Caregiver strain in spouses of stroke patients

Thesis submitted in accordance with the requirements of the University of Nottingham, for the degree of Doctor of Philosophy, in the Faculty of Science

by

Holly Blake, B.A. (Hons)

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WHO AM I?

I am the comforter

But never the comforted

I must always be there

I must never intrude

I must be the watcher

But never show I am watching

I must be in control

But never be the controller

I must listen

But never speak of my feelings

I must always be strong

I must always be happy

I must always be second

Who am I?

I am the one who cries through the nights

And smiles through the days

I was the partner

But now I am the carer.

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I

ABSTRACT

The aim of this thesis was to identify both patient and carer factors relating to caregiver strain in spouses of stroke patients. The secondary aim was also to assess the effectiveness of an intervention in reducing levels of strain, involving the provision of cognitive assessment information to both patients and spouses.

Previous research has not investigated specific cognitive impairment after stroke in relation to strain and reports of the relationship between patient disability and strain are not consistent. Assessment of physical function and detailed neuropsychological examination was carried out with stroke patients in Nottingham, Derby and Mansfield as part of a prospective, multicentre, single-blind randomised controlled trial. The assessment battery included measures of general mental state, language, perception, memory, executive function and praxis. Individualised information about cognitive function was provided in verbal and written form to each patient and carer. Carer strain was assessed in 57 spouses three and six months later. Around a third of spouses experienced significant strain. Results confirmed the importance of patient physical function with disability becoming an important factor with time. Basic self-care skills (Barthel Index) measured at three and six months, were significantly associated with carer strain at six months. Impairment of the patient's general mental state on the Mini-Mental State Examination (MMSE) and communication difficulties on the Sheffield Screening Test for Aphasia (SST) were related to carer strain and were also associated with emotional rather than physical strains. Carer strain was not significantly associated with other cognitive deficits, including impairments of perception, memory, executive function and praxis.

Previous research has not assessed specific carer characteristics in relation to strain. In order to identify these, 222 spouses of stroke patients were sent questionnaire measures of strain, stress, mood, handicap, adjustment, social support, life satisfaction and personality and their perceptions of the patient's mood and independence in activities of daily living. Univariate analysis suggested that strain was associated with increased carer

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handicap, high stress, poor mood, 'chance' health locus of control, expression of depressed mood, low optimism, low positive affectivity, high negative affectivity and low self-esteem. Strain was also related to poor adjustment, low satisfaction with life, less emotional and practical support and a greater discrepancy between actual and ideal levels of support and increased help from professional services. Strained carers also perceived poor mood and increased disability in the stroke patient. Multivariate analysis indicated that the most important factors were low carer mood on the General Health Questionnaire-12 (GHQ-12), poor perceived patient independence in activities of daily living on the Extended Activities of Daily Living Scale (EADL) and high negative affectivity on the Positive and Negative Affect Schedule (PANAS).

The relationship between these factors and strain needed to be tested prospectively. In a multicentre study of 116 spouses in Nottingham and Leicester, carers were sent the CSI, GHQ-12, EADL and PANAS at three and six months after the stroke. Again, over a third of carers experienced significant strain. Results confirmed those of the previous study and mood, perceived disability and negative affectivity at three months were found to predict high levels of carer strain six months after stroke. The most important caregiver factors were therefore the spouse's appraisal of their partner's disability, together with two emotional components of subjective well-being, one transient and one stable. The results also highlighted the role of other factors, including incontinence, disturbed sleep, communication difficulties and the amount of time spent caregiving in carer strain.

Early identification of carers who may be at risk of strain later on will enable services to be targeted at prevention rather than cure. There was a non-significant trend towards reduced strain in carers who had received information about cognitive deficits after stroke. Spouses may benefit from individualised information about their partner's stroke. Strain is emotionally laden and services might focus on teaching effective coping strategies to reduce depression and provide emotional support. More research is needed to identify services that are effective in alleviating or indeed preventing strain.

CHAPTER 1

General Introduction

This chapter provides a broad overview of the nature and physical impact of stroke and the resulting cognitive deficits. It is beyond the scope of this chapter to address in detail the methodological problems with each study of incidence and prevalence of stroke and its resulting deficits. To do so would detract from the main purpose of this section, which is to highlight the main deficits occurring after stroke. The aim is to give the reader some understanding of the extent and complexity of the disease.

Furthermore, research studies involving stroke patients often have similar methodological problems; particularly regarding sampling and selection bias and to some extent these problems may be unavoidable. For example, studies often exclude patients with severe language problems, or patients who are unconscious on admission. In addition, studies rely on different definitions and vary in their choice of measures or assessments. The possible relationships between resulting deficits following stroke and strain in the spouses is addressed in more detail elsewhere in this thesis.

The nature of caregiving and the effects on patient rehabilitation and caregiver well-being are also described. The study of caregiving is an attempt to link a number of antecedent variables to outcomes assessing the well-being of the carers. This chapter provides a brief description of a number of models of carer strain, ranging from basic stress-coping models to models that specifically address caregiving outcomes.

The models presented here are by no means exhaustive but provide a framework for understanding the caregiving process. Combining information and concepts from existing models, a new model is presented as a guideline for this thesis.

1.1 What is a Stroke?

A stroke is a condition in which part of the brain is suddenly severely damaged or destroyed. In 1978, the World Health Organisation (WHO) defined stroke as 'a focal or global neurological impairment of sudden onset, lasting more than 24 hours (or leading to death), and of presumed vascular aetiology'. This definition includes subarachnoid haemorrhages but excludes transient ischaemic attacks (TIA), subdural haematomas, silent cerebral infarcts and haemorrhage or infarction due to infection or tumour. The most common cause of stroke is infarction resulting from thrombotic or embolic occlusion of a cerebral artery. This is termed an 'ischaemic' stroke and accounts for approximately 85% of cases (Bamford et al, 1990). The part of the brain supplied by the blocked artery becomes deprived of blood and results in impaired brain function. Permanent damage can occur if the blockage persists for more than five minutes, although damage can be attenuated if the brain has an alternative blood supply. If there is no alternative supply, the effect can be devastating and irreversible. A less common cause of stroke is the spontaneous rupture of a vessel, which results in intra-cerebral or subarachnoid haemorrhage. The type and severity of dysfunction and impairment depends on the site of the haemorrhage.

1.2 Incidence and prevalence of stroke

Stroke has long been recognised as one of the major health problems in our society (Lawrence and Christie, 1979). One of the three leading causes of death in Europe and the United States (Matarazzo, 1982), stroke is thought to be the commonest cause of chronic disability in the U.K. (Martin et al, 1989), responsible for a significant proportion of the nations mortality and morbidity statistics (Fries, 1984; Gresham et al, 1979). According to Bamford et al (1990), about a third of those who suffer from a stroke die within the first month and a third will recover with minimal or no residual problems. However, the remaining survivors have moderate to severe disabilities, which require some form of services or assistance. The risk of a second stroke is high within the first seven days and remains high for the first month although the risk lessens as time passes. By five years post-stroke, 55% of patients will have survived although older patients are more likely to have died (Bamford et al, 1990). Mortality is greatest in the early months after discharge from hospital and decreases thereafter (Lai et al, 1999).

It is thought that stroke accounts for approximately 80,000 deaths every year. Approximately 50% of all deaths over the age of 40 are due to cerebrovascular conditions and stroke is solely accountable for the disabilities of around 24% of severely handicapped people living in the community (Harris et al, 1971). These facts serve only to accentuate the extensive impact of this major disabling disease and its consequences to the lives of individuals and their families. It has been estimated that one million acute ischaemic strokes occur in Europe every year (Wolfe et al,

1995) and there are approximately 100,000 new strokes each year in the United Kingdom. In 1992, the prevalence was estimated at around six per 1000 per year (Wade, 1992). The incidence of stroke rises exponentially with age and around 80% of strokes occur in those aged 65 years or over. It has been suggested that one man in four and one woman in five aged 45 or over can expect to have a stroke if they live to be 85 (Wolfe et al, 1996). The number of elderly people in the population is expected to increase significantly (Mittelmark, 1994) and it has been estimated that between 1983 and 2023 the number of patients experiencing a first-ever stroke will increase by around 30% (Malmgren et al, 1989).

Stroke represents a great economic burden. Calculating the exact cost of stroke is virtually impossible, although it is generally thought that between four and five per cent of the NHS budget is spent on stroke services, excluding social service and carer costs. The mean cost of managing a stroke in the UK over the first twelve weeks has been estimated to be approximately £8,000, constituted predominantly of hospital costs, followed by rehabilitation and outpatient services and use of a nursing home (Caro et al, 1999). Remaining lifetime costs have been estimated at around £76,000 for patients with a major impairment at twelve weeks or £28,000 for patients with a minor impairment (Caro et al, 1999).

The actual prevalence of stroke in the UK is not known and only estimates are available. Estimates of incidence vary widely and this may be due to variations in definition of stroke, increased use of neuroimaging or varying sources of information (clinical judgement, Bamford Classification (Bamford et al, 1990), computerised tomographic scanning) and

effectiveness of systems of notification. Also, estimates are often based primarily on standardised mortality ratios or the extrapolation of locally collected data (Bamford et al, 1988).

<u>1.3</u> Survival and recovery after stroke

The effects of stroke are profound; mortality rate is 30% during the first 30 days post stroke whilst the surviving 70% live an average of another seven years with some degree of physical impairment and/or psychosocial According to Mumma (1987), about 40% of those who disabilities. survive stroke are left with some disability and will require assistance with activities of daily living. The most important prognostic indicators for survival are thought to be age, initial level of consciousness following stroke and incontinence in the first 24 hours following stroke (Wolfe et al, 1993). In a sample of 2,000 stroke patients aged 85 years or over, Arboix (2000) also found that an altered level of consciousness was an independent predictor of in-hospital mortality after stroke. The presence of dysphagia is also related to an increased risk of death (Smithard et al, 1996). Paciaroni et al (2000) studied 3,156 stroke patients in Switzerland. They found that the main predictors of severe disability at discharge were impaired consciousness on admission, limb weakness, progressive neurological worsening, infarct in the superficial and deep territory of the middle cerebral artery, ischaemic heart disease and cardiac arrhythmia. According to Duncan et al (2000), less than 25% of stroke survivors are considered to have recovered if recovery is defined relative to reported prior function in higher levels of physical activity.

1.4 Effects of Stroke

Damage to the brain from stroke can result in an altered level of consciousness. In a population-based study of 976 acute stroke patients, 17% of patients had a reduced level of consciousness within the first week (Wade et al, 1989). Aside from being a threat to life, the symptoms of stroke can vary widely between individuals and can affect motor, sensory, cognitive and other functions, depending on which site of the brain is involved.

1.4.1 Motor Deficits

The loss of function of the affected brain site predominantly results in weakness or paralysis of limbs on the side of the body which is contralateral to the site of the stroke (hemiparesis). It has been estimated that approximately 80% of patients will have a hemiparesis (Herman et al, 1982). This can impact on both functional ability and quality of life for the patient. In a study of community stroke patients, Lincoln et al (1998) found that 27% had severe mobility problems and 47% had a clinically relevant arm impairment. Wyller et al (1995) found that subjective wellbeing was decreased one year after stroke, and this was mainly attributable to motor impairments of the arm. The face may also become weak, which may cause difficulty with eating and drinking. There may be changes in tone resulting in a loss of balance. The patient may lose the ability and/or the awareness to control the bladder or the bowels. The stroke patient may have difficulty in swallowing (dysphagia) or articulation (dysarthria).

Paralysis, together with incontinence and swallowing problems during hospitalisation has been shown to be predictive of disability or handicap at three months (Di Carlo et al, 1999). Fatigue is also common after stroke and although discussed here as a motor problem, may be related to disorders of mood (i.e. depression). Ingles et al (1999) assessed 181 stroke patients up to 13 months post-stroke, and 56 community residing elderly on the Fatigue Impact Scale. The frequency of self-reported fatigue was significantly greater in the stroke group (68%) than in the control group (36%). Stroke patients attributed many of their functional limitations to fatigue (Ingles et al, 1999).

1.4.1.1 Incontinence

Urinary incontinence is common and occurs in around 44-69% of people admitted to hospital after stroke (Schletter et al, 1999; Henrikson, 1991; Nakayama et al, 1997; Kamouchi et al, 1995). The variation in reported prevalence rates is likely to be due to differences in definitions used as the meaning of incontinence is not standardised and data are often collected on diverse populations (Brittain et al, 1999). The likelihood of urinary incontinence is linked to the severity of the stroke (Khan et al, 1981; Sakabibara et al, 1996) and lesions in areas thought to be primarily involved in micturation. However, clinical observation has highlighted additional factors that may contribute to difficulties with personal care and independence and therefore lead to practical difficulties in bladder control. These may include motor impairment, alteration of consciousness, sensory impairment, ataxia, pre-morbid continence state, depression and dysphasia

(Brittain et al, 1999). The prevalence of urinary incontinence is lower on discharge from hospital than on admission suggesting that incontinence following stroke may be transient (Henrikson, 1991) although this reduction in numbers may simply reflect the number of deaths on hospital wards rather than improvements in continence status (Brittain et al, 1999). Incontinence is a strong predictor of poor recovery (Gross, 1998; Taub et al, 1994). For example, the presence of incontinence in first-time stroke survivors under 75 years is the best predictor of severe or moderate disability at three months (Taub et al, 1994).

Urinary incontinence has been related to poor mobility and cognitive status (Brittain et al, 1998). Continence status has also been found to influence the place of discharge (Patel et al, 2001; Taub et al, 1994) although Gross (2000) did not find a significant relationship between continence status at discharge and discharge destination. Incontinence has been found to contribute to self-reported depression (Brittain, 1998) and dramatically increase the relative risk of death (Nakayama et al, 1997; Anderson et al, 1994). A community-based cohort study followed 221 stroke patients for three years and found that incontinence (together with pre-existing atrial fibrillation) was associated with mortality in patients who had survived to one month (Loor et al, 1999). Other studies have shown that incontinence adversely affects survival both during the first year (Thommessen et al, 1999) and at two years after stroke (Patel et al, 2001). This may be explained by the fact that both urinary and faecal incontinence are strongly related to the size of the lesion (Schletter et al, 1999).

Studies of faecal incontinence are sparse (Brittain et al, 1998). One German study found the prevalence of faecal incontinence to be 8% during the initial stage reducing to around 5% after three months (Schletter et al, 1999). In a study of 935 stroke patients in Copenhagen, Nakayama et al (1997) found that almost half of their sample had either urinary incontinence and/or faecal incontinence in the acute stage. By six months, one tenth of the surviving patients were incontinent of faeces. They report that the risk of both urinary and faecal incontinence was increased by advancing age, severity of stroke and co-morbidity.

1.4.1.2 Swallowing difficulties (dysphagia)

Swallowing dysfunction (dysphagia) is common after acute stroke (Mann et al, 1999; Smithard et al, 1997) and can be disabling and potentially fatal. For example, vocal cord mobility is reduced in this condition, which may result in reduced airway protection (Sellars et al, 1999). In addition, swallowing difficulties can place patients at risk for complications such as chest infection (Mann et al, 1999). Swallowing abnormalities may affect as many as half of all acute stroke patients (Smithard et al, 1997). It has been suggested that dysphagia may persist, recur or develop later on in the course of stroke (Smithard et al, 1997), although recovery is possible up to three years after stroke (Perie et al, 1999).

1.4.1.3 Speech problems (dysarthria)

Speech refers to the 'mechanical execution of spoken language' (Cummings and Benson, 1992). Disorders of speech production are common after a stroke. Dysarthria is a disorder of articulation, resulting from direct effects of the stroke on the main mechanisms of speech, such as the tongue or the voice box. The condition arises from damage to the motor speech pathways from the motor strip in the cortex via the pyramidal, extra pyramidal and spinal nerve tracts, the cerebellum and basal ganglia system. Depending where the damage lies, the outcome can be varying degrees of spasticity, paralysis, paresis or weakness in the muscles for speech and facial movement and may affect the patient's ability to chew or swallow. It can also result in drooling of saliva and slurred speech, grossly disrupting the pronunciation of words or phrases. Sufferers of dysarthria can understand and find the correct words, but have difficulty in articulating them.

1.4.2 Sensory problems

Sensory deficits may include a loss of sense of touch on one side of the body, or disturbance of sight. Visual fields may be affected with either hemianopia (half loss) or quadrantanopia (quarter loss). Studies have shown that between 33 and 46% of patients with right hemisphere lesions have hemianopia (Willanger et al, 1981; Hier et al, 1983; Kertesz and Dobrowolski, 1981). Problems with the visual field after stroke are associated with increased mortality (Cassidy et al, 1999, Wade et al, 1985) and poor functional recovery (Wade et al, 1985).

1.4.3 Cognitive Function

Aside from motor difficulties, the stroke patient may also suffer from cognitive impairment, such as impairment of perception, difficulties with language (dysphasia), impairment of reading (acquired dyslexia), writing (acquired dysgraphia) and calculating (dyscalculia). They may also suffer from impairment of memory, concentration and attention and difficulties with reasoning, decision-making and judgement. Stroke can also result in dyspraxia. Kase et al (1998) compared pre-stroke and post-stroke measures of cognitive performance, on the Mini-Mental State Examination (MMSE), of 74 subjects from the Framingham Study Cohort who had suffered a stroke during a 13-year period, with 74 controls matched for age and sex. They found that stroke was followed by a significant decline in cognitive performance when compared with controls.

Ebrahim et al (1985) identified cognitive problems in 12% of those surviving to six months. A later study by Kong et al (1998) detected cognitive impairment in 45% of their sample, although the difference may be explained by the greater mean age in Kong's sample. Cognitive impairment has been associated with both functional impairment (Sisson, 1995; Tatemachi et al, 1994) and place of discharge (Tatemachi et al, 1994). Tatemachi et al (1994) examined cognitive function in 227 stroke patients three months after admission to hospital for ischaemic stroke, and in 240 stroke-free controls. Cognitive impairment (defined as failure on any four items of a 17 item test) was present in 35% of patients. The domains most likely to be affected in stroke patients when compared to controls were memory, orientation, language and attention.

1.4.3.1 Intelligence

Intelligence has been described as 'an ability, or set of abilities, which permit an individual to solve a problem, or to fashion a product, which is valued within one or more cultural settings' (Gardner, 1987). There are substantial individual differences in intelligence within the population as a Normal functioning for one individual may represent severe whole. impairment for another. Premorbid level of intellectual functioning may serve as an individualised comparison standard for cognitive function after a stroke as it is relatively unaffected by the presence of neurological damage. In a study of IQ (as measured on Raven's Coloured Progressive Matrices) of 148 stroke patients, David and Skilbeck (1984) found that intelligence quotient (IQ) was related to severity of language dysfunction, although no relationship was found between intelligence and recovery of aphasia. IQ level was related to some measures of physical status and to mortality. A high level of intelligence has been associated with good prognosis after rehabilitation (Freed and Wainapel, 1983).

1.4.3.2 General mental state

General mental state refers to many different areas of cognitive functioning, including orientation, memory and attention, the ability to follow commands, calculating (including mental control and accuracy), language, and reasoning. It also includes the ability to read and write and psychomotor skills. A decline in mental state may result in difficulty with any of the above cognitive functions. Disorientation is common and persistent following stroke. Desmond et al (1994) studied 177 alert stroke

patients seven to ten days and three months after stroke found that 41% of patients were disoriented (on the MMSE) seven to ten days after stroke and 22% of patients remained disoriented three months later. Generalised deficits in neuropsychological function are common after stroke. Hom and Reitan (1990) assessed 60 patients with lateralised or diffuse cerebrovascular lesions and 20 controls on measures of cognitive and intellectual function. General cognitive performance in the cerebrovascular groups was poorer than that of controls.

A decline in mental state may also result in changes in activities of daily living (not due to illness or disability), especially motivation for personal care activities, home and social functions such as finances, hobbies, judgement and problem-solving skills (Morris et al, 1991) and behaviour changes, such as social withdrawal, apathy or mood disorders. Sisson (1995) assessed general mental state on the Neurobehavioural Rating Scale and results showed that the most frequently occurring mental status changes at six months were somatic concern, memory deficit, depressive mood and mental fatigue. Other mental changes include impaired judgement, decreased initiative, lack of energy and personality changes (Sisson, 1998). A decline in general mental state may herald the onset of dementia. Dementia is relatively frequent after a first stroke in patients younger than 80 years (Censori et al, 1996) and having a stroke has been found to increase the risk of dementia by a factor of nine (Tatemichi et al, 1992). In a cohort of 451 ischaemic stroke patients, general cognitive decline was present in 61.7% and dementia present in 6-25.5% (depending on classification scale) at 3 months after stroke (Tatemichi et al, 1992).

The frequency of dementia has been found to increase with age (Pohjasvaara et al, 1997). In a study of 216 stroke survivors, impairment of general mental state at 3 months after stroke was identified as a predictor of poor functional outcome (Woo et al, 1992). Significant global mental deterioration is often not identified by the patient or their family (Blass, 1985; Pinholt et al, 1989).

1.4.3.3 Perception

Visual perception deficits are distinct from problems with sight. Although good eyesight is needed in order to have good visual perception, the absence of good eyesight does not cause a perceptual problem. The reason for this is that perceptual deficit is not related to the structure of the eyes per se, but to the way in which messages from the eyes are interpreted by the brain. Nevertheless, research has suggested that problems with the visual field, such as hemianopia, may be related to perceptual problems (Agrell et al. 1997) and that visual field defects can exacerbate perceptual problems (Cassidy et al, 1999). According to Willanger et al (1981), approximately three-quarters of patients with hemianopia also have visual neglect described below. Perceptual function is often closely linked with motor performance, aspects of attention, memory and spatial orientation. There are many types of perceptual problems, but perceptual difficulties can be broadly classified into two categories: visuoperceptive problems and visuospatial problems. Visuoperceptive problems may include impaired object or colour recognition or difficulty in recognising faces. Visuospatial problems may include difficulty in differentiating the positions

of items in the visual field, difficulty in judging direction, distance and depth or a lack of awareness of how places relate to one another (topographical orientation), which may cause difficulty in finding their way around. For example, a patient with topographical disorientation may be unable to describe or draw a route from one familiar place to another (Pai, 1997).

Finally, they may suffer from unilateral visual neglect. This refers to a failure to attend to the side of space or side of the body contralateral to the brain lesion. Patients with right hemisphere lesions are more likely to have visual neglect and as a result, have poorer spatial function (Meerwaldt, 1983). It is possible for left hemisphere stroke patients to develop visual neglect but often this is less severe and more responsive to therapy (Lezak, 1983). Researchers have found that neglect can also occur following frontal lobe lesion (Heilman et al, 1993). The absence of awareness of visual stimuli on one side of vision can dramatically affect activities of daily living. For example, a patient with neglect may only eat food on one side of the plate, dress only one half of the body and shave or apply make-up to one side of the face. In addition, they may appear clumsy, have difficulty in finding their way around, have difficulty reading and telling the time and may be inattentive to persons standing on their affected side. In severe cases some patients may fail to recognise their own limbs. The incidence of neglect has been reported at around 30-40% (Halligan et al, 1989; Gainotti et al, 1986) although there is much variability in the reported rates of occurrence due to differences in subject selection, lesion localisation and the nature and timing of assessment (Bowen et al, 1999). Neglect has been

identified as an important predictor of poor functional recovery (Katz et al, 1999; Jehkohen et al, 2000). A prospective study of 273 consecutive stroke patients in a rehabilitation unit showed that the severity of stroke on admission together with hemispatial neglect were the strongest predictive factors. Patients with neglect had a significantly greater risk of impaired mobility and poor autonomy than patients without neglect (Paolucci et al, 1996).

Perceptual deficits are common in patients who have had a stroke on the right side of their brain with resulting paralysis on the left side of their body (Meerwaldt, 1983) However, people with stroke resulting in either right or left hemiplegias may have perceptual problems (Edmans and Lincoln, 1987). A study by Gupta et al (1997) showed that 32% of patients admitted to hospital with stroke had some sort of visuospatial dysfunction. However, studies of the prevalence of perceptual problems may not be accurate due to the number of patients commonly excluded for reasons such as having had a previous stroke, being unable to read or write, having language problems or severe cognitive impairment. Therefore, patients included in these studies may not be representative of stroke patients as a In Gupta et al's (1997) study, patients with visuospatial whole. dysfunction were compared with those without, and the researchers found that the perceptually impaired group were more dependent (i.e. had lower scores on the Barthel Index) at discharge. Difficulties in visual perception may affect ambulation, which may reduce the potential for independent living (Gouvier et al, 1984). Indeed, a study by Rapport et al (1993) found that perceptual deficit on the Rey-Osterreith Complex Figure Test was

associated with risk for falls (n=32). Visuo-spatial impairment has also been found to predict low subjective well-being one year after stroke (Wyller et al, 1997).

1.4.3.4 Memory and Attention

Attention refers to an individual's ability to receive and process incoming stimuli. A stroke may impact on an individual's ability to distinguish between different signals and decide which things they should attend to. This may affect their ability to respond simultaneously to two or more things at the same time (divided attention), their ability to exclude distracting information (selective attention), their ability to shift from one task to another when necessary (alternating attention), their ability to maintain awareness on a task (sustained attention) or their ability to concentrate on important matters (focused attention). An individual's capacity for attention can fluctuate depending on circumstance and across time. Attention can also be affected by impairments of other cognitive functions such as memory and executive functioning or by lowered mood. A deficit in attention may impair the ability to learn material.

In addition to taking in and processing information a stroke may affect a person's ability to store information and retrieve it when necessary. *Memory* refers to the system by which a person can register, store, retain and retrieve some previous exposure to an event or experience (Lezak, 1983). Impairment of memory has been associated with specific and localised brain damage (Mayes, 1988). However, it is often difficult to filter out the influence of intelligence and levels of motivation, attention

and concentration on memory. Although it is known that lesions in distinct regions of the brain can cause disturbances of memory, information about the effects on individual components of memory is far from exact (Mayes, 1988). There are many theories of memory and it is beyond the scope of this thesis to discuss each in detail. However, it is widely accepted that memory is not a unitary system but consists of multiple components (Baddeley and Hitch, 1974). In a rather simplified theory, memory has been broadly classified into three categories based on the length of time information is stored (Atkinson and Shiffrin, 1971). That is, a brief set of sensory stores, followed by a limited capacity short-term store, followed by a long-term store. Other types of memory are semantic memory (memory for knowledge), episodic memory (memory for autobiographical events), recognition memory (memory for previously presented material) and memory for colour (e.g. Schoppig et al, 1999).

Many stroke patients are aware of memory problems and self-report difficulties (Tinson and Lincoln, 1987). Stroke patients have been found to be impaired relative to controls on tests of verbal memory (Beeson et al, 1993). Wade et al (1986b) identified 29% of patients with memory problems on story and picture tasks. The fact that verbal memory performance does not seem to be highly correlated with language ability suggests that verbal memory impairment is not simply a consequence of language impairment (Beeson et al, 1993). A study by Kotila et al (1984) of 154 stroke survivors suggested that poor memory had a major negative influence on patient outcome in activities of daily living.

Problems with remembering may be an important factor in whether a patient will have difficulty coping with everyday life and can place great burden on relatives (Brooks et al, 1986).

1.4.3.5 Language

Language refers to 'symbolic systems of communication used by persons of the same cultural background' (Cummings and Benson, 1992). There is an intimate association between language and speech (see motor deficits) and damage to the brain can often affect both. The term used to describe these problems is aphasia. Aphasia denotes the loss or impairment of language following brain damage and is, by definition a neurological disorder. It is more common in stroke affecting the left hemisphere although it can also occur after right hemisphere damage (Schulz, 1997). There are many models of language, which are beyond the scope of this thesis to discuss in detail. Ellis and Young (1988) proposed a composite model for the recognition and production of spoken and written words.

Although language is a complex system, in clinical terms, language disorders are often categorised into two main types, which relate to the spoken word elements of Ellis and Young's model. The two main types of language disorder described by clinicians after a stroke are disorders of production, known as expressive dysphasia, and disorders of comprehension, known as receptive dysphasia. Receptive dysphasia refers to our understanding of language and the way in which a person attaches meaning to a word. Affected patients may be able to talk but their sentences may not make sense and they may have great difficulty with

writing. Some patients may experience word deafness where speech sounds to them like meaningless noise. Such individuals can speak, read or write, but may not be unable to understand the speech of another. These receptive difficulties can be mapped onto Ellis and Young's (1988) model as an impairment of either the auditory analysis system, the auditory input lexicon and/or the semantic system.

Examples of expressive disorders are difficulty in finding the correct word (anomia), the use of unintended words, phrases or sounds (paraphasia), difficulty with grammar or the structure of language (agrammatism) and the inability to repeat words or numbers without other language difficulties (conduction aphasia). These expressive difficulties can be mapped onto Ellis and Young's (1988) model as an impairment of either the speech output lexicon and/or the semantic system. Those patients who have difficulty in understanding (receptive) or producing (expressive) speech often have difficulty with reading (dyslexia), writing (dysgraphia) and calculating (dyscalculia). There may also be problems with non-verbal communication such as gesture or facial expression (Blomert, 1990).

Over a third of hospitalised stroke patients may experience difficulties with speech and language after a stroke (Bonita and Anderson, 1983). According to Wade et al (1986), in a Health District of 250,000 people, about 60 patients each year may be referred for speech therapy after an acute stroke. Recovery from language problems appears to occur spontaneously, predominantly within the first year after stroke. Recovery is most common when language problems are moderate, with less recovery occurring in those who are either severely or mildly affected (Shewan and

Kertesz, 1984). Aphasia has been associated with the severity of the disability (degree of limb weakness and loss of function), poor recovery of social activities (Wade et al, 1986) and post-stroke dementia (Censori et al, 1996). Aphasia has also been found to predict low subjective well-being one year after stroke (Wyller et al, 1997) and can impact on quality of life (LaPointe, 1999). Communication has been described as, '...almost by definition, the very core of human relationships' (Cant, 1999). Being unable to communicate effectively has been related to psychological distress in stroke sufferers and their relatives (Brumfitt, 1993). However, Wade et al (1986) did not find any measurable increase of stress in carers of stroke patients with aphasia.

1.4.3.6 Executive function

The frontal cortex contains thirteen anatomically distinct regions including systems that are implicated in an enormous range and complexity of behaviours from motor control to social behaviour. The frontal lobes make up one third of the entire cerebral cortex. Damage to the frontal lobes can result in deficits of executive function. Executive functioning is necessary for independent living and engagement in social situations. There are four components of executive functions, namely, volition, planning, purposive action and executive decision. All of these behaviours are required for appropriate and socially responsible adult conduct. Impaired executive behaviour usually involves a variety of deficiencies rather than a defect in a single area. *Volition* refers to the capacity to formulate a goal or intention. A person lacking volition cannot think of

anything to do, may be apathetic and may only carry out activities when instructed to do so. Preconditions for volitional behaviour are motivation and self-awareness. Planning refers to the ability to identify and organise the steps and elements required in order to carry out an intention. It involves conceptualising realistic alternatives and making choices. Α person unable to plan may not be aware of the situational and financial changes a disability may bring about and may be unaware of the impact of the disability on relatives. They may show poor judgement, be unrealistic or illogical. Purposive action refers to the translation of plans into productive activities and involves carrying out sequences of complex behaviour in an orderly manner. This element of behaviour is often disrupted when behaviour is novel, but routine behaviour is much more resistant to the effects of brain damage (Shallice, 1982). Patients who have trouble with purposive action may show a marked discrepancy between their verbalised plans and their actions. Executive function involves the ability to reason, which calls for logical thinking, concept formation and practical judgements. Estimations of size and shape, for example, test a patient's ability to apply the knowledge they have, make comparisons and mental projections and to evaluate and make conclusions. Executive functions are often conceptualised as the most complex of all intellectual functions (Goldstein and Levin, 1987). Following stroke, many patients experience difficulty with verbal production. Although this can be related to aphasia is does not necessarily signify the presence of aphasia. Impaired verbal fluency has also been associated with damage to the frontal lobes (Janowsky et al, 1989). A problem with verbal fluency can

affect a patient's speech, reading and writing ability (Perret, 1974; Taylor, 1979). Although it is known that damage to the frontal lobes can result in executive deficit, there is little research specifically relating to executive problems after stroke.

1.4.3.7 Praxis

Praxis refers to 'the ability to produce purposive movements' (Helm-Estabrooks and Albert, 1991) and is necessary in order to interact effectively with the environment. Dyspraxia generally refers to a 'failure of purposeful movement in the absence of any paresis of the musculature involved; automatic or involuntary acts remaining uncompromised' (Walker, 1992). Dyspraxia can therefore be described as a disorder of movement not caused by motor difficulty but by an inability to conduct purposeful movements in the correct sequence. This failure to perform gestures correctly can either be in response to initiation by someone else (imitation) or in response to a command. This disorder is said to represent a 'high level disorder of stimulus-response processing' (Mandell et al, 1994). Dyspraxia is predominantly a consequence of left hemisphere injury (Mandell et al, 1994) but it has been suggested that both the right and left cerebral hemisphere's contribute to different aspects of praxis (York and Cermak, 1995). Donkervoort et al (2000) suggested that approximately one-third of left hemisphere stroke patients have dyspraxia, although their study was based on patients in rehabilitation centres and nursing homes rather than those in the acute stage in hospital. Diagnosis and interpretation of dyspraxia are hampered by its frequent occurrence with
aphasia (Alexander et al, 1992). It has been suggested that the close relationship between the two may be related to sharing the same neural structures (Kertesz and Hooper, 1982) as praxis and language make use of two different but partly overlapping networks (Papagno et al, 1993).

Failure of praxis is more likely in the command than in the initiation condition (Goodglass and Kaplan, 1983) although the opposite can occur (Rothi et al, 1991). Dyspraxia may adversely affect activities of daily living (Buzzelli et al, 1998). Specifically, Foundas et al (1995) found that increased severity of dyspraxia of the limbs was related to an increased number of errors in mealtime eating behaviour and the sequencing of mealtime activities. Additionally, the presence of dyspraxia has also been found to predict subjective well-being one year after stroke (Wyller et al, 1997).

1.4.4 Mood after stroke

Stroke patients may suffer from emotional problems, including anxiety, distress, apathy, emotional lability, frustration and depression. Other features of emotional behaviour, such as disinhibition, denial, indifference, overt sadness and aggressiveness are not rare during the acute stages of stroke (Ghika-schmid and Bogousslavsky, 1997). Depression and apathy have been described as the two most frequent behavioural complications of stroke (Starkstein and Manes, 2000; Spencer et al, 1997). However, incidence and severity estimates of post-stroke depression vary as a result of different assessment methods (Schramke et al, 1998), different diagnostic criteria and the duration of stroke (Han and Haley, 1999).

Robinson (1997) suggests that depression can affect up to 40% of stroke patients. A study of 106 acute stroke patients found the prevalence of depression (based on DSM-III-R criteria) to be 53% at three months and 42% at 12 months after stroke. The prevalence of major depression was nine per cent at three months and 16% at 12 months (Kauhanen et al, 1999).

It has been suggested that the significance of depression after stroke in relation to neuropsychological recovery is under-rated (Mikulik, 2000). Research has demonstrated a relationship between depression and aphasia (Kellermann et al, 1999). Significant correlations have been found between the severity of the stroke, measured on the Barthel Index and Scandinavian and Orgogozo Scales, and the severity of depressive symptoms measured on the Beck Depression Inventory (Kellermann et al. 1999). Dennis et al (2000) assessed both depression and anxiety in 372 patients at six months after stroke on the General Health Questionnaire-30 (GHO-30) and the Hospital Anxiety and Depression Scale (HADS). They found that 60% of their sample had low mood on the GHQ-30 and 20% were suffering from anxiety on the HADS anxiety subscale. Patients with severe strokes resulting in physical disability were more likely to be depressed whereas there was a less strong relation between disability and anxiety (Dennis et al, 2000).

Others have also reported that ill health may be a predisposing factor to depression and that depression can exacerbate the effects of ill health by impeding functional recovery (Ramasubbu, 2000; Silverstone, 1990; Fiebel and Springer, 1982). Chemerinski and Robinson (2000) suggested that

both depressive disorder and anxiety disorder can inhibit physical recovery from stroke. It has even been found that mortality rates ten years after stroke are higher for patients who were depressed after the stroke than for those who were not (Morris et al, 1993). Emotionalism and lability after stroke is also relatively common (Hangar, 1993; Allman et al, 1990; House et al, 1989; Calvert et al, 1998). Emotional distress and mood disturbance amongst the patients has been frequently associated with stress in caregivers (Gilleard et al, 1984; Livingston et al, 1985; Wade et al, 1986; Brooks et al, 1986). Despite these findings, a study of six-year survivors of stroke in New Zealand has suggested that stroke patients appear to adjust well psychologically to their illness (Hackett et al, 2000).

There is a tendency in the literature to focus on the complex and pervasive deficits that confront the stroke patient without sufficient attention being paid to the involvement of relatives and spouses in the rehabilitation process and the subsequent effects on these caregivers' emotional and physical well-being (Anderson, 1995). Stroke impacts not only on the patient but also on those surrounding the patient and providing care. Buck (1968) described a stroke as a 'family illness' and Sanford (1975) went as far as to say that the primary supporter is the 'hub' around which the future of the patient revolves.

<u>1.5 What is caregiving?</u>

Carers look after relatives or friends who, because of their age, physical or other disability cannot manage at home without help. A book by Aneshensel et al (1995) portrays caregiving as an 'unexpected career' with part time assistance often developing into what can be described as an 'all Zarit and Edwards (1996) maintain that, "a encompassing' role. relationship develops into caregiving when an older person becomes dependent on another's help to complete tasks, and another family member (e.g. a spouse or a child) provides or arranges for this assistance". They add that "caregiving constitutes a change in ongoing patterns of exchange in response to a new disability, which results in one or more people providing regular help to the elder". Graham (1983) has described caring as consisting of two interdependent dimensions: love and labour. Love is associated with the affective aspects of caring, such as emotion, obligation, comfort and love. Labour is concerned with the caregiving role and represents the task, function or activity. These two dimensions are complementary, and have been distinguished as 'caring' and 'caregiving' (Mackenzie and Holroyd, 1996) although the two terms are used interchangeably within this thesis.

Medical developments and advances have increased the understanding and management of stroke and thus the number of surviving individuals (Muir and Roberts, 2000; Hock, 1998; Thomassen, 1995). This has accentuated the importance of research on rehabilitation and readjustment of stroke sufferers and their families. Stroke is primarily a disease of the elderly and as the average age of the population rises and the incidence and prevalence

of stroke increases, there will be greater numbers of people who require help in effectively adapting to and living with their condition. The provision of care to these individuals is divided (unequally) between the formal and informal sectors. Formal care consists of institutional care and community care services. Informal care refers to care provided by voluntary services, family, friends and neighbours. A large proportion of stroke patients are discharged back into the community where they rely on care from informal sources. In a study of 662 stroke patients who were discharged alive after acute hospitalisation with an initial stroke, Lai et al (1999) found that 128 (19%) were discharged to a nursing home, 17 (3%) went to a short-term hospital, 140 (21%) went to a rehabilitation facility and 375 (57%) were discharged to their homes. The type of community and home care support available is influential in deciding whether a patient is to be discharged home or into an institution (Lee et al, 1991). The following section outlines the main types of formal, institutional care and provides a discussion of community care services and informal care.

1.5.1 Institutional care

There are two main types of institutional care: residential care, and nursing or continuing NHS care. It is generally accepted that care is available outside of hospitals and in comparison to the number of stroke patients in the community, only a small minority remain in institutional care as a result of their stroke (Grievson et al, 1990; Thorngren and Westling, 1990). Studies have shown that patients sent to nursing homes have a greater risk of dying than patients sent home or to rehabilitation facilities (Lai et al, 1999) even when health status is controlled (Aneshensel et al, 1993).

Reports have highlighted the poor quality of life experienced by elderly people in institutions (Hackett et al, 2000; Meacher, 1972). Particularly relevant is the lack of control that residents have over their own care and the dehumanising nature of the regimens. However, considerable improvements to institutions have been made over the years in the quality of care offered. Some positive factors might be the security and freedom from worry that institutions can provide (Allen et al, 1992) and no longer feeling like a burden on the family (Higgs et al, 1992). Chiu et al (1997) found that the family costs of patients being in a nursing home were substantially lower than family costs for patients living at home.

Even so, studies have found the attitudes of both dependant elderly people and carers towards institutional care to be rather negative (Qureshi and Walker, 1989). Total expenditure on long-term care for older people, from all sources, has been estimated to be £6612 million a year (Laing, 1993), which represents 73% of national expenditure in this area.

The breakdown of funding for this is: NHS 23%, local authorities 12%, social security 30%, and the remainder from individuals. This high expenditure coupled with negative attitudes of patients and carers towards institutional care has been the prime motivating force behind the shift in attention from institutional to community based care.

1.5.2 Community Care (care *in* the community)

Community rehabilitation for stroke may include physiotherapy, occupational therapy, district nursing and social services. The Department of Health and Social Security has for many years held a policy of maintaining the elderly in the community rather than in residential care. As early as 1978, a DHSS report stated that, as far as older people are concerned, 'the primary objective of departmental policies...is to enable old people to maintain independent lives in the community for as long as possible. To achieve this, a high priority is being given to the development of domiciliary provision and the encouragement of measures designed to prevent or postpone the need for long term care in hospital or residential homes' (DHSS, 1978, p.13). This would include the use of statutory resources provided within the client's own home and in community-based centres rather than institutional care.

Home care of the frail elderly is 'advocated as both a humane and cost effective alternative to institutional care' (Silliman et al, 1986). There is an increasing tendency for patients to be discharged from the hospital as soon as it is plausible to continue rehabilitation from home (Beech et al, 1999; Bonita et al, 1987; Brocklehurst et al, 1981; Wade and Hewer, 1983) rather than maintaining patients in formal institutions. However, where community care services are unavailable or elderly people cannot afford to pay for such services, reliance is upon the informal sector to provide that care. A distinction can be made between care provided by community services and informal care. This distinction was recognised by the government in the 1981 White Paper, *Growing Older*, with the statement

that '...care in the community must increasingly mean care by the community' (DHSS, 1981a, p.3). This approach focuses on the use of resources available within the community from voluntary organisations, and informal caregivers such as family, friends and neighbours, with statutory services being used only as a last resort or supplementary to the care received from the family and informal sector.

1.5.3 The Informal Sector (care by the community)

The informal support system provides more assistance than formal organisations. 'In practice, informal care has become the cornerstone of policies for health care in the United Kingdom' (Anderson, 1988). Social services and the NHS rely on carers' willingness and ability to provide care and this care is worth an estimated £34 billion per year (Nuthall et al, 1993). Without the care provided by informal support networks, many elderly would be forced to leave their homes and enter institutions (Branch and Jette, 1983; Cantor, 1975). The recent shift in attention from institutional to home care (Anderson, 1995) has resulted in the increased significance of the well being of the patient after he/she has left the hospital environment. An increasing number of stroke patients are being cared for in their own homes or in the community (Greveson et al, 1991; Ebrahim and Souri, 1987; Wade et al, 1986; Brocklehurst et al, 1981), primarily by spouses and other relatives, and occasionally by friends and neighbours. The informal sector has been defined by Victor (1997) as 'care provided by family, friends and neighbours, that is not organised through a statutory or voluntary agency'. An informal carer can be described as 'someone who

looks after a family member or friend who cannot look after themselves because of frailty, disability or illness' (CNA, 1996). The social expectation of caregiving in the informal sector was proclaimed as early as 1930 in the Poor Law Act, which stated, 'It should be the duty of the father, grandfather, mother, grandmother, husband or child of a poor, old, blind, lame or impotent person, or other poor person, not able to work, if possessed of sufficient means, to relieve and maintain that person not able to work.' (Means and Smith, 1995). However, it was only by the 1980's that a significant body of research had identified the true extent of the care provided by the informal sector, who the carers were and how much care they provided. The key role of informal carers was recognised in the Griffiths White Paper (1988), which stated '...the reality is that most care is provided by family, friends and neighbours'.

Victor (1997) claims that implicit within this statement is 'the assumption that state services will not be forthcoming until the informal network is exhausted or non-existent'. In the 1989 White Paper on community care, *Caring for People* (DoH, 1989), the family is promoted as the main source of care, and the home as the ideal place to receive care. This ideology was based on the notion that people could then lead as normal lives as possible and independence would be promoted. This White Paper represented the first official acknowledgement of the extensive role played by the informal sector in the care of the elderly, although it was only in April 1996, in the implementation of the Carers Recognition and Services Act, that carers became eligible for assessment of needs in their own right. The implementation of the Act demonstrates the increasing awareness of the

strain suffered by caregivers. Holbrook (1982) stated that stroke is a "family matter". Despite the significant impact of stroke on the caregivers' quality of life and the ensuing adjustment required of them, caregivers are largely neglected by formal support and traditionally, attention has focused primarily on the dependent individual. It is evident that the overall burden of stroke cannot be assessed simply in terms of the damaging effects on patients alone. Carers are affected grossly by the patient's illness, from initial shock of the occurrence of stroke to eventual readjustment and reorganisation of lives and the provision of care often reaching exceptional levels. In addition to the toll of caring for someone with residual disabilities following stroke, it is often the long-term emotional, psychological and social effects of stroke that are the most disabling (Holbrook, 1982; Garraway et al, 1980).

1.6 Reasons for caring and networks of informal care

According to Finch (1995), 'such care is not provided for money but rather stems from the complex relationships of responsibilities and obligations which arise from within families'. Caregiving, therefore, takes place in a relationship between dependant and carer, which has developed over a period of time and is 'embedded in a web of family and community responsibilities' (Victor, 1997). Evandrou (1991) has identified three different types of carers: sole carers, joint carers (where the responsibility for care is shared equally with one other person) and peripheral carers (where there are more than two people providing care, which may equate to the 'network of informal support' referred to in the Griffiths report).

The 1985 GHS survey highlighted that 54% of carers were sole carers, 11% were joint carers and 35% were peripheral carers. The majority of dependants have a very limited network of informal care and responsibility for care is often consigned to a single caregiver (Bowling, 1984; Nissel and Bannerjew, 1982; Cartwright et al, 1973). Over half of co-resident carers in the 1995 GHS reported that they were the only carer, compared with 42% of carers in the 1985 GHS. This person is often a family member and usually a partner, who has no previous experience in caring for someone who has had a stroke, highlighting the definite need to improve provision of support for carers.

The changed needs of the stroke survivor must immediately be addressed by carers who concurrently must cope with their own overwhelming fears and anxieties together with dramatic changes from their former lifestyles. As a consequence it is essential that carers' perceptions of service provision are considered when planning support for patients discharged into the community (Levin et al, 1994). This thesis focuses on the impact of caregiving specifically on spouses of stroke patients and data from the 1982 National Long-Term Care Survey indicates than networks for married people are significantly lower than those for never married or widowed people (Barrett and Lynch, 1999). Although it is recognised that there are networks of informal care, it is beyond the scope of this thesis to address caregiving networks and involvement of friends and other family members.

1.7 Prevalence of informal caregiving

In 1988, Green estimated that there were over 6 million carers in the UK (one adult in seven) looking after dependent relatives. However, the latest figure on carers have been published in a 1998 report called 'Informal Carers' as part of the 1995 General Household Survey. The survey indicates that there are now around 5.7 million carers in the UK. This means that one in eight people are carers. Although these figures show a slight decline in the number of caregivers in the UK, they also show an increase in the number of carers providing support for 20 hours or more every week from 1.5 million to 1.7 million.

Parker (1985) estimated that one and a quarter million people living in Britain care for disabled or elderly people living in the community. It has been documented that between 10 and 50% of stroke patients are cared for at home without ever being admitted to hospital (Bamford et al, 1986; Wade and Langton-Hewer, 1985). The variability in estimates might be due to regional differences in notification systems and hospital referral or differences in the definition and diagnosis of stroke. The extent of home care is again highlighted by the fact that the majority of strokes occur at home (approximately 80%) and somewhere in the region of 80% of surviving stroke patients return to their homes following hospital treatment (Brocklehurst et al, 1981). However, the great psychological, physical and financial drawbacks of caring for a stroke patient at home are often not adequately considered when the benefits of home care are promoted.

1.8 Who are the caregivers?

It has been argued that carers should be regarded as 'experts' in their knowledge of the patient (Nolan et al, 1996). Spackman (1991) suggests that all too often health professionals see the carer not as a person in their own right, but merely an appendage to the patient. However, caregiving incorporates huge physical, psychosocial and emotional adjustments and represents a major life change for the individual accepting the role.

1.8.1 Identifying the caregiver

Research studies differ in the way in which they define and identify carers. Some researchers have requested that the patient identifies the person that they consider to be their primary caregiver whilst other studies rely on caregivers themselves coming forward as the primary individual who cares for an elderly person. However, it is important to acknowledge that some people who provide daily assistance to the older person may not identify themselves as a caregiver, and conversely, some people nominating themselves as caregivers may not actually provide regular care with activities of daily living. For the purpose of this thesis, spouses of stroke patient have been labelled as 'carers' or 'caregivers' and the terms used interchangeably, although it is recognised that in the case of married couples, an exchange of help may not be labelled as caregiving.

1.8.2 Living arrangements

Co-resident carers are estimated to number 1.7 million. In an analysis of carers of the elderly, Arber and Ginn (1990, 1991, 1995) distinguished between co-resident carers and extra-resident carers and claimed that the two types of caring situation are fundamentally different. Within household care is provided primarily for parents and spouses whilst extra-resident care is primarily for friends, neighbours and more distant relatives. The amount of time spent providing care differs between the two groups. Their study showed that on average in 1985, co-resident carers spent 53 hours a week providing care compared with nine hours for extra-resident carers (Arber and Ginn, 1991). They found that, in 1990, over 50% of co-resident carers spent 35 hours a week or more caregiving (Arber and Ginn, 1995). In the 1995 GHS, 53% of co-resident carers stated that they were the only carer, compared with 42% in the 1985 GHS.

According to Zarit and Edwards (1996), when the elder is co-resident with either a spouse, a child or other relative, that person almost always assumes the majority or all of the caregiving activities. Chappell (1991) also showed that co-residency was the most important factor in determining caregiving activities, particularly in activities of daily living.

The most assistance for the longest period of time is predominantly provided by the closest relatives;; usually spouses and daughters. There is clearly a great difference in the level of care and support and the needs of carers who are co-resident with the care receiver than those who are extraresident carers. According to Tennstedt et al (1993), co-residency is more important than kinship tie in determining the amount of informal care

provided. However, Cullen et al (1997) found that co-residence was not associated with caregiver stress in the cognitively impaired elderly. Also, in a community study of carers of elderly people with dementia, depression or physical disability, Livingston et al (1996) found no significant differences in levels of depression between carers overall and carers who were co-resident with the dependent person. In contrast, a study of 170 caregivers of dependent elderly persons in Sweden found that cohabitation of carer and recipient was the sociodemographic variable most closely associated with caregiving stress (Herlitz and Dahlberg, 1999).

