 20 were in *poor* health (e.g. osteoporosis, cancer, blind).

Table 3.5.4.2.1 Demographic data on PD caregivers

Gender (*n*)		Residence (*n*)	
Female	62	With patient	80
Male	21	Not with patient	3
Age (years)		Health Status (*n*)	
Mean (SD)	69.10 (10.35)	Good	39
Range	36-89	Fair	24
Dyadic Relationship (*n*)		Poor	20
Husband	19	Education (*n*)	
Wife	53	Primary	38
Son	2	Secondary	31
Daughter	6	Higher	14
Daughter-in-law	1	Employment (*n*)	
Friend	2	Paid employment	9
		No other employment	74

46% of caregivers had received a primary education, 37% had attained a secondary educational level, and 17% had higher education. Thirteen caregivers were working at the onset of illness; of this group, nine were still in employment at time of testing. With respect to the four caregivers who were no longer in employment, two had given up working in response to increased caregiving demands, and two had reached retirement age.

3.5.5 Procedure

Potential PD dyads were initially invited to join the research project by the patients' consultant during a routine visit to clinic. They were given an information sheet which contained brief details of the nature and design of the research to take away. The names, addresses, and telephone numbers of dyads who had indicated to their consultant that they would be willing to participate were subsequently passed on to the researcher at the University of Liverpool by the consultant.

Shortly after receiving these details, the researcher contacted the prospective participants by telephone. By this time the patients and caregivers would have had the opportunity to read the information sheet and consider the implications for them of joining the research. The dyad was asked if they would be willing to take part in the investigation. If they agreed to participate (only four dyads refused at this stage) then a mutually convenient appointment was made to visit the dyad at home for the next week and the week after. Unless unavoidable, the second appointment was made for the same day the following week.

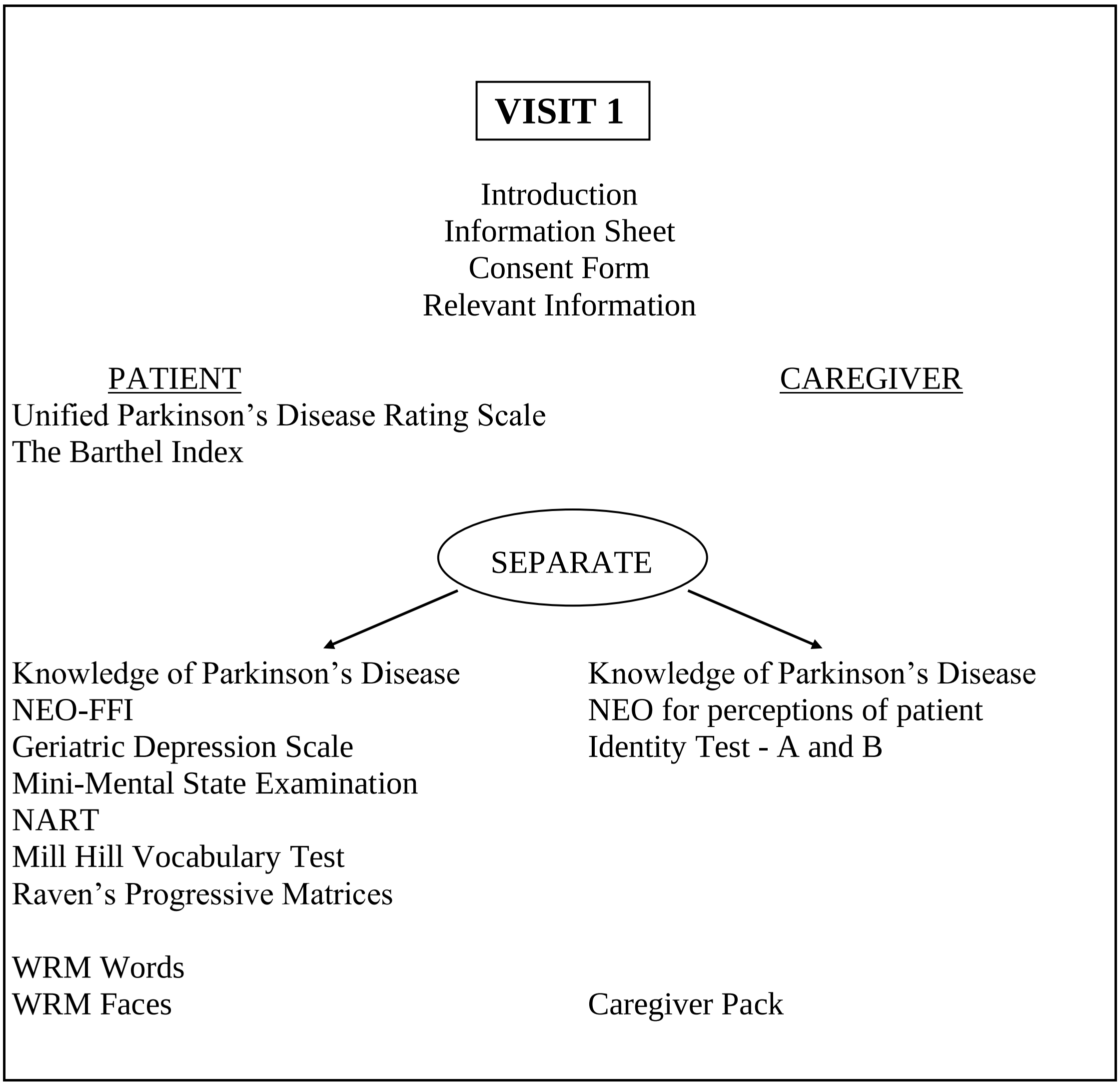
3.5.5.1 Phase I

3.5.5.1.1 Visit 1

On arrival at the patient's home for the first visit, the researcher briefly outlined the study. It was explained that the testing would be unhurried, that they could have a break at any time they needed one, and that the period of testing would generally be about two hours. In some instances, however, if the patient became too tired to effectively carry on, an additional visit was made to complete the battery.

The research began with the collection of sociodemographic information from the patient and caregiver (see fig. 3.5.5.1.1.1, below). Next the physical status of the patient was determined using the Unified Parkinson's Disease Rating Scale, and the Modified Barthel Index. The caregiver was asked to stay during this time to provide proxy information, if required, concerning ADL limitations.

Figure 3.5.5.1.1.1 Summary of the testing procedure for the first visit to participating dyads.



VISIT 1

Introduction
Information Sheet
Consent Form
Relevant Information

PATIENT	CAREGIVER
Unified Parkinson's Disease Rating Scale The Barthel Index	

SEPARATE

Knowledge of Parkinson's Disease	Knowledge of Parkinson's Disease
NEO-FFI	NEO for perceptions of patient
Geriatric Depression Scale	Identity Test - A and B
Mini-Mental State Examination	
NART	
Mill Hill Vocabulary Test	
Raven's Progressive Matrices	
WRM Words	
WRM Faces	Caregiver Pack

Following these two tests, the Knowledge of Parkinson's Disease (KPD) questionnaire was given separately to the patient and caregiver. The KPD was administered to all the patients. The caregiver was asked to go into a different room to do this questionnaire themselves (and also the NEO for the caregiver's perception of the personality of the patient, and Identity Tests A and B).

The KPD was followed by the NEO-FFI[2] and the GDS.

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[2] Following the recommendations of Costa & McCrae (1992) demented patients were not assessed on this test.

The patients' cognitive status was assessed by administering the MMSE, the NART, the Mill Hill Vocabulary scale and Raven's Progressive Matrices. Warrington's Recognition Memory Test and assessment of global slowing was also given to those patients were not excluded because (i) they scored less than 24 on the MMSE, (ii) they had eye problems (e.g. cataracts, glaucoma), or (iii) they had any other neurological damage (e.g. a history of stroke).

Before leaving the dyad's home after the first visit, the caregiver was given the *Caregiver Pack* with clear instructions. The *Caregiver Pack* contained four A4 sheets of plain paper which was to use as a diary for the seven days ahead. Of particular interest to the research was what the caregiver was actually doing for the patient, and how they felt about it. The caregiver was also asked to note any critical/important incidents that occurred during the week, and how they coped with them. The pack also contained the *Care Chart*, which was explained to the caregiver, and they were asked to start filling it in from that time until the interview the following week.

The *Caregiver Pack* also contained eight self-administer questionnaires for caregiver to do at their convenience during the interval between the first two visits. These were the IOC, P&R.B2, CES-D, GHQ, CISS, JSS, LOT and NEO-FFI.

3.5.5.1.2 Visit 2.

The second visit concentrated on the caregiving. Unless it was unavoidable, the caregiver was interviewed alone. Occasionally this was not possible: the care-receiver needed to be watched or was reluctant to be left on their own, or simply there was no other suitable room. With the exception of two occasions (one where the caregiver was blind, the other with a caregiver who had speech problems following a stroke), even if the care-receiver was in the room, they were not encouraged to participate in the interview.

In practice, there was a wide variation in the second visits according to how articulate the caregiver was, the amount and the nature of the caregiving, and the consideration of other life events that were going on simultaneously. Essentially though, the same basic structure was followed (see fig. 3.5.5.1.2.1 below).

Figure 3.5.5.1.2.1 Summary of the testing procedure for the second visit to participating dyads.

VISIT 2

Introduction

<u>CAREGIVER</u>

Structured Interview - including:

Life events Schedule
Dyadic Adjustment Scale
Index of Social Support
Motenko’s Frustration Scale
Life Satisfaction Index
Caregivers’ Hassles Scale

All the interviews were tape-recorded. The researcher explained to the caregiver "I have put my tape recorder on so that I can listen properly to what you have to say to me, and I am not distracted by having to make a lot of notes. We can talk more easily this way. As you have read on the information sheet, I will transcribe it fairly promptly, then use it again, so I will not be keeping your voice on record. Is that all right for you?" None of the caregivers objected to this procedure. Next the caregiver was asked "How did you get on with the pack I left you?" After being given the pack, it was essential to determine whether it had been done correctly. This was not always the case for a multitude of reasons. If a diary had been done, this was looked at quickly with view to expanding upon anything of interest during the course of the interview. One or two incomplete items could be dealt with quickly. Caregivers sometimes had not done a particular questionnaire(s). Sometimes it was possible to do it/them at the end of the interview, otherwise it had to be accepted that they had a reason for not doing it/them.

Qualitative data was collected by following a semi-structured interview. The caregiver was asked about the time when they were first aware that there was something wrong with the patient, what this was (i.e. the initial symptoms), and how they felt at this time.

To further the investigation of personality change in PD, three open-ended questions were asked:

1. In what ways has ________'s personality changed from before they had Parkinson's disease?
2. In what ways are they the same person as before?
3. Has any change in personality affected your relationship at any time?

To investigate job demand, the caregiver was asked what they regularly do for their care-recipient. The caregiver was also specifically probed as to whether they thought that they were doing a good job, and whether there were things that they thought they should be doing differently.

At this point, the *Index of Social Support* was administered, followed by the *Life Events Interview* (see Appendix) and the *Dyadic Adjustment Scale*.

With respect to job discretion, caregivers were asked three specific questions:

1. Do you think that looking after ______ because s/he had Parkinson's disease leaves you without any choice in what you have to do during the day?
2. Have you any alternative?
3. Would you like some respite from caregiving?

Two questions concerning the Caregivers' *expectations* were asked:

1. Knowing what you do about Parkinson's disease, how do you expect ______ to be in 12 months?
2. If there are any changes in ______, what would you expect these to be?

Motenko's *Frustration Scale* (MFS; Motenko, 1989) was then administered. Motenko found from interviews with 50 women caring for a husband with dementia that frustration was associated with distress. As the items do not make any specific reference to dementia but were essentially tapping the caregivers' emotional response towards the patients' illness, it proved a useful addition to understanding PD carers' experience of caregiving. This information is presented as frequency data in chapter six. Two additional questionnaires were administered to the caregivers: the Caregivers' Hassles Scale and the Life Satisfaction Index to measure caregivers' perception of job demand, and their current life satisfaction.

Finally, carers were directly asked:

1. What aspect of looking after ______ do you find most stressful?
2. What is the most important reason why you care for ______?

The responses to these open questions highlighted the similar and the different concerns of PD caregiving and are presented qualitatively in chapter six.

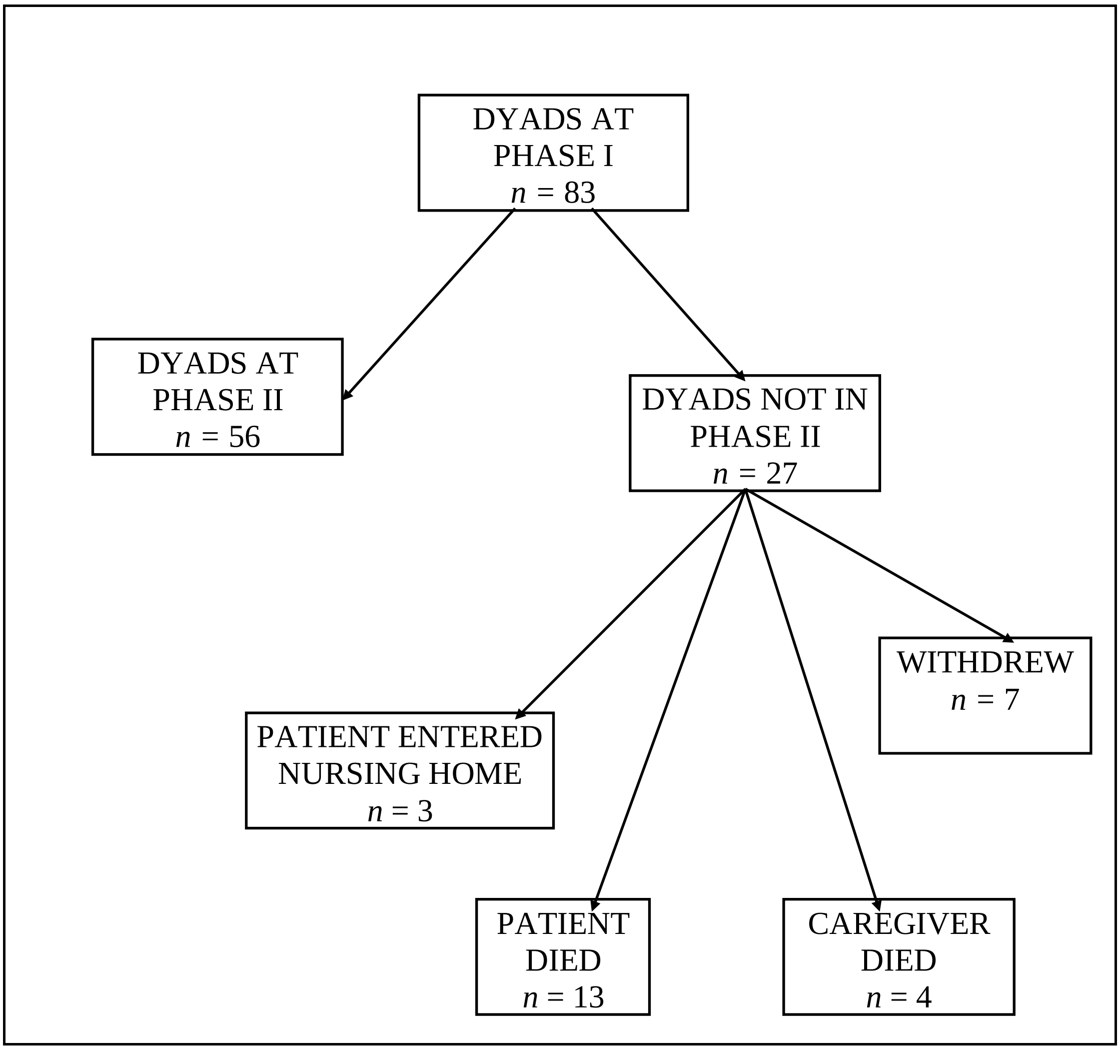
3.5.5.2 Testing interval

The period of testing for phase I was March 1995 to June 1996. The period of testing for phase 2 was May 1996 to June 1997. The planned time for the follow up study was 12 months after the first visits. For most dyads this was the case. There was, however, a longer interval between the two phases for the earlier dyads because recruitment to phase I took longer than originally planned. There was also a delay in follow-up for four dyads due to illness. The mean interval between phase I and phase II was 58 weeks (SD = 5.45; range = 48-81 weeks).

56 dyads participated in phase II of the research project. Some atrophy of the sample was expected, as the subjects of the investigation were essentially elderly and suffering from chronic illness, but nevertheless, the atrophy was far greater than envisaged. This was essentially a result of the dyadic nature of participation. If one of the dyad could not continue, then both individuals were necessarily not able to continue (see fig. 3.5.5.3.1, below).

Death was the overriding reason for not participating in phase II. 13 patients died in the intervening 12 months (and it must be noted, the youngest male in the study died at the age of 50 during the course of the research: this could not possibly have been foreseen at time of recruitment). Four caregivers also died in the intervening period. Three patients were institutionalised because the caregiver could no longer cope with looking after them at home. Of the seven caregivers who withdrew, three had terminal cancer and were no longer caregiving, another had Tourette's syndrome. This was a son who was able to keep his Stage IV mother at home. He had been able to do the caregiver pack at Phase I, but he could not cope with the interview. The dyad was visited at Phase II, but because of his language problems, it was decided the exclude them from the follow-up analyses. Two dyads declined to participate in phase II without being specific as to why they had chosen to withdraw. One dyad could not be contacted despite exhaustive efforts to do so.

Figure 3.5.5.3.1 Participation and Attrition at Phase II.



Marking questionnaires and transcribing interviews was done on a ongoing basis. A database of patient and caregiver information and scores from the measures used was built on Microsoft Access.

3.5.5.3 Phase II

Most tests were repeated. There were, however, some changes:

1. The Dyadic Adjustment Scale was replaced by the more detailed FAMIII to get additional information of the dyadic relationship.
2. A scale to directly measure caregiver discretion was added.
3. Two personality measures - the Hardiness Questionnaire and the Communal Orientation Scale replaced the NEO-FFI and the Life Orientation Test for caregivers. This was to provide additional information, assuming that caregiver personality is stable.
4. The NEO change test was added, to give further information about the change in patient personality following the diagnosis of PD.
5. Raven’s Progressive Matrices were replaced by the simpler Raven’s Coloured Progressive Matrices.

Before the second phase of testing began, letters were sent to the first ten dyads because the interval had exceeded the 12 months, and it was essential to inform them that the research was continuing. The letter informed them that they would be contacted the following week to arrange appointments for visits 3 and 4. Appointments were made at mutually convenient times, as in phase I.

3.5.5.3.1 Visit 3.

The emphasis was on how the patient had changed in the interval between visits because of Parkinson's disease. Patients and caregivers were asked for details of symptoms, and symptom change; current medication and whether this had changed from the previous year; and any other illnesses that either the patient or the caregiver may have had. For the patient, visit 3 testing was carried out in exactly the same way as visit 1, apart from the change of Raven's Matrices.

In Phase II, the caregiver was not asked to do any questionnaires during the time when the patient was being interviewed. When the testing of the patient was completed, the caregiver was again asked to do the *Caregiver Pack* in the week between visits 3 and 4. As in Phase I, this involved keeping a caregiving diary for a week, a Care Chart, and selected questionnaires. In phase II these were: FAMIII dyadic relationship scale, Identity Test B, IOC, P&R.B2, CES-D, JSS, GHQ, COS, Discretion Scale, and Hardiness Scale.

3.5.5.3.2 Visit 4.

The final visit was a follow-up to visit 2. The emphasis was on change from the caregiver's perspective. As in visit 2, unless it was unavoidable, the caregiver was interviewed in a separate room, and the interview was audiotaped.

The caregiver was asked specific questions relating to progression of Parkinson's disease, the effect of any change of medication, and change in job demand. Personality change was explored by an adaptation of the NEO-FFI alongside replicating the caregiver's perceptions of the patient's current personality.

The Index of Social Support was repeated, as was the Life Events Interview, the three questions relating to discretion, the Caregivers' Hassles Scale, and the Life Satisfaction Index. These were followed by a single question:

"Can you tell me if there are things which you enjoy, or find satisfying in your role as caregiver to ______, because s/he has Parkinson's disease?" (Following Reis *et al.* 1994). As in phase 1, questionnaires were marked, and interviews were transcribed by the research student on an ongoing basis following visits. The results were stored on database.

3.5.6 Data Analysis

Both quantitative and qualitative data was collected from this investigation of PD Caregiving. Quantitative data was analysed using descriptive statistics, t-tests, analyses of variance, correlation analyses, and multiple regressions using SPSS for Windows. These results are presented in chapters four and five. Qualitative data is presented separately in chapter six.

CHAPTER 4

RESULTS: PHASE 1

4.1 Introduction

The results are divided into two parts and are described separately in chapters four and five. In chapter four data collected during phase I is presented; chapter five contains longitudinal data collected during phase II. The data were analysed using summary statistics, t-tests, analyses of variance (ANOVAs), Scheffé post-hoc tests, Pearson's product-moment correlations and regression analyses. Many results are presented in tabular form for ease of reference. Control was exerted over the inflation of the probability of alpha error in conducting large numbers of relational comparisons by setting the alpha significance level to 0.01. For all other analyses, the alpha significance level was at the conventional 0.05.

Some hypotheses were tested only with phase I data. This was because either only one set of data was collected, as in the case of *Knowledge of Parkinson's Disease* and information about the *pre-morbid relationship*; or because a simple research question was being addressed which would benefit from the larger sample size, for example the relationship between caregiver distress and dementia, and hallucinations. These results are presented in this chapter. The only phase II data presented in this chapter is carers' perceptions of personality change at the factor level (from the NEO-FFI). For ease of presentation this data accompanies carers' perceptions of personality change at the trait level (from the Identity Test) which was assessed during phase I. They are presented together in tables 4.6.2.2 and 4.6.3.1. The correlation coefficients of the distress measures and the NEO-FFI factors were from phase II, and the correlation coefficients of the distress measures and the Identity Test traits were from phase I.

Chapter five contains phase II data and more complex analyses. The investigation of the major contributors to caregiver distress, using multiple regression techniques, is also presented in the following chapter.

The main aim of this study was to identify variables of the PD illness situation that predict or influence caregiver distress. To do this, first the phase I intercorrelations of caregiver distress and (i) patient variables, (ii) caregiver variables, and (iii) dyadic relationship variables were examined. Six different aspects of caregiver distress were used as dependent variables, and as seen in table 4.1.1, below, in phase I, these variables were all significantly related to each other.

Table 4.1.1 Correlation matrix of the six dependent caregiver distress variables (n=83)

BIR = Burden from impact on dyadic relationship
BIS = Burden from impact on social life
EB = Emotional Burden
CESD = Caregiver Depression
GHQ = Psychological Health
LSI = Life Satisfaction

	BIS	EB	CESD	GHQ	LSI
BIR	.47**	.74**	.68**	.43**	-.55**
BIS		.41**	.43**	.38**	-.29*
EB			.79**	.58**	-.62**
CESD				.76**	-.58**
GHQ					-.47**

*p<.01 **p<.001 (two-tailed)

4.2 Patient Variables and Caregiver Distress

Table 4.2.1, below, sets out correlations between the dependent caregiver outcomes variables and potential patient predictor variables. Because of the large number of variables in this investigation, an alpha level of 0.01 was used in all relational analyses.

Table 4.2.1 Correlations of patient variables and caregiver distress (n=83)

	Dependent Caregiver Distress Variables					
	BIR	BIS	EB	CESD	GHQ	LSI
Duration of illness	.37**	.27	.44**	.38**	.35*	-.25
Severity of illness (UPD)	.47**	.40**	.46**	.30*	.27	-.33*
Hoehn & Yahr disease stage	.37**	.41**	.40**	.28*	.26	-.38**
Activities of daily living	-.31**	-.32*	-.38**	-.26	-.22	.27
Depression (GDS)	.41**	.34*	.37**	.22	.10	-.28
Patient neuroticism (n=71)	.32*	.32*	.31*	.21	.13	-.29
Patient extraversion (n=71)	-.14	-.28	-.26	-.28	-.26	.18
Patient openness (n=71)	.04	.16	-.01	.00	-.04	.06
Patient agreeableness (n=71)	-.34*	-.21	-.30	-.28	-.19	.24
Patient conscientiousness(n=71)	-.15	-.25	-.14	-.13	-.02	.20
Mental status	-.25	-.21	-.27	-.24	-.25	.37**
Dementia[a]	.32*	.26	.34*	.19	.26	-.37**
Hallucinations[b]	.32*	.26	.38**	.31*	.26	-.51**
Global Slowing (n=57)	.26	.02	.34*	.16	.11	-.00
Non-verbal intelligence (n=47)	-.43**	-.24	-.45**	-.23	-.17	.56**
Verbal intelligence	-.05	.15	-.14	-.18	-.19	.21
WRM: words (n=54)	-.18	-.06	-.22	-.19	-.00	.19
WRM: faces (n=56)	-.04	.01	-.11	.00	-.00	.09
Cognitive demand (n=47)	.47**	.29	.49**	.28	.22	-.53**
Age	-.04	.04	-.13	-.08	.03	-.05
Age of Onset	.23	-.11	-.34*	-.28	-.16	.13

* p<.01 **p<.001 (two-tailed)

[a] 0 = without dementia (MMSE score of 24+) 1 = with dementia (MMSE score <24)

[b] 0 = no hallucinations 1 = has had hallucinations

The conceptualisation of distress as a multidimensional construct is supported by the complexity of the relationships between the patient variables and the different components of distress. Certainly patient variables are associated with the different dependent variables in a selective way. The correlation matrix shows that, as hypothesised, severity of illness was strongly related to caregiver burden, depression and life satisfaction, however, this objective measure was not associated with caregiver psychological health. In fact, apart from duration of illness, patient variables have no impact on GHQ scores.

The relationship between patient cognitive and behavioural variables and carer distress is complex. MMSE raw scores were positively related to the LSI, indicating that patient mental status is associated with life satisfaction, but MMSE scores were not related to the negative outcome measures. When the MMSE was used to differentiate those who are and are not demented, however, then *dementia* was positively related to emotional burden and impact on relationship, and negatively associated with life satisfaction. A similar pattern of results was found with the *cognitive demand* measure, and non-verbal intelligence performance, as measured by Raven’s matrices. Patient hallucinations were also negatively associated with life satisfaction, and positively related to emotional burden and to impact on relationship, and also to carer depression. There was no relationship between dependent caregiver distress variables and verbal intelligence or recognition memory. Patient depression was not related to caregiver depression, although it was associated with caregiving burden.

To summarise, 21 patient variables were initially considered to be potential predictors of caregiver distress. (Personality change measures are considered separately in section 4.6). Simple bi-variate correlations indicated that some patient variables such as disease severity (and hence physical demand), cognitive demand, hallucinations and dementia, have a strong impact on caregiver outcomes, while other patient variables, such as age, openness and conscientiousness, have no effect at all. Further analyses will therefore centre on those patient variables which have been associated with caregiver distress.

4.2.1 Duration of illness and caregiver distress

Table 4.2.1 above shows that duration of PD has a positive relationship with impact on relationship, emotional burden, and carer mental health outcomes. To investigate whether this was true both for long and short duration of illness the sample was divided into two groups using the median duration of PD which was seven years. One-way ANOVAs were then used to test whether caregiver distress was greater with long duration of illness.

Table 4.2.1.1 Means, SDs, and comparison F-values of caregiving outcomes according to duration of Parkinson's disease.

Group 0 = short: six years or less (n=39)
Group 1 = long: seven years or more (n=44)

Caregiver outcome variables:	Group 0	Group 1	F-value	*p*
Impact on Relationship (BIR)*:*	3.95 (4.21)	7.52 (6.16)	9.00	p<.01
Emotional Burden (EB):	24.47 (5.89)	29.88 (8.07)	11.51	p<.01
Depression (CESD):	7.23 (6.42)	13.37 (10.16)	10.16	p<.01
General Health (GHQ):	8.92 (2.25)	12.90 (6.75)	11.92	p<.01

These results indicate that although there was a general effect of duration of illness, and by inference duration of caregiving, on caregiving outcomes, the level of distress was significantly greater on all these aspects of distress for those who had been caring for a PD patient with a long duration of illness.

4.2.2 Severity of illness and caregiver distress

Table 4.2.1 above shows that severity of illness has a positive relationship with all three burden measures and caregiver depression and a negative relationship with life satisfaction. To investigate whether there were differences in the level of distress according of the level of severity of PD the sample was divided into three groups, based on patients' UPD motor examination score (Fahn *et al.*, 1987): *mild* (<10; *n* = 11), *moderate* (10-24; *n* = 36) and *advanced* (25+; *n* = 36). One-way ANOVAs were then used to see if distress levels increased with severity of illness (see table 4.2.2.1, below).

Table 4.2.2.1 Means, SDs, and comparison F-values of caregiving outcomes according to severity of Parkinson's disease.

Caregiver outcome variables:	Severity of Illness mild	moderate	advanced	F-value	*p*
Impact on Relationship	2.80 (3.19)	3.92 (3.30)	8.74 (6.71)	10.04	p<.01
Impact on Social Life	2.60 (3.34)	4.75 (4.23)	11.35 (8.28)	13.05	p<.01
Emotional Burden	22.40 (7.09)	24.67 (5.32)	31.55 (7.76)	12.42	p<.01
Depression	6.45 (7.13)	7.77 (7.03)	14.36 (10.03)	6.54	p<.01
Life Satisfaction	10.00 (2.05)	8.53 (2.24)	7.12 (2.67)	6.81	p<.01

It is clear that caregiver distress systematically increases with severity of illness. The difference in distress levels according to severity of illness was highly significant in each case. Post-hoc Scheffé comparisons were performed on each of the analyses: for each of the negative outcome measures there was a significant difference between the mild and moderate groups and the moderate and advanced groups, giving a clear illustration of greater physical demand caused by the severity of PD leading to greater distress. For life satisfaction, only the difference between the mild and advanced groups was statistically significant.

4.2.3 Hoehn & Yahr disease stage and caregiver distress

Table 4.2.1 indicates that Hoehn & Yahr disease stages have a positive relationship with all three burden measures and caregiver depression and a negative relationship with life satisfaction. One-way ANOVAs were used to see if there was a difference in level of distress according to disease stage. (See table 4.2.3.1, below).

The analyses show that there was a trend for scores to increase with severity of illness. This increase was significant for impact on relationship, impact on social life, and emotional burden; similarly, the decrease in life satisfaction scores was highly significant. Although an increase with disease stage was evident for caregiver depression, this did not reach significance.

A post-hoc Scheffé test was done on each of the significant tests. These showed that there were no differences between stages at the .05 level for impact on relationship and emotional burden. There were, however, significant differences between stages I and IV, and II and IV on impact on social life, and between stages I and IV on life satisfaction.

Table 4.2.3.1 Means, DSs, and comparison F-values of caregiving outcomes according to Hoehn & Yahr disease stage.

Stage I: *n-14;* stage II: *n=14;* stage III: *n=38;* stage IV: *n=13;* stage V: *n=4.*

Caregiver outcome variables:	**Hoehn & Yahr disease stage**						
	I	II	III	IV	V	***F-value***	***p***
Impact on Relationship	2.36 (2.53)	4.08 (3.57)	6.68 (5.85)	7.92 (6.95)	9.50 (6.95)	3.01	< .05
Impact on Social Life	3.29 (4.12)	4.53 (4.47)	7.49 (6.67)	13.00 (8.64)	11.25 (10.69)	4.52	< .01
Emotional Burden	22.64 (6.26)	24.77 (6.60)	28.19 (7.29)	30.42 (6.36)	34.50 (11.68)	3.65	< .01
Caregiver Depression	6.29 (6.24)	7.21 (6.23)	11.86 (9.95)	13.50 (7.88)	12.75 (15.17)	1.90	NS
Life Satisfaction	9.79 (2.48)	9.21 (1.93)	7.64 (2.49)	6.85 (2.54)	7.25 (2.63)	3.77	< .01

4.3 Caregiver Variables and Caregiver Distress

Table 4.3.1, below, sets out the correlation coefficients of the independent caregiver variables, and the dependent caregiving outcomes.

Table 4.3.1 Correlations of caregiver variables and caregiver distress (n=83)

	Dependent Caregiver Distress Variables					
	BIR	BIS	EB	CESD	GHQ	LSI
No. of hours caregiving	.42**	.43**	.37*	.39*	.42**	-.21
Job demand (No. of hassles)	.52**	.61**	.53**	.41**	.42**	-.46**
Hassles with ADL	.46**	.51**	.53**	.41**	.37**	-.43**
Hassles with IADL	.41**	.49**	.48**	.49**	.45**	-.51**
Hassles with cognitive status	.57**	.48**	.49**	.41**	.48**	-.37**
Hassles with patient’s behaviour	.53**	.53**	.49**	.38**	.43**	-.45**
Job satisfaction	-.51**	-.26	-.54**	-.61**	-.44**	.49**
Caregiver neuroticism	.49**	.20	.63**	.79**	.63**	-.55**
Caregiver extraversion	-.29	-.19	-.29	-.20	-.12	.21
Caregiver openness	-.03	.17	-.12	-.20	-.12	.06
Caregiver agreeableness	-.18	-.05	-.25	-.28	-.17	.32*
Caregiver conscientiousness	-.05	.08	-.13	-.16	.02	.20
Optimism	-.34*	-.23	-.47**	-.43**	-.18	.31*
Perception of P. neuroticism	.37**	.29*	.39**	.40**	.27	-.40**
Perception of P. extraversion	-.37**	-.21	-.32*	-.31*	-.41**	.32*
Perception of P. openness	-.02	.16	.01	.08	-.00	-.02
Perception of P. agreeableness	-.43**	-.24	-.34*	-.24	-.17	.37**
Pecept. of P. conscientiousness	-.35*	-.32*	-.30*	-.35*	-.21	.33*
Task-oriented coping style	-.07	.10	.02	-.04	-.06	.12
Emotion-oriented coping style	.48**	.18	.57**	.59**	.54**	-.41**
Avoidance coping style	.24	.10	.12	.28	.15	-.00
Index of social support	-.12	-.10	-.23	-.20	-.13	.19
Satisfaction with social support	-.26	-.28	-.46**	-.31	-.20	.13
Health status	-.06	-.05	.12	.12	.15	.03
Gender[a]	-.19	-.05	-.17	-.30*	-.26	.20
Age	-.16	.08	-.13	.00	.14	.03
Knowledge Parkinson’s disease	.57**	.43**	.50**	.41**	.39**	-.49**
Physical Knowledge	.36**	.34*	.33*	.19	.22	-.32**
Cognitive Knowledge	.52**	.31*	.44**	.44**	.39**	-.44**

* p<.01 **p<.001 (two-tailed) [a] 0 = female 1 = male

As hypothesised, there was a strong association between caregivers’ perception of job demands and negative outcomes. Even when the different components of job demand are considered, the positive relationship persists for all the distress measures. Similarly, job satisfaction has a strong relationship with all the distress measures apart from impact on social life.

Caregiver neuroticism (CN) was found to have very strong positive associations all the caregiver distress measures apart from impact on social life, but particularly with caregiver depression where the correlation coefficient was very high at $r = .79$. Caregiver optimism was significantly negatively related to four of the six distress measures. None of the other caregiver personality variables was related to any of the distress measures.

Caregivers' perceptions of patient's personality were widely associated with caregiver distress. Specifically, perceptions of neuroticism, introversion, disagreeableness and a lack of conscientiousness were all associated with greater impact on relationship. Perceptions of neuroticism, and a lack of conscientiousness were related to greater impact on social life. Emotional burden was associated with caregiver perceptions of neuroticism, introversion, disagreeableness and a lack of conscientiousness. Caregiver depression was associated with patient neuroticism and introversion. Caregiver perceptions of neuroticism, introversion, disagreeableness and a lack of conscientiousness were all associated with low life satisfaction.

With respect to coping style, only the use of emotion-focused coping strategies (EMOT) was associated with caregiver distress, although again, impact on social life remained immune. It was noted that EMOT followed exactly the same pattern as CN, except that for each outcome measure the correlation coefficient was slightly lower. A correlation analysis of the two variables revealed that they were strongly related: $R^2 = .43$, however this is below the $R^2 = .50$ level suggested by Lewis-Beck (1980) as a criterion for statistical treatment as independent constructs.

Therefore, both variables remain in subsequent analyses as predictors of caregiver distress.

Caregiver gender was significantly associated with depression, but with none of the other distress measures. Age had no relationship to any of the dependent variables. There was no relationship between social support and caregiver distress, although satisfaction with social support was negatively related to emotional burden.

Caregiver knowledge of Parkinson's Disease was found to be significantly related to all of the caregiver distress measures, although knowledge of the physical aspects of the disease had no effect on mental health outcomes. Contrary to expectation, however, the results indicated that greater knowledge was associated with caregiver distress. This led to further analyses being carried out on this data. These results are presented in section 4.5 below.

To summarise, caregivers' perceptions of job demand were found to be strongly associated with caregiver distress measures. In general, this extended to all aspects of distress. Similarly, certain caregiver characteristics, specifically, neuroticism, optimism and emotion-focused coping, were also strongly related to caregiving outcomes. The inclusion of a measure of knowledge of PD was justified as it was found to be strongly associated with burden.

4.3.1 Caregiver Gender

It has often been found that caregiver gender is a significant predictor of caregiver distress with the outcomes for females carers being worse than the outcomes for male carers (e.g. Horowitz, 1985, Pruchno & Resch, 1989a). In this study, however, caregiver gender was only significantly associated with depression. This was a negative relationship indicating that greater levels of depression were experienced by female caregivers.

Nevertheless, it was considered important to examine the gender issue with this sample of carers, in view of the large number of spouses involved in PD caregiving, and the greater number of males with PD living in the community. One-way ANOVAs were used to examine the difference in all the caregiving outcome measures according to gender. The significance level was set at the conventional 0.05 level.

Table 4.3.1.1 Means, SDs, and comparison F-values of caregiver outcomes according to caregiver gender.

Group 0: Female (n=62)
Group 1: Male (n=21)

Caregiver outcome variables:	Group 0	Group 1	F-value	*p*
Impact on Relationship (BIR)*:*	6.41 (6.12)	3.95 (2.68)	2.88	NS
Impact on Social Life (BIS):	7.49 (7.34)	6.63 (6.50)	.21	NS
Emotional Burden (EB):	28.03 (7.61)	25.00 (7.15)	2.36	NS
Depression (CESD):	11.93 (9.27)	5.65 (6.37)	7.89	p<.01
General Health (GHQ):	11.75 (5.81)	8.53 (3.06)	5.33	p<.05
Life Satisfaction (LSI):	7.84 (2.46)	9.05 (2.76)	3.44	NS

Table 4.3.2 above clearly shows there was a trend towards higher levels of distress in female carers, but that the gender differences were only significant for mental health outcomes.

4.4 Dyadic Relationship and Caregiver Distress

Correlations between dyadic relationship variables and caregiver distress measures are presented in Table 4.4.1, below. It can clearly be seen that dyadic relationship variables were related to caregiver distress. Both premorbid and current dyadic relationship and happiness were negatively related to the three burden measures and depression and positively related to life satisfaction. Current happiness was also related to caregiver general health although the other three independent variables were not associated with this outcome measure.

Table 4.4.1 Correlations of dyadic relationship variables and caregiver distress

	Dependent Caregiver Distress Variables					
	BIR	BIS	EB	CESD	GHQ	LSI
Premorbid dyadic relationship	-.46**	-.31*	-.51**	-.36**	-.11	.42**
Premorbid happiness	-.47**	-.33*	-.42**	-.36**	-.21	.48**
Current dyadic relationship	-.59**	-.35**	-.65**	-.45**	-.27	.46**
Current happiness	-.63**	-.38**	-.62**	-.49**	-.39**	.48**

* p<.01 ** p<.001 (two-tailed)

Further analyses revealed that there was also a strong relationship between premorbid and current dyadic relationship, $R^2 = .63$, and premorbid and current relationship happiness, $R^2 = .52$. As these variables share more than 50% of variance, they should not be considered as individual constructs (Lewis-Beck, 1980). That is, only one of each pair of variables should be considered in subsequent analyses. This was perhaps not surprising as it was necessary to use a retrospective measure of the caregivers' perception of the premorbid relationship. Nevertheless, the premorbid relationship was conceptually the more interesting variable, so it was the premorbid data that was used in the more complex analyses in chapter 5.

4.4.1 Dyadic Relationship, Dementia, and Caregiver Distress

It was hypothesised that the quality of the premorbid relationship would have a negative effect on caregiver distress. That is, a poor premorbid relationship would be associated with high burden, depression and poorer psychological health and life satisfaction. The hypothesis was generally supported although it there was no relationship between psychological health (GHQ scores) and either of the dyadic relationship, or happiness measures.

It was also hypothesised that the association between premorbid relationship and distress measures would persist, regardless of whether the PD patient also had dementia or not. Partial correlation analyses between the two premorbid relationship variables and the five significant caregiver distress variables, controlling for dementia were used to test this hypothesis (see table 4.4.1.1, below).

Table 4.4.1.1 Partial correlations of dyadic relationship variables and caregiver distress, controlling for dementia.

	Dependent Caregiver Distress Variables				
	BIR	BIS	EB	CESD	LSI
Premorbid dyadic relationship	-.43**	-.28*	-.49**	-.34**	.40**
Premorbid happiness	-.43**	-.28*	-.36**	-.32*	.42**

* p<.01   ** p<.001 (one-tailed)

These results clearly indicate that the quality of the premorbid relationship is a significant, independent predictor of distress in Parkinson’s disease caregivers. Even when the care-recipients’ dementia status was controlled for, the strong association between premorbid relationship and caregiver distress persisted. That is, a poor quality premorbid relationship is associated with greater impact on the relationship, greater impact on social life, greater emotional burden, greater depression and less life satisfaction for caregivers, regardless of the mental status of their care-receiver.

4.5 Knowledge of Parkinson's Disease

It was hypothesised that a lack of caregiver Knowledge of Parkinson's disease (KPD) would be associated with caregiver distress. However, as seen in table 4.3.1, above, there was a significant relationship between KPD and caregiving distress, but the relationship was positive. That is, greater knowledge was associated with greater distress. In this section more detailed analyses of the KPD are presented, both to further investigate the relationship between KPD and distress, and to address the additional hypotheses relating to a difference between knowledge of physical aspects (PHYS) and cognitive aspects (COG) of the disease. The latter issue is considered first.

4.5.1 Do patients and caregivers know more about physical aspects than cognitive aspects of Parkinson's disease?

To investigate differential knowledge of Parkinson's disease, the whole sample of patients and carers was used. Ten patients were excluded because they were demented. Three caregivers did not do the KPD; one was excluded because she was a specialised nurse, one could not do it because she was blind[3], a third spoiled his paper. This gave a total sample of 153. The means, standard deviations, range, and

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[3] Although it would have been possible to administer the questionnaire verbally with this lady, it was reasoned that she probably could not be expected to have the same opportunity to know about PD as she could no longer read.

percentage correct of patient's and caregiver's total KPD scores, and their scores from the two subscales, PHYS and COG, are set out in table 4.5.1.1, below.

Table 4.5.1.1 Mean KPD scores, SDs, range and percentage correct of sample

Means scores:		mean	SD	Range	% correct
KPD (max=32)	Total	17.67	5.16	5-31	55.22
	Patients	17.52	5.15	5-31	54.75
	Caregivers	17.81	5.19	6-29	55.66
PHYS (max=16)	Total	10.89	3.27	2-16	68.06
	Patients	11.11	2.95	4-16	69.44
	Caregivers	10.69	3.53	2-16	66.81
COG (max=16)	Total	6.78	3.34	0-16	42.37
	Patients	6.41	3.48	0-16	40.06
	Caregivers	7.12	3.19	0-14	44.50

It can be seen, from table 4.5.1.1, above, that knowledge of Parkinson's disease is not particularly good in either the patient or the caregiver sample. Whilst scores are well above chance levels of 25%, there is certainly no ceiling effect: for the total questionnaire, patients and caregivers only scored an average of just over half right. There was a difference of about 4 marks, or 25%, between scores on the PHYS and the COG subscales, even when patient and caregiver data were analysed separately. A paired samples t-test revealed that this difference was significant:

Paired T-tests (PHYS v COG)

Total	t = -12.29	p < .001
Patients	t = -10.33	p < .001
Caregivers	t = -7.42	p < .001

The hypothesis was therefore supported: patients and caregivers do have greater knowledge of the physical aspects of the disease than the cognitive aspects.

An important consideration, if the caregiver sample, the sample of interest, was to be used to demonstrate and explore the difference in PHYS and COG knowledge, was whether there was a difference between patient and caregiver knowledge. Certainly, there was no difference in educational level between patients and caregivers, $X^2=.32$, $p>.05$, which is likely to affect performance on a test like this. Similarly, although the difference in age between the patients (mean =74.47 (7.74) years), and caregivers (mean = 69.49 (9.84) years), was significant ($t = 3.45$, $p = .001$), there was no association of age and education level for the total sample ($r = -.12$, $p >.05$).

Patient and caregiver data was compared using independent t-tests. The results indicated that the differences in raw scores between the two groups were not significant.

<u>Independent T-tests</u> (patients v caregivers)

Total	t = -.35	NS
PHYS	t = .80	NS
COG	t = -1.32	NS

To summarise, the analyses above show that there is a significant difference between physical and cognitive knowledge of Parkinson's disease. This is true for both patients and caregivers. There were no differences in patient and caregiver knowledge. Because the focus of this investigation is caregiver knowledge of Parkinson's disease and its relationship to distress, subsequent analyses were confined to the caregiver sample ($n = 80$).

There was strong support for the contention that the two subscales were measuring different things: the correlation of PHYS and COG was $r= .19$, $p>.05$. Reliability coefficients of the questionnaire for the caregiver sample were: KPD $\alpha= .71$, PHYS $\alpha = .71$, COG $\alpha = .67$.

4.5.2 Education level and knowledge of Parkinson's disease

Means and standard deviations of caregiver physical, cognitive and total KPD, according to level of education, are set out in table 4.5.2.1, below. A two-factor repeated measures ANOVA was used to investigate whether level of education had an effect on type (i.e. PHYS and COG) of caregiver knowledge of Parkinson's disease (KPD). The results showed that there was a significant main effect of education (F= 3.59, p<.05), and a significant main effect of type (F= 51.88, p<.01). There was no education x type interaction (F<1).

Table 4.5.2.1 Means and standard deviations of caregiver physical and cognitive knowledge according to level of education.

EDUCATION LEVEL	*PHYSICAL (max=16)*	*COGNITIVE (max=16)*	*TOTAL KPD (max=32)*
Primary (n=38)	9.84 (3.92)	6.53 (3.07)	16.37 (5.66)
Secondary (n=29)	11.48 (3.11)	8.21 (3.18)	19.68 (4.61)
Higher (n=13)	11.38 (2.81)	6.46 (3.15)	17.85 (3.72)

For the total KPD, there was a significant difference in knowledge according to level of education (F= 3.59, p< .05). A post-hoc Scheffé test noted one significant comparison indicating that those with a primary education had significantly lower knowledge than those with a secondary education. A consideration of the two types of questions separately, however, revealed that education had no effect on PHYS (F= 2.13, p> .05) or COG (F= 2.73, p> .05) knowledge.

These results indicated that there was an effect of education on KPD, but it was not strong. The only significant difference was between the primary and secondary groups when both types of knowledge were considered together. No other comparisons were significant. There were no effects of education on the two subscales.

4.5.3 Age and knowledge of Parkinson's disease

A two-tailed Pearson's correlation analysis was performed to investigate whether caregiver age influenced performance on the KPD (see table 4.5.3.1, below). The results show that age did not affect caregiver knowledge of Parkinson's disease.

Table 4.5.3.1 Correlations of Age and KPD variables (n = 80)

	KPD	*PHYS*	*COG*
AGE	-.16	-.23	-.01

4.5.4 Duration of illness and knowledge of Parkinson's disease

To consider whether duration of illness had an effect on KPD, the median of 7 years was used to define two groups of *short* and *long* duration (see table 4.5.4.1, below).

Table 4.5.4.1 Means and standard deviations of caregiver physical and cognitive knowledge according to patient duration of illness.

DURATION OF ILLNESS	*PHYSICAL (max=16)*	*COGNITIVE (max=16)*	*TOTAL KPD (max=32)*
Short (*n* = 40)	9.60 (3.76)	6.30 (2.80)	15.90 (5.18)
Long (*n* = 40)	11.78 (2.96)	7.95 (3.37)	19.73 (4.49)

A two-factor repeated measures ANOVA showed a significant main effect of duration (F= 12.45, p< .01): those caring for a patient with a long duration of illness had greater knowledge of Parkinson's disease than those caring for a patient with a short duration of illness. There was a significant main effect of type (F= 54.54, p< .01), and no significant duration x type interaction (F< 1).

Simple one-way ANOVAs were used to investigate whether duration of illness had an effect on the two different aspects of knowledge. It was found that duration had an effect on both PHYS (F= 8.27, p< .01) and COG (F= 5.66, p< .05).

Those caring for patients with a longer duration of PD had greater knowledge of both physical and cognitive aspects of PD.

4.5.5 Severity of illness and knowledge of Parkinson's disease

To consider whether severity of illness had an effect on caregiver KPD, care-recipients scores from their UPD motor examination (Fahn *et al.*, 1987) were used to divide the sample into three groups: *mild* (<10), *moderate* (10-24) and *advanced* (25+), (see table 4.5.5.1, below).

Table 4.5.5.1 Means and standard deviations of caregiver physical and cognitive knowledge according to severity of illness.

SEVERITY OF ILLNESS	*PHYSICAL (max=16)*	*COGNITIVE (max=16)*	*TOTAL KPD (max=32)*
Mild (*n* = 11)	8.45 (3.59)	6.00 (3.07)	14.45 (5.01)
Moderate (*n* = 33)	10.12 (3.38)	6.48 (3.23)	16.61 (4.85)
Advanced (*n* = 36)	11.88 (3.28)	8.06 (3.01)	19.94 (4.74)

A two-factor repeated measures ANOVA showed a significant main effect of severity of illness (F= 7.22, p< .01). Those caring for a PD patient with a greater severity of illness, as measured by the UPD motor examination, had greater knowledge of Parkinson's disease as compared with those caring for a patient with lower UPD scores. There was a significant main effect of question type (F= 35.31, p< .01), and no significant severity x type interaction (F< 1).

One-way ANOVAs revealed that when the two types of knowledge were considered separately there was no difference in caregiver's cognitive knowledge according to their care-recipient's severity of illness (F= 3.02, p>.05). There was, however, a significant difference in physical knowledge according to physical severity of illness (F= 5.20, p< .01). Post-hoc Scheffe tests indicated that there was a significant difference in PHYS scores between the mild and advanced groups, but despite a trend in the right direction, the difference between mild and moderate, and moderate and advanced PHYS scores were not significant.

