UNIVERSITY OF SOUTHAMPTON

AN INVESTIGATIVE STUDY ON INFORMAL STROKE CARERS COMPARING THE IMPACT OF TWO METHODS OF COMMUNITY STROKE REHABILITATION.

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ABSTRACT

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AN INVESTIGATIVE STUDY ON INFORMAL STROKE CARERS COMPARING THE IMPACT OF TWO METHODS OF COMMUNITY STROKE REHABILITATION.

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Stroke rehabilitation aims to improve survivors' functional status, but little empirical research has looked at the impact that these services have on informal stroke carers. This study sought to investigate the impact of a new domiciliary stroke team on carers' quality of life compared with the traditional day hospital. A combined methodological approach was used, in which quantitative methods were used to evaluate the effectiveness of the two services in improving quality of life and qualitative methods were used to explore carers' perceptions of these different services.

The quantitative study was an exploratory study, which was nested in a larger randomised controlled trial. Carers were allocated to either an intervention or control group by paired randomisation with the stroke survivor. The outcome measures employed to evaluate quality of life were the SF-36, the General Health Questionnaire, the Caregiver Strain Index and the Frenchay Activities Index. Mean changes were calculated for 0-6 months and 6-12 months to show the impact of the two different service deliveries. The qualitative study used a semi-structured interview to explore carers' perceptions at baseline and 6 months. The data were analysed using both a content analysis involving a specifically designed coding frame and an in-depth thematic analysis using a purposive sample of 15 carers.

Sixty informal stroke carers (mean age 67.9; S.D. 12.4) were identified from stroke survivors involved in an RCT on post-discharge rehabilitation. 31 carers were allocated to the domiciliary arm and 29 to the day hospital arm. Forty six out of the 60 carers further took part in the qualitative study. Data from 40 of these carers were analysed.

Quantitative study. Both domiciliary and day hospital carers had poorer psychological health than the general population at baseline. However, by the 0-6 month period, domiciliary carers showed better clinical outcomes in psychological health (mean difference in MCS 6; mean difference in GHQ 2.3) and physical health (mean difference in PCS 4). By 6-12 months, only improvements in physical health were seen in favour of day hospital carers (mean difference in PCS 4). None of these differences reached statistical significance.

Qualitative study. Carers saw the advantages of domiciliary stroke teams in terms of comfort, convenience and greater opportunities for therapy education. The main advantages of day hospitals were the respite time for carers and the opportunity for stroke survivors to mix with other people with stroke. The in-depth thematic analysis also identified that disruption to carers' lives and a loss of shared life themes as a result of caring for a person with may have an impact on carers' quality of life.

Policy implications: domiciliary stroke teams had no adverse impact on carers' quality of life when compared to the day hospital. They may also provide greater convenience and comfort for survivors and more opportunities for carers to be involved in survivors' rehabilitation. However, they should not be seen as a way of improving carers' quality of life if the ethos of the service is centred specifically on survivor rehabilitation.

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CHAPTER 1: AN OVERVIEW OF STROKE: DEFINITIONS, EPIDEMIOLOGY, HEALTH CARE PROVISION AND THE ROLE OF REHABILITATION

1.1. Chapter overview

This chapter has three main objectives. The first is to give a brief clinical description of stroke and the main findings of epidemiological studies looking at incidence/prevalence rates and risk factors. The second is to give a summary of the different levels of health service provision in stroke care, looking at the main preventive strategies and acute management. The final is to review the literature on stroke rehabilitation, specifically focusing on the different management models in organising stroke rehabilitation and placing an emphasis on post-discharge rehabilitation models.

1.2. Public health issues in stroke

Stroke is a major health problem in the United Kingdom (Department of Health, 1992) where it is the second largest cause of mortality (Office for National Statistics, 1998). It is the main cause of disability, leaving a large proportion of its survivors functionally dependent on others for support (Clark & Opit, 1994). The impact of a stroke places a large economic burden on the country's resources: 4.5% of the British National Health Service's (NHS) total expenditure is spent on stroke care (Department of Health, 1992). Furthermore, the residual disability resulting from a stroke requires Social Service departments to provide survivors with social care either in the form of additional support or residential home placement. The burden of stroke affects not only stroke survivors, but also the close kin relations who elect to care for this group of individuals. As a result, many of these "new" carers are then obliged to withdraw from the workforce either on a temporary or permanent basis to provide care for these survivors, leading to a loss of employment and income (Anderson, 1992).