1.8.3 Kin relationship

The close kin relationship between the caregiver and care receiver impacts on their feelings of commitment and obligation to the caregiving situation and may influence the length of time that a caregiver is willing to provide assistance. Closeness of kin relationship may also determine the amount of distress experienced by the care provider across comparable circumstances. Some studies have shown that spouses are more likely than adult children to provide care at home (Enright, 1991; Soldo and Myllyuoma, 1983). A caregiving partner almost always shares the same household as the care receiver, whereas daughters and other caregiving relatives and friends are more likely to reside in separate households.

Caring for a spouse represents the most frequent form of caregiving (Zarit and Edwards, 1996; Braithwaite and McGown, 1993) and so this group have been selected to be the focus of research presented in this thesis. Indeed, a large, population-based study by Schulz et al (1997) showed that

approximately 80% of persons living with a spouse with a disability provided care to their spouse. An older, married couple often provide assistance to one another, which is mutual and complimentary, for example in the sharing of household tasks. In a number of studies, marriage has shown to be the factor that was ultimately related to successful home care (Evans et al, 1991; Schulz et al, 1988; Lewis, 1984). Marriage has been associated with good health and the decreased use of health care resources (Lewis, 1984) and marital status has been identified as a strong predictor of survival three years after stroke (Bonita et al, 1988).

In a study by Cantor (1983), spouses appeared to be the highest risk group among 111 carers (33% were spouses) followed by child, other relatives, friends and neighbours. Cantor suggested that this was because household incomes in these caregiving dyads were lowest and they were most likely to be old themselves. Most carers in this sample were at least 60 years old and almost half were 75 years or over. Increased age predisposed them to poor health and 84% perceived their own health to be either fair or poor. In addition to this, caregiving spouses tended to be more involved in providing personal care, shopping, cooking and housework. In most cases, couples lived alone. According to Cantor this factor increased the potential for isolation and psychosocial stress. Jackson and Cleary (1995) suggested that spousal caregivers of chronically ill elders are particularly vulnerable because of the 'relentless demands of caregiving combined with the grief process associated with changes in role expectations'. However, a study of carers of heart-attack patients by Young and Kahana (1987) showed that despite the physical and psychological demands of caregiving,

spouses felt less burdened than other carers by the demands placed upon them. So, although physical and emotional distress of caregiving may be high in this group, spouses might feel less resentful about performing the caregiving role, and may be more willing to look after their partner 'in sickness and in health'.

Therefore, one might expect spouses to persist longer in the caregiving role than non-spouse caregivers yet research has shown evidence to the contrary. Studies have suggested that kin relationship is not related to likelihood of institutionalisation of the elderly person (Aneshensel et al, 1995; Aneshensel et al, 1993). One explanation for this may be that spouses are more likely to be expected to take on the role of caregiver than a child who is more likely to be self-selected in taking on the caregiving role (Zarit and Edwards, 1996). It is beyond the scope of this thesis to address the differing needs of all potential carers. The thesis will therefore examine the group who spend the greatest number of hours in the caregiving role and have been identified as the group experiencing the most strain. The focus here is on spouses of stroke patients who are co-resident with their marriage partner. Co-resident spouses are referred to as carers or caregivers throughout this thesis.

1.9 Nature of caregiving

This section addresses the physical and psychological nature of caregiving on the caregivers and how that may result in the experience of strain. There is also a discussion of how the reaction of the caregiver can impact on patient rehabilitation and well-being and how caring can affect family functioning.

1.9.1 Effects on caregivers

1.9.1.1 Tasks and demands

Caregiving tasks were clearly identified in the GHS survey, which included the following eight tasks: personal care, physical care, paperwork, practical help, keeping the person company, taking them out, giving them medicine and keeping an eye on them. On the basis of this survey, Parker and Lawton (1994) demonstrated that, of those carers providing both physical and personal help, 80% were sole carers and 69% were co-resident with their dependants. When reviewing the literature it is important to recognise the many different definitions of caregiving that are utilised (Blum et al, 1989). An operational definition of caregiving may be, for example, providing help on a regular basis with at least one activity of daily living. Caring is generally taken to refer to assistance in activities of daily living such as washing, eating, walking, getting up and toileting (Stone et al, 1987). Caring involves a substantial amount of close contact with the care receiver in order to be available to help, and often a degree of physical strength to provide support. For example, physical support is often required for the carer to assist the dependent person in getting out of bed

and dressing. Additionally, caring may involve dealing with incontinence, washing, cleaning the home and general household activities and perhaps changing a catheter. There are also psychological demands associated with Carers must provide a phenomenal amount of emotional caregiving. support to the dependent person, and be able to respond empathetically to psychological change in that person and understand their perceptions and fears. Caregiving may also demand that the caregiver gives up their own interests and needs and enforces them to deal with tasks they may not have had to deal with before the stroke, for example, family matters or financial According to Keith (1979), psychological well-being is decisions. sometimes diminished by personal and role losses. Role changes may also disturb interaction patterns and social rewards derived from activities in ways that have consequences for adjustment to the new life situation (Lemon et al, 1972). Carers have to maintain a cheerful, supportive environment, often when feeling unable to do so and may need help to overcome psychological stresses. Carers may also have a great deal of time for introspection and those unable to discuss their concerns with others may be vulnerable to breakdown.

1.9.1.2 Carer strain and burden

A study by Ebrahim and Nouri (1987) found that two-thirds of their sample of carers of stroke survivors in Nottingham (n=81) reported that the caregiving role had an adverse effect on their lives. Caregiver strain is frequently used as an outcome measure of the impact of stroke on an informal supporter. Some researchers have referred to 'burden' as

opposed to 'strain'. The concept of 'burden' has been defined in numerous ways. Thompson and Doll (1982) defined burden as emotional costs due to feelings of embarrassment and overload. According to Fatheringham et al (1972) burden refers to specific changes in caregivers day to day lives, such as disruption of daily routine. However, some researchers define burden as financial difficulties, role strain, and physical health deterioration (Robinson, 1983; Zarit et al, 1980).

The terms 'burden' and 'strain' are often used interchangeably in the literature. Studies are often difficult to compare because they have varying samples and designs, define carers in different ways and differ in their measurement and definition of strain or burden. Burden can be defined as 'anything difficult to bearloadencumberment' (Collins Gem Dictionary). Using this definition it would therefore seem sensible to view strain as the resulting state of exposure to burden or load. Strain has been defined as, 'a burden of care arising from the patient's illness, which threatens either the physical or mental well-being of the relatives or both' (Isaacs, 1971).

Strain occurs in approximately a third of caregivers of stroke patients (Robinson, 1983; Greveson et al, 1991; Greveson and James, 1991). However, the strain experienced by those in the caregiving role is highly subjective in nature, the result of what has been described as, 'highly personal and individualised responses to specific caregiving contexts' (Poulshock and Diemling, 1984). Bugge et al (1999) investigated levels of caregiver strain at one, three and six months after stroke using the Caregiver Strain Index (CSI) (Robinson, 1983). Various caregiver

characteristics, patient characteristics and service inputs were also assessed. At six months after the stroke, 37% of caregivers were experiencing significant strain. Multiple regression analysis showed that strain was best predicted by the amount of time the carer spent with and spent helping the patient and the carer's own health. Stroke severity was also important although was not consistently related to strain. In this study, neurological impairment had been assessed only by level of consciousness and a single screening measure of neuropsychological deficit. Detailed assessment of cognitive function was not included. Carer individual differences were not addressed.

A study of long-term outcome for patients and carers following hospital admission for stroke assessed strain in carers at least three years after the stroke (Greveson et al, 1991) using the CSI. They found that 30% of their carers were suffering from significant levels of strain on the CSI, although the study included both community and institutionalised patients and carers from a range of kin relationships. This suggests that the presence of marked strain is not only apparent in the earlier stages of recovery, but continues over time, despite continued functional improvement in many of the patients (Langton-Hewer, 1990).

In 1971, Isaacs conducted a study investigating the reasons for the admission of 280 patients from their own homes to a geriatric unit in the east-end of Glasgow. Their main finding showed that one third of the patients were admitted primarily in order to provide respite and relieve high levels of strain on relatives. In an investigation of the major predictors of strain they concluded that the experience of strain was

determined by multiple factors, including factors in the patient, factors in the helper and factors in the helper's 'life space'. Factors in the patient referred to the specific nature of their symptoms, including immobility, incontinence and mental abnormality. Important factors in the helper were found to be age, physical and mental health, relationship to the patient, living arrangements and personality. Finally, the 'life space' factor referred to competing demands on the caregiver's time, and the impact of loss of normal social life and leisure activities. However, this early study included geriatric carers of various kin relationships, and so was not specific to stroke carers or spouses. Also, strain and patient and carer characteristics were identified via a geriatrician's report rather than using standardised measures.

Research has suggested that the burden of caregiving in partners of stroke survivors may be more closely related to caregiver factors rather than patient characteristics. Scholte op Reimer et al (1998) assessed the burden of caregiving in 115 stroke partners at three years after stroke. Explanatory factors of burden were studied in terms of characteristics of the patient (socio-demographic status, severity, type and localisation of stroke, disability, handicap and unmet care demands) and characteristics of the spouses (age, sex, disability, quality of life, loneliness, amount of care provided and unmet care demands). Although a high level of burden could be partly explained by patient disability (14%), burden was primarily explained by characteristics of the spouses, including emotional distress, loneliness, disability, amount of informal care provided, unmet demands for psychosocial care and unmet demands for assistance in activities of daily

living. They concluded that higher levels of burden are primarily related to carer's emotional distress and less to the amount of care they provide or the stroke patient's characteristics. However, the study contained information only on those who were 'long-term' carers and therefore may have had more time to adjust to the caregiving role and perhaps develop effective coping strategies. Characteristics of the patients accounted for severity of stroke but failed to include cognitive impairment. Additionally, the study did not include an assessment of the possible relationship between individual differences and caregiver strain.

In an evaluation of a stroke unit (Miller et al, 1997) carers were given the CSI and the General Health Questionnaire-28 (GHQ-28) to complete. Results indicated that 24% of carers reported significant strain. The main factors associated with strain were physical independence of the patient as assessed by the Barthel Index (BI), and orientation of the patient as assessed on the CAPE. The assessment of carer mood indicated that 39% of carers at three months and 37% of carers at six months had a level of psychological distress sufficient to indicate that they would be classed as psychiatric cases. Although the characteristics of the patients that were associated with carer strain were examined, there was no evaluation of the features of the carer that were associated with either carer strain or psychological distress. A survey of stroke patients not admitted to hospital, who were assessed one month after stroke, examined similar factors (Lincoln et al, 1998). In this study there were 15% of carers who showed significant levels of caregiver strain. This is lower than the proportion reported by Miller et al (1997) but the level of disability was

lower. The main determinants of carer strain were anxiety and handicap in the patient. However, the characteristics of the carer that were associated with strain were not assessed (Lincoln et al, 1998).

Caregiver strain is important as it has been suggested that the experience of strain is detrimental to the physical and emotional health of the caregiver. Caregiver physical and emotional health have been addressed in more detail in chapter three. Researchers have suggested that prolonged distress, physical demands of caregiving and the biological vulnerabilities of older caregivers may compromise their physiological functioning and increase their risk for physical health problems, which in turn can lead to increased mortality. The impact of caregiver strain on health has been clearly demonstrated by research. A recent study of 392 caregivers of disabled elderly people and 427 non-caregiving couples, followed up four years after stroke suggested that being a caregiver who is experiencing mental or emotional strain is an independent risk factor for mortality among elderly spousal caregivers (Schulz and Beach, 1999). The authors report that caregivers who were providing care and experiencing strain had mortality risks that were 63% higher than non-caregiving controls. They concluded that caregivers who report significant strain associated with caregiving are actually more likely to die than non-caregiving controls.

1.9.1.3 Other Effects of Caregiving

Physical strain is common in caregiving. Brown and Mulley (1997) investigated injuries sustained by caregivers of 46 elderly people in the community and found that 31 caregivers had injured themselves whilst lifting or handling a dependant. Most of these were back injuries and eight caregivers were temporarily unable to continue caring as a result of the injuries they sustained. Maladjustment is also common in carers. In a study of 180 patients and families interviewed between two and five years after the onset of stroke, Holbrook (1982) found that one third of carers described themselves as not adjusted. Difficulties were identified in areas such as finances, social mobility, interpersonal relationships, sex life, working life and health. Adjustment is discussed in greater detail in chapter three. Additionally, it has been suggested that there is a general decline in sexual activity and libido in both genders after stroke (Bray, 1981; Boldrini et al, 1991). Stroke in a partner can often lead to a loss of prior roles and status, significant relationship changes and potential strain on economic security. Loss of social life may affect three quarters of carers (Holbrook, 1982) and disruption of sleep, described by Sanford (1975) as the, 'least tolerated aspect of caring for someone', is often a difficulty (Brocklehurst et al, 1981).

A large amount of individual variation exists in the way that caregivers adapt to newfound roles. Some carers cope relatively successfully whilst others become progressively more burdened (Aneshensel, 1995). Carers of elderly people sometimes feel that the burden of care is intolerable (Jones and Peters, 1992) and some caregivers of those with only slight

disabilities report overwhelming levels of distress and strain (Zarit et al, 1980). However, in marked contrast, some caregivers report little or no problems and minimal levels of psychological distress when caring for a stroke survivor with severe disabilities. Caregivers differ in their inclination and capability to carry out this role and in the practical resources that they have available to them (Zarit and Edwards, 1996). In a study of 256 community elders and their primary caregivers, Jones and Vetter (1985) concluded that carers support elderly dependants at great cost to themselves and often with inadequate support from community services. The authors pointed to the inadequate levels of relief care services for the elderly living in the community and stated that " the more disabled or mentally infirm the dependent the less likely the carer was to have breaks and holidays".

Caregiving situations are diverse in nature as stroke survivors vary tremendously in their level of disability and extent of impairments, individual personality characteristics and both prior and current relationship with the caregiver (Zarit and Edwards, 1996). Research has shown that major illness can prove as traumatic for the carer as for the afflicted person themselves (Draper et al, 1992; Wade et al, 1986; Brocklehurst et al, 1981). Studies have identified numerous difficulties encountered by caregivers, including an altered social life (Webster and Newhoff, 1981), role changes (Sarno, 1971), communication difficulties (Shewan and Cameron, 1984), shock, depression, guilt, loneliness, irritability and bitterness (Emerson, 1979; Malone et al, 1970).

Greveson et al (1991) found difficulties on the Nottingham Health Profile with emotional reactions, sleep and social isolation in 44 carers of stroke patients. Research by Field et al (1983) on 13 stroke patients living in the community found that at six months after stroke, spouses were able to cope with the practical aspects of caregiving, but all had difficulty with the emotional aspects of caregiving. Field and colleagues highlighted the fact that the desire for independence and self-sufficiency held by these caregivers, that tended to prevent them from accepting help, aggravated their ability to cope. Additionally, poor communication between hospitals and community services accentuated this difficulty.

Nevertheless, Ebrahim and Nouri (1986) found that only 15% of patients receiving help from a caregiver had not actually been visited by a health or social services worker within the month prior to their interview.

The caregiving role may have a financial impact on the care provider. In the 1992 Carer's National Association survey, 47% reported experiencing some financial difficulty since becoming a carer, with problems reported more frequently by younger carers as opposed to those aged 65 or over. Financial difficulty may therefore not be such a significant factor for spouses of elderly and often retired stroke patients. Nevertheless, it is possible that differences between younger and older carers may be attributable to differences in expectations rather than actual differences in the level of financial difficulty. Even so, the extra costs inevitably incurred when looking after a disabled person may still represent a strain for coresident spouses of stroke patients. Despite the increasing number of studies in this field, there still inadequate information available that allows

us to distinguish between those caregivers who will cope effectively and those who will experience a high level of distress (Montgomery, 1989). To make these predictions it is necessary to understand fully the existing interrelationships between the variables present in the caregiving situation. Above all it would seem that subjective perceived strain is critical and not any single component of the caregiving situation (Brown et al; 1990; Wade et al, 1986). To illustrate this, research has suggested that objective severity of stroke does not correlate with carer strain or it may be a factor in the early stages, however, it does not appear to predict long-term outcome for carers (Draper et al, 1992; Schulz et al, 1988; Wade et al, 1986; Brocklehurst et al, 1981).

The adverse effects of caring for the stroke patient may often extend beyond the immediate carer and can interfere with family functioning. In turn, family functioning may be related to effective rehabilitation of the patient (Garraway et al, 1980). Cassidy and Gray (1991) quoted, "it is important not to forget the carer and the family; a happy family will result in better patient compliance with rehabilitation and a better functional outcome from stroke".

1.9.2 Gender differences

It has also been suggested that gender of the caregiver may be an important factor in caregiver strain, with women experiencing a greater level of strain in a spousal caregiving relationship (Enright, 1991). Other research has also demonstrated that husband caregivers typically report less emotional distress than wives, even after controlling for disease

severity (Schulz et al, 1993; Zarit and Whitlatch, 1992; Williamson and Schulz, 1990; Anthony-Bergstone et al, 1988). Despite the fact that husbands and wives as caregivers may spend similar amounts of time caring for their partner, husbands tend to receive more help from informal sources than do wives, which may lessen the impact of caregiver strain. However, results are mixed and some researchers have not demonstrated gender differences in caregiving outcomes. In one Dutch study, 167 caregivers of dementia patients were assessed on a 'Self-Perceived Pressure from Informal Care' Scale (Pot et al, 1995) and the authors found no differences in perceived pressure between male and female caregivers.

The role that caregivers play is critical and may influence or even determine the patient's emotional reactions concerning the outcome and success of rehabilitation (Carnwath and Johnson, 1987). Evans et al (1991) demonstrated that depression in the carer may affect the stroke patient themselves, as they may receive less than optimal care if their carer is depressed. The spouse's understanding attitude and ability to cope may be crucial in the rehabilitation process (Kinsella and Duffy, 1979) and in determining whether or not the patient continues to receive adequate care outside of formal institutions (Glass et al, 1993).

The family functioning literature suggests that family cohesiveness and communication may be related to the success of rehabilitation (Evans et al, 1987; Garraway et al, 1980). However, some researchers in this field have provided evidence to the contrary. Labi et al (1980) suggested that the cohesiveness of family surroundings may result in over-protection of the patient, slowing the recovery process. Their study showed that stroke

survivors who lived alone were less likely to decrease their outside socialisations than patients who lived with their family. Family System Theory advocates that healthy family functioning is dependent upon the functioning of each individual within the family system. Douglas and Spellacy (1996) suggest that the influence of caregiver adjustment and coping in some families may actually outweigh the adjustment and coping of the patient.

<u>1.10</u> Theoretical basis to caregiving – Global outcome models

The study of caregiving is an attempt to link a number of antecedent variables to outcomes assessing the well-being of the carers. A number of models have already been developed and applied to caregiver strain, ranging from basic stress-coping models to models that specifically address caregiving outcomes. The models presented here are by no means exhaustive but provide a framework for understanding the caregiving process. By combining information and concepts from existing models a new model is presented as a guideline for this thesis.

1.10.1 Basic Stress-Coping Model

At the most basic level, the caregiving experience can be described as interactions between the individual and the environment (Elliot and Eisdorfer, 1982). The Stress-Coping Model is a generic model (see figure 1) consisting of three primary elements: a potential activator (x), an individual's reaction to the activator (y), and the consequences to these reactions (z).

Figure 1. The x-y-z Stress Model: A framework for interaction between the individual and the environment.

SOURCE: Elliott and Eisdorfer (1982)



At each stage of the x-y-z sequence, modifiers and filters act to produce individual variations. *Potential activators* have been described as events or conditions that are ' empirically known to change an individual's state under some circumstances. A potential activator can be defined independently of its actual effects; it must have only the potential to produce a change' (Elliott and Eisdorfer, 1982). These potential activators may therefore be viewed as stressors, to which an individual's reaction may be physical or psychosocial. Different individuals may react in different ways to the same activator, and the same individual may react differently to the activator at different points in time. Reactions to stressors or activators may be transient or re-occur over time and their consequences may be minimal or intense. For example, an inappropriate emotional outburst from a stroke patient may elicit a strong reaction the first time it occurs but not on subsequent occasions. Where reactions are more transient, responses to an activator, *consequences* are more prolonged and tend to have an evaluative component (ie. desirable or undesirable).

A consequence may be biological in nature such as physical illness, or psychological, such as the experience of depression. The final element of the model is the *mediators*. Again, these can be either biological or psychological. They may impact on an individual's reaction to an activator and therefore impact on the way in which this reaction is translated into the long-term consequences. Mediators help to explain why activators or stressors may impact heavily on some individuals but not on others. An example of a mediator may be social support. Each component of the model interacts with the others and is continually modified with the cumulative effects of past experiences and consequences.

Although the model is useful as a basis on which to build, it does not give enough information about variables of specific relevance to caregiving to be used in isolation.

1.10.2 Stress-Coping Model in dementia caregivers

Haley et al (1987) have developed a model of stress and coping among caregivers, based on an earlier model by Lazarus and Folkman (1984) in a study of coping in carers of dementia patients (see figure 2).

Figure 2. A model of stress and coping among caregivers SOURCE: Haley, Levine, Brown and Bartolucci (1987)



Again, this model is relatively basic. The key elements are stressors, coping responses and adaptational outcomes. Here, coping responses are held together with appraisals and social support as mediating variables. The model is limited in that it fails to include the basic reaction component of the stress-coping model. In addition, the model is simplified in that it only identifies a limited number of links between its components. For example, it is likely that the way in which a stressor is appraised may be influenced by social supports yet this is not portrayed in Haley et al's model. Also, the model fails to include factors such as the health status of the carer, the relationship between the caregiver and the care receiver and sociodemographic factors such as gender.

1.10.3 ABCX Model

The ABCX Model was developed by Hill (1949) to describe the way in which stressors impact on family systems (see figure 3).

Figure 3. The ABCX Model – Hill (1949)



The model can be described as follows. An external event (A) interacts with the ability to cope with that event (B) and with the perception of the stressor (C). The result of this can be crisis and mental health problems (X). This model can be applied easily to the caregiving situation. Caregiving stressors might include the health, level of ADL and cognitive status of the patient and other life events. The way in which the carers cope with the stressors is facilitated by the resources available to them. These might include personal resources such as their health, socioeconomic status and coping skills, and social resources, such as contact and assistance from family and friends and the presence of a confidant. The way in which the carer perceives the situation may be evident in the level of burden or strain they experience. Stressors, resources and the perceptions of the caregiving situation together determine the mental and physical health crises, such as depression or anxiety. The model includes many more specific variables than the previous two models discussed and so is more applicable to the caregiving situation. However, the model has been criticised for being too static (McGubbin and Patterson, 1982) and so it is difficult to study changes over time using this model. The Double ABCX Model has been proposed to take this into account (Cohler, In Press). Although the model is useful, more detail is needed for a model specific to caregiving in stroke spouses.

1.10.4 Caring in Alzheimer's Disease

This model (see figure 4) was developed by Given et al (1988) to investigate the influence of caregiver responses to the patient with Alzheimer's disease. It bears much similarity to the stress-coping models. Although this model contains elements of the stress-coping model it focuses more on the type and quality of prior relationship between the family caregiver and the patient. In addition it is specific to caregivers of Alzheimer's patients. However, it is difficult to directly generalise from Alzheimer's carers to stroke carers as there are many differences in the caregiving experiences.

Figure 4. Factors influencing caregiver responses to the patient with

Alzheimer's disease

SOURCE: Given, Collins and Given (1988)



As an example, many studies have found that illnesses with a sudden onset, such as stroke or heart attack, or sudden diagnosis, such as cancer, cause great carer distress which is heightened during the acute phase of the illness as they attempt to cope with it's life altering implications. This pattern contrasts with that of caregiving in Alzheimer's disease or mental illness as families are often already aware of behavioural disturbances and patient changes long before a diagnosis is made.
1.10.5 Caregiver Stress-Coping Model

A model was developed by House (1974) and elaborated by George (1980) in an attempt to demonstrate the relationships between a number of variables thought to be important in understanding caregiving. This model (see figure 5) has been adapted in studies of caregivers of elderly spinal cord injured patients (Schulz et al, 1987), stroke patients (Schulz et al, 1988; Tompkins et al. 1988) and Alzheimer's patients (Schulz et al. 1989). The model incorporates five classes of variables including: objective conditions conducive to stress, individual perceptions of stress, short-term responses to perceived stress, enduring outcomes and individual and situational conditioning variables that affect relationships between the other categories. Patient disability and illness may represent an objective stressor to the caregiver. In general, studies have shown that as severity of illness increases, so does the emotional impact on the caregiver (Wade et al, 1986). This appears to remain true across illnesses that vary greatly in onset and symptomology.

Figure 5. Caregiver Stress-Coping Model

SOURCE: Adapted from House (1974) and George (1980)



Stressors may include disability in self-care, cognitive impairment and emotional reactions. For example, a stroke patient may have great difficulty in activities of daily living or may have memory problems, which represent objective stressors. The *nature of the illness onset* (sudden or insidious) has also been identified as a stressor. How suddenly the caregiver is confronted with the illness may contribute greatly to stress and this varies between illness types. Also related to caregiver distress are *changes in pre-existing patient behaviours*. This may include memory or communication problems, personality and behavioural changes. Finally, *patient prognosis* (recuperative, stable, degenerative or terminal) may impact on the level of strain experienced by the caregiver. All these factors represent objective stressors which may initiate different reactions in caregivers. Virtually all studies of caregivers include some measure of perceived stress, strain or burden, and can either be viewed as specific caregiving tasks or can include general well-being. Strain can be viewed as a subjective state, which reflects the individual's perceptions of the caregiving role. Therefore, the caregivers themselves are the most appropriate targets for measurement of felt strain or burden. According to Poulshock and Deimling (1984), burden should be treated as an intervening measure between impairment and other indicators of caregiving effects. Therefore, strain or burden can be related to measures of depression and physical health but these measures in isolation do not represent measures of strain. Finally, the model suggests that it is important to measure not only care-related stressors but also takes into account other sources of stress.

Caregiver outcomes may be affected by contextual or situational variables including social support systems, characteristics of the carers and personality attributes. This might include factors such as socio-economic status, gender, living arrangements, health and relationship between the caregiver and the care-receiver, and personality factors such as control beliefs and attitudes towards helping. *Social support* is another factor that may intervene and prevent a negative appraisal response from a stressor, or may reduce the strength of emotional reactions to stressors. The availability of others may reduce the level of strain or burden the caregiver experiences (Clyburn, 2000).

These factors may be conditioning in terms of mediating the impact of the caregiving situation. For example, the stress-buffering hypothesis applied to social support suggests that those carers who suffer from high levels of stress benefit from social contacts and support from others. However, the benefits of social support are debatable; a study by MaloneBeach and Zarit (1995) of caregiving women showed that whilst instrumental support was related to depression, informational and emotional support were not related to caregiving outcomes. Social support is discussed further in chapter three. Outcomes of caregiving can be described as the prolonged or cumulative consequences of being exposed to stressors. Outcomes might be the decision to institutionalise the patient, satisfaction with life and the caregiving role or psychiatric morbidity. Outcome may also include physical morbidity of the caregiver.

The Caregiver Stress-Coping Model is useful, although it applies to caregiving in many illnesses and so may include some components which are not relevant to stroke spouses.

1.10.6 Caregiving in Alzheimers disease

In a review of studies of caregivers in Alzheimer's disease, cancer, heart disease, mental illness and stroke, Biegel et al (1991) have summarised factors relating to caregiver burden in the model shown in figure 6.

Figure 6. Summary of variables predicting caregiver strain

SOURCE: Biegel, Sales and Schulz (1991)



Again, the model is useful but is aimed at caregivers in various role relationship and family life stages. The model focuses on burden as an outcome and does not include other caregiver consequences such as mood, life satisfaction and physical well-being. In addition, it does not include specific characteristics of the caregiver that may influence their level of strain, such as personality factors.

1.11 Theoretical basis to caregiving – Focused outcome models

Rather than focusing on relatively long term enduring outcomes such as carer physical and psychological well-being, some researchers have produced models based on specific decision points in the caregiving These models help determine the circumstances under which process. carers are no longer willing or able to take care of the patient in the community setting. Although the present study concentrates on strain rather than focused outcomes such as institutionalisation, these models are useful to identify characteristics of the patient and carer that might result in a negative outcome. Morycz (1985) developed an empirically based model based on interviews of 80 families of Alzheimer's patients. The emphasis of the model is on patient, caregiver and environmental variables as predictors of strain and the desire to institutionalise. The range of variables examined focus on patient care issues and the availability of support. Montgomery et al (1985) developed a conceptually based model (see figure 7) on the measurement of burden and its impact on both the length of caregiving and living arrangements of the caregivers. Like Morycz's model, Montgomery's model views burden or strain as the variable that contributes towards the decision to institutionalise the patient. However, it differs in that the range of variables focus on issues such as affection and obligation. Montgomery also distinguishes between objective and subjective measures of burden.

Figure 7. Model predicting length of time in the caregiving role and institutionalisation of the elderly person

SOURCE: Montgomery, Stull and Borgatta (1985)



The models presented here outline the endpoints of caregiving, which include physical and psychological morbidity or changes in the caregiver's life circumstances, such as the decision to institutionalise the patient. These models show the long-term impacts of caregiving, which may ultimately result in some kind of professional intervention. The models were predominantly designed with Alzheimer's caregivers in mind and include aspects of caregiving that may be less applicable to stroke patients. Patient characteristics are often limited to 'illness severity' or disability and do not take into account the possible influence of specific cognitive deficits which are common after stroke. The models are also rather limited in that characteristics of the caregiver are rarely addressed in detail, with only one model including personality factors. The most useful model was the Caregiver Stress-Coping Model, which included a wide range of variables as stressors, conditioning variables or enduring outcomes. This model has been used in early studies of stroke caregivers (Schulz et al, 1988; Tompkins et al, 1988). The present study draws heavily on the Caregiver Stress-Coping Model (House, 1974; George, 1980) yet includes additional aspects which may be relevant to stroke spouses. The adapted model is presented in figure 8.

Figure 8. Model of strain in spouse caregivers of stroke patients



Firstly, the model will address what are known as objective stressors or conditions conducive to stress. The onset of stroke is by nature sudden rather than progressive and as the model is intended to relate specifically to carers of patients from the same patient group, suddenness of disease onset was not included as an objective stressor. One common theme amongst the models of strain is the presence of patient disability or functional state as an important objective stressor. Patient affective state has also been included as a condition conducive to stress in the carer¹. Based on this, the new model will include these patient factors. Other manifestations of stroke may also be important.

The model of caregiver strain provides a theoretical perspective and portrays a large number of variables that may be influential in the experience of strain in spouses of stroke patients. The intention is not to test the adequacy of the model but to use it as a guideline by which to address the relevant issues. The model is not free from conceptual flaw. For example, psychological distress is treated as an outcome or endpoint whereas mood may be viewed as a conditioning variable pertaining to strain. Enduring outcome in the literature is often caregiver strain although the model views caregiver stress or strain as an intervening variable between stressors, mediators and outcomes. The model therefore does not take into account the differences in emphasis in the literature, often dependent on the research orientation of the investigator. Nevertheless, these are primarily differences in emphasis rather than disagreements regarding the nature of the phenomenon under scrutiny.

Previous research has tended to focus on specific issues pertaining to caregiving such as carer mood and health and patient disability without adequately incorporating other aspects of the caregiving situation. However, this study uses the model as a framework from which to begin,

¹ Although patient affective state has been identified as an objective stressor, mood of the patient was measured in the caregiver characteristics study (Chapter Three) rather than the patient characteristics study (Chapter Two). This was because carers' perceptions of patient mood were assessed rather than objective patient mood.

by identifying and addressing the central variables relevant to our understanding of caregiving. It is not practical to address all the relevant factors in a single study, as this would over burden both patients and their spouses. Therefore, the focus of this thesis will be two main streams of investigation relating to the outcome of caregiver strain; the first addressing objective stressors (factors relating to the patient and the caregiving role) and the second primarily addressing conditioning variables and enduring outcomes (factors relating to the caregiver).

1.13 Methodology

The following section is provided to justify the methods of analysis to be used in this thesis. Throughout the studies, relationships with carer strain are examined for each variable independently, using Mann-Whitney U Tests, Kruskal-Wallis Tests, correlations and logistic regression. Correlation is a useful technique for the identification of relationships between variables, although is limited in that it does not imply causality. However, correlation was appropriate to use with the given sample given the small sample size. Also, conducting multiple pairwaise comparisons increases the chance of making a type I error. Bonferroni corrections are used to adjust for this problem, although this has been criticised for being too stringent a test when the number of pairwise comparisons is greater than five (MacArthur and Jackson, 1984). Therefore, while the Bonferroni test is unlikely to produce a type I error, it is not very powerful and is

likely to result in a type II error as the number of comparisons increases. Logistic regression is a powerful technique for determining the probability of group membership from a number of dependent variables. However, the fact that numerous measurements taken on an individual may be correlated (multicollinearity) leads to the possibility of a certain amount of redundancy in the data. Additional variables may not provide any new information about a person. However, it is not always immediately obvious as to which variables may contain the most information and therefore be the most useful. It may be argued that factor analysis is a more appropriate method of exploring the interrelationships between variables to determine whether some of the measures may be reflections of a smaller number of underlying factors. Or an alternative is structural equation modelling which allows for the combination of various techniques and takes into account the element of error in observed measures. However, these methods of analysis are more complex to conduct and interpret than other techniques and involve more decisions about how the data will be treated. They are more controversial methods (Clark-Carter, 1997) which are often used inappropriately or may give a solution which is only applicable to a particular set of data and may not be generalisable. Also they generally require large sample sizes to produce a reliable analysis and sample sizes in elderly patient and carer groups are generally small due to high rates of attrition from mortality, morbidity and movement into residential care. Therefore, whilst the methods of analysis employed here have their limitations, they were considered appropriate to the dataset.

CHAPTER TWO

A study of cognitive impairment and patient characteristics in caregiver strain

2.1 Introduction

2.1.1 Patient characteristics and cognitive impairment

The model of strain in spouses of stroke patients suggests that patient factors after stroke may be important in determining the level of strain experienced by the spouse. There are many patient-related factors that may be important to caregiver strain, the most obvious being the severity of the stroke and functional disability. The resulting deficits of stroke and their effects on the patient in terms of mortality and rehabilitation have been discussed at length in Chapter One. Death within the first four weeks after stroke is approximately 20% and of the survivors, around 50% will have a significant disability (Wolfe et al, 1996). This might include motor or sensory dysfunction, disturbance of speech or cognitive impairment.

Severity of stroke may be assessed in numerous ways. An important factor is the extent to which the stroke has affected the patient's functional status. Functional status can be defined as 'the degree to which an individual is able to perform socially allocated roles free of physically related limitations' (Bowling, 1997). This includes their independence in activities of daily living, resulting from the level of weakness in the limbs, continence of the bowels and bladder and swallowing status. Activities of daily living (ADL) are important indicators of functional status and according to Gresham (1986), 'independence in ADL will continue to be a

suitable hallmark of physical restoration'. ADL refers to the necessary day to day tasks carried out by an individual and includes such tasks as feeding, toileting, bathing and dressing at a more basic level, and making oneself a hot snack and walking on uneven ground at a higher level. They highlight the effects of stroke rather than the disease itself. Assessment of these tasks is more meaningful to people's lives than assessing, for example, grip strength in a weak arm or taking objective biochemical measures.

In 1980, the World Health Association produced the International Classification of Impairments, Disabilities and Handicaps², which defined the three terms and linked them together conceptually. Impairment was defined as, 'any loss or abnormality of psychological, physiological or anatomical structure or function'. This may lead to disability, defined as, 'any restriction, or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being'. This in turn leads to handicap, which is the social consequence of disease. Handicap has been defined as, 'a disadvantage for a given individual, resulting from an impairment or a disability, that limits or prevents the fulfilment of a role that is normal (depending on age, sex and social and cultural factors) for that individual.

² Note that the ICIDH: International Classification of Impairments, Disabilities and Handicaps has been changed in 2001 to ICIDH-2: International Classification of Functioning, Disability and Health. This version moves away from the 'consequence of disease' classification to a 'components of health' classification. ICIDH-2 has been released for the 54th World Health Assembly although it is not for widespread use at this time.

This can lead to dependency on service providers or other people, for example, the carer or spouse. Wilkin (1987) has defined dependency as, 'a state in which an individual is reliant upon other(s) for assistance in meeting recognised needs'. Therefore, an inability to carry out normal tasks of everyday life may result in an increased dependency on the caregiver and may result in a heightened level of stress for a spouse suddenly 'thrown' into the caregiving role.

It has been demonstrated that poor patient functional status and increased dependency is associated with psychological distress and depression in stroke caregivers (Dennis et al, 1998; Wade et al, 1986; Robinson, 1983; Cantor, 1983; Silliman et al, 1986) as well as other caregiving groups (Jones and Peters, 1992; George and Gwyther, 1986; Poulshock and Deimling, 1984). A recent study found that patient disability on the Barthel Index (BI) was significantly correlated with carer overload (Carod-Artal, 1999) and other studies have suggested that physical disability on the BI is associated with caregiver depression (Schulz et al, 1988; Wade et al. 1986). However, not all studies have identified patient disability as the primary factor involved in negative caregiving outcomes. For example, many studies have suggested that disability on the BI is not significantly related to caregiver depression (Kotila et al, 1998; Anderson et al, 1995; Draper et al, 1992; Schulz et al, 1988; Macnamara et al, 1990) although these studies assessed caregiving outcomes later after stroke. Scholte op Reimer et al (1998) investigated burden in carers of 115 longterm stroke survivors three years after the stroke. They found that patient disability only accounted for a small part of caregiver burden and that the

majority of burden could be explained by poor carer mood. A more detailed discussion of caregiver characteristics can be found in chapter three.

A decrease in functional ability may result from paresis in the limbs. A greater degree of paresis in the limbs has been associated with reduced quality of life. For example, Jonkman et al (1998) found a relationship between degree of paresis and quality of life assessed on the Sickness Impact Profile (SIP) in 30 patients between three and 12 months after a first unilateral middle cerebral artery ischaemic stroke. It is possible that a lower quality of life in the patient may indirectly affect the level of strain the spouse may experience. In addition, limb weakness has been identified as a main predictor of severe disability and therefore dependency at discharge (Paciaroni et al, 2000).

The relationship between incontinence, mortality, disability and recovery of the patient has been discussed previously. Incontinence has been associated with disability and handicap (DiCarlo et al, 1999) and therefore increased dependency of the patient. Incontinence has been found to impact on the lives of caregivers in stroke (Brittain et al, 1998) and other elderly groups, such as dementia (Lim et al, 1999) and has been associated with increased levels of carer strain or burden. Flaherty (1992) investigated the impact on 148 caregivers of supporting urinary function in non-institutionalised chronically ill senior persons. They found that 22% of those caring for a continent senior reported caregiving as a burden, whereas 75% of caregivers of incontinent seniors reported caregiving as a burden. The burden of maintaining urinary function was

associated with lack of social support, time spent providing care and the care receiver's immobility. Caregiving for urinary incontinence was associated with depressive symptoms in the caregiver. In a study of 100 caregivers of people with dementia, Hope et al (1998) demonstrated that incontinence was related to an increased risk of institutionalisation of a dependent elderly person. Other research has linked incontinence with increased levels of depression in caregivers of elderly dependants. For example, Heok and Li (1997) studied 50 family caregivers of elderly persons with dementia and found a significant relationship between patient incontinence has also been found in other groups of caregiving spouses (Knight et al, 1991).

Swallowing difficulties on admission are indicative of a more severe stroke. Dysphagia may also cause further complications such as dehydration, weight loss, aspiration pneumonia and airway obstruction. Smithard et al (1996) prospectively studied 121 consecutive patients admitted to a hospital with acute stroke. Patients were assessed for dysphagia within three days of stroke onset. The presence of dysphagia was associated with increased risk of death, disability, length of hospital stay and institutional care. The strong association between initial swallowing difficulties and level of patient disability may indirectly be an important factor in caregiver strain. Increased disability may result in increased dependency on the caregiver for physical support. As dysphagia is associated with a more severe stroke with more complications and increased length of hospital stay, it is possible that this

may lead to an increase in the worry and level of stress experienced by their spouses. Level of consciousness on admission is also a useful indicator of stroke severity. No studies have been identified that address whether level of patient consciousness on admission is related to caregiver strain. However, given the fact that a reduced level of consciousness is associated with more severe strokes and poorer functional outcome (Paciaroni et al, 2000), the increased dependency of a patient who had a reduced consciousness level on admission may indirectly impact on the level of strain in the spouses.

Providing care to persons with neurological disabilities presents special There may be physical demands arising from lifting and challenges. assisting with ambulation. However, more taxing demands may arise from living with and caring for a person who has difficulty with cognition, language, appropriate expression of emotion and difficulty exercising rational judgement in everyday life situations. Cognitive impairment is common after stroke (Starr et al, 2000). Cognitive deficits may include difficulties with language or perception and less obvious but nevertheless important cognitive impairments, such as apraxia, memory problems and reasoning difficulties. Cognitive deficits have often been viewed as subtle problems, which recover spontaneously and contribute little to functional recovery or quality of life. One study proposed that cognitive deficits were almost non-existent by three months after stroke (Hier et al, 1983). However, other research has suggested that impairment of cognitive function may persist beyond six months after stroke (Wade et al, 1986) and can impact significantly on the stroke patient.

Recent research has shown that cognitive impairment may impact on the recovery process (Katz et al, 1999; Kong et al, 1998). For example, repeated practice of dressing, transfers and independent walking may fail or achieve only limited success if a patient has a disorder of short-term memory or object recognition. Rehabilitation may be abandoned on the grounds of patients having what appear to be 'motivational problems'. Galski et al (1993) found that deficits in cognition, specifically abstract thinking, judgement, short-term verbal memory, comprehension and orientation are important in predicting functional status following inpatient rehabilitation. Lincoln et al (1989) also found that recognition memory on admission to a stroke unit was an important factor in predicting the level of physical disabilities and independence in ADL nine months after the stroke. Nevertheless, rehabilitation is often provided on the basis of physical function, rather than cognitive function (Lincoln et al, 2000).

The importance of cognitive function has been emphasised by Hajek et al (1997) who suggested that cognitive impairment should be carefully considered when describing or predicting a patient's level of independence. They suggest that rehabilitation outcome can be better predicted if functional assessments are coupled with in-depth cognitive assessments. Other studies have shown that cognitive performance (e.g. memory, orientation and abstract thought) is associated with success of rehabilitation (Stahelin, 2000; Prescott et al, 1982) and reintegration into the community (Neistadt, 1987).

It has been suggested that impairment of cognitive function is associated with increased severity of stroke. Friedman et al (1991) found that impairment on a clock drawing task was associated with increased length of hospital stay and a greater risk of discharge to long-stay hospitals rather than home (n=188). Studies have shown that cognitive impairment can influence performance in activities of daily living and social activities. For example, Pederson et al (1996) assessed orientation in 524 patients with acute stroke. Ability in basic activities of self-care were measured on the Barthel Index at discharge, and an assessment was made of abilities in higher level activities of daily living and social functions on the Frenchay Activities Index at six month follow-up. They found that the level of orientation influenced basic and higher level activities of daily living and social activities in acute as well as chronic stroke. Similarly, after adjusting for age and severity of stroke, Paolucci et al (1996) showed that impairment of cognitive function was a significant independent predictor of poor functional outcome. Greveson et al (1991) found that cognitive impairment in stroke patients (measured on picture drawings and Mental Test Score) was related to increased institutionalisation. Cognitive deficit is therefore likely to be a major barrier to independent Such deficits may impact on quality of life, not only for the living. patient, but also for their relatives and may ultimately affect the willingness of caregivers to maintain the caregiving role.

Studies have shown that carers may be uncertain as to how to relate to the patient after a stroke, and may be disturbed by the patient's personality change and the patient 'not being himself' (Carnwath and Johnson, 1987). The specific impact of patient cognitive impairment on caregiver strain is unclear. Many studies have measured general mental state or cognitive decline using short screening tests of global impairment. These have frequently shown an increased level of strain or burden in caregivers with cognitively impaired dependents. For example, a study of carer burden after proximal femoral fracture found that carers of patients who were cognitively impaired on the Short Portable Mental Status Questionnaire suffered from higher levels of burden than carers of patients who were not cognitively impaired (Quine et al, 1994). Drinka et al (1987) linked caregiver burden and depression to patient cognitive impairment as measured on the Jacobs Cognitive Capacity Screening Exam.

In a study of family caregivers of the dependent elderly, Topinkova and Neuwirth (1997) measured cognitive impairment on the Mini-Mental State Examination and found that cognitive impairment was significantly related to high levels of caregiver burden. Other studies have linked cognitive impairment with poor caregiver mood (Ballard et al, 1995). Ballard et al (1995) found that cognitive impairment was related to mood in carers who were co-resident with the demented elderly but not those who were extra-resident. An early study by Greene et al (1982) showed no significant relationship between cognitive functioning in the demented elderly and levels of reported stress in relatives. However, the sample size was small (n=38), less than half the carers were spouses and around a

third of carers did not live with the dependent elder. Moreover, they found that behavioural difficulties were most closely related to strain. These are less common in stroke carers than in dementia carers and so less likely than cognitive deficits to be related to strain.

Another reason why cognitive impairment may impact on caregiver strain is the increased amount of care required by those who have cognitive deficits. For example, Clipp and Moore (1995) studied 160 patients with mild to moderate Alzheimer's disease to assess whether cognitive impairment increased the amount of caregiving hours required for both formal and informal caregivers. Caregivers completed time allocation surveys at baseline and at 24 weeks. Cognitive function was measured using the cognitive and non-cognitive subscales of the Alzheimer's Disease Assessment Scale (ADAS). Unpaid caregiver and paid professional caregiver time were assessed using the Caregiver Activities Time Survey (CATS). They found that unpaid caregiver time per day increased significantly with cognitive impairment at baseline. This increase in the amount of time spent caregiving for patients with cognitive impairment may contribute significantly to caregiver strain. However, the literature is not consistent and some researchers have failed to find a relationship between cognitive impairment and caregiver strain or mood. For example, studies involving dementia patients have shown that the severity of cognitive impairment is not associated with depression in the caregiver (e.g. Fitting et al, 1986; Zarit et al, 1981; Zarit and Zarit, 1982). Other studies assessing caregiver burden and cognitive impairment have yielded negative results. For example, Coen et al (1997) studied a

convenience sample of 50 patients with Alzheimer's disease, and their primary caregivers. Patients were assessed for cognitive impairment on The Cambridge Cognitive Examination (CAMCOG), the Mini-Mental State Examination (MMSE) and other scales measuring functional status and behaviour disturbance. Burden was measured using the Zarit Burden Interview. The study showed that neither patient cognitive nor functional status predicted the level of caregiver burden. They found patient behaviour disturbance and informal support to be significant predictors of burden. However, factors relating to strain in carers of patients with Alzheimer's disease may be different to those of stroke carers and also the study was based on a highly selected sample attending a memory clinic and so results must be interpreted with caution. Deimling and Bass (1986) examined the relationship between caregiving stress and elder's symptoms of mental impairment, including cognitive incapacity, problems in the elder's social functioning and the presence of disruptive behaviour. The study included 614 families living with and caring for an impaired Results showed that cognitive incapacity was less elderly person. important in determining caregiver stress than disruptive behaviour and impaired social functioning. Nevertheless, it is possible that cognitive impairment may still have an important indirect effect through its influence on disruptive behaviour and social functioning.

Studies of caregiver strain and cognitive impairment are sparse and results published in the literature so far are inconclusive. In addition, the majority of available studies are based on caregivers of patients with dementia and not stroke. With the exception of communication

difficulties, the majority of previous research on caregiver strain has assessed cognitive deficit on global measures of impairment or cognitive decline rather than detailed assessment of specific areas of deficit. Although global measures can detect general cognitive impairment they are unable to detect impairment in higher level cognitive functioning. Detailed neuropsychological assessment is more labour intensive than the administration of a single mental status test or a neurological examination, yet it provides more precise information regarding the pattern of cognitive deficits exhibited by patients and therefore a method of investigating which elements of cognitive functioning may be important in caregiver strain. There are relatively few studies that address the impact of specific cognitive deficits on caregiver outcomes. The following section will discuss existing literature that addresses specific cognitive impairments with relation to strain in caregiving groups, including carers of stroke patients where possible.

As previously discussed, perceptual deficits can interfere with activities of daily living such as dressing and consequently hinder the rehabilitation process. The functional dependence that can be caused by severe perceptual problems may contribute to strain in caregivers. However, no studies have been identified that specifically target perceptual impairment as a factor relating to caregiver strain.

Memory problems in the patient are likely to represent a source of strain for caregivers (Shyu et al, 1996; Nygaard et al, 1988). Patients may forget things that have been said to them, things they have to do and plans they have made. They may misplace things or lose their way in familiar areas.

Memory problems have been reported as an important factor by caregivers of stroke patients (Williamson and Schulz, 1993). Hangar et al (1998) conducted interviews with stroke patients and their carers at six and 24 months after the stroke. Respondents were asked what sort of things they still wanted to know about the stroke. At 24 months, 32% of respondents asked about concentration and memory difficulties. Some studies in other patient groups have suggested that patient memory problems are not related to strain in caregivers (Loguidice et al, 1999; Hadjistavrapoulos et al, 1994). For example, Hadjistavrapoulos et al (1994) examined the relationship between patient's deficits and caregiver burden. In 136 elderly patients attending a dementia clinic, caregiver perceptions of everyday patient functioning were related to strain, but caregiver perceptions of patient memory problems were unrelated to caregiver burden. This suggests that functional problems may be more important in determining caregiver strain than memory problems. However, these studies may be specific to those with dementia and research is needed that addresses the relationship of memory problems with caregiver strain in stroke patients.

Problems with speech and language may result in delays in the recovery process and have psychological and social effects for both the individual and the spouse and family. The inability to talk to or interact with friends, relatives and health professionals may make it impossible for patients to grasp their own clinical symptoms and ultimately accept them (Tacke, 1999). Aphasia may result in little or no interaction between patients and their carers. It is likely that these difficulties of communication may

cause frustration, misunderstandings and tension in the carer-patient relationship. Kinsella and Duffy (1979) found that spouses of aphasic stroke patients had poorer overall social adjustment and a higher incidence of minor psychiatric disorder than spouses of non-aphasic patients. However, Rau et al (1986) found that adjustment and burden of spouses did not differ with respect to the presence of aphasia in the stroke spouse.

Other studies have also suggested that language difficulties may not be an important factor in determining caregiver strain and stress. Wade et al (1986) found that although aphasia was associated with increased disability and a poor recovery of social function, this did not result in any measurable increase in stress in the caregivers of aphasic patients. Research has suggested that other factors may be more important in determining caregiver distress than communication difficulties. For example, McClenahan and Weinman (1998) administered questionnaires to carers of people with non-acute aphasic and non-aphasic stroke. They included measures assessing distress, perceptions of stroke, generalised self-efficacy, optimism, coping strategies, self-rated physical health and Their relatives were assessed on mood and ability social support. measures. The authors found that stroke disability and dysphasia did not account for caregiver distress. Distress was accounted for by carer factors rather than communication difficulties.