4.5.6 Patient cognitive status and knowledge of Parkinson's disease

To consider whether PD patient's cognitive status had an effect on caregiver KPD, care-recipients scores from their mini-mental state examination (MMSE; Folstein *et al.*, 1975) were used to divide the sample into three groups: *intact* (29/30), *impaired* (24-28) and *demented* (<24), following Hodges' observation that while a score below the cut-off of 24 on the MMSE is a fairly good marker of dementia, many patients with cognitive impairments achieve a score above this cut-off, especially if they have a good background intellectual ability (Hodges, 1994). (See table 4.5.6.1, below).

Table 4.5.6.1 Means and standard deviations of caregiver physical and cognitive knowledge according to cognitive status.

COGNITIVE STATUS	*PHYSICAL (max=16)*	*COGNITIVE (max=16)*	*TOTAL KPD (max=32)*
Intact (*n* = 43)	10.35 (3.63)	6.12 (2.90)	16.47 (5.19)
Impaired (*n* =27)	10.85 (3.56)	7.96 (3.41)	18.81 (5.05)
Demented (*n* =10)	11.70 (3.13)	9.20 (2.15)	20.90 (3.81)

A two-factor repeated measures ANOVA showed a significant main effect of mental status (F= 4.01, p< .05): those caring for a patient with minimal cognitive impairments had less knowledge of Parkinson's disease than those caring for a patient with evidence of mental impairments. There was a significant main effect of question type (F= 31.43, p< .01), and no significant mental status x type interaction (F= 1.17, p>.05).

Simple one-way ANOVAs were used to investigate whether patient's mental status had an effect on the two different aspects of knowledge. It was found that mental status had no effect on PHYS (F<1), but a highly significant effect on COG (F= 5.83, p< .01). Post-hoc Scheffé tests indicated that there were significant differences between both the intact and impaired groups and the intact and demented groups, but not between the impaired and demented groups.

4.5.7 Membership of PDS and knowledge of Parkinson's disease

It was also questioned whether caregivers who were members of the Parkinson's Disease Society (PDS; *n*=31) had greater knowledge than those who were not (*n*=49). A two-factor repeated measures ANOVA showed that there was no difference in KPD scores according to PDS membership. However, there was a highly significant effect of question type (F= 62.88, p< .01), and a significant interaction of PDS membership and knowledge (F= 5.19, p< .05).

Consideration of PDS membership and PHYS and COG separately, using one-way ANOVAs, indicated that there was a simple effect of PDS membership on PHYS (F= 7.16, p< .01), but not on COG (F<1). (See table 4.5.6.1, below).

Table 4.5.7.1 Means and standard deviations of caregiver physical and cognitive knowledge according to membership of the PDS.

MEMBERSHIP OF PDS	*PHYSICAL (max=16)*	*COGNITIVE (max=16)*	*TOTAL KPD (max=32)*
Non-member (*n*=49)	9.88 (3.79)	7.16 (3.06)	17.04 (5.34)
Member (*n* = 31)	11.97 (2.68)	7.06 (3.44)	19.03 (4.76)

4.5.8 Summary of predictors of caregiver knowledge of Parkinson's disease.

The analyses above show that not only is there a consistent difference between caregiver knowledge of the physical and cognitive aspects of Parkinson's disease, but that the predictors of the two types of knowledge differ.

Caregiver physical knowledge was found to be related to duration of illness, physical severity of illness and membership of the Parkinson's disease society. Together these accounted for 18% of the variance in a regression analysis. Caregiver physical knowledge was not predicted by education level or by their care-recipient's mental status.

Caregiver cognitive knowledge was found to be related to duration of illness and their care-recipient's mental status. Together these accounted for 15% of the variance in a regression analysis. Caregiver cognitive knowledge was not related to education level or their care-recipient's physical status.

4.5.9 Relation between caregiver knowledge of PD and caregiver distress

Bi-variate correlations of the caregiver distress measures and the two knowledge variables shows that there are rather stronger relationships between distress and cognitive knowledge than distress and physical knowledge, except for burden from impact on social life (see table 4.5.9.1, below).

Table 4.5.9.1 Correlations of caregiver distress measures and physical and cognitive knowledge of Parkinson's disease.

Caregiver outcome variables:	PHYS	COG
Impact on Relationship:	.36**	.52**
Impact on Social Life:	.34*	.31*
Emotional Burden:	.33*	.44**
Depression :	.19	.44**
General Health:	.22	.39**
Life Satisfaction:	-.32*	-.44**

* p< .01 ** p< .001 (two-tailed)

High cognitive knowledge was associated with adverse mental health symptoms in addition to the burden and low life-satisfaction that were also associated with high physical knowledge.

The finding that more knowledge leads to greater distress was unexpected. It was hypothesised that this could be a result of caregivers having to "learn on the job", particularly with respect to cognitive aspects of PD. That is, they have little knowledge of what Parkinson's disease is at diagnosis, and the main source of their subsequent knowledge is experience: although information about the physical aspects of PD may be professionally presented, and available in PDS documentation, information about the cognitive aspects of PD do not seem to so readily available. If this is true, then if duration of illness and variables assessing the psychological state of the patient are taken into account, the association between greater knowledge and greater distress should disappear.

This hypothesis was tested with a partial correlation analysis, controlling for duration of PD, patient cognitive status and current verbal intelligence (Mill Hill score), and cognitive and behavioural hassles associated with caregiving (see table 4.5.9.2 below).

Table 4.5.9.2 Partial correlations of caregiver distress measures and physical and cognitive knowledge of Parkinson's disease, controlling for duration of illness, patient psychological status and cognitive and behavioural hassles for carer.

Caregiver outcome variables:	PHYS	COG
Impact on Relationship*:*	.15	.23
Impact on Social Life:	-.02	.03
Emotional Burden:	.04	.09
Depression:	-.07	.24
General Health:	-.08	.12
Life Satisfaction:	-.16	-.17

* p< .01 ** p< .001 (two-tailed)

A comparison of the coefficients of tables 4.5.9.1 and 4.5.9.2 clearly indicates that when the psychological state of the patient is taken into account, the significant relationship between greater knowledge and greater burden disappears. None of the relationships between either PHYS or COG and the various caregiving outcomes were significant, even at the .05 level. The hypothesis that the positive association between knowledge of PD and caregiver distress was due to knowledge being gained from the progressive experience of PD caregiving was strongly supported.

4.6 Personality

It was hypothesised that both patient and caregiver personality are potential predictors of caregiver distress. In this research the NEO-FFI (Costa & McCrae, 1992) was used as the assessment tool for both patient and carer personality because it has well validated norms. These norms were used to consider the personality distribution of non-demented Parkinson's patients and caregivers.

It can be seen from Table 4.6.1, below, that caregiver's perceptions of their care-recipient's personality were generally more conservative than the patient's own assessment of their personality. Whilst over 16% of patient's responses were outside the normal range with respect to neuroticism, only 2.5% of carers described the patients in a similar way. The only deviation from this trend was patient conscientiousness. Caregivers perceived patients to be less conscientious than the patients themselves.

Table 4.6.1 Percentage of patients and carers more than two standard deviations above or below the norm mean on NEO-FFI personality scales[4].

	Patients (n = 73)		Carer's perception of patients (n = 80)		Carers (n = 69)	
	Below %	Above %	Below %	Above %	Below %	Above %
Neuroticism	1.4	16.4	-	2.5	-	7.2
Extraversion	15.1	1.4	8.8	-	1.4	-
Openness	12.3	2.7	8.8	-	10.1	1.4
Agreeableness	4.1	4.1	1.3	-	1.4	4.2
Conscientiousness	8.2	1.4	12.5	-	1.4	2.9

The caregiver sample was less extreme than the patient sample with respect to the NEO norms. Nevertheless, over 7% rated themselves as abnormally neurotic, and over 10% rated themselves as not having the normal open outlook on life. Reliability coefficients for the NEO-FFI were rather inconsistent according to sample, however, as can be seen in table 4.6.2, below.

Table 4.6.2 Alpha coefficients of the NEO-FFI, according to sample.

	Patients (n = 73)	*Carer's perception of patients (n = 80)*	*Carers (n = 69)*
Neuroticism	.85	.76	.88
Extraversion	.67	.67	.53
Openness	.67	.53	.69
Agreeableness	.58	.40	.66
Conscientiousness	.77	.87	.48

4.6.1 Caregiver personality and caregiver distress

It was hypothesised that caregiver personality would be a direct predictor of PD caregiver distress. Caregiver neuroticism, as measured by the NEO-FFI was found to have a strong positive relationship with emotional burden, impact on relationship, caregiver mental health outcomes - depression and psychological health, and a highly significant negative relationship with life satisfaction (see table 4.3.1, p. 179). Optimism was also significantly negatively related to emotional burden, impact on relationship, caregiver depression in a negative direction, and in a positive direction with life satisfaction. The question of carer personality and distress was explored further in phase II, the results of which are presented in chapter 5.

4.6.2 Carers' perceptions of patient personality change and caregiver distress

It was hypothesised that caregiver distress would be greater where a caregiver perceives a marked change in their care-recipient's core psychological characteristics. Personality change was investigated at the factor level, with an

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[4] In a normal distribution, one would expect around 4% of a sample to be above or below two standard deviations from the mean.

adaptation of the five-factor NEO (Costa & McCrae, 1992), and at a simpler level, using the Identity Test (Brooks & McKinlay, 1983). The identity test consists of 20 bi-polar dimensions of personality. According to caregivers, PD patients significantly changed from their pre-morbid personality on 19 of these 20 traits. Only *mindful-forgetful*, was not perceived as being unaffected by PD. This is interesting because it suggests a lack of sensitivity to cognitive changes being part of PD. Nevertheless, this trait was not included in the subsequent analyses.

Personality change on the five factors of the NEO was indicated by a score above zero (max. = 48). As seen in Table 4.6.2.1, below, for carers, the largest change in patient personality was a decrease in extraversion. There was also a decrease in conscientiousness and an increase in neuroticism. Caregivers' perceived little change in patient openness or agreeableness.

Change on the Identity Test was indicated by a score above or below zero. Negative scores indicate a change for the worse, positive scores indicate a change for the better. It is immediately clear from the table below that all the mean scores are negative, although the range scores indicate that some carers' thought there was an improvement in patient personality for most of these personality traits. Interestingly, not one caregiver described their dependent as more co-operative.

The biggest changes in trait personality, according to the mean change scores, were that patients were seen as being more irritable, more inactive and more difficult. Smaller, but still significant changes was seen in less friendliness and less cleverness.

Table 4.6.2.1 Mean scores, standard deviations and range of patient personality change, according to the NEO-FFI (n=55) and Identity Test (n=61).

NEO factor	*Mean Score*	*Standard deviation*	*Range*
Neuroticism	8.71	7.84	0 - 32
Extraversion	11.55	7.81	0 - 31
Openness	2.05	2.87	0 - 15
Agreeableness	1.20	2.52	0 - 13
Conscientiousness	7.00	7.33	0 - 28
Bored-Interested	-1.57	2.04	-6 - 1
Unhappy-Happy	-1.43	1.91	-6 - 5
In Control-Helpless	-1.74	1.96	-6 - 3
Worried-Relaxed	-1.20	1.71	-6 - 3
Dissatisfied-Satisfied	-1.49	1.89	-6 - 3
Attractive-Unattractive	-0.84	1.34	-5 - 1
Hopeful-Despondent	-1.31	1.66	-6 - 1
Lack Confidence-Confident	-1.82	1.95	-6 - 3
Stable-Emotional	-1.11	1.85	-5 - 5
Worthless-Of Value	-0.92	1.45	-6 - 1
Irritable-Calm	-2.02	2.04	-6 - 1
Unfeeling-Caring	-0.74	1.46	-4 - 3
Skilful-Clumsy	-0.64	1.32	-5 - 3
Independent-Dependent	-1.80	1.84	-6 - 2
Active-Inactive	-2.72	2.25	-6 - 1
Difficult-Co-operative	-2.79	2.01	-6 - 0
Talkative-Withdrawn	-1.31	1.96	-6 - 2
Friendly-Unfriendly	-0.39	1.19	-5 - 3
Stupid-Clever	-0.54	0.94	-3 - 1

To investigate the effect of these changes in personality on caregiving outcomes, one-tailed bi-variate correlation analyses were carried out on the independent personality change variables and the dependent caregiver distress variables (see table 4.6.2.2, below).

Table 4.6.2.2 Correlations of carers' perceptions of patient personality change and caregiver distress (NEO-FFI, n=54; Identity Test, n=61).

	Dependent Caregiver Distress Variables					
	BIR	BIS	EB	CESD	GHQ	LSI
Neuroticism	.23	.17	.13	.15	.13	.06
Extraversion	.35*	.23	.21	-.06	.01	-.25
Openness	.18	.03	.08	.12	.17	.07
Agreeableness	.21	.13	.18	-.08	.15	-.03
Conscientiousness	.41**	.16	.33*	.07	.22	-.35*
Bored-Interested	-.59**	-.51**	-.50**	-.49**	-.29	.47**
Unhappy-Happy	-.33*	-.16	-.42**	-.44**	-.31	.40*
In Control-Helpless	-.36*	-.20	-.38*	-.36*	-.29	.28
Worried-Relaxed	-.20	-.17	-.17	-.17	-.11	.11
Dissatisfied-Satisfied	-.28	-.10	-.26	-.15	-.08	.18
Attractive-Unattractive	-.09	-.30	-.23	-.14	-.01	.24
Hopeful-Despondent	-.28	-.13	-.28	-.29	-.11	.30
Lack Confidence-Confident	-.44**	-.26	-.51**	-.45**	-.38*	.47**
Stable-Emotional	-.31	-.27	-.31	-.28	-.06	.17
Worthless-Of Value	-.32	-.32	-.26	-.18	-.00	.16
Irritable-Calm	-.22	-.09	-.39*	-.29	-.28	.34*
Unfeeling-Caring	-.18	-.07	-.06	-.01	.01	-.00
Skilful-Clumsy	-.37*	-.35*	-.25	-.21	-.17	.26
Independent-Dependent	-.33*	-.12	-.22	-.13	.02	.23
Active-Inactive	-.45**	-.43**	-.46**	-.35*	-.25	.28
Difficult-Co-operative	-.40**	-.30	-.48**	-.41**	-.41**	.37*
Talkative-Withdrawn	-.42**	-.21	-.42**	-.35*	-.21	.43**
Friendly-Unfriendly	-.27	-.20	-.21	-.29	-.13	.26
Stupid-Clever	-.27	-.20	-.30	-.11	-.08	.05

* p<.01 **p<.001 (one-tailed)

The results show that the perceived decrease in patient extraversion had a significant negative impact on the dyadic relationship, but none of the other aspects of distress. The perceived decrease in conscientiousness also had a negative impact on the dyadic relationship, emotional burden and life satisfaction. Changes in patient neuroticism, openness and agreeableness, however, were not associated with caregiver distress.

At the trait level, there were particularly strong relationships between distress and the patient showing increased apathy, decreased happiness, less confidence, more inactivity, less co-operation, and being less talkative. More specific effects on caregiving outcomes include the relationship between increased patient irritability and emotional burden; increased clumsiness and an impact on both the dyadic relationship and the carer’s social life; increased dependence and impact on relationship; becoming more helpless was related to emotional burden, depression and impact on relationship.

Not all personality changes at the trait level had a negative effect on PD carers. Perceptions of the patient worrying more, being less satisfied, less attractive, less hopeful, more emotional, of less value, less caring, less friendly, and not as clever had no effect on caregiver distress.

4.6.3 Patient personality change, job demand and caregiver distress

The results above indicated that certain aspects of PD patient personality change had a strong association with caregiver distress. As illustrated in table 4.3.1 (p. 178), it was also clear that job demand has a strong impact on all six measures of burden. It was hypothesised that caregiver distress would be greater where the caregiver perceives a change in patient personality, regardless of job demand. To ascertain whether perceived patient personality change does exert a direct influence on caregiving outcomes at both high and low levels of job demand, it was necessary to account for job demand when calculating the relationships between perceptions of personality change and caregiving distress.

Table 4.6.3.1, below, sets out the correlations between the six distress measures and those personality variables which had an effect on caregiving outcomes, after controlling for job demand. These calculations used the carers’ perception of job demand measure (JDH), on the basis that it was also carers’ appraisals that were used to assess personality change, rather than an objective measure.

Table 4.6.3.1 Partial correlations of patient personality change and caregiver distress, controlling for job demand (NEO-FFI, n = 50; Identity Test, n=56).

	Dependent Caregiver Distress Variables					
	BIR	BIS	EB	CESD	GHQ	LSI
Extraversion	.19	.06	-.04	-.20	-.19	-.10
Conscientiousness	.21	-.08	.02	-.06	.01	-.18
Bored-Interested	-.34*	-.31*	-.19	-.31	-.02	.25
Unhappy-Happy	-.14	-.02	-.28	-.36*	-.21	.30*
In Control-Helpless	-.28	-.18	-.32*	-.33*	-.25	.24
Lack Confidence-Confident	-.20	-.06	-.31	-.32*	-.24	.32
Irritable-Calm	.15	.24	-.10	-.08	-.07	.12
Skilful-Clumsy	-.28	-.37*	-.14	-.16	-.12	.21
Independent-Dependent	-.22	-.10	-.11	-.08	.09	.20
Active-Inactive	-.19	-.20	-.20	-.15	-.02	.03
Difficult-Co-operative	-.14	-.09	-.27	-.24	-.25	.17
Talkative-Withdrawn	-.17	-.02	-.18	-.21	-.03	.29

* p<.01 **p<.001 (one-tailed)

It can be seen from the table above, that when caregivers' perceived job demands are taken into account, the relationships between patient personality change and caregiver distress are considerably reduced. Essentially, the hypothesis that caregiver distress will be greater where the caregiver perceives a marked change in patient personality was partially supported, and the hypothesis that this would be so at both high and low levels of job demand was also only partially supported.

These results make it clear that it is not personality change, *per se*, that is distressing, but particular personality changes on particular outcomes. The significant relationship between patient personality change and caregiver distress remained for five aspects of personality from the Identity Test, regardless of job demand. Now though, only five aspects of distress were selectively associated with these five personality descriptors. When job demand is taken into account, the association of carers' perception of patient personality change and poor psychological health is no longer present.

4.6.4 Summary

A global measure of personality change was not used in this investigation, in order to retain the ability to describe the aspects of personality change that were important to PD caregiver outcomes. Twenty-five assessments of patient personality change were taken from caregivers: the above analyses suggest that just five are important contributors to caregiver distress. That is, (i) a decrease in interest has a significant impact on the dyadic relationship and on social life, (ii), a decrease in happiness has a significant association with caregiver depression and lower life satisfaction, (iii) increased helplessness is positively related to emotional burden and caregiver depression, (iv) reduced confidence is positively related to caregiver depression, and (v) becoming more clumsy is associated with a negative impact on caregivers' social life.

4.7 PD Patients' Mental Status and Caregiver Distress

It was hypothesised that greater caregiver distress would be experienced by PD caregivers whose care-recipient was also demented. In phase I, ten of the 83 patients who were tested with the MMSE were classified as demented (12%). To examine whether there was a difference in outcomes for the carers of these patients was tested using one-way ANOVAs (see table 4.7.1 below).

The results indicate that those who were caring for a PD patient who was also dementing experienced higher levels of distress as measured by the BIR, BIS, EB, GHQ and LSI. The two groups, however, were similarly depressed. Although PD + dementia caregivers were, on average, more depressed than PD without dementia caregivers, the difference was not statistically significant. The hypothesis is supported with respect to burden, psychological health status and life satisfaction, but from these results it is not possible to report that dementia in a PD patient increases caregiver depression.

Table 4.7.1 Means, SDs, and comparison F-values of caregiver outcomes according to whether the PD patient is also classified as dementing.

Group 0: MMSE score of 24 or over (n=73)
Group 1: MMSE score of 23 or less (n=10)

Caregiver outcome variables:	Group 0	Group 1	F-value	*p*
Impact on Relationship (BIR)*:*	5.29 (5.43)	9.60 (5.46)	5.51	p<.05
Impact on Social Life (BIS):	6.59 (6.77)	12.20 (7.91)	5.77	p<.05
Emotional Burden (EB):	26.36 (6.99)	34.00 (8.51)	9.90	p<.01
Depression (CESD):	9.70 (8.56)	14.80 (11.21)	2.87	NS
General Health (GHQ):	10.43 (4.76)	14.60 (8.21)	5.44	p<.05
Life Satisfaction (LSI):	8.49 (2.51)	5.60 (1.43)	12.65	p<.01

4.8 Caregiving and hallucinations

It was hypothesised that greater caregiver distress would be experienced by PD caregivers whose care-recipient had experienced hallucinations. To test this hypothesis, the caregiver sample was separated to form a group whose care-recipient was currently suffering from hallucinations or had previously endured a period of hallucinating (*n* = 32), and a group of caregivers who had not had to deal with a hallucinating care-recipient (*n* = 51). One-ways ANOVAs were used to see if there was a difference in caregiving outcomes for the two groups.

Table 4.8.1, below, shows that there was a significant difference between the two hallucinations groups for all of the caregiving outcome measures. These results strongly suggest that caring for someone who experiences hallucinations during PD is more distressing than caring for a Parkinson's patient who has not hallucinated. The hypothesis was strongly supported.

Table 4.8.1 Means, SDs, and comparison F-values of caregiver outcomes according to whether the PD patient has experienced hallucinations.

Group 0: no experience of hallucinations (*n*=51)
Group 1: experienced hallucinations (*n*=32)

Caregiver outcome variables:	Group 0	Group 1	F-value	*p*
Impact on Relationship (BIR)*:*	4.58 (4.85)	7.69 (6.19)	6.32	p<.05
Impact on Social Life (BIS):	5.79 (6.61)	9.53 (7.36)	5.60	p<.05
Emotional Burden (EB):	24.96 (7.01)	30.84 (7.10)	13.40	p<.01
Depression (CESD):	8.02 (8.07)	13.75 (9.37)	8.41	p<.01
General Health (GHQ):	9.78 (4.97)	12.66 (5.66)	5.59	p<.05
Life Satisfaction (LSI):	9.18 (2.30)	6.53 (2.14)	27.22	p<.01

4.9 Patient Variables and Perceived Job Demands

In the hypothesised model of Parkinson's disease caregiving (p. 132), it was assumed that patient variables would have a direct effect on perceived job demands. It is, however, feasible that some patient variables have more important influence on perceived demands than others, and indeed there may be some patient variables which are irrelevant to caregiver's perception of job demand. To ascertain which of the patient variables measured in this investigation of PD caregiving predict perceived job demand, two-tailed bi-variate relational analyses were undertaken on the relevant variables. The results are in table 4.9.1, below.

Table 4.9.1 Correlations of patient variables and perceived job demand (*n* = 76).

JDH = Perceived job demand (Number of hassles)
HA = Hassles with Activities of Daily Living
HB = Hassles with Instrumental Activities of Daily Living
HC = Hassles with patient's cognitive status
HD = Hassles with patient's behaviour

	Job Demand Variables				
	JDH	HA	HB	HC	HD
Duration of illness	.41**	.47**	.38**	.35*	.31*
Severity of illness (UPD)	.61**	.62**	.51**	.47**	.41**
Hoehn & Yahr disease stage	.64**	.58**	.55**	.49**	.47**
Activities of daily living	-.58**	-.61**	-.55**	-.39**	-.35*
Depression (GDS)	.43**	.36**	.25	.38**	.35*
Neuroticism (n=66)	.35*	.17	.11	.27	.28
Extraversion (n=66)	-.05	.02	.03	.02	.01
Openness (n=66)	.14	.08	.08	.21	.29
Agreeableness (n=66)	-.01	-.02	.00	-.10	-.21
Conscientiousness (n=66)	.25	-.09	-.11	-.07	-.01
Mental status	-.55**	-.57**	-.54**	-.66**	-.49**
Dementia[a]	.55**	.53**	.55**	.64**	.47**
Hallucinations[b]	.53**	.55**	.38**	.46**	.44**
Global Slowing	.35*	.63**	.36*	.49**	.35*
Non-verbal intelligence	-.53**	-.50**	-.49**	-.55**	-.48**
Verbal intelligence	-.07	.01	.02	.02	.12
Recognition memory: words	-.17	-.15	-.12	-.10	-.06
Recognition memory: faces	-.04	-.02	-.14	.05	.19
Cognitive demand	.62**	.61**	.62**	.72**	.55**
Age	.13	-.02	.08	.05	.05
Age of Onset	-.12	-.28	-.14	-.15	-.13

* p<.01 **p<.001 (two-tailed)
[a] 0 = without dementia (MMSE score of 24+) 1 = with dementia (MMSE score <24)
[b] 0 = no hallucinations 1 = has had hallucinations

These results clearly show that the physical and the mental status of the patient have a strong bearing on the caregiver's perception of job demand. All the physical PD measures relate to all the perceived job demand measures, and similarly all the major cognitive variables - MMSE, dementia, hallucinations, global slowing, non-verbal intelligence and the computed cognitive demand variable - relate to all the perceived job demand measures.

In addition to the above, patient depression was seen to influence hassles with ADL and cognitive status, and patient neuroticism was associated with total job demand. The other patient personality variables, however, had no influence on perceptions of job demand. Verbal memory, recognition memory for words and faces, patient age and age of onset also exerted no effect on the carers' perception of job demand.

The results above demonstrate that, as far as the link between patient variables and perceived job demands is concerned, the hypothesised model of PD caregiving is supported.

4.10 Attrition Status

If phase I data were to be used as a baseline for evidence of change with progression of illness, it was clear that phase I data must first be analysed to see if there were any important differences between the group who also took part in phase II, and those who did not. That is, is there a difference in scores on phase I variables between patients and caregivers who completed the two phases of testing, and those who did not? One-way ANOVAs were used on both patient and caregiver variables to address this question (see table 4.10.1, below).

Table 4.10.1 Means, SDs, and comparison F-values according to attrition status.

Group 0: took part in both phase I and phase II (n=56)
Group 1: took part in phase I only (n=27)

Variable	Group 0	Group 1	F-value	*p*
a) Patient variables:				
Hoehn & Yahr Disease Stage:	2.63 (1.02)	3.00 (1.14)	2.28	NS
Severity of Illness (UPD score):	21.09 (10.88)	28.00 (11.82)	2.71	NS
Duration of Illness:	8.14 (4.56)	8.33 (6.20)	.03	NS
Activities of Daily Living:	15.88 (4.15)	14.74 (4.61)	1.27	NS
Job Demand (No. of Hassles):	11.21 (7.77)	14.75 (9.24)	3.02	NS
Mental status (MMSE score):	28.13 (2.59)	26.37 (4.16)	5.54	p<.05
Global slowing (Word RT):	7.95 (3.41)	8.41 (8.31)	.13	NS
Depression:	11.84 (6.18)	14.27 (5.77)	2.86	NS
Age:	72.91 (7.79)	78.41 (9.28)	9.28	p<.01
b) Caregiver variables:				
Neuroticism:	20.16 (9.21)	17.94 (7.83)	.83	NS
Extraversion:	26.63 (4.75)	26.33 (4.70)	.05	NS
Optimism (LOT score):	19.27 (4.49)	22.21 (3.29)	6.74	p= .01
Emotion-focused coping:	38.67 (9.51)	38.74 (9.01)	.00	NS
Job Satisfaction:	29.41 (4.31)	28.55 (5.23)	.50	NS
Premorbid Relationship:	21.39 (3.89)	20.62 (4.27)	.67	NS
Premorbid Happiness:	4.04 (.93)	4.00 (.94)	.03	NS
Social Support:	9.33 (5.88)	10.46 (7.01)	.55	NS
Satisfaction with Social Support:	6.35 (2.20)	6.00 (2.04)	.43	NS
Age:	68.41 (10.20)	70.70 (10.83)	.88	NS
c) Caregiver outcomes:				
Impact on Relationship:	5.55 (5.07)	6.46 (6.72)	.44	NS
Impact on Social Life:	7.23 (7.41)	7.42 (6.55)	.01	NS
Emotional Burden:	27.02 (5.07)	28.00 (7.80)	.28	NS
Depression:	11.02 (9.18)	8.79 (8.62)	1.02	NS
General Health:	10.84 (5.08)	11.26 (6.33)	.10	NS
Life Satisfaction:	8.30 (2.55)	7.76 (2.65)	.77	NS

The comparisons show that the only significant differences between the two groups were for age and mental status of PD patients, and in caregiver optimism. The care-recipients who did not take part in the follow-up were older and scored less on the MMSE. Caregivers who did not take part in phase II were significantly more optimistic. There was no difference between the two groups on any other predictor variable. With respect to caregiver outcome measures, there were no differences between the two groups. The results indicate that, with the exception of patient age, mental status and caregiver optimism, the characteristics of the caregiving sample of phase II, were representative of the larger phase I sample. Carers who did not take part in phase II were caring for significantly older and more cognitively impaired patients, and interestingly they were significantly more optimistic. Because of these differences, all analyses which consider the progression of PD caregiving only included those dyads (n = 56) from whom longitudinal data was collected, as a means of avoiding any contamination of the data.

4.11 Summary

Phase I results have clearly indicated that, as in the proposed model of PD caregiving, there are patient variables, caregiver variables and dyadic relationship variables that directly affect outcomes for caregivers. The patient variables that are associated with caregiver distress include duration of illness, severity of illness, activities of daily living, personality, depression, dementia, hallucinations, and cognitive demand. It was found that both premorbid and present dyadic relationship directly predicted caregiver distress, although there was considerable shared variance between these variables. Caregiver variables that predicted distress include neuroticism, optimism, emotion-focused coping, perceptions of care-recipient's personality, perceived job demand, and knowledge of Parkinson's disease. Social support and caregiver health status, however, were not associated with caregiving outcomes, and caregiver gender was only relevant with respect to depression.

CHAPTER 5

RESULTS: PHASE II

5.1 Introduction

In this chapter, data from phase II is presented. In addition to repeating the simple bivariate correlations between predictors and the dependent caregiver outcome variables, with a view to replicating, and hence strengthening the findings of phase I, longitudinal comparisons are made. Specifically, it was hypothesised that there would be an increase in caregiver distress in relation to the progression of Parkinson's disease. Where longitudinal comparisons are made, they are with filtered data from phase I. That is, only those who participated in both test phases are compared ($n = 56$). As with phase I data, to prevent the inflation of the probability of alpha error when conducting large numbers of bi-variate correlation analyses, the alpha significance level was set at 0.01. For all other computations, the alpha significance level was set at the conventional 0.05.

In this chapter, the relationship between caregiver distress and job demand, discretion and strain is more extensively investigated using phase II data. This is presented in section 5.4.2. The hypothesised model of caregiving is considered with respect to predictors and outcomes of the stress process in Parkinson's disease caregivers and analyses are presented which were used to identify intervening variables which moderated and suppressed predictor-outcome relationships.

Finally, all the important predictor variables for each of the dependent variables were analysed in order to identify those variables which significantly accounted for variance. That is, multiple regression techniques were used to identify the biggest predictors of each component of distress for caregivers of Parkinson's disease patients.

Demographic data of the reduced phase II sample, at follow up, is recorded in Tables 5.1.1 and 5.1.2, below.

Table 5.1.1 Demographic data on PD patients at phase II (n = 56).

Gender (*n*)			
Female	17	Hoehn & Yahr Stage (*n*)	
Male	39	Stage I	10
Age (years)		Stage II	11
Mean (SD)	73.95 (7.79)	Stage III	27
Range	49-87	Stage IV	6
Age of Onset (years)		Stage V	2
Mean (SD)	64.88 (9.50)	MMSE score	
Range	36-79	Mean (SD)	27.35 (3.30)
Early Onset (<60)	11	Range	14-30
Typical Onset (60-70)	28	Demented	5
Late Onset (>70)	17	Without dementia	51
Severity of Illness (UPD)		Education (*n*)	
Mean (SD)	23.38 (10.04)	Primary	27
Mild (<10)	3	Secondary	20
Moderate (10-24)	29	Higher	9
Advanced (25+)	24	Premorbid IQ (NART)	
Duration (years)		Mean	106
Mean (SD)	9.18 (4.59)		
Range	2-19		

5.1.2 Demographic data on PD caregivers at phase II (n = 56).

Gender (*n*)		Residence (*n*)	
Female	41	With patient	54
Male	15	Not with patient	2
Age (years)		Health Status (*n*)	
Mean (SD)	69.45 (10.15)	Good	27
Range	37-90	Fair	12
Dyadic Relationship (*n*)		Poor	17
Husband	15	Education (*n*)	
Wife	36	Primary	27
Son	1	Secondary	20
Daughter	3	Higher	9
Friend	1		

5.2 Longitudinal changes

Parkinson's disease is a progressive illness. It follows from this that a straight replication of results at follow-up is unlikely. Nevertheless, it was expected that if patient or caregiver variables related to the illness situation (e.g. perceived job demand) are strong predictors of caregiver distress then relationships between these independent variables and the dependent caregiver distress variables should be strong both at phase I and phase II.

5.2.1 Severity of illness and objective job demand

To reiterate, PD is a progressive illness. But, as outlined in chapter 1, judicious medication can provide stability, and indeed improvement at the early stages. An important question then was whether there was observable progression of PD in this patient sample in the year between phases I and II.

Paired t-tests were used to investigate whether there were differences in the same PD sample in the 12-months time period on the UPD motor examination, the Barthel ADL scale, the MMSE, and the computed cognitive demand variable (see table 5.2.1.1, below).

Table 5.2.1.1 Means, SDs, and longitudinal comparison t-values of PD illness measures.

	Phase I	*Phase II*	*t-value*	*p*
UPD Motor Examination	21.09 (10.88)	23.38 (10.05)	-2.32	p<.05
Barthel ADL	15.88 (4.15)	15.39 (4.43)	1.10	NS
MMSE	28.13 (2.59)	27.25 (3.38)	2.84	p<.01
Cognitive Demand	3.17 (3.33)	109.21 (185.84)	-3.53	p<.001

These results indicate that there was a measurable progression of illness, both physical and cognitive, between the two test periods. There was a significance increase in mean UPD score, showing increased disability, and by inference, increased job demand. The small decrease in ADL level, however, was not significant. Mean MMSE scores significantly fell, which supports the notion that there is subtle cognitive changes in PD. Following from that, cognitive demand significantly increased in phase II.

5.2.2 Caregiver distress

If distress is directly associated with severity of illness, then it would be expected that levels of distress will be higher in the follow-up. Paired t-tests were used to investigate whether there was an increase in distress levels in phase II (see table 5.2.2.1, below).

Table 5.2.2.1 Means, SDs, and longitudinal comparison t-values of caregiver distress measures (n=56)

	Phase I	*Phase II*	*t-value*	*p*
Impact on Relationship (BIR)	5.55 (5.07)	5.79 (4.99)	-.48	NS
Impact on Social Life (BIS)	7.23 (7.41)	8.04 (6.95)	-.94	NS
Emotional Burden (EB)	27.02 (7.54)	26.71 (6.99)	.51	NS
Caregiver Depression (CESD)	11.02 (9.18)	10.65 (8.21)	.40	NS
Psychological Health (GHQ)	10.84 (5.08)	10.51 (3.82)	.71	NS
Life Satisfaction (LSI)	8.36 (2.53)	8.27 (2.35)	.27	NS

A simple observation of the mean scores of phase I and phase II reveal that there were subtle differences on each of the distress measures, however a computational analysis indicated that there was no significant change in level of distress from phase I to phase II.

Certainly carers of PD patients, as a group, do experience raised levels of psychological distress compared to non-caregiving controls (Miller *et al.,* 1996). Moreover, this is clearly demonstrated in this study, if one accepts that a score above zero on the BIR and the BIS, and a score above 17 on the EB indicates the presence of burden. Generally, the distribution charts of all the distress measures (see appendix) indicate that less than 10% of this sample had no experience of burden from PD caregiving. Similarly, the distribution of scores on the CESD indicates that 23% of the phase I sample and 21% of the phase II sample scored above the cutting point of 16, indicating the presence of depressive symptoms (Barnes & Prosen, 1984). Indeed 4 caregivers in phase I, and 1 in phase II scored over 30, indicating severe depression.

The change in mean score on each of the distress measures was small and not significant, but nevertheless, the changes were large enough to alter the intercorrelations of the six measures (see Table 5.2.2.2, below).

Table 5.2.2.2 Correlation matrix of the six dependent caregiver distress variables in phase II (n=56).

	BIS	EB	CESD	GHQ	LSI
BIR	.35*	.68**	.43**	.33	-.43**
BIS		.57**	.20	.24	-.28
EB			.67**	.63**	-.48**
CESD				.74**	-.30
GHQ					-.34

*p<.01 **p<.001

In phase II, the six distress measures were not all strongly related to each other, as they had been in phase I. Emotional burden alone was significantly related to each of the other distress measures; the three burden measures were significantly associated with each other, as were the two mental health outcomes. Life satisfaction was only significantly related to two of the burden measures.

This change provides some support for the idea that distress is comprised of qualitatively different domains.

5.2.3 Perceived job demand and job satisfaction

Although there was a measurable increase in objective job demand in the subjects who took part in both phases I and II, there was no longitudinal increase in caregiver distress. This led to the question of whether there was any change in *perceived* job demand between phases I and II. Paired t-tests were used to detect any longitudinal changes in carers' appraisals of job demand and job satisfaction (see Table 5.2.3.1, below).

Table 5.2.3.1 Means, SDs, and longitudinal comparison t-values of perceived job demand and job satisfaction measures (n=56).

	Phase I	*Phase II*	*t-value*	*p*
Job demand (No. of hassles)	11.21 (7.77)	11.42 (6.26)	-.31	NS
Hassles with ADL	6.09 (7.31)	6.06 (4.97)	.05	NS
Hassles with IADL	4.27 (4.86)	3.67 (3.18)	1.05	NS
Hassles with cognitive status	4.02 (5.50)	3.19 (4.20)	1.62	NS
Hassles with behaviour	3.35 (5.08)	3.25 (3.78)	.20	NS
Job satisfaction	29.52 (4.39)	30.48 (4.12)	-1.70	NS

The results above show that despite a significant increase in objective job demand, there was no change in carers' perception of job demand. There was a significant association of objective job demand (UPD) and subjective job demand (JDH), both at phase I (r= .61, p< .01) and at phase II (r= .63, p< .01). However, regressions of JDH on UPD indicated that the two variables shared just 37% variance in phase I and 39% variance in phase II, which confirms the fact that they are separate constructs (c.f. Lewis-Beck, 1980).

In line with the finding of no change in caregivers' appraisals of job demand, there was no change in carers appraisals of job satisfaction between phases I and II.

5.2.4 Patient personality

There is a large literature on Parkinsonian personality, reviewed in chapter 1. In this research, it was considered that patient personality may change following diagnosis, and that patient personality change may contribute to caregiver distress. Although retrospective measures of personality change following the diagnosis of PD were used (NEO-PI-R change, and Identity Test), it was of interest, to investigate prospectively whether there was a change in patients' self-appraised personality, and / or whether caregivers perceived a change in personality during the time course of one year. Paired t-test were used to examine this issue (see Table 5.2.4.1, below).

There was no change in patient neuroticism or openness according to the patients themselves, or their caregivers. Changes were recorded, however, for the other three personality dimensions. Whilst the patient mean for extraversion was very similar on the two testing occasions, caregivers perceived that patient extraversion had significantly diminished. Patients rated their conscientiousness significantly lower in phase II, but whilst carers' mean rating of patient conscientiousness was also slightly lower, this difference did not reach significance. Patient agreeableness also appears to have changed. However, there was no consensus between patients and caregivers with respect to how it has changed. Patients rated themselves as significantly less agreeable at phase II, whilst their carers rated them as significantly more agreeable at phase II.

Table 5.2.4.1 Means, SDs, and longitudinal comparison t-values of patient personality and perceived patient personality.

	Phase I	*Phase II*	*t-value*	*p*
Neuroticism (N) (n=54)	23.11 (10.72)	22.00 (8.36)	1.25	NS
Extraversion (E) (n=54)	21.52 (7.02)	20.89 (5.48)	.98	NS
Openness (O) (n=54)	21.78 (7.37)	20.85 (6.63)	1.42	NS
Agreeableness (A) (n=54)	34.56 (5.52)	32.81 (4.49)	2.62	p<.05
Conscientiousness (C) (n=54)	31.70 (7.41)	28.81 (7.13)	3.54	p<.01
Carers' perception of N (n=53)	20.30 (7.60)	20.00 (8.25)	.28	NS
Carers' perception of E (n=53)	22.45 (6.32)	20.09 (6.26)	3.03	p<.01
Carers' perception of O (n=53)	21.77 (4.66)	21.62 (4.73)	.25	NS
Carers' perception of A (n=53)	34.98 (5.92)	36.91 (5.09)	-2.50	p<.05
Carers' perception of C (n=53)	32.23 (7.95)	30.81 (7.94)	1.74	NS

5.2.5 Patient depression

As outlined in chapter one, depression is a common occurrence in PD patients. A paired t-test was used to investigate whether there was a measurable change in patient depression between phase I, where the mean GDS score was 11.55 (5.83) and phase II where the mean GDS score was slightly higher at 12.04 (5.28). The analysis indicated that there was no longitudinal change in patient depression: t = -1.05, p > .05.

The mean GDS scores for both phase 1 and phase II, indicated that the average level of depression for this sample of PD patients was mildly depressed. 38% of the patients on both sampling occasions scored 0-10 on the GDS, which is classified as normal (McDowell & Newell, 1996); 53.5% in phase I and 56.5% in phase II scored 11-20, which indicates mild depression. 8.5% in phase I and 5.5% scored over 20 in phase II, and therefore should be classified as moderate to severely demented, according to McDowell & Newell's criteria.

The figures above indicate that patient depression is a feature for about two-thirds of this caregiving sample.

5.2.6 Cognitive Change

Several neuropsychological measures were taken from patients. Some of these were repeated at phase II. It was noted above that there was a decrease in general cognitive status at phase II, so it was of interest to see if there was a significant decline in word and face recognition between phases I and II. The NART and the Mill Hill were also repeated longitudinally.

As shown in Table 5.2.6.1, below, when paired t-tested were used to compare the same subjects there was no difference in patients' performance on any of these neuropsychological tests between phases I and II.

Table 5.2.6.1 Means, SDs, and longitudinal comparison t-values of patient neuropsychological tests.

	Phase I	*Phase II*	*t-value*	*p*
NART (errors) (n = 54)	18.67 (9.54)	19.59 (10.48)	-1.01	NS
Mill Hill (n = 51)	29.35 (6.01)	30.21 (4.59)	-1.26	NS
WRM Words (n = 37)	41.98 (5.79)	42.40 (5.60)	-.53	NS
WRM Faces (n = 34)	36.76 (5.60)	36.62 (6.15)	.15	NS

The lack of change on face recognition memory was unexpected as the mean score clearly shows that the PD patients are impaired on this test. Indeed, the mean score of this PD sample was below that of a previous sample of PD patients shown to be impaired on face recognition when compared to normal age-matched controls (Dewick *et al.*, 1991). In Dewick *et al.* sample, the PD patient mean was 37.8 (4.2), as compared to the control performance of 45.0 (3.5). Diesfeldt & Vink (1989) give norms for recognition memory for words and faces in the very old. Their mean for WRM faces for those aged 69-79 (the mean age of this sample being 73.95) was

41.8 (2.7). Even using the lower Diesfeldt & Vink age-related norms, this PD sample is impaired.

The lack of change in impaired performance suggests that this impairment may occur quite early in the disease process. To investigate this, a one-way ANOVA was used to compare performance on this test according to severity of illness. The patient sample was divided into three groups, *mild*, *moderate* and *advanced* as reported above (see Table 5.2.6.2, below).

Table 5.2.6.2 Means, SDs, and comparison F-values of WRM face recognition according to severity of Parkinson's disease.

	Severity of Illness				
	mild	moderate	advanced	F-value	*p*
Phase I	n = 8	n = 18	n = 19		
Phase II	n = 3	n = 20	n = 12		
WRM faces: phase I	36.63 (6.86)	35.77 (4.15)	36.00 (6.55)	.06	NS
WRM faces: phase II	40.33 (3.21)	35.30 (5.09)	37.67 (7.70)	1.22	NS

The results above show that performance is impaired at all levels of severity, and that there is no difference between the three groups at phase I or phase II. These results support previous suggestions that face processing is impaired in PD, and in addition, provide tentative evidence that this cognitive impairment occurs early in the disease process.

5.2.7 Summary

Parkinson's disease is a progressive illness, and this leads to the need for change in the course of caregiving. In the 12-months period between phase I and phase II, however, there were no changes in distress levels in carers. This was despite a significant increase in severity of illness, a decrease in cognitive capacity and specific changes in patient personality. Although there were longitudinal changes in objective job demand, as measured by severity of illness, there was no difference in the caregiver's subjective job demand measure between phases I and II. This discrepancy suggests that although many variables were significantly associated with distress at phase 1, some variables are more important for the prediction of distress than others.

5.3 Patient Variables and Caregiver Distress

There was no difference in caregiver levels of distress at phase II, so it would be expected that as there had been a significant progression of PD, that replication of the significant associations of distress and patient variables should be replicated in phase II. Table 5.3.1, below, sets out the relationships between potential patient predictor variables and the dependent caregiver distress variables. All these data were collected during phase II testing.

One thing that is immediately clear is that the relationships between the independent patient variables and the dependent caregiver distress that existed at phase I (see Table 4.2.1, p 173) were not systematically replicated. The most striking observation is that there were far fewer significant relationships from the phase II data, although most of the strong significant associations of patient predictor variables and caregiving outcomes are in fact of greater magnitude than in phase I.

Table 5.3.1 Correlations of patient variables and caregiver distress measures at follow-up (n=56).

	Dependent Caregiver Distress Variables					
	BIR	BIS	EB	CES D	GHQ	LSI
Duration of illness	.23	.34	.28	.23	.17	-.17
Severity of illness (UPD)	.22	.60**	.47**	.25	.19	-.38*
Hoehn & Yahr disease stage	.31	.61**	.42**	.22	.16	-.32
Activities of daily living	-.31	-.51**	-.40*	-.14	-.21	.23
Depression (GDS)	.54**	.16	.33	.13	.12	-.33
Patient neuroticism (n=51)	.45**	.24	.24	.21	.17	-.18
Patient extraversion (n=51)	-.20	-.10	-.09	.06	-.07	.48**
Patient openness (n=51)	.18	.36	.14	.03	.03	-.00
Patient agreeableness (n=51)	-.07	-.02	-.23	-.14	-.26	-.06
Patient conscientiousness(n=51)	-.22	-.17	-.17	.06	-.05	.36*
Mental status	-.33	-.40*	-.47**	-.23	-.17	.31
Coloured RPM (n=30)	.08	.07	.04	-.02	.12	-.22
Verbal intelligence	.15	.07	.05	-.03	.05	-.04
RPM: words (n=35)	-.42*	.03	-.17	-.19	-.12	.28
RPM: faces (n=35)	-.21	.10	-.17	.13	.24	.25
Cognitive demand (n=34)	.51*	.34	.56**	.27	.12	-.40
Age	-.06	.03	-.17	-.22	-.00	.08
Age of Onset	-.16	-.14	-.28	-.29	-.07	.14

* p<.01 **p<.001 (two-tailed)

The relationship between severity of illness and impact on social life, for instance, increased from a highly significant .40 in phase I to .60 in phase II. Similarly, the correlation coefficient between patient depression and impact on relationship went up from .41 to .51 the association between cognitive demand and emotional burden grew from .49 to .56. But several previously highly significant relationships disappeared. Most notably, in phase II there was no relationship between duration of illness and caregiving outcomes.

In the follow-up, severity of illness was found to have a much more selective effect on caregiver distress. There was a very strong association of impact on social life and severity of illness, as measured by not only UPD motor examination scores, but also by Hoehn & Yahr disease stage and activities of daily living. These three measures of patient disability also had a strong relationship with emotional burden, but no relationship with impact on relationship, caregiver depression or psychological health. Severity of illness was also associated with low life satisfaction.

With respect to patient personality, there were strong positive relationships between life satisfaction and patient extraversion and conscientiousness. There was also a strong association of impact on relationship and patient neuroticism. No other aspect of patient personality was associated with caregiver distress. Patient depression also was strongly related to impact on relationship, but no other aspect of distress. (There was, incidentally, also a very strong relationship between patient neuroticism and patient depression: they share 57% variance, suggesting that these two measures have considerable overlap).

Patient mental status, as measured by MMSE scores, was significantly related to emotional burden and impact on social life. Cognitive demand, as measured by multiplying standardised MMSE error scores and standardised Raven’s matrices error scores (c.f. pp. 144-5), was strongly related to emotional burden and impact on relationship, such that higher cognitive demand was associated with greater burden.

Word recognition memory was significantly associated with impact on relationship. The negative correlation indicates that poorer performance by patients on this memory test was associated with a negative effect on the dyadic relationship. There were no other associations between patient neuropsychological performance and caregiver distress. This result was unexpected as word recognition memory was not as impaired as face recognition, and not significantly different from the Diesfeldt

& Vink (1989) older sample mean of 44.3 (4.3)[5]. However, the mean age of this PD sample who completed the WRM tests was 74.05 years. The mean age of the Diesfeldt & Vink sample who were tested for word recognition was 79.5 years. A t-test for a difference between a sample mean and a population mean indicated that this difference was significant (t = 5.19, p<.01). There was a significant difference between Dewick *et al.'s* (1991) control sample mean of 45.8 (3.9), and this PD sample on word recognition (t = -3.40, p<.01), but again there was also a significant difference between the two samples with respect to age (t = 2.94, p<.01); this PD sample was significantly older. Essentially, then, it is not clear whether the PD patients' performance at phase II was impaired or not. That is, the finding that there was a significant association between word recognition and impact on relation is not easily understood from the point of view that a clear impairment in word recognition was not demonstrated.

To summarise, the strongest patient predictors of caregiver distress from phase II data remained physical severity of PD and cognitive demand. However, this was not true for all components of distress. Whilst patient variables continued to provide strong predictors of burden and life satisfaction, there were no patient predictors of mental health outcomes. In phase II, even severity of illness was not associated with caregiver depression or caregiver psychological health. Of importance to modelling caregiver distress, this suggests that there may be disease specific outcome variables, and non-specific outcome variables.

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[5] It is acknowledged that Diesfeldt & Vink's sample were Dutch and were given Dutch words. Therefore, this may not be a good comparison, but the authors published in English and suggested their results were generalisable.

5.3.1 Severity of illness and caregiver distress

Severity of illness was positively related to three of the distress measures at follow-up. The finding that greater physical severity of illness has a significant impact on social life and is significantly related to emotional burden and lower life satisfaction was replicated. At follow-up, however, the associations between severity of illness and impact on relationship and carer depression were weaker and failed to reach significance. The finding that severity of illness has no effect on caregiver psychological health was replicated.

Three caregiver distress measures were consistently influenced by severity of PD. In chapter 4, it was shown that phase I distress increased alongside the increase in severity of illness. It was important that this was also seen to be the case in phase II. The sample was similarly divided into three groups based on their phase II UPD motor examination score: *mild* (<10; *n* = 3), *moderate* (10-24; *n* = 29) and *advanced* (25+; *n* = 24). One-way ANOVAs were used to investigate whether caregiver social life, emotional burden and life satisfaction were systematically affected by the progression of severity of illness (see table 5.3.1.1, below).