1.3. Clinical description of stroke

Stroke has been clinically defined as "an acute neurological dysfunction of vascular origin with sudden or rapid occurrence of symptoms and signs corresponding to the involvement of focal areas in the brain, lasting more than 24 hours or leading to death" (Bamford, 1992). Traditionally, strokes have been classified into three pathological types: **Cerebral infarction**, which accounts for 85% of new strokes, is caused by a thrombus becoming displaced from an artery being carried to the brain (embolism) where it becomes lodged in one of the cerebral arteries. **Primary intracerebral haemorrhage,** which accounts for 10% of new strokes, is caused when a blood vessel ruptures within the brain leading to direct destruction of the brain cells. **Subarachoid haemorrhage,** accounting for 5% of new strokes, is the rupture of blood vessels on the brain surface causing blood to leak between the membranes covering the brain. This condition is clinically distinct from both cerebral infarction and primary intracerebral haemorrhage, having a different age distribution, management and risk factors than the other two conditions.

The significance of strokes is the loss of blood supply to brain cells, which require a constant supply of oxygen and enzymes for metabolism. Once this occurs, these tissues become irreversibly damaged, as brain cells are unable to regenerate themselves, so the size and location of the infarct or haemorrhage determines the extent of the neurological impairment. The destruction of these brain cells have a potentially devastating effect on an individual's ability to function independently and there are a wide range of clinical sequelae associated with a stroke, which are related to the areas affected in the brain. These include unilateral paralysis (hemiplegia), speech problems (dysphasia), swallowing problems (dysphagia), difficulty with performing complex tasks (apraxia), visual deficit, problems with control of muscle movement (ataxia) and other sensory and perceptual losses, leading to problems in motor co-ordination, mobility, and communication skills. Other medical complications include respiratory infections, incontinence, urinary tract infection, constipation, deep vein thrombosis, pressure sores, spasticity and depression, and these are partly due to immobility in the acute phase of the stroke (Pearce, 1983).

Recovery from a stroke is fastest within the first three weeks with most of the recovery occurring within the first three months (Wade, 1994). Reliable prognostic indicators for a poor stroke outcome include urinary incontinence, major cognitive deficit, complete paralysis, initial reduced level of consciousness and loss of vision in half the visual field (heminopia) after one week (Wade, 1994). Generally, 30% of all people affected by the illness will die within the first three weeks, leaving 35% with a moderate or severity disability requiring further rehabilitation and the remaining 35% making a rapid recovery after one month with minimal/no residual disability (Wade, 1994).

1.4. Stroke epidemiology

Stroke epidemiology is the study of the distribution and risk factors of health-related states within a stroke population (Last, 1995). To help understand the risk factors responsible for stroke, incidence rates and prevalence have been used in epidemiological studies to investigate these, but despite their close interrelationship with each other, each provides different types of information. Incidence rates show the number of new cases of strokes that occur in a population at risk during a specified time interval and have been used in identifying determinants of disease occurrence (Hennekens & Buring, 1987). Prevalence shows the number of stroke cases in a population which occurs in a specified time scale (Last, 1995). Prevalence rates are used to assess the public health impact of a disease as they allow health service providers to estimate the number of people affected by that disease and so allow for the planning of services (Hennekens & Burring, 1987).

1.4.1. Incidence rates in stroke

The three sources of data used to study incidence of stroke are death certificates, hospital data and population-based registers (Wade, 1986). Death certificates are the easiest method, but there may be some under-recording of stroke if another cause of death other than stroke e.g. bronchopneumonia is noted down as the main underlying cause of death. Hospital stroke registers are another source of stroke incidence data and some have been set up in various UK hospitals (Wolfe et al, 1995), but rates obtained using these figures may underestimate the true incidence rate as many mild or very severe stroke cases may not be admitted to hospital. Therefore, community registers offer the most accurate ways of measuring the stroke incidence rate as all new stroke cases in a defined population are being continuously recorded over a given time period. Ideally, the collection of these data should employ the following criteria (Malmgren et al, 1987):

a) the use of a standard diagnostic criteria in defining a stroke e.g. the World Health Organisation (WHO) terminology
b) a prospective study design should be used, in which data on cases are collected throughout the whole year.
c) cases to be ascertained from patients with a first-ever lifetime stroke.
d) a pathological classification of stroke type is needed either using an early Computerised Tomography (CT) or necropsy data.
e) data to be collected from a large and representative population, from which accurate sociodemographic data on each case can be obtained.