A deficit of executive function may cause difficulties in reasoning, planning ahead and making decisions. It is not unreasonable to hypothesize that this may impact on quality of life for both the patient and the spouse. Elias and Treland (1999) have suggested that impairments of

executive function may be a source of stress for caregivers of patients with Parkinson's disease and have suggested ways in which adjustment to these deficits can be facilitated. Despite the difficulties caused by impairments of executive function, no studies have been identified that specifically address the impact of these deficits of caregivers of stroke patients.

Dyspraxia can have a significant effect on patient functional ability affecting eating behaviour (Foundas et al, 1995) and other activities of daily living. As a cause of functional limitations, dyspraxia may indirectly affect strain in caregivers, through limiting the abilities of the patient. However, no studies have been identified that specifically address the impact of dyspraxia on caregiver strain.

This chapter identifies a gap in the literature and highlights the fact that studies of patient factors relating to caregiver strain are often limited to ADL or disability measures, but do not take into account the influence of specific cognitive deficits following stroke. Where cognitive factors have been taken into account, studies have limited this to global assessment of cognitive decline rather than addressing areas of cognitive functioning in detail. The purpose of this study was to assess in detail cognitive functions including intellectual ability, spatial perception and neglect, language, memory, executive function and praxis, in order to determine the relationship between cognitive deficit of the stroke patient and caregiver strain. The aim was to ascertain whether the presence of certain cognitive deficits are more stressful to caregivers than others.

2.1.2 **Providing information about stroke**

Research has shown that patient insight into cognitive impairment may play a significant role in caregiver strain or burden. Seltzer et al (1997) studied awareness of deficit in patients with Alzheimer's disease. They found that caregiver burden was predominantly associated with impaired patient awareness of memory deficit, independent of disease stage. This suggests that patient insight into cognitive problems, such as memory, may be an important mediator of caregiver burden. Information has been identified as an important need for stroke survivors and their carers (Wellwood et al, 1994; Greveson and James, 1991; van Veenendaal et al, 1996; O'Mahoney et al, 1997) and this need is longstanding (Greveson and James, 1991). However, many patients are poorly informed about the nature of their illness, recovery and treatment (Anderson, 1988; Murray et al, 1982; Anderson, 1987). A study by Lomer and McLellan (1987) found that 93% of patients, and 70% of relatives, stated they had received little or no information about stroke illness since admission to the hospital.

It has even been reported that more than one quarter of primary caregivers of stroke patients on medical wards may see neither the consultant nor the junior doctor during the admission period (Murray et al, 1982). Wellwood et al (1994) interviewed 65 stroke patients and 80 caregivers and found that caregivers were significantly more likely than patients to want to know all the details about the patients' condition and treatment, to discuss the risk of recurrence and to receive written information. In addition, Wellwood and colleagues found that carers of stroke patients were significantly more dissatisfied than the patients themselves with the

amount of information provided by existing stroke services (Wellwood et al, 1995). This supports the notion that there is a definite need for providing information about stroke to both patients and their carers (Mclean et al, 1991).

Educating people about stroke not only provides information but can also generate increased self-determination, reduce anxiety and encourage better coping strategies (Lorner and McLellan, 1987; Dzau and Boehme, 1978; Well, 1974; Spitz, 1984; Evans et al, 1988; Reynolds, 1978). Providing education after stroke may also increase confidence in order that individuals feel more able to approach health professionals with their questions (Evans and Held, 1984). It can also empower family members for coping with illness and can help to moderate caregiver stress (Houts et al, 1996; Russell et al, 1989). A study of enquiries at a stroke advice centre, made by 1,397 people, showed that nearly one quarter needed basic information about the nature of stroke (Hangar and Mulley, 1993). This lack of understanding regarding the basic concepts of stroke is cause for concern. Other common enquiries included help at home (community support), requests for information about stroke clubs, speech difficulties, rehabilitation and personality changes and depression.

Wiles et al (1998) sought to identify the information needs of patients and their informal caregivers at three different times post-stroke: during hospitalisation, up to one month post-discharge, and between two and twelve months post-discharge. They interviewed 31 patients and carers and found that their information needs related to: recovery, treatment and prognosis; practical caregiving tasks; social activities; and resources

available in the community. The study indicated that information needs of patients and carers following stroke are not currently met and a desire for individualised information was identified.

Despite the obvious need for the provision of information and advice, a randomised controlled trial of the impact of specialist nurse support on well-being and social activities in 240 patients and stress in carers, found no significant differences between intervention and control groups following the provision of information advice and support over the period of a year (Forster and Young, 1996). However, this was a single-centre, pragmatic trial, and results may have been confounded by interactions between group members at stroke clubs. The authors also point out that the most frequent visiting was only sustained for six months which may not have been long enough to address some of the deep rooted problems imposed by stroke (Evans et al, 1987).

A randomised trial by Pain and McLellan (1990), in which individualised booklets were given to half of patients with stroke at discharge, found no differences in social functioning three months later. However, other research studies have demonstrated more positive findings. Lomer and McLellan (1987) randomly selected patients with stroke to receive a leaflet one to two weeks after admission. After one week the intervention group were found to have greater knowledge about stroke, although their knowledge about benefits they may be entitled to was no greater. A randomised controlled trial investigating the impact of an information pack on patients with stroke and their carers found no significant effects of information packs on patients' and carers' knowledge about stroke or

satisfaction with information received (Mant et al, 1998). However, despite non-significant results, some of the differences between the intervention and control group suggested a trend in the direction of greater knowledge and satisfaction, which suggests that further research in this area is needed. Carers in the intervention group were found to have significantly better mental health. In addition, Hanger et al (1998) interviewed stroke survivors in New Zealand at six and 24 months post stroke and provided them with opportunities to ask about questions about stroke. They found nearly one fifth of their sample asked similar questions at different interviews, which highlights the need to repeat information several times over, preferably in different ways (eg. discussions, leaflets, video presentations). This may explain why the impact on knowledge levels is not significantly greater following the provision of information leaflets.

A recent randomised controlled trial of a comprehensive Stroke Education Program (SEP) for patients and caregivers did not demonstrate benefits from the provision of information. In this study, 204 patients and 176 informal caregivers were randomised to attend the SEP or to receive conventional stroke unit care. The SEP consisted of twelve one-hour sessions, six inpatient sessions followed by six sessions after discharge.

Primary outcome was patient and carer perceived health status at six months after stroke. Knowledge, satisfaction with services and emotional outcome were secondary measures. Although patient and carer knowledge was greater in the SEP group, there were no significant differences in health status between groups and the carers in the control

group had greater social functioning than the carers in the SEP group (Rodgers et al, 1999). The literature suggests that patient and carer knowledge of cognitive problems after stroke is poor and that there is an unmet need for more information (Wellwood et al, 1994; 1995; Hangar and Mulley, 1993), in particular, specific individualised information (Wiles et al, 1998) provided in more than one way (Hangar et al, 1998). A better understanding of stroke has been associated with clearer expectations of rehabilitation (Kinsella and Duffy, 1980) which may contribute to the ability to comprehend and participate actively in the rehabilitation programme. Additionally, greater knowledge about stroke has been associated with less stress in the patient and lower levels of caregiver strain or burden (Seltzer et al, 1997; Houts et al, 1996; Russell et al, 1989). However, studies have generally assessed the impact of providing generic stroke information and there is little evaluation of information and advice of a more specific, individualised nature relating to cognitive function after stroke. Therefore, it was hypothesised that carers who received specific detailed information about the patient's cognitive functioning would suffer from lower levels of strain.

Research Questions:

- Are cognitive impairments and other patient characteristics related to caregiver strain in stroke spouses?
- Does the provision of detailed cognitive assessment information result in lower levels of caregiver strain in the spouse?

2.2 Methods

2.2.1 Ethical consideration

Ethical approval for the study was granted in July 1997, by the Research Ethics Committees of the Queen's Medical Centre in Nottingham, Derby City General Hospital, Derby Royal Infirmary and Mansfield Community Hospital. Approval was granted for access to patient records and a randomised controlled trial of cognitive assessment after stroke, on the understanding that full informed consent would be gained from the patient prior to recruitment onto the study. If the patient had a severe impairment (e.g. severe language deficit), which prevented them from giving consent, informed consent was then sought from the caregiver or next of kin. The nature and purpose of the study was explained in detail to the patient, and where possible, family members. Patients were assured that they were able to withdraw from the study at any time and those who did not wish to be involved in the study were assured that it would not affect their care in any way.

2.2.2 Patient selection

Patients who suffered strokes according to the WHO (1978) definition, between September 1997 and May 1999, were recruited from the Queen's Medical Centre in Nottingham (QMC), Derby City General Hospital (DCGH), Derby Royal Infirmary (DRI) and Mansfield Community Hospital (MCH) within four weeks of admission to the ward. Patients giving consent were considered for inclusion in the study if they were conscious on admission and could sit and co-operate with assessments for 30 minutes at a time (thus excluding patients who were unlikely to survive) and had no significant hearing and visual problems preventing them from completing the assessments.

2.2.3 Procedure

The study was a part of a large multicentre, single-blind randomised controlled trial (RCT) to evaluate the impact of detailed neuropsychological assessment on patient functional outcome and patient and carer quality of life. Patients were considered for inclusion consecutively on admission to hospital. All eligible patients were assessed on a screening battery to determine the presence of any cognitive problems. This information also represented baseline data to check for comparability between the control and intervention groups. In addition, basic demographic information was collected including age, sex, residence prior to the stroke and pre-stroke Barthel Index. A record was also made of marital status and carer support. Details of the stroke including side affected, extent of weakness in the limbs and the resulting impairments including continence of bowels and bladder, swallowing status and level of consciousness on admission were also recorded. Personal independence in self-care activities following the stroke was assessed at the time of recruitment using the BI. Patients were then randomly allocated to one of two groups using numbered, sealed, opaque envelopes prepared from random number tables and stratified according to centre (Nottingham, Derby or Mansfield). Group A received routine care, which was representative of usual clinical practice. Results of the

screening assessment were not made available to rehabilitation staff or the patients and their relatives. Group B patients received a battery of detailed cognitive assessments, in addition to the patients' routine care. This was intended to reflect a service that could reasonably be provided in many stroke services despite the national shortage of clinical psychologists. In addition to this, supplementary assessments were used to clarify the nature of any cognitive deficits identified, targeted towards suspected areas of deficit identified on the basis of their performance on the battery of tests. The time allowed for this additional assessment was four hours in the first month and up to one hour in any subsequent month. This time frame was designed to ensure that the assessment service was representative of what might be provided by an assistant psychologist in clinical practice.

The information obtained and recommendations for approaches to the patient's care were summarised in a detailed structured written report and made available to all hospital staff involved in the patient's care and the General Practitioner. Information was also summarised in written form for patients, and if they agreed, their spouses and relatives. A verbal explanation of the neuropsychological assessment results was also provided to each patient, their spouse and relatives in order to increase their knowledge about the patient's cognitive status. The feedback contained information regarding the patients' specific cognitive impairments together with advice about how they might impact on everyday function. This advice included changes in behaviours on the part of caregivers to enable patients to compensate for deficits and advice

on designing or restructuring the environment for patients. Implementing simple compensatory techniques based on neuropsychological test results can help patients attain therapeutic goals (Cook and Thigpen, 1993).

Patient and carer outcome was assessed three and six months after recruitment by an independent assessor who was unaware of the random allocation of the patients. The outcome measures were selected to examine the effect of the intervention on patient disability and quality of life of both the caregiver and the patient. Outcome measures for the patient included the Barthel Index, Extended Activities of Daily Living Scale, London Handicap Scale, General Health Questionnaire-28, Cognitive Failures Questionnaire and Satisfaction with Services Scale. Carer outcome was assessed on the Caregiver Strain Index.

The results of the randomised controlled trial and the impact of providing cognitive assessment information to staff are currently in press (McKinney et al, In Press). All patients recruited into the RCT who were married and living at home with a spouse were considered for inclusion in the present study. This provided a sample for two streams of investigation. Firstly, it allowed an investigation into the relationship between patient characteristics and cognitive function after stroke and caregiving spouse outcomes three and six months later. Secondly, it allowed an investigation of the provision of individualised cognitive deficit information and caregiver strain.
2.2.4 Cognitive assessment

The screening battery administered to all patients included the Mini-Mental State Examination (MMSE) (Folstein et al, 1975), Raven's Coloured Progressive Matrices (RCPM) (Raven, 1977) and the Sheffield Screening Test for Acquired Language Disorders (SST) (Syder et al, 1993). The standard battery of detailed assessment included the Shortened National Adult Reading Test (NART) (Beardsall and Brayne, 1990) as an assessment of premorbid intellectual level. The Behavioural Inattention Test (BIT) Star Cancellation (Wilson et al, 1987) was used to assess inattention and the Rey-Osterreith Complex Figure (see Spreen and Strauss, 1998) was used to assess spatial perception.

Immediate and delayed verbal recall were assessed on the Adult Memory and Information Processing Battery (AMIPB) Story Recall (Coughlan and Hollows, 1985) and recognition memory was assessed on the Salford Objective Recognition Test (SORT) (Burgess et al, 1996). Language and executive function were assessed on the Controlled Oral Word Association Test (Benton and des Hamsher, 1976) and executive function on the Cognitive Estimation Test (Shallice and Evans, 1978). The Apraxia Test (Kertesz and Ferro, 1984) was used to assess for apraxia. The reasons for the selection of these assessments are discussed below. Reliability of each cognitive test within the *present* sample is not provided as only total scores were available for analysis rather than individual item scores. Nevertheless, published support for the reliability of each measure is demonstrated where possible.

2.2.4.1 Screening Assessments

Mini-Mental State Examination (Folstein et al, 1975)

The MMSE (see Appendix 1) assesses 'cognitive aspects of mental function' (Folstein et al, 1975) and attempts to reflect an abbreviated form of a typical neuropsychological mental status examination (Katzman et al, 1990). It was originally developed for use with psychiatric patients (Folstein et al, 1975) but has been used with neurological patients (Dick et al, 1984; De Paulo et al, 1980) and is frequently used by doctors working with the elderly as a brief screening measure of cognitive function and dementia. However, this measure can be criticised as its brevity does not allow for the provision of detailed information about neuropsychological functions.

The test consists of two sections, the first covering orientation, memory and attention and requiring only verbal responses, the second addressing the ability to follow verbal and written commands, name, write a sentence spontaneously and copy a complex polygon figure similar to a Bender-Gestalt figure (Folstein et al, 1975). The test is untimed and takes about 5-10 minutes to administer. A composite score may be obtained and those who score less than the cut-off point of 21 are considered to be impaired (Dick et al, 1984).

Validity and reliability have been demonstrated (Folstein et al, 1975; Engedal et al, 1988). The MMSE shows good discrimination between cognitively impaired groups and controls (Ebrahim, 1990). Inter-rater reliability is good (above 0.65) and test-retest reliability falls between 0.80 and 0.95 (Folstein et al, 1975). Specifically, the scale has been shown to

be both reliable and valid in assessing a limited range of cognitive functions in patients with stroke (Robinson et al, 1986). Performance on the MMSE is highly correlated with the Dementia Rating Scale (Fillenbaum et al, 1987; Thal et al, 1986) and WAIS IQ (Dick et al, 1984). However, the test includes various aspects of memory, attention and language making interpretation of test scores difficult. It is also highly dependent on verbal function, which means the scores are affected by the presence of dysphasia.

This assessment has the advantage of speed of administration and is useful in the assessment of patients who cannot withstand a full test battery. Additionally, the MMSE appears to be more widely used in clinical practice with stroke patients than comparable tests such as the Kendrick Cognitive Tests for the Elderly or the Clifton Assessment Procedures for the Elderly (CAPE) (Pattie and Gilleard, 1979). The MMSE has been found to be useful in gaining information from neurological patients in areas of memory and other cognitive functions (Dick et al, 1984). The scale is a global screening measure and the literature suggests that individual items or subsections may not be viewed as specific measures of cognition (Giordani et al, 1990). Although the MMSE does not measure specific areas of cognitive function in great detail the assessment is useful as a tool for the detection of general cognitive impairment.

Raven's Coloured Progressive Matrices (RCPM) (Raven, 1977)

The RCPM (see Appendix 2) was used as a measure of visuospatial problems and to assess reasoning in the visual modality. The test is based on Raven's Standard Progressive Matrices (SPM) (Raven, 1977) which consists of 60 items in five tests. The RCPM provides a shorter and simpler version of the test and was specifically developed for use with either children or the elderly and for clinical work. The RCPM consists of 36 items grouped into three sets (A, Ab and B) of 12 items each. Each item contains a pattern problem with one part removed and six picture inserts, one of which contains the correct pattern. The items become increasingly more difficult throughout each set. The test is untimed and takes approximately 25 minutes to complete, depending on the ability of the patient. Raw scores are converted to percentiles based on age. The highest score is 36 (12 for each section). A separate 'neglect' score can be obtained by simply counting the number of responses on the left (1's and 4's), in the middle (2's and 5's) and on the right (3's and 6's).

Test scores correlate with the WAIS Block Design which also assesses visuospatial skills (Mills et al, 1993). Test-retest reliability data are acceptable (above 0.8) and internal consistency is acceptable (above 0.7) (Burke, 1985). The Raven's tests correlate with conventional measures of intelligence such as the Weschler (Burke, 1985). There is some evidence for the detection of hemisphere neglect (Villardita, 1985; Zaidel et al, 1981). The test was selected as it does not require verbalisation or skilled manipulation ability. Verbal instruction is also kept to a minimum (Zaidel et al, 1981). It can be used with the elderly, people who suffer from

aphasia, do not speak English or who have physical disabilities and so is appropriate for the patient group in question.

Sheffield Screening Test For Acquired Language Disorders (SST)

(Syder et al, 1993)

The SST (see Appendix 3) was developed as a screening test of expressive and receptive language skills. The SST is made up of two sections; eleven items assessing expressive skills and nine assessing receptive skills. Five main areas of comprehension are included to assess receptive language skills. These are: verbal comprehension of single words, comprehension of sequential commands, comprehension of a complex command, recognition of differences in meaning between words and comprehension of a narrative. There are also five areas of assessment of expressive language skills. These are: word finding, abstract word finding, sequencing, definitions and verbal reasoning. The test is untimed and takes between five and 20 minutes to administer, depending on the ability of the patient.

The SST has established reliability and validity (Syder et al, 1993) and predictive value for the screening and diagnosis of language difficulties (Al-Khawaja et al, 1996). There are many available assessments of speech and language difficulties. However, some language assessments are merely subsections of tests assessing general cognitive disturbance such as the Mini-Mental State Examination or the Middlesex Elderly Assessment of Mental State. In a comparison of the SST and the Frenchay Aphasia Screening Test (FAST) (Enderby et al, 1987), Al-

Khawaja et al (1996) found that the two tests were equally short, simple and similar in their predictive value for the screening and diagnosis of language difficulties. However, the SST does not require any additional stimulus material and the fact that it does not make use of stimulus cards means the test is not affected by visual neglect. Also, the SST is able to detect milder communication problems than the FAST. The SST was therefore thought to be the most suitable measure as a screen for language difficulties.

2.2.4.2 Detailed Assessments

<u>Pre-morbid intelligence</u>

Shortened National Adult Reading Test (NART) (Beardsall and Brayne, 1990)

The NART (see Appendix 4) measures premorbid intellectual level by testing current reading ability and is relatively resistant to neuropsychological or psychiatric disorder. It is the most commonly used measure of premorbid intelligence. The NART is a single-word reading test. It is not appropriate for use with aphasic or dyslexic patients, or with patients who have significant articulatory or visual acuity problems.

The shortened NART consists of 50 items; 25 in part one and 25 in part two. The subject is required to read aloud each word on the test and their response is compared to the correct pronunciation. Part two is only administered if more than 21 words are pronounced correctly on part one. A 'correct' score and an 'error score' can be gained for each part, together with a 'total error score' and an estimated IQ. The test is untimed and takes 5-10 minutes to administer. All the words used in the NART are short which means that subjects do not have to analyse a complex visual stimulus. The words are also irregular; that is, they do not follow normal grapheme-phoneme correspondence rules (eg. ache, debt, gauche). This means that 'intelligent guesswork' will not result in the correct pronunciation. Nelson and O'Connell (1978) have argued that successful test performance requires previous familiarity with the words but makes minimal demands on current cognitive capacity. Any test estimating premorbid IQ must correlate highly with IQ in the normal population, must be reliable and must be resistant to neuropsychological and psychiatric disorder. The NART has high split-half reliability (Crawford et al, 1988b; Nelson, 1982), inter-rater reliability (Crawford et al, 1989b; O'Carroll, 1987) and test-retest reliability (Crawford et al, 1989b). A factor-analytic study of the Weschler Adult Intelligence Scale (WAIS) and the NART demonstrated high construct validity (Crawford et al, 1989d). The NART has been shown to be a powerful predictor of the WAIS Full Scale IQ and Verbal IQ although it did not perform well at predicting WAIS Performance IQ. On the basis of this, the NART has been widely used in clinical practice as an estimate of premorbid IQ. More recent studies (Egan et al, 1990; Crawford et al, 1990b) have confirmed the appropriateness of the NART as a measure of premorbid ability. For example, NART performance of clinical subjects has been compared with a demographically derived estimate of their expected performance (Egan et al, 1990). This method involves building regression equations to estimate premorbid IQ from demographic variables known to

be related to IQ test performance, such as education, social class, age and sex (Crawford et al, 1990b). Overall the NART has been found to be resistant to depression (Crawford et al, 1987) and a cross-validation study showed that the accuracy of the Shortened NART was virtually equivalent to the full NART (Crawford et al, 1991).

The NART was appropriate as word-reading tends to produce a fairly accurate estimate of pre-injury IQ (Moss and Dowd, 1991) and also the ability to pronounce irregular words is generally retained in mild and moderately demented individuals (Crawford et al, 1988a; Fromm et al, 1991). The test is not insensitive to cerebral damage in that deterioration does occur in patients with moderate to severe levels of dementia (Fromm et al, 1991; Stebbins et al, 1990), however it is suggested that the test is less sensitive to cerebral damage than many other cognitive measures (Berry et al, 1994; Maddrey et al, 1996). The NART is a more powerful predictor of IQ test performance than estimations with demographic information (e.g. Klesges et al, 1985). Studies that have directly compared the NART with the Vocabulary subsection of the WAIS have found that the NART is consistently the more sensitive of the two (e.g. Crawford et al, 1988; Crawford et al, 1987; Hart et al, 1986). The scale is also fairly straightforward to administer.

Perception

Behavioural Inattention Test (BIT) Star Cancellation (Wilson et al, 1987)

The BIT consists of nine behavioural tests of neglect and six conventional tests of neglect, one of which is the Star Cancellation Test (see Appendix 5). It was designed with the goal of increasing cancellation tests sensitivity to inattention by increasing its difficulty. Interspersed within a jumble of words, stars and letters are 56 small stars, which constitute the target stimuli. The subject is required to scan the page and cross out all the small stars. The stars are arranged into columns to facilitate scoring. The examiner demonstrates the nature of the task by crossing out the two small stars in the centre of the page, leaving a total score of 54. Although the Star Cancellation Test requires a motor response, this response is minimal and so the test represents a measure of visual inattention rather than visuomotor functions.

The Star Cancellation Test correlates well with other tests of inattention $(r=0.65 \text{ with drawing a clock face, a person, a butterfly, to }r=0.80 \text{ with copying a star, a cube, a daisy and three geometric shapes). It also identified all of a group of 30 patients (26 left, 4 right) with inattention (Halligan et al, 1989) and has demonstrated moderate sensitivity (Agrell et al, 1997). The test has also been documented to be the most sensitive of the 15 BIT subtests at detecting visuospatial neglect (Halligan et al, 1989). Ishiai et al's (1993) study showed that cancellation tasks or line bisection tasks were a better indicator of neglect than drawing tasks. The inclusion of a distractor in the Star Cancellation task results in increased$

sensitivity of this particular subtest. The Star Cancellation has been used in other recent studies of stroke patients (e.g. Rorsman et al, 1999; Small et al, 1994) and can be administered without the use of language.

Rey-Osterreith Complex Figure Test (see Spreen and Strauss, 1998)

The Rey-Osterreith Complex Figure Test (see Appendix 6) or the Rey Figure Copy was designed for the assessment of visuospatial ability and can also be used to assess visual neglect. It is also known as the Complex Figure Test. Administration and scoring of the test has been described by Spreen and Strauss (1998). The subject is given a complex drawing to copy as accurately as possible. Scoring criteria are applied for both the correctness of the details and their placement, whilst allowing for slight inaccuracies due to motor difficulties and freehand drawing. The figure is broken down into 18 scorable elements, with points awarded for accuracy, distortion and location. Two points are awarded if the unit is correct but placed poorly. One point is given if the unit is distorted but placed correctly, half a point is given if the unit is distorted and placed poorly and no points are given if the unit is absent or not recognisable. The highest possible score is 36 with a cut-off of<30 for impairment in the elderly.

The test can be administered as a timed assessment to be completed within a cut-off point of five minutes. However, as the test was administered during the acute stage of stroke, often on the hospital ward when many patients had severe motor difficulties, a time limit was not utilised for the purposes of this study. Therefore, the test takes between 10 and 30

minutes to administer, depending on the ability of the subject. Scores on the Rev show a modest correlation (0.23-0.47) with measures of general intellectual ability (Chiulli et al, 1989). Patients with posterior lesions are more likely to have difficulty with spatial organisation of the figure whereas patients with frontal lobe lesions are more likely to have difficulty in planning their approach to the task (Lezak, 1983; Pillon, 1981). There is little decrement in copy scores with advancing age and normative data have been provided by Chuilli et al (1989). Despite the clear scoring criteria there may be individual differences in deciding what constitutes a distortion or misplacement (Duley et al, 1993). However, both inter- and intra-rater reliability have been demonstrated (Fastenau et al, 1996; Tupler et al, 1995; Carr and Lincoln, 1988). Internal consistency has been demonstrated above 0.60 for the copy task (Fastenau et al, 1996). Lincoln et al (1998a) examined the sensitivity and specificity of the Rev as a screening measure for perceptual deficit. The authors found that the test was sensitive (i.e. will detect all those that have perceptual problems) although specificity was low (i.e. some patients may be identified as having a perceptual problem when they do not). Although not ideal, sensitivity is deemed to be of more clinical importance than specificity in order not to 'miss' patients who have perceptual problems that may then hinder their rehabilitation.

The Rey Figure Copy is used extensively in the assessment of perceptual deficit after stroke, predominantly by psychologists and occupational therapists. It is simple to administer and does not require the use of language. The test is not affected by depression or anxiety (Chuilli et al,

1995; Vingerhoets et al, 1995). Some tests of visuospatial ability require basic abilities of colour recognition and are thus affected by colour blindness, which is not problematic for the Rey. The Rey can also be used in isolation as a measure of spatial perceptual ability and is not as time consuming to administer as perceptual assessments such as the Rivermead Perceptual Assessment Battery (Winting et al, 1985).

Memory

Adult Memory and Information Processing Battery (AMIPB) Story Recall (Coughlan and Hollows, 1985)

The AMIPB is an assessment of memory and information processing ability and was originally developed for use by clinical psychologists. The battery consists of six subtests including Story Recall, Figure Copying and Recall, List Learning, Design Learning, Information Processing A and Information Processing B. It is not necessary to give all subtests as each test has its own norms and cut-off points for different age ranges. The Story Recall subsection of the AMIPB battery assesses immediate registration of verbal information and recall following a 30minute delay.

The Story Recall Test (see Appendix 7) consists of a short story, which is read aloud to the patients, who are then required to immediately recall it in as much detail as they can. They are allowed up to two minutes for recall. The story is divided into separate scoring units for verbatim recall and for content ideas, which are credited as correctly recalled if the exact wording is replaced with synonyms or suitable phrases. For each scoring unit it is possible to score zero, one or two depending on the accuracy of the recall. It is likely that scores for this test may vary a little depending on the individual doing the scoring but this is accounted for if the examiner accepts that there is a margin of error for any given score. Scores can range from zero to 56. Raw scores are compared against age adjusted cutoff points provided in the manual. After a period of 30 minutes, the patient is then required to recall the same story in as much detail as they can, and the same scoring system is applied.

The test has established reliability and validity (Coughlan and Hollows, 1985). There is adequate standardisation data (n=180) on age, IQ, social class and educational achievement for use within a clinical population. The test correlates with other memory tests, has good test-retest and interrater correlations and has detected a higher incidence of poor performance in a group of 54 neurological subjects, than non-neurological subjects (Coughlan and Hollows, 1985).

Unlike the Weschler Memory Scale tests, the AMIPB was developed on an English population and so was thought to be more appropriate for use in the present study. It has also been suggested that a story recall test is the strongest predictor of reported memory performance in everyday life in elderly adults (Tinson and Lincoln, 1987; Sunderland et al, 1986). Story recall has been described as a 'more natural medium than testing smaller speech units' (Lezak, 1995).

Salford Objective Recognition Test (SORT) (Burgess et al, 1996)

Recognition memory tests have the advantage that they require little speech and so can be used with some aphasic patients. They are also relatively simple to administer. Recognition memory has the advantage of being less vulnerable to the effects of anxiety and depression than tests of verbal recall (Coughlan and Hollows, 1984). The SORT (see Appendix 8) was developed in response to problems with the Recognition Memory Test (RMT) (Warrington et al, 1984).

In the SORT faces there are 12 photographs, each on a separate page, in each presentation set (male or female); and each correct choice in the recognition set is presented with three distractors, chosen to appear reasonably similar to the photograph seen originally. The faces include minimal verbalisable features, so shoulders and clothing have been omitted. Recognition stimuli for faces have been controlled for features such as orientation, hairstyle and glasses. In the SORT Words, there are 12 words, each on a separate page, in each presentation set; and each correct choice in the recognition set is presented with three distractors. The distractors include one phonemically similar to the target word, one semantically similar to the target word and one phonemically similar to the semantic distractor (to prevent the target being deduced). The position of the correct choice has been allocated by a pseudo randomised latin square technique. The words have been derived from ones published by Paivio et al (1968) and have been selected from high frequency, concrete, high imagery words. After being shown the presentation set (each page at approx. three second intervals), immediate recognition is tested by the

examiner asking 'Which face/word have you seen before?' Each test has a maximum score of twelve. There is a cut-off point below a score of six for impairment on both faces and words. The test is not timed and takes about 15 minutes to administer depending on the ability of the patient.

The validity of the SORT has been demonstrated. The SORT has been shown to detect memory impairment in stroke patients (Yeo et al, 1996) and can discriminate between dementing and non-dementing elderly people (Burgess et al, 1994). It correlates with the Revised Weschler Memory Scale Logical Memory and Visual Reproduction subtests. Good test-retest reliability has been demonstrated (Burgess et al, 1994). Splithalf reliability ranged from $r_s=0.73$ to $r_{s=}0.76$. Selecting the correct item from a choice of four (rather than two in the RMT) decreases the chances of selecting the correct stimulus by chance alone.

The SORT is not as lengthy to complete as the RMT which may be less tiring for patients who are elderly and those who are depressed and perhaps poorly motivated. It is valid and reliable and was initially developed for use with stroke patients and so is appropriate for this elderly group and patients with language difficulties.

Executive function

Controlled Oral Word Association Test (Benton and Hamsher, 1976) This is a test of verbal association fluency (also known as the Word Fluency Test). It was developed to evaluate the spontaneous production of words, under restricted search conditions, within a limited amount of time. The failure to *initiate* appropriate behaviour is a major inadequacy of frontal lobe patients. This test is one of the most widely used tests of frontal lobe dysfunction. It is quick and easy to administer and can discriminate between frontal and non-frontal patients (Benton and Hamsher, 1976).

Subjects are required to say how many words they can think of beginning with a letter of the alphabet provided by the examiner. The score is a total of all acceptable words spoken (numbers, plurals and changing suffix are not allowed). The patient undergoes three one-minute trials in the order of letters in the selected triad. Triads are either FAS, PRW or CFL, the latter being selected for the present study as this version is used by the authors. Due to variations in linguistic skills within the population as a whole, the raw score is then corrected for age, sex and years of education to give percentiles. This provides an individualised standard against which a patient's current fluency ability can be compared (Lezak, 1983). A low score is indicative of impairment. Impairment is usually taken to be a score below the 10th percentile.

Studies have shown that oral verbal fluency as assessed by this test is sensitive to frontal damage (in particular, left frontal) (Bornstein, 1986; Miceli et al, 1981; Perret, 1974). The generation of lists of words on the basis of their initial letter is an unusual activity and calls upon the subject to devise a strategy, which probably explains the sensitivity of the test at detecting frontal lobe impairment. For example, frontal injuries are not always apparent when subjects are asked to provide lists of semantically related items from well-established categories such as animals or plant names (Newcombe, 1969). Inter-rater reliability for the test is said to be near perfect (Des Rosiers and Kavanaugh, 1987) and test-retest reliability after one year has been reported at 0.70 for older adults and 0.88 for younger adults (Des Rosiers and Kavanaugh, 1987). Concurrent validity has also been established (Coelho, 1984). Bruyer and Tuyumbu (1980) reported high sensitivity of word fluency to frontal lobe damage regardless of side of lesion whereas others have shown that patients with left or bilateral frontal lesions had the most severe impairment on the test (Ruff et al, 1996). The measure is relatively simple to administer and has evidence of reliability and validity. The word fluency test is an assessment of language, it is also sensitive to frontal lobe impairment and has been selected in this case to screen for both language impairment and executive problems.

Cognitive Estimation Test (Shallice and Evans, 1978)

A classic deficit arising from frontal lobe damage is the inability to produce adequate estimates. Answering questions such as 'what is the length of the average man's spine' and 'what is the best paid occupation' satisfactorily demonstrates the ability to utilise knowledge to select and regulate an appropriate cognitive plan. For example, estimating the length of a spine may involve guessing the average height and subtracting the length of a head and legs, or perhaps estimating the length of a jacket. Many patients with frontal lobe deficit may provide an absurd answer without realising its inappropriateness. The Cognitive Estimation Test (see Appendix 9) was designed to quantify the tendency of some patients to produce bizarre answers in response to questions requiring the subject to estimate answers to questions, where knowledge of an exact answer is not expected. This test was derived from 26 questions that did not demand specialist knowledge, administered to 96 right-handed patients with unilateral focal cortical lesion.

The Cognitive Estimation Test is made up of 10 questions, each scoring between zero and three points. A higher score is indicative of frontal lobe impairment. The maximum score is 30. The test is not timed and takes approximately 10 minutes to administer. O'Carroll et al (1994) showed that scores on the Cognitive Estimation Test were moderately related to general intellectual ability. Inter-rater reliability was adequate, but internal reliability was poor (O'Carroll et al, 1994). Recent studies have also called into question the sensitivity of the test (Taylor and O'Carroll, 1995). Performance in normal subjects on the Cognitive Estimation Test significantly correlated with other tests of executive functioning (e.g. COWAT r=-0.22, Stroop r=0.22, WCST r=0.19) although the magnitude of the associations was low (Ross et al, 1996).

The test is fairly brief and straightforward to administer. The study was not reliant on information from this test alone; information regarding executive function was also collected using the word fluency test and so the Cognitive Estimation Test was selected to supplement this information. Although a test such as the Modified Card Sorting Test (MCST) (Nelson, 1976) may have provided more valid information, this was not practical for use with patients in an acute setting as it requires the patient to be sitting and utilises instruments that need to be arranged across a surface. Also, the MCST is long and tedious for the patient to

complete, which also provides support for using the Cognitive Estimation Test as it is much shorter and only requires a verbal response.

<u>Apraxia</u>

The Apraxia Test (Kertesz and Ferro, 1984)

The Apraxia Test (see Appendix 10) consists of twenty items in four subsections assessing facial apraxia, intransitive (upper limb) apraxia, transitive (instrumental) apraxia, and complex apraxia. There are five components to each subsection. The Facial Apraxia subsection includes items such as 'put out your tongue' and 'close your eyes'. The Intransitive Apraxia subsection includes items such as 'make a fist' and 'scratch your head'. The subsection assessing Transitive Apraxia includes such items as ' pretend to use a comb' and 'pretend to use a key'. Finally, the Complex Apraxia subsection includes items such as 'pretend to knock on the door' and 'pretend to play the piano'. The patient is asked to carry out each movement by verbal command first. If there is no response the patient is shown the movement by the examiner and is encouraged by words and gestures to imitate. The same scoring system is applied to performance using either method. Each item is scored between zero and three. A score of zero refers to no performance, unrelated performance or unrecognisable performance. A score of one refers to poor or approximate performance. Two is gained from an impaired, but recognisable, performance. A maximum score of three is gained for a good performance. A maximum score of 15 can be gained for each section with a total overall score of 60.

This is a clinical and therefore subjective rating scale although high reliability (r=0.99) has been found between examiners (Kertesz, 1979). As apraxia is rarely formally assessed in clinical practice and standardised measures of apraxia are infrequently used, there was not a wide selection of tests to choose from at the time the study was designed. This test was selected as it is standardised, has good inter-rater reliability, is quick and easy to administer and does not require the use of any stimulus materials other than the administration sheet.

2.2.5 Outcome measures

2.2.5.1 The Barthel Index (Collin et al, 1988)

Feinstein et al (1986) identified 43 published ADL indices, which highlights the wide variety of measures available. Three popular measures are the Rivermead Activities of Daily Living Scale (Whiting et al, 1980), the Nottingham 10-point ADL Index (Ebrahim et al, 1985) and the Barthel Index (Collin et al, 1988). Activities of daily living scales (ADL) are the most common method of assessing disability (Barer and Nouri, 1989). The Barthel Index was developed by Mahoney and Barthel (1965) as an assessment of personal ADL, or basic self-care skills and is one of the most commonly used scales in stroke rehabilitation research. The Barthel Index covers ten areas of self-care, including continence of bowels and bladder, grooming, toileting, feeding, transfers, mobility, dressing, stairs and bathing. The scale is designed to assess what people actually do and not what they can do. For example, if someone lived in a bungalow and therefore never went up stairs they would be classed as

dependent for the ADL of 'stairs'. The most recent version of the Barthel Index, developed by Collin et al (1988), was selected for use in this study (see Appendix 11).

Scores for each of the ten items range from zero to one, two or three (dependent to independent), making a total possible score of 20. Studies have demonstrated the reliability (Collin et al, 1988; Roy et al, 1988) and predictive validity (DeJong and Branch, 1982) of the Barthel Index. It has been shown to be sensitive to change in intervention studies in a hospital setting (Indredavik et al, 1991) and in the community (Young and Forster, 1992). The main disadvantage of this measure is that it has ceiling effects when used in the community, but not in hospital. There is strong justification in using the Barthel Index with acute stroke patients. Firstly, the scale can be administered within a few minutes, is easy to interpret and doesn't require observation of each activity unlike the Rivermead Activities of Daily Living Scale (Whiting et al, 1980). Secondly, it was known that many of the staff on the hospital wards included in this study were familiar with the scale which may make them more likely to provide or allow access to the necessary information to complete the scale at baseline. Thirdly, as a measure of functional ability was needed in the acute period soon after stroke (baseline and screen) the Barthel was deemed to be more appropriate than measures of extended activities of daily living, which may be more useful during rehabilitation. Fourthly, it is the most widely used ADL index in stroke rehabilitation research (Wade and Collin, 1988). Additionally, use of the scale does not require specific training.

2.2.5.2 Caregiver Strain Index (CSI) (Robinson, 1983)

The CSI (see Appendix 12) was developed as a screening tool and for research purposes for the identification of strain in informal caregivers. The CSI was formulated from the identification of thirteen primary stressors including: inconvenience, confinement, family adjustments, changes in personal plans, competing demands on time, emotional adjustments, upsetting behaviour, the person seeming to be different, work adjustments, the feeling of being completely overwhelmed, disturbed sleep, physical strain and financial strain. The primary stressors are represented by a series of 13 statements covering physical and psychological situations thought to act as stressors. The carer is simply required to read the statements and answer 'yes' or 'no' to each of them. 'Yes' is scored as one and 'no' is scored as zero with scores therefore ranging from zero to13 where high scores indicate a greater level of strain. Robinson (1983) found no significant differences in CSI scores between men and women, relationship of the caregiver to the patient or health of the caregiver. However, the author found higher scores among younger caregivers than older caregivers.

The validity and reliability of the scale have been established for caregivers of hip surgery and heart patients (Robinson, 1983) where Cronbach's Alpha for internal consistency was 0.86 and construct validity was demonstrated as the CSI correlated with measures of patient characteristics, caregiver'' subjective perceptions of the caregiving relationship and the physical and emotional health of the caregiver. The CSI is brief and easily administered which makes it appropriate for postal

use with elderly people. It is also comprehensive and covers a wide range of factors which contribute towards strain. The scale is widely used as a measure of strain, which will allow for comparability between the present study and other current health services research. It has been widely used in studies of caregivers for patients with traumatic brain injury (Watanabe et al, 2000), carers of physically disabled older adults (Burch et al, 1999), elderly stroke carers (Lincoln et al, 1998; Walker et al, 1999; Mant et al, 1998; Wilkinson et al, 1997; Rudd et al, 1997; Greveson et al, 1991) and other elderly groups (Payne et al, 1999).

2.3 Analysis and Results

In this section results of the data screening are reported. Descriptive statistics are reported for all variables in the study. Comparisons are made between caregiver strain and each of the patient factors.

2.3.1 Data Screening

Data Screening contributes significantly to the legitimacy of any inferences that are made from the data and ensures that the data meet the criteria for the most appropriate statistical test. The raw data were checked for any missing values and outliers, and an analysis was made of the distribution of scores and equality of the variances. According to Cook's Distance, no scores were considered to be significantly influential outliers and so no data was removed from the analysis. Missing data is discussed throughout the section. The data were not normally distributed and so non-parametric analysis was carried out. Skew ranged from -4.15 to 0.49 and kurtosis ranged from -1.01 to 10.81.

2.3.2 Description of the sample

Of 228 patients recruited into the randomised controlled trial, 129 (57%) were married, 12 (5%) were single, 64 (28%) were widowed, 16 (7%) were divorced or separated and seven (3%) were of unknown marital status. Of the 129 spouses, 71 (55%) completed the CSI at three months, of which 26 (36%) were men and 46 (64%) were women. Fifty-eight (45%) spouses did not complete the three-month CSI. Of these, two were too ill to assess, nine had a spouse who died before the follow-up, twelve either refused to be involved or withdrew from the study and thirty-five carers agreed to be involved in the study but then did not complete the assessment. Seventy-four (57%) of the spouses completed the six-month CSI, of which 29 (39%) were men and 46 (61%) were women. Fifty-five (43%) spouses did not complete the six-month CSI. Of these, one was too ill to assess, eleven had a spouse who died before the six-month outcome, eleven either refused to be involved or had withdrawn from the study and thirty-one carers agreed to be involved but then did not complete the There were a total of 57 (44%) married patients whose assessment. spouses had completed both the three and six-month CSI, of which 22 (38%) were men and 36 (62%) were women.

2.3.2.1 Caregiver Strain Index

Cronbach's Alpha for the scale was 0.80 at three months and 0.81 at six months. Table 1 shows the median CSI scores and interquartile ranges at three and six months. Using the Wilcoxon Signed Ranks Test, no significant differences were found between strain in the spouse at three and six months (z=-1.08, p=0.28).

Table 1. Descriptive statistics for overall CSI scores at 3 and 6 months

	3 month	6 month
N	57	57
Median	5	5
IQR⁺	2-8	1-8

interquartile range

Distribution of strain was examined separately at three and six month. Spouses who scored equal to or greater than seven on the CSI were considered to be under significant strain (Robinson, 1983). There was no significance between men and women spouses in the level of strain at either three months (U=331, p=0.44) or six months (U=343, p=0.56). Table 2 shows the number and percentage of spouses under strain at three and six months.

Table 2. Distribution of strain at 3 and 6 months

	3 month	6 month
Not strained	45 (63%)	49 (66%)
Strained	26 (37%)	25 (34%)

Strain at three months was evident in 37% of carers whilst 34% of carers were strained at six months. In order to investigate the components of strain, frequencies (and percentages out of total completed) of this group's responses to each of the items on the CSI at both three and six months are shown in Table 3.

Item on CSI	3 month	6 month
Disturbed sleep	32 (45%)	35 (47%)
Inconvenient	46 (65%)	43 (57%)
Physical strain	16 (22.5%)	13 (10%)
Confining	28 (39%)	29 (39%)
Family changes	28 (39%)	28 (37%)
Changes in personal plans	40 (56%)	39 (52%)
Other demands	18 (25%)	.13 (17%)
Emotional adjustments	25 (35%)	22 (29%)
Upsetting behaviour	31 (44%)	23 (31%)
Patient has changed	23 (32%)	22 (29%)
Work adjustment	20 (28%)	22 (29%)
Financial strain	36 (28%)	42 (56%)
Feeling overwhelmed	30 (42%)	27 (36%)

Table 3. Three and six month CSI 'yes' responses for individual items

At three months, inconvenience was reported by the greatest percentage of spouses, followed by changes in personal plans and upsetting behaviour. At six months, the item selected by the greatest percentage of spouses was again, inconvenience, followed by financial strain and changes in personal

plans. For the majority of items, the percentage of spouses selecting the item remained relatively constant from three months to six months. However, there was a notable drop in the percentage of carers reporting upsetting behaviour by six months, and a notable increase in the percentage of carers reporting financial strain. Mann-Whitney tests showed that the spouses who reported that caring was a financial strain cared for patients who were significantly younger than those who reported that caring was not a financial strain at both three months (U=167, p<0.001) and six months (U=209.5, p=0.015). The least frequently reported was physical strain, which had the lowest proportion of 'yes' responses.

2.3.2.2 Patient characteristics

Characteristics of the patients are described for those patients whose spouses completed both the three and six month CSI. Functional ability prior to the stroke was collected for all patients using the Barthel Index. Cronbach's Alpha for the Barthel ranged from 0.85-0.92. Mean prestroke Barthel score in this group was 19.47 (s.d.=1.47). Mean Barthel score at the time of recruitment was collected for 54 patients with a mean of 11.93 (s.d.=5.47). Barthel scores were also collected to determine the level of functional ability in the patient at three and six months after stroke. Mean Barthel score at three months was 15.86 (s.d.=4.35) and at six months was 15.68 (s.d.=4.75). A Friedman analysis of variance detected a significant difference between Barthel scores indicating that there was a significant change in functional ability between the four time points (χ^{2} =143.03, p<0.001). Wilcoxon Signed Ranks Tests were used to see where these differences lay. Functional ability had improved from recruitment to three months after stroke and a Wilcoxon Signed Ranks Test showed this difference to be significant (Z=-4.13, p<0.001). There was, however, little improvement in functional ability between three and six months after stroke and a Wilcoxon Signed Ranks Test showed no significant difference between the three and six month Barthel scores (Z=-0.07, p=0.95). Despite improvements from recruitment to outcome, patients were significantly less functionally able at both three (Z=-5.24, p<0.001) and six months (Z=-5.40, p<0.001) than they had been prior to the stroke. This pattern of change in functional ability is shown in the bar chart below.





Frequencies of patient characteristics are shown in Table 4. Nine patients reported having had a previous stroke (16%) and 35 (61%) patients reported not having had a previous stroke and information was unavailable for 13 (23%) patients.

Patient characteristic	n (%)
Centre	
Nottingham	25 (15%)
Derby	
Mansfield	
Hospital	<u> </u>
OMC	25 (1494)
· DCGH	
	6 (10%)
MCH	9 (16%)
Level of consciousness	<u> </u>
Alert	44 (79%)
Drowsy	5 (9%)
Semi-conscious	2 (3.5%)
Unknown	6 (10 5%)
Ture of Accommodation	0 (10.370)
Private address	57 (100%)
Warden-aided	
Side affected	0 (078)
Ieft	20 (35%)
Bight	30 (53%)
No signs	1 (1.5%)
Piloteral	1 (1.5/6) 1 (1.5%)
Unknown	1 (1.370) 5 (0%)
Swallowing difficulties	5 (370)
Difficulties	20 (35%)
No difficulties	20 (5376)
Unknown	51 (5476) 6 (1194)
Incontinence of bladder	0 (11/0)
Continent	24 (609/)
Incontinent	
Unknown	18 (3270)
	5 (8%)
Continent	A2 (759/)
Treentinent	(43 (7576)
Unknown	9 (10%) 5 (0%)
	3 (9%)
No definit	6 (119/)
Weekmeen	0 (1176)
W CALICSS	44 (770)
Internet in the second	7 (7/0)
Weakness in lea	
No deficit	7 (1204)
Weekness	/ (1270) A5 (700/)
W CALICSS	
Ino movement	
CHEIDWII	5 (576)
Le la comme de la companya de la com	1

Table 4. Frequencies of patient characteristics

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2.3.3 Descriptive results for the cognitive assessments

Of the 57 patients who completed both the three and six month CSI, there were 28 (49%) patients who completed only the screening assessments (group A) and 29 (51%) patients who completed both the screening assessments and the detailed assessments (group B). The two groups were compared for functional ability and on the baseline screening assessments. Mann Whitney U Tests showed that patients in group A and group B were not significantly different in terms of pre-stroke Barthel score (U=374, p=0.47), Barthel at the time of recruitment (U=355, p=0.88), the MMSE (U=309, p=0.12), the SST (U=287.5, p=0.06) or the RCPM (U=326.5, p=0.20). There were no significant differences between patients in each group in age (U=382.5, p=0.71), years of schooling (U=209, p=0.53) or side of weakness (χ^2 =1.60, p=0.45).

Descriptive results for the screen and detailed cognitive assessments are shown in Table 5. All 57 patients completed the MMSE, SST and RCPM. Of the 29 group B patients, 20 completed the NART. Nine patients did not complete the NART. One patient was unable to complete the assessment due to poor English, one was unable to read or write (before the stroke), one had visual problems, five had language difficulties and one refused. The Rey Figure Copy was completed by 29 patients. The Star Cancellation and the Apraxia Test were completed by 28 patients, with one patient refusing to complete the test. Twenty-eight patients completed the SORT Words and Faces. Two patients did not complete the test, including one patient with visual problems and one who refused to complete the test. Immediate and delayed recall on the AMIPB Story Recall was assessed in 27 patients (delayed recall expressed as percentage of immediate recall). One patient was unable to complete the test due to poor English and one refused. Word Fluency was assessed in 28 patients; one patient refused to complete the test. Twenty-nine patients completed the Cognitive Estimation Test.

Assessment	Ability	n	Median	IQR
	<u> </u>		· · · · · · · · · · · · · · · · · · ·	
SCREEN TEST				
MMSE	General Intellectual Ability	57	24	17.5-28
SST total score	Dysphasia (expressive and	57	16	11-18
RCPM	Visual Inattention/ Reasoning	57	20	13.5-29
DETAILED TEST				
NART (estimated IQ)	General Intelligence	20	98	87-105.75
Rev Figure Copy	Spatial Perception	29	27	21-31.75
Star Cancellation	Visual Inattention	28	53	48.25-54
SORT				
Words	Recognition	27	11	9-12
Faces	Recognition	27	8	5-10
AMIPB Story Recall	Recall memory	27	81	61-100
Cognitive Estimates	Executive function	29	4	3-11
Word Fluency	Executive	29	27.5	18-42
	function/language			
Apraxia Test	Praxis	28	60	58-60

Table 5. Descriptive results for the screen and detailed assessments

2.3.4 The relationship between strain and patient characteristics Mann-Whitney U Tests were conducted to compare strain levels according to continence of bladder and bowel on admission (yes/no), swallowing difficulties on admission (yes/no), previous stroke (yes/no), gender (male/female) and whether the patient was randomised to group A (non-intervention) or group B (intervention). Results are shown below.