These results clearly demonstrate that as the severity of PD increased, the impact on social life and emotional burden also increased, and life satisfaction decreased. Post-hoc Scheffé comparisons indicated that the difference between the mild and advanced groups and the moderate and advanced groups was significant for all three measures.

Table 5.3.1.1 Means, SDs, and comparison F-values of caregiving outcomes according to severity of Parkinson's disease.

Caregiver outcome variables:	Severity of Illness mild	 moderate	 advanced	F-value	*p*
Impact on Social Life	1.00 (1.73)	5.20 (4.78)	12.33 (7.20)	11.89	p<.01
Emotional Burden	20.66 (6.35)	24.20 (5.94)	30.50 (6.53)	8.22	p<.01
Life Satisfaction	10.33 (1.15)	9.14 (1.77)	6.91 (2.45)	9.02	p<.01

5.4 Caregiver Variables and Caregiver Distress

As described in section 5.2 above, there were no longitudinal differences in caregiver distress measures or in perceived job demand. Following from this, it was expected that perceived job demand would remain an important predictor of caregiver distress in phase II. The role of perceived job demand in caregiving outcomes was investigated further with the inclusion in phase II of a quantitative measure of job discretion, and a computed strain variable, which accounts for the combined effects of job demand and job discretion, which Karasek (1979) argued was a better predictor of (occupational) job stress. Four additional caregiver personality variables were also included in phase II. They are presented here with the phase I NEO-FFI assessments. As normal personality is assumed to be stable (Gross, 1987), the caregiver personality measures collected during phase I were not repeated. Similarly, caregiver coping strategies were presumed to be situation specific (Anshel & Kaissidis, 1997) and the situation was still PD caregiving, so again, the data collected at phase I was taken to be relevant at phase II.

Table 5.4.1 below sets out the correlations between potential caregiver predictor variables collected in phase II and the follow-up caregiver distress measures.

Table 5.4.1 Correlations of caregiver variables and caregiver distress at phase II (n=56).

	Dependent Caregiver Distress Variables					
	BIR	BIS	EB	CESD	GHQ	LSI
No. of hours caregiving	.12	.34	.36	.25	.13	-.17
Job demand (No. of hassles)	.49**	.46**	.57**	.30	.39*	-.39*
Hassles with ADL	.53**	.43**	.52**	.28	.36*	-.46**
Hassles with IADL	.44**	.30	.42**	.30	.27	-.47**
Hassles with cognitive status	.51**	.22	.50**	.20	.15	-.35*
Hassles with patient’s behaviour	.55**	.38	.54**	.28	.23	-.31
Job satisfaction	-.42*	-.09	-.30	-.04	.11	.24
Job discretion	-.44*	-.40*	-.50**	-.25	.24	.29
Job strain	.49**	.48**	.60**	.32	.32	-.36
Caregiver neuroticism	.39*	.27	.62**	.64**	.62**	-.33
Caregiver extraversion	-.21	-.15	-.09	-.02	-.01	.00
Caregiver openness	-.02	.09	-.01	.04	.05	.07
Caregiver agreeableness	-.03	.06	-.15	-.22	-.07	.05
Caregiver conscientiousness	.01	.15	-.05	.02	-.01	-.09
Optimism	-.48**	-.19	-.46**	-.37*	-.23	.30
Hardiness: challenge	.22	-.03	.06	.10	.14	-.07
Hardiness: commitment	.41*	.19	.45**	.36*	.18	-.15
Hardiness: control	.50**	.21	.44**	.30	.25	-.32
Communal orientation	-.03	.27	.18	.15	.25	-.25
Perception of P. neuroticism	.42**	.05	.22	.28	.19	-.14
Perception of P. extraversion	-.33	-.29	-.37*	-.16	-.16	.36
Perception of P. openness	.22	.14	.02	.20	-.01	-.02
Perception of P. agreeableness	-.41*	-.14	-.25	-.05	.10	-.06
Pecept. of P. conscientiousness	-.53**	-.21	-.41*	-.20	-.30	.35
Task-oriented coping style	-.04	.18	.21	.26	.24	-.20
Emotion-oriented coping style	.33	.42*	.57**	.41*	.47**	-.29
Avoidance coping style	.16	.10	.21	.29	.28	.09
Index of social support	-.36*	-.07	-.19	-.24	.05	.17
Satisfaction with social support	-.43**	-.20	-.29	-.08	-.02	.16
Health status	-.04	-.15	.06	.11	.15	.10
Gender[a]	-.31	-.15	-.33	-.26	-.31	.37*
Age	-.31	-.09	-.28	-.16	-.00	.03

* p<.01 **p<.001 (two-tailed) [a] 0 = female 1 = male

Within the correlation matrix there are many replications of the phase I data, but it is clear that not all relationships that were significant at phase I were also significant at phase two. One obvious illustration of this is the lack of association between the number of hours caregiving and burden at follow-up. Most of the correlation coefficients were lower, with respect to these two variables, at phase II, however, the correlation coefficient of number of hours caregiving and emotional burden was virtually the same at phase I and phase II (.37 and .36 respectively). The smaller sample size of phase II effectively made the alpha level of significance of .01, more stringent. This had the effect of demanding stronger relationships between any pair of variables for the association to be acknowledged as significant, and perhaps introduced the risk of Type II errors. However, it was determined that this was preferable to overstating the case. Certainly a stringent level of significance had the effect of identifying the most pertinent predictors of caregiver distress.

5.4.1 Perceived job demand and caregiver distress

In phase two the strong association of perceived job demand, and negative outcomes was replicated for five of the six burden measures. At follow-up, however, there was no relationship between caregiver depression and job demand, even when all the components of demand were separately considered.

When the separate types of hassle were considered, then demand from activities of daily living (ADL) was also positively associated with the three burden measures, psychological health consequences and low life satisfaction. That is, high perceived demand from ADL predicted greater distress. Similarly, high demand from instrumental ADL and cognitive status predicted a negative impact on relationship, emotional burden, and low life satisfaction. High demand from the PD patients behaviour predicted emotional burden and a negative impact on the dyadic relationship.

To summarise, caregiver’s assessments of job demand indicated that all the components of demand serve to predict emotional burden and an impact on the dyadic relationship. This was the case at phase I, and it was replicated at phase two. There were also additional significant negative effects on carers according to type of demand. Collectively, higher job demand was associated with greater impact on relationship, greater impact on social life, greater emotional burden, worse psychological health and lower life satisfaction. Again, this was the case at both phase I and phase II.

5.4.2 Job strain and caregiver distress

Karasek (1979) argued that discretion was as important to the stress process as job demand. Phase II data indicated that low job discretion was a strong predictor of caregiving burden. Like job demand, discretion had no relation to caregiver depression. Following Karasek, it was hypothesised that caregiver distress would be directly related to the interaction of job demand and job discretion, as measured by the computed strain variable. This was only partly supported: as seen in table 5.4.1, above, job strain was strongly associated with the three burden measures, but not with mental health outcomes or life satisfaction.

An additional *a priori* hypothesis was that low strain would be associated with low levels of distress, and high strain would be associated with high levels of distress. To test if this was the case for the burden measures which were significantly related to job strain, an analysis of the frequency of the strain indices was used to divide the sample into three groups: *low strain* (<2.00; *n* = 16), *medium* *strain* (2.00 - 4.35; *n* = 15) and *high strain* (4.36 +; n=15). One-way analyses of variance were used to investigate whether levels of burden increased as the level of strain increased (see table 5.4.2.1, below).

Table 5.4.2.1 Means, SDs, and comparison F-values of caregiver outcome according to job strain.

Caregiver outcome variables:	low	Job Strain medium	high	F-value	*p*
Impact on Relationship	3.13 (2.53)	5.80 (4.33)	8.00 (5.12)	5.67	p<.01
Impact on Social Life	4.38 (4.90)	5.73 (4.28)	13.29 (7.51)	11.30	p<.001
Emotional Burden	21.88 (4.35)	24.73 (5.40)	31.76 (4.82)	18.14	p<.001

These results clearly show that burden scores increase as levels of job strain increase. Post-hoc Scheffé tests indicated that there was a significant difference in impact on relationship between the low strain group and the high strain group; and there was a significant difference between the low and the high strain groups and the medium and high strain groups on impact on social life and emotional burden. Although this analysis was restricted to the burden measures, the hypothesis that levels of distress increase with level of strain was supported.

The Karasek theory argues that *strain* should predict outcomes, rather than demand or decision latitude (discretion). Using the computed strain variable (Theorell *et al.,* 1988), rather than using median splits to provide high and low groups for demand and discretion (Orbell & Gillies, 1993) offers two advantages: (i) it avoids the problem of poor distribution between categories, and (ii) it presents a subject variable which can be entered into regression analyses.

To investigate whether Karasek's theory was true for all aspects of distress, stepwise regressions were performed where the six distress measures were used separately as the dependent variable, and perceived job demand (JDH), job discretion (JDS) and STRAIN were independent variables (*n* = 48). The alpha level of significance for entry into the equation was set at 0.05.

1. Impact on Relationship

Variables entered on step 1: STRAIN
Multiple R = .49, R square = .24, Adjusted R square = .22, Standard Error = 4.02
F = 14.26 *p* < .001

Variables in the Equation

Variable	B	SE B	Beta	T	*p*
STRAIN	.96	.26	.49	3.78	<.001
(Constant)	2.32	1.06		2.18	.034

Variables not in the Equation

Variable	Beta In	Partial	Min. Tolerance	T	*p*
JDH	.02	.01	.20	.07	NS
JDS	-.17	-.12	.41	-.83	NS

2. Impact on Social Life

Variables entered on step 1: STRAIN
Multiple R = .48, R square = .23, Adjusted R square = .21, Standard Error = 6.18
F = 13.72 *p* < .001

Variables in the Equation

Variable	B	SE B	Beta	T	*p*
STRAIN	1.45	.39	.48	3.70	<.001
(Constant)	2.88	1.63		1.76	.084

Variables not in the Equation

Variable	Beta In	Partial	Min. Tolerance	T	*p*
JDH	-.09	-.05	.20	-.31	NS
JDS	-.09	-.06	.41	-.42	NS

3. Emotional Burden

Variables entered on step 1: STRAIN
Multiple R = .60, R square = .37, Adjusted R square = .35, Standard Error = 5.15
F = 26.55 *p* < .001

Variables in the Equation

Variable	B	SE B	Beta	T	*p*
STRAIN	1.68	.33	.60	5.15	<.001
(Constant)	20.39	1.36		14.99	.000

Variables not in the Equation

Variable	Beta In	Partial	Min. Tolerance	T	*p*
JDH	.23	.13	.20	.87	NS
JDS	-.08	-.06	.41	-.43	NS

4. Caregiver Depression

Variables entered on step 1: STRAIN

Multiple R = .32, R square = .10, Adjusted R square = .08, Standard Error = 7.49

F = 5.18 *p* < .05

Variables in the Equation

Variable	B	SE B	Beta	T	*p*
STRAIN	1.08	.48	.32	2.28	<.05
(Constant)	6.49	1.98		3.27	.002

Variables not in the Equation

Variable	Beta In	Partial	Min. Tolerance	T	*p*
JDH	.08	.04	.20	.24	NS
JDS	-.01	-.01	.41	-.04	NS

5. Psychological Health

Variables entered on step 1: Job Demand (JDH)

Multiple R = .39, R square = .15, Adjusted R square = .13, Standard Error = 3.66

F = 8.03 *p* < .01

Variables in the Equation

Variable	B	SE B	Beta	T	*p*
JDH	.24	.08	.39	2.83	<.01
(Constant)	7.72	1.11		6.97	.000

Variables not in the Equation

Variable	Beta In	Partial	Min. Tolerance	T	*p*
JDS	-.07	-.06	.76	-.43	NS
STRAIN	-.13	-.07	.20	-.45	NS

6. Life Satisfaction

Variables entered on step 1: Job Demand (JDH)

Multiple R = .39, R square = .15, Adjusted R square = .13, Standard Error = 2.23

F = 7.97 *p* < .01

Variables in the Equation

Variable	B	SE B	Beta	T	*p*
JDH	-.15	.05	-.39	-2.82	<.01
(Constant)	10.05	.69		14.60	.000

Variables not in the Equation

Variable	Beta In	Partial	Min. Tolerance	T	*p*
JDS	.14	.13	.76	.86	NS
STRAIN	-.05	-.03	.21	-.20	NS

The results of the stepwise multiple regressions show that the computed variable strain is a better predictor of caregiver burden and depression, than job demand or job discretion, indeed the latter variables were not significant predictors of burden or depression after the variance provided by strain was accounted for. With respect to psychological health and life satisfaction, however, job demand was the only significant variable of the three potential predictors. These results indicate that Karasek’s theory of work stress is applicable to informal caregiving to PD patients with respect to burden and depression, but not to all aspects of distress. Perceived job demand was the only significant predictor of psychological health and life satisfaction when demand, discretion and strain were entered into a stepwise regression.

5.4.3 Caregiver personality, coping style and caregiver distress

Table 5.4.1 (p. 227) shows that the strong relationship between caregiver neuroticism and distress found in phase I was replicated in phase II. The lack of association of neuroticism and impact on social life was replicated as well as the positive relationship of neuroticism and depression, emotional burden, impact on relationship and poor psychological health. In phase II, however, the correlation coefficient of neuroticism and life satisfaction failed to reach significance.

In phase II there was no relationship between caregiver distress and the other NEO personality dimensions, which, again is a virtual replication of the phase I data. There was a significant relationship between life satisfaction and caregiver agreeableness in phase I, but this was not evident in phase II.

Similarly, optimism was negatively related to impact on relationship, depression, emotional burden, and poor psychological health, and not to impact on social life, as in phase I. The correlation coefficient between optimism and life satisfaction was almost identical at phase I and phase II, but in the follow-up, this was not large enough for significance.

In phase II, an emotion-focused coping style was positively associated with emotional burden, depression and poor psychological health, as in phase I. In phase

II, an emotion-focused coping style was also positively associated with an impact on social life, but not to impact on relationship and life satisfaction. Avoidance coping and task-oriented coping had no relationship at all to PD caregiver distress, replicating the findings of phase I.

In phase II, it was considered that dispositional hardiness and communal orientation have an effect on caregiving outcomes. However, as seen in table 5.4.1, communal orientation was not associated with any of the dependent caregiver distress measures; the same was true of the challenge subscale of the Hardiness Questionnaire (Bartone *et al.*, 1989). Control was positively related to impact on relationship and emotional burden, and commitment was positively related to impact on relationship, emotional burden and also to depression. These associations indicate that greater hardiness in commitment and control was associated with lower levels of these distress measures.

5.4.4 Patient personality and caregiver distress

Caregivers' perception of patient personality had a weaker influence on distress in phase II. Only impact on relationship (BIR) and emotional burden (EB) were affected. Carers' appraisals of (i) patient neuroticism was positively related to BIR, (ii) patient extraversion was negatively related to EB, (iii) patient agreeableness was negatively related to BIR (iv) and patient conscientiousness was negatively associated with BIR. Essentially all these significant relationships were replications of the phase I analyses, but the effect of carers' appraisals of patient personality on life satisfaction paled into insignificance in phase II. The phase I finding that patient openness had no effect on caregiving outcomes was replicated in phase II.

5.4.5 Summary

PD caregivers' perceptions of job demand was consistently related to all the distress measures except depression. Greater demand was associated with greater burden. However, the use of multiple regression analyses indicated that the interaction of demand and discretion measure - job strain - was a better predictor of the three burden measures.

Strong associations with caregiver depression were only found with caregiver personality variables. The particularly strong association between caregiver neuroticism and depression seen in phase I was seen again in phase II. Optimism and emotion-focused coping remained other important caregiver predictors. Whereas social support had no effect on caregiver distress in phase I, in phase II it was found that lower levels of social support, and lower satisfaction with social support were both significantly associated with a greater impact on relationship. Caregiver age and health status had no effect on outcomes, and the association of gender and depression was not replicated. In phase II, gender was significantly associated with life satisfaction; male carers had significantly greater life satisfaction than female carers of PD patients.

5.5 Dyadic Relationship and Caregiver Distress

In phase II, the present dyadic relationship and its association with caregiver distress was investigated using the seven subscales of the FAMIII (Skinner *et al.,* 1995). This questionnaire provided a means of differentiating which aspects of the dyadic relationship were relevant to caregiving outcomes. The premorbid relationship was seen to be an important predictor of distress in phase I, so the two measures used in the first phase of testing, dyadic adjustment and happiness were considered again with the dependent caregiver distress variables in phase II. Two-tailed bi-variate correlations were carried out on all these variables; the correlation coefficients are presented in table 5.5.1 below.

The results show that the component of distress most vulnerable to dyadic relationship variables, was impact on relationship. The premorbid relationship, premorbid happiness, and current task accomplishment, role performance, communication and involvement were all associated with impact on relationship such that problems in these areas were significantly related to this burden measure. Problems in the premorbid relationship, premorbid happiness, task accomplishment and role performance were also strongly related to emotional burden. A low level of premorbid happiness was also associated with low life satisfaction.

These results also revealed that dyadic control, values and norms and affective expression had no bearing on the outcomes of this sample of caregivers.

Table 5.5.1 Correlations of dyadic relationship and caregiver distress at phase II (n=56)

	Dependent Caregiver Distress Variables					
	BIR	BIS	EB	CESD	GHQ	LSI
Premorbid dyadic relationship	-.52**	-.30	-.52**	-.28	-.15	.30
Premorbid happiness	-.43**	-.20	-.43**	-.26	-.21	.47**
Task accomplishment	.51**	.16	.45**	.19	.21	-.26
Role performance	.46**	.28	.45**	.21	.18	-.19
Communication	.35*	.07	.22	.04	.06	-.01
Control	.14	-.02	.06	-.04	-.05	.07
Involvement	.43**	.16	.24	.25	.19	-.13
Values and Norms	.16	-.08	.05	.08	-.15	-.08
Affective Expression	.32	.12	.19	.19	.07	-.27

* p<.01 **p<.001

5.6 Moderators of PD caregiver distress

In the hypothesised model of Parkinson's disease caregiving (p. 132), it was assumed that the specified caregiver variables would have a direct effect on caregiver distress. As illustrated in tables 4.3.1 and 5.4.1, however, some carer variables had no direct influence on caregiving outcomes at all. Nevertheless, it is feasible that these variables had an indirect effect on outcomes by moderating the relationship between other pairs of independent and dependent variables. For instance, although some studies have found social support to be a powerful predictor of caregiver burden (e.g. Zarit *et al.*, 1980), it has also been realised as a powerful mediator in stressful situation, including those associated with caregiving (Pearlin *et al.*, 1990). In this study social support did not consistently predict outcomes, but it is possible that social support exerted an effect as a moderating variable. A similar case could be made for gender, communal orientation, and dispositional hardiness. It has been also suggested that coping strategies serve as moderator variables in the caregiver distress process (Pearlin *et al.*, 1990; Saad *et al.*, 1995), although Pruchno & Resch (1989b) argued that coping style is not a moderator of the stressor-outcome relationship, but it can have a direct effect on outcomes. In this study there have been consistently strong associations of emotion-focused coping and caregiver distress, indicating that the characteristic manner in which carers deal emotionally with the (illness) situation is a direct predictor of outcomes. Nevertheless, this does not rule out the possibility that coping style also serves as a moderator. This was investigated in this study of PD caregiving.

To ascertain whether coping style, social support, gender, communal orientation and dispositional hardiness acted as moderator variables, a series of partial correlation analyses was performed between independent and dependent caregiver variables controlling for the potential moderators. If the strength of the relationship between a predictor variable and an outcome was strengthened or attenuated, then it was assumed that some form of intervention had occurred.

Following Cohen & Cohen (1983), it was determined that if a resultant correlation coefficient between a predictor and a dependent variable was notably *reduced* when a potential moderator was controlled for, then that variable must have served as a moderator in the initial bi-variate correlation analyses. That is, the intervening variable enhanced the predictability of a particular criterion. If a resultant correlation coefficient between a predictor and a dependent variable was notably *increased* when a potential moderator variable(s) was controlled for in the equation, then that variable must have served as a suppressor in the initial bi-variate correlation analyses. The intervening variable served to hide or suppress the real relationship between predictor and outcome variables.

5.6.1 Caregiver Gender

There was evidence that gender served both as a selective moderator variable and as a suppressor variable. For example, the non-significant correlation coefficient of r = .30 between perceived job demand (JDH) and carer depression (CESD) was raised to a highly significant r = .45**[6] when gender was controlled for, indicating that gender was suppressing the effects of job demand on depression. Gender was also found to similarly suppress the associations of hassles with ADL and depression (.28 → .45**), hassles with patient's behaviour and depression (.28 → .39*), job discretion and depression (.25 → .45**), and job strain and depression (.32 → .45**). Gender also served as a powerful moderator of predictors and outcomes. For

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[6] Throughout this section * is used to indicate p<.01, and **that p<.001.

example, the highly significant bi-variate correlation coefficient of carers' perception of patient's conscientiousness of -.41, was reduced to a nonsignificant -.31 when gender was controlled for. Similar moderating effects of gender were seen in the associations of impact of relationship and patient change on the unhappy-happy (-.33* → -.22), in control-helpless (-.36* → -.26), skilful-clumsy (-.37* → -.30), independent-dependent (-.33* → -.20), and difficult-co-operative (-.40** → -.31) personality dimensions, and in associations of emotional burden and both in control-helpless (-.38* → -.31) and talkative-withdrawn (-.42** → -.33) personality dimensions, JDH and GHQ (.39* → .31), and hassles with ADL and GHQ (.36* → .27).

To summarise, caregiver gender was found to act as both a moderator and a suppressor of caregiving outcomes, despite its weak direct effect on caregiver distress.

5.6.2 Social Support

There was evidence that social support also served both as a selective moderator variable and as a suppressor variable. Moderating effects were found when index of social support and satisfaction with social support were controlled for in the equations of job discretion and impact on relationship (-.44* → -.33), patient change on the active-inactive personality dimension and depression (-.35* → -.30), carers' perception of patient neuroticism and impact on relationship (.42** → .30), carers' perception of patient extraversion and emotional burden (-.37* → -.24), and carers' perception of patient conscientiousness and emotional burden (-.41** → -.31).

Suppressing effects of social support were found in the associations of job demand and depression (.30 → .47**), hassles with ADL and depression (.28 →.

49**), hassles with IADL and depression (.30 → .39*), hassles with patient's behaviour and depression (.28 → .39*), job strain and depression (.32 → .41*) and carers' perception of patient conscientiousness and depression (-.20 → -.37*). Suppressing effects of social support were also found in the dyadic relationship and its association with caregiver distress. Specifically, it was found that the relationship between affective expression and impact on relationship had been suppressed, for when social support was controlled for the correlation coefficient rose from an insignificant .32 to a significant .38.

To summarise, social support was found to be a convincing suppressor of caregiver depression. Social support was also seen to moderate several caregiver predictor-outcome relationships.

5.6.3 Coping Style

To ascertain whether carer's coping style moderates caregiving outcomes, the three coping strategies measured in this research - task-oriented, emotion-focused and avoidance - were together controlled in a series of predictor-outcome relational analyses. Evidence that coping strategies were moderating outcomes was found when coping style was controlled for in the following equations: neuroticism and impact on relationship (BIR; .39* → .30), optimism and emotional burden (EB; -.46** → -.33), job demand and poor psychological health (GHQ; .39*→.30), job demand and low life satisfaction (LSI; .39*→ .30), patient change on unhappy-happy dimension and BIR (-.33* → -.14), EB (-.42** → -.24), CESD (-.44**→ -.33), patient change on in control-helpless dimension and BIR (-.36* → -.18), EB (-.38* → -.08), CESD (-.36* → -.17), patient change on lack confidence-confident dimension and BIR (-.44** → -.29), EB (-.51** → -.38*), GHQ (-.38* → -.26), patient change on irritable-calm dimension and EB (-.39* → -.18), patient change on independent-dependent dimension and BIR (-.33* → -.24), patient change on difficult-co-operative dimension and BIR (-.40** → -.27), EB (-.48** → -.31), CESD (-.41** → -.32), GHQ (-.41** → .30) and LSI (.37* → .30), patient change on talkative-withdrawn dimension and BIR (-.42* → -.18), EB (-.42** → -.15), CESD (-.35** → -.13), carers' perception of patient extraversion and EB (-.37* → -.25), carers' perception of patient conscientiousness and EB (-.41* → -.28), and current dyadic happiness and emotional burden (-.52** → -.33).

There were also significant predictor-outcome relationships which were suppressed by coping style. These include job demand and depression (.30 → .41*), hassles with ADL and depression (.28 → .44*), hassles with IADL and depression (.30 → .39*), job strain and depression (.32 → .41*) and patient change on friendly-unfriendly dimension and depression (-.29 → -.38*).

These results clearly indicate that coping style should be regarded as a moderator variable as well as a direct predictor of burden.

5.6.4 Dispositional Hardiness

There was evidence that dispositional hardiness also served as a selective moderator variable and as a suppressor variable. When the three hardiness subscales were controlled for, it could be seen that they moderated the following equations: optimism and BIR (-.48** → -.39), EB (-.46** → -.26), CESD (-.37* → -.32), job demand and both GHQ (.39* → .30) and LSI (.39* → .30), hassles with ADL and GHQ (.36* → .26), hassles with IADL and EB (.42** → .24), job discretion and BIR (-.44** → -.29), job strain and BIR (.49** → .38), patient change on bored-interested dimension and CESD (-.49** → -.36), patient change on unhappy-happy dimension and BIR (-.33* → -.23), patient change on in control-helpless dimension and BIR (-.36* → -.24), patient change on lack confidence-confident dimension and BIR (-.44** → -.31), CESD (-.45** → -.35), patient change on skilful-clumsy dimension and BIR (-.37* → -.17) and BIS (-.35* → -.25), patient change on independent-dependent dimension and BIR (-.33* → -.18), patient change on active-inactive dimension and BIR (-.45** → -.20), BIS (-.43** → -.33), EB (-.46**→ -.26) and CESD (-.35* → -.08), patient change on difficult-co-operative dimension and BIR (-.40** → -.17), EB (-.48** → -.31, CESD (-.41** → -.31), and LSI (.37* → .26), carers' perception of patient extraversion and EB (-.37* → -.25), and carers' perception of patient conscientiousness and EB (-.41* → -.28). With respect to dyadic relationship and distress associations, hardiness was found to moderate current dyadic happiness and BIR (-.43** → -.18), EB (-.43** → -.18) and CESD (-.28 → .04), task accomplishment and BIR (.51** → .26) and EB (.45** → .19), role performance and BIR (.46** → .29) and EB (.45** → .28), communication and BIR (.35* → .08) and EB (.22 → -.04) and involvement and BIR (.43** → .27).

Hardiness was also seen to suppress the associations of patient change on the worthless-of value dimension and BIR (-.32 → -.45*) and BIS (-.32 → -.41*).

These results indicate that hardiness is a powerful moderator of caregiving outcomes, and it was seen that two predictor-outcome relationships were also suppressed by hardiness.

5.6.5 Communal Orientation

It was hypothesised that communal orientation, as a stable dispositional trait (Clark *et al.* 1987) would moderate predictor-outcome associations. This hypothesis was supported.

Communal orientation was found to suppress the relationships between depression and job demand (.30 → .48**), hassles with ADL (.28 → .50**), hassles with IADL (.30 → .39*), hassles with patient's behaviour (.28 → .40*), job discretion (-.25 → -.37*), strain (.32 → .44*) and carers' perception of patient conscientiousness (-.20 → -.43*). Communal orientation was also found to be an important suppressor of negative outcomes from patient personality change. Marked suppression was found in the association of patient change on the attractive-unattractive dimension and CESD (-.14 → -.37*), EB (-.23 → -.43*) and BIS (-.30 → -.41*); patient change on the hopeful-despondent dimension and BIR (-.28 → -.40*), EB (-.28 → -.49**), CESD (-.29 → -.41*) and LSI (.30 → .40*); patient change on the worthless-of value dimension and BIR (-.32 → -.52**), BIS (-.32 → -.44*) and EB (-.26 → -.46*); patient change on the talkative-withdrawn dimension and CESD (-.35* → -.50**) and GHQ (-.21 → -.46*); and patient change on the friendly-unfriendly dimension and BIR (-.27 → -.43*), EB (-.21 → -.46*), CESD (-.29 → -.40*) and LSI (.26 → .37).

Communal orientation was found to moderate the relationships between job demand and GHQ scores (.39* → .30) and change in patient personality on the skilful-clumsy dimension and BIR (-.37* → -.19).

These results indicate that communal orientation was effective in suppressing depression arising from job demand, and also distress from patient personality changes. Communal orientation also moderated two stressor-outcome variables.

5.6.6 Summary

In this section, it has been demonstrated that although some of the measures taken during the course of this research were not found to be direct predictors of caregiving outcomes, they nevertheless are important to outcomes because of the influence they exert on other variables. Five potential moderator variables were identified and tested in a series of partial correlations which were then compared to the simple bi-variate relationship of the predictor and dependent outcome measure. All five variables were found to moderate caregiving outcomes. Interestingly, all five moderators also acted as suppressor variables in the caregiver distress process.

It is interesting to note that gender was the weakest of the five moderators identified here; that dispositional hardiness and coping style were great moderators of distress, whilst the value of communal orientation was seen in its strong suppressor role. Caregiver depression was the distress measure that appeared to be most amenable to suppression, which may account for the relative scarcity of significant predictor-depression relationships. The burden measures impact on relationship and emotional burden were the distress variables that seemed to be most responsive to moderation.

5.7 Significant Predictors of PD Caregiver Distress

Many previous research studies have found weak or nonsignificant correlations between objective measures of care-recipient impairment and caregiving outcomes.

However, in this study of PD caregiving objective measures of disability proved to have particularly strong relationships with all aspects of distress apart from depression. But objective measures of disability were not the only variables related to caregiver distress. In chapters four and five, analyses have been put forward that have demonstrated that patient variables, caregiver variables and dyadic relationship variables all influenced PD caregiving outcomes. A full consideration of the correlation matrices, however, indicated that some of the variables had reasonably high intercorrelations with each other.

To investigate which of the independent variables were most important to each of the six distress measures used in this research, planned stepwise multiple regression analyses were used to determine those variables which significantly added to the variance. In view of the facts that (i) caregiving outcomes were not significantly different in phases I and II, (ii) some of the important independent variables were only measured at phase II, and (iii) conditions were more stringent in phase II, these analyses were restricted to phase II data[7]

To avoid entering variables which shared a lot of variance into a regression equation, preliminary stepwise regression analyses were undertaken to eliminate those variables which had no additional variance to add. For instance, there were large correlations between variables with respect to perceived job demand. A stepwise regression was done entering all the job demand variables which were significant predictors of a particular dependent distress variable, to determine which variables provided significant variance. A similar preliminary step was also provided with carer personality, patient personality change, and all groups of variables which were clearly intercorrelated. Thus, only those variables which provided some "unique" variance were then entered into the important regression to determine the significant predictors of each component of burden. The results of this process are detailed below and summarised in Figure 5.7.1 (see pp. 250-1). The alpha level of significance for entry into the equation was set at 0.05.

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[7] Exceptions were the caregiver personality measures and the retrospective assessment of premorbid relationship where the data was assumed to be stable and therefore used in both the phase I and phase II analyses.

1. Impact on Relationship
Variables entered on step 1: STRAIN
Multiple R = .72, R square = .52, Adjusted R square = .50, Standard Error = 3.70
F = 22.59 *p* < .001
Variables entered on step 2: HARDINESS: CONTROL (HCO)
Multiple R = .83, R square = .70, Adjusted R square = .67, Standard Error = 3.02
F = 22.87 *p* < .001
Variables entered on step 3: COGNITIVE DEMAND (COGDEM)
Multiple R = .87, R square = .76, Adjusted R square = .72, Standard Error = 2.76
F = 19.74 *p* < .001

Variables in the Equation

Variable	B	SE B	Beta	T	*p*
STRAIN	1.59	.34	.66	4.70	<.001
HCO	.83	.20	.52	4.08	<.001
COGDEM	-.01	.00	-.30	-2.19	<.05
(Constant)	-8.91	2.37		-3.77	<.01

Variables not in the Equation

Variable	Beta In	Partial	Min. Tolerance	T	*p*
PC*	-.06	-.09	.56	-.38	NS
LOT*	-.12	-.22	.60	-.96	NS

*PC = Carers' perception of patient's conscientiousness, LOT = Carer optimism

2. Impact on Social Life
Variables entered on step 1: HOEHN & YAHR DISEASE STAGE (HY)
Multiple R = .65, R square = .42, Adjusted R square = .40, Standard Error = 5.77
F = 21.03 *p* < .001
Variables entered on step 2: EMOTION-ORIENTED COPING (EMOT)
Multiple R = .74, R square = .55, Adjusted R square = .52, Standard Error = 5.16
F = 17.36 *p* < .001

Variables in the Equation

Variable	B	SE B	Beta	T	*p*
HY	3.52	.98	.49	3.59	<.01
EMOT	.29	.10	.40	2.89	<.01
(Constant)	-11.50	4.03		-2.85	<.01

Variables not in the Equation

Variable	Beta In	Partial	Min. Tolerance	T	*p*
COGDEM	-.19	-.02	.64	-.13	NS
COG*	-.03	-.04	.79	-.22	NS

* COG = Carer's knowledge of the cognitive aspects of PD

3. Emotional Burden

Variables entered on step 1: EMOTION-ORIENTED COPING

Multiple R = .67, R square = .45, Adjusted R square = .43, Standard Error = 5.91

F = 24.07 *p* < .001

Variables entered on step 2: COGNITIVE DEMAND

Multiple R = .80, R square = .64, Adjusted R square = .62, Standard Error = 4.86

F = 25.18 *p* < .001

Variables entered on step 3: PREMORBID DYADIC RELATIONSHIP (DASA)

Multiple R = .84, R square = .71, Adjusted R square = .68, Standard Error = 4.42

F = 22.53 *p* < .001

Variables in the Equation

Variable	B	SE B	Beta	T	*p*
COGDEM	.01	.00	.34	3.00	<.01
DASA	-.54	.21	-.29	-2.61	<.05
EMOT	.43	.08	.57	5.39	<.001
(Constant)	19.99	5.82		3.44	<.01

Variables not in the Equation

Variable	Beta In	Partial	Min. Tolerance	T	*p*
LOT	.07	.09	.51	.45	NS
UPD*	.21	.30	.57	1.61	NS

UPD = Severity of PD / Objective job demand

4. Caregiver Depression

Variables entered on step 1: CAREGIVER NEUROTICISM (CN)

Multiple R = .73, R square = .53, Adjusted R square = .52, Standard Error = 5.73

F = 43.40 *p* < .001

Variables in the Equation

Variable	B	SE B	Beta	T	*p*
CN	.62	.09	.73	6.59	<.001
(Constant)	- 1.97	2.15		-.92	.366

Variables not in the Equation

Variable	Beta In	Partial	Min. Tolerance	T	*p*
LOT	-.03	-.04	.79	-.28	NS
A*	-.07	-.10	.86	-.60	NS
HCM*	.09	.11	.72	.67	NS

* A = Perception of patient personality change on the Bored-Interested dimension

HCM = Dispositional hardiness: commitment

5. Psychological Health

Variables entered on step 1: CAREGIVER NEUROTICISM
Multiple R = .69, R square = .47, Adjusted R square = .46, Standard Error = 2.99
F = 35.08 $p < .001$
Variables entered on step 2: KNOWLEDGE OF PHYSICAL ASPECTS OF PD
Multiple R = .74, R square = .55, Adjusted R square = .52, Standard Error = 2.81
F = 22.94 $p < .001$

Variables in the Equation

Variable	B	SE B	Beta	T	*p*
CN	.34	.05	.77	6.75	<.001
PHYS	-.35	.14	-.28	-2.48	<.05
(Constant)	7.77	1.68		4.59	.000

Variables not in the Equation

Variable	Beta In	Partial	Min. Tolerance	T	*p*
LOT	.01	.01	.69	.08	NS
STRAIN	.09	.12	.84	.76	NS

6. Life Satisfaction

Variables entered on step 1: SEVERITY OF PD (UPD)
Multiple R = .56, R square = .31, Adjusted R square = .29, Standard Error = 2.20
F = 13.79 $p < .001$
Variables entered on step 2: PATIENT EXTRAVERSION (E)
Multiple R = .69, R square = .48, Adjusted R square = .45, Standard Error = 1.94
F = 13.63 $p < .001$
Variables entered on step 3: KNOWLEDGE OF PARKINSON’S DISEASE (KPD)
Multiple R = .78, R square = .62, Adjusted R square = .57, Standard Error = 1.70
F = 14.97 $p < .001$

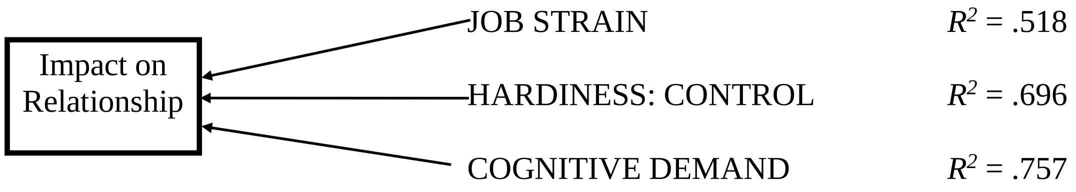
Variables in the Equation

Variable	B	SE B	Beta	T	*p*
UPD	-.11	.04	-.39	-3.20	<.01
KPD	-.22	.07	-.38	-3.10	<.01
E	.19	.06	.40	3.76	<.01
(Constant)	10.74	1.85		5.79	.000

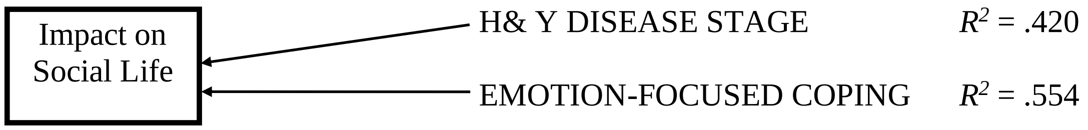
Variables not in the Equation

Variable	Beta In	Partial	Min. Tolerance	T	*p*
COGDEM	-.13	-.1876	.78	-.96	NS

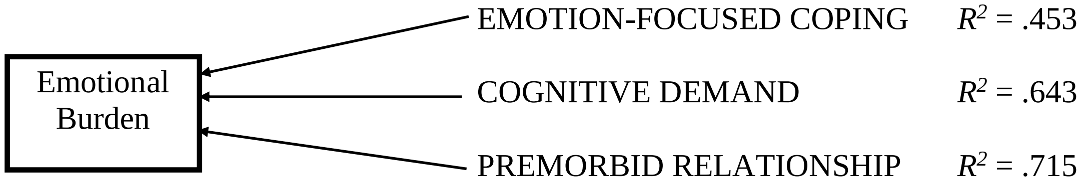
Figure 5.7.1 Predictors of Caregiver Distress



These three predictors explained 76% of the variance. Primary predictors not in the equation were *caregivers' perception of patient's conscientiousness* and *caregiver optimism.*

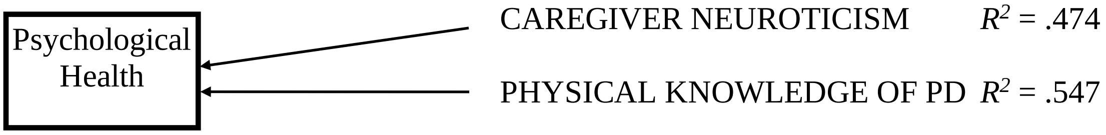


These two predictors explained 56% of the variance. Primary predictors not in the equation were *cognitive demand* and *caregivers' knowledge of PD.*

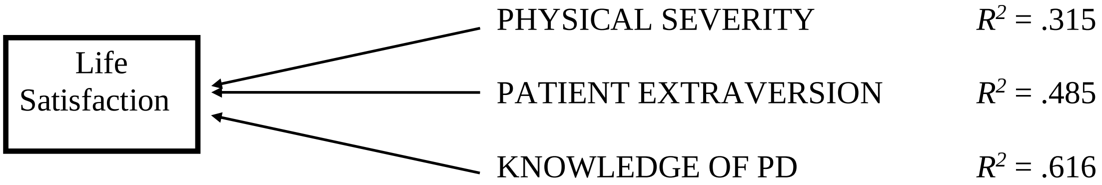


These three predictors explained 72% of the variance. Primary predictors not in the equation were *physical severity* and *caregiver optimism.*

Caregiver neuroticism was the only significant predictor of caregiver depression. It explained 53% of the variance. Primary predictors not in the equation were *caregiver optimism, caregiver dispositional hardiness: commitment* and *patient personality change on the bored-interested dimension.*



These two predictors explained 55% of the variance. Primary predictors not in the equation were *physical strain* and *caregiver optimism.*



These three predictors explained 62% of the variance. One primary predictor was not in the equation: *cognitive demand*.

5.8 Summary

The phase II analyses found that, as in the proposed model, there were patient variables, caregiver variables and dyadic relationship variables that directly predicted caregiver distress. Many of the significant and non-significant associations of potential predictors and distress measures were replicated. It was also found that five caregiver characteristics acted as intervening variables. Thus, these variables were identified as making an important contribution to the model of Parkinson's disease caregiving, and this indicated that changes were required to the hypothesised model.

An investigation of the changes in the illness situation in the 14 months interval between phases I and II revealed that the physical and cognitive severity of the care-recipients PD has increased, but that there was no change in carers' perception of job demand, or in caregiver distress levels.

The role of job demand in PD was investigated with a test of Karasek's theory and its relevance to the caregiving scenario. It was found that job strain, the interaction of perceived job demand and job discretion, was a better predictor of distress than job demand or discretion for four aspects of distress, but that the job demand, as determined objectively by the severity of Parkinson's disease, was found to be a better predictor of poor psychological health and life satisfaction.

An investigation of the best predictors of PD caregiver distress found that there was no one overwhelming contributor to caregiving outcomes. Indeed, the conceptualisation of distress as consisting of different components was justified. The predictor variables accounting for the maximum variance were different for each aspect of distress.

CHAPTER 6

THE EXPERIENCE OF PARKINSON’S DISEASE CAREGIVING

6.1 Introduction

This chapter focuses on the experience of caring for someone with Parkinson’s disease using qualitative, interview data and frequency data. While statistics, such as those published by Miller *et al.* (1996) and O’Reilly *et al.* (1996) have indicated that those caring for someone with Parkinson’s disease have raised psychological distress compared with matched controls, there is little information available with respect to the detail of daily living with Parkinson’s disease. If support is to be provided for PD caregivers, it is vital that the impact of this experience is understood.

A semi-structured interview technique was used to explore the many different circumstances of people living with Parkinson’s disease; this is conveyed in this chapter in the form of descriptive narrative, frequency tables and the use of specific examples and quotations, where appropriate, to illustrate the situation. Obviously only a flavour of the experience can be given, but nevertheless, using this technique it is possible to provide some insight on PD caregiving.

The chapter begins with the onset of symptoms and the impact of diagnosis, then job demand at different stages of the illness is illustrated. Patient personality change and caregiver discretion have already been seen to affect caregiving outcomes, here they are discussed qualitatively. The chapter also includes examples of how other life events - good and bad - are intimately involved with daily caregiving and colour the experience. Examples of what individual PD caregivers find most stressful and most satisfying in their current situation are also presented.

6.2 Onset of PD and Diagnosis

Parkinson's disease has an insidious onset. Symptoms appear gradually, so some compensation and adaptation is possible for, for example, the general slowing which is generally seen. Because PD is typically seen in later life, small changes are taken on board as part of the aging process, one frequent comment to the appearance of slowing and tiredness was "you expect that sort of thing at our age".

There comes a point, however, when more unexpected physical symptoms begin to appear (see table 6.2.1, below). The limbs may begin to shake, handwriting may fail, the walk may change, unsteadiness and even falling eventually lead not only the patient, but also their close family to the realisation that this is more than just a minor irritation that will, in time, go away. When that point is reached, there may be a considerable period of uncertainty and worry about the changes that are happening.

Table 6.2.1 Initial Symptoms of this sample of Parkinson's Patients

SYMPTOM	PERCENTAGE OF PATIENTS
Tremor	45.0
Stiffness	8.4
Depression, or other psychiatric disturbance	7.0
Gait Disturbance	5.6
Slowness	5.6
Could not lift feet off the floor	5.6
Fall	5.6
Handwriting disturbance	4.2
Muscle Pain / cramp	2.8
Loss of co-ordination	2.8
General fatigue	2.8
Loss of arm swing	2.8
Permanently cold hand	1.4

Certainly many of the 83 caregivers interviewed for this research had no idea that the changes they were witnessing in their care-recipient was due to Parkinson's disease.

Trying to make sense of the change in behaviour was typical. When the first symptom was the typical tremor in one hand, it was frequently put down to “a trapped nerve”, and so, for a time, it would be ignored by both patient and caregiver.

C113[8] recalled: I noticed him pulling his right leg whenever he used to worry, and it used to shake.

When asked how long it was before they went to see a doctor, she replied:

C113: I can’t say really, because when I used to tell him about it, he would deny it. But quite some time I suppose. It was only after he came in one night and said that he had fallen the full length of the pavement at Pier Head. The next thing I noticed him pulling his leg again to stop it shaking. I made some tea and asked him to pour it out, then I had to say “Look at your hand! It’s shaking! You should go to the doctor. I don’t know if you have trapped a nerve or something, but you should go and get it sorted out”.

RC: So, you knew something was wrong. Did you know it was Parkinson’s disease?

C113: No. No. Because I had never seen anybody with it. I mean I had seen people with shakes and things, but I never knew what it was.

A similar story was told by other caregivers, for example:

C116: His hands started to shake a bit, and he got very tired and listless, whereas he used to be always on the go. And tasks that he would have done in five minutes were taking over an hour..... I said “You should see a doctor about that”. He went, but the doctor gave him nerve tablets, and he started to take them. But then he nearly fell over in the kitchen, so he came to me that morning and whispered “There is something wrong with me”.

Ignorance at onset of PD, of the cause of the symptoms, was the rule rather than the exception. C174 remarked “... so between 1980 and 1983 we were wondering what was wrong”. Certainly two years between onset of first symptom - with the benefit of hindsight - and diagnosis was the norm. And even when dyads sought medical advice, over 25% initially came away without a diagnosis of PD. This was a particular problem in cases where there was no tremor.

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[8] Codes are used in the text to preserve patient and caregivers’ confidentiality. Gender, age and relationship of carer to patient for each case in this chapter can be found in the appendix.
Pxxx = PD patient, Cxxx = Caregiver, RC = interviewer.

C117: I thought he was having a nervous breakdown. The doctor thought it was just depression, and prescribed *prothiadon.* He took them for a while and was able to carry on working. Then I noticed his handwriting! I thought he had had a stroke.”

It was clear that even before diagnosis, there was stress for many carers, because of the uncertainty of the illness situation. Most caregivers in this sample admitted that this was a worrying time for them. When the diagnosis of PD was made, caregiver’s reactions were diverse. For example:

C126: Upset for her. But at the time I didn’t realise the full implications of it.

C121: Well, I was shocked actually. Then I was very curious. I found out by listening to any programme on it on the telly. I would always listen intently to what they were saying.

C120: I really didn’t think of anything. To be honest I think I went round with a blindfold on. I think my trouble is that I can’t accept it. And I think things are going to get right.

C134: I said to him “Oh heavens, we are going to have a long, hard row to hoe.” I didn’t know a lot, but I knew it was a very debilitating disease, and you could become a complete invalid.

C150: I have followed my mother around hospitals for a great many years. It was just another thing.

C167: I was obviously upset. But we tried to keep our lives as normal as possible.

C127: Astounded. And realising what Parkinson’s is, I would say frightened. I knew there were problems ahead.

C119: C. is so positive in everything, and it makes me positive as well. So, we said we would go on as normal.

Despite the often long wait for diagnosis, relief from knowing the reason for the manifest symptoms was rare. The vow to “carry on as normal” was frequently mentioned, but this was not always in the sense of trying to rise above the permanent problem that had arisen. Sometimes this was based on denying that there was anything wrong. When some trepidation was expressed, it was usually based on some knowledge of Parkinson’s disease. Those who were completely ignorant of PD tended to be less concerned, and expectant that the medication would solve the problem. For some time it often did:

C119: As soon as C. got on those pills that were prescribed, the difference was incredible.

C141: I can’t say life changed at all for some time after the diagnosis, except that we kept going to the hospital every six months, and he kept taking the tablets.

The “honeymoon period” however, sometimes came to an abrupt end:

C107: When she was eventually diagnosed as having PD, I was not concerned, because I knew so little about it. Things were all right for a while. I had no idea of the agony I would go through watching her wriggle and squirm.

6.3 Personality Change

A lot has been written about personality on Parkinson’s disease (c.f. Stern, 1994). In this research this interest has focused upon personality change. Caregivers were asked both at phase I and phase II whether they considered that their care-recipient had changed since they had Parkinson’s disease. 51% considered it had, 49% considered that there was no change. There was no pattern to the presence of personality change with respect to severity or duration of illness. P169 had stage III PD, with a duration of illness of 8 years. Her husband reported:

C169: Not personally no. Just her physical movements. In herself she is exactly the same as she was before. With people, family, everybody.

Where personality change was reported, carers where asked about the changes:

C153: Naturally, he has become very depressed. And there is a lack of communication.

C160: He doesn’t laugh anymore. He said to me last week that his chuckle muscles have gone. He used to have a real hearty laugh. And we used to the Empire [theatre] a lot because he likes the shows. We don’t go now. He doesn’t want to go. It is not the same. He has no interest.

C165: He tends to sit quiet and back off.

C151: She has gone a lot quieter and won’t let anybody in the house.

C133: I would say he is “disengaged”. He is depressed and he is miserable much of the time. He is much less communicative than he was before.

C156: I suppose a lot of it is frustration. He used to be very placid and easy going. But he is not the same now, He is different altogether. He is much more difficult and his temper is quick.

C105: Joe has changed completely. He won’t speak, he won’t go out, he won’t do anything. He is very depressed. Right from the time he was told he had this illness [14 years ago] he has been negative. I can’t seem to reason with him at all now.

It was possible to see that certain themes were recurring in carers’ descriptions of patient personality change. Certainly, depression was advanced as the change of note by many of these caregivers. Other changes included apathy, withdrawal and a diminution of communication, a reduction in confidence and an increase in worrying, a lack of appreciation, and agitation. Some of the “no change” caregivers recalled that the patient had recovered from early depression, which may have been a reaction to the diagnosis. But in the “change” group, caregiver’s descriptions were virtually the same at phase I and phase II. This suggests that there is some permanency in patient personality change, or at least in carers’ perception of personality change.

Caregivers were asked if the personality change had affected the dyadic relationship at any time. Most caregivers agreed that it had.

C133: I still love him deeply. I hope it will soon pass.

C156: It is not the same at all. I don’t feel we are as close.

C125: The fact that communication has somehow ground to a halt has made things difficult. He doesn’t complain, he never does, he is long-suffering and patient. The problem is that nothing is ever said.