Nevertheless, due to the high cost and difficulty in collecting data for a community survey, there have been relatively few population-based studies carried out in the UK, the main one being the Oxfordshire Community Stroke Project (Bamford et al, 1988). Using this study, incidence rates for new strokes were calculated at 2.0/1000 per annum and for recurrent stroke at 0.4/1000, giving a total stroke incidence rate of 2.4/1000 in the UK. This means that in a population of 500,000 (which corresponds to a population of a UK health authority), it is expected that 1200 people will have a stroke each year of which 1000 of these will be a new one. Nevertheless, the one main criticism of the Oxfordshire study is its use of a predominantly rural sample with a very small ethnic population and high social class area (Wade, 1997). Furthermore, this study is now a decade out of date and may need updating.

1.4.2. Stroke Prevalence

The few community surveys carried out mainly in Scandinavian countries have suggested that stroke prevalence for people in the community lies somewhere between 5-7 cases/1000 (Wade, 1994). Whilst there have been no comparable UK surveys, Clark & Opit (1994), using 1985 data from the Office of Population Census and Surveys (OPCS), estimated that in Great Britain (England, Wales and Scotland), 270,000 people with stroke are living in the community, with a further 60,000 people in residential care.

1.4.3. Future burden

Studies looking at stroke mortality have all shown a steady decline in Western countries since the turn of the 20th Century (Khaw, 1996; Department of Health, 1992). This decline in mortality is caused by either a fall in stroke incidence or a reduction in case fatalities, although little is still known about the mechanism of this decline (Ebrahim & Harwood, 1999). Some studies have highlighted the role of hypertension management in the reduction of stroke incidence as increased blood pressure is recognised as a major risk factor (Khaw, 1996; Whisnant, 1983). Other studies (Wolf et al, 1992) have attributed this to a reduction in stroke severity brought about by the following factors: a) reduced incidence of specific stroke subtypes with high case fatalities, b) increased recognition of transient ischaemic attacks (TIA) which enables high risk individuals to be placed on prophylactic aspirin therapy, c) improved diagnostic recognition of milder strokes and d) better acute management of strokes (though there have not been any specific effective treatments for acute stroke during this period). Nevertheless, stroke mortality rates provide little information on the impact of future stroke and trends in stroke incidence rates are a more appropriate tool for this (Wolfe & Burney, 1992).

As population trends in Western societies suggest that the cases of stroke will increase with the ageing population, it is important for health services to predict the estimated number of future stroke cases in the population as it enables them to plan for future demand. There are relatively few studies of this nature, but one UK study (Malmgren et al, 1989) looked at projections of stroke incidence rates for the year 2023. This study, taking into account population projections, found that whilst the number of first ever strokes will increase by 30%, the overall burden of health care will be concentrated on caring for stroke patients in the acute stages, many of whom will die at this stage. Hence, the number of people disabled by stroke in the year 2023 will increase by 8% in those with severe disability and 4% in those with moderate disability.

1.5. Risk factors associated with stroke

A risk factor is an attribute or exposure which is known to cause an increase in the occurrence of a disease (Last, 1995). For stroke, these risk factors can be divided up into the following four categories; fixed, physiological, social and behavioural. These risk factors are presented in Table 1.1 together with their relative risks, which indicate the probability that a person will have a stroke given that they have the risk factor. This table indicates that the major risk factors for stroke are age, a history of hypertension, previous TIAs and a history of heart disease.

Table 1.1. Risk factors for stroke (Ebrahim, 1990, p.19; *Wolfe et al, 1996, p.70)

Risk factor		Relative risk
Fixed	Age (75+ vs. 55-64)	5
	Gender (male vs. female)*	1.3
	Ethnicity ("black" v's "white")*	1.4
Physiological	Hypertension (160/95+ vs. <120/80)	7
	Ischaemic heart disease	3
	Heart failure	5
	Atrial fibrillation	3-7
	Past TIA	5.2
	Diabetes mellitus	2.2
Behavioural	Smoking	3
	Obesity*	1.8
Social	Social class (V vs. I)	1.6

1.5.1. Fixed factors

Age and gender have been identified as the major risk factors in this category. Data from the Oxfordshire Community Stroke Project (Bamford et al, 1988) have shown that after the 55th year of life, the risk of stroke increases with age, in which men in the age group 75-84 years were at greater risk from having a stroke than their female counterparts. Ethnicity has also been identified as a significantly important risk factor with Afro-Caribbeans being at greater risk of stroke than their white Caucasian counterparts (Stewart et al, 1999). Whilst higher prevalence of hypertension in Afro-Caribbeans may account for some of this increased risk, further studies are needed to look into difference in genetic, physiological and behavioural risk factors between Afro-Caribbeans and their white Caucasian counterparts.