Patient	3	3 months (CSI		6 months	CSI
characteristic						
	n	U	Р	n	U	P
Gender	57	305	0.49	57	606	0.50
Group $(A/B)^+$	57	327.5	0.21	57	288	0.06
Previous stroke	44	148.5	0.80	44	127.5	0.39
Swallowing	51	295.5	0.78	51	239	0.17
difficulties						
Weakness in arm	50	116.5	0.65	50	155.5	0.63
Weakness in leg	52	129	0.46	52	105	0.17
Incontinence	52	303	0.95	52	277.5	0.58
(bladder)						
Incontinence	52	117	0.06	52	173.5	0.63
(bowel)					 	

Table 6. Strain on the CSI and patient characteristics (Mann-Whitney)

⁺screen tests only (A) or detailed assessment intervention (B) as part of randomised controlled trial

No significant differences were found. However, a trend was identified between group A and group B in strain, where spouses of patients in the intervention group tended to experience lower levels of caregiver strain at six months. The bar chart below demonstrates this trend.





Although this trend was evident from the Mann Whitney U Test and the barchart and verged on statistical significance at six months, it did not meet the criteria for significance at p<0.05. Nevertheless, the finding is clinically relevant and will be discussed as such. Although no other significant relationships were found, there was a trend towards greater strain at three months in spouses of those who were incontinent of the bowel. Also, it is interesting to note that the median CSI score at three months was slightly higher in spouses of patients who were incontinent of the bladder than in spouses of continent stroke patients. This is demonstrated in figure 11.

Figure 11. Incontinence of the bladder by strain



Kruskal-Wallis Tests were conducted to compare strain according to side of stroke (left/right/no signs/bilateral), presence of weakness in arm and leg (no deficit/weakness/no movement), recruitment hospital (QMC/DCGH/DRI/MCH), centre (Nottingham, Derby, Mansfield) and level of consciousness (alert/drowsy/semi-conscious). Results are shown in Table 7.

Patient		3 month	s		6 month	S
characteristic	n	χ^2	р	n	χ²	р
Centre	57	1.67	0.43	57	1.67	0.43
Hospital	57	2.50	0.48	57	1.85	0.61
Side affected	57	5.23	0.27	57	3.62	0.46
Level of consciousness	57	4.07	0.13	57	3.54	0.17

Table 7. Strain on the CSI and patient characteristics (Kruskal-Wallis)

No significant differences in strain were found between any of the characteristics compared.

2.3.5 Correlations between cognitive assessments, patient

characteristics and caregiver strain

Spearman correlation co-efficients were calculated between patient age, pre-stroke patient function on the Barthel Index, baseline, three and six month Barthel Index and caregiver strain measured three and six months after recruitment. Scores on the CSI at three months were significantly correlated with CSI scores at six months (rs=0.62 p<0.001). Carers of younger patients reported significantly greater levels of strain at three months ($r_s=-0.34$ p=0.004) although age was not related to strain at six months after stroke. There were no significant relationships between strain and patient function on the Barthel Index either prior to stroke or at the time of recruitment. Physical function at three months was not associated with strain at three months. However, low Barthel scores at three months (r_s =-0.41 p=0.002) and six months (r_s =-0.39 p=0.003) were significantly related to strain at six months after stroke. Spearman correlation co-efficients were also calculated between each of the cognitive assessments and caregiver strain. Results are shown in Table 8. General mental state on the MMSE was significantly related to strain at three and six months after stroke. Overall language deficit and expressive language skills were significantly related to strain at three months but not at six months. No other cognitive function was significantly related to caregiver strain.

Table 8. Correlations between cognitive assessments and caregiver strain

Assessment	Ability		CSI at 3 n	nonths		CSI at 61	nonths
		u	r,	d	E	rs	d
SCREEN TEST MMSE	General intellectual ability (mental state)	IL IL	-0.25	0.03*	74	-0.24	0.04*
SST RCPM	Dysphasia (expressive and receptive skills) Visual inattention/reasoning	12	-0.26 0.07	0.03* 0.59	74 74	-0.18 -0.15	0.14 0.22
DETAILED TEST NART estimated IQ	General intellectual ability	23	-0.22	0.31	25	-0.29	0.16
Rey Figure Copy Star Cancellation	Spatial perception Visual inattention	34 32	0.05 -0.08	0.79 0.67	35 33	0.06 -0.10	0.74 0.58
SORT words SORT faces AMIPB Story recall	Recognition memory Recognition memory Recall memory	31 31 32	0.02 0.01 -0.17	0.94 0.94 0.36	32 32 32	0.03 0.27 -0.21	0.86 0.13 0.25
Cognitive Estimates Word Fluency	Executive function Executive function/ Language	34 33	0.01 -0.01	0.96 0.99	35 33	0.03 0.04	0.88 0.82
Apraxia Test	Praxis	32	-0.11	0.55	33	-0.16	0.39

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Significant at p≤0.05 for a two-tailed analysis
The Bonferroni adjusted p value for MMSE and SST was p<0.004 (see sections 1.13 and 2.4.2 regarding adjustment for multiple tests). Spearman's correlation coefficients were also calculated between MMSE scores and Barthel scores to investigate the relationship between general mental state and disability. No significant relationship was found between MMSE soon after stroke and functional ability pre-stroke (p=0.36), at the time of recruitment (p=0.32), at three months (p=0.39) or at six months (p=0.37). In order to investigate which aspects of strain were most affected by general mental state, Mann Whitney U Tests were conducted between each item on the CSI and MMSE scores. Results are shown in Table 9.

There was no significant relationship between general mental state on the MMSE and disturbed sleep, physical strain, feelings of confinement, family changes, changes in personal plans and other demands on the caregiver's time. MMSE was not significantly related to work adjustments or feelings of being completely overwhelmed. Spouses of patients with low MMSE scores were more likely to report that caregiving was inconvenient at six months although no relationship was found at three months. Low MMSE scores were also significantly associated with spouses reporting upsetting behaviour at six months (but not three months) and reporting at both time points that it was upsetting to find that their partner had changed so much from their former self. Low MMSE scores were also significantly associated with the reporting of financial strain at three months (but not six months), and a trend was noted between emotional adjustments at three months at low MMSE scores although this

did not reach statistical significance. The Bonferroni adjusted p value for 'inconvenient' at six months and 'upsetting behaviour' at six months, 'patient has changed' and 'financial strain' at three months was p<0.002, and for 'patient has changed' at six months was p<0.0004 (see sections 1.13 and 2.4.2 regarding adjustment for multiple tests).

Item on CSI	n	M	P	
		Median	Median	1
		Yes	No	
Disturbed sleep				
3 month	57	24	25	0.27
6 month	57	24	25	0.60
Inconvenient				
3 month	57	24	25	0.59
6 month	57	19.5	26	0.02*
Physical strain				
3 month	57	23	25.5	0.18
6 month	57	24.5	24	0.67
Confining				
3 month	57	24	26	0.21
6 month	57	24	26	0.09
Family changes				
3 month	57	24	25	0.84
6 month	57	24	25.5	0.15
Changes in personal plans				
3 month	57	24	24.5	0.56
6 month	57	25	24	0.54
Other demands				į
3 month	57	22.5	25	0.45
6 month	57	26	24	0.51
Emotional adjustments		ļ		
3 month	57	22.5	26	0.06
6 month	57	24	24.5	0.70
Upsetting behaviour				
3 month	57	24	26	0.10
6 month	57	24	26	0.04*
Patient has changed				
3 month	57	22.5	26	0.03*
6 month	57	22.5	26	0.01**
Work adjustment				
3 month	57	26	24	0.68
6 month	57	24	25	0.85
Financial strain				
3 month	57	23	26	0.03*
6 month	57	22	25	0.13
Feeling overwhelmed			-	
3 month	57	24	24.5	0.51
6 month	57	23.5	25	0.32

Table 9. Individual CSI item relationships with MMSE scores

*significant at p<0.05 **significant at p<0.001 (for a two-tailed analysis)

In order to investigate which aspects of strain were most affected by communication difficulties, Mann Whitney U Tests were conducted between each item on the CSI and SST scores. Results are shown in Table 10.

There was a significant relationship between lower scores on the SST (and therefore more language difficulties) and the spouses reporting upsetting behaviour at both three and six months and emotional adjustments at three months. No other significant relationships were found. Communication difficulties resulted in emotional strains and upset rather than the more physical strains of caregiving. Bonferroni adjusted p value for 'emotional adjustments' at three months and 'upsetting behaviour' at three and six months was p<0.002 (see sections 1.13 and 2.4.2 regarding adjustment for multiple tests).

Item on CSI	n	SST		Р
		Median	Median	1
		Yes	No	1
Disturbed sleep				
3 month	57	16	17	0.39
6 month	57	16	16	0.95
Inconvenient				
3 month	57	16	16	0.56
6 month	57	13	17	0.11
Physical strain				
3 month	57	15	17	0.18
6 month	57	16	16	0.99
Confining	ł			
3 month	57	15.5	17	0.22
6 month	57	14.5	17	0.12
Family changes				
3 month	57	16	16	0.94
6 month	57	13	16	0.17
Changes in personal plans				
3 month	57	16	17	0.45
6 month	57	17	15.5	0.21
Other demands				
3 month	57	13.5	16	0.34
6 month	57	17	16	0.75
Emotional adjustments				
3 month	57	12.5	17	0.04*
6 month	57	16	16	0.94
Upsetting behaviour				
3 month	57	11	17	0.03*
6 month	57	13	17	0.03*
Patient has changed			1	
3 month	57	15	17	0.36
6 month	57	15.5	17	0.22
Work adjustment				
3 month	57	17	16	0.68
6 month	57	14	16	0.70
Financial strain				
3 month	57	16	16.5	0.21
6 month	57	12.5	16	0.33
Feeling overwhelmed				
3 month	57	15	17	0.20
6 month	57	15.5	16	0.91

Table 10. Individual CSI item relationships with SST scores

*significant at p<0.05 for a two-tailed analysis

2.4 Discussion

2.4.1 Patient characteristics and cognitive impairment

Approximately one third of spouses in this sample were suffering from high levels of strain and this finding is consistent with previous studies in this area (Robinson, 1983; Greveson et al, 1991; Bugge et al, 1999). The strong correlation between CSI scores at three and six months suggests that those spouses who experience strain early after the stroke are also likely to experience high levels of strain at later on. It also demonstrates that carer strain levels remain relatively high across time and this has been demonstrated in other studies to continue up to three years after the stroke (Langton-Hewer, 1990).

In the literature, age was not related to caregiver outcomes when the outcome was an assessment of depression. Three studies did not find a significant relationship between carer age and depression (Draper et al, 1992; Schulz et al, 1988; Ross and Morris, 1988). However, two of the studies did not present the mean time interval between data collection and the onset of stroke (Draper et al, 1992; Schulz et al, 1988) which Ross and Morris (1988) suggested was important as older caregivers were less likely to be depressed at six to nine months after stroke, but not at three to ten weeks after stroke. In addition, the outcome variable was depression rather than strain per se. The present study has demonstrated that age was related to carer strain and early after stroke, spouses of younger patients suffered from a greater level of strain than spouses of older patients. This is consistent with the findings of other research (Robinson, 1983). The findings of the present study are also consistent with other studies of carer

For example, in a study of informal carers in palliative care, strain. younger age was found to be correlated with both psychological morbidity on the GHQ-30 and strain on the Caregiver Strain Index (Payne et al, 1999). In the present study, strain was greater in younger patients early on after stroke, although by six months, age was not related to strain. Some researchers have postulated that family life stage is a critical factor in caregiving in chronic illness, acting as a mediating factor, which may impact on the way in which an individual reacts to the demands of the caregiving situation (Rolland, 1988). Here we can apply Neugarten's (1968) concept of the 'social clock'. This concept highlights the notion that society leads individuals to expect to experience certain life events at particular times in their lives, which allows us to anticipate and prepare for these transitions to occur. When these events occur 'out of time' they can disrupt psychosocial adjustment and there may not be the support of others in the same age cohort who are experiencing this change at the same time.

The concept of 'social clock' would provide another explanation for why spouses of older patients experience less strain than spouses of younger patients. Older age is naturally associated with an increased risk of illness in our society. It is possible that older persons may therefore be more psychologically prepared for illness than younger patients, to whom the occurrence of a life threatening condition may initially be shocking and difficult to come to terms with. In addition, younger patients and their spouses may have more life events to contend with, such as the impact of stroke on working life, whereas older patients are predominantly retired. Indeed, results showed that the spouses who reported caring to be a financial strain were caring for younger patients than those who reported that it was not.

The study addressed the objective stressors outlined in the model of caregiver strain (see figure 8). Results confirmed the importance of patient function. Basic self-care skills, both before and immediately after the stroke, were not related to strain in the spouses either three or six months later. Patient disability assessed immediately after the stroke may not be related to caregiver strain later on due to the fact that functionally dependent patients are predominantly cared for in hospital during the early stages after stroke and so many aspects of caregiving strain, such as disrupted sleep, physical strain and confinement, are not experienced until some time afterwards. By three months, the majority of patients were being cared for at home by their spouse and were significantly less functionally able than they had been prior to the stroke. Patient disability at three months was not related to strain at three months, which suggests that factors other than functional status of the patient may be important in determining strain earlier on. These factors may include mental state and communication problems, which may require greater emotional adjustment than physical disablement. However, disability at both three months and six months was associated with high levels of caregiver strain at six months, which suggests that patient disability may become more important with time. It is possible that spouses are able to cope with a disabled and maybe cognitively impaired partner for a short time but if disability and impairments persist, then caregiver strain becomes an issue.

This relationship with strain later on, together with the fact that little physical improvement was seen in this sample between three and six months suggests that patient functional status becomes more of a strain to spouses as they realise that things may not get any better. This lends support to results found by Carod-Artal (1999) who showed that disability on the BI was associated with high levels of overload in carers of stroke patients.

Although the numbers of patients recruited, particularly from the Derby and Mansfield centres, were too low for firm conclusions to be drawn, no significant differences were found in carer strain between patients recruited from hospitals in Nottingham, Derby and Mansfield. This suggests that the level of caregiver strain in spouses of stroke patients did not vary between the admitting hospitals. A larger study designed specifically for a comparison of this sort is needed to confirm this finding, as no published studies have been identified that address the possibility of regional variations in caregiver strain.

It is interesting to note that spouses of patients in the control group experienced similar levels of strain at six months that they did at three months. However, spouses of patients in the intervention group appeared to experience a reduction in strain at six months compared with three months after stroke. Although many patients completed the detailed assessments very soon after the screen assessments, for some patients, the administration of detailed cognitive assessments continued throughout the first three months, up until the point of three-month outcome. This was dependent on factors such as how easily they tired, how ill they were and

how many more detailed assessments were to be conducted. Strain levels appear to be much lower by six months when the full neuropsychological report had been completed, full verbal and written feedback had been given and the spouses had had time to 'digest' the information and adapt to any new compensatory strategies that had been recommended.

The fact that the sample was hospital based and not all patients with stroke are admitted to hospital may have resulted in a bias in the sample. However, the majority of patients who have residual deficits from stroke are admitted to hospital. Also, the study included both first and recurrent strokes and thus the findings are applicable to the spouses of most patients with clinically significant deficits from stroke. However, those patients who were unconscious on admission were excluded due to poor prognosis and inability to complete the cognitive assessment battery. Although patients who were unconscious on admission were excluded from the study, a record had been made of whether the patient was alert, drowsy or semi-conscious on admission.

Level of consciousness, swallowing difficulties, having had a previous stroke, weakness of arm and leg and incontinence of bowel and bladder are all indicative of a more severe stroke with poorer functional outcome. Poor functional ability has previously been associated with caregiver strain (Carod-Artal, 1999; Robinson, 1983; Dennis et al, 1998). However, these factors were not statistically related to strain, which suggests that these patient characteristics and impairments early after stroke were not useful in determining the level of strain the spouse will experience later on. This is consistent with the finding that functional status immediately

after the stroke, as assessed on the Barthel Index, is unrelated to caregiver strain at three and six months.

The literature suggests that incontinence and patient disability may represent a major source of strain and psychological distress for caregivers. The present study suggests that patient functional status both three and six months after the stroke is associated with carer strain at six months. Functional status at the time of the stroke was unimportant with regard to later strain. Studies have shown that incontinence can negatively impact on carer burden and mood (Brittain et al. 1998; Flaherty, 1992; Heok and Li, 1997; Lim et al, 1999). Despite the lack of statistical significance, bar charts suggested increased strain in spouses of incontinent patients by three months. This is consistent with conversations with spouses suggesting that incontinence is one of the least tolerated aspects of stroke. It has been found that the prevalence of incontinence is lower on hospital discharge than admission, which suggests that for many patients incontinence following stroke may be transient (Henrikson, 1991). It may be that many of the incontinent patients regained their continence by the time the three-month CSI was completed, which would explain why the trend did not reach significance. However, for those patients living at home with persistent incontinence, carer strain may be high, and further exploration is required. In the present study, continence status was assessed on admission to the hospital ward. However, continence status needs to be assessed some time after the stroke to investigate whether persistent incontinence in the months following stroke is stressful to caregivers.

Spouses of patients whose general mental state was poor on the MMSE suffered from increased levels of strain at both three and six months after stroke. This finding is consistent with other research (Drinka et al, 1987; Quine et al, 1984; Topinkova and Neuwirth, 1997), which also suggested that cognitive impairment (as assessed on screening measures of global impairment) was related to strain. The MMSE addresses numerous areas of general cognitive functioning including orientation, memory, attention, language and the ability to process basic verbal commands. Previous research has suggested that orientation is important for activities of daily living and social activities (Pederson et al, 1996). A deficit in orientation may result in confusion. Other studies have shown that orientation of the patient specifically relates to caregiver strain (Miller et al, 1997). Disorientation may be longstanding and persist for many months after the stroke (Desmond et al, 1994).

Poor performance on the MMSE indicates a global, widespread impairment likely to delay recovery and impact significantly on everyday life for both the patient and their spouse. Such a decline in mental state can lead to marked behavioural changes, including lowered motivation for personal care, home and social life; lack of judgement, apathy and social withdrawal. Impairments of orientation can greatly affect the ability of the spouse to effectively relate to the stroke patient and significantly alter the cohesion of the marital relationship. Further investigation demonstrated that only certain aspects of strain on the CSI were significantly associated with general mental state on the MMSE. Aspects of strain reported by the spouses of patients with poor mental state

suggested that emotional strains are more strongly associated with general mental deterioration than physical factors such as disruption of sleep, changes in personal or work plans and physical strains such as lifting in and out of bed. The most notable strain was the spouse finding that their partner had changed so much from his/her former self. This supports work done by Carnwath and Johnson (1987) who also noted that the carer may be disturbed by the patient's personality change and the patient 'not being himself'. Other factors significantly related to general mental state of the patient were inconvenience and upsetting behaviours, together with a non-significant but nevertheless interesting trend with emotional adjustments. Financial strain was significant at three months; this might be due to the relationship between poor mental state and increased disability of the patient found by some researchers (Paolucci et al, 1996) as extra costs might be incurred from travelling to and from hospital to visit a highly dependent inpatient. However, further investigation of the present sample did not reveal such a relationship. For younger spouses, early financial strain may result from having time off work to help their partner. By six months, financial strains may be lessened as benefits and other financial supports may have been arranged. It would seem, therefore, that (with the exception of financial difficulty) impaired mental state in the patient is most strongly related to the more emotional aspects of strain in the spouses.

The literature addressing the relationship between caregiver strain and language difficulties in the stroke patient is inconclusive. In the present study, language deficits on the screening test for aphasia were related to

increased strain in the spouses at three months after stroke. This contests the findings of Rau et al (1986) and Wade et al (1986) who suggested that the presence of aphasia did not affect the adjustment, burden or level of stress in stroke caregivers. Similarly, McClenahan and Weinman's (1998) study highlighted the importance of caregiver factors related to strain rather than communication difficulties. Nevertheless, the present study lends support to early research by Kinsella and Duffy (1979) who found that spouses of aphasic partners had lower mood and were more poorly adjusted to the stroke than spouses of non-aphasic partners. Other researchers have also found that an inability to communicate effectively can result in psychological distress in caregivers (Brumfitt, 1993; Shewan and Cameron, 1984).

It seems plausible that a deficit of speech and language may have a significant psychological impact not only on the afflicted but also on their marital relationship. The loss of the ability to produce speech or to understand the speech of others can lead to a complete inability to communicate. Those patients that understand the speech of others but are unable to correctly pronounce words, or whose speech is limited to just a few words, may have difficulty expressing themselves and their attempts may be difficult for the listening spouse. The spouse may then wrongly assume that their partner is unable to understand what they have to say, again, leading to an inability to communicate and feelings of frustration and isolation. The relation between aphasia and poor recovery of social activities may also have repercussions for isolation in the spouse. In this sample, language problems early on were unrelated to strain six months

after the stroke. There are a number of possible explanations for this finding. It could be due to the fact that recovery from language problems often occurs within the first year after stroke and many patients with milder expressive and receptive difficulties improve with time. Initial difficulties may have improved by six months after the stroke, thus reducing strain in the spouses by this time.

Alternatively, where language problems are long-term, patients and their spouses may have developed their own strategies to cope with the situation. For example, rather than feeling overwhelmed by the inability to communicate through conversation, they may have adapted by using gesture, writing or drawing to communicate. Although the exact figure is not known in this sample, by six months, most, if not all patients with aphasia would have been in contact with a speech and language therapist who would teach the patient and their partner new ways to cope. It is also possible that there would have been a significant relationship between communication difficulties and strain at six months had the sample size have been larger. This relationship needs to be investigated further. Subsequent investigation of the relationship between individual items on the CSI and language difficulties demonstrated that communication problems resulted in emotional strains rather than physical strains. The relationships found between items of the CSI and the MMSE and SST are interesting in the context of previous work by Field et al (1983) who found that six months after stroke, stroke spouses were able to cope with the practical aspects of caregiving but all of their sample had difficulty with the emotional aspects of caregiving.

It is likely that communication difficulties may impact heavily on the marital relationship and this impact may be greater with increasing severity of impairment. A Dutch study of 22 spouses one year after stroke showed that spouses of patients with severely impaired communication had fewer opportunities to relax, reported more deterioration of the marital relationship and were more depressed than spouses of patients with only slight communication problems (Schure et al, 1992). Williams (1993) assessed 40 spouses of stroke patients with aphasia on measures of marital satisfaction and knowledge about aphasia. The author found lower levels of marital satisfaction after the stroke than ratings of marital satisfaction prior to the stroke. The study also demonstrated that increased knowledge about aphasia buffered the negative effects of the stroke on marital satisfaction. It may be that providing information to stroke spouses about aphasia may reduce strain and enhance marital cohesion.

The results showed that global cognitive decline on the MMSE and communication deficits on the SST were significantly related to strain in the spouse. However, further detailed examination of other specific areas of deficit suggested that other cognitive impairments were not as important in determining the level of strain experienced. Deficits of spatial perception and visual inattention did not affect later strain in the spouse. Although perceptual impairments may cause difficulty with activities of daily living such as dressing and walking, and can be a barrier to functional rehabilitation early after a stroke, in the majority of cases they improve significantly with time. Acquired perceptual problems are often amenable to treatment and treatment gains can lead to improvements

in daily functioning (Gouvier and Cubic, 1991). Slight perceptual deficits may persist, but as patients learn to compensate for these impairments, by three months after the stroke it seems they may not impact significantly on the well-being of the spouse. It seems that impairments of perception represent less of a strain to the spouse than an inability to communicate with their partner.

Although research has suggested that memory problems may be stressful for the carers and stroke carers have reported memory problems to be an area in which they require further knowledge (Brooks et al, 1986; Hangar and Mulley, 1998), recognition and recall memory were unrelated to strain. Although no previous study of caregiver strain has objectively measured memory in stroke patients, these results are consistent with research on caregiver's perceptions of dementia patient's memory problems (Loguidice et al, 1999; Hadjistavrapoulos et al, 1994) which also suggest that memory is not an important factor in caregiver burden. However, in the present study the MMSE was significantly related to strain and a large proportion of the MMSE deals with memory. Memory problems should therefore not be ruled out as a potential influence on caregiver strain. Memory assessment is not always accurate as it is difficult to rule out the effects of intelligence, poor motivation, attention and concentration. The Spearman's rho correlation coefficients for the verbal memory assessments with strain did not differ greatly from the figures obtained for MMSE with strain. It may be that a larger sample might clarify the influence of memory deficit and further research is needed in this area.

Despite the suggestion by Elias and Treland (1999) that executive deficit in Parkinson's patients may represent a source of stress for carers, the present study suggests that executive deficit in the stroke patient was not related to caregiver strain. More detailed assessment of executive problems after stroke may have revealed different results. The COWAT-CFL was used as an assessment of executive functioning, yet this test also addresses higher-level language abilities. The Cognitive Estimation Test also assessed executive deficit. More detailed tests are available, such as the Behavioural Assessment of the Dysexecutive Syndrome (BADS) (Wilson, 1996) and the Modified Card Sorting Test (Nelson, 1976). These tests were used with selected patients where problems had been identified on the Cognitive Estimation Test or the COWAT-CFL, as part of the randomised controlled trial. However, these tests were too lengthy to be conducted with every patient as part of the battery of detailed assessments. The number of patients for whom more detailed assessment took place were too few to include as part of the present study and would not allow for meaningful statistical analysis. Nevertheless, results gained from the assessments included in the present study suggest that other factors may be more important than executive functioning in caregiver strain.

Problems of praxis following stroke have been found to affect the wellbeing of the patient up to one year later (Wyller et al, 1997). However, these problems have not been found to impact on strain in spouses of stroke patients. It is often difficult to distinguish between dyspraxia and disorders of language and communication and many tests require a degree of language and expression in order to complete. Nevertheless, one

reason for selecting Kertesz and Ferro's Apraxia Test was that imitation could be used where language was a difficulty and so language problems should not have influenced the assessment. Furthermore, difficulties on tests of apraxia may be secondary to a number of other cognitive deficits including neglect and perceptual abnormalities. In this sample, and assessing apraxia on the Apraxia Test, no relationship was found between praxis and strain in the spouse. The results suggested, therefore, that language and general mental state were important aspects of cognitive function and that other specific cognitive impairments were unrelated to caregiver strain. However, as patient numbers were low, univariate analysis was employed and therefore no conclusions can be drawn as to how different cognitive functions interact with each other and influence caregiver strain in combination. Additionally, in clinical practice, a combination of tests might be employed to diagnose a deficit in a particular cognitive function which might provide more information than simply saying whether a patient was impaired or not on a single neuropsychological test. Nevertheless, it would seem language is the impairment likely to have most impact on carers and that isolated cognitive impairments may be less important than general cognitive decline.

2.4.2 Providing information about stroke

The provision of information and advice about the patient's cognitive functioning to patients and carers in the group who underwent detailed cognitive assessments had been aimed at increasing both patient and carer This was to determine whether increasing knowledge of knowledge. cognitive problems could reduce caregiver strain. With all patients taken into consideration, there was no statistically significant difference between levels of strain in spouses of patients who received a detailed cognitive assessment with feedback (group B) and levels of strain in spouses who received only the screening test with no feedback (group A). From this non-significant finding one might conclude that the provision of detailed information to patients and their spouses regarding the existence and nature of their cognitive deficits did not impact upon caregiver strain. It may be that knowledge about cognitive function after stroke does not reduce levels of carer strain. Or it is possible that undergoing the screen assessments could highlight difficulties to patients and their spouses, thus increasing awareness and knowledge in the non-intervention group. Also, there was no measure of how well informed the spouses were about cognitive functioning prior to recruitment. However, figure 10 clearly demonstrates that the number of spouses under strain is lower in group B than group A at both outcome times. This trend remained when all carers in the RCT were taken into consideration, including adult offspring, siblings and friends. This suggests that cognitive assessment may contribute to reducing carer strain through the provision of information.

There are several conceivable explanations for this finding. It is possible that providing specific neuropsychological information to the rehabilitation team may have resulted in staff changing their rehabilitation strategies based on this information in order to compensate for impairments, which reduced strain in the caregivers. However, findings from the RCT (McKinney et al, In Press) showed no evidence of this as no significant differences were found in patient functional abilities between the control and intervention groups.

Research has suggested that caregiver involvement in patient rehabilitation is paramount and that caregivers can promote the rehabilitation process by reinforcing patient behaviour and treatment regimes whilst maintaining a supportive environment (Evans et al. 1992). Proulx (1999) highlighted the importance of providing information to families about how to compensate for the patient's cognitive impairments in order to help modify behaviour and roles to deal more appropriately with their impact on everyday function. A high proportion of carers in the RCT (McKinney et al, In Press) reported that the information had been useful and many claimed that they had changed their behaviour on the basis of the cognitive assessment information (unpublished data). Although the present study provides no measure of how information was used by spouses in the intervention group, it may be that understanding the nature of their partner's impairments may have given them less cause for concern.

An alternative explanation is that the trend towards reduced strain in the intervention group may be the result of providing personalised care and support over and above the level provided from routine care. Indeed, research has shown that providing packages of support in various forms to patients and carers can increase knowledge and satisfaction (Mant et al, 1998; Rodgers et al, 1999) and reduce caregiver strain (Walker et al, 1999), anxiety (Dennis et al, 1997) and psychological distress (Mant et al, 1998). The present study lends support to these findings. The fact that carer strain may be reduced with various interventions including information packs, individualised booklets, family support services and additional community therapy services suggests that simply providing additional support may be of greater importance than the type of support provided. However, it is important to note that these findings are based on a non-significant trend and so no firm conclusions can be drawn.

Due to the nature of the neuropsychological assessments, those patients who were not able to sit and cooperate with assessment for more than 30 minutes at a time were excluded from the patient characteristics study. Due to their poor prognosis, patients who were unconscious on admission were also excluded. Finally, patients were excluded if they had dementia or if they had a significant visual and hearing impairment. It was necessary to exclude these patients as detailed neuropsychological assessment would not have been possible. However, excluding them means that the spouses of stroke patients included in this study may not have been representative of stroke patients as a whole. It may be that carers who were excluded from the study due to the severity of the

patient's illness may have been the group suffering from the most strain. This problem is to some extent unavoidable although it is important to be aware of this limitation. In the study, 55% of caregivers completed the three-month CSI and 57% completed the six-month CSI. This figure is fairly low and could have been higher given the number of patient visits that were made in total for the randomised controlled trial. On some occasions, spouses were too busy or not at home when an arranged visit had been made and the CSI was left at the house for them to complete and send in the mail. However, carers did not always send back the form and despite chasing up by telephone the CSI was not completed.

On some occasions the CSI was not completed as the spouse had taken ill and was in hospital or was in institutional care. The study was limited to carers who were well enough to participate in follow-up assessments over a six-month period. It may have been that, with the exception of mental state and language, other specific cognitive impairments are not related to strain. Alternatively, it may be that the small sample size was the reason for non-significance of the results. The overall response rate of the full randomised controlled trial was higher but the present study only included spouse caregivers.

In the present study, patients were stratified according to centre but not ward type. However, it may be that the benefits of information may differ according to the type of ward the patient was treated on. Staff working on stroke units, for example, have been trained specifically in stroke rehabilitation and therefore may possess a certain expertise not found on general medical wards. Stroke Units offer 'co-ordinated multidisciplinary

team care for stroke patients in hospital' (Langhorne, 2000). A metaanalysis showed that there are notable differences in Stroke Units compared with conventional wards (Langhorne et al, 1993).

It may be that there are differences in treatment regimes employed in specialist units. Stroke unit treatment may include monitoring of physiological parameters and early treatment of complications, care by specialist nurses and early implementation of physiotherapy, speech therapy and occupational therapy. It is likely that rehabilitation staff on stroke units may possess more knowledge about cognitive impairment and may recognise and provide more feedback to patients and their carers about specific deficits than staff on non-specialist units. Therefore, providing information to carers of patients on non-specialist units may have more of an impact than providing information to carers of patients on a stroke unit who may already have received adequate feedback regarding their impairments from the rehabilitation team. Staff expertise and increased involvement of the family often found in stroke units may reduce strain in the spouses. The increased knowledge and awareness of stroke on specialist units may lead to a greater level of communication between staff and patients and their families. Furthermore, caregivers often want to know more about the stroke and those with greater knowledge experience lower levels of strain. Additionally, improved functional outcomes evident following treatment on a specialist unit (Indredavik et al. 1999; Kalra and Eade, 1995; Stroke Unit Trials Collaboration, 1997) may reduce physical dependency on the spouses after discharge, which in turn may reduce the level of strain they

experience. Studies that consider the possible relationship between the type of ward on which the patient was treated, and caregiver strain, are sparse. Although one might expect that decreased dependency of patients on their caregivers to reduce the level of strain, current studies have not supported this hypothesis (Miller et al, 1997; Lincoln et al, 2000). Research is needed to examine more fully the relationship between ward type and strain and this could be achieved in a randomised controlled trial of carer strain after treatment on a stroke unit or general medical ward.

Although Treece et al (data from the RCT: In Preparation) found that 87% of rehabilitation staff rated cognitive assessment information as 'useful' when planning rehabilitation strategies, there was no formal method of assessing the way cognitive assessment information was used by staff. It may be worthwhile investigating differences between the use of detailed cognitive assessment information between staff on stroke units and those on general medical or geriatric wards and also examining the way in which the spouses themselves utilised this knowledge.

The study needs to be replicated with a larger sample in order for the results to be generalisable. Future research should include large-scale assessment of cognitive deficits and more follow-up of caregivers to ensure a higher completion rate. Obtaining written consent from the carer at the time of patient recruitment might be one method of increasing the number of completed carer outcomes. In addition, the difficulty of assessing cognitive function has been identified as patients' performance on cognitive tasks can be affected by sensory and motor deficits (Starr et al, 2000).

Although providing information about cognitive deficits appeared to be beneficial it is important to note personality differences in the carer's desire for this information. Whilst some spouses are keen to know the facts and want detailed discussion about their partner's impairments and how to compensate for them, others are not. It seems important to consider information giving on an individual basis depending upon the wishes of the patient and their spouse. In addition, different methods of providing this information may be more effective than others for individual carers (eg. support meetings or written information). Knowledge levels, needs and wishes of carers could be assessed in individuals by a stroke family support worker although this type of intervention has considerable resource implications and support workers have no formal training in cognitive assessment. It would be worth examining whether positive effects on strain could be achieved by providing an educational programme to existing rehabilitation staff about cognitive deficits, their relation to everyday function and techniques to compensate for them. This might be more practically achieved than providing a clinical psychology service to conduct batteries of assessments.

The present study relied on non-parametric statistics as the method of analysis. Although less powerful than parametric statistics, they make no assumptions about the distribution and were appropriate given the small sample size and predominantly ordinal data. As the study had only a single dependent variable (outcome of caregiver strain) univariate statistics were used in the analysis. Although commonly used and

appropriate to the data, the main disadvantage of univariate analysis is that variables are analysed in isolation and no information can be gained as to how different variables behave in combination. The method of analysis used was thought to be appropriate to the dataset. However, it has been argued that traditional statistical analysis is not applicable to serial measurements collected as part of medical research and Matthews et al (1990) endorse the analysis of summary measures, rather than undertaking separate analyses at each time point. It may be useful to utilise this method in future research of this type, although it must be recognised that this technique requires full datasets and often in clinical research full outcome data is not available due to death, further illness or cognitive impairment. Additionally, conducting multiple tests within the same study increases the probability of finding a significant result by chance. Bonferroni correction reduces the possibility of type one error by adjusting the alpha level to take into account the number of comparisons Using these extremely stringent adjusted p values, the being made. significant effects reported here were not significant. This suggests that the results should be treated with caution as the chance of type one error is increased. Although the use of Bonferroni correction is recommended, it may be too conservative a test if the number of comparisons is greater than five (MacArthur and Jackson, 1984). Variables included in this study that were significant at p<0.05 could be assessed in another sample of patients to test for their true significance and restrict the analysis to a small number of comparisons.

Whilst taking into account the methodological weaknesses and limitations of the study, this research has enabled early identification of patient characteristics evident in the acute stage of stroke that may be associated with caregiver strain later on. Spouses of incontinent patients with impaired orientation and communication problems would appear to be at the greatest risk from strain. It may be possible to target spouses of patients suffering from these impairments early after stroke and involve them in interventions that may prevent the occurrence of caregiver strain. However, this study addressed only the objective stressors identified on the model of caregiver strain and did not include any characteristics of the caregivers that may make them susceptible to strain and psychological distress. The next study will address a number of conditioning variables identified in the model of strain that may affect caregiver's responses to stress and thus impact on the level of strain experienced.

2.4.3 Conclusion

The present study suggests that caregiver strain in stroke spouses may be associated with global cognitive impairment and communication problems. This is not unexpected in a marital relationship, given the difficulties with normal human interaction that may be caused by disorientation or loss of language. Incontinence and independence in basic self-care skills may also play a role in caregiver strain. However, strain is not well predicted by other patient characteristics at the time of hospitalisation or other cognitive impairments. It would seem that language impairments are more likely to impact on caregiver strain than

other deficits, and that communication problems are most likely to affect the continuity of the marital relationship in the ability of the spouses to communicate effectively with and relate to their partners. Cant (1999) described the ability to communicate as, '....almost by definition, the very core of human relationships'. The present study showed that communication problems were related to caregiver strain. Whereas physical disability may result in the experience of more physical strains, the present study showed that communication difficulties may result in more emotional strain. As one carer said:

"I don't feel as close to him anymore....he doesn't know what I'm saying and he can't say anything back. I've got no-one to talk to now.....and I'm lonely".

Providing individualised information may help to alleviate the strain associated with communication problems. Later on after stroke, communication deficits are less of a problem although global cognitive impairment remains to be influential. It is possible that later after stroke, as the spouse has to come to terms with the reality of the caregiving situation, caregiver factors may play more of an important role. It may be that there are certain characteristics of the carer that may make them more susceptible to strain and psychological distress. The part of the model of caregiver strain addressing caregiver characteristics has so far not been considered and will be investigated in the following study.

CHAPTER 3

A study of the relationship between caregiver characteristics

and caregiver strain

3.1 Introduction

In Chapter Two, a number of objective stressors were addressed that may have been associated with caregiver strain. These included patient disability and self-care skills, patient cognitive status, patient affective state and length of time since the stroke. The present chapter addresses a number of conditioning variables that may be related to strain. These include caregiver function and health, economic self-sufficiency, social support and satisfaction with support, personality characteristics and gender. These factors are important as caregiver problems have been found to more important predictors of nursing home placement for frail older patients than patient factors such as functional disability (Tsuji et al, 1995).

3.1.1 Caregiver Function and Health

According to Gurin (1960) good health is one of the most frequent reasons given for overall happiness. Given the vast literature linking stress to physical health it would be reasonable to assume that caregiver health would be affected by their chronic exposure to high levels of stress. Indeed, many studies have reported that caregiving is associated with significant tolls on physical health (Synder and Keele, 1985; Silliman and Sternberg, 1988; Horowitz, 1985; Kiecolt-Glaser et al, 1991).

The proportion of caregivers suffering from a decline in physical health varies from 25% (Mumma, 1988) to approximately 70% (Synder and Keele, 1985) and this difference might be explained by differences in the methods and assessments used. Studies have suggested morbidity effects from caregiving but the evidence is equivocal. Self-report studies have consistently shown that health of caregivers is worse than aged-matched peers (Stone et al, 1987; Haley et al, 1987) and that carers perceive that providing care is detrimental to their health (Synder and Keefe, 1985). Some health care utilisation studies have suggested that carers visit their physician and take prescription drugs more frequently than matched controls (Haley et al, 1987b) although others have failed to find that carers use more medical services than community dwelling older adults (George and Gwyther, 1986) or matched control groups (Kiecolt-Glaser et al, 1991).

However, the demands of caregiving might limit opportunities for carers to attend to their own physical needs and so health care utilisation studies may not be a useful indicator of carer physical health. Immune function may be impaired by stressful life events and studies have suggested that carers may be more vulnerable to infectious disease (Vedhara et al, 1999) and have poorer immune responses than matched controls (Kiecolt-Glaser et al, 1991). However, carers in these studies were recruited from an Alzheimer's support group or a memory clinic, which may be biased towards the more 'stressed' end of the caregiving continuum. Additionally the study did not address whether immune function was related to self-reported health or other indicators of health status.

A study of immunological functioning in Alzheimer's disease carers, stroke carers and a non-caregiving group found no significant differences between the groups (Reese et al, 1994). Studies investigating the needs of caregivers for frail and disabled adults have shown that physical strain is related to the level of disability of the care receiver (Cantor, 1983; Synder and Keele, 1985). In a survey of 678 elderly community dwelling residents, Santariano et al (1984) documented the effects of having an ill spouse. Respondents who reported their spouses as being ill in the last six months were more likely to report their own health as being poorer than those respondents whose spouses had not been ill. In addition, the health status of the ill spouse was found to be the best predictor of the respondent's health. These studies suggest that carer physical health is related to the physical state of the patient. It would seem that the reverse is also true as carer health has been documented as an important predictor of well-being in the elderly partner (Bowling and Browne, 1991).

The relationship between caregiver physical health and adverse caregiving outcomes is not consistent. Studies of stroke caregivers using measures of physical symptoms demonstrated that carers with more phyiscal symptoms were more likely to be depressed (Carnwath and Johnson, 1987; Schulz et al, 1988; Tompkins et al, 1988). However, studies that utilised a self-rated global health scale evaluating health from poor to excellent failed to find a significant relationship between carers' self-rated health and depression (Draper et al, 1992; Schulz et al, 1988; Silliman et al, 1986; Tompkins et al, 1988).

Many studies assessing caregiver physical health are focused on carers of Alzheimer's patients. In many cases, sample sizes are small and carers are recruited in ways that may have assured relatively distressed groups (eg. from support groups). Also, without objective health status data it is difficult to interpret self-reported physical health. The relationship between self-reported health and objective measures of health is only a moderate one (Maddox and Douglas, 1973) and the rates of concordance decrease with complexity of diagnosis (Colditz et al, 1986). Emotional distress can influence reports of somatic symptoms (Katon, 1985) which suggests that self-reports of physical illness and somatic symptoms must be viewed with caution. Many studies have focused solely on caregiver physical health without considering how this might impact on their everyday functioning. It may be more pertinent to measure the influence of health on everyday life. The measurement of the caregiver's physical health per se only provides information about their physical abilities. This gives no indication of severity as the same level of disability can result in a different level of disadvantage.

The assessment of handicap focuses on what was normal to that individual and incorporates a wide range of factors including physical, social and economic disadvantage. At the time of the design of this study, the International Classification of Impairments Disabilities and Handicaps (ICIDH) proposed by the World Health Organisation (WHO, 1980) acted as a conceptual framework to describe the consequences of disease. Under this classification, disablement was the umbrella term, covering the three dimensions of impairment, disability and handicap (see footnote 1).

The ICIDH definition of handicap was '....the disadvantage for a given individual, resulting from an impairment or disability that limits or prevents the fulfilment of a role that is normal (depending on age, sex and social and cultural factors for that individual'. A more concise description of handicap is, 'the freedom the patient has lost due to the pathology....it determines the real severity of an illness' (Wade, 1992). As the definition of handicap focuses on what is normal to the individual, the same level of disability can result in a different level of handicap.

Handicap has been investigated in stroke survivors and was found to be associated with physical disability and post-stroke depressive symptoms at three months and one year after stroke (Clarke et al, 1999). However, research on caregivers of stroke patients tends to focus more on disability Handicap may refer to such things as mobility and than handicap. physical independence, orientation, social isolation, occupation of time or financial difficulty due to the caregiving role. Increased dependency and functional disability of their partner may restrict the places the spouse is able to go. Additionally, handicap may result from the caregiver's own physical health. It has been suggested that the caregiving role may have a financial impact on the caregiver (Joshi, 1994; Baldwin, 1995; Parker and Lawton, 1994) and these financial repercussions have been identified in caregivers of stroke patients (Holbrook, 1982; Brocklehurst et al, 1981). Financial difficulty has been identified as a handicap (Harwood and Ebrahim, 1995) and so measurement of handicap would take economic self-sufficiency into account. No studies have been identified that assess handicap per se in carers of stroke patients.

3.1.1 Social support

Social support can be viewed as an umbrella term referring to the support structures that are generated by an individual's social contacts. According the Evans and Northwood (1983), "Being associated with others is an aspect of human experience which is important for achieving and maintaining a high level of individual function and life satisfaction". Social support may be important as studies of dementia caregivers have found that a supportive social environment can be protective against institutionalisation of the patient (Bergmann et al, 1978).

The positive effects of social support have been identified in research studies over the past decades. The benefits of social support have been demonstrated in studies of patients with serious illness. For example, DiMatteo and Hays (1981) found that social contacts proved to be a source of substantial reinforcement, a gauge against which comparison could be made and feedback against which to evaluate progress. Social supports may lead to significant reductions in anxiety, increased selfesteem and understanding and an opportunity for emotional release and resolution of feelings. One early study showed that social supports may assist in the modification of attitudes and behaviours towards a healthier lifestyle and the mere existence of a confidante can be negatively correlated with the presence of affective disorder (Brown et al, 1977).

Social supports are often viewed as mediators. Mediators help explain why objective stressors may be experienced by some individuals without any apparent detrimental effects whereas others may react markedly. The very fact that stressful events do not have an entirely predictable effect on

different individuals suggests the presence of modifiers on the relationship between stress and outcome. Consistent support can be found in studies of various populations for idea that coping and social support can both be powerful predictors of outcome in stressful times (Cohen and Will, 1985; Folkman and Lazarus, 1985) and the adequacy of social supports can impact on family functioning (Douglas and Spellacy, 1996). Modifiers can be seen as filters or alleviators of the effects of stress and these 'buffers' or 'modifiers' are of interest in research as they may be amenable to therapeutic manipulation.

Early patient studies showed that social support may act as a buffer against psychological distress in patients with stroke (Friedland and McColl, 1987) and rheumatoid arthritis (Fitzpatrick et al. 1988). The relationship between emotional distress and social support has also been identified in studies of caregivers. Research on caregiving for the elderly has shown that carers who have greater emotional and social support usually report lower levels of depression and higher levels of life satisfaction (Schulz et al, 1995; Franks and Stephens, 1996). In addition, caregivers who are actively engaged in social and recreational activities, such as church attendance or visiting with family members and friends, also adapt to caregiving with less depression than those who are socially isolated (Haley et al, 1987). A more recent study by Sander et al (1997) of the psychological health of caregivers of patients with closed head injury found that increased satisfaction with social support was associated with less emotional distress.
Research in the area of traumatic brain injury (TBI) demonstrated that high levels of distress or burden in the carers can lead to families becoming isolated or cut off from their social support networks (Thomsen, 1984). According to Lezak (1978) families frequently feel isolated by their caretaking role, and additionally may suffer a concomitant increase in their own social isolation (Liss and Willer, 1990). Research on carers of stroke patients suggests that carers with a strong support network and more social contacts suffer fewer negative consequences (e.g. depression) than carers with less supporters in their network (Schulz et al. 1988; Carnwath and Johnson, 1987) and this has also been demonstrated in other disabled groups (Schulz and Decker, 1985). The relationship between depression and less social support is maintained regardless of whether it is earlier or later after stroke (Thompkins et al, 1988). Patient studies have shown that social support and the ability to express social needs is associated with adjustment in stroke (Evans and Northwood, 1983) and adjustment in other patient groups including self-reported disability (Patrick et al, 1986), rheumatoid arthritis (Fitzpatrick et al, 1988) and spinal cord injury (Schulz and Decker, 1985). Social support and expressing social needs may be the reason why some individuals cope better in a crisis than others. Caregiving and high levels of caregiver strain may lead to isolation due to a lack of time to restore social networks (Lezak, 1978) and this has been demonstrated in studies of carers of patients with traumatic brain injury (Liss and Willer, 1990; Thomsen, 1984).

Studies of caregiving in chronic illness suggest that the number of social contacts is significantly related to the more positive aspects of caregiving (Rabins et al, 1990). However, these results are inconclusive. For example, Zarit et al (1980) reported that high numbers of outside visitors predicted low self-reported burden. In marked contrast, Colerick and George (1986) found that higher numbers of visitors predicted institutionalisation two years later. More recent studies suggest that satisfaction with social support may be more relevant than the number of social contacts. For example, studies have shown that the *perception* of the adequacy of social support, is associated with severity of depressive disorder (Morris et al, 1991). The importance of social contacts differs from individual to individual and therefore it is useful to look not only at actual size of social network and actual number of contacts, but at the ideal support the individual would like to receive to measure the discrepancy between them. According to Labi et al (1980) carers need to be restored to that level of social function which was NORMAL to them before the stroke; that is, support may be important to some carers but not Taking this into consideration it seems likely that a high others. discrepancy between actual and ideal amounts of social support received may relate to increased levels of strain experienced, low mood and poor adjustment.

It also seems tenable to consider that increased amounts of professional help and support might predispose lower levels of strain in the carers. The available literature on social support in caregiving is limited, often based on non-standardised measures of support, with the majority of studies

focusing on TBI or dementia caregivers. Social support needs to be investigated further in carers of stroke patients.

3.1.2 Individual differences

It is necessary in the study of caregiver strain to determine what modifiable factors would impact most strongly on caregiver quality of life, since some aspects, such as the patient level of disability or nature of impairments present, may be unalterable. Those factors which are potentially modifiable could then be identified by the hospitals and targeted in an intervention programme to reduce carer strain. Some features of the individual have traditionally been perceived as fixed and Personality traits have often been viewed as relatively unalterable. permanent and enduring characteristics. However, more recent approaches have concluded that individual differences in emotional and cognitive styles may be variable and potentially modifiable, and have accentuated the role of situational variables in the explanation of observed behaviour. Distinctions need to be made between state and trait concepts of individual differences and those patterns of behaviour that are temporary and situational need to be detached from those that are enduring and characteristic of the individual. Measures included in the present study aim to detect personal styles or dispositions that are expected to remain relatively stable over time. Since the focus of the study is factors associated with strain in carers of stroke patients, it is important to ask whether or not individual differences result in different levels of strain experienced. Is it possible to predict the level of strain a

carer will experience based on these trait and style differences? Level of self-esteem, personal control, emotional style and expressivity, positive and negative affectivity and dispositional optimism are examined for relationships with carer strain. This allows for the identification of individual differences that may predispose an individual to high and potentially damaging levels of strain.