C175: Everybody says to me “I think he is wonderful because he doesn’t complain”. No, he doesn’t moan, because I am sure I would. And he is quite grateful for anything that I do. This makes it a lot easier. The sexual side has gone. Completely. He is impotent now. That is not something that bothers me. At my age it is not worrying me.

C176: Oh yes. I mean we are just like strangers really. It is like me looking after a stranger.

It was clear that a lack of communication was the most damaging aspect of personality change on the relationship. It had the potential to make caregivers frustrated and lonely. But this was more of a problem for some carers, than others. It seemed that if the patient expressed some gratitude, then the carer was more likely to accept that “it’s not him, it’s the Parkinson’s”.

6.4 Job demand

This sample consisted of the full range of patient severity of illness, and as result there were caregivers who regarded themselves as doing very little for the patient that they could not do for themselves, and caregivers who were giving care 24 hours a day. This section is used to illustrate the physical load on Parkinson’s caregivers according to severity of illness.

6.4.1 Mild Parkinson’s Disease

There were eleven PD patients fitted this category (based on a UPD score of less than ten). Patients were able to do most things for themselves. Caregivers who had a job at onset were able to continue working and so life had not changed dramatically for this group. For some caregivers the situation had actually improved from the pre-diagnosis period where the patient was without medication.

To investigate job demand caregivers were asked a single specific question:

“What do you actually do regularly for _______?”

C119: Nothing ... Oh Yes! I do! Fasten those little teeny-weeny buttons. That is the only thing. And it is only that he gets impatient with them.

C161 (Works full-time): I don’t do a lot. I perhaps do a little more around the house. During the week she will do the cooking, but at weekends I do it. She does need help putting on an awkward item of clothing, or her necklace. Very occasionally she might be ironing and I will have to carry on for her. Perhaps I am a bit more attentive and do more washing up than I used to. Things like that. Well, she won't let me do anything. She is very good in the house because she really tries. When she feels she needs help with anything, she asks me, and I will do it. That is basically what it is.

C163: Although we have always shared the driving, I drive the car more now. If he wants to put his tie on, buttons things, or undo a belt, or even pick things up, I will usually help. Sometimes he will struggle and do it himself, but it is slower. I have to do all his correspondence for him because he can't write now.

6.4.2 Moderate Parkinson's disease

This group was made up of half the remaining caregivers. There was quite a range in the amount these 36 caregivers did for the patient, partly influenced by amount the patient was able to do, and partly influenced by the use of formal services.

C114: I give him some assistance getting dressed - with buttons and his hearing aid. He needs help getting in and out the car. Chairs - we changed the suite because he had difficulty getting out of the other one because it was too floppy. Even this one, I've had to put a bit of extra foam in that one where he usually sits, behind him, to help him get out. The only other change we have made, is the two banister rails because he came down the stairs, backwards of course, and knocked himself out at midnight one night. I ran him over to Arrowe Park [Hospital] for a quick check. He is up in the night most nights, and we now sleep in separate beds because he sleeps so badly. I have to keep my dressing gown handy. The one thing that is demanding is that I always liked to be in the kitchen on my own. But unless he is asleep this is no longer possible because he is there at my side <u>all</u> the time.

C175: Most mornings I help him out of bed, because he is pretty stiff. He showers himself, but I help him get dry, then help him get dressed. He can do it on his own, but it takes forever. I mean last Saturday, I was working and I didn't wake him until just as I was going out. Because he was fast asleep I thought I would let him lie in. So, I left at a quarter to nine. He probably didn't get down until a quarter to twelve. It would have taken him that long.

He used to do a lot of cooking, but now it takes for-ev-er. He does try. The days I am at work, he will often have started to get the meal ready, but I have to take over. Peeling the potatoes and that sort of thing he can't manage now.

C169: I take her up a cup of tea in the morning. She has a Madopar and a biscuit in bed. She has to wait a bit for the tablet to work, so then I get washed and dressed and start the breakfast off. I then nip back up periodically to see if she needs any help dressing. And then she comes down. From then on, I know she is all right for the day.

C118: Everyday is the same. I have to help him out of bed in the morning and twice in the night. He washes himself, but I help him to shave and if he has a bath. I help him get dressed, then get the breakfast. I make sure he takes his tablets. I do everything in the house, all the gardening, and I do the decorating. I have certain jobs to do on certain days and I get them done in the morning. I spend the afternoon with him. Sometimes we go for a walk; I hang on to him all the time. When he falls he goes forwards onto his hands. I make all the meals. He just needs a little help getting undressed for bed. He is not bad really. He is all right at the moment.

At this stage of PD, most carers need to provide some assistance with getting out of bed, bathing and dressing. Some dyads started to make adaptations to their home to increase the independence of the patient. It was clear that most help is required first thing in the morning, particularly for those patients with early morning dystonia. These patients cannot do anything for themselves until their first dose of medication of the day is metabolised, but after that they require less assistance. Patients can eat by themselves, although some will start to need their food cutting up, and they may make some mess. Some carers have to get up in the night to attend to their care-recipient, but this is not the norm. At this time, some carers also reported that patients would get distressed if the carer went out. Those caring for patients who were prone to falling increased their vigilance with each successive fall.

6.4.3 Advanced Parkinson's disease

Giving care to someone with advanced PD is often a 24-hour job. In this sample there were (originally) 36 advanced PD dyads. Two of these patients were managing to live alone; to achieve this, they had well-organised formal care to supplement the care provided by their daughters. Some advanced patients were mentally alert, but hallucinations and dementia were frequent features. To provide a flavour of advanced PD caregiving, detailed excerpts from the interviews of four carers follow: two carers were wives (C105, C120), one a husband (C106), and one was a non-resident daughter (C126). To reiterate, carers were asked a single specific question: What do you actually do regularly for _______?

C105: Everything. I do literally everything. I wash him, I shave him, I dress him, I catheterise him every four hours. I give him enemas. I see to all his medication. He

does nothing for himself. I write cheques, I sort out all his finances. I never knew before how much money he had in the bank. I try to get him to do things, but then he says he cannot do it. I would like him to do more because it is stimulation. I mean I never used to consult him about what we are going to eat. Now I ask him "What shall we have for dinner" to stimulate him. I think he draws on me.... I mean he uses my strength. He is that dependent now that if anything happened to me..... I have got to be in good health. I can never leave him.
RC: Do you have anyone to help you? Do you have a home help?
C105: I would not have one. I would rather live in dirt. I had a home-help with my mother and they let me down very badly. My son helps with the garden and if I ever need anything doing in the house. We rely very much on our son.
RC: Is there any help you would like?
C105: Oh there are times when I do feel like I am going under, and it is too much. There are dark areas, but I don't tell J., and I don't tell D., but I have got a very good GP. She is marvellous. She thinks I am better off without medication, and I manage to pull myself round, and get on until the next time.

This interview was from phase I. In phase II, P105 was receiving even more personal care after a bowel infection. He had also started having periods of confusion and hallucinations. In response to the ever increasing demands on his mother, their son and family moved into their (large) house, taking over the upstairs. Nevertheless:

C105: The minute he opens his eyes I am on call. No matter how much I tell him, he is oblivious to my needs.

The next case is a lady who was similarly disabled to P105 above in phase I, although she was continent. They had moved from a large house to a warden-assisted flat to make life easier.

C106: I do virtually everything. I have to help her to dress. I do all the cooking, the shopping, the laundry. I fetch and carry. I organise everything. I have to watch to make sure she doesn't fall, and I have to support her if we go out. We sometimes go out for a drive; I do all the driving, but then I always have. She like to do things for herself when she can. But sometimes she takes too much out of herself trying to do things that are a struggle and take her a long time. But I like to help her too. I often feel on edge when I watch her struggling to do a simple task.
RC: Do you have anyone to help you? Do you have a home help?
C106: Yes. We have a cleaner. She comes for three hours on a Wednesday morning. You see Wednesday is wash day, so I am busy, and not here all the time.

In phase II, P106 was much weaker and now needed support even to go to the toilet. In addition to this, she had recently begun to have early morning periods of confusion. They were having no additional help, but rather less. The cleaner had been sacked for stealing from them and C106 was visibly tired during the visit. Nevertheless, he proclaimed that the caregiving had given him something to do with his retirement, and he seemed pleased with his ability to cope.

The next case was the youngest male in the sample with an age at onset of 36 years and duration of illness of 14 years at phase I. His caregiving wife was four years younger. Two of their three children were still at home. P120 was also demented.

C120: I help him get dressed. He used to be able to do that a little bit, not long ago. Everything really.
RC: Everything?
C120: Well yes. Help him get round, help him in and out the car. I mean he can walk around a bit, but you have to watch him because he falls. He has been falling a lot more lately. His legs just seem to give way - especially on the stairs. On Wednesday night I went to the front door and as usual, J. followed me. The next thing I heard a smash. I couldn't believe it! J. had fallen backwards into the side porch window and the glass had gone right through. He was covered with glass, and I just can't believe that he wasn't seriously hurt. I mean one of the pieces of glass cut my foot and it was bleeding quite heavily. I don't know what to do about the window. Do I get it replaced, or do I have it blocked up with wood, and lose a lot of light in the hallway? J. didn't seem bothered at all, and the trouble now is watching that he doesn't go near the glass until it is repaired.
Our eldest son and his wife come and sit with him while I go to get the weekly shopping. He likes it when people visit, but he is not keen on me going. He likes to go out in the car. But I can't leave him outside Asda for an hour. He does like to go out. My friend Wyn rang up on Friday and asked if we would like to for a walk in Calderstones Park. I said no, because I didn't think I could cope with supporting him. John heard the conversation and seemed to want to go, so I thought about it and rang her back and said we'd decided we would go. I started to get us ready. I can't stand all the hassle of getting J. ready - it just wears me out. And to make matters worse he had wet his trousers which meant all clean clothes. We got there, and had a short walk and J. wasn't too bad. Then we went back to Wyn's for a cup of tea. J. just fell asleep. He was worn out.

RC: Is there any help you would like?

C120: We are waiting to have a downstairs toilet put in. We have got the grant and everything, but that was 18 months ago, and it has still not been done. When J. wants to go to the toilet I have to help him a lot more now … because he doesn't seem to be managing the stairs as well. And it is very tiring standing behind him and pushing him up.

RC: Do you have any formal help?

C120: No. The neurologist says that J. is in the advanced stages of PD and medically there is nothing else that could be done, so the only help he can give is to ask for a social worker to see me and advise on what help is available. He thinks that all the extra work I have with J. is going to make me ill. He also suggested respite care or a nursing home. I said categorically “No” to a nursing home, and he looked at me as though “well it will come to that in the end”. So I’ve got to decide now what to do next, not an easy decision. Everybody keeps telling me I’ve got to think of my own life, but my life is with J. and I think I will have to carry on as best as I can. Perhaps I will accept more help.

In phase II, C120 had done just that. She was having respite care in the house two afternoons a week.

C120: I have been having this service for the past six months and it really has made a great difference to me, I can go shopping in peace and know that J. is being cared for.

The long-awaited downstairs toilet was built as an extension with a shower so C120 did not have to struggle up and down stairs with him several times a day. J. could no longer get out of the chair without help so this prevented him from following her everywhere and cut down on the number of falls. Nevertheless, she reported

C120: I really hate bedtimes now though. I have to get him upstairs and it is really tiring. Helping him come downstairs in the morning is a hard task these days too. I think that is why I have rather a lot of shoulder pain at the moment. I seem to be really tired at the end of the day lately, and I think that over the last year I have had to do much more for J. than I used to.

The fourth case in this section illustrates the way of life for a daughter caring for her mother who has advanced PD with severe dyskinaesias. P126 was also intelligent, very articulate, and had lost none of her previous sharpness. She was widowed before the onset of PD. C126 spent most days at her mothers. She didn’t drive and a single journey would usually take her over an hour. Ideally, she would like to go by taxi, but at £9.00 return, and with no income, she could not afford to.

C126: The problem is that she still wants to be independent, and it is a struggle for her to have to accept that I have to do some things for her now. So, it has all been very gradual. The first thing was the shopping. She couldn’t get to the shops on her own, so we used to take her in the car. Then one day I discovered, quite by chance, that the effort of preparing her midday meal would render her too exhausted … or having too many movements to actually sit down and eat it. So, I started to filter help in. It was when my son first went to college, about nine years ago, I would pretend I had been absent minded and had cooked for my son as well. “So, could you eat it up”, and I brought it round, and she did enjoy the food. Over a period of a few months she came to accept me cooking her dinners and freezing them. It was easy enough. I’d just cook for five instead of four. Now we have reached the stage where I have to leave her something for her tea too. She can manage a piece of bread and butter, and to put the meals in the microwave. I also do her laundry; she can’t hang things out now. The cleaner changes her bed. She comes once a week for 3 hours. And the gardener always comes on a Friday for four hours. When Mum was capable, she got into the habit of making him sandwiches and tea. When she couldn’t do that I started coming on a Friday just to feed the gardener.

RC: Do you get her up in the morning?

C126: Not at the moment. Although I have noticed the problem is increasing, so I think that before long I will be. But then I can get dropped off at 7:45 in the morning.

C126 was right. In phase II, her mother’s mobility, strength and dexterity had deteriorated dramatically. P126 refused to agree to the Social Services assessing her, as she was convinced that things would improve with the medication change to Apomorphine. As a result, C126 was at her mother’s house 7 days a week from 7:45 am until 6:30 pm for six months. In her diary she wrote:

C126: This caused tremendous strain for several reasons (including):
1. No time for my own home, decent meal preparation, etc.
2. My husband had to contribute a lot of help on top of a demanding job and a lot of travelling.
3. My health deteriorated as I had so much back pain I lost sleep.
4. I became totally exhausted, mentally and physically.

In despair, C126 eventually arranged for a social worker to visit “as routine”.

C126: He was able to make Mother realise that she would be in a nursing home if I was ill, and it was coming to that. A home help started coming six hours a week. I still went seven days a week to give her tea and get her to bed. I was there all day at weekends and Wednesdays and Fridays. Once mother was used to people coming into the house, the care increased to the present level. Now carers are coping with the heavy work - bathing, dressing, bed-making, putting her to bed and getting her up. But I still feel that I am always on call. Now I don’t go on Tuesdays, but I am preparing food for her at home. I try to let Mother know where I will be when I am not visiting her, in case she is so frozen that she is frightened. She has become totally reliant on me to make all phone calls and write all letters. She rarely answers the phone. She has lost all her confidence and relies on me to protect her from visitors. She will not agree to anyone, not even other relatives, visiting her unless I stay there all the time to protect her from their conversation if she is exhausted or frozen. She is still intelligent and still a decision maker, controlling her life, but she seems to want my opinions these days before making decisions.

The case of C126 above illustrates how very demanding meeting the needs of an advanced PD patient can be. She was 50: a lot younger than most PD carers yet admitted to total exhaustion. She alluded to the fact that it was perhaps harder because her mother was mentally sharp and understood her situation painfully well. She found it difficult to withdraw from some of the impossible workload that had crept up on her, despite the negative effect it was having on her own family life.

The intention of going into some detail with respect to job demand was to emphasise the importance of severity of illness in caregiving outcomes. Job demand in mild PD, where patients enjoy the full benefits of levodopa medication, was construed as being of relatively low demand. Job demand increased gradually with progression of illness, until in advanced PD it was invariably described as physically and mentally exhausting. Delegating some responsibilities to formal services was crucial to some caregiving situations continuing.

6.5 Ethical Issues in PD Caregiving

To investigate whether caregivers were happy with the caregiving situation, or whether there were times when they were caught in situations where an action may have been good for themselves, but not the patient, or vice versa, they were following question was put to them:

"I am sure you find that sometimes you are pleased with the way you care for _______, but that sometimes you think you should be doing things differently. Is this true for you?"

One prominent theme was the worry of how much help carers should be giving patients. A PD patient can be very, very slow, and carers often wanted to "help them" get a particular task done, but this could be at the expense of the patient's independence.

C119: Sometimes I do want to do things for C., you know, just help him because he might be struggling a bit, then I think no, it helps him if he can do it himself.

There were also frequent admissions from caregivers that they get frustrated, and they needed more patience.

C156: In a way. I have to make it a matter of prayer, to give me more patience. That is what I am lacking. Because it is so frustrating for me as well as for him when he is trying to tell me something and he can't get the words out. Then he tries to write it, and I can't understand his writing.

C120: I do lose my patience with him. So, I could be a little more patient. I am not very good in the morning, you know, when you first wake up. And when you have to think about getting someone else ready and not just yourself. Sometimes I think, oh, I can't cope with all this.

For C128, a point of great frustration was her mother's expectation that she would attend to her immediately, even when she only wanted something passing to her.

C128: Sometimes Mum asks me for things and I am in the middle of something. In the end I'll say "Will you hang on". I may be washing up, and I need to dry my hands. I can be in and out, in and out to her while I am doing it. I can be up and down, up and down, and I think "How can I get things done". Sometimes I say to her that I am going to finish the dishes, *then* I will come. But I don't always do that. I seem to be up and down.

In contrast, C127, whose wife was mentally impaired as well as having PD, declared:

C127: I try to avoid all unnecessary things, naturally. Lots of days, if I don't feel like it, I think to myself - is that really essential today? And if it isn't, then I don't do it. I am not a perfectionist. The case is that sometimes things are left undone or unsaid just to keep things normal.

An example of how a potentially difficult ethical situation was dealt with is that of a widow, P140. She made the decision to move across the country to be near her youngest daughter, who didn't work because she had three young children.

C140: We talked about it very openly, because I think a tension could have arisen. She had made a few comments about plated meals, and microwaving them, and it set a few alarm bells going in me really. I asked her to write down exactly what she expected of me if she came to live on the Wirral. The last thing I wanted her to do was to move from Sheffield where she was with all her friends and expect things from me that I did not feel it was right to be giving at this point. My youngest one has gone to school now, so I do have a bit more time, but I mean I just did not think it was good for her. And that is a continual process really. I mean - how much should I be doing and how much should I be standing back? So, I don’t see her every day. I think the day-to-day, and having to get out and get her shopping, and having to do her washing and her ironing and her cooking is very good for her to keep her mobility going. I think that if she were to expect meals to be cooked, washing done, and shopping done for her, then she would just sit in the flat and vegetate.

It is interesting here, to compare the above response with that of C171 who had an identical UPD score of 15.

C171: I cannot possibly do any more for him than I do. He is waited on hand and foot. Three good cooked meals a day. Mid-morning coffee, afternoon tea. How can I do less for him when he has to be followed round?

Guilt was not a common reaction to this question, but one non-resident caregiving daughter said:

C150: I could be spending more time with her. I mean we have been invited to go away for three days after Christmas, and I would like to do this. We will go down Wednesday morning before we go, and we will be back Friday lunchtime. So, there is only Thursday....... Why I feel I have to do this I don’t know. I still feel guilty about going away when she can’t.

In a similar vein, a caregiving wife who worked said:

C117: As things are, we are fine. Sometimes I think that as I have been at work all week, I had better be home when I can.

6.5.1 The Financial Situation

Chronic illness has the potential to cause financial worries if illness prevents the sufferer from working. As reported in chapter 3, in this sample just 18% were working at onset of illness; the remaining 82% had finished their working life and had retired. Diagnosis of PD, however, did not mean that this 18% were immediately unemployable and all continued to work for some time which enabled some preparation for the drop in income. At time of testing, just one patient was still employed, and he, incidentally, was over the normal retirement age of 65 years. Given the fact that the majority of this sample were already pensioners at onset, it was perhaps not surprising that when caregivers were asked the following direct question:

"Has ______'s disability put a strain on your financial situation?"

only 17.3% said yes in phase I; 82.7% said no. In the reduced follow-up sample a year later, 25% agreed that PD had caused a financial strain, but 75% said not. It is possible that this is a cohort effect, for as pointed out by C167, many of these caregivers had lived through rationing during and after the war.

C167: No. I have never been the sort of person to waste money. I still make all my own jam and do all my own cooking. The way one did. I still say I had the best training because when we got married everything was on rationing, so you had to learn to cope. And you go on that way.

Another younger caregiver who was working at onset, 15 years ago, feels she has to continue working full-time until she is 65 and can draw a pension, because her husband lives on disability benefit. She pointed out that although they had no money worries at the moment, they would have is she stopped working:

C117: We don't go out much, which helps, but that is not because of the money.

Carers were also asked if the financial situation bothered them, 79% responded *none of the time,* 8.6% were bothered *a little of the time,* 6.2% were bothered *some of the time,* and 6.2% were bothered *all the time.* Together, this information suggests that finances are not a major concern in PD caregiving.

6.6 Emotions in PD Caregiving

Emotions are an intimate part of the stress process, and so to explore caregiver's feelings about the situation they were in, they were asked to consider the nine emotions on Motenko's Frustration Scale (MFS) both at phase I and Phase II. For each emotion, carers were asked "How (e.g.) angry do you feel about the fact that

____ has got PD, and its subsequent effect on you? The coded responses are presented in tables 6.6.1 and 6.6.2, below.

The frequencies were similar at phase I and phase II, although the percentage of carers who were *very much* regretful about the illness situation had doubled in phase II, and the percentage of carers who were *not at all* hopeful had more than halved. Generally, if the findings from phase I and phase II are considered together, then caregivers tended not to feel ashamed or guilty about their care-recipient having PD and the consequences of that for them. About a third were in some way overwhelmed by the illness situation, but less than 9% were very overwhelmed. Four-fifths were resigned to the situation and more than two-thirds were regretful. A third of the carers were angry about the effect of PD on their lives and similarly, about a third were resentful. Approximately half the sample expressed some fear concerning the situation. In phase I nearly half the sample was not at all hopeful, but in phase II, that figure had dropped below 20%.

Table 6.6.1 PD caregiver's expression of the nine MFS Emotions in Phase I (n = 81)

EMOTION	*NOT AT ALL* %	*A LITTLE* %	*QUITE A LOT* %	*VERY MUCH* %
ANGRY	67.9	19.8	6.2	6.2
RESENTFUL	61.7	24.7	8.6	4.9
ASHAMED	96.3	2.5	-	1.2
RESIGNED	19.8	27.2	29.6	23.5
REGRETFUL	29.6	22.2	32.1	16.0
OVERWHELMED	59.3	24.7	4.9	11.1
FEARFUL	54.3	24.7	12.3	8.6
HOPEFUL	48.1	17.3	22.2	12.3
GUILTY	91.4	6.2	1.2	1.2

Table 6.6.2 PD caregiver's expression of the nine MFS Emotions in Phase II (n = 56)

EMOTION	*NOT AT ALL* *%*	*A LITTLE* *%*	*QUITE A LOT* *%*	*VERY MUCH* *%*
ANGRY	67.9	17.9	7.1	7.1
RESENTFUL	64.3	25	5.4	5.4
ASHAMED	98.2	-	1.8	-
RESIGNED	21.4	17.9	37.5	23.2
REGRETFUL	17.9	28.6	21.4	32.1
OVERWHELMED	67.9	19.6	7.1	5.4
FEARFUL	48.2	39.3	7.1	5.4
HOPEFUL	19.6	39.3	26.8	14.3
GUILTY	92.9	7.1	-	-

6.7 Discretion

Hypothesising that caregiver discretion may be a direct predictor of caregiving outcomes, several aspects of discretion were explored in the caregiver interview. Of particular interest were the use of respite care, making time for leisure pursuits and making time for personal care. Caregivers were also asked a simple direct question (from Motenko, 1989) to look at the amount of flexibility caregivers perceived that they had during caregiving:

"Do you feel obliged to comply with all the demands of caregiving?"

In phase I, 63% said YES, and 37% said NO. In the follow-up, the numbers of caregivers who felt obligated had risen to 84%. In phase II, only 16% said NO. Certainly a large majority of this sample of PD carers felt they should always consider their care-recipient's needs first. About 32% said that this bothered them.

6.7.1 Respite care

The interviews indicated that where the care-recipient had *mild* PD, caregivers had a good amount of discretion in so far as choosing what they do with their days, and where the patients had very *advanced* PD, caregivers had very little discretion with respect to having some time away from the caregiving situation. But even in Stage V PD, caregivers do ultimately have the ability to influence the daily routine. For instance, C120, giving care to a Stage V demented patient remarked in phase I:

C120: I couldn’t leave him on his own ever, not the way he is now.

In phase II, the patient was even more physically demanding, yet this caregiver took the opportunity she had for respite care, which gave her two free afternoons each week. They changed her outlook because she looked forward to her “free” time.

It is true that not every carer has the opportunity to have respite care. It is not really needed by carers who can, if they wish, leave the care-recipient on their own for half a day. Respite care is usually an option, however, for advanced cases. All three of the hospitals from which this sample was drawn had a day centre where PD patients could go once or twice a week, in addition to social services respite centres.

In this sample 43% of patients were classified as “advanced” in so far as they scored over 25 on the UPD motor examination, but just 14% used weekly respite care. That is 31% of the advanced PD sample. This suggests that most carers sustain a 24-hour caregiving regime, or that respite care is not seen as a viable option.

It is true that one of the *advanced* caregivers would have liked NHS respite, but was not offered it. She arranged her own and paid for Wirral carers to look after her husband on a regular basis to give her a break. Consideration of carers’ interviews sheds some light on this issue. Caregivers were asked:

“Do you think that looking after ______ because s/he has got Parkinson’s disease leaves you without any choice in what you have to do during the day?”

C127: Well … the only time I can leave B. and do leave her is between about 11 o'clock and 1 o'clock, when I go shopping. Then I leave her upstairs, because of the toilet and facilities. Otherwise, I do not leave her.

RC: Would you like any respite from caregiving?

C127: Yes. We looked into all that recently. Social services arranged for B. to go to Crofton House [a day-care centre] a couple of days a week. It didn't work out I'm afraid. B didn't take kindly first of all to going at all. She wanted me to be there with her. Well … this defeats the object. The first time she went for about three hours and just had some lunch - some sandwiches. The next week she went for four hours. Before she came away she was speaking to the manager and trying to tell him something. There wasn't a problem, but because of her speech, making herself clear he thought that a problem had arisen and there was some criticism of his staff. There wasn't. Not at all. The other thing was that again she can't talk to the other people who were there freely. She couldn't chatter to them very well, so she got isolated, and more so because of her problems going to the toilet and this sort of thing. Again, she felt a large sense of embarrassment more than anything. So, the two things together introduced some state of trauma. So, I thought if this is going to happen then there is no point in her going. But this was instituted by our GP, because he thought that I should have a day, or two days a week, not just to rest, but to be able to have the time to go where I want to. For business reasons and that sort of thing. Because this didn't work out, I have to do things by dashing there and dashing back. As quickly as possible. If I need to go out for more than the two hours, then someone would probably have to come in.

C164: When he came out of hospital, on each occasion, he was supposed to go to the day hospital. But when he comes home he doesn't want to go! Mind you, it might have been hard to get him ready, because the first Wednesday when he should have gone the ambulance men were ringing the bell at a quarter past eight! Another thing, which is a nuisance, is the waterworks problem. So, he hasn't wanted to go. People have said I should press him, but I haven't. It doesn't bother me that much, I probably would benefit, but I wouldn't press it.

C121: Yes. I could leave him for an hour if he was asleep in a chair. You are like a caged bird.
RC: Is that how you feel?
C121: Yes.
RC: Would you like some respite from caregiving?
C121: If I did get relieved, I would go and get my hair done. But I wouldn't be happy leaving him now, because I actually think he is getting worse. And last night he didn't know me. I got a shock. The doctor doesn't say much. He didn't say it was the end, but he said it is the last part of Parkinson's when they get like this.

These three cases illustrate the main reasons why more respite care is not used, despite its seeming to be a good arrangement for both the patients and caregivers, according to those who do successfully use respite. The first reason is that it has been tried, but it has not worked out. Key problems for the patient are communication and toileting. Secondly, the patient may not want to go a day-care centre, and the caregiver cannot or will not use persuasion. Thirdly, the caregiver does not want to leave the patient in day-care. In the case above, the caregiver thought that death was near. Other carers have a negative attitude to formal care, and / or do not think that the patient would be properly looked after or be happy there.

6.7.2 Time for personal care

It is critically important that caregivers remain in optimal health if they are to continue caregiving. That means that they should have enough time, or indeed make the time, to continue their own personal care. To investigate this, carers were asked:
“Do you have enough time to take care of yourself?”
Figures were very similar in phase I and phase II: about 74% said YES and 26% said NO. Most of those who agreed that they did not have enough time to look after themselves, said that this bothered them at least a little of the time. But they did not seem to see a way round it. There was an attitude of “the patient comes first”, and not always the realisation that it may be in the patients’ best interest, in the long run, for the caregiver to attend to their own basic needs.

6.7.3 Time for own interests

If a caregiver is spending an increasing amount of time attending to a PD patients’ needs, this suggests that there is a decreased time for leisure, and perhaps personal care. Caregivers were asked what they did with their leisure time. It was found that 37% maintained or adapted most previous leisure pursuits, 32% enjoyed a limited range of leisure pursuits, and 31% had very little leisure time or social interaction. Considering leisure time according to severity of illness, it was found that many *mild* and *moderate* carers were able to continue most of their previous leisure pursuits. As the disease progressed, the more active hobbies and pastimes would be dropped, earlier when this was a shared interest, such as rambling. Many *advanced* carers, however responded in a similar way. For example:

C120: I don’t have any at the moment. At the moment nothing.

A few advanced caregivers did make a particular effort to keep some social activities on their calendar by carefully considering the capabilities of the patient. For example, P106 is at Hoehn & Yahr stage IV, with limited mobility, yet she enjoys watching films, as does C106. Besides spending time together selecting what to watch on the television, they go to the cinema, and to the theatre, together. He also manages to get out on his own for a limited period, with the patient’s blessing.

C106: We get the car and go to Bromborough, to those big cinemas, and select which film we are going to see. And we go to our old Amateur Dramatics Society. We get out, weather permitting. And yes, I am a season ticket holder for Tranmere Rovers. I used to play for them, as an amateur. H. has said to me “You love your football, and as long as you can get there, you are guaranteed your seat, so go. You are not to stay in.” I am away for three hours, sometimes three and a half hours, and that concerns me more than anything. I come out of the game, *always,* five minutes before the end, so that I can get into the car and away. It enables me to beat the traffic. That causes anxiety. H. usually watches the television while I am out, but once or twice she has fallen. I have bought her one of those personal alarms now though, which has helped me. I put it around her neck before I go out. She hasn’t had to use it, but if she were in distress the warden would be here very quickly, and I would not be long after. That has helped me to feel comfortable enough to carry on going.

Premorbid social life naturally has some bearing on the type and amount of leisure pursuits undertaken while caregiving, as well as the amount of care required. It was clear, however, that severity of illness alone did not determine the extent to which a caregiver had a social life. Patient attitudes and caregiver characteristics also had an important influence.

6.8 Life Events

A diagnosis of Parkinson’s disease provides a chronic difficulty for patients and caregivers, and it has an ongoing impact on their lives. Other subsequent critical incidents are similarly likely to have an effect on the PD and the caregiving. There were caregivers who were aware of this:

> P101: Life is very smooth at the moment. We’ve had no major catastrophes. I try to keep it that way. That’s the secret with this illness. If you keep things running smoothly it is all right. But if it isn’t then it just makes them [the PD patient] more agitated and that upsets their thinking, so it is no good.

Sometimes though, accidents do happen, and equally, good things can happen to improve one’s life. In this section, four short illustrations will be given of the effect of a life event on the experience of caregiving. One was positive, two were negative, and one was mixed.

6.8.1 Caregiver Accident

In phase I P104 had tremor, but his main complaints were slowness and tiredness. He was aged 80. Much of C104’s caregiving, by her own admission, was doing things for him to save time.

> C104: When he takes the car out, I open the garage doors and the gates, things like that. Sometimes he starts a job, and he gets tired, so I finish jobs.

But C104 had not worked outside the home for a long time, so she was already completely running the house. She was perfectly fit and healthy. Then their circumstances changed quite dramatically. C104 fell over a workman’s brick in the street against steel railings and broke her hip and pelvis. She was in hospital a fortnight for a hip replacement, and then had a long recovery period. Ten months later she was still on penicillin because her hip became infected.

The accident had great impact on both of them. P104 admitted that it frightened him and upset him a lot. His tremor had increased noticeably. His balance was affected. He had had several falls. Twelve months after the initial visit he was struggling to get out of the chair, despite the fact that his levodopa intake had been doubled. When C104 came home, he accepted that she could not do as much for him, and he struggled to what he could for himself. They have no children.

> C104: For the first two weeks after my accident, it was absolute hell. I was so worried about S. while I was in hospital that the doctor gave me some tranquillisers. But not now. He knows I wouldn’t take them. I am fed up of it all though. We had some help from the social services for six weeks, but that was terminated and there was nothing I could do about it. I was crying because I was so upset and worrying about S. And how we were going to manage.
>
> How can I put it? I can’t alter what has happened. So … I just live with it. One thing is that I talk about it [PD and caregiving] to S. I never used to. But I sometimes think of how life could have been. S. says to me that I am bitter, but I am not.

C104 thought that her accident had affected P104’s PD symptoms, increasing job demand at a time when she could not respond to his needs. This compounded the stress of the situation for her, and ten months after the accident, when the phase II interview was made, she had changed from a confident woman who was only slightly affected by PD, to one who was frustrated because she could not continue with caregiving and housekeeping as she would have liked. She also remarked that besides the accelerated physical deterioration in her husband “he does get a bit depressed now.”

6.8.2 Death in the Family

P171 had a long duration of illness but had only deteriorated to his current advanced state over the two years before the interview. Now he was also dementing. He and his wife had moved into a warden assisted retirement complex eight years previously. They were very close to their daughter, their only child, although she lived in Germany. They spoke every day on the phone and went to stay with her for a month each year, and she also come home for frequent visits, as a highflyer. Six months before this interview, she had been killed, run over by a drunk driver, the day before she was due to come home for a visit. C171 still felt absolutely devastated, even now, six months later. This may have been accentuated by the arrival of her daughter's belongings a week before the interview.

C171: The light has gone out of our lives now that D. has gone. She was the hope. What is there now?

C171 reeled off a whole catalogue of problems that P171 had, and how coping with them was getting her down. She acknowledged that she had only felt like this since her daughter's death. She was not sure whether her husband appreciated that their daughter had died. He had, however, gone worse since that time. He had had falls, but now he was falling every day. She remarked "I only keep the car for the convenience of getting to Arrowe Park to get him stitched up". He began having "accidents" before getting to the toilet, and he began hallucinating. This was the worse change for C171 because he frequently saw their dead daughter.

C171: Now I haven't got a shoulder to cry on. He is quite immune to any emotion. He has never shed a tear about D. because he doesn't understand. He has receded and keeps referring to what time is she coming home. I say "She is not coming home anymore. She is in God's Presence." and he will say "She is sitting by you there".
He should be in hospital. He must be looked after and cared for all the time. He has to be watched around the clock whatever he is doing. I have to get up at 6 am just to see to him, and I have all D.'s things to sort out and I just have no time to do it.

She needed to grieve and did not feel she had the space to do it.

C171: Sometimes I feel like packing a bag and clearing out, and then the thought comes "it is not his fault. He can't help it". It bothers me that I am not well enough to look after him now, when he needs me most, to the best of my ability.

C171 was not able to work-through her understandable grief following the unexpected death of her daughter because of the demands of caring for her advanced PD with dementia husband. He also seemed to have been affected, in so far as she perceived his symptoms to have increased. It was not, however, possible to verify this objectively. Nevertheless, it is likely that that P171's progression was accelerated by some form of grief: within the twelve months to follow-up he was dead.

6.8.3 Birth in the Family

Several caregivers noted that seeing the grandchildren was a highlight for both them and their care-recipient. There was also some delight that young children readily accept disability. One patient, who had recently had a birthday, had been delighted to receive a card "To my wibbly-wobbly grandma". It did not depress her but gave her a real uplift.

A birth in the family also perceived as a positive life event for both patients and caregivers. C113 reported that her husband's mood was better, and his previous apathy gone since the birth of their first grandchild, 7 months old previously.

C113: This was marvellous for B. It really has picked him up a lot. It has made him more confident. He used to try and lift her to the child seat in the car. My daughter said, "I am not saying anything Mum, but I am terrified in case he falls with the baby". He wants to do it to help, and he still tries to do it. I say to him "Just take it easy". He really looks forward to P. coming, so that he can play with the baby. It has helped him a lot.

6.8.4 Bankruptcy

C172 and her husband have three children but had lived alone for over 20 years. P172 was diagnosed with PD 11 years ago. 18 months ago, their unmarried son's business went bankrupt. He lost everything and turned to his parents for help. He moved back in with them.

C172: P. had a good job four years ago, and he gave it up to go into business. He hired out hats and ball gowns. But it did not work out. He tried not to go bankrupt, but in the end, he had to. That was 12 months ago. It worried me, and it worried his dad. He came back here, and well, it is good knowing he is safe. But, well I have still got about 90 hats upstairs. He has got rid of the ball gowns - I had them all up hanging around, as if I haven't got enough to do.

RC: So, P. is around a lot now during the day? Does he help you and his dad?

C172: Not really. We gave him the lounge you see. His choice of music and television are not ours. So, it saved a lot of hassle. So, really we see him mostly at mealtimes. But if there is any football on, he will come in and discuss it with J. They will talk football. But if I said to him, "I am going out, please keep an eye on your Dad." he does. I can rely on him for that. He is trying to get work, but he is 44, and they all want younger people.

The circumstances of their son moving back home had provided some worry for both patient and caregiver, but C172 was unable to say whether her husband's symptoms had changed. There were costs to him being home in so far as the extra housework was concerned, but there were also some benefits, particularly in that C172 was able to go out more, because she knew someone else was in the house. This was to prove more important in phase II when J. began having periods of confusion.

Life events happened to many of the PD dyads, and they do need to be considered if caregiving is fully portrayed. Four cases were given here to illustrate the general effect of life events on PD and PD caregiving. In this sample, there was little influence of some life events on PD symptomatology, but major life events, positive and negative, did have an effect. This was most pertinent with negative life events because it was apparent that there was often acceleration of progression. There is no remission in PD, but the interview data suggested that patient mood was considerably better in the presence of a positive life event, and evidence of progression of illness was not seen.

6.9 Medication

Medication is a major issue in Parkinson’s disease. Quality of life is compromised by PD, but the medication enables a degree of normality to be maintained. As reported in chapter one, however, the drugs can be likened to a two-edged sword in so far as continued use eventually reduces their potency, and they also have side-effects.

In Parkinson’s disease, unlike many other chronic illnesses compliance to medication regimes is very high. Indeed, there seemed to be great faith in the tablets. One patient set an alarm clock to ensure that she never missed getting her medication at the “right” time. Another young-onset patient reported that “I live watching the clock, because my life revolves around the tablets.” Many of the older patients, however, had given the responsibility for their medication to their caregiver. Here too though, caregivers adopted formal methods to remember to keep to what were often complex drug schedules. Some patients were ingesting more than 20 different types of tablets during the course of each day. Many caregivers bought daily or weekly pillboxes into which the tablets were sorted at a regular time. One caregiver had a diary in which she had written down every tablet and every Apomorphine injection her mother had and the exact time at which taken / administered. She had done this for over three years.

Most caregivers were rigid in following the exact prescription from the doctor. There were, however, two caregivers who had manipulated the medication to help themselves. In both cases, they were troubled by dyskinaesias. C120 completed removed her husband’s Sinemet (levodopa + carbidopa) after he became demented because:

> C120: He didn’t know where he was. It was frightening. He was flinging himself all over the room and he had absolutely no awareness. He would only have to have one and he was off. Now he sits happily, and he is no worse off. He is not going to get any better. I couldn’t cope with it. Occasionally I will give him one if he is frozen.

For C112, there was a more subtle form of manipulation. Her husband was medicated solely by Apomorphine following a very distressing period of hallucinations. This meant he actually administered the drug himself, via a syringe driver, during the day. He could only do this, however, after his wife had set up the syringe driver for him. In the early days before C112 had been trained to do this, nurses used to come at 9 am to do this for him. He still got up at the same time, but C112 would wait up to 3 hours before injecting him "because he doesn't need it".

RC: When do you know it is time to inject T. with the syringe driver?

C112: He starts to look unwell. And it is an effort for him to talk. I will then put the syringe driver in, and he is soon benefiting.

6.9.1 Surgery

This sample of PD patients contained three patients for whom surgery was seen as an improvement to their current medication. All three were under 60 and had severe tremor / dyskinaesias which were much worse on one side than the other. P109 was currently waiting for his third thalamotomy.

C109: At the moment R. is pretty poorly, because it [violent tremor] has started on the other side now. I never thought that would happen after the operations.

RC: Why did he have to have the second?

C109: The [effects of the] first one only lasted three weeks. We thought it had been a success because the tremor stopped, and then it came back. It was roughly 11 months before he had the next one. R. didn't want to go through it all again, obviously, because it is not a nice operation. It is not like getting a tooth out because he is awake while it is all going on. But we encouraged him. I didn't think it wouldn't work. It was the only hope he had, put it that way. And it turned out brilliantly. The second time his arm was left completely normal. He still had to take the tablets, of course, but he was virtually normal. And then this started on the other side (dyskinaesias) which is, I must admit, a lot worse than the first. It is more violent.

When we went six months ago, they said they didn't operate on both sides. So, we thought there was no hope. But between us going for the next appointment, the surgeon said he will do both sides, and he asked R. whether he would be willing to have it done. I was waiting for him to refuse, but he said yes.

RC: Do you want him to have the operation?

C109: Oh yes, yes. He can’t go on like this, can he?

The improvement in P109 following the second thalamotomy enabled him to stay at work for another six years and they had a relatively normal life. He was still under retirement age and the carer was working part-time. C109 was very keen to seize the opportunity to have a normal life again. At phase II, however, the third operation still had not been done. Drugs were not helping his dyskinaesias at all. But C109 remained hopeful that it would still go ahead.

In phase I C140 mentioned that her mother, who had a severe unilateral tremor and dyskinaesias had been offered surgery.

C140: She is worried about being a guinea pig. Perhaps they need to be tried and tested a bit. I also worry about her brain. I don’t think she has any memory loss at all, I feel she is quite on the ball. I don’t know. It will have to be her decision.

Before phase II, P140 went ahead with the thalamotomy.

C140: I was surprised that she was so poorly after the operation. She was confused for a couple of days, and I slept beside her in the hospital because I was so concerned. But it has turned out marvellously. Her movements are much, much better and she is just the same mentally.

This was true. P140 was tested on the neuropsychological tests included in this study two weeks after the operation, and again two months later. There was no reduction in her previously very high scores.

The third patient who had this operation was also improved His caregiver regarded it as “great”, and although it was winter, they had been out walking much more than they had done for some time. All three caregivers regarded their experience of caregiving to have been greatly improved by surgery, but it is not widespread. It appears that it is only suitable for patients who are relatively young, and who have severe unilateral disease. Not one of the older patients in this sample was offered surgery as a means of controlling symptoms.

6.10 Reason for Caregiving

As outlined in chapter two, there are several suggestions as to why people take on the caregiving role. To investigate why this sample of PD carers gave care they were asked a direct question at interview in phase I:

“What is the most important reason why you care for _____?”

It was interesting that caregivers rarely hesitated before answering. A sample of the responses follows:

C133: Because we love each other, and love overcomes all other things.

C140: I love her. She has given me years and it is about time I did something.

C159: I married him. Put it that way.

C165: I just care about him. He’s always been good to me. And if it were the other way round, he would look after me.

C113: I know the girls would be very good to him, but he wouldn’t feel the same. He is more at ease when I am doing things for him.

C123: We were married in church and we made our vows for better for worse, in sickness and in health. We made our vows, so we keep them.

C128: Really … I have no choice in these matters. I do feel trapped.

C126: Because she is my Mum! And she needs me.

C134: Because I love him.

In fact, 71% of the caregivers gave quick and simple response indicating that the reason why they give care is because they love the person with Parkinson’s disease. Although the majority of this sample were spouses, daughters also freely gave their reason for caregiving to be love of the PD patient.

All the responses were coded by the interviewer, and it was found that there were just four qualitatively different categories, which were (i) *love* which was the reason for caring for 70.7% of the sample; (ii) *responsibility* was the reason for 18.7% of caregiving; (iii) *reciprocity* was the reason for 6%; and (iv) being *trapped* in the situation was the reason for 4% of caregiving.

6.11 Most Stressful Aspects of PD Caregiving

In phase I, caregivers were asked a single question to determine what the one most stressful aspect of PD caregiving was for them. There was a surprising amount of variety in the responses. In line with the quantitative data, 19% of caregivers said that they did not find anything stressful, but 81% described a particular aspect of their caregiving that caused them concern. To reiterate, carers were asked:

"What aspect of looking after _____ do you find most stressful?"

Examples of responses were:

C117: The worry of it progressing and J. deteriorating.

C113: That I can't drop off to sleep because I am listening for him all the time.

C168: The hallucinations. Definitely.

C129: The need to provide cover <u>all</u> the time.

C139: Always being alert in case she falls.

C120: I wonder what would happen if I was ill.

C133: The depression. I feel that I should be able to get him motivated, and I can't.

C140: The unpredictability of the disease. Not knowing how she is going to be from one day to the next, let alone one year to the next.

The full range of types of responses to this question is presented in table 6.11.1, below. There were some surprises in patient responses. Firstly, not one caregiver mentioned dementia, either in the sense of dealing with it, or fearing it.

Table 6.11.1 Aspects of PD caregiving that were the most stressful for individual carers at phase I (n = 77)

Most Stressful Aspect	Number of carers
Watching the patient deteriorating	10
Patient personality change	8
Fear of being ill oneself	6
Patient falls	6
The need for patient cover	3
Relationship change	3
Patient forgetfulness	2
Dressing patient	2
Having no spare time	2
Being patient with patient’s slowness	2
Toileting	2
Not getting enough sleep	2
Lifting patient	2
Leaving patient alone	2
Dying first	2
The unpredictability of the illness	2
Feeding patient	1
Having to learn to drive	1
Hallucinations	1
Dyskinaesias	1
Money problems	1
Totally resigned to situation	1
Nothing stressful	15

Two caregivers did say the patient’s forgetfulness was most stressful for them; both these patients were demented. Secondly, only one caregiver said that patient hallucinations was the most stressful thing for her, even though in the body of the interview many carers had indicated that they found patient hallucinations distressing. This may be because the patients who were hallucinating had more advanced PD, and therefore these caregivers had many other stressors on an ongoing basis, whereas the hallucinations appeared periodically. Thirdly, lack of communication was not explicitly stated, although it may have been seen as part of personality change and relationship change. The most frequently endorsed stressful aspects to come out of this exercise were more global concerns - what would happen to the patient if the caregiver was ill, or if the caregiver died first; watching the patient deteriorate and not being able to do anything about it; the observation that the patient's personality had changed, and the need for constant vigilance because of their care-recipient is liable to fall. Most of the other stressful aspects mentioned were directly related to PD.

6.12 Satisfaction in PD Caregiving

In phase II, caregivers were asked a single question to determine what they found satisfying in PD caregiving.

"Can you tell me if there are things which you enjoy, or find satisfying in your role as caregiver to _______?"

C113: I hope I am helping him find ways of doing things which are easier for him.

C142: Dear me. Well, I don't mind shopping. That part doesn't worry me. I can spend money all right.
RC: Anything else?
C142: Not really. Even the cooking side, well you have got to do that because you have to eat yourself, haven't you.

C159: No, I can't think of anything.
C162: It is not what I would have chosen at all, but yes, I do enjoy his company and being with him more.

C110: We have become closer as he has become more dependent on me, especially in the last 12 months.

C123: You just get on with things.

C112: I always wanted to be a nurse, and especially since I learnt to do the syringe driver and inject T. I have felt like I have become one.

C118: Everything I do is satisfying to me. I enjoy doing the jobs.

All responses were coded by the interviewer, and it was seen that as in the Reis *et al.* (1994) study, there were essentially six categories of qualitatively different sources of satisfaction. Almost 22% of the sample found nothing enjoyable at all in PD caregiving, but several caregivers listed more than one aspect of satisfaction (see table 6.12.1, below).

Table 6.12.1 Aspects of satisfaction from PD caregiving at Phase II (n = 56)

Source of Satisfaction	Number of Carers[9]
Satisfaction from accomplishing a duty	30
The sense of acting from love	25
The company of the relative	12
Preventing institutionalisation	6
Learning new skills	2
Nothing enjoyable	12

It has been argued that there are positive aspects in caregiving as well as negative, though the negative aspects have received far more attention (Stone *et al.*, 1987). Asking PD caregivers what they found satisfying in their job, showed that 78% of this caregiving sample did get some satisfaction from their caregiving efforts. The most frequent satisfactions were from accomplishing a duty, and from the sense of giving care out of love. Six carers mentioned that they were preventing institutionalisation, but all of these carers also gave one of the two main responses.

It is true that many caregivers qualified their answer by pointing out that it was not something that they would have done by choice, nevertheless, the vast

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[9] Carers who gained some satisfaction from PD caregiving mentioned an average of 1.7 sources.

majority did get some satisfaction from the efforts to meet the needs of their care-recipient with Parkinson’s disease.

6.13 Summary

Qualitative data were used in this research to illustrate the experience of looking after someone with Parkinson’s disease using detail that would have remained hidden had quantitative analyses alone been used. The interviews with the PD carers provided a wealth of descriptive detail on the whole process of the caregiving experience, from the initial presentation of symptoms, the diagnosis of the disease and the effect that this had on them and their care-recipient. Excerpts were taken from selected cases to show that the insidious onset of the disease often leads to a period of worry and uncertainty. It was also seen that when a diagnosis is finally made, relief was not a common emotion.

Carers were asked about their care-recipient’s personality. Half the caregivers reported that there had been personality change and they were able to describe those changes. Depression, apathy and withdrawal were the major changes, and it was noted that patient personality changes usually led to a change in the dyadic relationship.

It was seen in chapters four and five that job demand was an important variable with respect to outcomes for caregivers. In this research, carers were asked exactly what their caring consists of. The selection of cases featured in this chapter illustrates caregiving at different stages of the disease and emphasises that there is a large physical load when caring for someone with advanced PD.

PD caregiving had a lot of variation, and this was not just due to the heterogeneity of the symptoms. This chapter includes illustrations of how caregivers respond differently to similar illness situations and indicated that caregivers bring their own characteristics to the caregiving task. Qualitative evidence was also put forward to support the view that other major life events affect both the caregiving and the PD symptomatology.

There was not a large variety of reasons why people cared for these PD patients. For nearly three-quarters of the sample, the answer was simple: for the love of the patient.

Responses to a direct question indicated that over 80% of this caregiving sample found the caregiving task stressful, and the most stressful aspect for individual caregivers was watching the patient deteriorating. This is probably not surprising if one considers that they are watching the one they love become progressively disabled. Nevertheless, despite the stresses of PD caregiving, the majority of this sample of PD caregivers were able to say that they got some satisfaction from the experience of caregiving. Again, this largely stems from successfully performing a duty and love.

CHAPTER 7

DISCUSSION

7.1 Introduction

In this chapter, the results of the investigation of caregiving in Parkinson's disease are evaluated. Various *a priori* hypotheses were made following a review of the Parkinson's disease literature and the caregiving literature. The results of the tests of these hypotheses are discussed in a systematic way, and other notable findings to come out of the research are examined. A revised model of PD caregiving that is based on the findings is presented.