1.5.2. Physiological factors

This category can be further sub-divided into the following;

i) hypertension.

Hypertension (raised blood pressure) has been identified as the major risk factor for stroke, in which a 27 mmHg difference in diastolic blood pressure (102 vs 75mmHg) has led to a five fold increase in stroke risk (Prospective Studies Collaboration, 1995). This is because hypertension increases the risk of cerebral infarction by accelerating the process of atherosclerosis (the build-up of fatty deposits on the arterial walls) and increases cerebral haemorrhaging by placing greater strain on the blood vessel walls.

ii) Evidence of vascular disease.

Individuals with a history of cardiovascular disease are at increased risk of having a stroke. A history of atherosclerotic disease (such as angina or myocardial infarction) is indicative of a build-up of fatty deposits on the arterial wall. This build-up causes a narrowing of the blood vessels and increases the risk of emboli forming either in the blood vessels of the brain or in the arteries leading to it. Heart diseases such as atrial fibrillation (irregular heartbeat) increases the risk of an emboli forming from the heart which in turn cuts the blood supply to the brain.

iii) History of Transient Ischemic Attack (TIA) or previous stroke.

Current estimates indicated that 50% of people who have a TIA will have a stroke within 10-15 years after the onset of the TIA (Hankey, 1996).

iv) History of diabetes mellitus.

Epidemiological studies have shown people with diabetes are at higher risk of having a stroke (Burchfield et al, 1994). Diabetes mellitus increases the stroke risk due to accelerated major and minor arterial disease, and associated hypertension.

1.5.3. Behavioural factors

Smoking, chronic alcohol consumption and obesity are the three main factors in this category, which help contribute to the risk of stroke. Smoking is the major behavioural risk factor for stroke as it increases the process of atherosclerosis. Chronic alcohol consumption and obesity increase the risk of stroke through hypertension, whilst a diet high in fatty content increase the probability of stroke through atherosclerosis.

1.5.4. Social factors

Social class has been identified as a risk factor with people from the lower social classes at higher risk from stroke. The exact mechanism is unknown, but it may be that differences between the social classes such as social deprivation, dietary or environmental differences e.g. smoking (Wolfe et al, 1996) may contribute. For example, people from lower social classes may be more likely to smoke and be obese. They may also have less access to high quality medical care and may be less likely to take treatment for asymptomatic high blood pressure.

1.6. Preventive strategies.

As the burden of stroke on society is immense, it is important to reduce the stroke incidence rate, something which epidemiological studies have indicated is preventable in many cases (Khaw, 1996; Whisnant, 1983). Stroke prevention strategies aim to reduce the risk of stroke by controlling for the three major stroke risk factors; hypertension, evidence of cardiovascular disease or history of TIAs (Wade, 1994) and take the following two approaches to do this.

The first strategy is the identification of individuals with a high risk associated with one of these factors. In cases identified with moderate to high hypertension, anti-hypertensive therapy is known to be clinically effective where a drop of 5-6 mmHg in diastolic blood pressure can reduce stroke risk by 33-50% (Khaw, 1996). Individuals with a history of TIAs or a minor stroke benefit from prophylactic therapy using aspirin (an anti-platelet drug which reduces the stickiness of the platelets and hence their tendency to aggregate into clots) as the first line of treatment. Carotid endarterectomy (the removal of atherosclerotic lesions from the inner wall of the carotid artery) is effective in reducing stroke risk (European Carotoid Surgery Trialists Collaborative Group, 1991; North American Symptomatic Carotid Endarterectomy Trial Collaborators, 1991). This procedure, however, should only be considered in certain groups of individuals who present with 70-99% stenosis of the inner carotid artery (the main blood vessel to the brain), due to the potential complications of surgery. Individuals with a history of ischemic heart disease (angina and myocardial infarction) are considered for prophylactic therapy with aspirin whereas therapy with warfarin (an anti-coagulant) and alternatively, aspirin is effective in patients with atrial fibrillation.