3.1.2.1 Self-esteem

Self-esteem can be described as self-acceptance or a basic feeling of selfworth (Rosenberg, 1965). Studies using the Rosenberg Self-Esteem Scale and involving elderly participants have demonstrated gender differences. For example, in a study of 5,000 retired teachers and telephone company employees, Atchley (1976) reported that men had higher self-esteem than women. Age has been found to be unrelated to self-esteem (Kaplan and Pokorny, 1969). Predictors of self-esteem may be gender specific. Ward (1977) examined predictors of self-esteem in an elderly group (aged 60-92) and found that for women, attitudes towards old age are predictive of self-esteem, whereas for men, income and education are predictive of self-However, these studies are old and the results may now be esteem. outdated. The importance of informal social support in self-esteem has been demonstrated in studies of disabled patients (Fitzpatrick et al, 1988) and caregivers (Robinson, 1990). For example, Robinson (1990) assessed self-esteem on Rosenberg's Self Esteem Scale on a convenience sample of 31 adult caregivers. They found that a higher level of self-esteem was gained from increased affection and support from the social network,

whereas those with lower self-esteem reported losing a greater number of important relationships in the past year. Self-esteem has been found to be an important factor in the prediction of functional outcome for *patients* (n=152) following stroke (Chang and Mackenzie, 1998). Silliman et al (1986) found 84% of stroke carers in their sample reported increased selfesteem from caregiving. Nevertheless, there is a lack of studies that specifically address self-esteem in carers of stroke patients.

3.1.2.2 Health locus of control and attribution

Attribution Theory focuses on the way in which people attribute the cause of events to either dispositional (internal to the actor) or situational (external to the actor) causes. As a facet of the more general theory of attribution, the Locus of Control refers to the individual's perception of whether rewards are dependent on the individual's own actions, behaviour or personality or are dependent on forces external to the individual, such as chance, the environment or the acts of another. If the individuals' own behaviour is perceived to be the influential factor in the initiation of outcomes or rewards, it is labelled an INTERNAL attribution. Conversely, the perception of outcomes to be dependent on fate, chance or powerful others is labelled an EXTERNAL attribution (Rotter, 1966). The major difference between locus of control and attribution is that while attributional measures are concerned with the *causes* of past events, locus of control measures are concerned mainly with the *expectation* of future events.

Research on Attribution Theory originated from studies of the specific thought processes evident in depressed individuals. These demonstrated the increased vulnerability of those who habitually attribute negative outcomes to elements of their own personality (internal, stable or global factors) in the development of depressive symptomology. This suggested that individuals may manifest unique attributional styles which result in a regularity of attributions made across different situations and time scales, thus emphasising the role of attribution theory in the explanation of a more dispositional approach to causal behaviour. However, less evidence supporting the concept of an attributional style is available from the study of non-depressed individuals. Nevertheless, a growing body of research focuses on the relations between control beliefs and overall emotional health, specifically subjective well-being.

A number of researchers have provided evidence of relationships between views on control and various indices of mood, personality and states of being. Hanes and Wild (1977) found that external locus of control correlates with depression in the elderly, whereas internal locus of control has been associated with a positive self-concept (Reid et al, 1977; Fish and Karabenick, 1971) and higher morale (Chang, 1980). The type of attribution an individual makes may influence the way in which they contend with a threat to their own or others (in this case, a partner's) health. Turnquist et al (1988) proposed that certain attributions (usually internal) may help individuals to feel more in control of their situation and hence can be associated with better adjustment, facilitated recovery and increased emotional adaptation. Knowledge about locus of control may therefore be important in understanding an individual's behavioural response to a changed life situation.

Internals, for example are often 'active copers' who seek control over their environment often via simple methods such as information gathering. Partners and interests including religious beliefs are often used as a support system for these individuals. In marked contrast, externals are often 'passive copers', who submissively accept their situation, perhaps express guilt feelings and channel thoughts towards a more unrealistic view of religion as a 'cure' rather than a support. Externals are typically characterised by a strong sense of denial, which may lead to increased anxiety for these individuals. Donovan et al (1975) support the relationship between anxiety and external locus of control. Other research has shown that actions that promote individuals' maximum control over their lives will maintain or improve overall well-being (Fuller, 1978). Control is also related to psychological adjustment, life satisfaction and the self-concept (Zeigler and Reid, 1979). The relationship between gender and control beliefs is inconsistent. It has been suggested that men have more internal control orientation than women (Rotter, 1966; Palmore and Luikart, 1972). However, other studies have found no consistent gender differences (Hersch and Scheibe, 1967; Hamsher et al, 1968; Lichtenstein and Keutzer, 1967).

Locus of control has been investigated in relation to stressful life events such as recovery from illness. In a cross-sectional study of stroke and orthopaedic patients, tendency towards internal locus of control was related to better functional outcome than patients who identified chance

factors or other people, such as doctors, in determining their recovery (Partridge and Johnston, 1989). The multidimensional model expands on Rotter's original notion that individuals have a prevailing tendency towards a particular facet of control (e.g. internal versus external) and instead includes three main control components: self, others and chance. There is little published research addressing the relationship between attributional style and control beliefs with caregiver outcomes. A study of 19 spouses of patients with Motor Neurone Disease (MND) investigated the relationship between depression, strain and control beliefs (Goldstein et al, 2000). The authors found that depressed mood was not related to internal/external, stable or global attributions. However, perceived strain was greater in those carers who viewed their partner's illness as having a more global impact on their lives and was related to self-perceived control over their thoughts about their partner. No studies have been identified that address control beliefs in carers of stroke patients.

3.1.2.3 Positive and negative affectivity

There is extensive evidence available supporting the existence of two broad mood factors, positive affect and negative affect, as dominant dimensions in self-reported mood (Mayer and Gaschke, 1988; Watson and Clark, 1984; Watson and Tellegen, 1985). Despite a temptation to view these constructs as opposites within a single dimension, it must be recognised that these two mood dimensions are largely independent of one another and have distinct patterns of relations with other variables, for example, daily events, seasons or weather and both biological and social rhythms (Clark and Watson, 1988; Watson et al, 1988; Bradburn, 1969). It is possible for a person reporting high PA to report either high or low NA and the reverse, as the two dimensions have been shown to be virtually uncorrelated (Hillerås et al, 1998; Kercher, 1992; Watson and Tellegen, 1985; Diener and Emmons, 1984). Both negative and positive affect can be measured either as a state (e.g. transient fluctuations in mood) or as a trait (e.g. stable, individual differences in general affective tone). Negative affect (NA) is a general factor of subjective distress. It represents the extent to which a person experiences negative mood states, including upset, angry, worried, guilty, afraid and disgusted. High NA individuals often report distress, discomfort and dissatisfaction over time regardless of the situation, even in the absence of any overt or objective source of stress.

In contrast, low NA is characterised by mood states including calm, relaxed and at ease. When viewed on a state (rather than trait) level, NA is a broad and pervasive predisposition to experience negative affect (Watson and Clark, 1984). Whereas life satisfaction represents the cognitive component of subjective well-being, positive and negative affect represent the affective and emotional components of subjective well-being (Argyle, 1987; Myers and Diener, 1995). Research has demonstrated that high NA subjects are more introspective and honest with themselves, dwelling particularly on their failures and shortcomings. They also tend to focus on the negative side of others and the world in general and report a decreased desire for affiliation (Teichman, 1974). Consequently, they have a less favourable view of self and other people and are less satisfied

with themselves and with life. In marked contrast, the general positive affect (PA) factor subsumes a broad range of positive mood states, reflecting energy level, mental alertness, joy and enthusiasm, selfconfidence and determination. Overall, PA refers to one's level of pleasurable engagement with the environment. Low PA is related to quiescence and fatigue, for example, still, quiet, tired, sluggish, drowsy and dull.

Trait PA and trait NA roughly correspond to the dominant personality factors of extraversion and anxiety/neuroticism, respectively (Watson and Clark, 1994; Headey et al, 1984; Headey et al, 1985). Research has suggested that NA is related to self-reported stress and less adaptive coping strategies (Gunthert et al, 1999), health complaints (Denollet, 2000; Beiser, 1974; Bradburn, 1969; Tessler and Mechanic, 1978; Watson and Pennebaker, 1989) and reporting of stressful life events (Brett et al. 1990). In contrast, PA (but not NA) is related to social activity and satisfaction and to the frequency of pleasant events (Beiser, 1974; Bradburn, 1969; Clark and Watson, 1988; Watson, 1988). The distinction between NA and PA has generated an interesting pattern of the relations between affectivity, anxiety and depression. According to Watson et al (1994), negative affectivity can be viewed as a vulnerability factor for the development of anxiety and depression where positive affectivity is related more to depression. Thus NA is a confounding influence that is common to both anxiety and depression and is a major factor in producing the strong correlation found between them. In a sample of 159 psychiatric outpatient adults. Jolly et al (1994) found that negative affectivity

correlated with a broad range of anxiety and depressive symptoms but was not useful in differentiating anxiety from depression. Watson and Kendal (1989) remind us, however, that the data also suggest that the loss of pleasurable engagement (ie. low PA) is a significant and largely unique aspect of depression. Clarke et al (1994) also suggest that positive affectivity is related to depression and may be a risk factor for its development. Consequently, PA (rather than NA) may be an important factor in the differentiation between depression and anxiety (Watson and Tellegen 1985).

Denollet (1991) studied 178 male cardiac patients undergoing rehabilitation in order to investigate the relationship between self-reported stress and coronary-prone behaviour. They found that high-NA patients reported more negative mood states and health complaints than either low-NA patients or patients using repressive coping styles. Early work with undergraduate students also highlighted a relationship between high negative affectivity and increased self-reported somatic symptoms (Vassend, 1989). Positive and negative affectivity have been found to vary with age. For example, studies have shown that younger adults tend to report higher levels of PA and NA than older adults. The greater emotional turmoil experienced by younger adults may be a result of differences in life stages between young and old adults (Diener, 1984; Headey and Wearing, 1992; Myers and Diener, 1995; Stacey and Gatz, 1991). The literature on work-related stress has addressed the relationship between negative affectivity, gender, stress, strain and depression. In a study of 442 subjects, Heinisch and Jex (1997) provided support for the

moderating role of negative affectivity in the stressor-strain relationship. Negative affectivity was found to moderate the relationship between work stressors and work related depression in females but not males. Dowdy et al (1996) also demonstrated gender differences in the experience of negative affectivity in a study of community rheumatoid arthritis patients. In their study, women reported higher levels of negative affect then men.

A study of carers of chronic pain patients demonstrated a significant relationship between high NA and high levels of carer strain on the Caregiver Strain Index (Blake, 2000). However, these results may not generalise to stroke carers as the patient group in this study was younger and also carer age and kin relationship with the patients was varied. No studies have been identified that include the assessment of negative affectivity in carers of stroke patients or other elderly groups. The present study therefore addressed positive and negative affectivity and how these relate to levels of caregiver strain.

3.1.3.4 Dispositional optimism

Optimism has been defined as 'the generalised expectation of a positive outcome' (Schweizer et al, 1999). It is commonly believed that positive thinking can help a person endure personal hardship and triumph over adversity. Interest in the power of positive thinking has been popular for decades (e.g. Cousins, 1977) and has developed into a scientific interest in the beneficial effects of optimism as a personality trait and a coping mechanism. Dispositional optimism may have important implications for the way in which people deal with the stresses of life. An optimistic person may view outcomes as attainable and so will continue to exert efforts to attain these outcomes even when doing so is difficult. A pessimistic person, however, may view outcomes as unattainable, which may lead to reduced efforts and eventual disengagement. Outcome expectancies may therefore be influential in determining whether a person continues striving or gives up and turns away. The implications of positive and negative expectations have become evident in research on physical and mental health. Optimists have displayed better physical and mental health than pessimists (e.g. Peterson and Bossio, 1991; Taylor et al, 1992).

Studies have shown that optimism can impact on physical well-being. Reker and Wong (1983) measured optimism in institutionalised and noninstitutionalised elderly people, then measured physical, psychological and general well-being one year later. They found that individuals assessed as optimists reported fewer symptoms at follow-up along with more positive physical, psychological and general well-being. However, the results must be interpreted with caution, as their measure of optimism was a list of all positive things individuals had to look forward to in the future, rather than a standardised measure of optimism or outcome expectancies. Nevertheless, a prospective study of college students during the final few academic weeks of a semester also showed that optimism was negatively associated with physical symptom reporting (Scheier and Carver 1985, Study 3). Studies have investigated the link between outcome expectancies and development and recovery from disease. Cardiovascular responsivity has been implicated as a risk factor in the

development of coronary heart disease (eg. Krantz and Mantuck, 1984). Research has shown that pessimists show greater cardiovascular reactivity than optimists (Van Treuren and Hull, 1986) and so are at greater risk of developing cardiovasular disease. Scheier et al (1986) studied the impact of optimism on recovery of 54 patients from coronary artery bypass surgery. Results showed that although there were no significant differences between optimists and pessimists in post-operative health or risk factors, optimists were judged by members of the cardiac rehabilitation team as showing a significantly faster rate of recovery six to eight days post-operatively than pessimists. Optimists also showed fewer signs of intraoperative complications than pessimists and reported better quality of life six months post-operatively.

Some research has also led to speculation that optimism may be related to immunological functioning (Levy, 1986). The positive effects that dispositional optimism appears to have on health may be explained by self-regulation theory, which proposes that individuals who hold positive expectations for the future are more likely to make greater efforts to reach their goals than those who do not hold positive future expectations. It must be noted that although optimism can seemingly alter physical wellbeing, variations in health do not lead to changes in optimism over time (Scheier and Carver 1985, Study 3). Studies of caregivers involving the measurement of optimism are relatively sparse. Optimism has been assessed in studies of stroke patients. A study of stroke victims and primary support persons by Schulz et al (1988) showed that the level of optimism on the Life Orientation Test dropped over a six-month period

for both the patient and carer, although the magnitude of the drop was small. This research is consistent with the view that physical well-being is not a potent determinant of one's level of optimism and supports arguments that personality is robust in the face of major health problems (eg. Taylor, 1983). Nevertheless, Beckham et al (1995) studied 65 rheumatoid arthritis patients and their caregivers and found that patient physical status was strongly related to caregiver pessimism on the Life Orientation Test. Optimism has been associated with low levels of depression in caregivers (Sumi et al, 1997; Hinrichsen and Niederehe, 1994; Hooker et al, 1992). Fostering positive expectations may therefore lower levels of depression in caregivers.

In some research studies, optimism is measured by assessing related but distinct concepts such as, morale, self-esteem, satisfaction and attribution. Optimism is positively correlated with self-esteem (Marshall and Lang, 1990) and negatively correlated with depression (Scheier et al, 1994). Although optimism and pessimism are related concepts, they are not opposite ends of a continuum (Mroczek et al, 1993; Scheier et al, 1994). That is, an individual may lack optimism without necessarily being pessimistic. Although pessimism overlaps with depression, they also represent distinct constructs. There is an argument, therefore, for assessing life orientation (optimism and pessimism) in its own right. Scheier and Bridges (1999) evaluated the trait of optimism as a predictor of re-hospitalisation after coronary artery bypass surgery (n=309) using the Life Orientation Test. They found that optimism predicted a lower rate of re-hospitalisation, independently of self-esteem (on Rosenberg's

Self Esteem Scale) and depression (on the Center for Epidemiologic Studies Depression Scale). Scheier and Carver (1986) also found that optimism predicted outcomes that self-esteem did not. It is therefore valid to include both optimism and self-esteem scales in the present study as they are not measuring the same thing. Similarly, attributional style has been deemed unsuitable for the assessment of optimism. Studies have suggested that optimists are characterised by an Internal Locus of Control which indicates that their expectations are based on evaluation of their own resources (e.g Marshall and Lang, 1990; Schweizer and Schneider, 1997). However, according to Scheier and Carver (1986), 'locus of causality is not necessarily an important determinant of outcome expectancies. In order to adequately measure generalised expectancies for favourable or unfavourable outcomes, one must measure these expectancies per se. Locus of control is simply not a suitable proxy'. Hence, dispositional optimism was measured on a distinct scale in the present study.

Schulz et al (1996) have demonstrated age differences in optimistic and pessimistic tendencies amongst cancer patients (n=238) using the Life Orientation Test. They found that pessimism is a risk factor for mortality but only among younger age groups (ages 30-59). They suggest that younger people's endorsement of pessimism may reflect genuine hopelessness and despair about the future. However, they suggest that for older people, endorsing pessimism may simply reflect a coping strategy that has become adaptive in the face of a declining ability to control important life outcomes.

Although optimism is often considered to be a stable personality trait rather than a transient state, lability in optimism has been demonstrated. For example, Shifren and Hooker (1995) administered assessments of optimism every day, to 30 spouse caregivers of persons with probable Alzheimer's disease, over 30 consecutive days. Caregivers demonstrated variability in optimism over time.

3.1.3.5 Emotional expressivity

There is a substantial amount of literature which addressess the psychological responses of individuals to various emotions and the possible adverse consequences of such reactions. Emotional expressivity has been investigated in groups of cancer patients (Watson et al, 1991) and ulcer patients (Talley et al, 1988) although no studies have been identified that address control of emotions in either stroke patients or their carers. In a study of 359 women with early stage breast cancer, seen 1-3 months after diagnosis, Watson et al (1991) found that higher levels of psychological morbidity were associated with a tendency to control the expression of depression and anxiety. This in turn, they suggested, leads to feelings of helplessness. The authors also found a significant association between the control of anger and a helpless attitude.

A helpless attitude and fatalistic outlook may be of some prognostic significance (Schmale and Iker, 1961; Antoni and Goodkin, 1988; Jenson, 1987; Pettingale et al, 1985). Research has suggested that women with breast cancer are more likely to control emotions than those with benign breast disease or healthy controls (Morris et al, 1981; Wirshing et al,

1982; Pettingale et al, 1985; Anagnostopoulos and Vassilaros, 1986). Following these studies, Gross (1989) concluded from a review that emotional suppression might contribute some degree of risk in cancer patients. However, the evidence is not consistent. Studies of other patient groups have not found differences between patients and controls in emotional expression. Talley et al (1988) used the Courtauld Emotional Control Scale to assess emotional expressivity in 81 patients with essential dyspepsia and 53 patients with duodenal ulcer compared with 82 randomly selected dyspepsia-free community controls. No significant differences were found between groups in the control of anger, anxiety and unhappiness or overall emotional control.

Nevertheless, the way in which an individual psychologically responds to emotion may be of significance, and that effective coping may involve some 'ventilation' of emotions. Individuals who chronically block the expression of needs and feelings are known as 'Type C' individuals who hold the belief that 'it is useless to express one's needs' (Temoshok, 1987). The suppression of anger has been found to be a prominent feature of Type C behaviour patterns (Greer and Watson, 1985; Watson, 1990).

Watson et al (1991) suggest that people who demonstrate patterns of Type C behaviour are more likely to develop feelings of helplessness under extreme stress. Helplessness, as an emotional reaction, has also been associated with a more enduring attitude, or belief, regarding an individual's perception of control; that is, 'fatalism'. Watson et al's (1991) study proposed an overall link between emotional control, fatalism, helplessness and psychological morbidity. In order to

discourage fatalism, helplessness and the resulting anxiety and depression it has been proposed that by encouraging individuals to ventilate their emotions, perhaps even by therapeutic intervention, it may be possible to enhance quality of life (Collinge, 1987). In addition, the approach might focus more on the development of a more 'internal' locus of control as opposed to a more helpless 'external' locus of control connected with fatalism. Although research on emotional control is limited to the reactions of clinical patients and no studies of control in caregivers have been identified, there is much scope for further investigation of emotional suppression in carers of clinical patients.

3.1.4 Mood

Rather than dealing with trait measures of emotionality or factors which moderate the impact of stressors (e.g. coping and social support) this section deals with overall mood and transient, 'here and now' emotional states. Neugarten et al (1963) have proposed five factors as being essential to positive well-being. Firstly, that the individual takes pleasure from the round of activities that constitute everyday life and secondly, regards his/her life as meaningful, accepting resolutely that which life has Thirdly, the individual should feel that they have succeeded in been. achieving their major goals and fourthly, should possess a positive image of themselves. Finally, essential to well-being is that the individual maintains happy and optimistic attitudes and mood. The general consensus in the literature is that caregiving can have detrimental effects on emotional health (Dennis et al, 1998; Greveson et al, 1991; Draper et

al, 1992; Schulz et al, 1988; Cantor, 1983), which may persist even after nursing home placement or death of the patient (Bodnar and Kiecolt-Glaser, 1994). This pattern has been found in carers of various patient groups including stroke (Dennis et al, 1998), traumatic brain injury (Mitchley et al, 1996), Alzheimer's (Haley et al, 1997) and cancer (Rabins et al, 1990), although prevalence rates of emotional difficulties vary across patient disorders (Rabins et al, 1990).

Estimates of the prevalence of depression among carers of stroke patients vary from 34% (Schulz et al, 1988) to 55% (Dennis et al, 1998) depending on the assessment scales used. One study demonstrated that stroke caregivers were statistically more depressed than a control group on the Zung Self-Rating Depression Scale (Reese et al, 1994) although the study did not report the proportions of depression in the caregiving and control Depression may be longstanding, with caregivers who are groups. initially depressed after stroke being the most likely to remain depressed at follow-up one year later (Tompkins et al, 1988). The high prevalence of emotional problems is not surprising given the persistence of negative attitudes and unrealistic expectations often held by carers, which may render them prone to depression. Qualitative research has shown that patient and carer's expectations of recovery may differ greatly from the professional's goals for rehabilitation (Hart, 1998) and an early study showed that at least 65% of spouses still expected the patient's full recovery even up to 16 months after stroke (Kinsella and Duffy, 1979). Nevertheless, it should be recognised that many studies of stroke caregivers rely on small sample sizes and self-selected, opportunistic

samples that may be biased towards more depressed carers. No studies have been identified that estimate the prevalence of depression in random samples of stroke caregivers.

Caregiver mood is important as it has been suggested that emotional distress is a primary factor relating to caregiver burden (Scholte op Reimer et al, 1998). In addition, depression in the carer may impact negatively on the 'homecare' routine and patient rehabilitation (Evans et al, 1991) up to a year after stroke. Therefore, identifying low mood and helping spouses to overcome their depression might play an important role in patient rehabilitation. Indeed, Bedsworth and Molen (1982) reinforced the view that the attitudes of family members may impact strongly on patient's reactions to medical regimens, emotional adaptation and Research has suggested that successful rehabilitation rehabilitation. depends on the degree to which social interests, activities and occupations are taken up again (Gresham et al, 1979). Carnwath and Johnson (1986) found that social rehabilitation after stroke was less successful when the spouse was depressed. They concluded that proper attention paid to the spouses of patients with stroke might improve the prospects of these patients.

Caregiver mood has been related to patient disability and patient mood. For example, Dennis et al (1998) investigated the emotional outcomes of those caring for stroke patients and attempted to identify both patient and caregiver factors that were associated with poor caregiver outcomes. Two hundred and forty-six caregivers were interviewed six months after stroke, as part of a randomised trial to evaluate a stroke family care worker. Both

patients and caregivers were asked to complete two measures of emotional distress: the General Health Questionnaire-30 and the Hospital Anxiety and Depression Scale (HADS). They found that 55% of responding caregivers scored more than four on the GHQ-30, indicating that emotional distress was common in their sample. Regression analysis showed that caregivers were more likely to be depressed if the patients were severely dependent or were emotionally distressed themselves. Previous studies have supported the notion that caregiver depression is related to depression in the patient (Drinka et al, 1987) and patient functional disability (Wade et al, 1986; George and Gwyther, 1986; Poulshock and Deimling, 1984; Robinson, 1983; Silliman et al, 1986; Cantor, 1983), although these studies are relatively old and failed to include detailed assessment of patient attributes such as cognitive deficits or measures of caregiver personality characteristics.

In an early study of 103 stroke couples in Stockport, Carnwarth and Johnson (1986) conducted assessment interviews comprising the Psychiatric Assessment Schedule and the Hamilton Depression Rating Scale for the spouses, and the Barthel Index and the Frenchay Activities Index for the patients. They found that between one and three years after stroke, carers were more likely to be depressed (39% compared with 12%) and exhibit more physical symptoms than the control group of 51 age matched normal elderly. Depression in the spouse increased with severity of stroke and with time during the three years. In a two-year longitudinal study of a community sample of carers, Wade et al (1986) found that

patient's functional disability was associated with depression in the caregiver over the first year, but not at two years.

Other studies have found no significant relationship between emotional distress and patient disability. As part of the follow-up for the Perth Community Stroke Study (Anderson et al, 1985), 84 one-year stroke survivors with residual handicap, and their chief caregivers underwent a semi-structured interview. Emotional distress was assessed in the caregivers using the Hospital Anxiety and Depression Scale and the 28item General Health Questionnaire. The patient's functional state was assessed on the Barthel Index, the Mini-Mental State Examination, the Frenchay Activities Index and the Psychiatric Assessment Schedule. Sections from the Social Behaviour Assessment Schedule were used to assess the patient's behaviour and the impact on the caregiver's life. Caregivers were predominantly female spouses, other carers including children, siblings, nieces, nephews, grandchildren and one neighbour. Eighty-eight per cent reported adverse effects on their lives including emotional health, social activities and leisure time and adverse effects on social relationships. Fifty-five per cent scored above the cut-off for emotional illness on the two screening instruments, HADS and GHQ. No association was found between the provision of formal services and levels of emotional distress amongst caregivers and there was no relationship between emotional illness among caregivers and the degree of disability in the patient. Individual differences of the caregiver were not accounted for.

Some researchers have suggested that patient factors may be less important in determining carer distress than caregiver factors. McClenahan and Weinman (1998) administered questionnaires to carers of people with non-acute aphasic and non-aphasic stroke, assessing distress, perceptions of stroke, generalised self-efficacy, optimism, coping strategies, self-rated physical health and social support. They found that stroke disability and aphasia did not account for carer distress, but that a significant amount of carer distress was accounted for by carer factors. However, the study addressed caregiver strain in carers from a range of kin relationships, although the majority were co-resident with the dependent person. Carer mood on the General Health Questionnaire was taken as the outcome rather than caregiver strain and so caregiver 'appraisal', often assessed on a measure of stress, strain or life satisfaction, was not accounted for. Although patient characteristics included disability, intelligence and language there was no assessment of specific and perhaps more subtle deficits such as memory and executive Nevertheless, the inclusion of carer dispositional measures function. suggested that carer factors may be of great importance.

Gilleard et al (1984) found that poor mood on the GHQ was associated with poor self-rated health of caregivers. This lends support to the view that psychological outcome may in fact be determined by cognitive appraisal. In a study of fifty one-year survivors of stroke and their carers, Hodgson et al (1996) conducted assessments of a range of demographic, environmental and psychosocial variables at three months post-stroke. Psychological well-being of the carers was assessed at 12 months using

the General Well-Being Index. Within this sample, the three most significant predictors of carer well-being were carer's appraisal of caregiving stress, carer's physical health and carer's satisfaction with service provision. From this they concluded that cognitive appraisal is an important determinant of psychological outcome (Schulz et al, 1988; Taylor, 1983). The results of this study provide support for findings from studies in other caregiving populations (Zarit et al, 1986; Chwalisz, 1992). Some studies have suggested that women experience greater strain (Enright, 1991), burden (Miller and Cafasso, 1992) and psychological distress (Schulz et al, 1993; Zarit and Whitlach, 1992) than men. Briscoe (1982) suggested that this gender difference might be due to differences in emotional expressiveness, and Zarit et al (1981) claimed that the difference could be attributed to some particular differential stressfulness for women caring for elderly infirm relatives. Either way it must be noted that in the majority of studies, caregivers are mostly women.

3.1.5 Life satisfaction

Life satisfaction can be described as a facet of overall well-being. Although most measures of adult well-being incorporate measures of level of activity and social involvements, it may not be appropriate to measure well-being in old age by the same standards that apply to middle age. The concept of life satisfaction focuses on the individuals themselves as the only judge of their well-being and is centred around the individual's own internal frame of reference.

It has been described as a comparison reflecting a perceived discrepancy between a person's aspiration and their achievement (Campbell et al, 1976). Whether or not an individual is inherently satisfied with their life is not dependent upon the conditions which befall them but upon their own interpretations, perceptions and feelings. According to Palmore and Luikart (1972), life satisfaction should be a major component of any comprehensive conception of 'adjustment' or 'mental health'. The more satisfied tend to be healthier, more socially active, tend to have more income and education and tend to be younger (Palmore and Luikart, 1972).

Many studies have identified low life satisfaction in caregivers. For example, Schofield et al (1999) examined differences between women family caregivers (n=857) of people with chronic illnesses or disabilities and a group of women non-caregivers (n=219) in life satisfaction and other variables such as physical and psychological health and social support. The study utilised a computer-assisted telephone interviewing system, a random survey of 26,000 households and interviews with a representative sample of caregivers. Schofield and colleagues found significantly lower levels of life satisfaction among the caregiving group than the control group.

Reduced life satisfaction has also been found specifically in elderly caregiving groups. In one study, 44 caregivers of patients with senile dementia were compared with 44 matched controls in a series of questionnaires and interviews. Caregivers reported significantly lower overall life satisfaction than controls (Haley et al, 1987).

Aarsland et al (1999) compared 94 caregivers of persons with Parkinson's disease with two control groups (patients with diabetes mellitus and healthy elderly). They found that caregivers, in particular, spouses, had lower satisfaction with life compared with healthy elderly subjects. Life satisfaction is important as decreased life satisfaction has been associated with high levels of burden across caregiving groups, including caregivers of adults with dementia (Acton, 1997; Haley et al, 1995) and multiple sclerosis (Knight et al, 1991; O'Brien et al, 1995). Sugisawa et al (1992) conducted a survey in Tokyo of self-rated health and life satisfaction of 94 caregivers of elderly persons living at home and 73 of these were included in a survey four years later. They found that a decrease of cognitive ability of the elderly person, low social support and negative perception regarding caregiving, measured at baseline, was associated with reduction in life satisfaction after a four-year interval.

Life satisfaction in carers of elderly people was measured as part of the Sydney Older Persons Study, involving 630 elderly people in Australia. Caregivers were divided into 'full carer' (n=21) or 'partial carer' (n=187) depending on the amount of time spent caregiving. Full carers reported lower life satisfaction than non-carer groups (Broe et al, 1999). This suggests that a greater amount of time spent caregiving is associated with a reduction in life satisfaction. Decreased life satisfaction has been reported among 170 spouses of former stroke patients who were between three and eight years post-stroke (Coughlan and Humphrey, 1982). Research has indicated that some forms of leisure activities may contribute to life satisfaction, particularly those that involve social

support. For example, increased life satisfaction has been associated with informal contacts with friends (Lemon et al, 1972; Martin, 1973) and membership in formal organisations (Bull and Aucion, 1975).

Palmore and Luikart (1972) proposed that self-rated health is, by far, the strongest variable related to life satisfaction. Early studies have provided support for this theory and shown that physical health is associated with life satisfaction in old age (Kutner, 1956; Maddox and Gisdorfer, 1962). However, an individual's perception of their own physical health may be of more importance than objective assessments of health. Since life satisfaction is dependent upon the individual's own perceptions, interpretations and feelings, it may be influenced more by a person's own evaluation of their health than by the objective rating of their health. For example, a person may have greater satisfaction with their life if they believe that their health is good, even if their objective health is poor. Conversely, a person who believes their health is relatively poor even if their objective health is good may have low life satisfaction. This highlights the importance of the individual's internal frame of reference; interpretations, perceptions and feelings. In addition to physical health, research has suggested that life satisfaction may be related to mental health of the caregiver. For example, a low level of life satisfaction has been associated with psychiatric morbidity in caregivers of persons with dementia (Schulz et al, 1995). Personality traits may also be important. Studies have investigated the role of attributional style in satisfaction with life. A higher satisfaction with life has been associated with an Internal Health Locus of Control (Palmore and Luikart, 1972) suggesting that

those who believe that they have more control over their lives are more satisfied than those who believe that their life is controlled by powerful others, or forces such as luck, fate or destiny. It has been suggested that this may be due to the fact that Internal control has been associated with such concepts as autonomy (Erikson, 1959; Havighurst, 1963), competence (Neugarten, 1963) and achievement motivation (Atkinson and Feather, 1966). Wallhagen (1992) also linked perceived control with life satisfaction in elderly caregivers (n=60). However, no studies have been identified that address life satisfaction in caregivers of patients with stroke.

3.1.6 Adjustment

Adjustment is a multifaceted concept, influenced by many factors including social support, physical and mental health and so on. These factors are addressed elsewhere in this chapter. There are relatively few studies of adjustment per se as many studies simply take measures of mood, for example, to represent level of adjustment. Maladjustment is common in stroke caregivers. Holbrook (1982) found that one third of stroke patient's families in their sample described themselves as not yet adjusted between two and five years after stroke. Adjustment for the caregiver not only refers to the physical aspects of dealing with new life circumstances. Adjustment may also involve structural changes to the home in order to accommodate disabilities of the stroke patient, which may restrict living space. In addition to this, carers may have to adapt to a life with little or no time alone, and less time for social interaction (Nichols, 1980; Saxon and Etton, 1984).

Adjustment after stroke often involves some kind of role reversal. For example, a spouse who has always assumed the dominant role in the marriage may find it very difficult to change from being breadwinner, driver and maker of executive decisions to a more subservient role, and to being dependent upon spouse and children for many activities. Similarly, a spouse who has always been dependent may find difficulty with taking over the executive role within the household. A previously dependent spouse may have to adjust to the role of dealing with all business and finance at the same time as encouraging an unhappy spouse (Holbrook, 1982). Changes to established patterns of daily life can represent a major strain for carers (Periard and Ames, 1993). Qualitative American studies of the effects of stroke on wives of stroke patients have demonstrated the unfamiliar new responsibilities of role changes, in addition to caring for the stroke patient (Rosenthal et al, 1993; Enterlante and Kerne, 1995; Robinson-Smith and Mahoney, 1995).

Caregiver adjustment may be related to aspects of the patient's illness. Communication difficulties, for example, may have a profound effect on adjustment after stroke. In an early study by Artes and Hoops (1976), the attitudes of wives whose husbands had aphasia were compared with the attitudes of wives whose husbands had suffered a stroke without loss of language function. They found that adjustment problems were greater in the wives whose husbands had aphasia after stroke.

Similarly, Christenson and Anderson (1989) proposed that stroke with aphasia impacted more negatively on the caregiving partner than stroke without aphasia. Kinsella and Duffy (1979) studied 79 spouse caregivers of stroke patients and found that spouses caring for a partner with aphasia showed poorer overall social adjustment, especially within social and leisure activities and marital relationships. However, the relationship between communication difficulties and adjustment is not consistent. Rau et al (1986) found that adjustment and burden of spouses did not differ with respect to the presence or absence of aphasia in the stroke spouse.

It is well documented that social support plays a mediating role in adjustment to undesirable life events (Lin et al, 1986; Barnett and Gotlib, 1988; Sarason et al, 1985; Schaeffer et al, 1981). Social support has been associated with adjustment in patients with stroke (Evans and Northwood, 1983), self-reported disability (Patrick et al, 1986) and spinal cord injury (Schulz and Decker, 1985). It is possible that caregiver adjustment may also be related to social support. However, stressors and mediating factors may be different in caregivers than patients. Indeed, studies have shown that patient adjustment to stroke does not necessarily lead to caregiver adjustment (Holbrook, 1982).

Both stroke patients and their carers have been found to be better adjusted if they reported finding meaning in the experience, if they did not hold themselves responsible and if they had identified a 'cause' of the stroke (Thompson and Sobolew-Shubin, 1993). However, it is difficult to determine whether successful adjustment leads to a reduction in the tendency to blame oneself or vice versa. Adjustment is important as those

who are better adjusted are likely to suffer from lower levels of psychological distress and caregiver strain and this has been demonstrated in caregivers of other patient groups (Blake, 2000). As previously discussed, those carers with increased levels of caregiver strain may be less likely to continue successful home care and more likely to institutionalise the patient.

3.1.7 Stress

Stressful life events are not themselves the cause of illness and poor health. Health risks elicited by certain stressful life events depend on the transaction between the person and the environment (Lazarus, 1966; Lazarus and Folkman, 1984). Researchers have suggested that perceived stress moderates the relationship between negative life events and the experience of depression (Kuiper et al, 1986). In the study by Kuiper and colleagues, for those who were low on perceived stress, negative life changes had only a minimal impact on depression level. For those high on perceived stress, the positive relationship between negative life changes and depression was more pronounced.

High stress levels have been demonstrated in various caregiving groups. Mayou et al (1986) found that one-quarter of spouses of patients with myocardial infarction recorded moderate to high stress two months after the episode. In a study of relatives of patients with closed head injury, almost two thirds of the sample suffered from high levels of stress during the first year (Brooks and McKinlay, 1983). Research has suggested that perceived stress may be associated with patient disability and this has

been demonstrated in spouses of heart patients (Croog and Fitzgerald, 1978) and carers of elderly dependants (Jones and Peters, 1992). In a sample of 263 wives whose husbands suffered a first myocardial infarction, Croog and Fitzgerald (1978) examined stability and change in reported subjective stress. They found that patterns of subjective stress remained relatively stable over the year of study. Stress appeared to be related to the level of severity of illness in the husbands at particular points in time, although the results were not consistent. Jones and Peters (1992) studied 256 carers of dependent elderly people and found stress to be significantly related to disability of the dependant.

3.1.8 Length of time caregiving

Neurological function often improves significantly within the first three weeks after stroke and functional recovery can continue up to 18 months after stroke (National Stroke Association, 1986). Thus, stroke patients at different time periods after stroke have a different severity of functional and neurological impairment. Studies have suggested that post-stroke patients may be more likely to develop dementia over time (Wilkinson et al, 1997). The impact of caregiving is therefore likely to differ over time due to the level of adjustment and adaptation of caregivers and the changing status of the patient. The measurement of time interval after the stroke may therefore be an important factor in studies of caregiving.

However, time since the stroke is rarely measured and results of studies addressing the influence of the length of time in the caregiving role have been inconclusive. Some researchers have shown that emotional and

physical problems encountered in spouses and carers of stroke patients (Fitzgerald, 1989; Carnwarth and Johnson, 1986) and other elderly carers (Gaynor, 1990) increase with length of time in the caregiving role. In contrast, Blood et al (1994) found that strain in spouses of patients with laryngeal cancer decreased with time from the diagnosis.

Emotional problems decreasing with time has also been demonstrated in studies of stroke carers. Two studies demonstrated that spousal caregivers were more likely to be depressed during the acute care phase after stroke than during the chronic phase (Schulz et al, 1988; Tompkins et al, 1988). Other research has not shown any significant association between length of time in the caregiving role and negative caregiver outcomes such as depression or anxiety (Williams, 1993; Draper et al, 1992; Ross and Morris, 1988).

It is possible that kin relationship with the care receiver may influence the relationship between strain and time in the caregiving role. For example, Seltzer and Li (1996) showed that daughters in the later stages of caregiving had a more distant relationship with the care recipient and more subjective burden than daughters in the earlier stages. In contrast, wives who had provided care for a longer duration of time reported lower levels of burden than those who had been caregiving for a shorter time. Those in the later stages of caregiving also reported having a closer relationship with their spouse (Seltzer and Li, 1996). Nevertheless, the results reported in Chapter Two did not reveal any significant relationship between strain and length of time caregiving. Previous published research has revealed contradictory findings, although this might be explained by

the differences in measures used to assess levels of distress or burden and differences across patient illnesses and kin relationships.

The previous study assessed carer strain at three and six months after stroke. However, these assessments may have been too close in time to reveal any differences that may have existed between those new to the caregiving role and those who had been caring for many months or even years. Examining the relationship between strain and time in the caregiving role needed to be done in a large, cross-sectional sample of spouses. In the present study, length of time caregiving was taken to be the length of time that had passed since the occurrence of the stroke.

3.2 Methods

3.2.1 Ethical consideration

Ethical Approval for the research study was granted in February 1997 by the Nottingham City Hospital Research Medical Ethics Committee. Approval was granted for postal contact of carers, and telephone contact or home visits to carers when it was requested. A covering letter sent with the questionnaires explained the objective of the study and reassured carers that any information they provided would be treated as confidential material. Carers were also reassured that non-completion of the forms would not in any way affect their future care. Carers who did not wish to be involved in the study were asked to telephone or write to the researcher to inform her that they did not wish to be involved. As the voluntary nature of the research was emphasised in the covering letter, it was assumed that by completing and returning the form the carers who

responded had consented to their involvement in the study, therefore a signed form from the carers was not required.

3.2.2 Nottingham City Hospital Stroke Register

Patients admitted to City and University Hospitals, Nottingham, who had a stroke according to the WHO (1978) definition, were recorded on a register. Names on the register were obtained from those admitted to all general medical and health care of the elderly wards of both hospitals and additional information was obtained from patient medical notes.

This register was updated on a weekly basis and contained demographic information, such as name, gender, marital status and admission details.

3.2.3 Selection of subjects

Co-resident spouses of patients on this hospital register, who had a stroke between 1995 and 1997, were considered for inclusion in the study. As carers are not registered like stroke patients, carer information was more difficult to obtain. Spouses were identified using the Patient Administration System (PAS), which contains information about marital status in addition to the demographic information of the patient. Further information about the carer was not available from this register. The name and telephone number of each patient's General Practitioner (GP) was extracted from this register, and all GP's were contacted in order to check whether the address and marital status had changed since the recording of the register. There were a total of 1,350 patients on the stroke register in July 1997. Of these, 885 patients were either living in nursing or old
people's homes, were in hospital, had moved away or were unobtainable, or had died. There were 465 patients on the stroke register, who were living in the community with an identifiable co-resident spouse. A series of questionnaire measures were sent to the carers. Due to the large number of measures being used, the questionnaires were compiled in two separate batches.

The 465 spouses were sent the first batch of questionnaires. Those who had not returned the first forms within one month were recontacted and reminded about the questionnaire. They were invited to either request another questionnaire (had the first been mislaid), seek help or advice on its completion over the telephone or arrange a home visit for physical help with its completion. Information was collected by postal questionnaire unless the carer required help with completion of the forms. In these situations, home visits were made or help was provided over the telephone. Help was given reading the questions or writing the answers, but no extra information was provided, so that data from these questionnaires was comparable with that received through the post. Carers were reminded that they were under no obligation and should they not wish to take part, they should ignore the reminder and dispose of the form, had they not already done so. Approximately two weeks after return of the first questionnaire, a second was sent out, again with a covering letter explaining the voluntary nature of the research and a replypaid envelope for convenience.

3.2.4 Procedure and data collection

To provide a comprehensive and interpretable data set it was thought that standardised measures (ie. measures administered in a consistent way on each occasion) would be the most appropriate. These measures should demonstrate good reliability and validity, and given the large number of measures being administered, should also be easily understood by the target sample and relatively quick for self-administration. A single caregiver strain or burden scale used in isolation was not considered appropriate, as this would only provide a global measure of strain and would not alone permit adequate understanding of the mental and physical health effects and psychosocial outcomes of caregiving. Since the current research attempts to understand which aspects of caregiving appear to be particularly stressful together with the overall range of effects of caregiving it was thought that a combination of measures would be more useful. In accordance with the model outlined in Chapter One, the study therefore incorporated measures of overall stress and strain, personality characteristics of the carer (attributional style, self-esteem, emotional style etc), measures of carer and patient mood and disability and a measure of financial strain included in an assessment of carer 'handicap'. There were also measures of overall life satisfaction and adjustment and level of support from both informal and formal services.

3.2.5 Assessments

Data was collected in a total of 14 standardised measures. As the study incorporated a large number of measures, they needed to be compiled into two batches of assessments. It was necessary to decide which measures would be included in which package. It was decided that the Caregiver Strain Index (CSI) should be included in the first batch as this was considered the most important scale. Factors that have been strongly associated with carer strain in the literature, such as patient and carer mood, health of the patient and the carer and social support, were included in the first questionnaire. The measure of adjustment was also included in the first questionnaire. The first questionnaire therefore addressed existing physical status of patient and carer, the carers' reactions to the caregiving situation (mood, adjustment) and their perceptions of their partner's reaction to their stroke and external resources of informal support available to them. Measures such as these are frequently used in research on stroke rehabilitation for the patient and the carer and so carers may be more familiar with the style of the questions and may have completed the same or similar scales as part of another research study. It was thought that it might be more appropriate to have the more familiar measures included in the first contact with carers, as this may encourage return of the forms.

Therefore, batch one incorporated the following:

- □ Caregiver Strain Index (Robinson, 1983)
- □ *GHQ-12 (Goldberg, 1978)*
- □ London Handicap Scale (Harwood and Ebrahim, 1995)

□ Acceptance of Illness Scale (Felton, 1984)

□ Significant Others Scale (Power et al, 1988)

Since it was thought to be the carers' perception of the situation that would determine the level of strain, the carer completed the following for the patient, to provide the carers' subjective perception of the patients' mood and disability:

□ *GHQ-12 (Goldberg, 1988)*

• Extended Activities of Daily Living (Nouri and Lincoln, 1987)

The rest of the assessments addressed stress, life satisfaction and the individual differences in the carers. These measures contained many personal questions and measures of personality characteristics, which many carers would not be familiar with, as these are not so frequently used in research on stroke rehabilitation. It was though more appropriate to include these in the second contact with carers so as not to initially deter carers from completing and returning the forms.

Therefore, the second batch of measures incorporated the following:

□ The Perceived Stress Scale (Cohen et al, 1983)

□ Rosenberg's Self-Esteem Scale (Rosenberg, 1965)

D Courtauld's Emotional Control Scale (Watson and Greer, 1983)

D Multidimensional Health Locus of Control Scale (ref)

D The Life Orientation Test (Scheier and Carver, 1985)

D The Positive and Negative Affect Schedule (Watson et al, 1988)

D The Satisfaction with Life Scale (Deiner et al, 1985)

Gender and relationship with the patient were available from PAS and the stroke register. The carers' date of birth had been requested on pilot forms, but had only been completed by one out of nine carers involved and so was not included on the form rather than gaining an incomplete data set. It was therefore assumed that the carers, as co-resident spouses, would probably represent a similar age distribution to the patients themselves.

Reliability of each measure within the *present* sample is provided in the results section only for those measures where individual items were available for analysis. Published support for the reliability of each measure is included in the following sections where possible.

3.2.5.1 Caregiver Strain Index (Robinson, 1983)

This measure was discussed in detail in section 2.2.5.2. The CSI (see Appendix 12) was slightly modified for use in the present study in that the score categories changed from were simple yes/no а to never/rarely/sometimes/often. The method of scoring was 0,0,1,1 in order to classify carers into 'cases' of those who were strained and those who were not. In order to maintain comparability with other studies using the CSI, 'sometimes' and 'often' was compared with an answer of 'yes' (with that factor representing a significant strain) on the standard version of the CSI. This was intended to make the scale easier to understand for carers, rather than asking them to judge a situation which may occur sometimes, but not all the time, as a straight answer of 'yes'. Although the classification of 'caseness' was required for the analysis of the current study, this expanded version of the CSI allows for 0,1,2,3 scoring to detect severity of strain, which may be required in further analysis. This method of scoring may render the scale more sensitive to detecting carers under strain and may detect strain not picked up by the simple dichotomous selection. According to Streiner and Norman (1989) adjective scales provide more information and are more reliable than dichotomous judgements.

3.2.5.2 General Health Questionnaire (Goldberg, 1988)

Although the ideal method of assessing mood is by psychiatric interview, the study was postal and so a self-report measure of mood was required. The GHQ is a self-report questionnaire used to detect non-psychotic psychiatric disorder in people in both community and medical settings. There are several versions of the GHQ including 12, 28, 30 and 60 items. The GHQ-12 (see Appendix 13) was selected as the measure to be used in This scale has 12 items assessing present mood state in this study. relation to usual mood state. There are two possible methods of scoring; GHQ scoring (or binary method) which assigns either a '0' or a '1' to each answer, or Likert scoring, which assigns either a '0', '1', '2', or '3' to each answer. Higher scores with binary scoring are indicative of a higher probability of clinical disorder. Higher scores with Likert scoring indicate increased severity of clinical disorder. In the original development of the GHQ-60 scale, the sensitivities of both scoring methods were compared and generally produced similar results.

Goldberg and Williams (1988) showed that little difference in results could be found between the scoring methods and suggested that little is gained by a Likert severity score. Binary scoring was therefore selected

as the interest lay in 'caseness' not severity. For the purposes of this study, the conventional cut-off point of 2/3 was adopted, where those scoring 0, 1 or 2 were designated non-cases and those endorsing three or more items were designated cases³. The GHQ-12 shows evidence of reliability and validity (Hardy et al, 1999). The original validation study showed sensitivity to be 93.5% and the specificity in detecting cases of disorder to be 78.5%. Later studies have reported 74% and 84% respectively (Hardy et al, 1999). Over 50 validity studies have been conducted. Predictive validity is good when compared with other wellknown tests of depression (Goldberg, 1985; Williams, 1987). Split-half and test-retest reliability studies have been carried out showing good results (Goldberg and Williams, 1988). The GHQ has been shown to be a sensitive measure in studies of stroke rehabilitation (Juby et al, 1996; Dennis et al, 1997). The GHQ-12 was selected for the study as it is brief and easily administered and has been used in other studies involving elderly stroke patients and their carers (Lincoln et al, 1998; Walker et al, 1999) and other elderly groups (Payne et al., 1999). It is well-validated for self-administration in a British population and has also been validated for other populations and translated into at least 38 languages. Although questions in version 12 are not classified in subscales (somatic, anxiety and insomnia, social dysfunction and severe depression) as in the 28 version, the GHO-12 was chosen in preference to the GHQ-28 and other

 $^{^3}$ Although a threshold of 2/3 has been widely utilised, work published after completion of the study has revealed that a cut-off threshold of 3/4 may be more appropriate to obtain caseness rates (Hardy et al, 1999).

depression scales as it does not include questions about suicide which may discourage carers from completing and returning the forms. It also does not include questions that may be endorsed only by those who are physically ill. The GHQ-12 has been used in studies of informal caregivers (Horsley et al, 1998) including caregivers of Alzheimer's patients (Schneider et al, 1999) and stroke caregivers (Harding and Lincoln, 1998).

3.2.5.3 London Handicap Scale (Harwood et al, 1994)

Handicap can be defined as "the disadvantage experienced by an individual due to ill health". The London Handicap Scale (see Appendix 14) was developed as a generic health status measure for quantifying this disadvantage. The measure takes account of both the physical and psychological aspects of handicap. The LHS generates a profile of handicaps on six different dimensions together with an overall handicap severity score. The six dimensions are mobility, physical independence, occupation, social integration, orientation and economic self-sufficiency. Each dimension consists of a question, which the subject is asked to read and then select (by ticking a box) one of six responses of increasing severity (response one denotes no disadvantage and level six denotes extreme disadvantage).

Overall handicap severity scores are calculated using a table of scale weights. Total score is out of 100 where a lower score indicates increased handicap⁴.