In preparing for this research, it was noted that there was no consensus on the best way to measure caregiving outcomes. Consideration of the components of measures that have been used in the caregiving literature suggested that there were at least six qualitatively different domains in which caregiving was potentially having a negative impact on carers. The six domains identified were three different types of burden - emotional burden, burden from impact on the dyadic relationship, and burden from impact on carer's social life - and depression, psychological health, and life satisfaction.

Accepting that a lack of specificity in the operationalisation of caregiver distress may prevent a full appreciation of the caregiving situation, it was decided to include measures of all six aspects of distress. This decision was a good one in so far as the results clearly showed that the potential predictors of distress were not associated with all the different aspects of distress in the same way. Some independent variables did have an "all-or-none" relationship with the dependent variables, but there were also many examples of specific relationships between an independent variable and specific caregiving outcomes. This information would have been missed if Montgomery *et al.'s* (1985a) defence of the use of a global burden score had been accepted. If a summated distress score had been used then it would not have been clear that cognitive demand was strongly associated with emotional burden and impact on relationship, and that it had no impact on social life. Similarly, it would not have been clear that severity of physical illness was strongly associated with emotional burden and impact on social life but had no impact on the dyadic relationship (see Table 5.3.1, p. 222). Poulshock & Diemling (1984) advocated that burden should be seen as a multidimensional concept in which specific burdens are associated with specific impairments. The results from this investigation support that notion. Certainly, it is argued that the reduction of distress to its component parts assists with understanding the PD caregiving situation. To say that physical disability has a very strong impact on carers' social life is intuitively sensible, but it was not previously obvious that physical disability would have no direct effect on caregivers' mental health outcomes. From a clinical perspective, the reduction of caregiver distress allows for the identification of specific areas of problems for carers and provides a focus for interventions.

Further support for the notion that the six outcomes measures were indeed measuring different aspects of distress was provided by the fact that phase II results revealed that the six distress measures were not all intercorrelated with each other. The three burden measures were significantly related to each other, as were the two mental health outcomes. It was clear though, that the three burden measures were conceptually distinct because of the pattern of correlations with the other dependent variables. Impact on social life was not associated with depression, poor psychological health or poor life satisfaction, whilst emotional burden was related to all three. Carer depression was related to impact on relationship whereas poor psychological health was not. The pattern of the relationships between the caregiver distress variables alone indicates that it was correct to consider that distress is a multidimensional concept.

7.2 Job demand and Caregiver Distress

It was hypothesised that there would be a positive relationship between the physical demands of caring for someone with PD and caregiver distress. This hypothesis was strongly supported for both objective job demand (as measured by patient severity of illness) and subjective job demand (as measured by caregivers' assessment of number of hassles). It was also hypothesised that there would be a positive relationship between the cognitive demands of PD caregiving and caregiver distress. There was some support for this hypothesis with respect to dementia and the computed cognitive demand variable, but subtle changes in mental status, verbal intelligence and recognition memory were not associated with caregiver distress. These findings will be discussed in greater detail below.

7.2.1 Severity of illness and caregiver distress

Severity of PD was significantly related to five of the six distress measures in phase I. The significant association of severity of illness and emotional burden, impact on social life and low life satisfaction was replicated in phase II. The absence of a relationship between carers' psychological health and patient severity of illness was also replicated. It might have been expected that all the significant relationships would have been replicated when using the same set of subjects, and especially as there was a significant increase in UPD scores between phase I and phase II. Caregiver distress, however, did not change in intensity between phases I and II, suggesting that caregiving outcomes were not solely dependent on the patients' severity of illness. It was noted that the correlation coefficients of the three replicated relationships were higher, and the two distress measures that were not replicated were lower in phase II. Certainly the conditions for significance were more stringent in phase II, but it is difficult to explain why the impact on relationship and depression from physical severity was not seen a year later, if one assumes that there is a stable model of PD caregiving. One suggestion is that some adaptation was possible by caregivers with respect to the impact of PD severity on the dyadic relationship, and their mood, but that adaptation to the changes in social life, emotional response and life satisfaction which stemmed from patients' physical limitations was not possible in the same way.

The finding that dependent PD patients' physical limitations had a significant effect on caregiving outcomes supports the work of Calder *et al.* (1991). They found that Hoehn and Yahr disease stage was significantly associated with carer stress, as measured by the Relatives' Stress Scale (Greene *et al.*, 1992). Hoehn & Yahr disease stage was also measured in this study: the associations of distress and disease stage mirrored the associations of distress and UPD score.

Miller *et al.* (1996) also considered that physical impairment might be a predictor of distress in PD caregivers but found this was not so. The reason that motor impairments did not make a significant contribution to carer distress in their study was probably due to the distress measures they used. They only considered caregiver depression and psychological health. Therefore, the results from this research actually replicated the Miller *et al.* results. There was no relationship between UPD scores and GHQ scores at phase I or phase II, and although there was a relationship between UPD scores and carer depression at Phase I, this was not replicated in phase II. In this study, it was found that physical impairment was an important predictor of impact on social life, emotional burden and poor life satisfaction. If Miller *et al.* has used these measures, it is likely that their hypothesis would have been supported. This shows the importance of the choice of measures when investigating a particular hypothesis.

The finding that PD patients' physical status was associated with caregiving outcomes is in contrast to previous findings of weak or non-significant relationships between measures of elderly dependants' physical limitations and caregiver burden (e.g. George & Gwyther 1986, Pruchno & Resch, 1989a, Zarit *et al.,* 1980). However, the patient populations used in these studies were not suffering from a motor disorder. This indicates that models of SDAT caregiving do not generalise to PD caregiving because it is clear that when giving care to a much more physically dependent Parkinson's patient, physical demand is an important predictor of distress.

Calder *et al.* (1991) caution that because of the association of PD with cognitive impairment, "it might not be justified to claim that motor impairment causes more stress to relatives than dementia or cognitive impairment" (p.741). It is true that in this research the greatest distress was seen in the *advanced* PD group, and most (but not all) of the demented patient were also in this advanced group. However, when all the potential predictors of caregiver distress were entered into a multiple regression equation it was found that for *impact on social life,* patient cognitive demand did not enter the equation, and Hoehn & Yahr disease stage was the best predictor of this aspect of distress, explaining over 45% of the variance. Similarly, for *life satisfaction* cognitive demand did not enter the equation, but physical severity was the biggest predictor of this aspect of distress, explaining 31.5% of the variance. However, for *emotional burden*, the other distress measure that was consistently and strongly associated with severity of PD, physical severity did not significantly add to the variance, but cognitive demand contributed a significant 19% to the variance.

These results indicate that Calder *et al.* were correct to advise caution with respect to the role of motor impairments in caregiving outcomes, but the results from this research show that the job demand put on carers by patients' motor impairments is the biggest contributor to burden from impact on social life and poor life satisfaction in PD caregivers.

7.2.2 Cognitive demand and caregiver distress

In phase I, cognitive demand, an objective experimenter variable based on patients' performance on the MMSE and Raven's Standard Progressive Matrices (RPM), was significantly associated with impact on relationship, emotional burden and poor life satisfaction. In phase II, the correlation coefficients of cognitive demand and these three distress measures were again high, although because of the reduced sample size, the relationship between cognitive demand and life satisfaction failed to reach significance.

The presence of dementia and performance on RPM were similarly associated with impact on relationship, emotional burden and poor life satisfaction, but mental status *per se,* as measured by raw MMSE scores, was associated with poor life satisfaction in phase I and emotional burden and impact on social life in phase II. Global slowing was associated with emotional burden. Current verbal intelligence, word recognition memory and face recognition memory were not related to any measure of distress.

Together, these results indicate that cognitive demand does not affect carers' mental health outcomes. It may have an impact on the dyadic relationship, an impact on social life, affect life satisfaction and be associated with emotional burden, but it appears that considerable cognitive decline has to occur before the caregiver is depressed.

Performance on the RPM was generally poor, and this non-verbal intelligence test was associated with distress. Verbal intelligence, as estimated by Mill Hill vocabulary scores were better preserved (when compared to NART performance) and scores on this test were not associated with carer distress. Word recognition memory was associated with impact on relationship in phase II, but face recognition memory, which was significantly impaired when compared to age-matched controls was not related to distress. This may have been because the impairment is specific to the recognition of unfamiliar faces, and PD patients may not have the need to remember many unfamiliar faces, so the impairment is not an everyday problem.

The MMSE was used a screen for dementia in phase I; the positive correlations indicated that caring for someone with dementia was associated with three measures of distress. However, when the raw scores were used, a decrease in score was only related to poor life satisfaction. To get a better understanding of this it was decided to standardise the MMSE scores and the RPM scores: the nature of these tests means they do not have a normal distribution. They were multiplied together to exaggerate the difference in performance - the range of scores on the MMSE being particularly small. This computed objective measure of cognitive demand score was significantly related to impact on relationship, emotional burden and poor life satisfaction, and it was found to be a better predictor of the impact of cognitive decline. That is, *cognitive demand* was found to explain a significant 6% of the variance of burden from impact on relationship, and a significant 19% of the variance of emotional burden.

Therefore, the hypothesis that there will be a positive relationship between the cognitive demands of caring for someone with PD and caregiver distress was partially supported. That is, in Parkinson's disease considerable cognitive decline has to occur before it was associated with distress, but even then cognitive decline was not associated with mental health outcomes. However, the observation that (considerable) cognitive decline is associated with burden and poor life satisfaction is in contrast to the SDAT literature, where most studies have found weak or nonsignificant associations of cognitive decline and caregiver burden (e.g. Gilhooly, 1984; Gilleard, 1982, 1984; Zarit *et al.*, 1980, 1986). Pruchno & Resch (1989a) suggested that this is because in Alzheimer's disease cognitive problems cause less problems as intellectual impairment advances because patients then become less active. In Parkinson's disease however, physical demands will continue to increase with a decrease in cognitive functioning. Essentially, this means that a model of PD caregiving cannot be the same as a model of SDAT caregiving.

7.2.3 Subjective job demand and caregiver distress

There was strong support for the hypothesis that carers' perception of job demand would be related to caregiver distress. In phase I, subjective job demand was related to all six measures of caregiver distress. This was true even when subjective job demand was reduced to its component parts. In phase II, the association of subjective job demand and caregiver distress was replicated for five of the six aspects of distress demonstrating that carers' appraisals of their work situation are important predictors of outcomes.

It was interesting to note that in phase II, when there was more specificity in the significant associations of the different types of caregiver hassles and caregiving outcomes, the relationship between caregiver distress and hassles from ADL remained strong, although as with total job demand, there was no relationship between ADL hassles and carer depression in phase II. Hassles from patients' cognitive status and behaviour were significantly associated with impact on relationship and emotional burden, and not with impact on social life, as with the objective measure of cognitive demand. Hassles with IADL were also associated with impact on relationship and emotional burden, and poor life satisfaction, and not with impact on social life. It was initially thought that hassles with IADL would have the same impact on carers as hassles with ADL. However, consideration of the items on this scale (e.g. "Care-receiver causing extra expense to the household"; "Care-receiver requires supervision at night"), leads one to conclude that these items are probably as sensitive to patients' behaviour as to their physical disability. This then, may explain the significant relationship of hassles with impact on relationship, rather than impact on social life.

Interestingly, there was no difference in caregivers' appraisals of job demand between phases I and II, despite a measurable progression of physical and cognitive symptoms in the patients. This could have been because there was some kind of ceiling level on this questionnaire, but there was no evidence that this is the case. There was a normal distribution of responses and no carer scored the maximum. It is likely then, that carers' perceptions of job demand do not exactly reflect their care-recipients' physical and mental status. A self-report of a demanding job will also express an element of subjective perception of stress (Lazarus, 1966). There was some indication of this in the interview data. Nevertheless, it is very clear that carers' perception of job demand had a significant effect on caregiving outcomes.

7.2.4 Job strain and caregiver distress

Although carers' perceptions of job demand were strongly associated with caregiver distress, it was hypothesised that Karasek's (1979) job stress model would be relevant for stress associated with informal caregiving. Thus, it was hypothesised that caregiver distress would be directly related to the interaction of job demand and job discretion. A job *strain* variable was computed to reflect this interaction (c.f. Theorell *et al.*,1988).

The job strain and job demand variables used to test the hypothesis were subjective job demand measures rather than objective job demand measures for two reasons. First, Karasek's job demand scale measured the psychological stressors involved in accomplishing a workload. "There is no attempt....to measure the impact of physical job stressors" (p. 291). The items on Karasek's scale (e.g. "My job requires working very fast", "My job requires long periods of intense concentration on the task") require decisions, and therefore the responses are perceptions. The job demand measure from the Caregiving Hassles Scale (Kinney & Stephens, 1989) has a similar decision-based response format, and therefore this was preferable to using the objective job demand measure based on severity of illness. Second, the subjective job demand measure includes demand from both physical and cognitive aspects of caregiving. A new variable would have had to have been created to provide an inclusive objective measure of job demand.

To test whether job strain was more important for predicting caregiver distress than job demand, stepwise multiple regression analyses were used. Separate analyses for each aspect of distress indicated that the hypothesis was partially supported. Job strain was a better predictor of caregiving burden and depression, but job demand was a better predictor of psychological health and life satisfaction than job strain. That is, discretion had an important influence on job demand with respect to burden and depression, but not on psychological health and life satisfaction. Indeed, further analyses indicated that the interaction of job demand and discretion was the best predictor of burden from impact on relationship, explaining 52% of the variance.

Orbell & Gillies (1993) similarly looked at the interaction of job demand and discretion in a population sample of elderly caregivers. Their only outcome measure was the 12-item General Health Questionnaire (GHQ; Goldberg, 1978) which was used in this research to measure psychological health. They called it *strain*. They did not compute a job strain measure but made four (uneven) groups by using median splits to determine high and low demand and high and low discretion. Their results indicated that there was a significant main effect of demand and a significant interaction between demand and discretion. Further analyses showed that discretion only had a significant impact on GHQ scores at high levels of demand. Therefore, “the results provide only partial support for Karasek’s theory” (p. 285).

The different methodology makes it is difficult to provide a direct comparison of Orbell’s test of Karasek’s theory, using carers of frail elderly inhabitants of Dundee, and this test of Karasek’s theory in PD caregiving, despite the fact that the same version of the GHQ was used in both studies. It is noteworthy though, that neither study found full support for an influence of caregiver discretion on job demand when the GHQ is used as an outcome measure. Job demand was a better predictor of GHQ scores than the computed strain variable, and there was a main effect of job demand in the Orbell & Gillies study.

It is important to point out that although job strain was found to be a better predictor of carer depression than job demand, neither variable was significantly associated with this outcome measure. Job strain was strongly associated with the three burden measures, but not the mental health outcomes measures or with life satisfaction. It follows from this that Karasek's theory applies to the prediction of burden in PD caregiving, but not distress in general.

7.2.5 Summary

Objective job demand, subjective job demand, and job strain were all significantly related to specific aspects caregiver distress. Further, job strain was the biggest predictor of burden from impact on relationship, Hoehn and Yahr stage was the biggest predictor of burden from impact on social life, physical demand was the biggest predictor of life satisfaction, and cognitive demand was a significant contributor to the explained variance of impact on relationship and emotional burden.

Caregiver depression was the only distress measure that was not affected by the demands of caring for someone who has Parkinson's disease. These results are in contrast to the general findings in the caregiving literature that there is no relationship between dependants' impairment and caregiver distress. Draper *et al.* (1995) suggested that the type of the dependant's impairment may be relatively unimportant in the evolution of caregiver distress, but these results indicate that it is inappropriate to consider that there can be a general model of caregiving. Patient variables are important to a model of Parkinson's disease caregiving.

7.3 PD plus Dementia and Caregiver Distress

In phase I, 12% of this PD sample were also dementing. The results revealed that the PD plus dementia carers had significantly more emotional burden, greater burden from the impact on the dyadic relationship, greater burden from the impact on social life, poorer psychological health, and lower life satisfaction than the PD without dementia carers. The difference in depression scores between the two groups, however, was not statistically significant. The hypothesis that greater distress would be found in the PD caregivers whose care-recipient was also dementing, than those whose caring for a PD patient without dementia was therefore supported - except for caregiver depression.

Dura *et al.* (1990) found that there was no difference in caregiver depression according to whether the dementia was caused by Alzheimer’s disease or Parkinson’s disease, but both these caregiving groups were more depressed than control subjects. In this study the mean depression scores of the two groups of carers were both below the cut-off point for mild depression, despite the fact that 23% of the total sample scored above the cutting point. This indicates that there were depressed caregivers in the PD without dementia group, and that dementia *per se,* was not a source of depression in this group of people giving care to PD patients with dementia.

The results provide tentative support for Clipp & George (1993) who matched cancer patients and dementia in terms of functional limitations and found that the dementia caregivers were more distressed than the cancer caregivers. Similarly, Palmore *et al.* (1985) argued that the additional difficulty of dealing with cognitive and behavioural changes puts dementia carers at greater risk of poor outcomes. It is true that the added difficulty of having to deal with dementia caused more adverse consequences for these PD caregivers. It is not possible, however, to say that dementia is more distressing than PD, because the functional impairment was present in both groups. The small number of demented PD patients made it impractical to match subjects in terms of functional disability, but it is not clear that if this had been done, that the answer to this would have been any clearer. The dementia would still have been in addition to the PD. It also seems unlikely that a sample of dementia patients without PD could be matched to a PD sample in terms of functional disability.

According to Palmore *et al.*, dementia represents a distinct type of limitation that leads to a unique experience among caregivers. It is also possible to say the Parkinson's disease represents a distinct type of limitation that leads to a unique experience among caregivers. It was shown here that the addition of dementia to this experience, provides additional burden, poorer psychological health, and lower life satisfaction.

7.4 Hallucinations and Caregiver Distress

It was hypothesised that greater distress would be found in PD caregivers whose care-recipient had experience of hallucinations as compared with those whose care-recipient had never had a hallucination. The hypothesis was strongly supported. Caregivers of hallucinating patients were significantly more distressed than those caring for a PD patient who had not had any hallucinations. This was so for all six aspects of distress measured in this research.

Experience of hallucinations was also found to be a strong predictor of impact on relationship, emotional burden, caregiver depression and poor life satisfaction, although this independent variable did not significantly add to the variance of any of the distress measures when all the potential predictors were considered. It is suggested that this may be because experience of hallucinations was overshadowed by severity of illness. Pearce (1992) noted that hallucinations are uncommon in the early stages of the disease and this was certainly true for this sample. Patient hallucinations were strongly associated with duration and severity of illness, Hoehn & Yahr disease stage and dementia. That is, hallucinations were absent in the early stages, they were frequently present in the later stages.

Hallucinations may be intimately associated with severity of illness, but they were still reported to be a significant problem for caregivers in their own right. At interview, caregivers spoke of their distress from their experience of witnessing their dependant hallucinating. They often became involved in the hallucinations, and, as the quantitative results show, this resulted in impact on the dyadic relationship, emotional burden, depression and low life satisfaction.

The prevalence of hallucinations in this study was at the top end of the range found in the previous studies reviewed by Cummings (1992). The average prevalence was 20%, but he cautioned that the actual prevalence was likely to be higher because they are underreported by patients who see them as a sign of mental illness. In this study, the experience of hallucinations was systematically sought and the prevalence rate of 38% was very similar to the 36% found in a recent study of the prevalence of psychotic symptoms in PD (Naimark *et al.* 1996).

Despite the relatively high prevalence of hallucinations in PD, little consideration has been given to the impact of hallucinations on the caregiver in the literature. Hallucinations are normally attributed to a side effect of medication, and there may be some medical intervention for the patient by way of changing the medication. This worked for just one patient in this sample. He completely withdrew from levodopa therapy in favour of Apomorphine therapy and his severe hallucinations never returned. All the other patients in this study, however, continued to have hallucinations, even after a medication change, although for some this was on a less frequent basis.

To summarise, the results of this investigation of PD caregiving clearly show that patient hallucinations are associated with caregiver distress. A substantial minority of PD patients had experienced hallucinations and their caregivers were more distressed than caregivers of patients who have not suffered from hallucinations.

7.5 Personality Change in Parkinson's Disease and Caregiver Distress

Parkinson's disease is associated with subtle cognitive changes in the frontal lobes (Dubois *et al.*, 1994), and the frontal lobes have been linked with multiple changes in personality (Stuss *et al.,* 1992). It follows from this that personality change may be a feature of Parkinson's disease. Some support for this notion was put forward by Poewe *et al.* (1990), Glosser *et al.* (1995) and Mendelsohn *et al.* (1995), although it is not clear whether the personality changes they found in PD patients are specific to PD, or are common to all neurological illnesses. But whether personality changes are specific to PD or not is essentially immaterial to this investigation. The focus was on the effect of changes in patient personality on caregiving outcomes. It was hypothesised that caregiver distress would be greater where caregivers perceive a marked change in patients' personality, and that this would be so at both high levels and low levels of job demand.

Interviews with the caregivers indicated that just over half the sample perceived a marked change in their care-recipient's personality, albeit retrospectively. To investigate the nature of personality changes, and the effect of any changes on caregiving outcomes, two quantitative measures of personality change were administered to caregivers. An adaptation of the five-factor NEO-FFI (Costa & McCrae, 1992) sought personality change at the factor level, and the Identity Test (Brooks & McKinlay, 1983) was used to investigate personality change at the trait level. For both tests, the caregiver was asked to consider patient personality before PD, and then as they were at time of testing. This was the best that could be done in the absence of documented evidence of patients' personality from a certain period before they became ill.

7.5.1 Personality change at the factor level and caregiver distress

The NEO-change test required carers to say whether there had been a change in how the patient would have been before PD for each of the 60 questions. A yes response prompted an evaluation of the extent of the change, which was then rated from one to four. The direction of change was determined: this never altered; the change was always more neurotic, more introvert, less open, less agreeable and less conscientious. Essentially then, a score above zero was indicative of some change on that factor. For each of the five factors, some caregivers considered that there had been no change, and some caregiver did report change. The largest changes were seen on the extraversion factor, with modest changes also being reported on the neuroticism and conscientiousness factors. There was, however, little change with respect to openness and agreeableness. It was not surprising then, that changes on the latter personality factors were not associated with caregiver distress. It was surprising, however, that changes in neuroticism were not associated with distress either. A reason for this might lie in the fact that carers' appraisals of current patient neuroticism indicated that only 2.5% of the sample were abnormally neurotic after the changes. It appears that the changes in patient neuroticism were not perceived as amounting to problem behaviour.

Changes in extraversion were associated with burden from impact on the dyadic relationship. This is probably explained by the fact that almost 9% of the sample were rated as abnormally introverted, and at interview many carers mentioned that withdrawal by their dependent had led to a breakdown in communication between them.

Changes in patient conscientiousness were also associated with caregiver distress; less conscientiousness was related to burden from impact on relationship, emotional burden and poor life satisfaction. 12.9% of patients were abnormally low in conscientiousness according to carers ratings of current patient conscientiousness, and none were more than two standard deviations above the mean. These findings are similar to those of Welleford *et al.* (1994) who reported a similar significant decrease in conscientiousness in SDAT patients, and that current patient conscientiousness was a significant predictor of objective and subjective burden.

It was also hypothesised that job demand would have no influence on the relationship between carers' perception of personality change and carer distress. This hypothesis was not supported. When partial correlation analyses of carer distress measures and extraversion and conscientiousness (the two personality change variables associated with distress) were computed, controlling for perceived job demand, the previously significant associations disappeared. It must be concluded from this that personality change at the factor level is not a primary predictor of caregiving outcomes.

7.5.2 Personality change at the trait level and caregiver distress

The Identity Test required caregivers to rate their dependents on 20 bi-polar dimensions of personality separately for premorbid and current personality. A change score was computed by subtracting the “now” ratings from the “before PD” ratings. Considerations was not given to the actual ratings made because the nature of this tests means that there are no norms, and the experimenter noted that some caregivers used the extremes, but others preferred to make their marks towards the middle of the dimension line (see appendix for illustration). Carers were fully aware that the purpose of the exercise was to look for change.

Preliminary analyses indicated that there were significant differences between the premorbid and current personality on 19 of the 20 dimensions. This strongly supports the notion that there is personality change in PD. (The trait *mindful-forgetful* was not perceived to be affected by PD, perhaps because forgetfulness is associated with ageing). A change score was then computed for each subject for each on the 19 dimensions on which there was change. Some carers did indicate that the change was for the better on a particular dimension, but the mean scores were all negative, indicating that generally, the change was not for the better.

The hypothesis that marked personality change would be associated with caregiver distress was partially supported at the trait level. Ten of the nineteen identity variables were associated with distress. This was not simply due to the size of the change, however. The larger change scores were associated with carer distress, but so was the more modest change that was seen on the skilful-clumsy dimension. Following from this, it is suggested that the actual personality trait of change is more important than the extent of the change. For example, there was no relationship between change on the satisfied-dissatisfied dimension and caregiver distress, despite the mean change being more than double that of the skilful-clumsy dimension which was significantly associated with burden from impact on relationship and impact on social life. The anecdotal interview data indicated that it is relatively easy for a caregiver to accept that the chronically ill PD patient becomes dissatisfied with their life, but it is more difficult to deal with the fact that the patient is more clumsy and that this can restrict social life.

The hypothesis that job demand would not influence the association of identity change and carer distress was also partially supported. When perceived job demand was controlled for in partial correlation analyses of the ten identity change variables and carer distress measures five traits were still significantly associated with distress, although to a lesser extent. That is, changes on the bored-interested, unhappy-happy, in control-helpless, lack confidence-confident and difficult-co-operative dimensions were associated with caregiving outcomes, regardless of job demand.

The most important personality change, with respect to caregiving outcomes is probably the change on the bored-interested dimension. The analyses to find the best predictors for each of the distress measures indicated that this variable was a primary predictor of caregiver depression. Despite their direct associations with specific distress measures none of the other identity change variables could significantly add to the explained variance of the distress measures.

7.5.3 Summary

There has been no previous research considering the effect of personality change in Parkinson's disease on their caregivers. It was found that carers could quantify changes in their dependants' personality, but only a selection of the identified changes were related to caregiving outcomes. The extent of change was not as important as the nature of the change. Further analyses indicated that patient personality change is not a major influence in caregiver distress. When job demand was taken into account most of the significant associations of personality change and distress disappeared. Five aspects of identity change remained associated with distress. Only one of these was found to be a primary predictor of distress. That is, changes on the bored-interested dimension, which can be interpreted as an increase in apathy, was found to be important in explaining the variance of caregiver depression. As such, it is argued that this variable is probably the most pertinent of the personality changes to caregiver distress.

7.6 The Influence of Caregiver Personality on Caregiving Outcomes

It was hypothesised that caregiver characteristics would have a direct influence on caregiving outcomes since caregivers of PD patients, like all other adults, have well-established personality structures which they bring with them into the caregiving situation. Neuroticism and optimism had previously been identified as the most salient aspects of personality in the understanding of the outcomes of Alzheimer's disease caregiving (Hooker *et al.,* 1992; Reis *et al.,* 1994; Welleford *et al.,*1994) and, as expected, it was found that carer neuroticism was positively related to distress, and carer optimism was negatively related to distress in this study of caregiving in Parkinson's disease.

Although Hooker *et al.* only measured neuroticism, and Reis *et al.* only considered neuroticism and extraversion, in this research the role of caregiver personality on caregiving outcomes was investigated using all five personality factors of the NEO-FFI (Costa & McCrae, 1992). It was found that extraversion, openness and conscientiousness had no association with caregiver distress. Agreeableness was significantly associated with life satisfaction at phase I, but this was not replicated in phase II. Essentially, these results replicated the findings of Reis *et al.* and Welleford *et al.*

A study by Rabins *et al.* (1990) used the GHQ as a measure of emotional distress and found that neuroticism and openness predicted distress in SDAT patients and cancer patients. This relationship of carer openness and distress was not seen in either this study, or that of Welleford *et al.*, however neuroticism was an important personality variable with respect to caregiver distress in all three studies.

Hooker *et al.* (1992) reported that SDAT caregiver neuroticism and optimism predicted caregiver physical health and mental health. One of the two mental health measures they used was the CESD - the depression measure used in this study. They reported a similar very large correlation (r = .75) between this measure of distress to that seen in this study (r = .79). The relationship of optimism and depression in the two studies was also similarly strong.

Together these results suggest that the effect of personality on outcomes is similar in different caregiving situations. That is, the effect of personality on distress is not affected by the particular illness situation.

Preliminary analyses on the results from phase I, indicated that neuroticism and optimism were the personality variables of importance in caregiving, but it was also conceivable that dispositional hardiness - which is usually described in terms of three closely related styles: challenge, commitment and control - may influence caregiving outcomes. Kobasa *et al.* (1982) had reported that in an organisational situation, hardiness is an important dimension in influencing how people process and cope in stressful life situations. Bartone *et al's* (1989) adaptation of Kobasa *et al's* hardiness scale was therefore included in phase II. It was found that hardiness did directly influence PD caregiving outcomes, but not as a whole. Challenge was not related to any aspect of distress, but it was found that low commitment was related to emotional burden, depression, and burden from impact on relationship. Similarly, control was related to emotional burden and burden from impact on relationship.

Two aspects of hardiness were seen to be predictors of caregiver distress. This represents a step forward in so far as identifying predictors of caregiving outcomes because these personality characteristics are quite different from neuroticism and optimism, and not just another label for the same thing. Hardiness commitment has been defined as having a strong sense of meaning and purpose in life; having high hardiness control indicates a strong sense of autonomy and ability to direct one's own life (Maddi & Kobasa, 1984). From these results, it seems that low levels of hardiness leave a caregiver vulnerable to negative outcomes.

Of the six aspects of distress measured, only burden from impact on social life remained immune to the influence of caregiver personality. This is likely to be because of the overwhelming influence of Parkinson's disease on social life. It is true that in phase II, the phase I associations of neuroticism, agreeableness and optimism, and low life satisfaction were not found, but the other significant relationships between carer distress and neuroticism were replicated. It follows from this that caregiver neuroticism is a consistent predictor of burden from impact on relationship, emotional burden, depression and poor psychological health. Similarly, caregiver optimism is a consistent protector of burden from impact on relationship, emotional burden, and depression. As discussed above, this association of caregiver personality characteristics and distress is probably not specific to Parkinson's disease caregiving, as similar influences of carer personality have been found in SDAT and cancer caregivers.

Braithwaite (1990) also found that her idiosyncratic measure of emotionality (similar to neuroticism) was a significant predictor of burden and "minor psychiatric symptoms" (depression and anxiety). However, she argued that "personality measures are likely to be influenced by the caregiver's level of anxiety and depression" (p. 92). This was illustrated by hierarchical regression analyses where the dependent variable was burden, and anxiety and depression were entered before emotionality. She found that emotionality no longer predicted burden.

It is arguable that there is a problem in the logic of doing this. It ignores the fact that carer anxiety and depression are likely to be very much a consequence of personality styles. Evidence from this study, and that of Hooker *et al.* (1992) clearly indicates that caregiver neuroticism is significantly associated with depression, but it is accepted that this does not indicate the causal direction. Nevertheless, when all the patient, caregiver and dyadic relationship variables in this study were subjected to regression analyses, it was found that caregiver neuroticism was the only significant predictor of caregiver depression. It explained 53% of the variance.

It is true that there is a general assumption in caregiving investigations that the caregiver was not depressed before their dependent became ill, and therefore it is not controlled for. However, in this investigation all caregivers were asked about previous depression at interview. One caregiver had a history of depression but claimed to be completely cured after ECT. There were no other clinical cases. Certainly it seems unlikely that there would have been a background of depression in the amount of caregivers that would be needed to achieve the highly significant association of neuroticism and depression seen in not only this study, but also that of Hooker *et al.* (1992).

Braithwaite (1990) stands alone in not accepting that neuroticism predicts burden and depression, even though her own published results indicate that it does. It is therefore concluded that caregiver personality - specifically neuroticism, optimism and hardiness control and commitment are important predictors of caregiver burden from impact on relationship, emotional burden, poor psychological health and caregiver depression.

7.7 The Dyadic Relationship and Caregiver Distress

7.7.1 The premorbid relationship

It was hypothesised that the quality of the premorbid relationship would be negatively related to caregiver distress, regardless of whether the PD patient was also dementing or not. This hypothesis was strongly supported. In phase I, when this data was collected, it was found that premorbid relationship quality, and premorbid happiness were strongly related to five of the six distress measures. That is, carers (retrospective) perceptions of the relationship quality before PD, were negatively associated with burden from impact on relationship and impact on social life, emotional burden, depression and poor life satisfaction. Moreover, all these significant relationships remained when partial correlation analyses were made, controlling for the patients' dementia status. This indicates that the quality of the premorbid relationship before Parkinson's disease is an important predictor of distress that is distinct from patients' (mental) impairments.

It was assumed that carers' perceptions of the premorbid relationship would remain stable, so the short Dyadic Adjustment Scale (Sharpley & Cross, 1982) was not administered again in phase II. When correlation analyses of this same assessment of relationship quality and the phase II distress measures were computed, it was found that premorbid relationship only predicted burden from impact on relationship and emotional burden. Premorbid happiness was also positively associated with life satisfaction, besides these two variables. It was also found that premorbid relationship added a significant 7% to the explained variance of emotional burden.

These results support previous finding in other groups of caregivers that the premorbid dyadic relationship is an important predictor of caregiving outcomes (e.g. Morris *et al.*,1988; Williamson & Schulz, 1990). However, these results do not support Gilhooly (1984) and who reported that the quality of the dyadic relationship before the onset of dementia was not related to caregiver well-being, or Majerovitz (1995) who found that spouses pre-dementia "adaptability" was not related to caregiver burden, or depression. The results also do not support Gilleard *et al.* (1984) who found that a negative view of the premorbid relationship was associated with caregiver distress.

Whilst this may seem contradictory, the reason for that discrepancy is due to the distress measure used. In this research five of the six distress measures were related to caregiver distress in phase I. However, there was no relationship between GHQ scores and the pre-morbid relationship. Gilleard *et al.* (1984), who found a significant relationship between the quality of the pre-morbid relationship and caregiver well-being used the GHQ as a measure of well-being.

There are other contradictions in the literature. For instance, Morris *et al.* (1988) found that low levels of past intimacy were associated with increased levels of perceived strain and depression, whereas Williamson & Schulz (1990) found that the quality of the pre-morbid relationship was negatively related to burden, but that it was not related to depression. In this study, the quality of the premorbid relationship was related to carer depression in phase I, but not in phase II, which is not very satisfactory for clarifying the issue.

One could say from this set of results is that the premorbid dyadic relationship does have the potential to affect caregiver depression. One possible reason for the different results could lie in the differences between the caregiving samples in the different studies. Morris *et al.'s* sample consisted of spouse caregivers, whereas only 40% of the Williamson & Schulz sample were spouses. This sample was also mixed, although the proportion of spouse caregivers in this sample was much higher (87% in phase I and 91% in phase II). Coyne & DeLongis (1986) noted that the quality of the premorbid relationship was particularly important for married dyads because this is likely to be the caregiver's primary relationship, although this could also be true of an unmarried daughter caring for her mother. Future work which specifically sets out to investigate whether the relationship of the caregiver and dependent influences the way in which relationship quality affects caregiving outcomes is necessary to resolve this issue.

The assertion that premorbid dyadic relationship is a predictor of caregiver burden is less controversial, but even here, not all studies have found support for this association (e.g. Majerovitz, 1995). A basic problem is that besides studies using different outcome measures, there is also little consensus regarding the measurement of premorbid relationship. Of course, none of the present scales is ideal, because of their reliance on retrospective perceptions. This could be surmounted in a prospective study where insidious onset is not a feature of the caregiving (e.g. following traumatic brain injury), but it is likely that descriptions of the predictors of PD caregiving will have to rely on carers' retrospective appraisals of the relationship.

To summarise, the results of this study of PD caregiving indicate that the premorbid relationship is an important direct predictor of caregiver distress, particularly of emotional burden. This relationship variable was a significant contributor to the explained variance of emotional burden.

7.7.2 The current relationship

Townsend & Franks (1995) argued that the importance of quality of the present relationship between carer and dependent differed according to whether the dependent had a cognitive impairment or not. The results from this experiment with Parkinson's disease patients who could be classified as demented or not demented, suggest that this notion is wrong. Dementia status had no influence on the association of the dyadic relationship and caregiving outcomes.

It is true that these analyses used the premorbid relationship data, but that was unavoidable, as it was clear that there had not be a significant amount of change in relationship quality in this sample post-diagnosis. Following Lewis-Beck's (1980) criteria, the size of the shared variance of these two variables indicated that they could not be considered as individual constructs. It is therefore argued that these results support the *a priori* hypothesis that the influence of the quality of the dyadic relationship is not influenced by the presence of cognitive impairments.

In phase II, the present dyadic relationship was reduced to some of its component parts using the FAMIII scale (Skinner *et al.,* 1995) to investigate whether particular aspects of the relationship were associated with caregiving outcomes. There was no *a priori* hypothesis. The results were interesting in so far as it was clear that only certain aspects of the dyadic relationship were important for caregiving distress. In line with the phase II results using the short Dyadic Adjustment Scale (Sharpley & Cross, 1982), only burden from impact on the dyadic relationship and emotional burden were associated with the components parts of the dyadic relationship. Specifically, low levels of task accomplishment, role performance and involvement were all significantly associated with burden from impact on relationship, and low levels of task accomplishment and role performance were also associated with emotional burden.

These results indicate that, as has been argued with distress, a global consideration of relationship quality may not be as useful as assessing the component parts if effective interventions to minimise the distress of chronic caregiving are to be offered to carers.

7.8 Moderators of Caregiver Distress

Caregiving is characterised by much variation in what are essentially similar circumstances, so moderators are usually called upon to provide an explanation for the differences in outcomes (Pearlin *et al.,*1990). Several variables have been identified in the literature as being potential moderators of caregiver distress. For instance, in the Pearlin *et al.* (1990) model of SDAT caregiving (see fig. 3.2.1, p.109), coping style and social support were conceptualised as moderators of caregiver stress. Gender has also been seen as a mediator of stress generally (Jenkins, 1991) and of caregiving outcomes (e.g. Zarit *et al.*,1986). Similarly, Williamson & Schulz (1990) proposed that communal orientation has a mediating effect on carer distress. Following from this, it was hypothesised that carers' gender, coping style, social support and communal orientation would moderate caregiving outcomes.

Outside the caregiving situation, Kobasa and her colleagues argued that individual differences in hardiness moderate the stress-outcome relationship (Kobasa *et al.*, 1981, 1982; Kobasa & Puccetti, 1983). It was considered that the same would be true in where the stressor is Parkinson's disease.

The results indicated that all five variables hypothesised to moderate predictor-outcome relationships did so - but in a selective way. Interestingly, all five variables also acted as suppressor variables. Whether a particular intervening variable acted as a moderator or a suppressor was very much dependent on the outcome measure. It is not possible to discuss all the individual interventions on the large number of stressor-outcomes relationships, but there are several important points to come out of this exercise.

7.8.1 Gender

The most consistent finding in the caregiving literature is that the majority of carers are women (Stone *et al.*, 1987). The extent to which men and women differ in their caregiving has attracted much interest as gender differences are believed to influence the type and the amount of care given, as well as appraisals of the caregiving experience (Pearlin *et al.*, 1990; Miller, 1990).

In this study, however, there was no major differences between women and men in terms of caregiving outcomes. Gender only had a direct influence on caregiver depression in phase I; women reported greater depression than men. Further analyses indicated that there was a trend towards higher levels of distress in female carers, but even when the conventional significance level of .05 was used, gender differences were only significant for mental health outcomes. The picture was slightly different in phase II, in so far as there was no difference in male and females for depression, only for life satisfaction.

Although most studies suggest that female caregivers report higher levels of burden than male caregivers (Horowitz, 1985, Pruchno & Resch, 1989a), there was no effect of gender on the reporting of burden in either phase I or phase II in this study of PD caregiving. These results can be seen to support the social role hypothesis (c.f. Aneshensel & Pearlin, 1987) which asserts that few differences in burden should occur “as long as the stressors, use of social resources, and other factors are similar” for female and male carers (Miller & Cafasso, 1982, p.500). Certainly the course of PD is the same for male and female sufferers of PD.

Nevertheless, it seemed feasible that the reason direct effects of gender on burden were not seen in this study because gender was acting as an moderator variable. This was tested in phase II. The main findings were that gender had served to suppress the relationship of several measures of job demand and depression, and to moderate the association of several patient personality change variables and burden from impact on relationship and emotional burden. Gender had no effect on burden from impact on social life, even as an intervening variable.

The composition of this sample may have had some influence in the lack of a major influence of gender on caregiving outcomes. As Gutmann (1980) argued, in postparental and postretirement stages of life, gender differences become less salient. If this is true, then greater differences in caregiver distress should be seen in adult-child caregivers than among spouse caregivers. As this sample was composed of approximately 90% spouses maybe the conclusion that gender made a relatively small contribution to the outcomes for this PD caregiving sample is not surprising.

7.8.2 Social Support

In this study caregivers' perception of the extent of social support had no direct effect on caregiving outcomes in phase I, although burden from impact on relationship was negatively related to the extent of and satisfaction with social support in phase II. These results were similar to those of Miller *et al.* (1996), who thought it was "unexpected that the measure of the social support network showed no significant relationship with the dependent variables" (p.267). Yet although some studies have found social support to be a predictor of caregiver burden (e.g. Zarit *et al.* 1980), social support is usually modelled as a principal mediator in stress research (Pearlin *et al.,* 1990). Zarit has recently also taken this view declaring "Social support is perhaps the most important modifying variable for family caregivers" (Zarit & Edwards, 1996; p.349).

Because social support is a latent dimension of coping in that it defines a potential for action, rather than the action itself (Gore, 1985), it was hypothesised that social support would act as a mediator of predictor-distress outcomes in this PD caregiving situation. The hypothesis was supported. Specifically, social support was found to be a convincing suppressor of caregiver depression, and a moderator of carer discretion and impact on relationship, and a moderator of three measures of carers' perception of patient personality and burden. Miller *et al.* considered that their lack of a direct effect of social support on PD caregiving outcomes could have been due to a lack of variance in social support in their sample: they noted that social support was generally very low. Nevertheless, it seems more likely that their results, which were replicated here, are consistent with several caregiving studies that have found that caregiving outcomes are not directly affected by social support (e.g. Gilhooly, 1984; Gilleard *et al.,* 1984).

7.8.3 Coping Strategies

In the Pearlin *et al.* (1990) model of SDAT caregiving, coping strategies were modelled as moderators of the stress process, and there has been much recent support for this position (e.g. Intieri & Rapp, 1994; Parkes, 1994; Saad *et al.*, 1995). However, Pruchno & Resch (1989b) have argued that coping styles are not moderators of caregiving outcomes, but they do have direct effects on stressor-outcome relationships, as well as acting as mediators of caregiver distress. Braithwaite (1990) specifically supported the mediator position and the rationale that followed indicated that she also expected coping style to have a direct effect on caregiver burden.

In this study, it was found that although task-oriented coping and avoidance coping had no relationship with caregiving outcomes, emotion-focused coping was directly associated with five of the six distress measures at phase I, and four of the six distress measures at phase II. Moreover, it was found that emotion-focused coping was a major predictor of two of the burden measures. When all the significant predictors of emotional burden were analysed by multiple regression techniques, it emerged that emotion-focused coping was the biggest predictor of emotional burden and that this style of coping also significantly contributed to the explained variance of burden from impact on relationship. It follows from this that Pruchno & Resch’s (1989b) argument that coping style can have a direct effect on caregiving outcomes is supported.

The study also had an *a priori* hypothesis that coping strategies would moderate caregiving outcomes. To test this hypothesis, the three coping strategies measured were all included as a whole. The results revealed that coping strategies were moderators for patient variables, caregiver variables and relationship variables, and that all six distress variables were affect by the influence of coping strategies. Therefore, the hypothesis was supported.

The literature contains some controversy over the role of coping strategies in caregiving outcomes. Further, in the Pearlin *et al.* (1990) conceptual model of SDAT caregiving coping style was modelled as a moderator variable only, whereas Kahana & Kinney (1991) modelled coping style as a direct resource. These results make it clear that a model of PD caregiving should indicate that caregiver coping style acts as a predictor and as a moderator of caregiving outcomes.

7.8.4 Hardiness

Hardiness is defined as the additive effects of high commitment, personal control, and challenge seeking in daily life (Kobasa *et al.*,1983). Kobasa *et al.* (1981) published a prospective study of the effect of personal hardiness on the relationship of work stress and recent illness. The results suggested a main effect of hardiness, and the pattern of group means was taken to be consistent with a moderating effect for hardiness. A moderating role for hardiness has been found in a variety of other occupational groups, including lawyers, accountants, nurses and secretarial staff (Cox & Ferguson, 1991). However, according to Cohen & Edwards (1989), the evidence for individual differences in hardiness moderating stressor-outcome relationships is weak, and there have been many failures to demonstrate such an effect. To date, it appears that this study is there first to consider the role of hardiness in caregiving.

As mentioned in section 7.6, above, hardiness commitment and hardiness control were found to be direct predictors of caregiving outcomes. It was also found that the hypothesis that hardiness would serve to moderate predictor-outcome relationships was strongly supported. Many caregiver and dyadic relationship variables interacted with hardiness to modify all six aspects of caregiver distress.

These results suggest that hardiness is an important variable in describing Parkinson's disease caregiving. The pattern of results was similar to many investigations of occupational stress, which probably was not surprising, as for many of the caregiving sample, caring was essentially a full-time job.

7.8.5 Communal Orientation

Clark *et al.* (1987) viewed communal orientation as a dispositional trait. It was therefore considered that differences in communal orientation might provide a reason for individual differences in caregiving outcomes. That is, it was hypothesised that communal orientation would moderate stressor-outcome relationships in PD caregiving.

Williamson & Schulz (1990) found that SDAT caregivers low in communal orientation reported greater depression, as measured by the CESD, and that communal orientation moderated the association of pre-morbid relationship and depression. In this study of PD carers communal orientation was not directly associated with caregiver depression, however, communal orientation was found to be a powerful suppressor of caregiver depression. When communal orientation was controlled for, several non-significant associations of job demand and depression became highly significant. In addition to this, communal orientation was seen to be a suppressor for all aspects of distress from negative patient personality changes.

Essentially, these results make it clear that communal orientation is an important variable to a descriptive model of caregiving. In a model of PD caregiving, communal orientation should be described as a moderator variable.

7.8.6 Summary

It was hypothesised that carers' gender, social support, coping style, and dispositional style would moderate stressor-outcome relationships in Parkinson's disease caregiving. This hypothesis was strongly supported. All the potential moderators were able to both potentiate and to suppress relationships between independent and dependent caregiving variables. Essentially these results indicate that the simple conceptual model of Parkinson's disease caregiving presented in chapter 3 (see p. 132) should be modified to take account of these results.

7.9 Knowledge of Parkinson's Disease and Caregiver Distress

Because motor abnormalities dominate the clinical picture of Parkinson's disease, and the cognitive aspects of the illness have been overlooked, it was hypothesised that patients and caregivers would know significantly more about the physical aspects than the cognitive aspects of the disease. This hypothesis was strongly supported. Even when education level, a potential moderator of knowledge, was accounted for.

As hypothesised, knowledge of both physical and cognitive aspects of PD was similar for patients and caregivers. This was important for the hypotheses that knowledge would be influenced by duration and severity of illness. It was found that a longer duration of illness did account for greater knowledge of both physical and cognitive aspects of the disease. However, there was no interaction of type of knowledge and duration. Essentially this was not in line with the *a priori* hypothesis. It was thought that duration of illness should not influence cognitive knowledge in the same way as physical knowledge because an increase in duration of illness is associated with more physical symptoms, but this may not be true for cognitive symptoms in the same way. The results indicated that this reasoning was wrong.

The hypothesis that dependants' severity of illness would influence physical knowledge, but not cognitive knowledge was strongly supported. Severity of illness was measured by a motor examination, and carers' *physical* scores increased with physical severity. This grouping made no concession to cognitive status, and, as expected, there was no difference in *cognitive* scores according to physical status. In contrast it was found that cognitive knowledge was highest for carers of demented patients, then cognitively impaired patients, and lowest for intact patients, but there was no difference in carers' *physical* scores according to their dependant's mental status. Together, these results indicated that knowledge was gained by experience.

In view of the positive association of uncertainty and stress in the organizational literature, it was hypothesised that a lack of knowledge of their illness situation would be a predictor of distress for PD caregivers.

The results were unexpected. It was found that total knowledge of Parkinson's disease (KPD) was positively related to the six distress measures. That it, greater knowledge was associated with negative outcomes for the caregivers. The hypothesis was not supported. The results were not expected because in the organizational literature it is uncertainty that is associated with stress - not knowledge. Even in the caregiving literature there were indications that greater knowledge should be beneficial for caregiving outcomes. Certainly, poorer health was associated with a greater level of uncertainty in cancer caregivers (Stetz, 1989), and Brown & Powell-Cope (1991) identified uncertainty as a basic psychological problem for caregivers of AIDS patients.

There were stronger relationships (positive, not negative) between all the caregiver distress measures and cognitive knowledge as compared to the relationships of distress and physical knowledge, with the exception of burden from impact on social life. This is probably not surprising considering that the biggest predictor of this variable was Hoehn & Yahr disease stage. It was also found that although greater physical knowledge is associated with burden and low life satisfaction. In contrast to cognitive knowledge, physical knowledge was not associated with mental health outcomes. The hypothesis that a lack of cognitive knowledge would be associated with greater caregiver distress was not supported.

The fact that knowing more about Parkinson's disease was related to greater distress poses a problem for effective intervention. Moreover, Montgomery *et al.* (1994) published a paper asserting that a low-cost patient education improved PD patients' quality of life, stabilised of their progression of illness and decreased their caregivers' stress levels as compared with a control sample of PD patients and caregivers who did not receive the intervention. The "PROPATH program" contained information about exercise, disease severity and co-morbidity, diet, compliance and side effect control, and information about dealing with their specific reported problems. These results are similar to those found in other health education intervention studies (e.g. Clark *et al.*,1992).

These results do not dispute the Montgomery *et al.* (1994) results. Indeed, it was envisaged that supplementing the generally low levels of knowledge of PD[10] seen in this study would provide benefits for carers. This was not an intervention study; patients and caregivers were all essentially at baseline knowledge. That is, the knowledge they had was basically gained through experience. Support for this assertion is provided by the fact that knowledge increased with duration of illness, severity of illness (physical) and mental status (cognitive). It is true that members of the Parkinson's Disease Society had greater knowledge of the physical aspects of PD, but there was no difference between members and non-members with respect to cognitive knowledge.

The *a posteriori* hypothesis that greater knowledge was a result of learning by experience was supported by the fact that when duration of illness, patient cognitive status and verbal intelligence and cognitive and behavioural hassles associated with caregiving were controlled for in partial correlation analyses, the associations of caregiver knowledge and distress disappeared.