Nevertheless, the main problem of the above approach is that it does not bring about risk reduction on the population level, which can only be done using population-based interventions such as the introduction of lifestyle changes. These involve tackling dietary factors in reducing sodium/potassium intake, obesity, alcohol consumption, the cessation of cigarette smoking and increasing physical activity. These measures are mainly aimed to reduce blood pressure though they also have an impact on other stroke risk factors like cardiovascular disease, and studies have illustrated that implementing these lifestyle changes can reduce the risk of stroke (Khaw, 1996).

1.7. Acute treatment

There are two main aims of acute treatment in stroke care; the first is to minimise the impact of predictable medical complications such as deep vein thrombosis, pneumonia, pressure sores, epilepsy, cardiac abnormalities and nutritional problems (Rudd, 1996). The second is to minimise stroke pathology (Wolfe et al, 1996), though evidence is limited for their effectiveness in reducing mortality or limiting brain damage (Ebrahim & Harwood, 1999). Meta-analyses have identified certain interventions, which have brought some benefits and these have been listed in the recommendations for the National Clinical Guidelines for Stroke (The Intercollegiate Working Party for Stroke, 2000). These are: a) aspirin to be given as soon as possible if diagnosis of haemorrhage has been discounted; b) anticoagulation for all patients with atrial fibrillation, once a diagnosis of intracerebral haemorrhage has been excluded, c) thrombolysis with tissue plasminogen activator to be administered three hours after onset of stroke, provided diagnosis of haemorrhage is excluded and treatment is carried out in a centre with appropriate experience of this type of therapy. A range of new treatments such as calcium antagonists, gangliosides and steroids still need further evaluation to evaluate their potential benefit (Ebrahim & Harwood, 1999).

1.8. Stroke rehabilitation

1.8.1. Definition of rehabilitation

Rehabilitation is the process of active change by which a person who has become disabled acquires the knowledge and skills needed to optimise their physical, psychological and social functions. (Advisory Group on Rehabilitation, 1997). This disability may have resulted from a loss of body function, which prevents an individual from functioning at a level considered 'normal'. Traditionally, the rehabilitation process has focused on the restoration of functional independence, working on activities of daily living (ADL) such as feeding or items of personal care. There is now a growing realisation for the need not only to reduce individuals' level of handicap, but to also help them cope with the distress that their handicap might have on both themselves and their families (Wade, 1994).

1.8.2. The process of stroke rehabilitation

It is estimated that 35% of all stroke survivors have residual disability, often long-term and severe which require some form of rehabilitation. If this disability was not addressed, these survivors would have poorer functional and social outcomes and so utilise more health and social service resources. Rehabilitation services seek to redress this balance by retraining these group of people to the highest possible level of functional ability (Dombovy et al, 1986) to reduce their handicap and so improve quality of life and minimise both the social consequences of disability and the service input from statutory bodies.

Stroke rehabilitation is carried out in multi-disciplinary teams consisting of physiotherapists, occupational therapists (OT), speech therapists, dieticians, medical social workers and occasionally clinical psychologists with input from medical and nursing staff. The process of rehabilitation involves the assessment of stroke survivors' needs from which goals can be planned and a suitable intervention put in place. This is continually reassessed to evaluate the impact of treatment. Each profession is responsible for different aspects of rehabilitation though in many cases, these roles may overlap. The emphasis of physiotherapy is to work on mobility and limb movement, whilst occupational therapists work on activities of daily living, cognitive and perceptual problems arising from the stroke and the provision of aids and equipment to improve survivors' Activities of Daily Living and accessing to domestic and community activities. Speech therapists play an important role in the assessment and intervention of swallowing difficulties and communication deficits. Medical and nursing input at this stage is mainly centred on stabilising survivors' medical condition and preventing complications arising from immobility.

1.8.3. The effectiveness of rehabilitation techniques on stroke-related disability

There are a few well-designed randomised control trials (RCT) that have evaluated the effectiveness of stroke rehabilitation, which show good evidence on the effectiveness of occupational therapy and physiotherapy after stroke (Effective Health Care Bulletin, 1992). This was further supported by a recent study, which looked at patients not initially admitted into hospital for their stroke. It found that those allocated to receive additional occupational therapy had significantly reduced disability when compared to patients receiving only the standard care (Walker et al, 1999). There is also evidence to recommend the use of a speech and language therapist in the management of dysphasia (The Intercollegiate Working Party for Stroke, 2000). These studies have illustrated the effectiveness of these different professions in stroke rehabilitation. However, there is more debate about the components of therapy, which are effective in bringing this change. Ashburn et al (1993), in their review of physiotherapy in stroke rehabilitation, have found the following findings: one, active early intervention improve both functional independence and mobility of stroke patients; two, intensive rehabilitation is better than less intensive treatments for a sub-group of physically resilient patients. However, a review looking at RCTs of specific rehabilitation therapies, have generally been inconclusive into which approach was most effective in improving patients' physical outcome (de Pedro-Cuesta et al, 1992).