The LHS has been validated specifically for use with stroke patients (Harwood and Ebrahim, 1995; Goonetilleke and Harwood, 1995; Harwood et al, 1994). It has been found to have good reliability (Harwood et al, 1994; Harwood and Ebrahim, 1995) and is sensitive to differences between groups in intervention studies (Harwood and Ebrahim, 1995; Walker et al, 1999). Since this study was designed, a new handicap scale has been developed for use with the elderly, which significantly correlates with the London Handicap Scale and other indices of disability and handicap (Rai et al, 1999). However, the scale was developed specifically for use with hospitalised patients and so the London Handicap Scale was thought to be a more appropriate measure for use in the community. The London Handicap Scale is appropriate for this study as it was designed for use with elderly people and was intended for self-completion so is appropriate for a postal study.

As the authors point out, handicap refers to individual perception. Disadvantage, therefore, is phrased in a more general nature leaving overall interpretation open to the individual user.

⁴ Research published after the completion of this study on the validity of a simple summation scoring technique found that simple summation scoring did not lead to any change in the properties of the instrument compared with standard weighted scoring (Jenkinson et al, 2000). The authors therefore recommend summation scoring as it is easier to calculate and interpret. However, the old and new methods are comparable and since the old method has been frequently utilised it was not deemed necessary to retrospectively change the method of scoring.

For example, on the mobility dimension, disadvantage is suffered when the carer cannot move as far as they would like. However, how far they actually want to move and the degree to which this is compromised, is subjective. Professionals may make poor judgement about the quality of people's lives, which implies that more accurate data would come from the individual themselves. Previous research has documented that selfrated health is a strong correlate of objective measures of health and that it predicts subsequent mortality more accurately than physicians' reports or medical records (La Rue et al, 1979; Mossey and Shapiro, 1982). It has been reported that many measures lack a clear conceptual base (McDowell and Newell, 1996; McDowell and Jenkinson, 1996). The LHS however is based on the World Health Organisation's international classification of impairments, disabilities and handicaps (ICIDH) (WHO, 1980). Each of the six dimensions of handicap outlined by the ICIDH are addressed by the LHS. A more recent framework of the WHO has replaced the term 'handicap' with 'participation' (WHO, 1997). Nevertheless, the dimensions of the LHS are still very relevant within the newer classification (Jenkinson et al, 2000). The LHS can be used with people of all ages, chronic disease and multiple pathologies. It is one of the most popular measures of handicap in the UK (Turner-Stokes and Turner-Stokes, 1997) and has been used in studies of the ageing population (Harwood et al, 1998a; Harwood et al, 1998b) and in other studies of stroke patients and their carers (Harwood et al, 1997; Walker et al, 1999).

3.2.5.4 The Extended Activities of Daily Living Scale (Nouri and Lincoln, 1987)

This hierarchical scale (see Appendix 15) is a measure of disability in extended activities of daily living and was developed for use with stroke patients living in the community. The scale consists of 22 questions in four categories: mobility, kitchen, domestic and leisure. The kitchen and domestic sections may also be combined to form a single 'household' category (Gladman et al, 1993). For each activity the respondent is required to answer whether the stroke patient is able to do this activity 'not at all', 'with help', 'on their own with difficulty', or 'on their own'. This is given a score of 0,0,1,1 respectively. Scores range from 0-22 where a lower score indicates a greater level of disability in extended activities of daily living.

The scale has well-established validity (Gladman et al, 1993; Lincoln and Gladman, 1993) and reliability (Nouri and Lincoln, 1987; Gompertz et al, 1993). As the patients being assessed by their spouses were living in the community, it would be reasonable to assume that they may be participating in extended activities of daily living, such as making a hot drink, washing up and using the telephone. Therefore, an assessment of basic self-care tasks such as the Barthel Index (Mahoney and Barthel, 1965) would not be sufficient to cover the activities carried out by community stroke patients. In addition, the EADL does not depend on the ability to recall the frequency of participating in activities of daily living as in scales such as the Frenchay Activities Index (Holbrook and Skilbeck, 1983). The EADL is one of the most popular measures of ADL in the UK

(Turner-Stokes and Turner-Stokes, 1997) and has been widely used in other studies of stroke patients (Gilbertson et al, 2000; Walker et al, 1999; McKinney et al, Submitted) and their carers (Harding and Lincoln, 2000).

3.2.5.5 The Perceived Stress Scale (Cohen et al, 1983)

The Perceived Stress Scale (see Appendix 16) measures the 'degree to which situations in one's life are appraised as stressful'. This scale addresses the individual's subjective appraisals of events across a one-month time frame, as opposed to the more objective indices of stress evident in other general measures of strain, such as the CSI. The scale has 14 items. Items are scores from 0-4 with selected items scored in the reverse direction (4, 5, 6, 7, 9, 10, 13). Scores range from 0 to 56 and higher scores are indicative of increased levels of perceived stress.

As there is no recommended cut-off point, the cut-off in this study was taken to be two standard deviations greater than the mean score (mean 19.62 s.d. 7.49), which was obtained from a stratified random sample of 2,387 people interviewed by telephone (Cohen and Williamson, 1988).

Internal consistency as assessed by Cronbach's Alpha was 0.75 for the PSS-14 in a general population study (Cohen and Williamson, 1988). For college students completing the PSS-14 test re-test reliability was 0.85 over two days and 0.55 over six weeks (Cohen et al, 1983). This indicates the authors' suggestion that test re-test reliability is only high over short time intervals, since perception of stress is influenced by everyday hassles and the availability of adequate coping resources. High test-retest reliability has been demonstrated for the PSS in a healthy adult sample

over a one-month interval (Machulda et al, 1998). The PSS-14 also has both concurrent and predictive validity and correlates significantly with indices of depressive symptomology (Cohen et al, 1983). It has been described by Hewitt et al (1992) as a 'multidimensional and internally consistent measure of perceived stress'.

The PSS was selected as it is brief and concentrates on the APPRAISAL rather than the NUMBER of events. Although the PSS does not cover as many facets as other scales, such as diminished self-esteem, depressed affect and so on, these additional domains of distress are detected by other measures in this study. The PSS has been used in studies of family caregivers of patients with traumatic brain injury (Groom et al, 1998) and Alzheimer's (Gallagher-Thompson et al, 1992), spouses of disabled adults (Weitzenkamp et al, 1997) and caregivers to patients (including stroke) discharged from a rehabilitation hospital (Fredman and Daly, 1997).

3.2.5.6 Acceptance of Illness Scale (Felton et al, 1984)

The AIS (see Appendix 17) is based on Linowski's (1971) scale to measure acceptance of disability and was originally administered as part of a face-to-face interview on illness and coping. The scale was developed as a measure of the extent to which respondents are able to "accept their illness without experiencing negative feelings or responses" and focuses on the adjustment level of the individual. On this eight-item scale, respondents are required to rate the extent to which they agree or disagree with statements about their health/ illness on a five point scale ranging from 1 (strongly agree) to 5 (strongly disagree). With the exception of

item 6, all statements are in the negative direction and are scored 1 to 5 with scoring reversed for item 6. Scores range from 8 to 40 where a higher level of adjustment is signified by higher scores on the scale. Normative data is not available although the authors have presented means from a sample of 151 people with one of four chronic illnesses (hypertension, diabetes, arthritis or cancer) (Felton and Revenson, 1984). The AIS has high internal consistency (Cronbach's Alpha= 0.81 to 0.83) and a relatively high test-retest reliability over a seven month period (r^{s} = 0.69). The authors report a significant negative correlation between the AIS and the use of wish-fulfilling fantasy as a coping strategy, which suggests that the scale has construct validity, although this seems a rather limited test.

It was originally intended to measure coping style as a variable. However, coping may be viewed as a multi-faceted concept that cannot be fully assessed by a single measure but requires several diverse assessment measures. The present questionnaire package was kept relatively short for ease of self-administration and so lengthy assessment of coping was not practical. The additional length might have reduced the likelihood of the form being completed and returned. Rather than assessing coping in its broader sense, the interest here is solely in the carer's adjustment to their partner's stroke. However, the majority of studies of adjustment measure related concepts such as mood or social functioning rather than acceptance per se. In the present study, the AIS was selected as a brief and easy to complete, specific measure of adjustment. Although more detailed, multidimensional approaches to adjustment are available (e.g. the Global

Adjustment to Illness Scale, Derogatis, 1975 and the Psychosocial Adjustment to Illness Scale, Morrow et al, 1978) such scales were too lengthy to be included. For this study, the wording was altered slightly in order that the scale would be applicable to the carers rather than the patients. For example, the sentence, "Because of my health I miss the things I like to do most" became, "Because of my partners' health I miss the things I like to do most".

3.2.5.7 Satisfaction with Life Scale (Diener et al, 1985)

Overall subjective well-being has two primary components: emotion (or affect) and a cognitive-judgmental component. The cognitive-judgmental component is more commonly referred to as life satisfaction. The Satisfaction with Life Scale (SWLS) (see Appendix 18) is a self-report measure of the judgmental component. The scale was constructed from 48 items, which addressed many different aspects of well-being, including affect. Factor analysis identified three factors, positive affect, negative affect and satisfaction. Once affect and any items that correlated less than 0.6 with the satisfaction factor were removed the authors were left with 10 items, which were reduced to five when semantically similar items were removed.

This scale has five items in the form of statements to which the subject must indicate their agreement. Level of agreement with each statement is measured on a seven-point scale. Scores are obtained by adding the ratings for each item. Test scores range from five (minimal life satisfaction) to 35 (best possible life satisfaction). No normative data are available, although the authors present data on two student samples and two samples of older individuals (Deiner et al, 1985).

The SWLS has been found to have good reliability and validity (Pavot et al, 1991). The scale was not significantly correlated with the Marlowe-Crowne Scale, which indicates that it was not influenced by a social desirability response. Convergent validity was demonstrated in a study where the SWLS was completed by older adults, family and peers and good agreement was found between these ratings (Pavot et al, 1991).

Distinct from other scales of its type, the scale distinguishes between the different components of subjective well-being, removing elements of positive and negative affect and focusing on overall life satisfaction itself. The present study taps into emotional well-being using assessments such as the GHQ-12, as a measure of mood, and the Perceived Stress Scale, as a measure of distress.

The SWLS addresses the cognitive-judgmental aspect of subjective wellbeing. It is briefer than other life satisfaction scales such as the Cantril Ladder (Cantril, 1965), it is easily administered and suitable for all age groups, which makes the scale appropriate for self-completion by the target population. Other scales of life satisfaction are not satisfactory and some consist of only one item or measure a number of components of well-being including affect and energy levels.

3.2.5.8 Rosenberg Self-Esteem Scale (Rosenberg, 1965)

The Rosenberg Self-Esteem Scale (see Appendix 19) is a measure of global self-esteem, or perceived self-worth encapsulated within the wider frame of the self-concept. Self-esteem may be viewed as a 'personal resource', which may serve to moderate the harmful effects of a threatening life situation, in this case, the occurrence of a stroke in a partner. The RSE has ten items scored from one to four in the direction of negative self-esteem (1=strongly agree, 4=strongly disagree). There are two methods of scoring; either 0, 0, 1, 1 or the Likert method of 1, 2, 3, 4. The latter was chosen for the present study as it was found to be a superior method by Rosenberg. The Likert score is simply the sum of the scores for each item on the scale. Scores therefore range from 10 to 40 where a high score indicates low self-esteem.

Rosenberg (1965) has reported that the scale has face validity and acceptable predictive validity. A recent study has suggested that the scale has convergent validity (Griffiths et al, 1999). Construct validity was demonstrated by the correlation between positive self-esteem and a number of social and psychological characteristics, including reduced shyness and depression and more assertiveness and social activities (Rosenberg, 1965). The scale also has acceptable internal consistency (Rosenberg, 1965; Ward, 1977) and test-retest reliability (Rosenberg, 1965; Silber and Tippett, 1965). Little recent work has been done using the scale and a review by Wylie (1974) suggests that the scale is worthy of further research and development. This scale was selected as it is brief, global and unidimensional and has been used in a wide variety of settings.

It is easily understood, and is the most widely used measure of self-esteem in health psychology in the U.K. However, it must be recognised that it does not attempt to make distinctions between state or trait indices of selfesteem. The scale has been successfully used in other studies of older adults (Ward, 1977; Atchley, 1976) and studies of caregivers (Silliman et al, 1986; Robinson, 1990).

3.2.5.9 Multidimensional Health Locus of Control Scale (MHLC) (Wallston et al, 1978)

The MHLC scale (see Appendix 20) comprises three subscales each representing a dimension of control. The first subscale, 'internality' (IHLC), measures the extent to which individuals believe the locus of control for health is internal, that is, to what extent they believe in their own personal control over the nature and outcome of events in their lives. 'Chance' (CHLC), the second subscale, measures the belief in chance or external factors in determining health outcomes, and finally, 'powerful others' (PHLC) measures the belief in the control of powerful others, specifically health professionals. Wallston et al (1978) developed two equivalent forms of the scale (A and B) from responses on a pool of 81 items from a sample of 115 volunteer adults. Form B was used in this study. The scale has a total of 18 items; six in each subscale. The three subscales produce separate scores by adding individual item scores for each of the six items. The subscale items are: Internal – 1, 6, 8, 12, 13, 17: Chance – 2, 4, 9, 11, 15, 16: Powerful other – 3, 5, 7, 10, 14, 18.

Scores on each item range from one (strongly disagree) to six (strongly agree) therefore scores on each subscale range from six to 36.

The greater the score obtained for each dimension, the more intensely the individual believes in that particular dimension of control. Internal reliabilities have been reported as high for the locus of control scales (Wallston et al, 1978; Winefield, 1982). The scale has alpha reliabilities ranging from 0.67 to 0.77. An intercorrelation matrix on the scale scores demonstrated the statistical independence of the IHLC and PHLC, negative correlations between the IHLC and CHLC and positive correlations between PHLC and CHLC. Additionally, the authors have demonstrated predictive validity by correlating the subscales with a two-item health status measure, and construct validity by correlating the MHLC scales with Levenson's (1973) Multidimensional Locus of Control Scale which is based on the same three dimensions (Wallston et al, 1978).

The MHLC scale is the most well-researched and widely used locus of control scale specific to health and replaces the earlier, Unidimensional Health Locus of Control Scale (Wallston et al, 1976). It incorporates Levenson's (1974) three-factor model locus of control beliefs. The scale is flexible in that the time period can be altered depending on requirements. The time period selected for the present study was "here and now" judgements as a basis for explaining present health related behaviours. The MHLC offers more specificity than the earlier (1973), more general locus of control measure, whilst allowing for the identification of a more general attitude or set of cognitions relating to

control. The MHLC has been used with stroke patients (Toedter et al, 1995) although it has not been used before with their caregivers.

3.2.5.10 Positive and Negative Affect Schedule (Watson et al, 1988)

Whilst the use of, for example, the GHQ-12, would give an indication of *current* mood of the carer (and the carers *perception* of the *present* mood of the patient), the Positive and Negative Affect Schedule (PANAS) was included as part of the second questionnaire as an assessment of emotional style or more enduring trait measures of affect. The PANAS (see Appendix 21) identifies a dual framework of both negative affectivity (NA) and positive affectivity (PA), which provide an estimate of an individual's predisposition to experience positive or negative mood states. According to Watson and Pennebaker (1989) "the NA factor subsumes a broad range of aversive mood states, including anger, disgust, scorn, guilt, fearfulness and depression. In contrast, PA reflects one's level of energy, excitement and enthusiasm". Items on the PANAS were selected using factor analytic techniques from an original set of 60.

The PANAS can measure either state (situation-specific) or trait (personality characteristics) measures of affect. The PANAS can be used for different time frames, including 'moment', 'today', 'past few days', 'past few weeks', 'year' and 'general'. In this case the time frame was 'general' (how the carer feels on average) which captures the trait rather than state dimension. Research has shown that the two scales are independent of one another, that is, an individual's score on one scale will not predict his/her score on the other (Watson and Pennebaker, 1989).

The Positive Affectivity (PA) score is derived by adding item scores (one to five) for each PA adjective, and the Negative Affectivity (NA) score is derived by adding item scores (one to five) for each NA item. Total scores for each scale range from 10 to 50. Means and standard deviations have been provided for each scale from large samples of college students (Watson et al, 1988). Although the Bradburn Affect Balance Scales (Bradburn, 1969) have often been used to measure positive and negative affect in the ageing population, these scales have been criticised on psychometric grounds as studies have shown them not to be 'pure' measures of either NA or PA and to have low reliability (Diener and Emmons, 1984; Larsen et al, 1985; Watson, 1988). Therefore, the PANAS was selected as the most appropriate measure. Both subscales of the PANAS show satisfactory internal consistency (>0.84) for students, non-student adults and a psychiatric population.

Test retest reliability for the trait measures was 0.68 and 0.71 respectively. The two subscales have been found to be independent of each other (r= - 0.09) demonstrating validity (Watson, 1988; Watson et al, 1988) and the PANAS correlates with other measures of general psychological distress and psychopathology. The PANAS was selected for inclusion due to its relatively unique capacity to assess BOTH positive and negative affects (general affectivity) whereas trait measures of positive affect are often not readily available. The test is also simple to self-administer and brief. Kercher (1992) developed a shorter, 10-item version of the PANAS to assess negative and positive affectivity in older adults. Although the author demonstrated that the shortened version of the scale has validity

and reasonable reliability, the standard 20-item scale was selected for use in this study as it has been more frequently used and its validity and reliability is better established. The length of the scale was not considered to be problematic for this group to complete. The PANAS scale has been used in other studies of older adults (Shapiro et al, 1999).

3.2.5.11 Life Orientation Test (Scheier and Carver, 1985)

The Life Orientation Test (LOT) is an assessment of dispositional optimism - a 'habitual style of anticipating favourable outcomes'. The scale (see Appendix 22) has eight items that count towards the dispositional optimism score. Of these, four are phrased in the positive direction and four in the negative direction. There are also four filler items designed to disguise the purpose of the test (2, 6, 7, 10). Each item is rated on a five point scale ranging from 'I agree a lot' to 'I disagree a lot'. Each positive item (1, 4, 5, 11) is scored from zero to four where 'I agree a lot' = 4, and 'I disagree a lot' = 0. Negative items (3, 8, 9, 12) are reverse scored, then item scores are added to make the overall score. High scores indicate high optimism as an enduring personality trait.

The LOT showed satisfactory internal consistency (Cronbach's Alpha= 0.76) and test-retest reliability (0.79 over a four week interval and 0.72 over a thirteen week interval). Other studies have shown the scale to have high reliability in both Cronbach's Alpha and split-half reliability (Andersson et al, 1995). Positive (but not overly high) correlations with internal control beliefs (Rotter, 1966) and self-esteem (Rosenberg, 1965), and negative correlations with depression (Beck, 1967), hopelessness

(Beck et al, 1974), alienation (Maddi et al, 1979) and perceived stress (Cohen et al, 1983) highlighted the theoretical validity of the scale. The scale is also independent of a social desirability scale (Crowne and Marlowe, 1964).

Again, this scale is brief and easily administered to the intended Smith et al (1989) have criticised the LOT for its population. measurement of low neuroticism as opposed to optimism itself. However the scale was included in the present study here as a measure of a generally positive rather than negative cognitive style. The measure was preferred as many other measures of optimism confound the expectancy of 'good versus bad outcomes' with other related but distinct variables such as morale, satisfaction and attributions of causes for the expectancies. The LOT is intended to specifically measure optimistic orientation, or generalised expectancies that good things will happen. Some other optimism scales include items that may not apply to many carers of stroke patients. For example, although the Generalised Expectancy for Success Scale (Fibel and Hale, 1978) conceptualises optimism in a similar way to the Life Orientation Test, it includes items such as, 'achieving career goals', which may not be relevant to many elderly stroke spouses of retirement age. The LOT has been used in studies of the elderly (Andersson et al, 1995) and other caregiving groups (Beckham et al, 1995).

3.2.5.12 Courtauld Emotional Control Scale (Watson and Greer, 1983)

The Courtauld Emotional Control Scale (CECS) (see Appendix 23) measures control over specific negative affective responses and a generalised tendency to control emotional reactions. Development of the scale came from interview studies by Greer and Morris (1975) and Temeshok (1985) who found that suppression of emotional expression may be predictive of tumour development. Although the CECS was originally developed and intended for use with breast cancer patients, the authors envisaged that the scale would have wider application to other clinical studies in which it is important to identify the extent to which people control their emotional responses to stress. Items in the CECS were selected from responses given by breast biopsy patients in semi-structured clinical interviews. From the transcripts of these interviews, 48 statements were selected with 16 statements reflecting the expression or control of each of the affective states, anger, depression and fear.

Each section is summed individually by adding rating scores for each item, with the exception of item four on the Anger subscale, item five on the Depression subscale and items one, four and five on the Anxiety subscale, where the scoring is reversed. Possible scores on each section range from seven to 28. Although each of the subscales measure different dimensions of emotional control and should be scored and interpreted separately, the subscale scores can be summed to give a total emotional control score. Total scores range from 21 to 84. However, the Watson and Greer warn that interpretation of this overall score should not be made without a consideration of how each subscale score contributed to the

total. Although normative data are not available, Watson et al (1991) have provided mean scores from 108 women in early stage breast cancer.

Each of the three sections has been shown to have adequate internal consistency (Alpha Coefficients 0.86, 0.88 and 0.88) and test-retest reliability over three to four weeks (0.86, 0.89 and 0.84 for anger, depression and anxiety respectively and 0.95 for the total score). Watson and Greer (1983) found significant positive correlations between scores on the three sections lending support to the view that the scale represents a valid measure of a general construct of emotional control. They claimed that the scores are largely free from social desirability response bias, based on the finding that the scale scores do not correlate with the Marlowe-Crowne Scale. The CECS was selected to look for links between emotional control (the tendency to hide or 'bottle-up' feelings versus the tendency to openly express emotions), adjustment and depressive symptomology in the carers. Other measures of emotional control involve trained rating of audiotaped interviews and so there is value in the use of a simpler measure.

3.2.5.13 Significant Others Scale (Power et al, 1988)

The Significant Others Scale (S.O.S.) (see Appendix 24) originated as an assessment of five emotional and five practical social support functions in 12 people (including spouse/partner, father, closest sibling, closest child, best friend, other). The present study makes use of the simplified version, which assesses four social support functions (two emotional and two practical) in up to seven individuals. Two versions have been developed:

SOS (A) in which the individuals are specified and SOS (B) in which the respondent can identify the key individuals. The latter was thought a more appropriate choice for this sample as many elderly carers would not have mothers, fathers, siblings etc. For each of the four social support functions each carer is rated in terms of the level of support actually received and their ideal level of support. Ratings are made using sevenpoint scales from one (never) to seven (always). Raw scores are obtained for each individual for both practical and emotional support. These scores are then summed across individuals to produce measures of emotional support (items one and two) and practical support (items three and four). These scores are then divided by the number of individuals rated (usually seven but in this case three) to give a mean score for each type of support. The resulting scores therefore represent both actual and ideal levels of support and the discrepancy between these can then be calculated. The discrepancy score provides an index of likely satisfaction with available emotional and practical support.

Although there are no normative data available on large samples, mean support and discrepancy ratings are available for various samples including students, Parkinson's patients and carers, and depressed patients. Power et al (1988) suggest that the S.O.S shows adequate reliability and validity. Test-retest reliability over a six-month interval ranged from 0.73 to 0.83 across the four summary support scores (actual versus ideal x emotional versus practical). Criterion validity has been tested by comparing the scores of three groups (non-cases, depressed cases, and non-depressed cases) classified according to scores on the

Power (1988) demonstrated a stress-buffering effect of GHO-28. emotional (but not practical) support. Power et al (1988) acknowledge that the number of individuals rated can vary between subjects thus rendering the S.O.S a flexible instrument. In this case up to three individuals were rated, since no carer reported more than three significant others in the pilot study. The S.O.S was chosen for the present study as many social support measures (see Cohen and Syme, 1985) do not sufficiently differentiate between either, social support and social network, or between different categories of support such as practical and emotional. The S.O.S. allows for the generation of an overall measure of 'satisfaction' in each area based on the discrepancy between ideal and actual scores. Although the scale does not provide a measure of the number of supports available for different support functions, it could be modified to do so. The S.O.S. has been used in other studies of caregivers (Power et al, 1988).

3.2.5.14 Formal Support

It was also thought necessary to gain information not only about informal support networks of the carer (as collected using the Significant Others Scale), but also the level of support (if any) they had received from professional services, for example, GP's, nurses, occupational therapy, physiotherapy and so on. The carers were asked to rate the amount of support they had received from formal services on a six-point likert-type scale ranging from 'none' to 'a lot'. Although not necessarily an accurate measure of objective, measurable support they had received in the time

since their partner had a stroke, it provided an estimate of the carers' perceived level of professional support.

3.2.5.15 Additional Comments

In addition to the standardised assessment instruments used in the questionnaire, there was also a section allowing for optional comments or free expression of thoughts and feelings relating to the experience of looking after someone who has had a stroke.

3.3 Analysis and results

3.3.1 Data screening

Data screening contributes significantly to the legitimacy of any inferences that are made from the data and ensures that the data meet the criteria for the most appropriate statistical test. The raw data were checked for outliers using Cook's Distance and no cases needed to be removed. An analysis was made of the distribution of scores and equality of the variances.

3.3.1.1 Missing data

In cases where questionnaires were returned with items missing, the carer was contacted as soon as the form was received and asked to complete the missing items. In three cases where a single item was missing from one of the measures and the carer was unavailable to complete the item, the mean was calculated and inserted as a response. The mean response was taken to represent an indication of what the missing response was likely to have been.

3.3.2 Normality

There are two components to normality: skew and kurtosis. Skew refers to the symmetry of a distribution and kurtosis refers to the peakedness of a distribution. In a normal distribution, skew and kurtosis are equal to zero. Most parametric statistical tests assume that the population from which the sample is drawn is normally distributed. An analysis of the distribution of data of the sample is often used as a guide to the distribution of the population. When the assumption of normality is met, the residuals of an analysis are also normally distributed and independent. Normality of the data can be checked using a number of statistical and graphical measures: by examining normal P-P plots and histograms, by comparing the mean and the median, by calculating Z scores for skew and kurtosis, and by conducting the Kolmogorov-Smirnoff Test with the Lilliefors correction. Skew ranged from -0.54 to 2.78 and kurtosis ranged from -1.52 to 10.41. The Z scores showed that 18 variables (included CSI) were normally distributed but 20 were significantly skewed. Seventeen had normal kurtosis but 20 did not. Logarithm transformations (log to the base 10) on the skewed variables did not greatly improve normality.

3.3.3 Homogeniety of variance

Homogeneity of variance is another assumption of parametric analysis. Homoscedasticity assumes that the variability in scores for one variable is approximately the same at all values of the other variable. The relationships between variables are homoscedastic when the data are

normally distributed. If the variables are heteroscedastic then the analysis is weakened. The 38 variables (excluding gender) were checked for homogeneity of variance using Levene's statistic: a statistical test to determine whether the variances are significantly different. Levene's statistic indicated that the variances for 22 of the dependent variables were not homogenous. It was concluded that, as a whole, the data did not meet the assumptions of normality and homoscedasticity required for parametric analysis.

3.3.4 Response rate

Altogether, 227 (49%) of the 465 carers contacted returned the first questionnaire of which five were incomplete and 222 (48%) were available for analysis. Of these carers, 74 (33%) were men and 148 (67%) were women. Of the patients, 148 (67%) were men and 74 (33%) were women. Patient ages ranged from 35 to 91 years (mean 71, s.d. 10.34). These 222 carers were sent the second questionnaire. Of these, 97 (44%) were returned, of which one was incomplete and 96 (43%) were available for analysis. Of these carers, 30 (31%) were men and 66 (69%) were women. Patient ages ranged from 35 to 91 years (mean 69, s.d. 11.16).

3.3.5 Descriptive statistics for each variable

Of 222 respondents, 82 (37%) scored equal to or above seven on the CSI indicating significant strain. A Mann-Whitney U Test failed to find significant differences between men and women carers in strain (p=0.84). As the data did not meet the assumptions of normality and homogeneity of variance it was not appropriate for parametric analysis. Therefore, the medians are reported here in place of the means. The distribution of scores on each measure is shown in Table 11.

Cronbach's Alpha was calculated for scales where individual item scores were available on the database. Alpha coefficients were as follows:

Caregiver Strain Index = 0.85

London Handicap Scale = 0.82

Carer General Health Questionnaire-12 = 0.87

Perceived patient General Health Questionnaire-12 = 0.89

Perceived patient Extended Activities of Daily Living Scale = 0.94

Perceived Stress Scale = 0.81

PANAS Negative Affectivity = 0.91

PANAS Positive Affectivity = 0.88

Forty-five per cent of carers had low mood on the GHQ-12 and the median value was at the clinical cut-off point for susceptibility to depression. Low mood was perceived in 53% of patients and the median value was above the clinical cut-off point.

Variable	Possible	n	median	IQR
	гange			
Age of Patient	-	222	71	64 - 77
Days Since Stroke	-	222	530	248 - 730
London Handicap	0-100	222	68	55 - 81
Occupation	0-6	222	3	2-5
Orientation	0-6	222	1	1-2
Independence	0-6	222	2	1-4
Mobility	0-6	222	3	2-3
Economic	0-6	222	2	2-4
Self-Sufficiency				1
Social Integration	0-6	222	2	2-3
Patient EADL ⁺	0-22	222	7	3 – 14
Kitchen	0-5	222	3	1-5
Domestic	0-6	222	2	0-2
Mobility	0-6	222	2	0-5
Leisure	0-5	222	2	1-3
Carer GHQ-12 ^x	0-12	222	3	1-6
Patient GHQ-12 ^x	0-12	222	4	1 – 7
Internal HLC ⁺⁺	6-36	96	23	19 – 27
Chance HLC ⁺⁺	6-36	96	19	14 - 22
Powerful HLC ⁺⁺	6-36	96	21	18 – 26
CECS [*] Total Expressivity ^x	21-84	96	57	48 - 63
CECS [*] Anger ^x	7-28	96	17	14 – 22
CECS [*] Depression ^x	7-28	96	20	16 – 23
CECS [*] Fear ^x	7-28	96	940	16 - 21
Life Orientation Test	0-48	96	17	13 - 21
Negative Affectivity ^x	10-50	96	20	14 – 29
Positive Affectivity	10-50	96	32	26 – 37
Rosenberg Self-Esteem Scale ^x	10-40	96	20	16 – 22
Acceptance of Illness Scale	8-40	222	27	21 - 33
Perceived Stress Scale ^x	0-56	96	25	18 – 31
Satisfaction with Life Scale	5-35	96	18	12 – 27
Support:				
Actual Emotional	0-7	222	6	5-7
Ideal Emotional	0-7	222	17	6 – 7
Actual Practical	0-7	222	6	4 – 7
Ideal Practical	0-7	222	6	5-7
Emotional Discrepancy ^x	0-7	222	0.2	0 - 0.8
Practical Discrepancy ^x	0-7	222	0.3	0-2
Professional Support	0-6	222	3	1-5

Table 11. Distribution of scores for each variable

* Courtauld Emotional Control Scale

Extended Activities of Daily Living Scale

++ Multidimensional Health Locus of Control

x indicates where high score is undesirable

+

3.3.6 Correlation analysis

Parametric tests make a number of assumptions about the data being analysed. The dependent variables must be continuous (measured on an interval or ratio scale), the underlying population from which the sample data are taken must have a normal distribution, and when difference or measures of statistical association are being analysed between two or more samples, the variances (or standard deviations) of these samples must not differ significantly. As the majority of data was ordinal, nonparametric Spearman Rank Correlation Coefficients were calculated using SPSS for Windows (Release 7). Thirty-one variables were correlated against strain on the CSI. Results are shown in Table 12.

CSI was not significantly correlated with age of the patient or time since the stroke. A high level of strain was associated with low mood in the carer, low perceived mood and EADL (kitchen, domestic, leisure and mobility) in the patient and increased handicap of the carer. The CSI was not significantly related to fear or anger emotional expressivity or internal or powerful others health locus of control. Strained carers had significantly lower depression expressivity scores, lower self-esteem, decreased positive affectivity and increased negative affectivity. Increased strain was significantly related to lower levels of dispositional optimism and adjustment to the stroke.

Variable		Correlation co-efficients			
	n	Γ _s	р		
Age of Patient	222	-0.003	0.96		
Days Since Stroke	222	-0.03	0.79		
London Handicap	222	-0.38 ***	<0.001		
Occupation	222	0.40 ***	<0.001		
Orientation	222	0.23 ***	0.001		
Independence	222	0.28 ***	<0.001		
Mobility	222	0.36 ***	<0.001		
Economic	222	0.37 ***	<0.001		
Self-Sufficiency					
Social Integration	222	0.32 ***	<0.001		
Patient EADL ⁺	222	-0.51 ***	<0.001		
Kitchen	222	-0.47 **	<0.001		
Domestic	222	-0.44 ***	<0.001		
Mobility	222	-0.46 ***	<0.001		
Leisure	222	-0.39 ***	<0.001		
Carer GHQ-12	222	0.51 ***	<0.001		
Patient GHQ-12	222	0.47 ***	<0.001		
Internal HLC ⁺⁺	96	0.06	0.54		
Chance HLC ⁺⁺	96	0.21 *	0.04		
Powerful HLC ⁺⁺	96	0.09	0.39		
CECS [*] Total Expressivity	96	0.18	0.09		
CECS [*] Anger	96	0.11	0.29		
CECS [*] Depression	96	. 0.20*	0.05		
CECS [*] Fear	96	0.15	0.16		
Life Orientation Test	96	-0.32 ***	0.001		
PANAS Negative Affectivity	96	0.56 ***	<0.001		
PANAS Positive Affectivity	96	-0.26 **	0.01		
Self-Esteem Scale	96	0.28 **	0.01		
Acceptance of Illness Scale	222	-0.36 ***	<0.001		
Perceived Stress Scale	96	0.42 ***	<0.001		
Satisfaction with Life Scale	96	-0.43 ***	<0.001		
Support:					
Actual Emotional	222	-0.22 ***	0.001		
Ideal Emotional	222	-0.12	0.08		
Actual Practical	222	-0.25 ***	< 0.001		
Ideal Practical	222	-0.13	0.06		
Emotional Discrepancy	222	0.23 ***	0.001		
Practical Discrepancy	222	0.28 ***	<0.001		
Professional Support	222	0.21 *	0.04		

Extended Activities of Daily Living Scale ** Multidimensional Health Locus of Control * p<0.05 **p<0.01 ***p<0.001 (two-tailed) Courtauld Emotional Control Scale

There was no significant relationship between CSI and ideal levels of emotional or practical support. High levels of carer strain were associated with higher levels of support from formal services and less satisfaction with their lives. The Bonferroni adjusted p value was 0.001 and the majority of the previously significant correlations were also significant at this more stringent level. Some relationships however, were no longer significant, including chance HLC, CECS depression, positive affectivity, self-esteem and professional support (see chapter two, discussion, for consideration of adjusted p values).

The dependent variable, CSI, was recoded using the suggested cut-off (Robinson, 1983) to form a new variable; 'strain', to be used in the multivariate analysis, where 'not strained' was equal to zero and 'strained' was equal to one. The relationships between each independent variable and strain are demonstrated in Figures 12-27.










On investigation of the distribution of responses to individual items on the CSI, it seemed that some items were reported more frequently than others by carers under strain. For the strained caregivers, confinement was reported by the greatest percentage of spouses, followed by feelings of being overwhelmed and the patient having changed from his/her former self. Three-quarters of the strained carers reported that caregiving was a financial strain

3.3.7 Logistic regression for factors relating to strain

The more variables included in the regression equation the more difficult it is to accurately predict the relationships between the IV's and the DV. Although all significant relationship have been noted, the 15 variables that were not significantly correlated at $p \le 0.001$ were removed from consideration in the following analysis to ensure that large numbers of variables weakly or not at all associated with carer strain did not reduce opportunities to find more global effects.

3.3.7.1 Predictor variables

The variables regressed against strain included acceptance of illness, handicap, optimism, patient and carer mood, negative and positive affectivity, self esteem, satisfaction with life, patient ADL, and support from significant others. Although ideal levels of practical and emotional support were not correlated with CSI at the p≤0.001 level some subsections of the Significant Others Scale were highly correlated with strain, and the scale would always be administered as a whole rather than

individual subsections being used. It was therefore considered appropriate to enter all subsections of the Significant Others Scale into the regression analysis. It has been suggested that a sample size of $N \ge 50 +$ 8m (m= number of IV's) is required for a regression model (Green, 1991). Fifteen independent variables were regressed against strain, so an ideal sample size would be at least 160 cases. Many of the IV's were available for 222 cases, however, some were only available for 96 cases and so this should be taken into consideration when interpreting the results.

The model selected was forward selection, where removal testing is based on the probability of the likelihood-ratio statistic based on the maximumlikelihood estimates. This model represented the parsimonious solution for the logistic regression equation.

3.3.7.2 Regression equation

The analysis was carried out on the 96 patients for whom all variables were available with strain as the dependent variable. The logistic regression model for strain showed that strain on the CSI was best predicted by carer mood. Other predictors of strain significant in the equation were perceived patient EADL and negative affectivity. No other variables were significant in the model. Results are shown in Table 13.

	SE	ar	Sig	ĸ	Exp(B)
.30	0.09	10.22	0.001	0.25	1.35
0.13	0.05	7.58	0.01	-0.21	0.88
.08	0.03	5.15	0.02	0.16	1.08
2.05	0.82	6.28			
	.30 0.13 .08 2.05	.30 0.09 0.13 0.05 .08 0.03 2.05 0.82	.30 0.09 10.22 0.13 0.05 7.58 .08 0.03 5.15 2.05 0.82 6.28	.30 0.09 10.22 0.001 0.13 0.05 7.58 0.01 .08 0.03 5.15 0.02 2.05 0.82 6.28	.30 0.09 10.22 0.001 0.25 0.13 0.05 7.58 0.01 -0.21 .08 0.03 5.15 0.02 0.16 2.05 0.82 6.28 0.01 0.25

Table 13. Logistic regression model: Factors related to caregiver strain

+ Extended Activities of Daily Living Scale

Logistic regression returns the probability that a carer will be strained or not. Exp(B) is referred to as the odds ratio and gives an approximation of the relative risk of the carer being strained or not strained. For carers with low mood the risk of being strained increased by a factor of 1.35. For carers who perceived their partner's independence to be poor, the risk of being strained increased by a factor of 0.12. For carers who had high negative affectivity, the risk of being strained increased by a factor of 1.08. That is, carers were significantly more likely to be strained if they had poor mood, perceived their partner to be more dependent and had high negative affectivity.

a) Goodness of fit

The predictions of the model were compared to the observed outcomes in order to assess the goodness of fit of the model. Goodness of fit can be assessed in several ways. Seeing how well the model *classifies* the observed data is one way of determining how well the logistic model performs. Classification results are shown in Table 14.

		Predicted	
Observed	CSI<7	CSI≥7	
CSI<7	45	10	81.82% correct
CSI≥7	14	27	65.85% correct
		Total:	75% correct

Table 14. Classification table for strain

The table shows that 45 carers, who were not strained as assessed by the CSI were correctly predicted by the model as not strained. Similarly, 27 carers, who were strained on the CSI were correctly predicted by the model as strained. A total of 24 carers were misclassified by the model. Fourteen carers who were observed as strained and 10 carers who were observed as not strained. Of the carers who were not under strain, 81.82% were correctly classified. Of the carers who were strained, 65.85% were correctly classified. Overall, 75% of carers were correctly classified.

b) <u>Residuals, deviance and influence</u>

After a statistical model has been built it is important to examine the adequacy of the resulting model, through examination of the residuals, measures of influence and indicators of colinearity. These are tools that identify points at which the model does not fit well, points that exert a strong influence on the coefficient estimates and variables that are highly related to each other.

The residual is the difference between the observed probability of the event and the predicted probability of the event based on the model. The standardised residual is the residual divided by an estimate of its standard deviation. For each case, the standardised residual can also be considered a component of the chi-square goodness-of-fit statistic. If the sample size is large, the standardised residuals should be approximately normally distributed, with a mean of 0 and a standard distribution of 1. If the value of the standardised residual is greater than +2 for any case, then that particular case is thought to be 'out of line' with the rest of the data. The standardised residuals were calculated for each case. For CSI, 198 cases had standardised residuals that fell within acceptable limits. There were four cases within the data-file which did not conform to these limits; cases 8, 116, 117 and 129. There appeared to be nothing unusual about these cases and so they were not removed from the analysis. The influence of each individual case on the regression equation was further investigated. Cook's Distance is greater than +1 for any particular case then that observation is considered to be influential in the regression equation, and may be an outlier. Cook's Distance was calculated for each case and all

cases fell within the acceptable range. Therefore, it is possible to conclude that no case was disproportionately influential in determining the regression model. The regression model deviance was related to the degrees of freedom using Chi Square. If the obtained value exceeds the Chi-Squared value then the model does not fit the data. For CSI, the obtained value of 48.92 (df=36) did not exceed the Chi-Squared value of 67.98 (p=0.001). This suggests that the regression model fits the data. The results showed, therefore, that strain was most strongly associated with carer mood, patient EADL and negative affectivity.

3.4 Discussion

In this study, there was a 48% return rate on questionnaires administered to the sample. This is an adequate return rate for a postal study with elderly participants and is comparable to other methodologically similar studies of stroke caregivers (Pound et al, 1993). The percentage of spouses who completed the CSI is slightly lower than in the patient characteristics study. It is likely that this is because data were collected postally whereas data collection in the previous study was by arranged home visit.

It must be acknowledged that the carers who failed to return the questionnaires may have perceived the additional time needed to complete the forms as an extra strain, which may explain why some carers chose not to participate. In addition to this, carers in the Nottingham area are often involved in other research studies based at either Nottingham City Hospital or the Queen's Medical Centre (University Hospital) and some of the carers contacted expressed a feeling that too much of their time was spent filling in questionnaires for research purposes. As one carer said "...caring is a full time job. We do our best but looking after someone 24 hours a day doesn't leave much time for anything else". The fact that almost half of those carers contacted agreed to take part was therefore viewed as satisfactory.

The factors most strongly related to strain were carer mood, perceived patient independence in extended ADL and negative affectivity. Therefore, the most important factors appear to be the spouse's appraisal of their partner's disability, together with two emotional components of

caregiver subjective well-being, one transient and one stable. Results showed that low mood was prevalent in stroke spouses and this finding is does not differ greatly from prevalence rates found in other studies of stroke caregivers (Dennis et al, 1998). In this sample, strained carers had significantly lower mood than carers who were not strained. These findings lend support to other work on carer strain that has demonstrated a strong relationship between emotional distress and caregiver burden or strain, both in stroke (Scholte op Reimer, 1998; Koopman-Boyden and Wells, 1979; Mitchley et al, 1996; Draper et al, 1992) and other patient groups (Blake, 2000).

Further analysis showed that carer mood was significantly related to their perceptions of their partner's disability and the emotional state of the patient, which is consistent with the findings of Dennis et al (1998). The experience of low mood did not significantly differ with respect to gender and this contrasts with previous findings (Shulz et al, 1993; Zarit and Whitlach, 1992), although is consistent with the findings of the previous study presented in Chapter Two. Gender is discussed further in Chapter Five.

Mood was assessed in this study using a self-administered inventory, the GHQ-12. However, it is important to note that this instrument was intended as a screening measure and although it provides an estimate of emotional disturbance it does not provide the amount of information regarding frequency and duration of symptoms that would be required for a clinical diagnosis of depression.

Spouses who cared for patients whom they perceived as having poor independence in extended activities of daily living were more strained than those who cared for patients who they perceived to be independent in extended ADL. It is well documented that patient functional ability exerts some influence on strain (Santariano et al, 1984; Synder and Keefe, 1985). Carod-Artal et al (1999) found a strong significant correlation between overload in caregivers of stroke patients and disability of the patient as measured on the Barthel Index. However, there may be differences between objective measures of patient disability in these studies and inferences made by the caregiver.

Indeed, the problems of using proxy ratings of the patients' functional abilities have been recognised for some time (Andrews and Stewart, 1979; Spranger and Aaronson, 1992) and studies have suggested that proxy assessment of functional ability can differ from assessments by both professionals (Wyller et al, 1995) and the patients themselves (Knapp and Hewison, 1999). Wyller and colleagues found that carers tend to report lower patient abilities than assessments made by occupational therapists (Wyller et al, 1995). Knapp and Hewison (1999) found differences between carer and patient ratings of the patient's abilities in activities of daily living, although the differences were small and ratings were highly correlated which suggests that proxy ratings were not globally unrealistic in their assessment. The study also showed that a higher discrepancy between patient and carer ratings was significantly associated with higher levels of carer strain, although both carer strain and discrepant ratings

were greater in more disabled patients which leads to the possibility of confounding.

The present study has suggested that carers' estimates of the patients' abilities are strongly related to carer strain. It may be that patients who are more dependent in EADL have spouses who are more strained. Alternatively, it may be that spouse's perceptions of their partner's abilities are distorted, perhaps from either a misunderstanding of stroke or from unrealistic expectations about recovery, and that these distorted beliefs are the factor that is related to strain. Clarification of this issue would require an assessment of the discrepancy between carer's ratings of the patient's function and objective measures of functional ability.

The relationship between negative affectivity and caregiving strain is not well studied. However, these findings support work done in other patient groups (Blake, 2000) that has also demonstrated a significant relationship between high negative affectivity and carer strain on the CSI. As a general factor of subjective distress it is logical that high negative affectivity would be associated with high levels of strain.

High NA individuals may be more introspective and dwell on their shortcomings thus rendering them prone to depression. Indeed, a strong correlation has been found between negative affectivity and mood both in the present study and other research in this area (Jolly et al, 1994). In addition, high NA individuals have a less favourable view of themselves and others and so may be more likely to appraise their partner as being less independent than they actually are. However, negative affectivity was not significantly related to perceived patient EADL which supports

the view that negative affectivity is a stable trait rather than a transient mood state which is influenced by objective stressors (i.e. patient disability).

The results suggest that high levels of carer strain are experienced by those carers who have low mood, perceive their partners to be more disabled and exhibit high levels of negative affectivity. Identifying carers who demonstrate these three factors may enable the recognition of those carers who are likely to suffer from high levels of strain. This would allow the identification of those carers towards whom intervention should be targeted. However, cross-sectional analysis only highlights associations between variables and it cannot be concluded as to whether these three factors measured early after stroke can predict high strain in carers later on after stroke. In order to clarify this issue, these factors need to be tested prospectively in a different sample of carers.

Other factors were also significantly related to strain although not significant in the regression equation. In the present study the length of time since the stroke ranged from two and a half months, to two and a half years. There was no significant relationship between strain and time since the stroke, which suggests that other factors may be more important in determining caregiver strain. This was surprising as one might expect time to be an influential factor in caregiver adjustment. It is possible that the effects might be curvilinear, for example, a carer may be able to cope early after stroke but the cumulative effects of providing care for a long time may result in later strain. Conversely, a carer may be initially overwhelmed and feel unable to cope yet with time, develop adaptive

coping strategies. It may be that the effects of time might interact for example, with individual differences in caregiver personality. This is worthy of further investigation. Length of time caregiving was taken to be the amount of time that had passed since the occurrence of the stroke. However, this is a limited assessment as it does not take into account whether or not the spouse was performing caregiving duties before the stroke and for how long, as a result of either a previous illness or prior stroke for example. The aim of the study was to assess length of time in the caregiving role, but no account was taken of the amount of time spent caregiving. At the same time after a stroke, one spouse may have provided care less than once a day whereas another may need to be continuously available to care for their partner. The amount of care provided needs to be addressed in another sample of carers.

Spouses who perceived their partner's mood to be low were under more strain than those who did not. These findings support work done with Parkinson's caregivers that demonstrated a relationship between ratings of patient depression and high levels of caregiver stress on the Relative Stress Scale (Aarsland et al, 1999). The results are also consistent with research on carers of stroke patients where stress among carers has been associated with emotional distress and mood disturbance of the patients (Wade et al, 1986). The findings therefore suggest that the mental health of the patient may be important in carer strain.

Livingston et al (1996) found that depression was more prevalent among co-resident carers of mentally frail elderly people than in co-residents of non-frail elderly people or in carers of those with a physical disability

only. It might be that it is not only the fact that one is living with an older person, but the mental health of that person, which influences the likelihood of psychological distress in co-residents. In the present study, spouses gave patients high scores on the GHQ-12 indicating that they perceived them to be under significant psychological distress. This is consistent with previous research indicating depression in the patients as measured by the GHQ (Brodaty and Hadzi-Pavlovic, 1990).

In addition, the present study found significant correlations between psychological distress of the patients and the carers.

The strained caregivers perceived their level of handicap to be greater than the non-strained caregivers, which supports the relationship between carer well-being and carer physical health demonstrated in the literature. However, it is difficult to ascertain whether handicap was the direct result of the caregiving situation or whether handicap was a result of prior physical condition and disadvantage. The relationship between poor economic self-sufficiency and strain highlights the importance of financial difficulty and supports the findings reported both here and in Chapter Two that financial strain on the CSI was selected by a high percentage of caregivers. As in Chapter Two, it was the spouses of younger patients that reported greater financial difficulty. The relationship between strain, physical independence, orientation and mobility also supports the notion that carer health and functional ability is related to strain. The fact that social integration was also associated with strain suggests that caregivers who perceive themselves to be socially isolated suffer from increased levels of strain.

This is consistent with the literature on social support, which suggests that social contact may be a buffer against the experience of strain.

Expression of the emotions of anger and fear were unrelated to strain. The study highlighted a significant relationship between expression of feelings of depression and caregiver strain and this was not surprising given Watson et al's (1991) finding that a tendency to control the expression of depression is associated with psychological morbidity. It has been suggested that controlling the expression of feelings of depression may be associated with feelings of helplessness under conditions of stress and helplessness in turn is associated with negative health-related outcomes (Schmale and Iker, 1961; Antoni and Goodkin, 1968; Jenson, 1987; Pettingale et al, 1985). Those carers who tend to control the expression of depression may be more likely to suffer from higher levels of strain and may also hold a helpless and fatalistic outlook. It may be that by encouraging carers to 'ventilate' emotions such as depression, helplessness may be reduced and carer strain may be lessened. Helplessness and fatalism has also been associated with an external locus of control. It is generally assumed that having an internal locus of control is adaptive in the face of adversity (Turnquist et al, 1988; Partridge and Johnston, 1989) and an external locus of control maladaptive (Schroeder and Miller, 1992; Donovan et al, 1995; Hanes and Wild, 1977). The results did not show a significant relationship between internal and powerful others health locus of control and strain. However, those carers who had a higher tendency towards an external chance health locus of

control suffered from greater levels of strain, suggesting that an external locus of control may indeed be maladaptive in carer strain.

Although a large proportion of caregivers report an increase in self-esteem from caregiving (Silliman et al, 1986) the present study has demonstrated that feelings of self-worth differ according to the level of strain experienced. It would seem that low self-esteem may predispose an individual to experiencing higher levels of carer strain. Dispositional optimism appeared to be protective against strain, supporting the belief in the power of positive thinking in the face of adversity. This result might be expected given the association found between optimism and mental health in the literature (Sumi et al, 1997; Hinrichsen and Niedhere, 1994, Hooker et al, 1992). Although optimism is often viewed as a relatively stable personality trait, more recent studies have demonstrated variability in optimism over time (Schifren and Hooker, 1995). It may be that optimism may be amenable to therapeutic intervention.