The issue of whether giving carers additional knowledge in advance, rather than having to learn "on the job" has not been fully resolved. The difference between these results and those of Montgomery *et al.* (1994) need to be explored prospectively, with baseline knowledge accounted for. It would also have been more

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[10] An epidemiological report by Lee *et al* .(1994) stated that only 6% of PD patients in Singapore were knowledgeable about the illness, 85% had no knowledge of the disease, and 9% had superficial / mistaken beliefs about their illness. "This poor understanding of the illness was also reflected in the

illuminating if Montgomery *et al.* had given more information about the stress scale they used beyond the fact that it had 20-items and was measured on a 7-point scale. This is important because in this study there was no relationship between knowledge of the physical aspects of PD and caregiver depression and poor psychological health.

It is suggested that the positive association of knowledge and distress is a result of learning on the job *without support.* Montgomery *et al.'s* knowledge program included “information about dealing with their specific reported problems” (p. 430). It is assumed that the latter type of information, together with the support provided by intervention, would provide support for current problems facing their participants and may be then knowledge of Parkinson’s disease may be beneficial, or at least immaterial with respect to caregiving outcomes. These results seem to indicate that caregivers learn more about Parkinson’s disease by watching their loved ones deteriorate without support. And so they become wiser, but sadder.

7.10 Progression of Illness and Caregiver Distress

It was hypothesised that caregiver distress would be related to progression of illness, as measured by an increase in burden, depression, poor psychological health and a decrease in life satisfaction from phase I to phase II. This hypothesis was not supported. A simple reason for this could have been that the average 14 months interval between phase I and phase II was not large enough to capture any increase in physical disability, but this was not the case. Indeed, as well as a significant increase

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family members” (p. 267). Unfortunately, there was no mention in the paper as to how knowledge was measured. Attempts to contact Dr. Lee were unsuccessful.

in motor symptoms and hence physical job demand, there was a significant decrease in mental status, and hence an increase in cognitive demand on carers.

The fact that there was a significant progression of PD, but not a significant increase in carer distress, clearly indicates that characteristics of the patient cannot be the sole cause of caregiver distress. It follows from this that caregiver characteristics and / or features of the dyadic relationship must contribute to caregiver distress. To address this issue, it was necessary to consider which were the biggest predictors for each of the distress measures.

As the main aim of this research was to fully describe caregiving in Parkinson’s disease and to identify those variables which, directly or indirectly, influenced caregiving outcomes, a considerable number of predictor variables were identified. Because a large number of variables were used, and it was a policy to reduce complex variables like perceived job demand to the component parts, there was a considerable amount of significant associations between variables - and hence shared variance.

A preliminary step to identifying which aspects of the caregiving situation were most relevant to carer distress was to limit the number of variables to be included in the final analyses. This was done by regressing those variables which were closely related to each other to discern which variables were significantly contributing to the variance. Moreover, the large number of variables and the relatively small number of subjects made this process essential to avoid moderator and suppresser variables perverting the results. Essentially, this procedure enabled a small number of primary predictors to be entered into stepwise regressions on each of the six distress measures.

When the primary predictors of the mental health outcomes were identified, it was immediately clear why the hypothesis that progression of illness would be related to an increase in caregiver distress was not supported. Quite simply, none of the objective measures of patient functioning contributed to the variance even before they were analysed alongside caregiver and dyadic relationship variables.

With respect to caregiver depression, there was only one variable which significantly explained the variance: caregiver neuroticism. The other primary predictors entered into the equation were also caregiver variables. These included two other aspects of caregiver personality - optimism and hardiness commitment, and carers' perception of patient personality change on the bored-interested dimension.

Carers' psychological health was also determined solely by caregiver variables. Again, the most important predictor of poor psychological health was caregiver neuroticism. Knowledge of the physical aspects of Parkinson's disease was also found to be significant predictor of this aspect of distress. The finding that this variable which has to be specific to PD caregiving is a major predictor of caregiver mental health outcomes (and life satisfaction) emphasises the fact that previous models of caregiving should not be generalised to PD caregiving. Other primary predictors not significantly contributing variance to psychological health were physical strain - a caregiver variable important to PD caregiving in that it is based on perceived job demands and job discretion, and again caregiver optimism.

It is worth noting here that Smith *et al's* (1989) assertions that neuroticism and optimism are virtually indistinguishable, were not supported by the results of this investigation. If one variable was coding for the other - as may have been the case for neuroticism and emotion-focused coping - then both variables would not have been identified as primary predictors.

Certainly it is interesting that caregiver neuroticism significantly explained the variance of two measures of distress and emotion-focused coping significantly explained variance of two other aspects of distress, but in the preliminary analyses, when one of these two variables was entered into the equation, invariably the other was not. The identification of caregiver neuroticism as the major predictor of mental health outcomes essentially provides a bleak picture if a purpose of modelling PD caregiving is to enable effective intervention to be provided to distressed caregivers. It is assumed personality traits are stable. The identification of emotion-focused coping as the biggest predictor of emotional burden and a major predictor of burden from impact on social life, however, offers some hope of effective intervention if, as Anshel & Kaissidis (1997) suggest, the use of particular coping strategies is a partial function of the situational demands. This suggests that practical assistance to reduce the demands of the illness situation (e.g. respite care) may help alleviate impact on social life and emotional burden. If the suggestion that neuroticism and emotion-focused coping code for one another is true, then caregiver depression would not be almost inevitable for someone who would score highly on the neuroticism subscale who takes on the caregiving role. Again, practical assistance to change the situational demand may be effective.

Progression of illness did not lead to an increase in distress levels even for burden from impact on social life, and low life satisfaction for which an object measure of patient functioning was the biggest predictor of distress. This leads to the conclusion that although patient variables were found to be important predictors of outcomes in Parkinson’s disease caregiving, caregiver variables have a overriding influence on the manifestation of distress.

7.11 Patient Depression

Depression is a frequent problem in Parkinson’s disease (Sano & Mayeux, 1992), even though in most patient’s depression is relatively mild (Lees, 1990). Miller *et al.* (1996) presented results that indicated that patient depression was the biggest predictor of distress in PD caregivers.

In this sample of PD caregivers, the influence of depression on caregiver distress was not so marked. There was no difference in the mean Geriatric Depression Scale (GDS) scores of the two samples (13.1 and 12.61), but the highly significant associations of GDS scores and GHQ scores found by Miller *et al.* (1996) were not seen in this sample at phase I or phase II. Similarly, in this sample, patient depression was not related to caregiver depression, although in the Miller *et al.* sample it was. Although different depression scales were used in the two samples, it is not proposed that this can entirely account for the discrepancy in the two sets of results.

Patient depression was a predictor of caregiver burden in this research: in phase I greater patient depression was positively related to burden from impact on relationship and social life, and emotional burden. In phase II greater patient depression was positively related to burden from impact on relationship only. Essentially then, patient depression was found to predict caregiver outcomes, but the pattern of results was different in the two studies. In this study, patient depression had a greater influence on burden from impact on relationship than caregiver depression and poor psychological health. But even for impact on relationship, patient depression did not contribute to the explained variance. That is, these results do not replicate Miller *et al's* findings that "levels of depression in the sufferer emerged as the offering the best prediction of distress in the carer" (p. 263).

7.12 Summary

In this investigation of Parkinson's disease caregiving the hypotheses took account of previous findings of outcomes of caregiving - particularly of another neurological disease, senile dementia of the Alzheimer type - and the nature of Parkinson's disease.

In contrast to previous caregiving research, it was hypothesised that the much greater physical demands put upon PD caregivers by their dependant's severity of illness would predict carer distress. This hypothesis was supported.

In contrast to previous caregiving research, it was hypothesised demand from cognitive decline would predict decline. This hypothesis was supported. Further, it was found that caregivers whose dependants are dementing and/or hallucinating <u>in addition to</u> having Parkinson's disease had greater distress than those caring for PD patients without these cognitive problems.

In line with other work it was found, as hypothesised, that carers' perceptions of job demand would predict distress. Further analyses, however indicated that job strain, the influence of discretion on demand, was a better predictor of burden than demand alone.

A change in patient personality did not necessarily predict caregiver distress. This investigation made it clear that the type of personality change was more important that the extent of change. Changes at the factor level were generally not a source of distress, however several changes at the trait level did predict negative outcomes for caregivers. Notably, an increase in patient apathy was a primary predictor of caregiver depression.

It was hypothesised that caregiver characteristics would have a direct influence on carer outcomes. As in other caregiving situations, this hypothesis was strongly supported. Further, caregiver characteristics were found to be the biggest predictor of emotional burden, caregiver depression and poor psychological health. Because caregiver distress was not related to progression of illness, it was also clear that caregiver variables were having a great influence on the caregiving situation.

As hypothesised, it was found that some variables are important to describing the caregiving situation because they have the ability to moderate the relationships between other independent and dependent variables. Specifically, carers' gender, social support, coping style, dispositional hardiness and communal orientation were all found to be important moderators of caregiving outcomes.

It was hypothesised that the premorbid relationship would have a direct influence on carer outcomes. As in other caregiving situations, this hypothesis was strongly supported.

In this investigation the question of whether a lack of knowledge of the illness situation is associated with distress was explored. It was hypothesised that a lack of knowledge would contribute to distress, as has been found in the organisational literature (Landy *et al.,* 1994). The results indicated that knowledge was important to the stress process in PD caregiving, but that <u>greater</u> knowledge was associated with distress. A series of analyses indicated that this is probably because carers learn about PD from their experiences, and thus because they only gain knowledge by watching their care-recipient progress in Parkinson’s symptoms, they eventually become wiser, but sadder.

7.13 Conclusions

The results of this investigation of caregiving in Parkinson's disease clearly showed that patient variables, caregiver variables, and dyadic relationship variables are all important in the prediction of caregiver outcomes. The results indicated that there are some elements of caregiving that were unique to the Parkinson's disease illness situation (e.g. physical demand and lack of knowledge of PD), and some predictors of caregiving outcomes that seem to be common to many caregiving situations (e.g. caregiver neuroticism, emotion-focused coping, pre-morbid relationship). Nevertheless, these results indicate that Parkinson's disease caregivers do face unique physical and psychosocial stressors, and therefore it is not appropriate to generalise other findings in the caregiving literature to PD carers (or indeed to any illness situation other than that specifically investigated).

The longitudinal design allowed for replication of the findings, which was important in view of the paucity of research with this group of caregivers. The fact that all findings were not replicated in a straightforward manner in a follow-up of the same group of caregivers, verified that PD caregiving is a dynamic process, particularly as progression of the illness is ever ongoing (Selby, 1990).

Conceptualising distress as being comprised of six qualitatively different components established the notion that the caregiving process is very complex, and perhaps more critically, reducing distress to its component parts indicated that some (unsupported) hypotheses in the literature may have been rejected simply because of the choice of measure(s). Certainly it is considered that a much richer description of the PD caregiving situation was achieved through considering each component of distress separately.

The biggest predictors of distress were not the same for all the different aspects of distress. What was clear, however, was that in Parkinson’s disease caregiving, objective measures of job demand are very important. Particularly for the prediction of burden from impact on social life, and poor life satisfaction. Also, carer’s perception of job strain, which was also essentially specific to PD caregiving, was the biggest predictor of burden from impact on relationship.

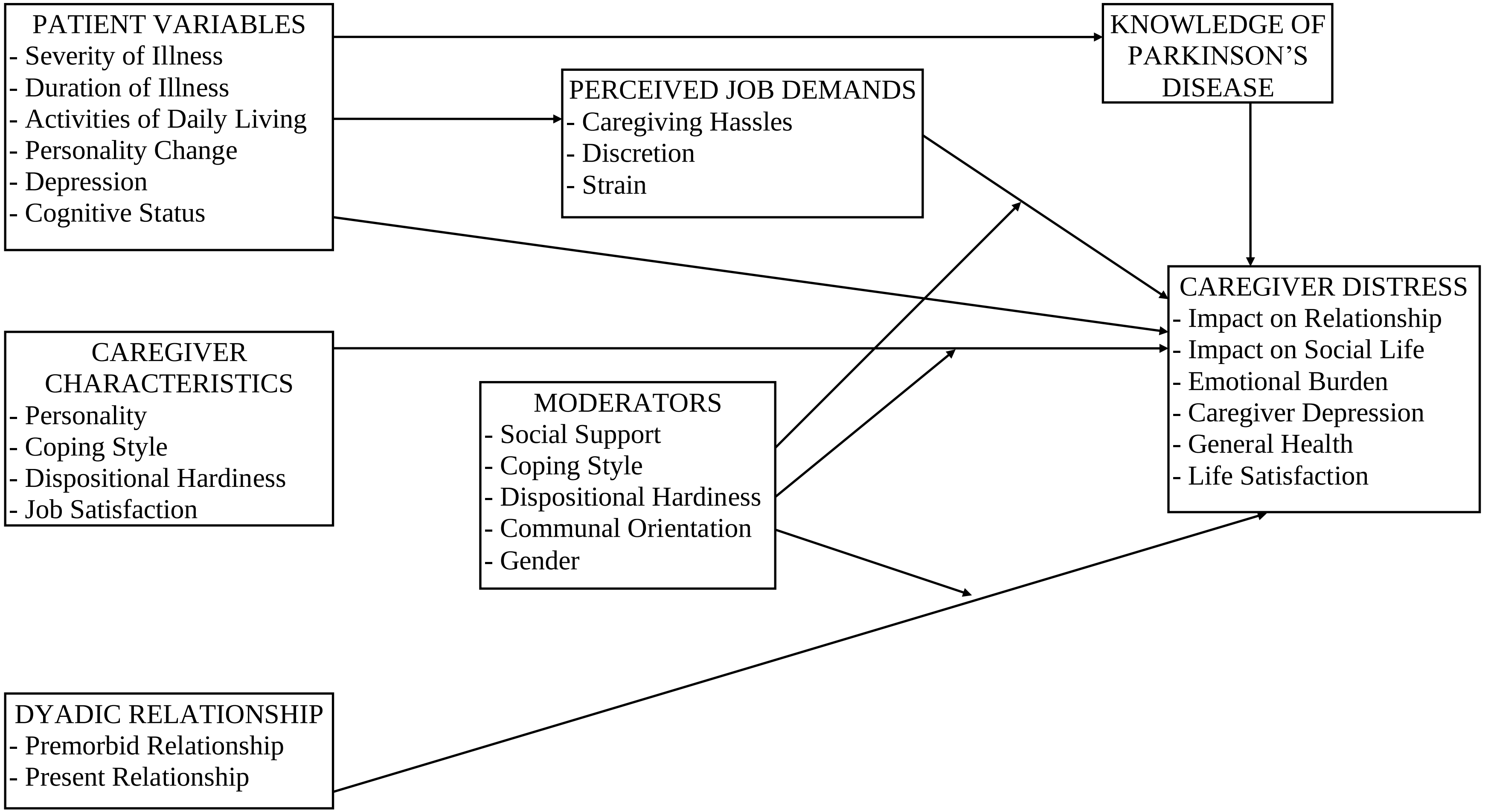
Some of the potential predictors of caregiver distress were found to be of great importance in the caregiving situation because they intervened to selectively moderate and suppress the association of other predictor variables and distress. As in other caregiving models, coping style and social support were found to be important moderators, and it was also clear that three other variables were moderating outcomes for the carers - dispositional hardiness, communal orientation and gender.

The results of this investigation, and the evaluation of the results with regard to the existing literature indicate that it is not appropriate to adapt a model of SDAT caregiving to describe PD caregiving. A very simple model of PD caregiving based on the hypotheses was presented in chapter three (p.132). A revised model which takes full account of the results is presented below.

The view that the model should be kept as clear and as simple as possible is adhered to. Although Kahana & Kinney (1991) considered that burden preceded mental health problems, it was not clear that that was true in this study. Whilst emotional burden was often felt when a caregiver was depressed, this was not always the case. Moreover, depression was clearly not dependent on burden from impact on relationship and burden from impact on social support. Similarly, in the Gold *et al.* (1995) model, burden preceded (psychological) health. Again, this was not systematically the case in this study. Thus, all the distress measures were grouped together.

The results of this investigation indicate that the dynamic nature of Parkinson’s disease will prohibit a comprehensive model that can be applied to describe the full course of the PD caregiving. Therefore, simple models like that illustrated in figure 7.13.1, below, may ultimately be more useful for the initial planning of interventions.

Figure 7.12.1 Model of Parkinson's Disease Caregiving



REFERENCES

Agid, Y., Ruberg, M., Dubois, B. & Pillon, B. (1987). Anatomoclinical and biochemical concepts of subcortical dementia. In S.M. Stahl, S.D. Iversen & E.C. Goodman (Eds.), *Cognitive Neurochemistry* (pp. 248-271). Oxford Science Publications.

Albert, S. (1992). Psychometric investigation of a belief system: caregiving to the chronically ill parent. *Social Science and Medicine,* **35,** 699-709.

Aldwin, C.M. & Reverson, T.A. (1987). Does coping help? A reexamination of the relation between coping and mental health. *Journal of Personality and Social Psychology,* **53,** 337-348.

Alloway, R. & Bebbington, P. (1987). The buffer theory of social support. *Psychological Medicine,* **17,** 91-108.

Almberg, B., Grafström, M. & Winblad, B. (1997). Caring for a demented elderly person - burden and burnout among caregiving relatives. *Journal of Advanced Nursing,* **25,** 109-116.

American Psychiatric Association (1987) Diagnostic and statistical manual of mental disorders, 3rd edition - revised. DSM-III^{TM}. American Psychiatric Association, Washington, DC.

American Psychiatric Association (1994). Diagnostic and statistical manual of mental disorders, 4th edition. DSM-IV^{TM}. American Psychiatric Association, Washington, DC.

Aneshensel, C.S. & Pearlin, L.I. (1987). Structural contexts of sex differences in stress. In R. Barnett, L. Biener & G. Baruch (Eds.), *Gender and Stress.* New York: Free Press.

Aneshensel, C.S., Pearlin, L.I. & Schuler, R. (1993). Stress, role captivity and the cessation of caregiving. *Journal of Health and Social Behaviour,* **34,** 54-70.

Anshel, M.H. & Kaissidis, A.N. (1997). Coping style and situational appraisals as predictors of coping strategies following stressful events in sport as a function of gender and skill level. *British Journal of Psychology,* **88,** 263-276.

Arie, T. (1977). Issues in the psychiatric care of the elderly. In Exton-Smith & Evans (Eds.) *Care of the Elderly: Meeting the Challenge of Dependency.* New York: Grune & Stratton.

Arling, G. (1987). Strain, social support, and distress in old age. *Journal of Gerontology,* **42,** 107-113.

Atkin, K. (1992). Similarities and differences between informal carers. In J. Twigg (Ed.), C*arers: Research and Practice.* London: HMSO.

Ball, B. (1882). De l'insanite dans la paralysie agitante. *Encephalé,* **6,** 22-32.

Ball, M.J. (1984). The morphological basis of dementia in Parkinson's disease. *Canadian Journal of Neurological Science,* **11 (Suppl. 1),** 180-184.

Barefoot, J.C., Siegler, I.C., Nowlin, J.B., Peterson, B.L., Haney, T.L. & Williams, R.B. (1987). Suspiciousness, health, and mortality: a follow-up study of 500 older adults. *Psychosomatic Medicine,* **49,** 450-457.

Barnes, G. & Prosen, H. (1984). Depression in Canadian general practice attenders. *Canadian Journal of Psychiatry,* **29,** 2-10.

Bartone, P.T., Ursano, R.J., Wright, K.M. & Ingraham, L.H. (1989). The impact of a military air disaster on the health of assistant workers: a prospective study. *The Journal of Nervous and Mental Disease,* **177,** 317-328.

Bass, D.M., McClendon, M.J., Diemling, G.T. & Mukherjee, S. (1994). The influence of a diagnosed mental impairment on family caregiver strain. *Journal of Gerontology,* **49,** 146-155.

Beck, A.T. & Beck, R.W. (1972). Screening depressed patients in family practice: a rapid technique. *Postgraduate Medicine,* **52,** 81-85.

Beck, A.T., Ward, C.H., Mendelson, M., Mock, J.E., & Erlbaugh, J.K. (1961). An inventory for measuring depression. *Archives of General Psychiatry,* **4,** 561-571.

Ben-Shlomo, Y. & Marmot, M.G. (1995). Survival and cause of death in a cohort of patients with parkinsonism: possible clues to aetiology. *Journal of Neurology, Neurosurgery & Psychiatry,* **58,** 293-299.

Ben-Shlomo, Y. (1996). How far are we in understanding the cause of Parkinson's disease? *Journal of Neurology, Neurosurgery & Psychiatry,* **61,** 4-16.

Berkman, L.F. & Syme, S.L. (1979). Social networks, host resistance and mortality: a nine year follow-up of Alameda County residents. *American Journal of Epidemiology,* **109,** 186-204.

Biegel, D.E. & Blum, A. (1990). Introduction. In D.E. Biegel & A. Blum (Eds.), *Aging and Caregiving: theory, research and policy.* Newbury Park: Sage Publications.

Bigot, A. (1974). The relevance of American life satisfaction indices for research on British subjects before and after retirement. *Age & Aging,* **3,** 113-121.

Binks, M.G. & Davies, A.D.M. (1984). The early detection of dementia. A baseline from healthy community dwelling old people. In D.B. Bromley (Ed.), *Gerontology: Social and Behavioural Perspectives* (pp 7-13). Croom Helm, London.

Blessed, B.E., Tomlinson, B.E. & Roth, M. (1968). The association between quantitative measures of dementia and of senile change in cerebral grey matter of elderly subjects. *British Journal of Psychiatry,* **114,** 797-811.

Bloxham, C.A., Mindel, T.A. & Frith, C.D. (1984). Initiation and execution of predictable and impredictable movements in Parkinson’s idsease. *Brain,* **107,** 371-384.

Blum, M.J., Kelly, M. & Gatz, M. (1989). *Empirically-defined Caregivers vs. Self-defined Caregivers for Aging Parents.* Paper presented at the meetings of the Gerontological Society of America, Minneapolis, MN.

Bolger, N. & Eckenrode, J. (1991). Social relationships, personality and anxiety during a major stressful event. *Journal of Personality and Social Psychology,* **61,** 440-449.

Boller, F., Mizutani, T., Roessmann, U. & Gambetti, P. (1980). Parkinson's disease, dementia and Alzheimer's disease: clinicopathological correlations. *Annals of Neurology,* **7,** 329-335.

Boller, F., Passafiume, D., Keefe, N.C., Rogers, K., Morrow, L. Kim, Y. (1984). Visuospatial impairment in Parkinson’s disease: role of perceptual and motor factors. *Archives of Neurology,* **41,** 485-490.

Bondi, M.W., Kaszniak, A.W., Bayles, K.A. & Vance, K.T. (1993). Contribution of frontal system dysfunction to memory and perceptual abilities in Parkinson’s disease. *Neuropsychology,* **7,** 89-102.

Bonnet, A.M., Loria, Y., Saint-Hilaire, M.H., *et al.* (1987). Does long-term aggravation of Parkinson's disease result from nondopaminergic lesions? *Neurology,* **37,** 1539-1542.

Booth, G. (1948). Psychodynamics in parkinsonism. *Psychosomatic Medicine,* **10,** 1-14.

Bowen, F.P., Hoehn, M.M. & Yahr, M.D. (1972). Parkinsonism: alterations in spatial orientation as determined by a route-walking test. *Neuropsychologia,* **10,** 335-361.

Bradburn, N. (1969). *The Structure of Psychological Well-Being.* Chicago: Aldine.

Bradshaw, J.L. & Mattingley, J.B. (1995). *Clinical Neuropsychology: Behavioural and Brain Science.* Sydney: Academic Press.

Braithwaite, V.A. (1990). *Bound to Care.* London: Unwin Hyman Limited.

Braithwaite, V.A. (1992). Caregiving burden: making the concept scientifically useful and policy relevant. *Research on Aging,* **14,** 3-27.

Brent, R.S. (1982). Community and institutional social spaces. *Therapeutic Recreation Journal,* **16,** 41-48.

Brewis, M., Poskanzer, D.S., Rolland, C. *et al.* (1966). Neurological disease in an English city. *Acta Neurologica Scandinavica,* **42(Suppl. 24),** 1-89.

Brink, T.L., Yesavage, J.A., Lum, O., Heersema, P.H., Adey, M. & Rose, T.L. (1982). Screening tests for geriatric depression. *Clinical Gerontologist,* **1,** 37-43.

British Medical Association (1994). *New Guide to Medicine and Drugs* (3rd Edition). London: Dorling Kindersley.

Brody, E. (1981). Women in the middle and family help to older people. *The Gerontologist,* **21,** 471-480.

Brody, S.J., Poulshock, S.W. & Maschiocchi, C.F. (1978). The family caring unit: a major consideration in the long-term support system. *The Gerontologist,* **18,** 556-561.

Brooks, D.N. & McKinlay, W. (1983). Personality and behavioural change after a severe blunt head injury: a relative’s view. *Journal of Neurology, Neurosurgery and Psychiatry,* **46,** 336-344.

Brown, M.A. & Powell-Cope, G.M. (1991). AIDS family caregiving: transitions through uncertainty. *Nursing Research,* **40,** 338-345.

Brown, R.G. (1994). Cognitive function in non-demented patients with Parkinson's disease. In E.C. Wolters & P. Scheltens (Eds.), *Mental Dysfunction in Parkinson's Disease* (pp.177-194). Vrieje University Press.

Brown, R.G. & Marsden, C.D. (1986). Visuospatial function in Parkinson's disaese. *Brain,* **109,** 987-1002.

Brown, R.G. & Marsden, C.D. (1988). Internal vs external cues and the control of attention in Parkinson's disease. *Brain,* **111,** 323-345.

Brown, R.G., Jahanshahi, M., Quinn, N. & Marsden, C.D. (1990). Sexual function in patients with Parkinson's disease and their partners. *Journal of Neurology, Neurosurgery and Psychiatry,* **53,** 480-487.

Burke, P.J. (1991). Identity process and social stress. *American Journal of Sociology,* **56,** 836-849.

Calder, S.A., Ebmeier, K.P., Stewart, L., Crawford, J.R. & Besson, J.A.O. (1991). The prediction of stress in carers: the role of behaviour, reported self-care and dementia in patients with idiopathic Parkinson's disease. *International Journal of Geriatric Psychiatry,* **6,** 737-742.

Calne, D.B. & Langston, J.W. (1983). Aetiology of Parkinson's disease. *Lancet,* **ii,** 1457-1459.

Canavan, A.G.M., Passingham, R.E., Marsden, C.D., Quinn N., Wyke, M. & Polkey, C.E. (1989). The performance on learning tasks of patients in early stages of Parkinson's disease. *Neuropsychologia,* **27,** 141-156.

Cantor, M. (1983). Strain among caregivers: a study of experience in the United States. *The Gerontologist,* **23,** 597-604.

Carson, R.C. (1989). Personality. *Annual Review of Psychology,* **40,** 227-248.

Celesia, G.G. & Wanamaker, W.M. (1972). Psychiatric disturbances in Parkinson's disease. *Diseases of the Nervous System,* **33,** 577-583.

Chappell, N.L. & Guse, L.W. (1989). Linkages between informal and formal support. In K.S. Markides & C.L. Cooper (Eds.) *Aging, Stress & Health* (pp. 219-237). London: John Wiley & Sons Ltd.

Christensen, A.L., Juul-Jensen, P., Malmroe, R. & Harmsen, A. (1970). Psychological evaluation of intelligence and personality in Parkinsonism before and after stereotactic surgery. *Acta Neurologica Scandinavica,* **46,** 527-537.

Clark, M.S. & Mills, J. (1979). Interpersonal attraction in exchange and communal relationships. *Journal of Personality and Social Psychology,* **37,** 12-24.

Clark, M.S., Ouellette, R., Powell, M.C. & Milberg, S. (1987). Recipient's mood, relationship type, and helping. *Journal of Personality and Social Psychology,* **53,** 94-103.

Clark, N.M., Janz, N.K., Becker, M.H. *et al.* (1992). Impact of self-management education on functional health status of older adults with heart disease. *The Gerontologist,* **32,** 438-443.

Clipp, E.C. & George, L.K. (1990). Caregiver needs and patterns of social support. *Journal of Gerontology,* **45,** S102-S111.

Clipp, E.C. & George, L.K. (1993). Dementia and cancer: a comparison of spouse caregivers. *The Gerontologist*, **33,** 534-541.

Cohen, C.A., Gold, D.P., Shulman, K.I. & Zucchero, C.A. (1994). Positive aspects in caregiving: an overlooked variable in research. *Canadian Journal on Aging,* **13,** 378-391.

Cohen, C.A., Gold, D.P., Shulman, K.I. *et al.* (1993). Factors determining the decision to institutionalise dementing individuals: a prospective study. *The Gerontologist,* **33,** 714-720.

Cohen, J & Cohen, P. (1983). *Applied Multiple Regression/Correlation Analysis for the Behavioural Sciences (2nd Edition).* Hillsdale, New Jersey: Lawrence Erlbaum Associates.

Cohen, S. & Edwards, J. (1989) Personality characteristics as moderators of the regulation between stress and health. In R.W. Neufeld (Ed.), *Advances in Investigations of Psychological Stress.* New York: Wiley & Sons.

Cohen, S. & Wills, T.A. (1985). Stress, social support, and the buffering hypothesis. *Psychological Bulletin,* **98,** 310-357.

Cohen, S., Kamarck, T. & Mermelstein, R. (1983). A global measure of perceived stress. *Journal of Health and Social Behaviour,* **24,** 385-396.

Colerick, E.J. & George L.K. (1986). Predictors of institutionalisation among caregivers of Alzheimer patients. *Journal of American Geriatric Society,* **34,** 493-498.

Collin, C., Wade, D.T., Davies, S. & Horne, V. (1988). The Barthel ADL index: a reliability study. *International Disability Studies,* **10,** 61-63.

Cooper, J.A., Sagar, H.J., Doherty, S.M., Jordan, N., Tidswell, P. & Sullivan, E.V. (1992). Different effects of dopaminergic and anticholinergic therapies on cognitive and motor function in Parkinson’s disease. *Brain,* **115,** 1701-1725.

Costa, P.T. & McCrae, R.R. (1980). Influence of extraversion and neuroticism on subjective well-being: happy and unhappy people. *Journal of Personality and Social Psychology,* **38,** 668-678.

Costa, P.T. & McCrae, R.R. (1980). Personality in adulthood: a six year longitudinal study of self reports and spouse ratings on the NEO Personality Inventory. *Journal of Personality and Social Psychology,* **54,** 853-863.

Costa, P.T. & McCrae, R.R. (1985). *The NEO Personality Inventory manual.* Odessa, Florida: Psychological Assessment Resources.

Costa, P.T. & McCrae, R.R. (1992). *The Revised NEO Personality Inventory (NEO PI-R™).* Odessa, Florida: Psychological Assessment Resources, Inc.

Cotzias, G.C. (1971). Levodopa in the treatment of Parkinson's disease. *Journal of the American Medical Association,* **218,** 1903.

Cotzias, G.C., Van Woert, M.H. & Schiffer, L.M. (1967). Aromatic amino acids and modification of Parkinsonism. *New England Journal of Medicine,* **276,** 374-379.

Cox, T. & Ferguson, E. (1991). Individual differences, stress and coping. In C.L. Cooper & R. Payne (Eds.), *Individual Differences in the Stress Process* (pp. 7-30). John Wiley & Sons Ltd.

Coyne, J.C. & DeLongis, A. (1986). Going beyond social support: the role of social relationships in adaptation. *Journal of Consulting and Clinical Psychology,* **5,** 454-460.

Coyne, J.C. & Fiske, V. (1992). Couples coping with chronic and catastrophic illness. In T.J. Akamatsu, M.A.P. Stephens, S.E. Hobfall & J.H. Crowther (Eds.), *Family Health Psychology* (pp. 129-149). Washington, DC: Hemisphere.

Cramer, D. (1994). Psychological distress and neuroticism: a two-wave panel study. *British Journal of Medical Psychology,* **67,** 333-342.

Crossman, L., London, C. & Barry, C. (1981). Older women caring for disabled spouses: a model for supportive services. *The Gerontologist,* **21,** 464-470.

Cummings, J.L. (1992). Neuropsychiatric complications of drug treatment of Parkinson's disease. In S.J. Huber & J.L. Cummings (Eds.), *Parkinson's Disease: Neurobehavioural Aspects* (pp 313-327). Oxford University Press.

Cummings, J.L. & Benson, D.F. (1983). *Dementia: A clinical approach.* Butterworth Inc.: Stoneham, Mass.

Cummings, J.L. & Benson, D.F. (1988). Psychological dysfunction accompanying subcortical dementias. *Annual Review of Medicine,* **39,** 53-61.

Curtis, L., Lees, A.J., Stern, G.M. & Marmot, M.G. (1984). Effect of L-dopa on the course of Parkinson's disease. *Lancet,* **ii,** 211-212.

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

De Smet, Y., Ruberg, M., Serdaru, M., Dubois, B., Lhermitte, F. & Agid, Y. (1982). Confusion, dementia and anticholinergics in Parkinson's disease. *Journal of Neurology, Neurosurgery and Psychiatry,* **45,** 1161-1164.

Dean A. & Lin, N. (1977). The stress-buffering role of social support. *Journal of Nervous and Mental Disease,* **165,** 403-417.

Delbecq-Derouesné, J. & Beauvois, M. -F. (1989). Memory processes and aging: a defect of automatic rather than controlled processes? *Archives of Gerontology and Geriatrics,* **(Suppl. 1),** 121-150.

DeLongis, A. & O'Brien, T. (1990). An interpersonal framework for stress and coping: an application to the families of Alzheimer's patients. In M. Stephens, J. Crowther, S. Hobfoll & D. Tennenbaum, *Stress and Coping in Later-Life Families.* New York: Hemisphere Pub. Co.

Derogatis, L.R. & Spencer, P.M. (1982). *The Brief Symptom Inventory (BSI). Administration, Scoring and Procedures, Manual 1.* Baltimore: Clinical Psychometrics Research.

Dewick, H.C., Hanley, J.R., Davies, A.D.M., Playfer, J. & Turnbull, C. (1991). Perception and memory for faces in Parkinson's disease. *Neuropsychologia,* **29,** 785-802.

DHSS (1981). *Growing Older*. Cmnd 8173. London: HMSO.

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

Diesfeldt, H. & Vink, M. (1989). Recognition memory for words and faces in the very old. *British Journal of Clinical Psychology,* **28,** 247-253.

Dohrenwend, B.S., Dohrenwend, B.P., Dodson, M. & Shrout, P. (1984). Symptoms, hassles, social support, and life events: problems of confounding measures. *Journal of Abnormal Psychology,* **93,** 222-230.

Draper, B.M., Poulos, C.J., Cole, A.M., Poulos, R.G. & Ehrlich, F. (1992). A comparison of caregivers for elderly stroke and dementia victims. *Journal of the American Geriatric Society,* **40,** 896-901.

Draper, B.M., Poulos, R.G., Poulos, C.J. & Ehrlich, F. (1995). Risk factors for stress in elderly caregivers. *International Journal of Geriatric Psychiatry,* **11,** 227-231.

Drinka, T.J., Smith, J.C. & Drinka, P.J. (1987). Correlates of depression and burden for informal caregivers of patients in a geriatric referral clinic. *Journal of the American Geriatrics Society,* **35,** 522-525.

Dubois, B. & Pillon, B. (1997). Cognitive deficits in Parkinson's disease. *Journal of Neurology,* **244,** 2-8.

Dubois, B., Boller, F., Pillon, B. & Agid, Y. (1991). Cognitive deficits in Parkinson's disease. In F. Boller & J. Grafman (Eds.) *Handbook of Neuropsychology, Vol. 5* (pp. 195-240). Elsevier, Amsterdam.

Dubois, B., Pillon, B., Legault, F., Agid, Y & Lhermitte, F. (1988). Slowing of cognitive processing in progressive supranuclear palsy: a comparison with Parkinson’s disease. *Archives of Neurology,* **45,** 194-199.

Dubois, B., Pillon, B., Malapani, C., Deweer, B., Vérin, M., Partiaud, A., Defontaines, B., Sirigu, A., Texeira, C. & Agid, Y. (1994). Subcortical dementia and Parkinson’s disease: what are the cognitive functions of the basal ganglia? In E.C. Wolters & P. Scheltens (Eds.), *Mental Dysfunction in Parkinson’s Disease* (pp.195-210). Vrieje University Press.

Dubois, B., Pillon, B., Sternic, N., Lhermitte, F. & Agid, Y. (1990). Age-induced cognitive disturbances in Parkinson's disease. *Neurology,* **40,** 38-41.

Dunbar, M., Alder, E., Evans, P. & Holmes, M. (1992). *Dementia severity and its relationship to caregiver’s psychological well-being: a meta-analysis.* Paper presented to the Annual Conference of the Health Psychology Section of the British Psychological Society. St. Andrews, Scotland.

Dunkel-Schetter, C. & Wortman, C.B. (1982). The interpersonal dynamics of cancer: problems in social relationships and their impact on the patient. In H.S. Friedman & M.R. DiMatteo (Eds.), *Interpersonal Issues in Health Care* (pp. 69-100). New York: Academic Press.

Dupont, E. (1977). Epidemiology of parkinsonism. The Parkinson investigation, Arhus, Denmark. In J. Worm-Peterson & J. Bottcher (Eds.) *Symposium on Parkinsonism.* Denmark: Merck-Sharp and Dohme.

Dupuy, H.G. (1984). The psychological well-being index. In N.K. Wenger, M.E. Mattson, C.D. Furberg & J. Elinson (Eds.), *Assessment of Quality of Life in Clinical Trials of Cardiovascular Therapies*. New York: Le Jacq.

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

Dwyer, D.J. & Ganster, D.C. (1991). Th effects of job demands and control on employee attendance and satisfaction. *Journal of Organizational Behavior,* **12,** 595-608.

Dwyer, J.W. & Coward, R.T. (1991). A multivariate comparison of the involvement of adult sons versus daughters in the care of impaired parents. *Journal of Gerontology: Social Sciences,* **46,** S259-S269.

Dwyer, J.W. & Seccombe, K. (1991). Elder care as family labour: the influence of gender and family position. *Journal of Family Issues,* **12,** 229-247.

Dwyer, J.W. (1995). The effects of illness on the family. In R. Blieszner & V.H. Bedford (Eds.), *Handbook on Aging and the Family*. New York: Greenwood Press.

Dwyer, J.W., Folts, W.E. & Rosenberg, E. (1994). Caregiving in social context. *Educational Gerontology,* **20,** 615-631.

Eagles, J., Craig, F., Rawlinson, F. Restall, J., Beattie, J. & Besson, J. (1987). The psychological wellbeing of supporters of the demented elderly. *British Journal of Psychiatry,* **150,** 293-298.

Eagly, A. (1987). *Sex Differences in Social Behaviour: a social role interpretation.* Hillsdale, NJ: Erlbaum.

Eatough, V.M., Kempster, P.A., Stern, G.M. & Lees, A.J. (1990). Premorbid personality and idiopathic Parkinson’s disease. In M.B. Streifler, A.D. Korczyn, E. Melamed & M.B.H. Youdin (Eds.), *Advances in Neurology, Vol. 53: Parkinson’s Disease: Anatomy, Pathology and Therapy* (pp. 335-337). New York: Raven Press.

Ebmeier, K.P., Calder, S.A., Crawford, J.R., Stewart, L., Beeson, J.A.O. & Mutch, W.J. (1990). Parkinson's disease in Aberdeen: survival after 3.5 years. *Acta Neurologica Scandinavica,* **81,** 294-299.

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

Ehringer, H. & Hornykiewicz, O. (1960). Verteilung von noradrenalin und dopamine (3-hydroxytriptamin) im gehirn des menschen und ihr verrhalten bei erkrankungen des extra-pyramidalen systems. *Klinische Wochenschrift,* **38,** 1236-1239.

Elizan, T.S., Sroka, H., Maker, H., Smith, H. & Yahr, M.D. (1986). Dementia in idiopathic Parkinson's disease: variables associated with its occurrence in 203 patients. *Journal of Neural Transmission,* **65,** 285-302.

Endler, N.S. & Parker, J.D.A. (1990). *Coping Inventory for Stressful Situations (CISS): Manual.* Multi-Health Systems, Toronto.

Enright, R.B. (1991). Time spent caregiving and help received by spouses and adult children of brain-impaired adults. *The Gerontologist,* **31,** 375-383.

Evarts, E.V., Teräväinen, H. & Calne, D.B. (1981). Reaction times in Parkinson's disease. *Brain,* **104,** 167-186.

Fahn, S., Elton, R.L. and UPDRS Development Committee. (1987). Unified Parkinson's disease rating scale. In S. Fahn, C.D. Marsden, D. Calne and M. Goldstein (Eds.), *Recent Developments in Parkinson's Disease* (Vol. 2, pp. 153-163 and 293-304). Forham Park, New York: McMillan Healthcare Information.

Felton, B.J., Revenson, T.A. & Hinrichsen, G.A. (1984). Stress and coping in the explanation of psychological adjustment among chronically ill adults. *Social Science Medicine,* **18,** 889-898.

Finch, J.F., Okun, M.A., Barrera, M., Zautra, A.J. & Reich, J.W. (1989). Positive and negative social ties among older adults: measurement models and the prediction of psychological distress and well-being. *American Journal of Community Psychology,* **17,** 585-605.

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

Folkman, S. (1984). Personal control and stress and coping processes: a theoretical analysis. *Journal of Personality and Social Psychology,* **46,** 839-852.

Folstein, M.F., Folstein, S.E. & McHugh, P.R. (1975). "Mini-Mental State": a practical method for grading the cognitive state of patients for the clinician. *Journal of Psychiatric Research,* **12,** 189-198.

Foreman, M.D. (1987). Reliability and validity of mental status questionnaires in elderly hospitalized patients. *Nursing Research,* **36,** 216-220.

Franzen, M.D. (1989). *Reliability and Validity in Neuropsychological Assessment.* New York: Plenum Press.

Friedman, H.S. & Booth-Kewley, S. (1987). The "disease-prone personality": a meta-analytic view of the construct. *American Psychologist,* **42,** 539-555.

Gallagher, D., Lovett, S. & Zeiss, A. (1989). Interventions with caregivers of frail elderly persons. In M. Ory & K. Bond (Eds.), *Aging and Health Care: Social Science and Policy Perspectives* (pp. 167-190). London: Routledge & Kegan Paul.

Gancher, S.T. (1992). Pharmacology of Parkinson's disease. In S.J. Huber & J.L. Cummings (Eds.), *Parkinson's Disease: Neurobehavioural Aspects* (pp. 273-287). Oxford University Press.

Ganster, D.C. & Victor, B. (1988). The impact of social support on mental and physical health. *British Journal of Medical Psychology,* **61,** 17-36.

Garron, D.C., Klawans, H.L. & Narin, F. (1972). Intellectual functioning in idiopathic Parkinson's disease. *Journal of Nervous and Mental Disease,* **154,** 445-452.

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

George, L.K. & Maddox, G. (1989). Aspects of institutional care. In M.G. Ory & K. Bond (Eds), *Aging and health care.* London: Routledge.

George, L.K. (1989). Stress, social support, and depression over the life course. In K.S. Markides & C.L. Cooper, *Aging, Stress and Health.* London: John Wiley and Sons Ltd.

George, L.K. (1994) Caregiver burden and well-being: an elusive distinction. *The Gerontologist,* **34,** 6-7.

Geraghty, J., Jankovic, J. & Zetusky, W. (1985). Association between essential tremor and Parkinson's disease. *Annals of Neurology,* **17,** 329-333.

Gerritsen, J.C. & van der Ende, P.C. (1994). The development of a care-giving burden scale. *Age & Ageing,* **23,** 483-491.

Gesten, G.M. & Jason, L.A. (1987). Social and community interventions. *Annual Review of Psychology,* **38,** 4-60.

Gibb, W.R.G. & Lees, A.J. (1994). Pathological clues to the cause of Parkinson's disease. In C.D. Marsden & S. Fahn (Eds.), *Movement Disorders 3* (pp. 147-166). Oxford: Butterworth-Heinemann Ltd.

Gibb, W.R.G. (1993). The neuropathology of Parkinson's disorders. In In J. Jankovic & E. Tolosa (Eds.), *Parkinson's Disease and Movement Disorders* (2nd ed.) (pp. 253-270). Baltimore: Williams & Wilkins.

Gilhooly, M. (1984). The impact of care-giving on care-givers: factors associated with the psychological wellbeing of people supporting a dementing relative in the community. *British Journal of Medical Psychology,* **57,** 35-44.

Gilhooly, M. (1986). Senile dementia: factors associated with care-givers preference for institutional care. *British Journal of Medical Psychology,* **59,** 165-171.

Gilleard, C.J. (1987). Influence of emotional distress among supporters on the outcome of psychogeriatric day care. *British Journal of Psychiatry,* **150,** 219-223.

Gilleard, C.J., Belford, H., Gilleard, E., Whittick, J.E. & Gledhill, K. (1984). Emotional distress amongst the supporters of the elderly mentally infirm. *British Journal of Psychiatry,* **145,** 172-177.

Gilleard, C.J., Boyd, W.D. & Watt, G. (1982). Problems in caring for elderly mentally infirm at home. *Archives of Gerontology and Geriatrics,* **1,** 151-158.

Girotti, F., Carella, F., Grassi, M.P., Soliveri, P., Marano, R. & Caraceni, T. (1986). Motor and cognitive performances of parkinsonian patients in the on and off phases of the disease. *Journal of Neurology, Neurosurgery and Psychiatry,* **49,** 657-660.

Girotti, F., Soliveri, P., Carella, F., Piccolo, I., Caffarra, P., Musicco, M. & Caraceni, T. (1988). Dementia and cognitive performance in Parkinson's disease. *Journal of Neurology, Neurosurgery and Psychiatry,* **51,** 1498-1502.

Given, B., Stommel, M., Collins, C., King, S. & Given, C. (1990). Responses of elderly spouse caregivers. *Research in Nursing and Health,* **13,** 77-85.

Glosser, G., Clark, C., Freundlich, B., Kliner-Krenzel, L., Flaherty, P. & Stern, M. (1995). A controlled investigation of current and premorbid personality:

characteristics of Parkinson's disease patients. *Movement Disorders,* **10,** 201-206.

Goetz, C.G. (1992). New strategies with dopaminergic drugs: modified formulations of levodopa and novel agonists. *Experimental Neurology,* **144,** 17-20.

Goetz, C.G. (1992). The historical background of behavioural studies in Parkinson's disease. In S.J. Huber & J.L. Cummings (Eds.), *Parkinson's Disease: Neurobehavioural Aspects* (pp. 3-9). Oxford University Press.

Goetz, C.G., Tanner, C.M. & Klawans, H.L. (1982). Pharmacology of hallucinations induced by long-term drug therapy. *American Journal of Psychiatry,* **139,** 494-497.

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

Gold, D.P., Cohen, C., Shulman, K., Zucchero, C., Andres, D., Etezadi, J. (1995). Caregiving and dementia: predicting negative and positive outcomes for caregivers. *International Journal of Aging and Human Development,* **41,** 183-201.

Goldberg, D.P. (1972). *The Detection of Psychiatric Illness by Questionnaire.* London: Oxford University Press.

Goldberg, D.P. (1978). *Manual for the General Health Questionnaire.* NFER-Nelson, Windsor.

Goldberg, D.P. & Hillier, V. (1979). A scaled version of the General Health Questionnaire. *Psychological Medicine,* **9,** 139-145.

Goldberg, D.P. & Williams, P. (1988). *A User's Guide to the General Health Questionnaire.* Windsor: NFER-Nelson.

Gore, S. (1985). Support styles and styles of coping with stress, In S. Cohen & S.L. Syme (Eds.), *Social Support and Health* (pp. 263-278). New York: Academic Press.

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

Grad, J., & Sainsbury, P. (1963). Mental illness and the family. *The Lancet,* **1,** 544-547.

Grad, J., & Sainsbury, P. (1965). An evaluation of the effects of caring for the aged at home. In World Psychiatric Associations Symposium, *Psychiatric Disorders in the Aged.* Manchester: Geigy.

Graham (1983). Caring: a labour of love. In J. Finch & D. Groves (Eds.), *A Labour of Love.* London: Routledge and Kegan Paul.

Green, H. (1988). Informal Carers: General Household Survey 1985. London: HMSO.

Greenberg, M.S. (1980). A theory of indebtedness. In K.J. Gergen, M.S. Greenberg & R.H. Willis (Eds.), *Social Exchange: Advances in Theory and Research* (pp.3-26). New York: Plenum.

Greene, J.G., Smith, R., Gardiner, M. & Timbury, G.C. (1982). Measuring behavioural disturbance of elderly demented patients in the community and its effect on relatives: a factor analytic study. *Age and Aging,* **11,** 121-126.

Gresham, G.E., Philips, T.F. & Labi, M.L.C. (1980). ADL status in stroke: relative merits of three standard indexes. *Archives of Physical Medicine and Rehabilitation,* **61,** 355-358.

Grimley Evans, J. (1991). Challenge of aging. In R. Smith (Ed.) *Health of the Nation: the BMJ View.* London: British Medical Journal.

Gross, R.D. (1987). *Psychology: The Science of Mind and Behaviour.* London: Hodder & Stoughton.

Guay, J. (1982). The social network of the ex-patient. *Canadian Mental Health,* **30,** 22.

Gudmundsson, K.R.A. (1967). A clinical survey of Parkinsonism in Iceland. *Acta Neurologica Scandinavica,* **43(Suppl. 33),** 9-61.

Guridi, J., Luquin, M.R., Herrero, M.T. & Obeso, J.A. (1993). The subthalamic nucleus: a possible target for stereotaxic surgery in Parkinson's disease. *Movement Disorders,* **8,** 421-429.

Gutmann, D.L. (1980). Psychoanalysis and aging: a developmental view. In S.I. Greenspan & G.H. Pollock (Eds.), *The Course of Life* (Volume 1). Bethesda, MD: National Institute of Mental Health.

Guy, W. (1976). *ECDEU Assessment Manual for Psychopharmacology*. Washington, DC: U.S. Department of Health, Education and Welfare.

Hackett, T.P. & Cassem, N.H. (1975). Psychological management of the myocardial infarction patient. *Journal of Human Stress,* **1,** 25-38.

Hadjistavropoulos, T., Taylor, S., Tuokko, H. & Beattie, B.L. (1994). Neuropsychological deficits, caregivers' perception of deficits and caregiver burden. *Journal of the American Geriatrics Society,* **42,** 308-314.

Hakim, A. & Mathieson, G. (1979). Dementia in Parkinson's disease. A neuropathologic study. *Neurology,* **29,** 1209-1214.

Haley, W.E. & Pardo, K. (1989). Relationship of severity of dementia to caregiving stressors. *Psychology and Aging,* **4,** 389-392.

Haley, W.E., Levine, E., Brown, L. & Bartolucci, A. (1987). Stress, appraisal, coping and social supports as mediators of adaptational outcomes among dementia caregivers. *Psychology and Aging,* **2,** 323-330.

Hall, J.N. (1990). Towards a psychology of caring. *British Journal of Clinical Psychology,* **29,** 129-144.