There are indeed several problems in evaluating therapy (Ashburn et al, 1993; Ebrahim, 1990). One, the goals of therapy are set in agreement with each stroke survivor so therapy tends to be individualised, non-standardised and multi-faceted, with different therapists using different components of therapy to treat the same problem. Two, stroke patients are a heterogeneous group, differing in their level of disability with a selection bias to treat those patients perceived to have a better outcome. Three, many studies have used crude functional or physical outcomes which have not been specifically designed to evaluate the effectiveness of goal-orientated therapy. Four, different therapists from the same professional body are likely to use different techniques to tackle the same problems. Therefore, future studies need to move away from perceiving stroke therapy as a homogenous activity and to concentrate on evaluating which components of therapy are effective in bringing about positive change (Ebrahim, 1990).

1.9. The organisation of different methods of stroke care

There has been a large emphasis on studies looking at the management of stroke care delivery during different stages of the rehabilitation process and the effectiveness of these different methods of stroke care on patients' outcomes, usually functional or clinical outcomes. As stroke rehabilitation is a long process which commences from the stabilisation of patients' medical condition and continues after discharge from secondary health care, this section has been sub-divided into two parts; acute and post-discharge rehabilitation.

1.10. Acute rehabilitation

The 1970's saw the introduction of the first specialised units designed to specifically undertake the rehabilitation of stroke patients, which had traditionally taken place in the general medical wards (Ebrahim, 1990). Stroke units were set up to be more cost-effective by concentrating existing health resources together and providing co-ordinated multi-disciplinary service for stroke rehabilitation. The evidence supporting the clinical benefits of stroke units are strong. A collaborative systematic review involving 19 trials and 3249 patients, showed that organised stroke unit care resulted in significantly fewer deaths, lower dependency and less need for institutional care, when compared with care provided by the general medical wards or a mixed assessment/rehabilitation unit (Stroke Unit Trialists' Collaboration, 1997). In addition, a Norwegian study has highlighted the long term impact of stroke unit management. This has showed that stroke unit patients still had significantly better functional outcome and survival rates, and were more likely to be living at home than their control counterparts both at 5 years post-stroke (Indredavik et al, 1997) and 10 years post-stroke (Indredavik et al, 1999[a]). These findings have been broadly supported by a similar study conducted in Nottingham, UK (Lincoln et al, 2000). However, Kalra et al (1993) suggested that not all stroke patients benefited from a stroke unit. They identified a sub-group of patients with moderate to severe disability who showed the greatest benefit with better functional outcomes, shorter length of hospital stay and a larger proportion discharged back home instead of institutional care.

The advantages of a stroke unit lie in their ability to provide co-ordinated care to their patients with a standard package of diagnosis, treatment and rehabilitation. This ensured that stroke unit patients were more likely to be receiving treatment with a shorter delay period in starting it (Indredavik et al, 1999[b]). Furthermore, the emphasis of physiotherapy on a stroke unit was more directed to the needs of individuals (Kalra et al, 1993). These characteristics were supported by Ottenbacher & Jannell (1993) from their meta-analysis of 36 studies which showed the following findings: First, focused rehabilitation programmes produced more quantifiable results. Second, the largest effect sizes were associated with earlier interventions. Finally, no significant relationship existed between the length of treatment and the overall patient outcome. Therefore, there is strong evidence to suggest that a well organised and co-ordinated system of providing stroke care e.g. stroke unit does lead to a reduction in disability, mortality and the use of institutional care.

1.11 Post-discharge stroke rehabilitation.

1.11.1. The development of day hospitals

People with strokes often need to continue with rehabilitation once they are discharged from hospital. Whilst the level and type of service provided is variable throughout the UK, geriatric day hospitals are one method by which further rehabilitation has been delivered. Geriatric day hospitals first appeared in Britain in the 1950's, but it was not until the 1960's that they were intensively developed as part of the health service (Brocklehurst, 1970) and they have now become firmly established in most health districts in the UK. Day hospitals were developed to provide four types of different service for people living at home; rehabilitation, physical maintenance, social care and medical and nursing procedures (Brocklehurst, 1970).