Actual practical and emotional support and the discrepancy between actual and ideal levels of practical and emotional support were strongly related to the experience of strain in the carers supporting the view that social support may act as a buffer against the experience of strain. These results suggest that both the perceived amount of support and the perceived adequacy of support are important in the experience of strain and this is consistent with previous research (Morris et al, 1991). Nevertheless, it has been suggested that social support may be more important to some carers than to others and that carers should be restored to a level of social functioning considered normal to each individual (Labi

et al, 1980). The results indicated high levels of caregiver strain in spouses who cared for a partner who had received a high level of support from formal services. It may be that carer strain was higher in this group due to more severe impairments in those patients who were receiving home care. A similar association was found in Aarsland et al's (1999) study of Parkinson's caregivers where an association was found between increased public home care and higher levels of caregiver distress.

One of the strengths of the study is that several different personality variables were included in the same analysis. Previous studies have tended to examine only one or two variables at a time, which makes it impossible to evaluate the unique contribution of each. Performing simultaneous analyses made it possible to determine whether the personality variables studies were having multiple independent effects on caregiver strain or whether one or two variables were particularly important (eg. negative affectivity), subsuming the effects of others. In the regression analysis, only negative affectivity emerged as a unique personality factor related to caregiver strain.

There are a number of methodological considerations that must be acknowledged. One limitation of the study is that carer age was not collected. It is important to recognise the possible influences of caregiver age on variables such as psychological and physical health outcomes (e.g. Murrel et al, 1983; Schulz et al, 1988) and in the previous study, carers of younger patients suffered from greater levels of strain at three months but not six months after stroke. However, in the present study, patient age

was not a significant factor in the regression equation and it is likely that patient age and carer age would be highly correlated.

On the GHQ-12, well-being is measured at a given point in time where response options include 'about the same' and 'no more than usual'. Unfortunately, those carers who's health has suffered for some time may just report that things are the 'same as usual' and so not have a particularly high score on the GHQ-12, which gives a false impression of well-being. However, the same is true for norms derived from studies of general population samples.

One methodological drawback of the study is that the sample was crosssectional rather than longitudinal and so relationships over time cannot be identified. Longitudinal research might prove more fruitful both in terms of studying the effects of elapsed time and in terms of identifying causal relationships between predictor variables and strain. For example, it would be interesting to detect a causal pattern between the personality factors measured in the study and carer strain. For example, does low self-esteem, low optimism and a tendency towards negative affectivity lead to the experience of strain, or does the experience of strain lower the self-esteem, lower dispositional optimism and increase the tendency There is clearly scope for further towards negative affectivity? prospective, longitudinal investigation of carer characteristics and their relations with strain. There was no control group in this study due to practical time constraints, leaving unanswered the question as to whether strain levels in this sample were higher than they would have been in a non-caregiving group. As caregivers were not compared with non-

caregivers or spouses of patients with other disabling illnesses it is not possible to conclude that stroke-related disability has a differential effect on spouses. The results may not be generalisable to stroke carers other than co-resident spouses and it is possible that this group are perhaps more motivated and positive about caring than those who are not co-resident.

The ability to accurately identify strain in these carers and assist carers with relevant interventions may reduce the number of hospitalisations for stroke couples and impact on the number of patient institutionalisations.

The ability to identify low mood in the carers soon after stroke might enable early prediction of those carers who will cope effectively with their partner's illness and those who will experience great distress and strain later on. In a review of current research it has come to light that the majority of existing community intervention services are initiated in response to a crisis situation, such as the breakdown of physical and psychological well-being after a partner has suffered a stroke (Warburton, 1994). However, it might be more effective to target services towards prevention as opposed to cure. By measuring carer mood, perceived EADL and negative affectivity early after stroke it may be possible to identify carers who are at greatest risk of strain later on. Rather than allow a situation to reach crisis stage, therefore, carers identified as being most at risk could be monitored and appropriate and more timely interventions could be made available as preventative measures. However, the predictive ability of these three factors cannot be ascertained from a cross-sectional study and the model needs to be tested across time, in a large, prospective sample of spouses of stroke patients.

CHAPTER 4

Follow-up study – testing the model

4.1 Introduction

The study of caregiver characteristics in strain indicated that strain was most closely related to caregiver mood, caregiver's perceptions of their partner's abilities in extended activities of daily living and negative affectivity. However, causal interpretations of these data were not possible as the measures were taken concurrently. The study was a crosssectional design and in order to confirm the results, the findings needed to be tested prospectively, on a new sample of carers. The present study was designed to assess whether these three factors, measured at three months after stroke were related to caregiver strain both at three months and six months after stroke. This would enable identification of those carers who were most likely to suffer from strain later on after stroke. Furthermore, consistent findings in more than one study showing an association between a risk factor and an outcome make it more likely that the association is causal and not the artifact of one study (Garb, 1996).

In addition, the study of patient characteristics identified language difficulties as an important factor in strain. Although this result was statistically significant at p<0.05, the strength of this relationship needed clarification as the numbers in the previous study were low. In the previous study, language problems were assessed very soon after stroke, but strain in the spouses was assessed later on, whilst language problems for some patients may have vastly improved in this period.

To assess the importance of persistent language difficulties in strain it is necessary to investigate the relationship between language problems that remain after discharge from the hospital and caregiver strain. Therefore, to confirm these results and assess the strength of the relationship, the present study included a brief assessment of perceived communication difficulties. McLoughlin et al (1996) proposed that in order to provide ecologically meaningful information about language, cognitive tests need to be corroborated and supplemented by either observation or carer report. Communication difficulties in the stroke patient were therefore assessed by method of carer report.

The study of patient characteristics also identified general mental state as an important factor in caregiver strain and this relationship held across time. Ideally, it would have been useful to assess this relationship in a new and larger sample. However, the MMSE is not designed for selfcompletion and so could not be included in the present study. Also, the fact that MMSE had been significantly related to strain at both three and six months in a sample of over 70 patients and spouses suggests that general mental state is consistently related to strain.

A non-significant trend had previously been identified suggesting that spouses of incontinent patients were under more strain than spouses of continent patients, six months after stroke. The study was limited to a small sample size and continence was assessed on admission to the hospital ward and so this trend needed to be addressed in a larger sample, later after stroke, to investigate the effects of persistent incontinence on

caregiver strain. Continence status was also included in the present study to clarify this issue as it could be reported by the spouses.

In the previous study of patient characteristics in strain, almost half of the spouses reported that they experienced disrupted sleep. In 1975, Sanford described the disruption of sleep as 'the least tolerated aspect of caring for someone'. In addition, whilst conducting the previous two studies, informal conversations with carers identified sleep as a problem area. Therefore, the present study included an item on disrupted sleep to allow for investigation into the relationship between broken sleep and caregiver strain. Sleep problems are relatively understudied in relation to caregiving. Nevertheless, the influence of sleep is paramount and may not only influence the level of caregiver strain but may contribute heavily to the decision to institutionalise the elderly person (Pollak and Perlick, 1991).

A recent study of dementia caregivers documented the high frequency of sleep difficulties amongst 90 older women (Wilcox and King, 1999). The study showed that caregivers reported more problems with sleep than agematched healthy adults on all seven components of the Pittsburgh Sleep Quality Index. Sixty per cent of their sample reported that night-time care recipient disruptions occurred three or more times a week. Quality of sleep was also related to psychological distress. Other studies of dementia caregivers have also identified a relationship between caregiver distress and disrupted sleep (Donaldson et al, 1998; McCurry et al, 1998; Bergman-Evans, 1994). Sleep problems have also been identified in spouses of patients with Parkinson's disease (Smith et al, 1997).

In a study of 153 PD-spouse pairs and 103 healthy controls, sleep problems were common and occurred more frequently in women than men (Smith et al, 1997). Sleep disturbance in the spouse was associated with the spouse's own rating of depression, and also waking during the night to help the patient, which was best predicted by patient factors (Smith et al, 1997). In an early study of stroke caregivers, loss of sleep was identified as one of the major problems encountered by primary caregivers (Brocklehurst et al, 1981). Sleep pattern disturbance was reported in two-thirds of stroke carers in a study by Williams (1993) and this figure is much greater than sleep disturbance in a similarly aged population reported by Karacan and colleagues (Karacan et al, 1976).

Sleep disturbance may lead to fatigue and low energy and these have been reported by carers of stroke patients (Williams, 1993). Deprivation of sleep can also be related to impaired decision making (Harrison and Horne, 2000) memory problems (Harrison and Horne, 2000a), mood disorders and lack of motivation (Mikulincer et al, 1989). However, very few published studies exist that document the existent of sleep problems in caregivers. A large proportion of the available literature focuses on problems experienced by caregivers of patients with Alzheimer's or Parkinson's disease rather than carers of stroke patients. Results from studies of dementia carers cannot be generalised directly to stroke caregivers due to the higher frequency of behavioural problems in dementia, such as night agitation ('sundowning'). However, studies of stroke carers and the high percentage of spouses in the previous study who

reported disrupted sleep suggested that sleep is also a problem for stroke caregivers and this needed to be tested empirically.

The previous study documented the length of time in the caregiving role and no relationship was found with carer strain. Although length of time caregiving was assessed, no measure was taken of the amount of care provided. General caregiving studies have suggested that caregiver strain or burden is positively associated with the amount of care required by the patient (Zarit et al, 1980; Koopman-Boyden and Wells, 1979; Cantor, 1983). The primary aim of the study was to ascertain the accuracy of the logistic regression model in predicting carers under strain. This was achieved by measuring carer mood, perceptions of patient independence and negative affectivity at three months and carer strain at six months. Using the values from the original regression model presented in chapter three, with the values obtained in the new sample at three months, predicted six month caregiver strain scores were obtained which were then compared with observed outcomes at six months. In addition, the study was extended by including concurrent measures of the frequency of sleep disturbance, frequency of incontinence and communication problems in order to examine their relationship with strain.

4.2 Methods

4.2.1 Ethical considerations

As the present study was a continuation of the study described in Chapter Three, ethical approval had already been granted in February 1997 from the Nottingham City Hospital. Ethical Approval was granted in December 1998, by the Queen's Medical Centre Research Ethics Committee. Ethical approval was later sought and granted from Leicester General Hospital in February 2000. It was not possible to collect data from this centre until April 2000 due to unforeseen difficulty accessing the patient records at this hospital. From all centres, approval was granted for postal contact of carers, and telephone contact or home visits to carers when it was requested. As in the previous study, a covering letter was sent with the questionnaires which explained the objective of the study and reassured carers that any information they provided would be treated as confidential material. Carers were also reassured that by not completing the forms they would not jeopardise their future care. Those carers who did not wish to be involved in the study were asked to telephone or write to the researcher to inform her that they did not wish to be involved. As the voluntary nature of the research was emphasised in the covering letter, it was assumed that by completing and returning the form the carers who responded had consented to their involvement in the study, therefore a signed form from the carers was not required.

4.2.2 Recruitment

4.2.2.1 Queen's Medical Centre Stroke Register

Patients admitted to Ward F21 (Stroke Unit) at the Queen's Medical Centre (QMC), who had a stroke according to the WHO (1978) definition, were recorded on a register in order of date of admission to the ward. Names on the register included those who had been previously admitted to general medical and health care of the elderly wards. This register was updated on a daily basis and contained the patient's name and hospital identification number. Further demographic information, such as gender, date of birth, marital status, GP details and hospital admission details were obtained from the Patient Administration System (PAS) or medical notes.

4.2.2.2 Nottingham City Hospital Stroke Register

Patients admitted to Nottingham City Hospital (NCH) who had a stroke according to the WHO (1978) definition, were recorded on a register in order of date of admission. Names on the register were obtained from those admitted to all general medical and health care of the elderly wards This register was updated on a weekly basis and contained demographic information, such as name, gender, date of birth, marital status, GP details and hospital admission details.

4.2.2.3 Leicester General Hospital Stroke Register

Patients admitted to Leicester General Hospital (LGH) who had a stroke according to the WHO (1978) definition, were recorded on a register in order of hospital discharge. Names on the register were obtained from those admitted to all general medical and health care of the elderly wards. This register was updated on a weekly basis and contained demographic information, such as name, gender, date of birth, marital status, GP details and hospital admission details. Permission to recruit was granted from the health care of the elderly consultant who saw the majority of stroke patients admitted. A register was then developed which contained all of the consultant's patients. The register contained information about patients who were admitted to only to LGH under one consultant and did not include patients under any other consultant.

4.2.3 <u>Selection of subjects</u>

Co-resident spouses of patients on the QMC hospital register, who had a stroke between October 1998 and July 2000, were considered for inclusion in the study. At NCH, spouses of patients who had a stroke between February 1999 and August 2000 were considered for inclusion, although no patients were recruited at this centre for a period of six months between January 2000 and June 2000 as the study was temporarily suspended during this period due to practical problems. At LGH, spouses of patients who were admitted between December 1999 and July 2000 were considered for inclusion in the study. Due to practical problems with accessing the LGH patient information system, it was not possible to access information regarding date of stroke for patients admitted to the LGH. However, date of stroke is often the same day as hospital admission or if not then within the few days prior to admission date and the date of admission to hospital was recorded.

Co-resident spouses were identified using the Patient Administration System (PAS), which contains information about marital status in addition to the demographic information of the patient. Further information about the carer was not available from the registers. The name and telephone number of each patient's General Practitioner (GP) was extracted from this register, and all GP's were contacted in order to check whether the patient was still alive and whether the address and marital status had changed since the recording of the register.

A total of 409 patients were identified from the registers as being alive, married and living in the community. Of these, 222 (54%) were identified from QMC, 158 (39%) from NCH and 29 (7%) from LGH.

4.2.4 Procedure

As the present study was designed to test the model previously developed, measures that were significant in the regression model were compiled into a large-print questionnaire format. These were posted to the spouses of the patients as they were identified each week from the registers, together with a covering letter explaining the voluntary nature of the research and a reply-paid envelope. Those carers who had not returned the forms within two to three weeks were re-contacted and reminded about the questionnaire. Carers were once again reminded that they were under no obligation and should they not wish to take part, they should ignore the reminder and dispose of the form, had they not already done so. Further questionnaires were posted out if the carer had mislaid the form and had requested another copy.

Information was collected by postal questionnaire unless the carer required help with completion of the forms. In these situations home visits were made or help was provided over the telephone. Help was given reading the questions or writing the answers, but no extra information was provided, so that data from these questionnaires was comparable with that received through the post.

The assessment package included the Caregiver Strain Index (CSI) (Robinson, 1983), the General Health Questionnaire-12 (GHQ-12) (Goldberg, 1988), the Extended Activities of Daily Living Scale (EADL) (Nouri and Lincoln, 1987) and the Positive and Negative Affect Schedule (PANAS) (Watson, 1988). The Perceived Stress Scale (PSS) (Cohen et al, 1983) was also included in order for comparisons to be made between carers' level of strain and stress in future research. As in the previous study, the CSI, PSS, GHQ-12 and PANAS were completed by the caregiver with reference to themselves. The carers were asked to complete the EADL in terms of how they perceived their partner's abilities. The background, structure and scoring details, reliability and validity and justification for selection have been provided for each measure in Chapter Three. Carers were also asked for their date of birth and how often they needed to be available to help the patient with day-today care. Responses for this question were either: 'not at all', 'less than once a day', 'daily', 'most of the time' or 'all the time'. In addition there was a question about disrupted sleep during the past week, incontinence requiring assistance during the past week and communication problems, including extent of the difficulty. These were:

How many times during the last seven days did you have to wake up and get up to help or see to the patient?

How many times during the last seven days was the patient incontinent of urine or faeces such that you had to change them or the bedclothes?

Can you have a conversation with the patient, where the patient makes spontaneous, reasonable comments? Please tick the box which applies to their abilities.

He/she is not able to communicate at all

He/she is only able to give yes or no answers

He/she can hold a reasonable conversation involving the use of sentences with <u>some</u> difficulty

He she can hold a reasonable conversation involving the use of sentences <u>without</u> difficulty

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4.3 Analysis and results

The data were screened for outliers using Cook's Distance and no cases needed to be removed. In cases where questionnaires were returned with items missing, the carer was contacted as soon as the form was received and asked to complete the missing items. The data were checked for normality by examining normal P-P plots and histograms, by comparing the mean and the median, by calculating Z scores for skew and kurtosis, and by conducting the Kolmogorov-Smirnoff Test with the Lilliefors correction. Skew ranged from -1.49 to 10.50 and kurtosis ranged from -1.77 to 17.90. Calculating Z scores showed that some of the variables did not have normal distribution and their variances were not homogenous and so it was concluded that the data did not meet the assumption of homoscedasticity and normality required for parametric analysis.

4.3.1 Response rate

Of the 409 patients and their spouses, 133 (33%) couples were excluded. This was because one patient had moved away, seven had poor English, three were separated or divorced, 39 patients died, fourteen were in institutional care, 37 spouses died, six spouses were too ill, four were in institutional care and 22 were omitted when the study was temporarily suspended at NCH. Altogether, 276 (67%) were considered for inclusion in the study. There were 63 (54%) from QMC, 46 (40%) from NCH and seven (6%) from LGH. The three-month form was returned by 130 (47%) spouses and the six-month form was returned by 116 (42%) spouses. There were 116 (42%) spouses that returned both the three and six month

questionnaires. Of these carers, 33 (28%) were men and 83 (72%) were women. Carer age ranged from 38 to 85 years (mean 66.35, s.d. 10.8). Of the patients, 83 (72%) were men and 33 (28%) were women. Patient age ranged from 45 to 88 years (mean 68.63, s.d. 10.53).

4.3.2 Descriptive statistics for each variable

Caregiver Strain Index

Table 15 shows the median CSI scores and interquartile ranges at three and six months. Using the Wilcoxon Signed Ranks Test, no significant differences were found between strain in the spouse at three and six months (z=-0.56, p=0.57).

Table 15. Descriptive statistics for overall CSI scores at 3 and 6 months

Γ	3 month	6 month
N	116	116
Median	5	5
IQR ⁺	1.25-8	1-8

interquartile range

Distribution of strain was examined separately at three and six months. Spouses who scored equal to or greater than seven on the CSI were considered to be under significant strain (Robinson, 1983). Table 16 shows the number and percentage of spouses under strain at three and six months. There was no significance between men and women spouses in the level of strain at either three months (U=1233, p=0.40) or six months (U=1293.5, p=0.64).

Table 16. Distribution of strain at 3 and 6 months

	3 month	6 month
Not strained	71 (61%)	70 (60%)
Strained	45 (39%)	46 (40%)

Frequencies (and percentages out of total completed) of this group's responses of 'yes' to each of the items on the CSI at both three and six months are shown in Table 17.

Table 17. Three and six month CSI responses for individual items

Item on CSI	3 months	6 months
Disturbed sleep	47 (41%)	48 (41%)
Inconvenient	38 (33%)	32 (28%)
Physical strain	25 (22%)	29 (25%)
Confining	59 (51%)	58 (50%)
Family changes	49 (42%)	41 (35%)
Changes in personal plans	63 (54%)	59 (51%)
Other demands	35 (30%)	39 (34%)
Emotional adjustments	36 (31%)	41 (35%)
Upsetting behaviour	58 (50%)	58 (50%)
Patient has changed	60 (52%)	57 (49%)
Work adjustment	23 (20%)	20 (17%)
Financial strain	44 (38%)	47 (41%)
Feeling overwhelmed	62 (53%)	59 (51%)

At three months, changes in personal plans were reported by the greatest percentage of spouses, followed by feeling overwhelmed and feeling that the patient had changed from his/her former self. At six months, the items selected by the greatest percentage of spouses were feeling overwhelmed and changes in personal plans, followed by upsetting behaviours and feelings of confinement. For the majority of items, the percentage of spouses selecting the item remained relatively constant from three months to six months. However, there was a notable drop in the percentage of carers reporting family changes by six months, and a notable increase in the percentage of carers reporting financial strain. The least frequently reported were work adjustments and physical strain, which had the lowest proportion of 'yes' responses.

As the data did not meet the assumptions of normality and homogeneity of variance it was not appropriate for parametric analysis. Therefore, the medians are reported here in place of the means. The distribution of scores on each measure is shown in Table 18.

Variable	Possible	n	3 month		6 month	
	range		Median	ÍQR	Median	IQR
CSI	0-13	116	5	1.25-8	5	1-8
Patient EADL	0-22	116	11	3-19	13	5-19
Carer GHQ-12	0-12	116	3	0-7	1	0-6
Negative Affectivity	10-50	116	19	13-29	17	13-29
Positive Affectivity	10-50	116	33	26-37	33	26-37
Perceived Stress	0-56	116	17.5	8.25-23	17	9-24
Scale		-				
Amount of care	0-4	116	2	0-3	2	0-3
Waking during night	-	93	0	0-5	0	0-4.5
Incontinence	-	93	0	0-1	0	0-1
Communication	0-3	93	3	2-3	3	2-3

Table 18. Distribution of scores for each variable

4.3.3 Correlation analysis

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As the majority of data was ordinal, non-parametric Spearman Rank Correlation Coefficients were calculated using SPSS for Windows (Release 9). Each variable measured at three months was correlated against strain on the CSI at six months. Results are shown in Table 19.

Variable at 3 months	Caregiver Strain Index at 6 months					
	Ν	۲ ^s	р	partial ⁺	р	
Carer GHQ-12	116	0.72	<0.001***	0.08	0.48	
Patient EADL ⁺	116	-0.65	<0.001***	-0.14	0.19	
PANAS-NA	116	0.66	<0.001***	0.19	0.08	
PANAS-PA	116	-0.17	0.07	-0.02	0.84	
PSS-10	116	0.60	<0.001***	0.05	0.67	
Amount of care	116	0.54	<0.001***	-0.01	0. 8 9	
Waking	93	0.51	<0.001***	-0.02	0. 8 6	
Incontinence	93	0.45	<0.001***	0.01	0.92	
Communication	93	-0.43	<0.001***	0.25	0.02*	

Table 19. Variable Relationships with Carer Strain

***p<0.001 * p<0.05 for a two-tailed analysis

+ partial correlations controlling for 3 mth CSI

All variables measured at three months were significantly correlated at p<0.001 with strain at six months, with the exception of positive affectivity. The Bonferroni corrected p value was p=0.0001 and all previously significant correlations were also significant at this more stringent level. Partial correlations controlling for CSI at three months showed that communication difficulties were significantly related to six month strain. The relationship between each of these three-month variables with strain at six months is shown in Figures 23 to 25.


Strain at 6 months

4.3.4 Testing the logistic regression model

In the previous chapter, multiple logistic regression analysis yielded a model containing three significant variables; the General Health Questionnaire-12, the EADL completed by the carer and the PANAS negative affectivity scale. The following analysis was intended to determine the accuracy with which the model could predict levels of caregiver strain six months after stroke. Using the values from the previous sample, presented in the regression model, with data from the three month outcome, it was possible to predict whether the carers in the new sample were likely to suffer from strain at six months (predicted outcome). Predicted outcomes were then compared with actual levels of strain at six months (observed outcome) to provide an indication of the accuracy and error levels of the regression model. A discriminant analysis was adopted to distinguish those carers who were likely to suffer from strain. Firstly, L was defined as the logit of the probability p that a carer would be under significant strain. The values for L were calculated for each carer using the regression coefficients from the original model.

As the three variables in the model were all continuous, the values for L were also continuous. Here, p refers to the probability of the carer being under strain and 1-p refers to the probability of the carer not being under strain. The probability of being under strain was calculated using the following formula: $p = \exp L/1 + \exp L$

The following formula was utilised to calculate L:

$$L = \log (p/1-p) = b_0 + b_1 \chi_1 + b_2 \chi_2 + b_3 \chi_3$$

Therefore:

$$L = -2.05 + (0.30 * GHQ-12) - (0.13 * EADL) + (0.08 * PANASNA)$$

A new dichotomous variable was created to represent the model predictions. If the probability of being under strain (p) was greater than the probability of not being under strain (1-p), carers were coded as being strained. If the probability of being strained was less than the probability of being not strained they were coded as not being strained. Predicted outcomes were then tabulated against observed outcomes and the results are shown in Table 20. One hundred and sixteen cases were available.

Tuble 20. Crossido didition of predicied and observed outcom	stabulation of predicted and observed outco	omes
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		Observeu Ou		
		Not strained	Strained	7
				Total
Predicted Outcome	Not strained	57	13	70
	Strained	13	33	46
	Total	70	46	116

Observed Outcome

The table shows that 90 carers were accurately predicted as being either strained or not strained on the CSI at six months. The number of carers for whom observed outcome was correctly predicted by the regression model was calculated and divided by the total number to provide an indicator of accuracy. Accuracy was 78% and therefore the margin of error was 22%. The results confirmed, therefore, that low carer mood, low perceived patient EADL and high negative affectivity, measured three months after stroke, predicted high levels of strain at six months.

4.3.5 Other factors

Although the model was relatively accurate in predicting carers at risk from strain, the 22% margin of error suggests that other factors may also be involved. Information was available for 93 patients regarding sleep disturbance, incontinence and communication problems. Figures 26 to 28 depict the relationship between these three factors and caregiver strain at six months. Disturbed sleep and patient incontinence were present in the strained group of carers but not in the group who were not strained. By six months there were no patients who were not able to communicate at all. Strain in the spouse increased as the level of communication difficulty increased. The relationship between the amount of care provided and caregiver strain is depicted in Figure 34. Those carers who were under strain at six months reported spending a greater amount of time providing care at three months than carers who were not under strain.





Strain at 6 months

Figure 34. Strain and amount of care provided



Strain at 6 months

4.4 Discussion

In this sample, levels of strain were high with 39% under strain at three months and 40% under strain at six months. There were no differences in strain at either time point and this is consistent with the findings reported in Chapter Two, which also failed to find a significant difference in strain between three and six months after stroke. This supports the view that strain remains relatively high over time and others have found this can remain up to three years after stroke (Langton-Hewer et al, 1990).

The model developed in the previous study was tested prospectively, in a large sample of caregivers. Although many caregiver characteristics were significantly associated with strain, the previous study had identified three factors that were most important, namely, carer mood, perceived patient EADL and negative affectivity. Results of the present study supported these findings and demonstrated that the model could accurately predict strain in carers six months after stroke. These three factors have been discussed in Chapter Three. The margin of error might be explained by other factors, such as incontinence, communication problems and disrupted sleep.

The importance of continence was demonstrated by a strong significant relationship with carer strain. This was not unexpected given the increase in sample size from the previous investigation of incontinence and also the trend presented previously between incontinence and strain. The results support the findings of previous research (Brittain, 1998; Flaherty, 1992; Heok and Li, 1997; Lim et al, 1999) which has also demonstrated a relationship between incontinence and caregiver outcomes.

In Chapter Two, a trend was reported between incontinence immediately after the stroke (on admission to hospital) and caregiver strain at three months although this trend was not apparent by six months. This might be explained by the fact that incontinence immediately after stroke can be transient (Henrikson, 1991) and for many patients, the problem may have disappeared within the months following stroke. In the present study, incontinence assessed at three months was significantly related to strain at six months. This study addressed carer strain in patients with persistent incontinence by assessing incontinence three months after stroke and strain at six months. The importance of incontinence is not surprising given that the likelihood of incontinence is linked to severity of stroke stroke (Burney et al, 1996; Khan et al, 1981; Sakabibara et al, 1996) and poor recovery (Ween et al, 1996; Gross, 1998), and perceived patient disability on the EADL appeared as one of the strongest factors in carer strain.

Results also showed that language difficulties were important in carer strain. This lends support to previous work suggesting that communication problems are associated with carer distress (Brumfitt, 1993; Shewan and Cameron, 1984) but again contests the findings of Rau et al (1986) and Wade et al (1986) who suggested that the presence of aphasia did not affect the adjustment, burden or level of stress in stroke caregivers. In Chapter Two, communication was significantly related to strain at three months but not at six months. However, language was assessed soon after stroke and many patients may have recovered in the following months. In the present study, communication ability was

assessed three months after stroke and was significantly associated with strain by six months. There are a number of explanations for this finding. It may be that the numbers in the previous study were too low to identify a clear relationship between language problems and carer strain later after stroke. Alternatively, it may be that persistent language problems are important in carer strain.

The only previous measure of disrupted sleep had been an item on the CSI that required the respondent to indicate whether or not sleep was disturbed. However, measuring the frequency of sleep disturbance across a week provided more information than simply saying that sleep was or was not disturbed. Strain increased as the frequency of sleep disturbance increased and this relationship was maintained across time. This study has highlighted the importance of disturbed sleep as a factor in carer strain although research is needed on methods of alleviating sleep problems and therefore reducing strain. Quality of sleep has been associated with psychological distress (Wilcox and King, 1999) and these findings were supported in the present study.

The relationship between fatigue and psychological variables, including depression suggests that control of fatigue may help to buffer carer distress and may therefore impact on carer strain. In Wilcox and King's (1999) study of dementia caregivers, over a third of their sample used some form of sleep medication. However, McCurry et al (1998) proposed that behavioural techniques may be a viable alternative to medication for sleep problems in ageing caregivers. The authors advocated the use of behavioural techniques to reduce sleep problems, including standard sleep

hygiene, stimulus control and sleep compression strategies as well as education about community resources, stress management and techniques to reduce patient disruptive behaviours (McCurry et al, 1998). Although patient disruptive behaviours are less common in stroke patients than dementia patients, behavioural techniques as a whole might be a useful method to employ with stroke caregivers.

Although the length of time since the stroke was unrelated to strain in the previous study, it seems that the amount of time spent caregiving may be more important. Carer strain increased with the amount of time the carer reported needing to be available to help with everyday care. One individual may have looked after their spouse for a long time but only need to help them as a caregiver once or twice a day. Another individual may need to be available for their partner all the time. This is consistent with feelings of fatigue and entrapment expressed by some of the carers during data collection. It may be that some form of respite care would help to alleviate this and potentially reduce carer strain.

The availability of carer age in this study overcame the methodological shortcoming of the previous two studies and demonstrated that younger carers were under greater levels of strain than older carers. Again, it is possible to apply the theory of family life stage in reactions to chronic illness (Rolland, 1988) discussed in Chapter Two. Neugarten's (1968) concept of the 'social clock' might explain why older carers may be more prepared to face illness in a spouse than younger carers.

There were some methodological issues that need to be identified. As the spouses were predominantly an elderly group it is possible that some carers could not complete the forms due to their own cognitive and language impairments. In addition, spouses were excluded if they were themselves too ill to take part in the study. Therefore the sample may be biased in the direction of a healthy population. On the contrary, names were taken from a hospital register and not all patients with stroke are admitted to hospital. The majority of patients with residual deficit after stroke are admitted to hospital, which may have resulted in a reduced number of carers whose spouses had only a very mild stroke with little or no resulting deficits.

The sample may have been affected by a high proportion of spouses who did not complete the forms. However, the response rate is comparable with the questionnaire study reported in Chapter Two and with other research on stroke carers using similar methodology (Pound et al, 1993). In addition, a low response rate is not unexpected in a client group that has a high mortality rate and a high rate of movement into residential care. As in the previous studies, carer information was more difficult to obtain than patient information as specific carer details are not recorded on the hospital system. Response rate might be improved if the full names of carers could be obtained to make the contact more personal. Alternatively, home visits could increase the response rate rather than postal collection of data although this is a more expensive and timeconsuming method.

Again, there was no control group in this study due to practical time constraints, and therefore it is impossible to tell whether strain levels in this sample were higher than they would have been in a non-caregiving Three and six months were selected as appropriate times for group. collection of data. Many studies of stroke patients and their carers have used three and six months as time points for data collection. Three months is still considered to be during the acute stage although the majority of patients being discharged back to the community have returned home by this time. Six months is long enough for carers to be aware of all the problems that may occur as a result of the stroke and to have settled into a routine of care. Rehabilitation is often still underway. Assessment at one year would have been useful as by then, optimal levels of functional capacity would be expected in the patient. However, this would have lengthened the time to complete the study and possibly reduced case numbers due to death and disability.

Due to practical problems with accessing the LGH patient information system, it was not possible to access information regarding date of stroke for patients admitted to the LGH. Therefore, carers were contacted three and six months after the date of the stroke at the Nottingham hospitals but contacted three and six months after the date of admission to the hospital in Leicester. However, date of stroke is often the same day as hospital admission or if not then within the few days prior to admission date. The difference in recruitment times between LGH and the other two centres was therefore considered to be minimal.

This study has provided supplementary evidence to suggest that caregiver strain can be predicted by carer mood, perceived EADL and negative affectivity. Other factors may also be important, including disturbed sleep, incontinence, communication problems and amount of time spent caregiving.

CHAPTER FIVE

Discussion and Implications

5.1 The findings and their implications

In the questionnaires used in Chapter Three, carers were provided with space to make free, written comments. Although there was not enough information for qualitative analysis, some of the carers' comments have been selected in this chapter to illustrate certain points.

5.1.1 Limitations of previous research

Although there is detailed information concerning the problems stroke carers experience, we have still been unable to adequately predict the carers who will cope and those who will experience difficulties. Despite a vast literature on caregiving, much of the available research focuses on dementia carers. However, stroke is hard to compare to dementia because of a greater frequency of physical disability and a lower frequency of behavioural problems. Additionally, previous research on stroke carers has tended to focus on patient characteristics and has not included a detailed examination of carer factors. Few studies have addressed carer individual differences, support, adjustment and life satisfaction within the same study. Where they have, only a small number of variables have been included which makes it difficult to assess the unique contribution of each and determine whether different factors have multiple independent effects or whether some characteristics are more important than others. Previous studies addressing patient characteristics have focused on disability and mood, sometimes including general cognitive impairment. However, studies have not examined specific cognitive impairments in relation to carer strain to see which aspects of cognitive function might be most stressful to carers.

5.1.2 What have we learned?

Despite its limitations, this research is the first to examine the impact of a spectrum of specific cognitive deficits on caregiver outcomes. The study is also the largest to address caregiver characteristics in detail and includes more aspects of caregiver individual differences than any study of stroke caregivers to date. Additionally, the study has evaluated the usefulness of providing individualised cognitive deficit information as an intervention to reduce carer strain.

The evaluation of the relationships between patient and caregiver variables and the enduring outcome of strain has included objective measures of stressors, the way in which stressors are perceived by the caregiver and the assessment of a large number of intervening or moderating variables. These studies have identified the patient and caregiver characteristics that may be most important in determining the level of strain the spouse experiences. Looking back at the model (see figure 8), results of the studies presented here suggest that of the conditioning variables, carer function, economic status, social support and satisfaction with support and personality factors were all associated with carer strain. The most important factors were carer mood and negative affectivity together with the carer's perceptions of the patient's function.

Objective stressors of greatest importance include general mental state and communication difficulties. Specific or subtle cognitive deficits may be less important. Patient affective state is important to caregiver outcomes. However, length of time caregiving was not associated with strain, rather, the amount of time spent caregiving was the important factor. Disrupted sleep was also found to be an important factor but was not adequately addressed by the model. The nature, prevalence and treatability of sleep problems needs further investigation. Of the enduring outcomes presented in the model, the studies demonstrated that all factors were associated with strain, including psychological well-being, life satisfaction, adjustment and handicap.

In conclusion, the main findings suggested that:

- Carers were more strained when they perceived their partner to be less independent in everyday activities of daily living.
- Carers were more strained if they had high negative affectivity and suffered from low mood.
- Carer strain was increased in spouses of patients with deteriorated general mental state and communication difficulties.
- Sleep disturbance, incontinence and the amount of time spent caregiving may be important factors.
- Providing individualised information to patients and carers may help to reduce carer strain

5.1.3 What does this suggest?

The findings presented here suggest that a number of interventions may be useful to reduce carer strain.

- Where perceived independence is poor, intervention could increase physical function using, for example, physiotherapy or occupational therapy or by increasing staff understanding of cognitive problems which may alter treatment and lead to greater independence. Alternatively, if poor independence is subjectively perceived rather than objectively poor, intervention might help to reduce distorted perceptions by increasing communication between carers and staff or by increasing carer understanding of stroke and cognitive impairments by providing individualised information.
- Where negative affectivity is high, carers may be prone to depression and so intervention could focus on improvement of carer mood.
- Where mood is low, emotional intervention such as support groups, counselling or groups teaching emotion-focused coping strategies might help to reduce carer strain.
- Mental state and language are related to emotional aspects of strain which also suggests that intervention targeted towards the improvement of mood may reduce carer strain.
- Dealing with incontinence, sleep disturbance and the amount of time spent caregiving are practical aspects of strain which suggests that respite care might provide some relief.

5.1.3.1 Perceived Extended Activities of Daily Living

If increased disability per se is related to strain, then there is little scope for psychological intervention and the appropriate action would be to offer respite care or help with the physical aspects of caregiving. However, the carer's assessment of the patient's level of disability is not necessarily an accurate account. Indeed, the differences between proxy ratings of disability by the carer and objective assessments of disability by health professionals have been acknowledged (Wyller et al, 1995).

Knapp and Hewison (1999) found that carer strain was higher where there was a greater discrepancy between patient and carer ratings of disability. It was not known whether carers in this sample were accurate in their assessment of patient disability. It may be that carer's estimates of patient disability are distorted. Distorted beliefs may be the result of a misunderstanding of stroke and therefore the most appropriate intervention would be the provision of information. Alternatively, distorted beliefs may be the due to misconceptions about recovery, which may be the result of poor communication between health professionals, patients and their families (see Ley, 1988). Carer's perceptions of their spouses being more disabled than either patients or professionals report Moreover, conversations with carers result in overprotectiveness. suggested that they tended to 'wrap patients up in cotton wool' and perhaps not allow patients to carry out activities they were capable of, for fear of them hurting themselves or having another stroke. Improving communications between professionals and carers may improve knowledge and expectations of recovery. This might reduce the tendency

to overprotect patients and increase the tendency for carers to encourage independence in their partners.

5.1.3.2 Carer mood and negative affectivity

Carer mood and negative affectivity are both components of caregiver subjective well-being. Studies have shown that carer mood is related to perceptions of the patients disability and if perceptions are distorted, then improving communications and providing more information about stroke and the patients recovery might go some way to improving carer mood. A more direct approach might be providing a support group where carers can meet to discuss their caregiving role with others in the same situation. High NA individuals may be prone to depression (Jolly et al, 1994) and may dwell on their shortcomings and failures. They have a negative attitude towards both themselves and others.

Although negative affectivity is a measure of trait subjective well-being, it may be possible to encourage optimism and positive attitudes in carers who display high NA and therefore high carer strain. It is possible that carers with high NA view their partners abilities in a less favourable light which may in turn distort their perceptions of EADL. Trait NA roughly corresponds to the personality factors of anxiety/neuroticism. Negative affectivity influences both anxiety and depression levels and the study has shown that strained carers are likely to have both high NA and high levels of depression. Anxiety was not studied as a separate factor in the present study, but psychological interventions aimed at treating anxiety and depression may be beneficial in the reduction of carer strain. High NA is

associated with poor coping and therefore interventions aimed at teaching carers effective coping strategies may also be useful in reducing strain.

5.1.3.3 General Mental State

Changes in general mental state after stroke can have profound effects on the caregiving spouse and the marital relationship:

'The hardest aspect of my husband's stroke has been his detachment, which is worse at times than others......My husband and I have always had an amazingly close relationship and he is my best friend which is why his detachment is hard to bear at times.....So often he seems distant and remote.....without his old twinkle'

Declining mental state is often associated with poor memory and individual carers identified memory problems in their partners:

'His memory for day to day things is unreliable and I have to check, far more, that important bills are paid on time and forms completed.....more household things fall to me than previously....'

'When he has something on his mind he repeats it over for about three days, then he starts on something else....his memory is very poor'

Although there is little that can be done for global impairments of cognitive function, there are compensatory techniques for aspects of cognition, such as memory, which may help to reduce patient memory difficulties and therefore potentially reduce carer strain.

5.1.3.4 Communication problems

Individual carers accentuated the strain caused by language difficulties. Carers identified the lack of communication and portrayed their situations as lonely:

'It is difficult to understand what she wants to say which makes my life lonely and tedious'.

'He has dysphasia so we are not able to have a real conversation......we both have a sense of humour and that helps. We have good and bad days' Language difficulties place a huge strain on the marital relationship and it is likely that carer strain is increased by a lack of sufficient and accurate knowledge about dysphasia. On a practical level, the study presented in Chapter Two demonstrated the potential benefits of providing specific information about cognitive deficits to carers and further research is needed to assess whether strain can be significantly reduced in partners of aphasic stroke patients by providing detailed individualised information, educating hospital staff about cognitive function (including language difficulties) and increasing communication between caregivers and speech and language therapists. On a psychological level, support groups and stroke clubs may be useful for carers to gain emotional support from others in the same situation.

5.1.3.5 Gender

The lack of gender differences in either study was surprising given the tendency towards higher strain in women that has been identified in the literature. Women typically report greater levels of strain (Enright, 1991),

burden (Miller and Cafasso, 1992) and psychological distress (Schulz et al, 1993; Zarit and Whitlach, 1992) than men. This might be explained by differences in role expectations and coping strategies. It has been suggested that women may have a different approach to caregiving than men and be involved in different tasks. A meta-analysis of 14 descriptive studies of gender differences in caregiving found that women may be more likely to carry out personal care and household tasks than men (Miller and Cafasso, 1992).

In studies of dementia caregivers, husbands and wives were found to have a different approach to caregiving, with male caregivers adopting a 'taskoriented' approach to their duties and carrying out duties in a linear fashion, and women tending to adopt a parent-child approach and nest activities inside one another in a constant stream of work (Corcoran, 1992). In addition, the gender-role socialisation hypothesis (Miller and Cafasso, 1992) suggests that men may be more likely to have other helpers whilst wives tend to be sole caregivers and this is supported by empirical evidence (Allen, 1994; Neal et al, 1997).

The different approaches to caregiving may result in the experience of different levels of strain. Greater distress may well be attributed to the nurturing role of women, and women having a greater overall investment in family care in this generation. An alternative explanation is that women may be more likely to express their feelings of strain and psychological distress than men. These two schools of thought have been summarised in two models proposed by Lutzky and Knight (1994). One model suggests that women are socialised to use coping styles that are less

effective for alleviating distress and the other model suggests that men are less likely to be attentive to their emotions and thus fail to recognise and report distress.

Despite this common finding, gender was investigated in each study conducted here and no significant relationship was found. It is therefore possible that gender may not be an important factor for carer strain in stroke spouses. Some studies have suggested that the observed gender differences in caregiver burden may be more to do with age differences between male and female caregivers (Barusch and Spaid, 1989). Although the age of the spouse was not available in study two, it is likely to represent a similar distribution to age of the patient and no significant differences were found in age between men and women. If the observed gender differences in the literature were due to age differences between male and female carers then the lack of age differences in the present studies might explain the lack of gender differences in strain.

5.1.4 Emotional intervention

Strain was strongly related to mood and negative affectivity, which suggests that reducing low mood may alleviate strain. Additionally, mental state and language were closely related to strain and these cognitive impairments were related to more emotional than practical aspects of caregiver strain. Some carers expressed a need for stroke carer support groups where they would be able to talk to other people in the same situation:

'I feel isolated and would like more help from the professional services. I think counselling would benefit most carers. And more support groups would help as well'

'I wish there was someone I could talk to, apart from friends.....someone who would understand my fears and worries...'

Support groups have shown to provide information and to promote interaction with others facing the same situation (Barnes, 1981; Bishop et al, 1986; Kanan and Kempt, 1985; Wilson, 1985) and they thrive on individuals sharing their personal experiences (Wilson, 1985).

Given the significant relationship between social support and carer outcomes and the positive effects of providing information an intervention of this sort may be beneficial in the reduction of carer strain.

Some support groups are developed specifically for carers of stroke patients and positive carer reactions to stroke clubs have been demonstrated (Printz-Fedderson, 1990). In this study, 50% of the carers found that the source of friendship was the most helpful. Forty per cent found the emotional support the most helpful and 10% found the educational and informational benefits to be the most important. Similar findings have been demonstrated in studies of carers of Alzheimer's patients. A study by Barnes (1981) of 15 family members who participated in a support group of caregivers for Alzheimer's patients found improved understanding of the disease to be the most important outcome. Other important outcomes of the group were sense of support, acceptance and realisation that emotional reactions experienced by the caregivers were normal. Support groups are valued by those that

participate, and carers cite the value of sharing information and learning about help available. However, studies evaluating the effectiveness of such interventions are limited and further research is needed to assess the usefulness of such groups for carers of stroke patients.

Although support groups and stroke clubs may be effective in alleviating the effects of strain and distress, some researchers have suggested that they may be less effective than structured group interventions or individual and family treatments that can individualise the treatment to the caregiver's needs (Teri, 1994; Gallagher-Thompson and DeVries, 1994). Indeed, this research has demonstrated that individualised information may be effective in reducing carer strain and therefore it is likely that individualised treatments may also be effective. Structured interventions may be used to teach carers specific skills such as anger management, coping strategies and increasing pleasurable activities. Such interventions may increase carer well-being and reduce depression and therefore impact on carer strain. Studies of Alzheimer's carers have shown that intensive psychosocial intervention reduces the rate of depression amongst caregivers (see Knight et al, 1993; Mittelman et al, 1995) and significantly lowers the level of nursing home placement of patients (Mittelman et al, 1993). However, no studies of stroke carers have been identified that evaluate such interventions. Additionally, specialist interventions are usually much less readily available than support groups.

Roberts et al (1999) found that individualised problem-solving counselling, for caregivers of cognitively impaired relatives, was valued by those who received the service. Caregivers receiving nurse counselling

showed no significant improvement in psychosocial adjustment to their relative's illness, psychological distress, or caregiver burden although they rated the service as being very helpful. A study of coping and marital equilibrium after stroke suggested that family counselling may be used to facilitate couple adaptation after stroke (Robinson-Smith and Mahoney, 1995).

5.1.5 Respite care

For many carers, counselling and support groups may not be the answer. One carer said:

'I don't want a shoulder to cry on. What I would desire most is someone to be interested in my husband's problems and to do something positive to alleviate them'

Caregiving for spouses of stroke patients is often a full-time role and this was accentuated by one carer:

'I do not fuss over him or try to 'wrap him in cotton wool' as he would hate it and in his place, so would I, but I do find myself noting every sign of fatigue or excess stress in his face or body language. I am therefore less relaxed in general, never quite off-duty, as it were'

On the basis of carer comments, respite care would be an appropriate intervention. Many caregivers report having little respite time from their caregiving role (e.g. Campbell and Travis, 1999). Respite services are valued by caregivers who use them and the need for respite care services has been expressed by spouses of stroke patients (Denman, 1998). Carers in the present study expressed a desire for time to themselves: 'I feel as though I would love to go out, but I can't because I don't want to leave him on his own'

'Just one day to myself a week would make a lot of difference'.

Caregiver reactions to offers of respite care may depend to some extent on the nature of the relationship between the informal carer and the dependent person (Clarke and Watson, 1991). However, respite services may enable continuing employment for the caregiver or simply allow the caregiver to have a break from their caregiving responsibilities. Some studies have highlighted the psychological benefits of respite care for family caregivers (Zarit et al, 1998) yet others have suggested that respite care has little impact on caregiver mental health and has not been found to delay nursing home placement (Lawton et al, 1991; Montgomery and Borgatta, 1989). Moreover, a systematic review of respite intervention studies revealed 29 studies from which there was little evidence that respite intervention has either a consistent or enduring beneficial effect on carers' well-being (McNally et al, 1999). These findings may be be due to methodological weaknesses in the design of these studies, or they may suggest that respite care often 'fails to facilitate the maintenance of socially supportive relationships' which may continue to moderate strain after the respite care has ended' (McNally et al, 1999). It may be that despite needing respite time, some carers feel unable to take breaks because either their partner does not wish to have respite care, or they feel some kind of obligation to continue the caregiving role alone. This was demonstrated in comments made by some carers:

'Looking at the system of care and support for someone his age there really isn't much long-term. Even if there were facilities would he want to use them?'

'I feel I would like respite but he won't go and I won't make him'.

'They are trying to persuade me to have respite care.....they said leave him for a week but I brought him back with me, I just couldn't leave him, there were no familiar faces.......I don't think I can let go of him, only if my health deteriorates more'

5.1.6 **Providing information**

Educating carers may be one way of reducing carer strain. Chapter Two outlines the literature on information giving in stroke and provides a discussion of the results of a study where carers were provided with individualised cognitive assessment information. Previous research suggests that providing information about stroke to carers may improve psychological well-being and reduce carer stress and the results of the present study suggests that the provision of information may be effective in reducing carer strain. Comments from carers clearly demonstrate that there is an unmet need for more information about stroke:

'I would like the doctors to give more information on strokes and exactly what they expect of the patient – laying out some basic ground rules. I feel very frustrated about the hospital doctor's lack of explanation'

The present study has supported previous research and has shown that providing carers with individualised information and practical

recommendations regarding their partners cognitive function may reduce carer strain.

However, this raises the question of who may be the best person to provide this information.

'I would feel better if there was more support that could make home visits from the stroke association when I am feeling particularly low. Sometimes it would help to think that someone who understands stroke could visit you'.

Family support services can help to raise awareness of risk factors and help to minimise recurrence of stroke (Richardson et al, 1996). McCallion et al (1999) evaluated the effectiveness of a family visit education program (FVEP) for nursing home residents with dementia (n=66) and found that the family visits educated family members and helped them to communicate more effectively with the dependent person. Dowswell et al (1997) evaluated the effects of five specialist stroke support nurses in a randomised controlled trial of a stroke support service (n=30 patients, n=15 caregivers). Eight caregivers received visits from a specialist nurse. The qualitative results were more positive than the quantitative results, with the less tangible aspects of the intervention (e.g. concern, attention, empathy and interest) being of value to the carers. The majority of caregivers in the intervention group believed that they had benefited from the visits by the specialist nurse.

Dennis et al (1997) examined the effect of contact with a stroke family care worker on the physical, social and psychological status of stroke patients and their carers. Four hundred and seventeen patients and their

carers were randomised to receive either contact by a stroke family care worker (n=210) or standard care (n=207). Although there were no significant differences in patient or caregiver physical well-being, contact with a support worker increased carer satisfaction with services and may have had some effect on psychological and social outcomes. Continuity of care is important and there is cause for a named individual to be responsible for offering advice, assistance in understanding and communicating with the patient and their spouse.

5.1.7 Summary

In conclusion, many support services and interventions are known to help patients and their caregivers. However, the availability of such services is variable and it is often unclear as to whose responsibility it is to organise and finance them (Ham, 1999). Given the heavy burdens of caregiving, even small interventions may translate into improvements in the quality of life and confidence of a caregiver (Gwyther, 1998). The ability to identify early on after stroke those carers who may be 'at risk' of strain later on would allow for interventions to be targeted towards specific groups, rather than caregivers as a whole. This research has demonstrated that spouse caregivers suffer from high levels of strain and has identified the factors that are most closely associated with strain. It is postulated that the group at risk of strain may be those carers who are perceived to be less independent in extended activities of daily living and have communication

problems and general cognitive decline are also at risk. This research has demonstrated that the provision of individualised information and practical recommendations may be effective in the alleviation of caregiver strain although this needs further validation. This work has also suggested that some form of emotional intervention may be helpful in reducing carer strain.