Harada, H., Nishikawa, S. & Takahashi, K. (1983). Epidemiology of Parkinson's disease in a Japanese city. *Archives of Neurology,* **40,** 151-154.

Harada, H., Nishikawa, S. & Takahashi, K. (1983). Epidemiology of Parkinson's disease in a Japanese city. *Archives of Neurology,* **40,** 151-154.

Harlow, J.M. (1868). Recovery after severe injury to the head. *Publication of the Massachusetts Medical Society,* **2,** 327-346.

Harvis, K. & Rabins, P. (1989). Dementia: helping family caregivers cope. *Journal of Psychosocial Nursing and Mental Health Services,* **27,** 6-12.

Helkala, E.L., Lauluma, U., Soininen, H. & Riekkinen, P.J. (1988). Recall and recognition memory in patients with Alzheimer's and Parkinson's diseases. *Annals of Neurology,* **24,** 214-217.

Hermanova, H. (1995). Healthy aging in Europe in the 1990's and implications for education and training in the care of the elderly. *Educational Gerontology,* **21,** 1-14.

Heron, A. & Chown, S.M. (1967). *Age and Function*. London: Churchill.

Hershey, L.A. (1982). Organic mental syndrome in Parkinson's disease. *Archives of Neurology,* **39,** 456-457.

Hickey, T. (1980). *Health and Aging*. Monterey, CA: Brooks/Cole.

Hietanen, M. & Teravainen, H. (1986). Cognitive performance in early Parkinson's disease. *Acta Neurologica Scandinavica,* **73,** 151-195.

Himmelfarb, S. & Murrell, S.A. (1983). Reliability and validity of five mental health scales in older persons. *Journal of Gerontology,* **38,** 333-339.

Hobfoll, S.E. & Vaux, A. (1993). Social support: resources and context. In L. Goldberger & S. Breznitz (Eds.), *Handbook of Stress: Theoretical and Clinical Aspects* (pp. 685-705). New York: Free Press.

Hodges, J.R. (1994). *Cognitive Assessment for Clinicians.* Oxford Medical Publications.

Hodgson, L.G. & Cutler, S.J. (1994). Caregiving and Alzheimer's disease. *Educational Gerontology,* **20,** 665-678.

Hoehn, M.M. & Yahr, M.D. (1967). Parkinsonism: onset, progression and mortality. *Neurology,* **37,** 485-487.

Hoenig, J. & Hamilton, M.W. (1967). *The Burden on the Household in an Extramural Psychiatric Service.* (H. Freeman, Ed.). London: Pergamon Press.

Hollingworth, C., Matthews, G. & Hartnett, O.M. (1988). Job satisfaction and mood: an exploratory study. *Work & Stress,* **2,** 225-232.

Hooker, K., Monahan, D., Shifren, K., & Hutchinson, C. (1992). Mental and physical health of spouse caregivers: the role of personality. *Psychology and Aging,* **7,** 367-375.

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

Horowitz, A. (1989). Sons and daughters as caregivers to older parents: differences in role performance and consequences. *The Gerontologist,* **25,** 612-617.

Horowitz, A. & Shindelman, l. (1983). Reciprocity and affection: past influences on current caregiving. *Journal of Gerontological Social Work,* **5,** 5-20.

Hotard, S.R., McFatter, R.M., McWhirter, R.M. & Stegall, M.E. (1989). Interactive effects of extraversion, neuroticism and social relationships on subjective well-being. *Journal of Personality and Social Psychology,* **57,** 321-331.

House, J.S. & Kahn, R.L. (1985). Measures and concepts of social support. In S. Cohn & S.L. Syme (Eds.), *Social Support and Health* (pp.83-108). New York: Academic Press.

Hovestadt, A., De Jong, G.J. & Meerwaldt, J.D. (1987). Spatial orientation as an early symptom of Parkinson’s disease. *Neurology,* **37,** 485-487.

Huber, S.J. Bornstein, R.A. (1992). Neurological evaluation of Parkinson’s disease. In S.J. Huber & J.L. Cummings (Eds.) *Parkinson’s disease: Neurobehavioural Aspects* (pp. 32-45). Oxford University Press.

Huber, S.J., Shuttelworth, E.L. & Paulson, G.W. (1986). Dementia in Parkinson's disease. *Archives of Neurology,* **43,** 987-990.

Hughes, , A.J., Daniel, S.E., Kilford, L. & Lees, A.J. (1992). Accuracy of clinical diagnosis of idiopathic Parkinson's disease: a clinico-pathological study of 100 cases. *Journal of Neurology, Neurosurgery and Psychiatry,* **55,** 181-184.

Hunter, K.R., Shaw, K.M., Laurence, D.R. & Stern, G.M. (1973). Sustained levodopa therapy in Parkinsonism. *Lancet,* **ii,** 929.

Hurtig, H.I. (1997). Problems with current pharmacologic treatment of Parkinson's disease. *Experimental Neurology,* **144,** 10-16.

Ingham, J.G. (1966). Changes in MPI scores in neurotic patients: a three year follow-up. *British Journal of Psychiatry,* **112,** 931-939.

Intieri, R.C. & Rapp, S.R. (1994). Self-control skilfulness and caregiver burden among help-seeking elders. *Journal of Gerontology,* **49,** 19-23.

Isaacs, B., Livingstone, M. & Neville, Y. (1972). *Survival of the Unfittest: A Study of Geriatric Patients in Glasgow.* London: Routledge & Kegan Paul.

Iwasaki, Y., Kinoshita, M., Ikeda, K. & Takamiya, K. (1989). Cognitive function in Parkinson’s disease in relation to motor symptoms. *International Journal of Neuroscience,* **47,** 295-300.

Jackson, J.A., Free, G.B.M. & Pike, H.V. (1923). The psychic manifestations in paralysis agitans. *Archives of Neurology and Psychiatry,* **10,** 680-684.

Jackson, S.E. (1989). Does job control job stress? In S.L. Sauter, J.J. Hurrel, Jr. & C.L. Cooper (Eds.), *Job Control and Worker Health* (pp.25-53). John Wiley & Sons Ltd.

Jacobsen, D.E. (1986). Types and timing of social support. *Journal of Health and Social Behaviour,* **27,** 250-264.

James, O. & Davies, A.D.M. (1987). Assessing social support and satisfaction in the elderly: development of a brief assessment instrument, the Index of Social Support. *International Journal of Geriatric Psychiatry,* **2,** 227-233.

James, O., Davies, A.D.M. & Ananthakopan, S. (1986). The life satisfaction index-well being: its internal reliability and factorial composition. *British Journal of Psychiatry,* **149,** 647-650.

Janssen, M., Philipsen, H. & Halfens, R. (1990, July). *Personal Networks of Chronically Ill People.* Paper presented at the Fifth International Conference on Personal Relationships, Oxford University, Oxford, UK.

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

Jellinger, K. & Grissold, W. (1982). Cerebral atrophy in Parkinson's syndrome. *Experimental Brain Research., (suppl.),* **5,** 26-35.

Jenkins, A.C. (1966). Epidemiology of Parkinsonism in Victoria. *Medical Journal of Australia,* **96,** 242-254.

Jenkins, R. (1991). Demographic aspects of stress. In C.L. Cooper & R. Payne (Eds.), *Personality and Stress: Individual Differences in the Stress Process* (pp. 107-132). John Wiley & Sons Ltd.

Jones, D.A. & Vetter, N.J. (1984). A survey of those who care for the elderly at home: their problems and needs. *Social science and Medicine,* **19,** 511-514.

Kahana, E. & Kinney, J. (1991). Understanding caregiving interventions in the context of the stress model. In R.F. Young & E.A. Olson (Eds.), *Health, Illness, and Disability in Later Life: Practice Issues and Interventions.* Newbury Park, Sage Publications.

Kahana, E. & Young, R. (1990). Clarifying the caregiving paradigm: challenges for the future. In D.E. Biegel & A. Blum (Eds.), *Aging and Caregiving: Theory, Research & Policy.* Newbury Park: Sage Publications.

Kahana, E., Kahana, B. & Young, R. (1987). Strategies of coping and postinstitutional outcomes. *Research on Aging,* **9,** 182-199.

Karasek, R.A. Jr. (1979). Job demands, job decision latitude, and mental strain: implications for job redesign. *Administrative Science Quarterly,* **24,** 285-306.

Karasek, R.A. & Theorell, T. (1990). *Healthy Work: Stress, Productivity, and the Reconstruction of Working Life.* New York: Basic Books.

Karnofsky, D.A., Burchenal, J.H., Armistead, G.C., Southam, C.M., Bernstein, J.L., Creaver, L.F. & Rhoads, C.P. (1951). Triethylene melamine in the treatment of neoplastic disease. *Archives of Internal Medicine,* **87,** 477-516.

Kerr, T.A., Schapira, K., Roth, M. & Garside, R.F. (1970). The relationship between the Maudsley Personality Inventory and the course of affective disorders. *British Journal of Psychiatry,* **116,** 11-19.

Kessler I.I. (1972). Epidemiologic studies of Parkinson's disease. III. A community-based survey. *American Journal of Epidemiology,* **96,** 242-254.

Kessler I.I. & Diamond, E.L. (1971). Epidemiologic studies of Parkinson's disease. I. Smoking and Parkinson's disease. *American Journal of Epidemiology,* **94,** 16-25.

Killeen, M. (1990). The influence of stress and coping on family caregivers' perception of health. *International Journal of Aging and Human Development,* **30,** 197-211.

Kinney, J.M. & Stephens, M.A.P. (1987). *The Caregiving Hassles Scale: Administration, Reliability and Validity.* Kent, OH: Kent State University, Psychology Department.

Kinney, J.M. & Stephens, M.A.P. (1989a). Hassles and uplifts of giving care to a family member with dementia. *Psychology and Aging,* **4,** 402-408.

Kinney, J.M. & Stephens, M.A.P. (1989b). Caregiving Hassles scale: assessing the daily hassles of caring for a family member with dementia. *The Gerontologist,* **29,** 328-332.

Kobasa, S.C. & Puccetti, M. (1983). Personality and social resources in stress resistance. *Journal of Personality and Social Psychology,* **45,** 839-850.

Kobasa, S.C., Maddi, S.R. & Courington, S. (1981) Personality and constitution as mediators in the stress-illness relationship. *Journal of Health and Social Behaviour,* **22,** 368-378.

Kobasa, S.C., Maddi, S.R. & Kahn, S. (1982). Hardiness and health: a prospective study. *Journal of Personality and Social Psychology,* **42,** 168-177.

Kobasa, S.C., Maddi, S.R. & Zola, M.A. (1983). Type A and hardiness. *Journal of Behavioural Medicine,* **6,** 41-51.

Kosberg, J.I. & Cairl, R.E. (1986). The cost of care index: a case management tool for screening informal caregivers. *The Gerontologist,* **26,** 273-278.

Kramer, B.J. (1993a). Expanding the conceptualization of caregiver coping: the importance of relationship-focused coping strategies. *Family Relations,* **42,** 383-391.

Kramer, B.J. (1993b). Marital history and the prior relationship as predictors of positive and negative outcomes among wife caregivers. *Family Relations,* **42,** 367-375.

Krantz, D.S. & Deckel. A.W. (1983). *Coping with Chronic Disease: Research and Applications.* New York: Academic Press.

Krause, A., Spasoff, R., Beattie, E., Holden, E., Lawson, J., Rodenberg, M. & Woodcock, G. (1976). Elderly applications to long-term care institutions. *Journal of the American Geriatrics Society,* **24,** 117-125.

Krause, N. & Borawski-Clark, E. (1994). Clarifying the functions of social support in later life. *Research on Aging,* **16,** 251-279.

Krause, N. & Markides, K.S. (1990). Measuring social support among older adults. *International Journal of Aging and Human Development,* **30,** 37-53.

Krause, N. (1986a). Stress and sex differences in depressive symptoms among older adults. *Journal of Gerontology,* **41,** 727-731.

Krause, N. (1986b). Social support, stress and well-being among older adults. *Journal of Gerontology,* **41,** 512-519.

Krause, N. (1987a). Chronic financial strain, social support, and depressive symptoms among older adults. *Psychology and Aging,* **2,** 185-192.

Krause, N. (1987b). Chronic strain, locus of control, and distress in older adults. *Psychology and Aging,* **2,** 375-382.

Krause, N. (1987c). Life stress, social support, and self-esteem in an elderly population. *Psychology and Aging,* **2,** 349-356.

Krause, N. (1987d). Understanding the stress process: linking social support with locus of control beliefs. *Journal of Gerontology,* **42,** 589-593.

Krause, N. (1989). Issues of measurement and analysis in studies of social support, aging and health. In K.S. Markides & C.L. Cooper (Eds.) *Aging, Stress and Health* (pp. 43-66). London: John Wiley & Sons Ltd.

Krause, N., Liang, J. & Yatomi, N. (1989). Satisfaction with social support and depressive symptoms: a panel analysis. *Psychology and Aging,* **4,** 88-97.

Kurland, L.T. (1958). Epidemiology: incidence, geographic distribution and genetic considerations. In W.J. Field (Ed.) *Pathogenesis and Treatment of Parkinsonism* (pp. 5-43). Springfield: Charles C. Thomas.

La Rue, A. (1992). *Aging and Neuropsychological Assessment.* New York: Plenum Press.

Landy, F., Quick, J.C. & Kasl, S. (1994). Work, stress and well-being. *International Journal of Stress Management,* **1,** 33-73.

Lang, A.E.T. & Fahn, S. (1989). Assessment of Parkinson’s disease. In T.L. Munsat (Ed.), *Quantification of Neurologic Deficit* (pp. 285-309). Butterworths.

Larsson, T. & Sjögren, T. (1960). Essential tremor. A clinical and genetic population study. *Acta Psychiatrica Neurologica Scandinavica,* **36 (Suppl. 144)**, 1-176.

Lawton, M.P., Kleban, M.H., Moss, M., Rovine, M. & Glicksman, A. (1989). Measuring caregiving appraisal. *Journal of Gerontology,* **44,** 61-71.

Lawton, M.P., Moss, M., Kleban, M.H., Glicksman, A. & Rovine, M. (1991). A two-factor model of caregiving appraisal and psychological well-being. *Journal of Gerontology,* **46,** 181-189.

Lazarus, R.S. (1966). *Psychological Stress and the Coping Process.* New York: McGraw-Hill.

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

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

Lees, A.J. (1985). Parkinson's disease and dementia. *Lancet,* **i,** 43-44.

Lees, A.J. (1990). The behavioural neurology of Parkinson's disease. In G.M. Stern (Ed.), *Parkinson's Disease* (pp. 389-413). London: Chapman and Hall Ltd.

Lees, A.J. Smith, E. (1983). Cognitive deficits in the early stages of Parkinson’s disease. *Brain,* **106,** 257-270.

Lesser, R.P., Fahn, S., Snider, S.R., Cote, L.J., Isgreen, W.P. & Barret, R.E. (1979). Analysis of the clinical problems in Parkinsonism and the complications of long-term levodopa therapy. *Neurology,* **29,** 1253-1260.

Lewis-Beck, M.S. (1980). *Applied Regression.* London: Sage.

Lewy, F.H. (1923). *Die Lehre von Tonus und der Bewegung zugleich systematische Untersuchungen sur Klinik, Physiologie, Pathologie und Pathogenese der Paralysis Agitans.* Berlin: Springer.

Li, S.C., Schoenberg, B.S., Wang, C.C. *et al.* (1985). A prevalence study of Parkinson's disease and other movement disorders in the People's Republic of China. *Archives of Neurology,* **42,** 655-657.

Lichtenberg, P.A. & Barth, J.T. (1989). The dynamic process of caregiving in elderly spouses: a look at longitudinal case reports. *Clinical Gerontologist,* **9,** 31-44.

Lichter, D.C., Corberr, A.J., Fitzgibbon, G.M., Davidson, D.R., Hope, J.K., Goddard, G.V., Sharples, K.J. & Pollock, M, (1988). Cognitive and motor dysfunction in Parkinson's disease. *Archives of Neurology,* **45,** 854-860.

Lieberman, A., Dziatolowski, M., Kupersmith, M. *et al.* (1979). Dementia in Parkinson's disease. *Annals of Neurology,* **6,** 355-359.

Lingoes, J.L. (1973). *The Guttman Lingoes Nonmetric Program Series.* Ann Arbor, MI: Mathesis Press.

Lit, A.C. (1968). Man behind a mask. An analysis of the psychomotor phenomena of Parkinson’s disease. *Acta Neurologica Belgie,* **68,** 863-874.

Litvan, I., Mohr, E., Williams, J., Gomez, C. & Chase, T.N. (1991). Differential memory and executive functions in demented patients with Parkinson's disease and Alzheimer's disease. *Journal of Neurology, Neurosurgery and Psychiatry,* **54,** 25-29.

Loranger, A.W., Goodell, H., McDowell, F. Lee, J.H. & Sweet, R.D. (1972). Intellectual impairment in Parkinson's syndrome. *Brain,* **95,** 405-412.

Lyons, R.F. (1986). *The Impact of Chronic Illness on Activity Patterns and Friendships*. Ottawa: Fitness & Lifestyle Research Institute.

Lyons, R.F. (1991). The effects of acquired illness and disability on friendships. In D. Perlman & W. Jones (Eds.), *Advances in Personal Relationships* (Vol. 3, pp. 223-277).

Lyons, R.F., Sullivan, M.J.L. & Ritvo, P.G. (1995). *Relationships in Chronic Illness and Disability.* Thousand Oaks, California: Sage Publications.

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

Maddi, S.R. & Kobasa, S.C. (1984). *The Hardy Executive: Health Under Stress.* Homewood, IL: Dow Jones-Irwin.

Mahoney, F.I. & Barthel, D.W. (1965). Functional evaluation: the Barthel Index. *Maryland State Medical Journal,* **14,** 61-65.

Mahurin, R.K., Feher, E.P., Nance, M.L., Levy, J.K. & Pirozzolo, F.J. (1993). Cognition in Parkinson's disease and related disorders. In R.W. Parkes, R.F. Zec & R.S. Wilson (Eds.) *Neuropsychology of Alzheimer's Disease and Other Dementias* (pp. 308-349). Oxford University Press.

Majerovitz, S.D. (1995). Role of family adaptability in the psychological adjustment of spouse caregivers to patients with dementia. *Psychology and Aging,* **10,** 447-457.

Manyam, B.V. (1990). Paralysis agitans and levodopa in "Ayurveda": Ancient Indian medical treatise. *Movement Disorders,* **5,** 47-48.

Marié, R.M., Rioux, P. Eustache, F., Travère, J.M., Lechevalier, B. & Baron, J.C. (1995). Clues about the functional anatomy of verbal working memory: a study of resting brain glucose metabolism in Parkinson's disease. *European Journal of Neurology,* **2,** 83-94.

Marsden, C.D. & Parkes, J.D. (1976). "On-off" effects in patients with Parkinson's disease on chronic levodopa therapy. *Lancet,* **i,** 292-296.

Marsden, C.D. & Parkes, J.D. (1977). Success and problems of long-term levodopa therapy in Parkinson's disease. *Lancet,* **i,** 345-349.

Marsden, C.D. (1994). Parkinson's disease. *Journal of Neurology, Neurosurgery and Psychiatry,* **57,** 672-681.

Martin, W.E., Loewenson, R.B., Resch, J.A. & Baker, A.B. (1973). Parkinson's disease. Clinical analysis of 100 patients. *Neurology,* **23,** 783-790.

Martinez, M.P., Gil, N.A., Gracia, L.M., Gomez, J.B., Martinex, S.J. & Bermejo, F. (1994). Unified Parkinson's Disease Rating Scale characteristics and structure. The Cooperative Multicentric Group. *Movement Disorders,* **9,** 76-83.

Marttila, R.J. & Rinne, U.K. (1976a). Epidemiology of Parkinson's disease in Finland. *Acta Neurologica Scandinavica,* **53,** 81-102.

Marttila, R.J. & Rinne, U.K. (1976b). Dementia in Parkinson's disease. *Acta Neurologica Scandinavica,* **54,** 431-441.

Matson, N. (1991). Coping, caring and stress: a study of stroke carers and carers of confused older people. *British Journal of Clinical Psychology,* **33,** 333-344.

Matthews, S.H. & Rosner, T.T. (1988). Shared filial responsibility: the family as the primary caregiver. *Journal of Marriage and the Family,* **50,** 185-195.

Mayeux, R., Stern, Y., Rosen, J. & Leventhal, J. (1981). Depression, intellectual impairment and Parkinson's disease. *Neurology,* **31,** 645-650.

Mayeux, R., Stern, Y., Sano, M., Cote, L. Williams, J.B.W. (1987). Clinical and biochemical correlates of bradyphrenia in Parkinson's disease. *Neurology,* **37,** 1130-1134.

Mayeux, R., Williams, J.B.W., Stern, Y. & Cote, L. (1984). Depression and Parkinson's disease. *Advances in Neurology,* **40,** 241-250.

McDowell, I. & Newell, C. (1996). *Measuring Health: a guide to rating scales and questionnaires* (2nd Ed.). New York: Oxford University Press.

McFall, S. & Miller, B. (1992). Caregiver burden and nursing home admission of frail elderly persons. *Journal of Gerontology,* **47,** 97-144.

McGrath, J.E. (1976). Stress and behaviour in organizations. In M.D. Dunnette (Ed.), *Handbook of Industrial and Organizational Psychology.* Chicago: Rand McNally.

McKeigue, P.M. & Marmot, M.G. (1990). Epidemiology of Parkinson's disease. In G.M. Stern (Ed.), *Parkinson's Disease* (pp. 295-306.) London: Chapman and Hall Medical.

Mendelsohn, G.A., Dakof, G.A. & Skaff, M. (1995). Personality change in Parkinson’s disease patients: chronic disease and aging. *Journal of Personality,* **63,** 233-257.

Menza, M.A., Forman, N.E., Goldstein, H.S. & Golbe, L.I. (1990). Parkinson’s disease, personality and dopamine. *Journal of Neuropsychiatry and Clinical Neuroscience,* **2,** 282-287.

Menza, M.A., Mark, M.H., Burn, D.J. & Brooks, D.J. (1995). Personality correlates of [18F]dopa striatal uptake: results of positron-emission tomography in Parkinson’s disease. *Journal of Neuropsychiatry and Clinical Neuroscience,* **7,** 176-179.

Miller, B. (1990). Gender differences in spouse caregiver strain: socialisation and role expectations. *Journal of Marriage and the Family,* **52,** 311-322.

Miller, B. & Cafasso, L. (1992). Gender differences in caregiving: fact or artifact? *The Gerontologist,* **32,** 498-507.

Miller, B., McFall, S. & Montgomery, A. (1991). The impact of elder health, caregiver involvement, and global stress on two dimensions of caregiver burden. *Journal of Gerontology,* **46,** S9-S19.

Miller, E. & Morris R.G. (1993). *The Psychology of Dementia.* Chichester: John Wiley & Sons.

Miller, E., Berrios, G.E. & Politynska, B.E. (1996). Caring for someone with Parkinson’s disease: factors that contribute to distress. *International Journal of Geriatric Psychiatry,* **11,** 263-268.

Mills, J. & Clark, M.S. (1982). Exchange and communal relationships. In L. Wheeler (Ed.) *Review of Personality and Social Psychology* (pp121-144). Beverly Hills: Sage.

Mindham, R.H.S. (1970). Psychiatric symptoms in Parkinsonism. *Journal of Neurology, Neurosurgery and Psychiatry,* **33,** 188-191.

Mindham, R.H.S., Ahmed, S.W.A. & Clough, C.G. (1982). A controlled study of dementia in Parkinson's disease. *Journal of Neurology, Neurosurgery and Psychiatry,* **45,** 969-974.

Mindham, R.H.S., Marsden, C.D. & Parkes, J.D. (1976). Psychiatric symptoms during L-dopa therapy for Parkinson's disease and their relationship to physical disability. *Psychological Medicine,* **6,** 23-33.

Mingo, F.E. (1993). *The Caregiver.* Halifax, Nova Scotia: Largo.

Mitchell, R.E. & Hodson, C.A. (1983). Coping with domestic violence: social support and psychological health among battered women. *American Journal of Community Psychology,* **11,** 629-654.

Mjönes, H. (1949). Paralysis agitans, a clinical and genetic study. *Acta Psychiatrica Neurologica Scandinavica,* **54,** 1-195.

Mohr, E., Livtan, I., Williams, J., Fedio, P. & Chase, T.N. (1990). Selective deficits in Alzheimer and parkinsonian dementia: visuospatial function. *Canadian Journal of Neurological Sciences,* **17,** 292-297.

Monahan, D.J. & Hooker, K. (1995). Health of spouse caregivers of dementia patients: the role of personality and social support. *Social Work,* **40,** 305-314.

Montgomery, E.B., Lieberman, A., Singh, G., Fries, J.F. and the remaining members of the PROPATH advisory board. (1994). Patient education and health promotion can be effective in Parkinson’s disease: a randomised controlled trial. *The American Journal of Medicine,* **97,** 429-435.

Montgomery, R.J.V., Gonyea, J.G. & Hooyman, N.R. (1985a). Caregiving and the experience of subjective and objective burden. *Family Relations,* **34,** 19-26.

Montgomery, R.J.V., Kosloski, K. & Borgotta, E. (1990). Service use and the caregiving experience: does Alzheimer's disease make a difference? In D.E. Biegel & A. Blum (Eds.), *Ageing and Caregiving: Theory, Research and Policy.* Newbury Park: Sage Publications.

Montgomery, R.J.V., Stull, D.E. & Borgatta, E.F. (1985b). Measurement and analysis of burden. *Research on Aging,* **7,** 137-152.

Morgan, M., Patrick, D.L. & Charlton, J.R. (1984). Social networks and psychosocial support among disabled people. *Social Science and Medicine,* **19,** 489-497.

Moritz, D., Kasl, S. & Berkman, L. (1989). The health impact of living with a cognitively impaired elderly spouse: depressive symptoms and social funtioning. *Journal of Gerontology,* **44,** S17-S27.

Morris, L.W., Morris, R.G. & Britton, P.G. (1988). The relationship between marital intimacy, perceived strain and depression in spouse caregivers of dementia patients. *British Journal of Medical Psychology,* **61,** 231-236.

Morris, R.G., Downes, J.J., Sahakain, B.J., Evenden, J.L., Heald, A. & Robbins, T.W. (1988). Planning and spatial working memory in Parkinson’s disease. *Journal of Neurology, Neurosurgery and Psychiatry,* **51,** 757-766.

Mortimer, J.A., Pirozzolo, F.J., Hansch, E.C. & Webster, D.D. (1982). Relationship of motor symptoms to intellectual deficits in Parkinson’s disease. *Neurology,* **32,** 133-137.

Morycz, R.K. (1985). Caregiving strain and the desire to institutionalize family members with Alzheimer’s disease: possible predictors and model development. *Research on Aging,* **7,** 329-361.

Moskovitz, C., Moses, H.III & Klawans, H.L. (1978). Levodopa-induced psychosis: a kindling phenomenon. *American Journal of Psychiatry,* **135,** 669-675.

Motenko, A.K. (1989). The frustrations, gratifications, and well-being of dementia caregivers. *The Gerontologist,* **29,** 166-172.

Mouradian, M.M. & Chase, T.N. (1994). Improved dopaminergic therapy of Parkinson’s disease. In C.D. Marsden & S. Fahn (Eds.), *Movement Disorders 3*. Oxford: Butterworth-Heinemann Ltd.

Mullen, B. & Suls, J. (1982). The effectiveness of attention and rejection as coping styles: a meta-analysis of temporal differences. *Journal of Psychosomatic Research,* **26,** 43-49.

Murphy, K.R. & Davidshofer, C.O. (1991). *Psychological Testing: Principles and Applications* (2nd Edition). New Jersey: Prentice Hall.

Mutch, W.J., Dingwall-Fordyce, I., Downie, A.W., Patterson, J.G. & Roy, S.K. (1986). Parkinson’s disease in a Scottish city. *British Medical Journal,* **292,** 534-536.

Naimark, D., Jackson, E., Rockwell, E. & Jeste, D.V. (1996). Psychotic symptoms in Parkinson’s disease patients with dementia. *Journal of the American Geriatric Society,* **44,** 296-299.

Naugle, R.I. & Kawczak, K. (1989). Limitations of the Mini-Mental State Examination. *Cleveland Clinical Journal of Medicine,* **56,** 277-281.

Naville, F. (1922). Les complications et les sequelles mentales de l'encephalite epidemique. *Encephalé,* **17,** 369-75, 423-436.

Nelson, H.E. (1982). *National Adult Reading Test: Test Manual.* Windsor: NFER-Nelson.

Neugarten, B.L., Havighurst, R.J. & Tobin, S.S. (1961). The measurement of life satisfaction. *Journal of Gerontology,* **16,** 134-143.

Nissel, M. & Bonnerjea, L. (1982). *Family care of the handicapped elderly: who pays?* London: Policy Studies Institute.

Novak, M. & Guest, C.I. (1989). Application of a multidimensional caregiver burden inventory. *The Gerontologist,* **29,** 798-803.

Nusselder, W.J. & Mackenbach, J.P. (1996). Rectangularization of the survival curve in the Netherlands, 1950-1992. *The Gerontologist,* **36,** 773-782.

O’Brien, R.A., Wineman, N.M. & Nealon, N.R. (1995). Correlates of the caregiving process in multiple sclerosis. *Scholarly Inquiry for Nursing Practice: An International Journal,* **9,** 323-338.

O’Reilly, F., Finnan, F., Allwright, S., Davey Smith, G. & Ben-Shlomo, Y. (1996). The effects of caring for a spouse with Parkinson’s disease on social, psychological and physical well-being. *British Journal of General Practice,* **46,** 507-512.

Office of Population Censuses and Surveys (1982). *General Household Survey 1980.* London: HMSO.

Office of Population Censuses and Surveys (1986). *Mid-1985 Population Projections*. London: HMSO.

Office of Population Censuses and Surveys (1988). *Survey of disability in Great Britain*. London: HMSO.

Orbell, S. (1996). Informal care in social context: a social psychological analysis of participation, impact and intervention in care of the elderly. *Psychology and Health,* **11,** 155-178.

Orbell, S. & Gillies, B. (1993). What’s stressful about caring? *Journal of Applied Social Psychology,* **23,** 272-290.

Orbell, S., Gillies, B. & Hopkins, N. (1992). *A survey of people providing care to an elderly person in Dundee.* Department of Epidemiology and Public Health, University of Dundee, Scotland.

Orbell, S., Hopkins, N. & Gillies, B. (1993). Measuring the impact of informal caring. *Journal of Community and Applied Social Psychology,* **3,** 149-163.

Ormel, J. & Worhlfarth, J. (1991). How neuroticism, long-term difficulties and life situation change influence psychological distress: a longitudinal model. *Journal of Personality and Social Psychology,* **60,** 744-755.

Owen, A.M., Belsinka, M., James, M., Leigh, P.N., Summers, B.A., Marsden, C.D., Quinn, N.P., Sahakian, B.J. & Robbins, T.W. (1993). Visuospatial memory deficits at different stages of Parkinson's disease. *Neuropsychologia,* **31,** 627-644.

Oyebode, J.R., Barker, W.A., Blessed, G., Dick, D.J. & Britton, P.G. (1986). Cognitive functioning in Parkinson's disease. *British Journal of Psychiatry,* **149,** 720-725.

Pagel, M.D., Becker, J. & Coppel, D.B. (1985). Loss of control, self blame and depression: an investigation of spouse caregivers of Alzheimer's disease patients. *Journal of Abnormal Psychology,* **94,** 169-182.

Pagel, M.D., Erdly, W.W. & Becker, J. (1987). Social networks: we get by with (and in spite of) a little help from our friends. *Journal of Personality and Social Psychology,* **53,** 793-804.

Palmore, E.B., Nowlin, J.B. & Wang, H.S. (1985). Predictors of function among the old-old: a ten years follow-up. *Journal of Gerontology,* **40,** 244-250.

Parkes, J.D. (1981). Adverse effects of antiparkinsonian drugs. *Drugs,* **21,** 341-353.

Parkes, K.R. (1986). Coping in stressful episodes: the role of individual differences, environmental factors, and situational characteristics. *Journal of Personality and Social Psychology,* **51,** 1277-1292.

Parkes, K.R. (1994). Personality and coping as moderators of work stress processes: models, methods and measures. *Work and Stress,* **8,** 110-129.

Parkinson, J. (1817). *An Essay on the Shaking Palsy.* London: Sherwood, Neely & Jones.

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

Paulson, G.W. & Dadmehr, N. (1991). Is there a premorbid personality typical for Parkinson's disease? *Neurology,* **41 (Suppl. 2),** 73-76.

Paulus, W. & Jellinger, K. (1991). The neuropathological basis of different clinical subgroups of Parkinson's disease. *Journal of Neuropathology and Experimental Neurology,* **50,** 473-755.

Pearce, J.M.S. (1992). *Parkinson's Disease and its Management.* Oxford University Press.

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

Pearlin, L.I., Menaghan, E., Lieberman, M. & Mullan, J.T. (1981). The Stress Process. *Journal of Health and Social Behaviour,* **22,** 337-356.

Pearlin, L.I., Mullan, J.T., Semple, S.J. & Skaff, M.M. (1990). Caregiving and the stress process: an overview of concepts and their measures. *The Gerontologist,* **30,** 583-594.

Pearlin, L.I., Turner, H. & Semple, S.J. (1989). Coping and the mediation of caregiver stress. In E. Light & B.D. Lebowitz (Eds.), *Alzheimer's Disease, Treatment and Family Stress: Directions for Research* (pp. 198-217). Washington D.C.: U.S. Department of Health and Human Services.

Pfeiffer, E. (1979). A short psychiatric evaluation scale: a new 15-item monotonic scale indicative of functional psychiatric disorder. In the proceedings of the Bayer-Symposium, VII, *Brain Function in Old Age.* New York: Springer-Verlag.

Piccirilli, M., D'Alessandro, P., Finali, G. Piccinin, G.L. & Agostini. L. (1989). Frontal lobe dysfunction in Parkinson's disease: prognostic value for dementia. *European Neurology,* **29,** 71-76.

Piccirilli, M., Piccinin, G.L. & Agostini. L. (1984). Characteristic clinical aspects of Parkinsonian patients. *European Neurology,* **23,** 44-50.

Pillon, B., Deweer, B. Agid, Y. & Dubois, B (1993). Explicit memory in Alzheimer's, Huntington's and Parkinson's diseases. *Archives of Neurology,* **50,** 374-379.

Pillon, B., Dubois, B. & Agid, Y. (1996). Testing cognition may contribute to the diagnosis of movement disorders. *Neurology,* **46,** 329-333.

Pillon, B., Dubois, B., Bonnet, A.-M., Esteguy, M., Guimares, J., Vigouret, J.-M., Lhermitte, F. & Agid, Y. (1989). Cognitive slowing in Parkinson's disease fails to respond to levodopa treatment: The 15-Objects Test. *Neurology,* **39,** 762-768.

Pillon, B., Dubois, B., Ploska, A. & Agid, Y. (1991). Severity and specificity of cognitive impairment in Alzheimer's, Huntington's and Parkinson's disease, and progressive supranuclear palsy. *Neurology,* **41,** 634-643.

Pillon, B., Ertle, S., Deweer, B., Sarazin, M., Agid, Y. & Dubois, B. (1996). Memory for spatial location is affected in Parkinson's disease. *Neuropsychologia,* **34,** 77-85.

Pines, A.M., Aronson, E. & Kafry, D. (1981). *Burnout. From Tedium to Personal Growth.* New York: Free Press.

Pirozzolo, F.J., Hanschm E.C., Mortimer, J.A., Webster, D.D. & Kuskowski, M.A. (1982). Dementia in Parkinson's disease. A neuropsychological analysis. *Brain Cognition,* **1,** 71-83.

Poewe, W., Gerstenbrand, F., Ransmayr, G. & Plörer, S. (1983). Premorbid personality of Parkinson's patients. *Journal of Neural Transmitter Supplement,* **19,** 215-224.

Poewe, W., Karamat, E., Kemmler, G.W. & Gerstenbrand, F. (1990). The premorbid personality of patients with Parkinson's disease: a comparitive study with healthy controls and patients with essential tremor. In M.B. Streifler, A.D. Korczyn, E. Melamed & M.B.H. Youdin ((Eds.), *Advances in Neurology, Vol. 53: Parkinson's Disease: Anatomy, Pathology and Therapy* (pp. 339-342). New York: Raven Press.

Pollock, M & Hornabrook, R.W. (1966). The prevalence, natural history and dementia of Parkinson's disease. *Brain,* **89,** 429-448.

Portin, R. & Rinne, U.K. (1984). Predictive factors for dementia in Parkinson's disease. *Acta Neurologica Scandinavica,* **69 (supplement 98),** 57-58.

Poulshock, S.W. & Deimling, G.T. (1984). Families caring for elders in residence: issues in the measurement of burden. *Journal of Gerontology,* **39,** 230-239.

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

Prick, J.J.G. (1966). Genuine Parkinsonism. A psychosomatic, anthropological-psychiatric approach. *Abstract World Congress of Psychiatry,* Madrid. Sandorama Special Number IV.

Pruchno, R.A. & Resch, N.L. (1989a). Husbands and wives as caregivers: antecedents of depression and burden. *The Gerontologist,* **29,** 159-165.

Pruchno, R.A. & Resch, N.L. (1989b). Mental health of caregiving spouses: coping as mediator, moderator, or main effect? *Psychology and Aging,* **4,** 454-463.

Pruchno, R.A., Michaels, J.E. & Potashnik, S.L. (1990). Predictors of institutionalization among Alzheimer disease victims with caregiving spouses. *Journal of Gerontology,* **45,** S259-S266.

Pullman, S.L., Watts, R.L., Juncos, J.L., Chase, T.N. & Sanes, J.N. (1988). Dopaminergic effects on simple and choice reaction time performance in Parkinson's disease. *Neurology,* **38,** 249-254.

Quinn, N. (1995). Parkinsonism - recognition and differential diagnosis. *British Medical Journal,* **310,** 447-452.

Qureshi, H. & Walker, A. (1989). *The Caring Relationship: Elderly People and their Families.* London: Macmillan.

Qureshi, H. (1990). A research note on the hierarchy of obligations among informal carers. A response to Finch and Mason. *Aging and Society,* **10,** 455-458.

Rabin, C., Bressler, Y. & Pragner, E. (1993). Caregiver burden and personal authority: differentiation and connection in caring for an elderly parent. *The American Journal of Family Therapy,* **21,** 27-38.

Rabins, D., Mace, N. & Lucas, M. (1982). The impact of dementia on the family. *Journal of the American Medical Association,* **248,** 333-335.

Rabins, P.V., Fitting, M.D., Eastham, J. & Fetting, J. (1990). The emotional impact of caring for the chronically ill. *Psychomatics,* **31,** 331-336.

Radloff, L.S. (1977). The CES-D scale: a self-report depression scale for research in the general population. *Applied Psychological Measurement,* **1,** 385-401.

Rajput, A.H. & Rozdilsky, B. (1975). Parkinsonism and dementia: effects of levodopa. *Lancet,* **i,** 1084.

Rajput, A.H., Offord, K., Beard, C.M. & Kurland, L.T. (1984a). Epidemiological survey of dementia in parkinsonism and control population. In R.G. Hassler & J.F. Christ (Eds.), *Advances in Neurology, Vol. 40, Parkinson-specific Motor and Mental Disorders* (pp.229-234). New York: Raven Press.

Rajput, A.H., Offord, K.P., Beard, C.M. & Kurland, L.T. (1984b). Epidemiology of parkinsonism: incidence, classification and mortality. *Annals of Neurology,* **16,** 278-282.

Rajput, A.H., Rozdilsky, B. & Rajput, A. (1991). Accuracy of clinical diagnosis in parkinsonism - a prospective study. *Canadian Journal of Neurological Science,* **18,** 275-278.

Randall, R. (1988). *Action for Carers.* London: Kings Fund Informal Caring Programme.

Rankin, E.D., Haut, M.W. & Keefover, R.W. (1992). Clinical assessment of family caregivers in dementia. *The Gerontologist,* **32,** 813-821.

Rankin, E.D., Haut, M.W., Keefover, R.W. & Fransen, M.D. (1994). The establishment of clinical cutoffs in measuring caregiver burden in dementia. *The Gerontologist,* **34,** 828-832.

Rautakorpi, I., Takala, J., Marttilla, R., Sievers, K. & Rinne, U.K. (1982). Essential tremor in a Finnish population. *Acta Neurologica Scaninavica,* **66,** 58-67.

Raven, J.C. (1943). *The Mill Hill Vocabulary Scale.* London: H.K. Lewis.

Raven, J.C. (1956). *Guide to using the Coloured Progressive Matrices: sets A, Ab, B.* London: H.K. Lewis.

Raven, J.C. (1960). *Guide to the Standard Progressive Matrices*. London: H.K. Lewis.

Redinbaugh, E.M., MacCallum, R.C. & Kiecolt-Glaser, J.K. (1995). Recurrent syndromal depression in caregivers. *Psychology and Aging,* **10,** 358-368.

Reese, D.R., Gross, A.M., Smalley, D.L. & Messer, S.C. (1994). Caregivers of Alzheimer’s disease and stroke patients: immunological and psychological considerations. *The Gerontologist,* **34,** 534-540.

Reid, W.G.J., Broe, G.A., Hely, M.A., Morris, J.G.L., Genge, S.A., Moss, N.G., O'Sullivan, P.M. & Rail, D. (1990). The evolution of dementia in idiopathic Parkinson's disease. Neuropsychological and clinical evidence in support of subtypes. Paper presented at the First International Congress of Movement Disorders, Washington DC, April 25th 1990.

Reis, M.F., Andres, D., Gold, D.P. & Markiewicz, D. (1994). Personality traits as determinants of burden and health complaints in caregiving. *International Journal of Aging and Human Development,* **39,** 257-271.

Reisberg, B., Ferris, S.H., DeLeon, M.J. & Crook, T. (1982). The Global Deterioration Scale for assessment of primary degenerative dementia. *American Journal of Psychiatry,* **139,** 1136-1139.

Reker, G.T. & Wong, P.T. (1985). Personal optimism, physical and mental health: the triumph of successful aging. In J.E. Birren & J. Livingston (Eds.), *Cognition, Stress, and Aging* (pp134-173). Englewood Cliffs, NJ: Prentice-Hall.

Revenson, T.A. (1994). Social support and marital coping with chronic illness. *Annals of Behavioural Medicine,* **16,** 122-130.

Riklan, M., Weiner, H. & Diller, L. (1959). Somato-psychologic studies in Parkinson’s disease. I. An investigation into the relationship of certain disease factors to psychological functions. *Journal of Nervous and Mental Diseases,* **129,** 263-272.

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

Robinson, B.C. (1983). Validation of a caregiver strain index. *Journal of Gerontology,* **38,** 344-348.

Robinson, K.M. (1990). Predictors of burden among wife caregivers. *Scholarly Inquiry for Nursing Practice,* **4,** 189-203.

Rogers, D. (1986). Bradyphrenia in parkinsonism. *Review of Psychological Medicine,* **16,** 257-266.

Rogers, D. (1992). Bradyphrenia in Parkinson's disease. In S.J. Huber & J.L. Cummings (Eds.), *Parkinson's Disease: Neurobehavioural Aspects* (pp. 86-96). Oxford University Press.

Rogers, D., Lees, A.J., Smith, E., Trimble, M. & Stern, G.M. (1987). Bradyphrenia in Parkinson’s disease and psychomotor retardation in depressive illness: an experimental study. *Brain,* **110,** 761-776.

Rogers, M.W. & Chan, C.W. (1988). Motor planning is impaired in Parkinson’s disease. *Brain Research,* **438,** 271-276.

Rondot, P., de Rocondo, J., Coignet, A. & Zeigler, M. (1984). Mental disorders in Parkinson's disease after treatment with L-DOPA. *Advances in Neurology,* **40,** 259-269.

Rook, K.S. & Dooley, D. (1985). Applying social support research: theoretical problems and future directions. *Journal of Social Issues,* **41,** 5-28.

Roos, R.A.C. (1994). Dpoaminometic psychosis: clinical manifestations, epidemiology and risk factors. In E.C. Wolters & P. Scheltens (Eds.), *Mental Dysfunction in Parkinson’s Disease* (pp. 281-284). Vrieje University Press.

Rosati, G., Granieri, E., Pinna, L. *et al.* (1980). The risk of Parkinson's disease in Mediterranean people. *Neurology,* **30,** 250-255.

Rotter, J.B. (1966). Generalized expectancies for internal versus external control of reinforcement. *Psychological Monographs,* **80.**

Saad, K., Hartman, J., Ballards, C., Kurian, M., Graham, C. & Wilcock, G. (1995). Coping by carers of dementia sufferers. *Age and Ageing,* **24,** 495-498.

Sacks, O.W., Kohl, M.S., Messeloff, C.R. & Schwartz, W.F. (1972). Effects of levodopa in Parkinsonian patients with dementia. *Neurology,* **22,** 516-519.

Sagar, H.J., Sullivan, E.V., Gabrieli, J.D., Corkin, S. & Growden, J.H. (1988). Temporal ordering and short-term memory deficits in Parkinson’s disease. *Brain,* **111,** 525-535.

Sano, M. & Mayeux, R. (1992). Biochemistry of depression in Parkinson's disease. In S.J. Huber & J.L. Cummings (Eds.), *Parkinson's Disease: Neurobehavioural Aspects* (pp. 229-239). Oxford University Press.

Scheier, M.F. & Carver, C.S. (1985). Optimism, coping, and health: assessment and implications of generalized outcome expectancies. *Health Psychology,* **4,** 219-247.

Schoenberg, B.S., Osuntokun, B.O., Ajeuja, A.O.G. *et al.* (1988). Comparison of the prevalence of Parkinson's disease in black populations in the rural US and in rural Nigeria: door-to-door community studies. *Neurology,* **38,** 645-646.

Schott-Baer, D. (1993). Dependent care, caregiver burden, and self-care agency of spouse caregivers. *Cancer Nursing,* **16,** 230-236.

Schulz, R. & Williamson, G.M. (1991). A 2-year longitudinal study of depression among Alzheimer's caregivers. *Psychology and Aging,* **6,** 569-578.

Schulz, R. (1990). Theoretical perspectives on caregiving: concepts variables and methods. In D.E. Biegel & A. Blum (Eds.) *Aging and Caregiving: Theory, Research & Policy.* London: Sage publications.

Schulz, R., Visintainer, P & Williamson, G.M. (1990). Psychiatric and physical morbidity effects of caregiving. *Journal of Gerontology,* **45,** 181-191.

Schwab, R.S. (1960). Progression and prognosis in Parkinson's disease. *Journal of Nervous and Mental Disease,* **130,** 556-566.

Selby, G. (1990). Clinical Features. In G.M. Stern (Ed.), *Parkinson's Disease.* London: Chapman and Hall Medical.

Shanas, E. (1979a). Social myth as hypotheses: the case of the family relations of old people. *The Gerontologist,* **19,** 3-9.

Shanas, E. (1979b). The family as a social support system in old age. *The Gerontologist,* **19,** 169-174.

Sharpley, C.F. & Cross, D.G. (1982). A psychometric evaluation of the Spanier Dyadic Adjustment Scale. *Journal of Marriage and the Family,* **44,** 739-741.

Shaskan D., Yarnell, H., & Alper, K. (1942). Physical, psychiatric and psychometric studies of post-encephalitic parkinsonism. *Journal of Nervous and Mental Disease,* **96,** 652-662.

Shaw, K.M., Lees, A.J. & Stern, G.M. (1980). The impact of treatment with levodopa on Parkinson's disease. *Quarterly Journal of Medicine,* **49,** 283-293.

Shaw, K.M., Lees, A.J. & Stern, G.M. (1980). The impact of treatment with levodopa on Parkinson's disease. *Quarterly Journal of Medicine,* **49,** 283-293.

Skinner, H.A., Steinhauer, P.D. & Santa-Barbara, J. (1983). The Family Assessment Measure. *Canadian Journal of Community Mental Health,* **2,** 91-105.

Skinner, H.A., Steinhauer, P.D. & Santa-Barbara, J. (1995). *FAM-III Manual: Family Assessment Measure Version III.* Multi-Health Systems, Inc., New York.

Smith, T.W., Pope, M.K., Rhodewalt, F. & Poulton, J.L. (1989). Optimism, neuroticism, coping and symptom reports: an alternative interpretation of the Life Orientation Test. *Journal of Personality and Social Psychology,* **61,** 335-340.

Snow, B.J. & Calne, D.B. (1992). The etiology of Parkinson's disease. In A.B. Joseph & R.R. Young (Eds.), *Movement Disorders in Neurology and Neuropsychiatry* (pp. 230-235). Oxford: Blackwells Scientific.

Spanier, G.B. (1976). Measuring dyadic adjustment: new scales for assessing quality of marriage and similar dyads. *Journal of Marriage and the Family,* **38,** 15-38.

Speer, D.C. (1993). Predicting Parkinson’s disease patient and caregiver adjustment: preliminary findings. *Behaviour, Health and Aging,* **3,** 139-146.

Spengelmeyer, R., Canavan, A.G., Lange, H.W. & Hömberg, V. (1995). Associative learning in degenerative neostriatal disorders: contrasts in explicit and implicit remembering between Parkinson’s and Huntington’s diseases. *Movement Disorders,* **10,** 51-65.

Sroka, H., Elizan, T.S., Yahr, M.D., Burger, A. & Medazu, M. (1981). Organic mental syndrome and confusional states in Parkinson's disease: relationship to computerised signs of cerebral atrophy. *Archives of Neurology,* **38,** 339-342.

Stacy, M. & Jankovic, J. (1992). Clinical and neurobiological aspects of Parkinson's disease. In S.J. Huber & J.L. Cummings (Eds.), *Parkinson's Disease: Neurobehavioural Aspects* (pp 10-31). Oxford University Press.

Stephens, S.A. & Christianson, J.B. (1986). *Informal Care of the Elderly.* Lexington, Mass: D.C. Heath.

Stern, G.M. (1994). Pre-morbid personality structure of patients with Parkinson’s disease. In E.C. Wolters & P. Scheltens (Eds.), *Mental Dysfunction in Parkinson’s Disease* (pp.103-112). Vrieje University Press.

Stern, Y., Richards, M., Sano, M. & Mayeux, R. (1993). Comparison of cognitive changes in patients with Alzheimer's and Parkinson's disease. *Archives of Neurology,* **50,** 1040-1045.

Stetz, K.M. (1989). Thr relationship among background characteristics, purpose in life, and caregiving demands on perceived health of spouse caregivers. *Scholarly Inquiry for Nursing Practice: An International Journal,* **3,** 133-153.

Stommel, M., Given, C.W. & Given, B.A. (1990). Depression as an overriding variable explaining caregiver burdens. *Journal of Aging and Health,* **2,** 81-102.

Stone, R., Cafferata, G. & Sangl, J. (1987). Caregivers of the frail elderly: a national profile. *The Gerontologist,* **27,** 616-626.