However, they are expensive to run, requiring qualified staff, the use of a specialised building with its associated overheads used on part time basis, and the use of ambulance transport to ferry patients to and from their homes (Royal College of Physicians, 1994). Furthermore, a survey conducted found that only 36% of day hospital time was spent in therapy, with 28% of time spent doing no activities (Nolan, 1987). Nevertheless, a recent systematic review (Forster et al, 1999) has highlighted two findings about the effectiveness of day hospitals in the rehabilitation of older people. The first was that patients receiving day hospital care have lower odds of death and better functional outcomes than patients receiving no comprehensive care. However, this difference was not seen when patient outcomes from day hospital were compared with other methods of comprehensive care.

1.11.2. Comparison of day hospitals with existing stroke management

Stroke patients account for 37% of all day hospital patients (Barker & McCarthy, 1989), but there has been little evidence to support their effectiveness in the rehabilitation of stroke patients (Vetter & Smith, 1989; Royal College of Physicians, 1994). A review looking at RCTs which involved day hospitals identified four studies comparing the effectiveness of day hospitals with existing methods of stroke rehabilitation (Dekker et al, 1998). These studies found mixed results; some showed that day hospital patients had better short term functional improvement than those receiving conventional rehabilitation, but this difference disappeared by six months (Hui et al, 1995; Tucker et al, 1984). Other studies found no significant differences in functional outcome between the two groups (Cummings et al, 1985, Eagle et al, 1991). Likewise, Tucker et al (1984) found a sustained improvement in mood status at six months, but this finding was not replicated in the other studies (Hui et al, 1995; Eagle et al, 1991). An economic analysis also found that day hospitals were not more cost-effective than the existing rehabilitation models (Hui et al, 1995; Tucker et al, 1984). However, the different definitions used to describe both the day hospitals and existing rehabilitation packages in these studies make it difficult for the results to be compared with each other. This is further compounded by the use of non-standardised measures in many of the studies (Dekker et al, 1998).

1.11.3. Comparison of day hospital with domiciliary stroke teams

There has been a shift in the emphasis of the delivery of health care away from centralised buildings to domiciliary settings, highlighted in recent policy trends towards the decentralisation of health care delivery (Department of Health, 1997). Within stroke rehabilitation, the high costs of delivering health care in day hospitals coupled with a lack of evidence about their effectiveness in bringing significant long term improvements in functional outcomes, has encouraged many health care providers to look at alternative methods of delivering this care. One such method is the introduction of domiciliary stroke teams to provide the therapy in the patient's own home. Studies in this area have tended to look at the effectiveness of domiciliary services with the current day hospital provision of stroke rehabilitation and have showed mixed results. Corr & Bayer (1995) found that domiciliary OT rehabilitation had no significant impact on functional outcome or activities compared to normal outpatient attendance, though re-admissions to hospital were significantly smaller for the former.

Likewise, the Nottingham-based DOMINO study found no significant difference between the domiciliary (physiotherapy and occupational therapy) and hospital-based rehabilitation (involving either day hospital or outpatient attendance) at six months (Gladman et al, 1992) and one year (Gladman & Lincoln, 1994) for the main functional and mobility outcomes. In the Nottingham study, recruited participants were sub-divided into three strata by ward status; Health care of the Elderly, General Medical and Stroke Unit. An analysis of the data found a small but non-significant differences in death and institutionalisation rates in favour of elderly frail patients receiving day hospital rehabilitation (Gladman & Lincoln, 1994). An explanation for this may be that these groups of patients benefit from the components not available from the domiciliary service such as the co-ordinated medical and nursing care, social input and speech therapy. On the other hand, younger stroke unit patients receiving domiciliary rehabilitation showed significant improvements in their level of household and leisure activities at six months (Gladman et al, 1992), though these improvements were not carried over at one year. It may be that domiciliary therapy accelerated the process of regaining instrumental ADL, but did not produce a higher level of ability (Gladman & Lincoln, 1994).