5.2 Methodology

There are a number of methodological issues that should be taken into consideration in the interpretation of these studies. The investigation of carer strain was divided into separate studies, as, for risk of overburdening the participants, it was not possible to combine all the possible patient and carer factors that may have been related to strain. For example, neuropsychological assessment is a lengthy and tiring process for the stroke patient. Assessment batteries can rarely be done as a whole and can take anything from days, to weeks or even months of visits to complete the full battery of assessments. For this reason, it is difficult to recruit a large number of patients. Even when large numbers of patients are initially available, the six months to final follow-up is long enough to drastically reduce the data available for analysis as many patients and carers are 'lost' from the study along the way, from moving away, withdrawal, separation, illness, hospitalisation, institutionalisation or death. Large, detailed assessment batteries would not be practical as a routine assessment of every patient admitted to hospital and therefore further research should concentrate on the important cognitive factors identified here, namely, communication difficulties and global cognitive impairment. Studies are needed that combines the significant patient and carer variables from this research, in particular orientation, language, disability and carer factors to see how they relate to one another.

Selection bias is possible as the studies did not include those patients who had had strokes in the community but were never admitted to hospital. It has been reported that 40% of first-time stroke patients are not admitted to hospitals (Spencer et al, 1997). However, the patients included in the studies presented here were all identified from admission hospital records. For an accurate study of all spouses of stroke patients it would be necessary to include all patients with stroke as the present research was based on spouses of stroke patients who were admitted to hospital.

This would mean recruiting patients via general practitioners in addition to recruiting through hospital admissions in order to include those patients who had a stroke in the community and were never admitted to hospital. However, it is unlikely that inclusion of these patients would significantly alter the results of the cognitive assessment study as the majority of patients who have residual deficits from stroke are admitted to hospital. Given that residual deficits from stroke such as dependence in EADL and incontinence are related to carer strain, the exclusion of the community patients from the postal studies of caregiver characteristics may have resulted in a loss of a proportion of carers likely to be under lower levels of strain. This is likely to have been counterbalanced in the present studies by the fact that spouses of severely impaired patients may spend a greater amount of time caregiving and therefore may have felt they did not

have time to return the forms. However, this may not be an accurate assessment as the most severely impaired patients are more likely to have been discharged from hospital into nursing homes and therefore would have been excluded anyway. This demonstrates how inclusion and exclusion criteria may lead to bias in the samples. Additionally, it would be interesting to look at how the factors relating to caregiver strain after stroke change in spouses of patients who are temporarily or permanently moved to residential care.

The prevalence of strain in all three studies was high. However, characteristics of the carers who chose not to participate in the studies are not known. It is not clear whether the carers who chose not to be involved did so because they were not strained and therefore saw no need, or whether they were under so much strain they did not feel able to be involved. In the assessment of strain, the studies did not take into account whether or not the patient was a first-time stroke or whether they had had more than one stroke. However, in the study of patient characteristics, having had a previous stroke was recorded and no significant relationship was found between previous strokes and carer strain, although the numbers were low and so this result may not be conclusive.

The studies did not control for previous caregiving history. That is, there was no assessment of whether the spouse had been involved in a caregiving role prior to the occurrence of the stroke, and an increased length of time in the caregiving role may have affected their level of strain. However, time since the stroke was not a significant factor in the present studies.

Previous psychiatric morbidity of the carers was not taken into account. These studies suggested that carer mood is an important factor in the experience of strain. However, it is not possible to ascertain whether the spouses had low mood before the occurrence of the stroke, unrelated to the caregiving role. It is possible that pre-existing psychological factors might play a role in the way in which an individual responds to a stressor. For example, a carer who has numerous other stressful life situations to contend with may suffer from increased adverse emotional reactions to the caregiving situation. A carer who is well adjusted prior to the illness may withstand the stress of caregiving better than those who were not well adjusted prior to the illness. However, this information is difficult to collect and is not available in the majority of research studies in this area. Even if the information were readily available it would be subject to the recall biases of retrospective, subjective reports.

Different researchers may select different measures to use in the study of caregiver and patient characteristics. However, the measures and assessments chosen were carefully selected, standardised measures with established validity and reliability. Furthermore, justification for the use of each measure with the study population has been provided where possible.

The studies relied heavily on self-report as a method of obtaining information. As the aim of the study was to identify factors related to strain as perceived by the carer, self-report measures were deemed most appropriate to gain subjective information about the extent to which the index individual was experiencing each construct. As the carer's

perceptions of each factor were important to perceived strain, self- report appeared to be inevitable. This is illustrated by the fact that social support, for example, has to be perceived in order for it to be effective. Therefore it seems relevant to measure *perceived* support as opposed to objective support, of which self-report is the only approach to measurement.

Similarly, empirical evidence has suggested that professionals are relatively poor judges of both the degree of disability experienced by the patients (or in this case, carer's view of the stroke sufferer's disability and the carer's own health) and the impact that this has on their lives (Martini and McDowell 1976). Again, the important factor is individual perception. However, the method of self-report in research may be susceptible to a number of response biases (Fordyce and Steger, 1979). Self-reports are extremely vulnerable to conscious and unconscious psychological defenses. Caregiver's perceptions of their situation may be biased by social desirability and may not be objective measures of the situation experienced.

For example, in a longitudinal research study, Collins and colleagues expressed concern about the reliability and validity of reports made by primary caregivers. In their study, a number of carers' responses were indicative of denial, and they noted that carers tended to put on a false front of 'everything's fine' (Collins et al, 1995).

The difficulties experienced by some caregivers may therefore be underestimated. This is particularly true of wife caregivers who may feel a sense of duty to their husbands or believe that reporting problems

betrays their husband's confidence (Gallagher et al 1989, Zarit and Toseland 1989). On the other hand, some carers may over-report difficulties and perceive their caregiving situation to be more severe than it actually is. For example, caregivers who are depressed may report their experiences more negatively than they may actually be due to biases in perception due to depression (Guarnaccia and Zautra 1989, Reifler et al 1981). Despite the limitations of self-report measures, this method of assessment will continue to play an important role in research methodology as there are no comparable alternatives for assessing an individual's perception or appraisal of a particular situation. With the exception of verbal report it seems that there is no alternative direct method of measuring subjective experience.

It is important to acknowledge that stroke patients with a prior history of dementia and other illnesses were not excluded from any of the studies and so it may be difficult to accurately identify the unique aspects of stroke caregiving. Finally, the studies are specific to stroke carers and there were no control groups. However, in order to differentiate unique caregiving impacts it would be necessary to compare stroke caregivers with a non-caregiving group. Without comparison with non-caregivers it is difficult to ascertain the extent of caregiving outcomes beyond outcomes found in the sociodemographically matched members of the general population.

5.3 Additional factors

Conversations with carers suggested that the nature of the marital relationship may be an important factor in carer strain and the quality of the pre-existing relationship between the caregiver and the care receiver may impact on the level of distress experienced. Indeed, marital cohesion was identified as one of the conditioning variables in the model of caregiver strain, but was not formally assessed in this study due to the methodological difficulties in collecting such subjective, retrospective information. It may be that increased marital cohesion and communication prior to the illness results in less strain and fewer emotional symptoms than those couples with poorer marriages. Increased quality of relationship prior to the stroke may result in caregivers feeling less resentful towards the caregiving role and more motivated towards providing care for their spouse.

In addition, less emotional distress is experienced by carers who believe that the assistance they provide reciprocates for assistance they received in earlier life (Goodman et al, 1994). Nevertheless, the research evidence on marital cohesion is inconclusive. Some studies of elderly carers have suggested that pre-morbid quality of relationship may be an important predictor of stress and emotional health (Broe et al, 1999; Yates et al, 1999; Dunkin and Anderson-Hanley, 1998). On the contrary, others have suggested that better quality of relationship may result in greater levels of carer overload (Lawrence et al, 1998).

The majority of studies that include an assessment of prior relationship are based around caregivers of heart or dementia patients or the frail elderly.

No studies have been identified that address this issue in carers of stroke The impact of pre-existing relationship may differ across patients. diseases as those with closer relationships may feel better able to cope with the demands of the caregiving role during the early stages of an illness, but in terminal illness or dementia, the impact may be greater among those with greater marital cohesion. Information about relationship quality may be of importance but is difficult to collect in quantitative studies and so was not collected in the present study. Many carers may not have wished to provide answers to such a probing question, which may have reduced the number of forms completed and returned. This information is not available in the majority of carer studies and future researchers should consider using qualitative interview techniques in order to assess the impact of relationship quality on spouses of stroke patients.

The studies presented here were predominantly caucasian samples with few patients and carers of ethnic minority groups. Those patients and carers considered to be of ethnic minority groups were only identified as such on the basis of their names on the stroke register, which may not be accurate. Possible differences in strain with culture and ethnicity were not addressed in these studies. Differences have been found in the occurrence of stroke between ethnic groups with Blacks being at greater risk of developing stroke than Whites and having a stroke at a younger age (Frey et al, 1998).

Ethnicity is not represented by the model of caregiver strain (see figure 8) and the influence of culture on perceptions of caregiving burden and strain
is relatively unexplored (Lim et al, 1996). The possible influence of ethnicity on strain was not explored here as the numbers within ethnic minority groups were too low to allow for statistical analysis. However, it has been suggested that ethnicity may have a substantial impact on the caregiving experience (Cox and Monk, 1996). A review of 12 studies by Connell and Gibson (1997) showed that, compared to white caregivers, non-white caregivers reported lower levels of caregiver stress, burden and depression. However, much of the research on ethnic and cultural differences has involved caregivers of persons with dementia.

The lower rates of strain and burden found in the literature might be explained by cultural differences in the way in which stressors are perceived. Non-white caregivers may appraise caregiving tasks as less subjectively stressful and appraise themselves as having greater effectiveness in managing caregiving problems than Caucasian caregivers (Haley et al, 1996). Additionally, it must be recognised that ethnic groups may differ in their values and beliefs about old age and disability in general, and the importance of caring for their elderly (Lawton et al 1992, Mintzer et al 1992).

Certain groups may differ in their acceptance of professional support and some may place utmost importance on caring for elderly relatives at home. However, the results are mixed and other studies have suggested that caring for a dependant elder evokes more race similarities than differences (Young and Kahana, 1995). In the stroke caregiving literature only a limited number of studies reported having black caregivers in their sample, ranging from 59% (n=89) to 61% (n=38) of the sample size

(Silliman et al, 1986; Segal and Schall, 1996; Silliman et al, 1987b). However, these studies did not investigate differences between cultures in negative caregiving outcomes. Due to the predominantly white samples, the present studies did not allow for ethnicity to be investigated as a factor in carer strain. Research is needed that investigates the effects of race, culture and ethnicity on caregiving for stroke patients.

In addition to ethnic group membership it is possible that there may be geographical differences between countries in the level of strain experienced. However, Schneider et al (1999) conducted a cross-national profile of 280 co-resident spouse carers of people with dementia across 14 European countries. They assessed living arrangements, formal and informal support, service satisfaction, perceived burden and psychological well-being. Although there were variations between countries, there were consistently high ratings of caregiver burden and psychological distress. Although no comparable study has been conducted with stroke caregivers, this study clearly demonstrates that the experience of caregiver strain may be similar across geographical locations and between the European cultures.

Socioeconomic status and educational level of the carer were not taken into account. In the literature, education has not been specifically examined in relation to caregiver strain although it has been assessed in terms of level of caregiver distress. In a study of caregivers of patients with Parkinson's disease, Aarsland et al (1999) found that patient's duration of education correlated inversely with the severity of caregiver

depression on the Beck Depression Inventory. That is, less depression was observed in caregivers of more highly educated patients.

However, no comparable studies have been identified in the stroke caregiving literature. According to Zarit and Edwards (1996) it is generally expected that individuals of a lower socioeconomic status have fewer available economic resources and therefore hold more of the burden of care on themselves. Although the present study included a measure of the caregivers' perception of their economic self-sufficiency there was no substantial measure of socioeconomic status included ìn the questionnaires. This was due to the large number of measures incorporated in the research. Again, adding more measures to the ones selected would lengthen the questionnaires and increase the likelihood that the forms would not be returned.

Although self-reported financial difficulty was assessed in Chapter Three using the London Handicap Scale and is also included as an item on the CSI, carers' actual income was not available. The relationship between income and strain is not clear. Some researchers have failed to find a significant relationship between income and carer strain (Ross and Morris, 1988). However, a relationship has been found between income and psychological distress. One study demonstrated that caregivers who had a higher income were less likely to be depressed at six to nine months after stroke (Schulz et al, 1988). Further research should include education, socioeconomic status and income as potential mediators of caregiver strain.

It is possible that carer strain could be influenced by satisfaction with stroke services. Pound et al (1993) conducted a postal survey of carer satisfaction with services after stroke. They found that 77% of carers were satisfied with the care that the stroke patient received whilst in hospital, but only 39% were satisfied with services received after discharge. Although carer satisfaction with services was relatively high in their sample immediately after stroke it rapidly declined after the patient was discharged from hospital. Dissatisfaction with services may represent a source of caregiver strain that was not accounted for in this study. One strained carer in the present study appeared dissatisfied with the services they had received after discharge:

'I would like more support and information from social services. It seems difficult to find things out without spending hours waiting to speak to someone who then doesn't know what you are asking'

Others appeared to be highly satisfied:

'The hospital services cannot be faulted ... '.

'All services have been most helpful and for that I shall be ever grateful'. A comment made by another carer suggested that the level of satisfaction with services may depend on an individual's personality characteristics:

'I am happy with the services received but my husband has a short fuse and expects everything to be done yesterday. Whereas I am more laid back and realise he is not the only pebble on the beach'

It would be useful to assess to what extent carer satisfaction with services is related to strain.

This research only focused on the negative consequences of caregiving and did not include any assessment of the positive aspects of the caregiving role. Despite the huge physical, emotional and financial strains placed on carers, research in a variety of caregiving groups has suggested that many caregivers are satisfied with their current life and have positive feelings about their caregiving roles (Grant et al, 1998; Draper et al, 1992; Dewis and Niskala, 1992; Schulz et al, 1988; Kinney et al, 1995; Silliman et al, 1987b). It has been shown that carers place great value on their relationship with the dependent person (Clarke, 1999). Indeed, one carer in the present study proclaimed:

'I have been quite happy to look after my husband and I intend to carry on doing so. I am blessed to keep him with me'

Conversations with carers throughout the present studies suggested that there are many rewards and gratifications associated with caregiving, including an improved relationship with the care recipient and this also has been demonstrated in empirical studies (Draper et al, 1992). Gender differences have also been found with women caregivers of dementia patients being more likely to report more aspects of caregiving as enjoyable than male caregivers (Gold et al, 1995).

The positive aspects of caregiving are not well studied, although measures have been developed that specifically address rewards of caregiving (e.g. Picot et al, 1997; Farran et al, 1999). Positive aspects of caregiving may be important as they have also been found to act as a buffer against caregiving stress. For example, Riedel et al (1998) examined the associations between self-reported rewards and difficulties (social,

emotional and physical) of caregiving in a sample of 200 informal caregivers to older post-rehabilitation patients. They found that caregivers who reported receiving more rewards from the caregiving experience reported fewer caregiving difficulties. They suggested that caregiving rewards had no independent effect on burden but modified the associations between social and emotional difficulties and burden. Authors have suggested that positive aspects of caregiving may be enhanced by good family relations and family functioning (Evans et al, 1992).

Positive aspects of caregiving were not investigated in the present study as further measures may have over burdened the caregivers. However, with regard to responses on the GHQ-12, it was interesting to observe the high proportion of spouses who agreed with the statement, 'have you felt that you were playing a useful part in things?', irrespective of whether mood was good or poor overall. Playing a useful part in things has been identified as a source of satisfaction for the caregiver. Given these observations, it would be interesting to expand on the positive aspects of caregiving for stroke spouses.

5.4 Conclusion

The ability to accurately predict carer strain could have considerable implications for the provision of support to stroke carers. Under the current system of care, a research review highlighted that many community interventions are initiated in response to a sudden crisis, such as the breakdown of carers health as opposed to being preventative measures (Warburton, 1994). If interventions were to be targeted at prevention rather than cure such situations may be avoided.

The prediction of carers' later well-being could be used to alert general practitioners to 'carers at risk', allowing monitoring and targeting of appropriate interventions at an earlier stage to avoid the crisis situation. Despite limitations, the present studies have identified important factors related to high levels of strain in carers of stroke patients. This research has shown that certain factors early after stroke may be predictive of carer strain later on.

The need for some alleviation of carer strain has been identified by the caregivers themselves. One carer proclaimed:

'I would have liked a back up service for people discharged from the hospital after suffering a stroke....some consideration for the health of the carer'.

Increased carer support might reduce the feelings of abandonment that seemed common to many of the spouses in the study:

'I feel we are abandoned and adrift and little is going to change in the foreseeable future'

'We feel strongly that... we have just been forgotten and left to cope by ourselves'

Reducing caregiver strain is important as it may contribute to a reduced number of health-care consultations and hospitalisations for both the stroke survivor and the elderly caregiver. Ultimately, there may be decreased institutionalisation of stroke survivors as caregivers are assisted in adapting to new situations. However, more research is needed to identify services that are effective in strain alleviation. On the basis of the present study, it is postulated that education and training of health professionals on cognitive deficit after stroke might improve communication between stroke services, patients and carers. This might be achieved by providing a training course or cognitive function workshop to increase staff knowledge of cognitive deficit following stroke. This could be evaluated in a randomised controlled trial of patient and carer outcomes between those admitted to a ward where staff have received additional training regarding cognitive deficits and those admitted to a general medical ward. Carers would benefit from increased knowledge about stroke, in particular individualised knowledge, which would ensure that they had realistic expectations of their partner's rehabilitation. This knowledge might be provided by staff trained to be aware of cognitive deficits or by a family support worker and evaluated in a randomised controlled trial of caregiver outcomes between those who were provided with individualised information and those who were not.

The availability of stroke clubs or support groups might be effective for those carers who require emotional support and understanding of living

with a patient with language difficulties or global cognitive impairment. Such groups could also be used to teach effective coping strategies which may reduce depression and hence strain. The availability of a named individual, such as a family support worker, would be useful for carers, not only for the emotional support of understanding, but also as a contact from which they could gain information and practical guidance, such as knowing how to deal with incontinence, where to obtain financial help or respite care. Further research might evaluate the usefulness of intervention strategies such as the provision of family support, stroke clubs and support groups for emotional support or structured interventions teaching emotion-focused coping strategies. This might be achieved using randomised controlled trials or using qualitative methods for more detailed evaluation.

Certainly carers at risk from strain and low mood would benefit from some form of intervention above and beyond the basic provision of stroke after-care. These additional care packages may serve to reduce carer depression and reduce the feelings of abandonment often expressed. Additionally, service providers need to identify caregivers at risk of greater strain and to help them to work through situations that services cannot alter.

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Appendix 1

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MINI MENTAL STATE EXAMINATION

	Study Ref:	Date:	Assessor:	Centre:
Max Score		ORIENTAT	TION	
5()	What is the:	Year? Date? Month?		Season? Day?
5()	Where are we:	Country? Town?. Floor?	2	County? Hospital? Ward?
		REGISTRA	FIO N	
3 ()	Ask the patient if y tree, penny), one so three are learnt, ma	you may test his/h econd to say each ux six trials, then	er memory. Name the Ask patient to reperation ().	nree objects (apple, eat. Repeat until all
	ATTE	NTION AND CA	ALCULATION	
5()	Ask the patient to o subtractions. If can backwards. Score r (93 86 7	count back from 1 not/will not perforumber of letters 9 72	00 by sevens, stop a orm this task, ask to in correct position. 65)	after five spell 'world'
		RECAL	Ĺ	
3 ()	Ask for the three of	bjects given previ	iously (apple, tree, p	enny).
		LANGUA	GE	
2 ()	Show patient a wat it is.	ch and ask what i	t is. Show patient a	pencil and ask what
1 ()	Ask the patient to r 'No ifs, ands or but	epeat the followings'.	ng sentence:	
3 ()	Give the patient a b 'Take a paper in yo Score one point for	blank piece of par our right hand, fol each correct stag	per and read the com d it in half and put i ge.	mand: t on the floor'.
1 ()	On a blank piece of and then do what it	f paper print: 'Clo says.	ose your eyes'. Ask	the patient to read it
1()	Give the patient a b for you (subject and	blank piece of pag d verb necessary,	per and ask him/her and punct	to write a sentence uation not).
1()	Copy pentagons de	sign. Ignore trem	or and rotation.	
3 ()	Total Score (Cut of	ff point: 20)		
	LE	VEL OF CONSC	IOUSNESS	
Alert	Drowsy		Stupor	Coma





:

A 8



œ B :

SHEFFIELD SCREENING TEST FOI ACQUIRED LANGUAGE DISORDER	R LS
NameDateReference	
RECEPTIVE SKILLS	score
1. Verbal comprehension of single words I'm going to ask you to point to some of the things in the room	
door light chair	_
ceiling corner	
2. Comprehension of a sequential command	لحصا
a) Point to the window and then to the door	
b) Before pointing to the ceiling, touch the chair	
3. Comprehension of a complex command	
Tap the chair twice with a clenched fist, while looking at the ceiling	
4. Recognition of differences in meaning between words	
I'm going to read you a list of words and I want you to tell me	
which is the odd one out:	
a) chicken, duck, apple, turkey	
b) run, drink, walk, sprint	
c) small, large, massive, huge	
5. Comprehension of a narrative	
a) I'm going to read you a story, then ask you a question about it.	
John went to the shop to buy a pen. When he got there, he found	
that he had forgotten his wallet, so he came home and made himselj	۰ ۱
a cup of tea. What should he have taken with him?	
b) I'm going to read you another paragraph.	
Mrs Smith visited several shops. She bought a newspaper,	
a cauliflower, a stamp and some sausages. What was the second	
shop she visited?	لـــــا ر

EXPRESSIVE SKILLS

6. Word finding

Tell me the names of three well-known places in the client's home town

7. Abstract word-finding

Tell me another word that means the same thing as:

- a) beautiful
- b) angry
- c) ridiculous

8. Sequencing

Describe how you would make a cup of tea.

A correct answer contains two or more appropriate stages in the right order.

9. Definitions

Describe what the following words mean:

- a) home
- b) search
 - c) ambitious

10. Verbal reasoning

- I'd like you to tell me:
- a) why you would use an umbrella
- b) why people go on holiday
- c) what you would do if you were locked out of the house

Receptive skills total score: Expressive skills total score: Overall score:







		1
-	-	-



score



PART ONE

chord aisle psalm ache bouquet thyme debt depot heir catacomb radix capon courteous nausea gaoled procreate deny hiatus equivocal naïve subtle assignate rarefy gouge gist

PART TWO

quadruped aeon zealot superfluous simile drachm cellist topiary abstemious façade placebo leviathan banal prelate détente beatify sidereal puerperal idyll aver gauche demesne syncope campanile

Appendix 5

STAR ¥ V A V A V щ 6 .4 Z L * * Ś REA ט 🗡 X ★ Ľ

Appendix 6



AMIPB STORY RECALL

Name	Date
Record number	

Mrs Angela / Harper / was sitting in her bedroom / mending the curtain /

When she heard a noise / coming from the kitchen /. She rushed to investigate /

and found a boy / climbing out of the window / with her handbag /.

She threw a vase at him / but it missed / and he ran off laughing /. She chased after him /

Past the shops / and into the park / but he got away / by squeezing through some railings /.

On her way back home / Mrs Harper phoned the police /.

She described / the theif as quite tall / and neatly dressed /. He had a scar / on his face /

But she could not remember / the colour of his hair /.





:

CC	GNITI	E ESTIMA	TION TEST
Study Ref:	Date	Assessor	Centre

1. What is the height of the Post Office Tower?

- 2. How fast do racehorses gallop?
- 3. What is the best paid job or occupation in Britain today?

4. What is the age of the oldest person in Britain today?

5. What is the length of an average man's spine?

6. How tall is the average English woman?

- 7. What is the population of Britain?
- 8. How heavy is a full pint bottle of milk?
- 9. What is the largest object normally found in a house?
- 10. How many camels are there in Holland?

Cognitive Estimation Test - Scoring Sheet

Question No	Answers	Score	Error Score
1	> 1500ft or < 60ft	3	
	= 1500 ft or $= 60 $ ft	2	
	800 to 1500ft or 60 to 100ft	1	
	101ft to 799ft	0	
· · · · · · · · · · · · · · · · · · ·			
2	> 50mph or < 9mph	3	
	= 50mph or < 15mph	2	
	41mph to 49 mph	1	
	15mph to 40mph	0	
3	Any kind of manual work	3	
	Any specialist (better paid) blue collar work (eg. car	2	
	workers)		
	Professional (up to and including the Prime Minister)	1	
	Queen, Chairman/ Company Director	0	
4	> 115 or < 103	3	
	= 115	2	
	= 103 or = 114	1	
	104 to 113	0	
5	> 5ft or < 1ft 6"	3	
	> 4ft 1" to 4ft 11"	2	
	= 4 ft or = 1 ft 6	1	
	1ft 7" to 3ft 11"	0	
6	> 6ft or < 5ft 2"	3	
	= 5 ft 11" or $= 6 ft$	2	
	= 5 ft 9" or $= 5 ft 10$ " or $= 5 ft 2$ "	1	
	5ft 3" to 5ft 8"	0	
7	>1000 million or <2 million	3	
	501 to 1000 million or 2 to 2.9 million	2	
	= 500 million or 3 to 10 million	1	
	11 million to 499 million	0	
8	> 3lbs or < 1lb	3	
	= 3lbs or = 1lb	1	
	> 11b or < 31bs	0	
9	Anything smaller than a carpet	3	
	Carpet	2	
	Bed, sideboard, settee, piano		
	Wardrobe	0	
		<u> </u>	
10	Any very large number	3	
	None	1	
	Reasonably small number which acknowledges likelihood	0	
	of zoos		
Total		<u> </u>	

Research Scores	L Front	R Front	L Post	R Post	Control
Mean	8.19	7.21	4.71	5.04	3.6
SD	4.28	3.73	3.91	3.88	1.92

<u>APRAXIA TEST</u> (Kertesz & Ferro. Brain 1984, 107, 921-933)

Study	Ref:		_Date:	Assess	or:	Centre:	
<u>Item</u>					<u>Verbal</u> <u>Command</u>	Imitation	<u>Score</u>
Faciat							
1.	Put ou	t your	tongue				
2.	Close	your e	yes				
3.	Whistl	e	-				
4.	Sniff a	flow	er*				
5.	Blow	out a r	natch*				
Intrans	sitive (u	pper l	imb)				
6.	Make a	a fist			·-		
7.	Salute						
8.	Wave	goodb	ye				
9.	Scratch	n your	head				
10.	Snap y	our fi	ngers				
Transit	tive (ins	strume	ntal)				
11.	Use a c	comb [*]	F				
12.	Use a t	coothb	rush*				
13.	Use a s	spoon	to eat*				
14.	Use a l	namm	er*				
15.	Use a l	key*					
Compl	ex						
16.	Pretend	d to di	rive a car				
17.	Pretend	l to k	nock on the d	loor			
18.	Pretend	d to fo	old a paper*				
19.	Pretend	d to lig	ght a cigarett	e			
20.	Pretend	i to pl	ay the piano				
~			То	tal			
Score	•	-	•				
	3	good	performance				
	2	impa	ired but reco	gnisable			
	1	poor	or approximation	ate pertorm	ance		
	0	no pe	rtormance, u	inrelated, u	nrecognisable		

Cut off

Facial	14
Intransitive	12
Transitive	12
Complex	11
Total	49

Study Ref:	_Date:	Centre:	Assessor:			
BARTHEL INDEX						
BOWELS	0 = Incontine 1 = Occasion 2 = Continen	ent al accident t				
BLADDER	0 = Incontine 1 = Occasion 2 = Continen	ent/Catheterised al accident (max t (for over 7 days	1 per day) s)			
GROOMING	0 = Needs He 1 = Independent	elp ent (face/hair/tee	th/shaving)			
TOILET USE	0 = Dependent 1 = Needs son 2 = Independent	nt me help but can o ent	do something			
FEEDING	0 = Unable 1 = Needs hel 2 = Independe	lp cutting/spread	ing butter			
TRANSFER	0 = Unable 1 = Major hel 2 = Minor hel 3 = Independe	lp (1-2 people, pl lp (verbal or phy: ent	nysical) sical)			
MOBILITY	0 = Immobile 1 = Wheelcha 2 = Walks wi 3 = Independent	air independent, i th help of 1 perso ent (may use aid,	ncl corners on (verbal/physic , eg stick)	al)		
DRESSING	0 = Depender 1 = Needs held $2 = Independer$	nt lp, but can do abe ent	out half unaided			
STAIRS	0 = Unable 1 = Needs hel 2 = Independe	lp (verbal or phy ent up and down	sical, carrying aid	i)		
BATHING	0 = Depender 1 = Independe	nt ent				

. -

TOTAL

I am going to present you with a list of situations which may relate to your experience of looking after your partner. They may apply to you either: never, rarely, sometimes or often.

Please tick the box which best fits your description.

		Never	rarely	sometimes
1.	Sleep is disturbed (eg. because my partner needs help to go to the toilet)			
2.	It is inconvenient (eg. because helping takes so much time)			
3.	It is a physical strain (eg. because of lifting in and out of bed)			
4.	It is confining (eg. helping restricts my free time)			
5.	There have been family changes (eg. because helping has disrupted routine/there has been no privacy			
6.	There have been changes in personal plans (eg. could not go on holiday)			
7.	There have been other demands on my time (eg. from other family members)			
8.	There have been emotional adjustments (eg. because of severe arguments)			
9.	Some behaviour is upsetting (eg. incontinence/trouble remembering things)			
10.	It is upsetting to find my partner has changed so much from his/her former self (eg. seems like a different person)			
11.	There have been work adjustments (eg. having to take time off)			
12.	It is a financial strain			
13.	Feeling completely overwhelmed (eg. worrying/ concerns about how you will manage			

QUESTIONNAIRE

(GHQ-12)

Appendix 13

Name:..

..... Date: ...

Please read this carefully.

We should like to know if you have had any medical complaints and how your health has been in general, over the last few weeks. Please answer ALL the questions simply by underlining the answer which you think most nearly applies to you. Remember that we want to know about present and recent complaints, not those that you had in the past.

It is important that you try to answer ALL the questions.

Thank you very much for your co-operation.

Have you recently . . .

1.	been able to concentrate on whatever you're doing?	Better than usual	Same as usual	Less than usual	Much less than usual
2.	lost much sleep over worry?	Not at all	No more than usual	Rather more than usual	Much more than usual
3.	felt that you are playing a useful part in things?	More so than usual	Same as usual	Less useful than usual	Much less useful
4.	felt capable of making decisions about things?	More so than usual	Same as usual	Less so than usual	Much less than usual
5.	felt constantly under strain?	Not at all	No more than usual	Rather more than usual	Much more than usual
6.	feit you couldn't overcome your difficulties?	Not at all	No more than usual	Rather more than usual	Much more than usual
7.	been able to enjoy your normal day-to-day activities?	More so than usual	Same as usual	Less so than usual	Much less than usual
8.	been able to face up to your problems?	More so than usual	Same as usual	Less so than usual	Much less able
9.	been feeling unhappy and depressed?	Not at all	No more than usual	Rather more than usual	Much more than usual
10.	been losing confidence in yourself?	Not at all	No more than usual	Rather more than usual	Much more than usual
11.	been thinking of yourself as a worthless person?	Not at all	No more than usual	Rather more than usual	Much more than usual
12.	been feeling reasonably happy, all things considered?	More so than usual	About same as usual	Less so than usual	Much less than usual

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Your Health and Your Life

This questionnaire is about the way your health affects your everyday life. Please read the instructions for each question and then answer by ticking the box next to the sentence which describes you best.

When answering the questions, it may help to think about the things you have done over the last week and compare yourself with someone like you who is in good health.

			mobility
Getting Aroun	d Think about how you get from one place to another, using any aids or means of transport that you normally have available.	help,]
1. Does you	r health stop you from getting around? Please tick one box only		
Not at all:	You go everywhere you want to, no matter how far away		1
Very slightly:	You go most places you want, but not all.		2
Quite a lot :	You get out of the house, but not far away from it.		3
Very much :	You don't go outside, but you can move around from room to room indoors.		4
Aimost completely:	You are confined to a single room, but can move around in it.		5
Completely :	You are confined to a bed or a chair. You cannot move around at all. There is no-one to move you.		6

					p	ibysizi indepen
Looking after	yourself	Think about this money, cooking, and using the to	ngs like houseword laundry, getting d ilet.	k, shopping, Iressed, was	, looking hing, sha	after ving
2. Does you	r health st	op you lookin	g after yourse	lf?	Please tick one box only	\mathbf{Z}
Not at all:	You do ev	erything to loc	k after yourself	:		
Very slightly:	You need	a little help no	w and again.			
Quite a lot:	You need housework	help with som or shopping),	e tasks (such a but no more t	as heavy han once	a day.	\Box
Very much:	You do so more than for a few l	me things for once a day. ours.	yourself, but yo ou can be left	ou need h alone sat	ielp fely	
Almost completely:	You need cannot be	help to be ava left alone safe	ilable all the tin ly.	me. You		
Completely:	You need attention, o	help with even lay and night.	/thing. You nee	ed constar	nt	
						occupa
Work and Leisure Think about things like work (paid or not), housework, gardening, sports, hobbies, going out with friends, travelling, reading, looking after children, watching television and going on holiday.						
3. Does your	health lin	iit your work	or leisure activ	vities?	Please tick one box only	
Not at all:	You do ev	erything you w	ant to do.			
Very slightly :	You do air	nost all the thi	ngs you want [.]	to do.		
Quite a lot :	You find s cannot do	omething to do some things f	o almost all the or as long as y	e time, bu you would	t I like.	
Very much:	You are ur something	to do a to do a	ot of things, b the time.	ut can fin	d	
Almost completely:	You are un something	hable to do mo to do some o	ost things, but f the time.	can find		

You sit all day doing nothing. You cannot keep yourself busy or take part in any activities. Completely:

Getting on v	vith People Think about family, friends and the people you might during a normal day.	ht meet
4. Does you	r health stop you getting on with people?	
Not at all:	You get on well with people, see everyone you want to see, and meet new people.	
Very slightly	: You get on well with people, but your social life is slightly limited.	
Quite a lot :	You are fine with people you know well, but you feel uncomfortable with strangers.	
Very much:	You are fine with people you know well but you have few friends and little contact with neighbours. Dealing with strangers is very hard.	
Almost completely:	Apart from the people who look after you, you see no-one. You have no friends and no visitors.	
Completely:	You don't get on with anyone, not even people who look after you.	
		oricati
Awareness o	f your surroundings world about you, and finding your way a in it.	; the round
5. Does your around yo	r health stop you understanding the world Please tick one box only	
Not at all:	You fully understand the world around you. You see, hear, speak and think clearly, and your memory is good.	
Very slightly:	You have problems with hearing, speaking, seeing or your memory, but these do not stop you doing most things	
Quite a lot	You have problems with hearing, speaking, seeing or your memory which make life difficult a lot of the time. But, you understand what is going on.	
Very much:	You have (he/she has) great difficulty understanding what is going on.	
Almost completely:	He/she is unable to tell where he/she is or what day it is. He/she cannot look after him/herself at all.	
Completely:	He/she is unconscious, completely unaware of anything going on around him/her.	
	Please t	um over

comonic self-sufficie

Affording the things you need Think about whether health problems have led to any extra expenses, or have caused you to earn less than you would if you were healthy.				
6. Are you a	able to afford the things you need? Please tick one box only box only box.	e y 🖊		
Yes, easily:	You can afford everything you need. You have easily enough money to buy modern labour-saving devices, and anything you may need because of ill-health.		1	
Fairly easily:	You have just about enough money. It is fairly easy to cope with expenses caused by ill-health.		2	
Just about	You are less well off than other people like you; however, with sacrifices you can get by without help.		3	
Not really:	You only have enough money to meet your basic needs. You are dependent on state benefits for any extra expenses you have because of ill-health.		4	
No :	You are dependent on state benefits, or money from other people or charities. You cannot afford things you need.		S	
Absolutely not:	You have no money at all and no state benefits. You are totally dependent on charity for your most basic needs.		6	

THANK YOU VERY MUCH FOR YOUR HELP

For these questions please record only WHAT YOUR PARTNER <u>HAS ACTUALLY DONE</u> IN THE LAST WEEK OR SO (not what you think they could do, ought to do or would like to do).

DID he/she	Not at all	with help	on their own with difficulty	on their own
1. Walk around outside?				
2. Climb stairs?				
3. Get in and out of a car	?			
4. Walk over uneven ground?				
5. Cross roads?				
6. Travel on public transport?				
7. Manage to feed themselves?				
8. Manage to make themselves a hot drink?				
9. Take hot drinks from one room to another?				
10.Do the washing up?				
11. Make themselves a ho snack?	t			
12.Manage their own money when out?				
13. Wash small items of clothing?				
14.Do their own housework?				
15.Do their own shopping?				

	No	With help	On their own with difficulty	On their own
16. Do a full clothes wash?				
17.Read newspapers or books?				
18.Use the telephone?				
19. Write letters?				
20. Go out socially?				
21. Manage their own garden?				
22. Drive a car?				

STRESS SCALE

Namo	
144116	

Date:

Instructions

The questions in this scale ask you about your feelings and thoughts during the last month. In each case, you will be asked to indicate how often you felt or thought a certain way. Although some of the questions are similar, there are differences between them and you should treat each one as a separate question. The best approach is to answer each question fairly quickly. That is, don't try to count up the number of times you felt a particular way, but rather indicate the alternative that seems like a reasonable estimate.

For each question choose from the following alternatives:

- 0 = never
- 1 = almost never
- 2 = sometimes
- 3 = fairly often
- 4 = very often
 - 1. In the last month, how often have you been upset because of something that happened unexpectedly?
 - 2. In the last month, how often have you felt that you were unable to control the important things in your life?
 - 3. In the last month, how often have you felt nervous and stressed?
 - 4. In the last month, how often have you dealt with irritating life hassles?
 - 5. In the last month, how often have you felt that you were effectively coping with important changes that were occurring in your life?
 - 6. In the last month, how often have you felt confident about your ability to handle your personal problems?
 - 7. In the last month, how often have you felt that things were going your way?
 - 8. In the last month, how often have you found that you could not cope with all the things you had to do?
 - 9. In the last month, how often have you been able to control irritations in your life?
- 10. In the last month, how often have you felt that you were on top of things?
- 11. In the last month, how often have you been angered because of things that happened that were outside of your control?
- 12. In the last month, how often have you found yourself thinking about things that you have to accomplish?
- 13. In the last month, how often have you been able to control the way you spend your time?
- 14. In the last month, how often have you felt difficulties were piling up so high that you could not overcome them?

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ACCEPTANCE OF ILLNESS SCALE

Name

Instructions

Please respond to each of the following items by choosing a number from 1 to 5 on the scale adjacent to the item which you feel best describes you. Then **circle** the number you have chosen. There are no right answers to any of the questions.

1.	1. I have a hard time adjusting to the limitations of my partner illness						artner's
stro agr	ongly ee	1	2	3	4	5	strongly disagree
2.	Because	e of my	partner's i	illness, I mis	s the thing	gs I like	to do mo st
stro agr	ongly ee	1	2	3	4	5	strongly disagree
3.	My par	tner's i	llness mak	es me feel us	seless at ti	nes	
stro agro	ongly ee	1	2	3	4	5	strongly disagree
4.	My par me than	tner's h I woul	ealth prob ld like him	lems make her to be	him/her m	ore dep	endent on
stro agre	ongly	1	2	3	4	5	strongly disagree
5.	My part friends	tner's i	llness make	es him/her a	burden o	n family	and
stro agre	ngly ee	1	2	3	4	5	strongly disagree
6.	My par	tner's h	ealth does	not make n	ie feel inad	lequate	
stro agre	ngly	1	2	3	4	5	strongly disagree
7.	My part happy	tner wi	ll never be	self-s ufficie	nt <mark>enough</mark>	to make	e me
stro agre	ngly	1	2	3	4	5	strongly disagree
8.	I think j partner	people : 's illnes	are often u s	ncomfortab	le around	me beca	ause of my
stro agre	ngly e	1	2	3	4	5	strongly disagree

LIFE SCALE

Name:		-
Date:	Record Number:	
Below are five stateme indicate your agreeme next to that item. Pleas	ents with which you may agree or disagree. Lent with each item by placing the appropriate se be open and honest in your responses. The	Ising a 1 to 7 scale, a number in the box a 7-point scale is:
	1 = strongly disagree 2 = disagree	
	3 = slightly disagree 4 = neither agree nor disagree	
	5 = slightly agree 6 = agree	
	7 = strongly agree	



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Name:		********	*******						
Date: Rec	cord Num	1ber:							
Here is a list of statements dealing with your general feelings about yourself. If you agree with the statement, circle A. If you strongly agree, circle SA. If you disagree, circle D. If you strongly disagree, circle SD. Thank you.									
	1 Strongly agree	2 Agree	3 Disagree	4 Strongly disagree					
1. On the whole, I am satisfied with myself.	SA	A	D	SD					
2. At times I think I am no good at all.	SA	А	D	SD					
3. I feel that I have a number of good qualities.	SA	A	D	SD					
 I am able to do things as well as most other people. 	SA	A	D	SD					
5. I feel I do not have much to be proud of.	SA	Α	D	SD					
6. I certainly feel useless at times.	SA	Α	D	SD					
7. I feel that I'm a person of worth, at least on an equal plane with others.	SA	A	D	SD					
8. I wish I could have more respect for myself.	SA	Α	D	SD					
9. All in all, I am inclined to feel that I am a failure.	SA	A	D	SD					
0. I take a positive attitude toward myself.	SA	Α	D	SD					

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LUCUS OF CONTROL SCALE (FORM B)

Name:

Date: _____ Record Number: _____

This is a questionnaire designed to determine the way in which different people view certain important health-related issues. Each item is a belief statement with which you may agree or disagree. Beside each statement is a scale which ranges from strongly disagree (1) to strongly agree (6). For each item we would like you to circle the number that represents the extent to which you disagree or agree with the statement. The more strongly you agree with a statement, then the higher will be the number you circle. The more strongly you disagree with a statement, then the lower will be the number you circle. Please make sure that you answer every item and that you circle **only one** number per item. This is a measure of your personal beliefs: obviously, there are no right or wrong answers.

Please answer these items carefully, but do not spend too much time on any one item. As much as you can, try to respond to each item independently. When making your choice, do not be influenced by your previous choices. It is important that you respond according to your actual beliefs and not according to how you feel you should believe or how you think we want you to believe.

	Strongly disagre	Modera _l disagre	Slightly disagre	Silghtly Agrae	Moderal ^a gree	Strongly Bgree
If I become sick, I have the power to make myself well again.	1	2	3	4	5	6
Often I feel that no matter what I do, if I am going to get sick, I will get sick.	1	2	3	4	5	6
If I see an excellent doctor regularly, I am less likely to have health problems.	1	2	3	4	5	6
It seems that my health is greatly influenced by accidental happenings.	1	2	3	4	5	6
I can only maintain my health by consulting health professionals.	1	2	3	4	5	6
I am directly responsible for my health.	1	2	3	4	5	6
Other people play a big part in whether I stay healthy or	•		•	•	•	Ŭ
become sick.	1	2	3	4	5	6
Whatever goes wrong with my health is my own fault.	1	2	3	4	5	6
When I am sick, I just have to let nature run its course.	1	2	3	4	5	6
Health professionals keep me healthy.	1	2	3	4	5	6
When I stay healthy, I'm just plain lucky.	1	2	3	4	5	6
My physical well-being depends on how well I take care of myself.	1	2	3	4	5	6
When I feel ill, know it is because I have not been taking care of myself properly.	1	2	3	4	5	6
The type of care I receive from other people is what is responsible for how well I recover from an illness.	1	2	3	4	5	6
Even when I take care of myself, it's easy to get sick.	1	2	3	4	5	6
When I become ill, it's a matter of fate.	1	2	3	4	5	6
I can pretty much stay healthy by taking good care of myself.	1	2	3	4	5	6
Following doctor's orders to the letter is the best way for me to stay healthy.	1	2	3	4	5	6
	If I become sick, I have the power to make myself well again. Often I feel that no matter what I do, if I am going to get sick, I will get sick. If I see an excellent doctor regularly, I am less likely to have health problems. It seems that my health is greatly influenced by accidental happenings. I can only maintain my health by consulting health professionals. I am directly responsible for my health. Other people play a big part in whether I stay healthy or become sick. Whatever goes wrong with my health is my own fault. When I am sick, I just have to let nature run its course. Health professionals keep me healthy. When I stay healthy, I'm just plain lucky. My physical well-being depends on how well I take care of myself. When I feel ill, know it is because I have not been taking care of myself properly. The type of care I receive from other people is what is responsible for how well I recover from an illness. Even when I take care of myself, it's easy to get sick. When I become ill, it's a matter of fate. I can pretty much stay healthy by taking good care of myself. Following doctor's orders to the letter is the best way for me to stay healthy.	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I'm just plain lucky.12345When I feel ill, know it is because I have not been taking care of myself properly.12345The type of care I receive from other people is what is responsible for how well I recover from an illness.12345When I take care of myself, it's a matter of fate.12345When I take care of movell I recover from an illness.12345When I take care of myself, it's a matter of fate.12345 <tr td="">When I</tr>

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AFFECT SCHEDULE

Name:									
Date:			ord Number:						
		· · · · · · · · · · · · · · · · · · ·							
This scale consists of a number of words that describe different feelings and emotions. Read each item and then mark the appropriate answer in the space next to that word. Indicate to what extent*									
Use the following	scale to record	your answers.							
1	2	3	4	5					
very slightly	a little	moderately	quite a bit	extremely					
or not at all									
		intereste	ed						
		distresse	ed						
	•••••••••	excited							
	*******	upset							
	••••••••••••	strong							
		guilty							
	••••••	scared							
		hostile							
	**********	enthusia	astic						
		proud							
		irritable							
		alert							
		ashame	d						
	************	inspired							
		nervous	6						
		determi	ned						
		attentive	9						
	••••••••	jittery							
		active							
		afraid							
*Insert appropriate tim	e instructions above	e from page 27							

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N										
Name:										
Date:	Date: Record Number:									
	·									
Please be as honest and accurate as you can be throughout. Try not to let your response to one statement influence your responses to other statements. There are no 'correct' or 'incorrect' answers. Answer according to your own feelings, rather than how you think 'most people' would answer. Using the scale below, write the appropriate letter in the box beside each statement.										
A	B	C	D	E						
l agree a lot	i agree a intie	or disagree	a little	a lot						
 In uncertain til It's easy for m If something d I always look d I always look d I'm always opt I enjoy my frie I enjoy my frie It's important f I hardly ever d Things never d I don't get ups I'm a believer I rarely count 	mes, I usually exp e to relax. can go wrong for r on the bright side. timistic about my ends a lot. for me to keep but expect things to go work out the way set easily. in the idea that fe on good things ha	ect the best. me, it will . future. sy. o my way. I want them to. every cloud has a si appening to me.	ilver lining'.							

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CONTROL SCALE

Name:

Section 1	Almost			Almost
When I feel angry (very annoyed)	never			always
1. I keep quiet.	1	2	3	4
2. I refuse to argue or say anything.	1	2	3	4
3. I bottle it up.	1	2	3	4
4. I say what I feel.	1	2	3	4 *
5. I avoid making a scene.	1	2	3	4
6. I smother my feelings.	1	2	3	4
7. I hide my annoyance.	1	2	3	4
Section 2				
When I feel unhappy (miserable)				
1. I refuse to do anything about it.	1	2	3	4
2. I hide my unhappiness.	1	2	3	4
3. I put on a bold face.	1	2	3	4
4. I keep quiet.	1	2	3	4
5. I let others see how I feel.	1	2	3	4 *
6. I smother my feelings.	1	2	З	4
7. I bottle it up.	1	2	3	4
Section 3				
When I feel afraid (worried)				,
1. I let others see how I feel.	1	2	3	4 *
2. I keep quiet.	1	2	3	4
3. I refuse to say anything about it.	1	2	3	4
4. I tell others all about it.	1	2	3	4 *
5. I say what I feel.	1	2	3	4 *
6. I bottle it up.	1	2	3	4
7. I smother my feelings.	1	2	3	4

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SIGNIFICANT OTHERS SCALE (B)



Name:

..... Record Number:.....

Instructions

Date:

Please list below up to seven people who may be important in the individual's life. Typical relationships include partner, mother, father, child, sibling, close friends, plus keyworker. For each person please circle a number from 1 to 7 to show how well he or she provides the type of help that is listed.

The second part of each question asks you to rate how individuals would like things to be if they were exactly as they hoped for. As before, please put a circle around one number between 1 and 7 to show what the rating is.

P	erson 1 –	Neve	r	Sc	metim	nes		Always
1	 a) Can you trust, talk to frankly and share your feelings with this person? b) What rating would your ideal be? 	. 1	2	3	4	5	6	7
2	 a) Can you lean on and turn to this person in times of difficulty? b) What rating would your ideal be? 	. 1	2 : 2	3 3	4 4	5 5	6 6	7 7 7
3	a) Does he/she give you practical help?b) What rating would your ideal be?	. 1 . 1	2 2	3 3	4 4	5 5	6 6	7 7
4	a) Can you spend time with him/her socially?b) What rating would your ideal be?	. 1 . 1	2 2	3 3	4	5 5	6 6	7 7
P	erson 2 –	•				_		
1	a) Can you trust, talk to frankly and share your feelings with this person?b) What rating would your ideal be?	. 1 . 1	2	3 3	4 4	5 5	6 6	7 7
2	a) Can you lean on and turn to this person in times of difficulty?b) What rating would your ideal be?	· 1 · 1	2 2	3 3	4 4	5 5	6 6	7 7
3	a) Does he/she give you practical help?b) What rating would your ideal be?	. 1 . 1	2 2	3 3	4 4	5 5	6 6	7 7
4	a) Can you spend time with him/her socially?b) What rating would your ideal be?	. 1 . 1	2 2	3 3	4 4	5 5	6 6	7 7
P	erson 3 –							
1	a) Can you trust, talk to frankly and share your feelings with this							
	person? b) What rating would your ideal be?	· 1 · 1	2 2	3 3	4 4	5 5	6 6	7 7
2	a) Can you lean on and turn to this person in times of difficulty?b) What rating would your ideal be?	1 · 1	2 2	3 3	4 4	5 5	6 6	7 7
3	a) Does he/she give you practical heip?b) What rating would your ideal be?	· 1 · 1	2 2	3 3	4 4	5 5	6 6	7 7
4	a) Can you spend time with him/her socially?b) What rating would your ideal be?	· 1 · 1	2 2	3 3	4 4	5 5	6 6	7 7

PLEASE CIRCLE ONE NUMBER ONLY FOR EACH QUESTION