Strauss, A.L., Corbin, J., Fagerhaugh, S. Gleason, B., Maines, D. Suczek, B. & Wiener, C. (1984). *Chronic Illness and the Quality of Life.* St. Louis, MO: C.V. Mosby.

Strong, C. (1984). Stress and caring for elderly relatives: interpretations and coping strategies in an American Indian and white sample. *The Gerontologist,* **24,** 251-256.

Stull, D.E., Kosloski, K. & Kercher, K. (1994). Caregiver burden and generic well-bieng: opposite sides of the same coin? *The Gerontologist,* **34,** 88-94.

Stuss, D.T., Gow, C.A. & Hetherington, C.R. (1992). “No Longer Gage”: Frontal lobe dysfunction and emotional changes. *Journal of Consulting and Clinical Psychology,* **3,** 349-359.

Sutcliffe, R.L.G. & Meara, J.R. (1995). Parkinson's disease epidemiology in the Northampton District, England, 1992. *Acta Neurologica Scandinavica,* **92,** 443-450.

Sutcliffe, R.L.G., Prior, R., Mawby, B. & McQuillan, W.J. (1985). Parkinson's disease in the district of the Northampton Health Authority, United Kingdom. *Acta Neurologica Scandinavica*, **72,** 363-379.

Sweet, R.D., McDowell, F.H., Feigenson, J.S., Loranger, A.W. & Goodell, H. (1976). Mental symptoms in Parkinson's disease during chronic treatment with levodopa. *Neurology,* **26,** 305-310.

Sykes, N. (1994). Palliative care in terminal neurological illness. Paper given at *4th Annual Lilly Neurocare Conference: Dementia and Parkinsonism.* Dublin, 20th-21st May.

Tandberg, E., Larsen, J.P., Nessler, E.G., Riise, T. & Aarli, J.A. (1995). The epidemiology of Parkinson's disease in the county of Rogaland, Norway. *Movement Disorders,* **10,** 541-549.

Tanner, C.M. (1994). Epidemiological clues to the cause of Parkinson's disease. In C.D. Marsden & S. Fahn (Eds.) *Movement Disorders 3* (pp. 124-146). Oxford: Butterworth-Heinemann Ltd.

Tanner, C.M., Vogel, C., Goetz, C.G. & Klawans, H.L. (1983). Hallucinations in Parkinson's disease: a populations study. *Annals of Neurology,* **14,** 136.

Taylor, A., Saint-Cyr, J.A. & Lang, A.E. (1985). Dementia prevalence in Parkinson's disease. Letter to the Editor. *Lancet,* **i,** 1037.

Taylor, A., Saint-Cyr, J.A. & Lang, A.E. (1986). Frontal lobe dysfunction in Parkinson’s disease. *Brain,* **109,** 845-883.

Taylor, A.E., Saint-Cyr, J.A. & Lang, A.E. (1988). Idiopathic Parkinson's disease: revised concepts of cognitive and affective status. *Canadian Journal of Neurological Sciences,* **15,** 106-113.

Taylor, A.E., Saint-Cyr, J.A. & Lang, A.E. (1990). Memory and learning in early Parkinson’s disease: evidence for a “frontal lobe syndrome”. *Brain and Cognition,* **13,** 211-232.

Tennstedt, S., McKinlay, J. & Sullivan, L.M. (1989). Informal care for frail elders: the role of secondary caregivers. *The Gerontologist,* **29,** 677-683.

Terry, D.J. (1991). Coping resources and situational appraisal as predictors of coping behaviour. *Journal of Personality and Individual Differences,* **12,** 1031-1047.

Theorell, T., de Faire, U., Johnson, J., Hall, E., Perski, A. & Stewart, W. (1991). Job strain and ambulatory blood pressure profiles. *Scandinavian Journal of Work and Environmental Health,* **17,** 380-385.

Theorell, T., Perski, A., Akerstedt, T., Sigala, F., Ahlberg-Hulten, G., Svensson, J. & Eneroth, P. (1988). Changes in job strain in relation to changes in physiological state. *Scandinavian Journal of Work and Environmental Health,* **14,** 189-196.

Thoits, P.A. (1991). On merging identity theory and stress research. *Social Psychology Quarterly,* **54,** 101-112.

Thompson, S.C. & Pitts, J.S. (1992). In sickness and in health: Chronic illness, marriage, and spousal caregiving. In S. Spacapan & S. Oskamp (Eds.), *Helping and Being Helped* (pp. 83-114). Newbury Park, CA: Sage.

Tobin, S. & Kulys, R. (1981). The family and institutionalisation of the elderly. *Journal of Social Issues,* **37,** 145-157.

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

Toseland, R., Rossiter, C. & Labrecque, M. (1989). The effectiveness of three group intervention strategies to support family caregivers. *American Journal of Orthopsychiatry,* **59,** 420-429.

Townsend, A., Noelker, L., Diemling, G. & Bass, D. (1989). Longitudinal impact of interhousehold caregiving on adult children's mental health. *Psychology and Aging,* **4,** 393-401.

Treves, T.A. & de Pedro-Cuesta, J. (1991). Parkinsonism mortality in the US, 1. Time and space distribution. *Acta Neurologica Scandinavica,* **84,** 389-397.

Twigg, J. (1994). Carers, families, relatives: socio-legal conceptions of caregiving relationships. *Journal of Social Welfare & Family Law,* **3,** 279-298.

Uhlenberg, P. (1996). The burden of aging: a theoretical framework for understanding the shifting balance of caregiving and care receiving as cohorts age. *The Gerontologist,* **36,** 761-767.

Ungerson, C. (1983). Why do women care? In J. Finch & D. Groves (Eds.) *A Labour of Love.* London: Routledge and Kegan Paul.

Ungerson, C. (1987). *Policy is Personal: Sex, Gender and Informal Care.* London: Tavistock Publications.

US Bureau of the Census (1990). The need for personal assistance with everyday activities: recipients and caregivers. *Current Population Reports,* Series P70-19. US Government Printing Office, Washington, DC.

Vitaliano, P.P., Becker, J., Russo, J., Magana-Amato, A. & Maiuro, R.D. (1989). Expressed emotion in spouse caregivers of patients with Alzheimer's disease. *Journal of Applied Social Sciences,* **13,** 215-250.

Vitaliano, P.P., Russo, J., Carr, J., Maiuro, R.D. & Becker, J. (1987). The ways of coping checklist: revision and psychometric properties. *Multivariate Behavioural Research,* **20,** 3-26.

Vitaliano, P.P., Russo, J., Young, H., Becker, J. & Maiuro, R.D. (1991a). The Screen for Caregiver Burden. *The Gerontologist,* **31,** 76-83.

Vitaliano, P.P., Young, H.M. & Russo, J. (1991). Burden: a review of measures used among caregivers of individuals with dementia. *The Gerontologist,* **31,** 67-75.

Vriezen, E.R. & Moskovitch, M. (1990). Memory for temporal order and conditional associative learning in patients with Parkinson's disease. *Neuropsychologia,* **28,** 1283-1293.

Waldo, D.R. & Lazenby, H.C. (1984). Demographic characteristics and health care use and expenditures by the aged in the United States: 1977-1984. *Health Care Financing Review,* **6.**

Ward, R. (1985). Informal networks and well-being in later life: a research agenda. *The Gerontologist,* **25,** 55-61.

Ware, J.E. & Karmos, A.H. (1976). *Development and validation of scales to measure perceived health and patient role propensity: Vol. II.* Carbondale, IL: Southern Illinois, University School of Medicine.

Warr, P.B. Routledge, T. (1969). An opinion scale for the study of managers' job satisfaction. *Occupational Psychology,* **43,** 95-109.

Warrington, E.K. (1984). *Recognition Memory Test.* Windsor: NFER-Nelson.

Weingartner, H., Burns, S., Diebel. R. & Le Witt, P.A. (1984). Cognitive impairments in Parkinson's disease: distinguishing between effort-demanding and automatic cognitive processes. *Psychiatry Research,* **11,** 223-235.

Wellaford, E.A., Harkins, S.W. & Taylor, J.R. (1995). Personality change in dementia of the Alzheimer's type: relations to caregiver personality and burden. *Experimental Aging Research,* **21,** 295-314.

Wells, Y. & Jorm, A.F. (1987). Evaluation of a special nursing home unit for dementia sufferers: a randomised controlled comparison with community care. A*ustralia and New Zealand Journal of Psychiatry,* **21,** 524-531.

Wethington, E. & Kessler, R. (1986). Perceived support, received support, and adjustment to stressful life events. *Journal of Health and Social Behaviour,* **27,** 78-89.

Wheaton, B. (1983). Stress, personal coping resources and psychiatric symptoms: an investigation of interactive models. *Journal of Health and Social Behaviour,* **24,** 208-229.

Williams, A. (1994). What bothers caregivers of stroke victims? *Journal of Neuroscience and Nursing,* **26,** 155-161.

Williams, D.G. (1992). Dispositional optimism, neuroticism and extraversion. *Personality and Individual Differences,* **13,** 475-477.

Williams, R.B., Barefoot, J.C., Haney, T.C., Harrell, F.E., Blumenthal, J.A., Pryor, D.B & Peterson, B. (1988). Type A behaviour and angiographically documented coronary atherosclerosis in a sample of 2,289 patients. *Psychosomatic Medicine,* **50,** 139-152.

Williamson, G.M. & Schulz, R. (1990). Relationship orientation, quality of prior relationship, and distress among caregivers of Alzheimer's patients. *Psychology and Aging,* **5,** 502-509.

Williamson, G.M. & Schulz, R. (1993). Coping with specific stressors in Alzheimer's disease caregiving. *The Gerontologist,* **33,** 747-755.

Wilson, H.S. (1989). Family caregiving for a relative with Alzheimer's dementia: coping with negative choices. *Nursing Research,* **38,** 94-98.

Wright, B.A. (1983). *Physical disability - a psychosocial approach* (2nd ed.). New York: Harper and Row.

Xeurub, J.H., Tomlinson, B.E., Irving, D. *et al.* (1990). Cortical and subcortical pathology in Parkinson's disease: relationship to Parkinsonian dementia. In M.B. Streifler, A.D. Korczyn, E. Melamed & M.B. Youdim (Eds.), *Advances in Neurology, Vol. 53. Parkinson's Disease: Anatomy, Pathology and Therapy* (pp. 35-40). New York: Raven Press.

Yahr, M.D. (1976). Evaluation of long-term therapy in Parkinson's disease: mortality and therapeutic efficacy. In W. Birkmayer & O. Hornykiewicz (Eds.) *Advances in Parkinsonism* (pp. 435-443). Basle: Editiones Roche.

Yesavage, J.A., Brink, T.L., Rose, T.L., Lum, O., Huang, V., Adey, M. & Leirer, V.O. (1983). Development and validation of a geriatric depression screening scale: a preliminary report. *Journal of Psychiatric Research,* **17,** 37-49.

Young, R.F. (1983). The family-illness intermesh: theoretical aspects and their application. *Social Science and Medicine,* **17,** 395-398.

Young, R.F. (1994). Elders, families, and illness. *Journal of Aging Studies,* **8,** 1-15.

Young, R.F. & Kahana, E. (1987). Conceptualising stress, coping, and illness management in heart disease caregiving. *The Hospice Journal,* **3.**

Zarit, S.H. & Edwards, A.B. (1996). Family caregiving: research and clinical intervention. In R.T. Woods (Ed.) *Handbook of the Clinical Psychology of Ageing.* John Wiley and Sons Ltd.

Zarit, S.H., Orr, N.K. & Zarit, J.M. (1985). *The Hidden Victims of Alzheimer's Disease.* New York University Press.

Zarit, S.H. & Zarit, J.M. (1983). *The Memory and Behavioural Problems Checklist and The Burden Interview.* University Park, PA: Pennsylvania State University.

Zarit, S.H. & Zarit, J.M. (1987). The Memory and Behavioural Problems Checklist - 1987R and The Burden Interview. University Park, PA: Pennsylvania State University.

Zarit, S.H. (1989). Issues and directions in family intervention research. In E. Light & B. Lebowitz (Eds.), *Alzheimer's Disease, Treatment, and Family Stress: Directions for Research.* Washington, D.C.: U.S. Government Printing Office.

Zarit, S.H. Todd, P. & Zarit, J.M. (1986). Subjective burden of husbands and wives as caregivers: a longitudinal study. *The Gerontologist,* **26,** 260-266.

Zarit, S.H., Reever, K.E. & Bach-Peterson, J. (1980). Relatives of the impaired elderly: correlates of feelings of burden. *The Gerontologist,* **20,** 649-655.

Zetuski, W., Jankovic, J. & Pirozzolo, P. (1985). The heterogeneity of Parkinson's disease. *Neurology,* **35,** 522-526.

Zhang, Z. & Roman, G.C. (1993). Worldwide occurrence of Parkinson's disease: an updated review. *Neuroepidemiology,* **12,** 195-208.

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Test Manual

SPSS Code	Test and Variables	Scoring Direction	Min. Score	Max. Score	Assessment Method
	Burden 2 *(P&R B2; Pruchno & Resch, 1989)*				The P&RB2 measures subjective feelings of burden, with reference to occasion. Caregivers were asked (via caregiver pack) how often (*never, sometimes, often)* during the past month they has experienced 17 specific emotions (e.g. irritable or grouchy, tired and fatigued, helpless). In this study reliability was high: EB1: α= .93, EB2: α= .92.
EB1	P&RB1: Emotional Burden Phase 1	Higher scores indicate greater burden	17	51	
EB2	P&RB2: Emotional Burden Phase 2				
	Care Chart				After the patient interview, caregivers were given a chart for the week ahead, with each day marked out by small half-hour squares. They were asked to make a mark in the relevant half-hour box if they were giving care to their care-recipient at that time. The aim of the chart was to (crudely) assess how much time the caregiver was devoting to the caregiving task. A weekly caregiving time - the total time spent caregiving for the specimen week according to the caregiver was recorded both in phase 1 and phase 2.
CCH1	No of hours per week caregiving: Phase 1	More hours = more caregiving			
CCH2	No of hours per week caregiving: Phase 2				
	Caregiver Hassles Scale *(Kinney & Stephens, 1989)*				The Caregiver Hassles scale was developed to measure the day-to-day demands of caregiving (to SDAT patients). 42 items represent five categories of hassles that the caregiver might encounter: hassles associated with ADL and IADL (9 and 7 items respectively), hassles associated with the care-receiver's cognitive status and behaviour (9 and 12 items respectively) and hassles from their support network (5 items). The test was administered to the caregiver at interview. For each item the carer is asked if the occasion occurred in the previous week. For example "Has ____ required assistance with toileting?". The yields a yes/no response. If the event has happened then the carer is asked "How much of was this a hassle for you?" Carers are asked to choose from four possible responses: *It wasn't, Somewhat, Quite a bit, A great deal.* These responses are scored from 1 to 4 respectively. Thus two sets of scores are obtained from the questionnaire. 1. A score representing the number of hassles/events from a list of 42
JDH1	Job demand (number of hassles): Phase 1	Greater number of hassles = high job demand	0	42	
JDH2	Job demand (number of hassles): Phase 2		0	42	
CHC1	Number of cognitive hassles: Phase 1		0	9	
CHC2	Number of cognitive hassles: Phase 2		0	9	
CHPC1	Perceived cognitive change: Phase 1	0 = <2 CHC1/CHC2			
CHPC2	Perceived cognitive change: Phase 2	1 = 2+ CHC1/CHC2			
CHS1	Total amount of hassle: Phase 1	Lower levels of hassle is good; greater amounts of hassle is bad.	0	168	
CHS2	Total amount of hassle: Phase 2		0	168	
HA1	Amount of hassle with ADL: Phase 1		0	36	
HA2	Amount of hassle with ADL: Phase 2		0	36	
HB1	Amount of hassle with IADL: Phase 1		0	28	
HB2	Amount of hassle with IADL: Phase 2		0	28	

SPSS Code	Test and Variables	Scoring Direction	Min. Score	Max. Score	Assessment Method
HC1	Amount of hassle caused by patient's cognitive status: Phase 1		0	36	that occurred in the week between patient and caregiver interviews. This gives an objective measure of job demand - in so far as it measures the help given by the caregiver. The presence of a hassle (did it happen) does not necessarily imply burden or distress (Vitaliano *et al.*, 1991). 2. A score representing caregiver's evaluation of how much trouble it was to them carrying out the hassle. The rating of the hassle can be seen as subjective. According to Kinney & Stephens (1989) hassles, individually, only exert a weak threat to caregiver health, but an accumulation can have a major impact. Ostensibly, the scale acts as both an objective and as a subjective measure of job demand. Kinney and Stephens reported an overall reliability coefficient of .91. In this study, the number of cognitive hassles was separately considered. The nine items scale had an alpha of .78 for year 1 data, and .68 for year 2 data.
HC2	Amount of hassle caused by patient's cognitive status: Phase 2		0	36	
HD1	Amount of hassle caused by patient's behaviour: Phase 1		0	48	
HD2	Amount of hassle caused by patient's behaviour: Phase 2		0	48	
HE1	Amount of hassle caused by carer's social network: Phase 1		0	20	
HE2	Amount of hassle caused by carer's social network: Phase 2		0	20	
	Centre of Epidemiological Studies-Depression Scale *(CES-D; Radloff, 1977)*				The CES-D is a 20-item single factor scale designed to measure depressive symptomatology in community populations. The CES-D does not diagnose depression according to clinical criteria, rather it primarily identifies psychological distress, with an emphasis on affective components: both positive and negative. The scale was put in the caregiver pack. Items refer to the frequency of depressive symptoms in the previous week. Caregivers were asked to read each item then to respond accordingly. Response categories were A. *Rarely or none of the time (less than 1 day),* B. *Some or a little of the time (1-2 days),* C. *Occasionally or a moderate amount of time (3-4 days),* D. *Most or all of the time (5-7 days).* With a possible range of scores from 0-60, scores of 0-15 indicate no depressive symptoms or distress; 16-20 indicates mild distress; 21-30 moderate distress, and more than 30 severe distress (Barnes & Prosen, 1984). The cutting points are somewhat arbitrary, but in wide use (Stommel *et al.* 1993). Radloff (1977) reported coefficient alphas of .85 for a general population sample, and of .90 for a patient sample. In this sample of caregivers CESD1: α= .87, CESD2: α= .85.
CESD1	CES-D: Phase 1	Higher scores mean greater depression	0	60	
CESD2	CES-D: Phase 2				

SPSS Code	Test and Variables	Scoring Direction	Min. Score	Max. Score	Assessment Method
COS	***Communal Orientation Scale*** *(Clark et al., 1987)* Communal orientation scale	High scores = high in communal orientation	14	70	People who are high in communal orientation are more prepared to help other people (Clark *et al.*, 1987; Williamson & Schulz, 1990). This caregiver characteristic may serve as a moderator of distress. The scale involves a caregiver self-rating each of 14 items on a 5-point scale, 1 = *extremely uncharacteristic of me,* 2 = *quite uncharacteristic of me,* 3 = *I am not really sure about this,* 4 = *quite characteristic of me*, 5 = *extremely characteristic of me.* The questionnaire was in the caregiver pack. Clark *et al.* reported a reliability coefficient α = .78; in this study α = .75.
	Coping Inventory for Stressful Situations *(CISS: Endler & Parker, 1990)*				The CISS is a 48-item inventory with 16 items for each of the three subscales. Caregivers were asked to read and consider the 48 behaviours that may be utilised if they are faced with a difficult or upsetting situation, then to respond according to whether they would typically engage in such behaviour. The five alternative responses were 1 = *not at all,* 2 = *rarely,* 3 = *sometimes,* 4 = *often,* 5 = *very much.* Responses were summed for each subscale.
TASK	Task-oriented coping	High scores are associated with greater use of that style of coping	16	80	
EMOT	Emotion-oriented coping		16	80	
AV	Avoidance-oriented coping		16	80	
JDS	***Discretion Scale*** *(adapted from Dwyer & Ganster, 1991)* Job Discretion	High scores indicate high discretion	1	5	A 18-item adaptation of Dwyer & Ganster's (1991) *Control Scale.* The original scale of 22 items was designed to measure job discretion in paid employees, which made three items unsuitable for unpaid caregivers. Hence these items were removed. A further item was removed at analysis as it proved to be unreliable. The wording was altered on some items to make the statement specific to caregiving, but without changing the essence of the item. This gave rise to a *Discretion Scale* suitable for use with informal caregivers. The questionnaire, which was in the caregiver pack, consists of nineteen caregiving situations. The caregiver is asked to judge how much discretion they have in each case. There were 5 alternative responses: 1 = *very little,* 2 = *little,* 3 = *a moderate amount,* 4 = *much,* and 5 = *very much.* To score, Dwyer & Ganster averaged responses to their 22 items to provide an overall index of how much perceived control an individual worker experienced in the workplace. This method of scoring was used in this 18-item adaptation. Item scores were summed, then divided by the number of item responses. JDS scores were taken to one decimal place. This method of scoring also

SPSS Code	Test and Variables	Scoring Direction	Min. Score	Max. Score	Assessment Method
					enabled non-resident caregivers to be assessed for discretion. Two of the items were not applicable for carers who did not live with the PD care-recipient; these carers just left these two items unanswered and the same calculation was made (i.e. the sum was divided by 16, rather than 18). Reliability for the adapted questionnaire was good. JDS: = .88
TA AE COM AE FI CON VN	***Family Assessment Measure: Dyadic Relationship Scale (FAM III)*** *(Skinner et al., 1995)* Task accomplishment subscale Affective Expression subscale Communication subscale Affective Expression subscale Involvement subscale Control subscale Values and Norms subscale	Raw scores converted to T-scores. T-scores < 40 = dyadic strength; T-scores 40-60 = normal; T-scores > 60 = dyadic problem.	<24	>80	A self-report instrument that provides quantitative indices of dyadic strengths and weaknesses. Caregivers completed the questionnaire in private, at their own pace. There are six items for each of the seven subscales. Caregivers responded to each item by indicating whether they Strongly Agree (SA), Agree (A), Disagree (D) or Strongly Disagree (SD) that the item was true for them. Each item is scored from 0 to 3, according to the direction of the question such that low scores indicate greater dyadic strength on that item. The six items for each subscale were summed. The raw scores were then converted to *T* score by means of a table. *T* scores less than 40 indicate dyadic strength on that dimension. *T* scores of 60 or above are considered clinically significant. The higher a caregiver's scale score is elevated above 60, the greater the likelihood of disturbance in the elevated area. The internal consistency coefficients for the subscales are: TA: α= .74, RP: α= .82, COM: α= .77, AE: α= .59, FI: α= .64, CON: α= .72, and VN: α= .72. The overall reliability rating for the 42-items scale is α=.95 (Skinner *et al.*, 1983)
MFS1 MFS2	***Frustration Scale*** *(MFS; Motenko, 1989)* MFS: Phase 1 MFS: Phase 2	Frequency data presented			This questionnaire consists of two separate subscales. The first is a 9-item 4-point Likert scale which taps caregivers' emotional response towards the patients illness (e.g. How angry do you feel?; How resigned do you feel?). Carers choose from 4 responses: *not at all, a little, quite a lot, very much.* Originally Motenko summed these responses to give a score of frustration (in SDAT caregivers). In this study, it was considered that the responses to each item were interesting in their own right to illustrate the emotional reaction of giving care to someone with PD. Hence they are presented as frequency data.

SPSS Code	Test and Variables	Scoring Direction	Min. Score	Max. Score	Assessment Method
					The second subscale consists of 5 questions concerning bother that may arise in the caregiving situation (e.g. financial strain, time for self). Again the responses to these questions are most informative when presented as frequency data to illustrate the experience of caregiving in this sample of PD caregivers.
  GHQ1 GHQ2	***General Health Questionnaire*** *(GHQ12; Goldberg, 1972)* GHQ: Phase 1 GHQ: Phase 2	 Higher scores indicate greater psychological distress.	 0	 36	The GHQ is a self-administered (in caregiver pack) screening tool designed to detect mild psychiatric morbidity. It concentrates on deviation from normal functioning rather than on long-term behaviours. It has been widely used in community surveys and studies of occupational stress. The 12-item version was used to ask caregivers about their general level of happiness, depression, anxiety and sleep disturbance in the previous month. Items were scored according to the modified 4-point Likert scale such that : 0 = first response, 1 = second response, 3 = third response, 4 = fourth response. This response format is considered to have greater face validity to those experiencing chronic strain (c.f. Orbell *et al.*, 1993). In this sample of caregivers, the reliability was very similar to that reported elsewhere: GHQ1: α= .86, GHQ2: α= .81.
  GDS1 GDS2	***Geriatric Depression Scale*** *(GDS: Brink et al., 1982)* Patient GDS: Phase 1 Patient GDS: Phase 2	 High scores = more depression (i.e. bad)	 0 0	 30 30	The GDS was developed for screening elderly people for depression (Yesavage *et al.* 1983). It concentrates on psychological aspects of depression and excludes somatic aspects of depression. The GDS was used as a personality, predictor variable for the patient sample. The scale consists of 30 statements which were read aloud to patients at interview. The time frame was the past week. Patients were simply required to make a yes/no response for each item. One point was noted for each depressive answer. These were summed to give a total score in the range 0-30. Scores of 0-10 are considered in the normal range; scores of 11-20 are associated with mild depression; and a score over 20 is taken to indicate moderate to severe depression (McDowell & Newell, 1996).
  HCM HCO	***Hardiness Questionnaire*** *(Bartone et al., 1989)* Commitment Control	 Low scores are associated with greater hardiness for	 0 0	 30 30	The Hardiness Questionnaire consists of 30-items measuring dispositional resilience. Bartone *et al.* (1989) argued that the personality style of hardiness, or dispositional resilience, is an important modulator of stress. There are three areas of hardiness each

SPSS Code	Test and Variables	Scoring Direction	Min. Score	Max. Score	Assessment Method
HCH	Challenge	each of the subscales	0	30	represented in a subscale of 10 items. The questionnaire was in the caregiver pack. The items are statements about life, and carers were required to give their opinion as to how much each one was true for them on a 4-point scale where 0 = *Not at all true*, 1 = *A little true*, 2 = *Quite true*, and 3 = *Completely true.* Half the questions were reversed marked in accordance with the direction of the statement. Scores for the three areas of hardiness were considered separately by summing the relevant items. Reliability coefficients for the questionnaire are CM: α = .82, CO: α = .66, CH: α = .62.
	Hoehn & Yahr Scale *(Hoehn & Yahr, 1967)*				The Hoehn & Yahr staging system provides a simple index of the distribution, severity, and progression of PD. Briefly, these are: Stage I unilateral disease only II bilateral disease III bilateral disease with early impairment of postural stability IV severe disease requiring considerable assistance V confinement to bed or wheelchair unless aided This is a well-established, if rather crude, assessment of severity of illness (Pearce, 1992).
HY	Hoehn & Yahr staging system	1 = Stage I 2 = Stage II 3 = Stage III 4 = Stage IV 5 = Stage V			
	Identity Test *(Brooks & McKinlay, 1983)*				The identity test consists of 20 bi-polar dimensions of personality. Position on each bi-polar scale is marked on a 7-point scale. The test was used to assess caregiver's perception of their dependent's personality at year 1 and year 2, in order that any changes in could be determined. A change score for each of the 20 dimensions was attained by subtracting year 2 assessment score from the year 1 score for that dimension.
A	Bored - Interested	Higher scores mean greater change	0	+/- 7	
B	Unhappy - Happy		0	+/- 7	
C	In Control - Helpless		0	+/- 7	
D	Worried - Relaxed		0	+/- 7	
E	Dissatisfied - Satisfied		0	+/- 7	
F	Attractive - Unattractive		0	+/- 7	
G	Hopeful - Despondent		0	+/- 7	
H	Lack Confidence - Confident		0	+/- 7	
J	Stable - Emotional		0	+/- 7	
K	Worthless - Of Value		0	+/- 7	
L	Mindful - Forgetful		0	+/- 7	
M	Irritable - Calm		0	+/- 7	
N	Unfeeling - Caring		0	+/- 7	

SPSS Code	Test and Variables	Scoring Direction	Min. Score	Max. Score	Assessment Method
P	Skilful - Clumsy		0	+/- 7	
Q	Independent - Dependent		0	+/- 7	
R	Active - Inactive		0	+/- 7	
S	Difficult - Co-operative		0	+/- 7	
V	Talkative - Withdrawn		0	+/- 7	
W	Friendly - Unfriendly		0	+/- 7	
X	Stupid - Clever		0	+/- 7	
	Impact of Caregiving *(IOC: Poulshock & Deimling, 1984)*				The IOC is a 19-item, 4-point self report questionnaire which was in the caregiver pack. It consists of two subscales which measure the impact caregiving has on the dyadic relationship (11 items) and the carer's social life (8 items). Caregivers are asked to carefully consider each of the statements, then to select the response that best described how they felt from the alternatives: 0 = *rarely or none of the time,* 1 = *some or a little of the time,* 2 = *occasionally, or a moderate amount of time,* 3 = *most or all of the time.* In this research, the reliability for the two subscales were: BIR1: α= .85, BIR2: α= .82; BIS1: α= .90, BIS2: α= .88
BIR1 BIR2	Impact on Relationship: Phase 1 Impact on Relationship: Phase 2	Higher scores indicate caregiving has greater negative impact on the dyadic relationship.	0	33	
BIS1 BIS2	Impact on Social Life: Phase 1 Impact on Social Life: Phase 2	Higher scores indicate caregiving has greater negative impact on the carer's social life.	0	24	
	Index of Social Support *(ISS; James & Davies, 1987)*				The ISS was constructed to quantify the availability of, and satisfaction with, social support. It is made up of 10 items. It was administered to the caregiver during interview. Carers were first asked to identify people on whom they could depend upon for support in eight specified situations, and whether they were satisfied (yes/no) with the level of support they had. Two further items refer to other people who may require help from them on a regular basis. This gives rise to separate measures for: 1. Caregivers' perceived availability of support - this is calculated by summing the number of supporters mentioned (only once: people often rely on the same people in different situations) then subtracting people who also require regular help from the caregiver. 2. Caregivers' satisfaction with the support they have.
ISS1 ISS2	ISS: Extent of Support: Phase 1 ISS: Extent of Support: Phase 2	High scores indicate greater availability of support.	0	∞	
SAT1 SAT2	ISS: Satisfaction with Support: Phase 1 ISS: Satisfaction with of Support: Phase 2	Higher scores indicate greater satisfaction with support	0	8	
	Job Satisfaction Scale *(adapted from Warr & Routledge, 1969)*				In this research caregiving was considered to be a job. As a means of examining job satisfaction, caregivers were asked to read 12 statements adapted from the 15-item job satisfaction subscale of Warr
JSS1	Job Satisfaction: Phase 1	Higher scores indicate	12	36	

SPSS Code	Test and Variables	Scoring Direction	Min. Score	Max. Score	Assessment Method
JSS2	Job Satisfaction: Phase 2	greater job satisfaction			& Routledge (1969), and to consider whether they agreed that the statement was true for them. (Three items were not used in this research because they measured autonomy, rather satisfaction). Following from this there were three alternative responses: *yes*, *uncertain*, and *no*. "Yes" and "no" responses scored 1 or 3 according to the direction of the item, a score of 2 was given for an "uncertain" response. The 12 item scores were summed to arrive as a JSS score. Reliability for the adapted questionnaire was satisfactory: JSS1: = .74 JSS2: = .73
PHYS COG	***Knowledge of Parkinson's Disease Questionnaire*** Knowledge of physical aspects of PD Knowledge of cognitive aspects of PD	Higher scores indicate greater knowledge	0 0	16 16	This 16-item questionnaire was specifically constructed for use in this research project with the aim of investigating whether patients and caregivers know as much about the cognitive aspects of the disease, and the relationship that knowledge has with caregiver outcomes. The questionnaire consists of eight questions concerning physical and medical aspects of PD, and eight questions tapping knowledge of cognitive and behavioural aspects of the disease. The questions were read out to patients; caregivers did the questionnaire on their own at the same time in a different room. Each individual was required to state whether the question was *definitely true*, *probably true*, *probably false*, or *definitely false*. (Patients were given a card with these responses printed in large letters, so that they had the choice of giving a verbal response, or they could point to their desired answer). "Definitely" correct responses scored 2, "probably" correct responses scored 1, and incorrect answers scored 0. The scores for the two subscales were summed separately to give a PHYS score and a COG score for both patients and caregivers. Reliability for the two subscales was PHYS: α= .63, COG: α= .70
LOT	***Life Optimism Test*** *(Scheier & Carver, 1985)* Caregiver Optimism: Phase 1	Higher scores mean greater optimism	0	32	The LOT is a 12-item questionnaire which was in the caregiver pack. Caregivers respond to the 12 statements according to whether they *strongly agree*, *agree*, are *neutral*, *disagree*, or *strongly disagree*. Eight items are directly concerned with measuring dispositional optimism; these are scored from 0 to 4 according to the direction of the question. The other four items are fillers. Scheier & Carver reported an

SPSS Code	Test and Variables	Scoring Direction	Min. Score	Max. Score	Assessment Method
					alpha coefficient of α = .76. In this study α = .75.
LSI1 LSI2	***Life Satisfaction Index*** *(LSI; Bigot, 1974; James et al., 1986)* LSI: Phase 1 LSI: Phase 2	High scores indicate greater life satisfaction	2	12	The construct of life satisfaction is a useful indicator of successful ageing (Neugarten *et al.*, 1961). The original 20-item LSI (Neugarten *et al.*, 1961), whilst extensively used and having several strengths including reliability and strong correlations with other scales, has been criticised in so far as it does not fully reflect the subtleties implied in the conceptual distinctions in the model of life satisfaction that she proposed. Bigot (1974) used an 8-item version which was essentially one of the subscales - *well-being* - of the original index. He argues that this shorter scale is able to distinguish between clinically depressed elderly patients and normal volunteers. James *et al.* (1986), however pointed out that two items in Bigot's questionnaire were not reliable and recommended that they should be eliminated. Following from this, in this investigation we used a 6-item version of the LSI, which should be interpreted as a single scale measuring current satisfaction. As in the original 20-item questionnaire, this 6-item version was scored on a three-point Likert scale: caregivers responded *agree, disagree,* or *uncertain,* to each of the six statements that was read out to them at interview. Four of the six items are scored 2, 1, 0 according to the direction of the question; two of the items are scored 2, 1, 1. (Equal weighting is given to *uncertain*, and *agree).* Cronbach's alpha coefficients for this sample were rather low: LSI1: = .67, LSI2: = .57.
MH1 MH2	***Mill Hill Vocabulary Scale*** *(Version B2; Raven, 1943)* Mill Hill Score: Phase 1 Mill Hill Score: Phase 2	Higher scores mean greater vocabulary	2	43	The Mill Hill vocabulary scale was used as a measure of present verbal ability. This test is not sensitive in that non-dementing people preserve their performance until their 80s (Heron & Chown, 1967). Patients were required to choose, from six alternatives, the correct synonym for 22 progressively more difficult words: 17 adult items and 5 junior items. The junior items were only presented if the patient made a mistake in the first six adult items, otherwise credit was given for these items. The test has one demonstration item for both adult and junior items for which credit is given. The version used was one of two half length versions of the original MH scale (Binks & Davies, 1984). To be able to use the published

SPSS Code	Test and Variables	Scoring Direction	Min. Score	Max. Score	Assessment Method
					norms for 44 items (Heron & Chown, 1967), scores for this short version were doubled and one of the two demonstration credits removed, to give a maximum of 43. This method gives a score that is comparable to using the complete scale for all but the most able subjects (Binks, personal communication).
	Mini-Mental State Examination *(Folstein et al., 1985)*				The MMSE is the most widely used assessment of global cognitive function. It is a screening test. It gives a brief assessment of the respondent's orientation to time and place, recall ability, short-term memory, and arithmetic ability. Traditionally, a score of less than 24/30 indicates cognitive impairment severe enough to be regarded as dementia.
MMSE1	Patient's Mental Status: Phase 1	High = good	0	30	
MMSE2	Patient's Mental Status: Phase 2				
DEM1	Patient's Dementia Status: Phase 1	0 = MMSE score 24+			Scores from this test were also used to categorise patients as demented or not, according to the above cut-off score.
DEM2	Patient's Dementia Status: Phase 2	1 = MMSE score <24			
	Modified Barthel ADL Index *(Collin et al., 1988)*				The Barthel index is an Activities of Daily Living (ADL) rating scale which measures functional independence in personal care and mobility. The measure is a record of what the patient actually does, as can be established by the best evidence available - i.e. the interviewer asks both patient and caregiver. The scale consists of 10 items which are rated 0 to 1, 2, or 3 to give a maximum score of 20.
ADL1	Patient Activities of Daily Living: Phase 1	Score decreases with increasing disability	0	20	
ADL2	Patient Activities of Daily Living: Phase 2				
	National Adult Reading Test *(Nelson, 1982)*	Error score: The fewer the errors, the higher the pre-morbid intelligence.			Patients are asked to read aloud each of the 50 irregular words on a list. As single word reading is relatively preserved, even in dementia, this test is of value for estimating premorbid intelligence. The score achieved is based on the number of words that are not pronounced correctly. Error scores can be converted to give an estimate of pre-morbid IQ.
NART1	Patient's premorbid intelligence: Phase 1		0	50	
NART2	Patient's premorbid intelligence: Phase 2				
	NEO-Five Factor Inventory *(Costa & McCrae, 1992)*				The NEO five factor inventory consists of 60 items: 12 items from each of the five subscales. Subjects are asked to choose the response which best fits their opinion for all 60 items. The response choices are *strongly agree* (SA), *agree* (A), *neutral* (N), *disagree* (D) or *strongly disagree* (SD). This gave a score of 0-4 for each item. Items from each of the five subscales were summed to give five separate dimension scores for each subject. The NEO-FFI was administered to the patient at phase 1 and phase 2.
N1	Patient Neuroticism: Phase 1	High scores = more neuroticism	0	48	
N2	Patient Neuroticism: Phase 2		0	48	
E1	Patient Extraversion: Phase 1	High scores = more extraversion	0	48	
E2	Patient Extraversion: Phase 2		0	48	
O1	Patient Openness: Phase 1	High scores = more openness	0	48	
O2	Patient Openness: Phase 2		0	48	

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A1	Patient Agreeableness: Phase 1	High scores = more agreeableness	0	48	The interviewer read the statements to the patient, and they responded verbally, or by pointing to their choice on an answer card. The response card simply contained the five responses in large print. It was given to all patients so that any speech impairments would not pose a problem with responding.
A2	Patient Agreeableness: Phase 2		0	48	
C1	Patient Conscientiousness: Phase 1	High scores = greater conscientiousness	0	48	
C2	Patient Conscientiousness: Phase 2		0	48	
CN	Caregiver Neuroticism		0	48	Caregivers were given the NEO-FFI as a self-assessment. It was included in the pack of questionnaires they were asked to do, at their leisure, during the period of one week. The items were printed on one sheet, and the responses were on another. Caregivers were asked to check the response (SA, A, N, D, SD) that was most true for themselves. Caregivers only made this self assessment at phase 1.
CE	Caregiver Extraversion		0	48	
CO	Caregiver Openness		0	48	
CA	Caregiver Agreeableness		0	48	
CC	Caregiver Conscientiousness		0	48	
PN1	Caregiver perception of patient Neuroticism: Phase 1		0	48	Caregivers also did two adaptations of the NEO-FFI. The first was a simple conversion to the third person (from the first person) in order to ascertain caregivers' perception of the personality of the person they were caring for - as measured by the five dimensions of the NEO. This testing was done as a self-assessment exercise in year 1: the NEO adaptation was done by the carer at the same time as the test was being administered to the patient in another room in the house. In year 2, the NEO adaptation was administered to the caregiver at interview because the second adaptation, considering caregivers' perception of change in patient personality from before PD, was administered at the same time For example, (item 1) RC: "It is true that [John] is not a worrier?" <response> RC: "Has this been a change in [John] from how he was before he had PD?" < yes/no>. A "no" response, indicating no change, received a zero score for that item. If the carer answered "yes", then he or she was asked to consider the degree of change from four alternatives: *very much, quite a lot, in some way, a little.* These were scored 4, 3, 2, 1 respectively. In this way the interviewer determined a "current perception" score and a "change from before PD" score for each of the 60 items on the NEO. As with the NEO-FFI, scores from the 12 items of each subscale were summed to give a composite score for each of the five personality domains.
PN2	Caregiver perception of patient Neuroticism: Phase 2		0	48	
PE1	Caregiver perception of patient Extraversion: Phase 1		0	48	
PE2	Caregiver perception of patient Extraversion: Phase 2		0	48	
PO1	Caregiver perception of patient Openness: Phase 1		0	48	
PO2	Caregiver perception of patient Openness: Phase 2		0	48	
PA1	Caregiver perception of patient Agreeableness: Phase 1		0	48	
PA2	Caregiver perception of patient Agreeableness: Phase 2		0	48	
PC1	Caregiver perception of patient Conscientiousness: Phase 1		0	48	
PC2	Caregiver perception of patient Conscientiousness: Phase 2		0	48	
PNC	Caregiver perception of change in patient Neuroticism since diagnosis		0	48	
PEC	Caregiver perception of change in patient				

SPSS Code	Test and Variables	Scoring Direction	Min. Score	Max. Score	Assessment Method
	Extraversion since diagnosis		0	48	
POC	Caregiver perception of change in patient Openness since diagnosis		0	48	
PAC	Caregiver perception of change in patient Agreeableness since diagnosis		0	48	
PCC	Caregiver perception of change in patient Conscientiousness since diagnosis		0	48	
	Raven's Coloured Progressive Matrices *(RCPM; Raven, 1956)*				
CP	Raven's Coloured Progressive Matrices	High scores indicate higher nonverbal intelligence	0	36	The RCPM is a simplified 36-item version of the RPM which was designed for children in the 5-11 years old range and for adults over the age of 65 years. It consists of sets A and B of the RPM and an intermediate set Ab which, like set B, contains both gestalt completion items and some simple analogies. As with the RPM, the RCPM is composed of (36) problem patterns with one piece removed. Underneath there are six or eight numbered pictured inserts, one of which contains the correct pattern which the patient is required to identify. One point was given for each correct response. These were then summed to give a RCPM score. The RCPM was administered in Phase 2: the experimenter stayed with those patients who were in the neuropsychological test group whilst they did the test. (This seemed to have the effect of encouraging the patients to continue to the end. One problem with the RPM which effected the change of tests was the sheer length of it: some patients got too tired to complete it. The other major reason for the change was that it was too difficult for a large number of patients. There was the potential confound of getting ceiling effects from the RCPM, but on the whole this did not happen.)
	Raven's Progressive Matrices *(RPM; Raven, 1960)*				
RPM	Raven's Progressive Matrices	High scores indicate higher nonverbal intelligence	0	60	The RPM consists of a series of visual pattern matching and analogy problems pictured in nonrepresentational designs. It requires the subject to conceptualise spatial, design and numerical relationships ranging from the very obvious and concrete to the very complex and abstract. There are 60 problems, which are grouped into five sets. Each problem is composed of a pattern with one piece removed, and underneath there are six or eight numbered pictured inserts, one of which contains the correct pattern. Although the test sequence does not

SPSS Code	Test and Variables	Scoring Direction	Min. Score	Max. Score	Assessment Method
					provide a uniform progression in terms of difficulty, the overall trend is from easy to hard (Franzen, 1989). Patients were asked to write the number of their response on a prepared answer sheet. The RPM was given to patients at phase 1. Only patients who fulfilled the criteria for inclusion in the neuropsychological testing did this test. All patients worked through the test book on their own, at their own pace (typically whilst the caregiver was being interviewed in a separate room). One point was given for each correct response. These were then summed to give a RPM score.
	Short Dyadic Adjustment Scale *(Sharpley & Cross, 1982)*				The Dyadic Adjustment Scale (Spanier, 1976) is a 32-item scale for assessing the quality of marriage or other similar dyads. Sharpley Cross (1982) argued that researchers can obtain almost as confident a classification using only six of the original items. This shorter scale yields one overall *dyadic adjustment* factor. They also point out that a seventh item is suitable for a quick global self-rating. Following from this, a 6-item DAS was administered to caregivers at interview. They were asked to respond first with respect to their relationship before PD, then as they perceive the relationship to be now. There were six response categories for each item, which were scored 0 to 5. The six item scores were then summed to give a DAS score for A premorbid relationship, and B current relationship.
DASA	Dyadic Adjustment Scale: Premorbid Relationship	High scores indicate a good dyadic relationship	0	30	
DASB	Dyadic Adjustment Scale: Current relationship				
HAPA	Dyadic Happiness: Premorbid Relationship	High scores mean greater happiness in the relationship	0	6	A question considering current *happiness* in the dyadic relationship was also administered to caregivers and scored as a separate item. There were 7 response categories which were scored from 0 (very unhappy) to 6 (perfect).
HAPB	Dyadic Happiness: Current Relationship				
	Warrington's Recognition Memory Test *(WRMT; Warrington, 1984)*				WRMT is a set of two tests, parallel in form which provide verbal (words) and nonverbal (faces) stimuli for assessing material-specific memory deficits. Each test contains of 50 stimulus items and 50 distractors. Patients were first pre-exposed to the target material, and then by means of a forced-choice paradigm, are required to identify it from a distractor. In this investigation, the words were presented first. The target words were printed in letters 1 cm high, each on a different page of a test booklet. Each of these common nouns was shown for approximately three seconds before the page was turned. Engagement
WORD1	WRMT Words: Phase 1	Higher scores indicate better memory. Chance level = 25	0	50	
WORD2	WRMT Words: Phase 2		0	50	
FACE1	WRMT Faces: Phase 1		0	50	
FACE2	WRMT Faces: Phase 2		0	50	

SPSS Code	Test and Variables	Scoring Direction	Min. Score	Max. Score	Assessment Method
					of the patient's attention was secured by asking them to judge whether each target item was pleasant or unpleasant. (The direction of these judgements is irrelevant (Delbecq-Derouesné & Beauvois, 1989)). Retention was tested immediately after the learning the words. The patients were given a large card in which each of the 50 target words was listed and paired to the right or left with a distractor word. They were required to say which word they had seen before. One point was given for each correct response. An identical procedure followed with faces as the stimuli. The black-and-white photographs of white men were each presented on a separate page of a booklet. At test they were paired with a photograph of a man of similar age and colouring. The patient was asked to point to the face he had seen before. One point was given for each correct response.
WRT	***Word Reaction Time*** Word Reaction Time (in seconds)	Greater time indicates more slowing			A simple measure for assessing global slowing was achieved by asking patients to read aloud 12 common nouns, which were written in 14-point block capitals, one underneath another on an A4 sheet of paper. Patients were given clear instructions - that they were to read the 12 simple words aloud as fast as they could - before they were given the test paper. The test paper was given to the patients upside down, then when the patient was prepared it was turned over by the experimenter whilst she simultaneously activated a stopwatch. The time taken to read all 12 words was measured to the nearest one-hundredth of a second.

Code, gender, age, and relationship to patient of caregivers in chapter six.

CODE	GENDER	AGE	RELATIONSHIP
C101	Female	74	Wife
C104	Female	75	Wife
C105	Female	58	Wife
C106	Male	80	Husband
C107	Male	71	Husband
C109	Female	54	Wife
C110	Female	70	Wife
C112	Female	67	Wife
C113	Female	65	Wife
C114	Female	68	Wife
C116	Female	68	Wife
C117	Female	60	Wife
C118	Female	70	Wife
C119	Female	62	Wife
C120	Female	47	Wife
C121	Female	77	Wife
C123	Female	77	Wife
C125	Female	61	Wife
C126	Female	51	Daughter
C127	Male	77	Husband
C128	Female	46	Daughter
C129	Female	57	Daughter
C133	Female	76	Wife
C134	Female	83	Wife
C139	Male	74	Husband
C140	Female	36	Daughter
C141	Female	87	Wife
C142	Male	48	Son
C150	Female	61	Daughter
C151	Female	56	Daughter
C153	Female	68	Wife
C156	Female	71	Wife
C159	Female	71	Wife
C160	Female	77	Wife
C161	Male	47	Husband
C162	Female	69	Wife
C163	Female	73	Wife
C165	Female	70	Wife
C167	Female	71	Wife
C169	Male	74	Husband
C171	Female	79	Wife
C172	Female	76	Wife
C174	Female	76	Wife
C175	Female	64	Wife
C176	Female	76	Wife

INTERVIEW SCHEDULE FOR LIFE-EVENTS AND DIFFICULTIES IN CAREGIVERS OF PATIENTS WITH PARKINSON'S DISEASE

I want to ask you some questions about things that may have happened to you, your family, or people that you are fond of in the last twelve months. That is, since (date).

1. If you had a problem of some sort who would be the first person with whom you would want to discuss it?
    a. Is this person someone you can talk to about your most private thoughts and feelings? Someone that you really trust with a personal problem?
    b. Can you discuss any problem with ________?, or are there certain topics which it is impossible to discuss? If so, is there someone else with whom you can discuss these things?
    c. If no confidant, ask: Have you ever known a person to whom you can talk to about your private thoughts and feelings?

HEALTH

2. Have you, or anyone else in the family besides ________ been ill in the last 12 months?
3. Have any relatives or close friends died?
4. Have you any relatives or close friends who are a worry to you for any other reason? E.g. relationships, drinking, gambling?
5. Have there been any accidents in the last 12 months?
6. Have there been any pregnancies in the family over the last 12 months?

ROLE CHANGES

7. Have you any close friends or relatives who have been divorced or separated in the last 12 months? *If yes, explore:*
    a. Were you involved at all? Did you expect it to happen?
8. Have there been any changes in the amount you see of your relatives or close friends? *If yes* - *explore:*
    a. What difference has this made to your life?
    b. How often do you see them now?
    c. Are you satisfied with this?
9. Has anyone close to you lost their job in the last 12 months? *If yes, explore:*
    a. Redundancy or other cause?
    b. What changes did it bring?

LEISURE AND INTERACTION

10. Have there been just the ______ of you at home during the last 12 months?
11. Has anyone come to stay? *If yes, explore.*
12. Has anyone left the household? *If yes, explore.*
13. Do you invite any of your friends to your home at all? *If not:* Why is this?
14. How do spend do with your leisure time?
    a. Are there thing you would like to do but for some reason do not?
    b. Are there things you used to do, but can't do now?
        i. How do you feel about this?
15. Have you had a holiday in the last 12 months? How did it work out?

HOUSING

16. How do you manage to carry out minor household repairs?
17. Have you considered living anywhere else? *If yes:* Have you done anything about this in the last 12 months?

MONEY

18. Is the state pension you only source of income? Do you have a private pension?
19. Have you any money worries? Especially in the last 12 months?
20. Have you had to cut down, or go without things you need?

RELATIONSHIP

21. How would you say that you and _______ get on in general?
    a. Do you like doing the same things together (present Dyadic Adjustment Scale)
22. Are there any problems in your relationship?
23. Have there been any changes in your relationship, or int eh way that the two of you get on, in the last 12 months? *If yes:* What do you think is the reason for this?
24. Do you feel that you can easily talk to ______? Do you talk about things that worry you?
25. Were there any problems you had 12 months ago which have now cleared up? *If yes:*
    a. What were they?
    b. How do you feel about this?