A trial in Bradford (Young & Forster, 1991) comparing domiciliary physiotherapy with day hospital rehabilitation found that patients treated at home had better functional and mobility outcomes at six months. One explanation given by the authors (Gladman et al, 1995) for the discrepancy between the Bradford and Nottingham studies may be that the domiciliary patients in Bradford were receiving more therapy visits [median = 14.5] than those in Nottingham [median = 5]. Another may be the different histories of the two services with Bradford having a well-established domiciliary physiotherapy service, whilst the Nottingham team was set up specifically for the study. Nevertheless, a combined analysis of both data sets found the only significant difference was an improvement in functional ability from discharge to six months in favour of the domiciliary stroke team (Gladman et al, 1995). An economic evaluation of both studies underlined the cost-effectiveness of a domiciliary stroke rehabilitation team with day hospital costs being about 60-70% more expensive than the domiciliary service due to ambulance transport for patients (Gladman et al, 1994; Young & Forster, 1992).

Generally, these results highlighted three main findings: The first showed that domiciliary stroke services were as effective as day hospitals in improving functional and physical outcomes. These services may also be more cost-effective, although Social Services costs were not fully taken into account in the economic analysis. The second illustrated that neither the domiciliary stroke teams or day hospital addressed the psycho-social issues of stroke patients (Young & Forster, 1992). Finally, there was no evidence from either the Bradford or Nottingham study to suggest that medical and nursing needs were unmet in the domiciliary group. Nevertheless, a qualitative study has shown that patients found domiciliary therapy both convenient and more comfortable, though a lack of equipment and floor space were identified as disadvantages of home therapy (Stephenson & Wiles, 2000). Nevertheless, quantitative studies have not found that the level of distress, though high, was significantly different between both groups (Young and Forster, 1992).

A domiciliary model was also used as part of an early discharge scheme in inner London (Rudd et al, 1997) and Newcastle upon Tyne (Rodgers et al, 1997) as a way reducing length of hospital stay. These schemes, which involved setting up a community discharge package with visits from domiciliary physiotherapy, OT and speech therapy, had significantly reduced length of hospital stay by a period of 6-9 days when compared to previous stroke management (involving a mixture of day hospital, out-patient and generic services). There was, however, no significant difference in any of the main patient outcomes on functional status, perceived health and physical functioning either three months (Rodgers et al, 1997) or one year after discharge (Rudd et al, 1997).

These findings indicated that domiciliary stroke teams were as effective as the day hospital in improving patients' functional outcome and were potentially more cost-effective. However, as the majority of trials involving domiciliary teams have been set up in predominantly urban areas of the UK (Nottingham, Bradford, Newcastle upon Tyne, London), these findings may only be applicable to domiciliary stroke teams in an urban setting. It may be difficult to generalise these findings to domiciliary stroke teams based in rural or semi-rural areas with the logistical problems of longer journey times to visit stroke patients and smaller caseloads. Further studies are therefore needed to evaluate the effectiveness of these teams to more rural parts of the UK (Gladman et al, 1995).

1.11.4. Psycho-social models of rehabilitation

Stroke often has a detrimental impact not only on a persons' physical and functional ability, but also on their personal and social life (Anderson, 1992). Nevertheless, stroke rehabilitation is still directed mainly at tackling this functional deficit, but do little in dealing with the psycho-social problems that accompanies the onset of stroke (Young & Forster, 1993).

There have been attempts to address this problem by developing service interventions to tackle these psycho-social issues aimed at helping stroke patients adapt to the change in their life circumstances, but the results from these studies have generally been disappointing. Dennis et al (1997) in a RCT looking at the effectiveness of stroke family care workers, found no significant difference in psychological outcomes or levels of social functioning between patients in the intervention or control group. Likewise, an RCT exploring the effectiveness of specialist outreach nurses in supporting stroke patients (Forster and Young, 1996), found no significant difference in any of the psycho-social outcomes between the intervention and control groups except for in a subgroup of mildly disabled stroke patients, who had improved social functioning at one year. A specific leisure intervention may be more effective than conventional occupational therapy in maintaining discharged patients' level of leisure activity (Drummond & Walker, 1995), but it was not clear whether improvement in leisure scores led to an improvement in psycho-social outcomes. Nevertheless, whilst these findings suggested that the implementation of these services did not bring an improvement in psycho-social outcome, there was evidence to suggest that stroke patients felt better supported as a result of these services (Dennis et al, 1997; Dowswell et al, 1997).

The voluntary sector may play an increasingly important role as a low cost resource in helping to support health care professionals in the rehabilitation of discharged stroke patients. A study looking at the use of Volunteer Stroke Schemes, which provided stroke patients with a mixture of home support and weekly club attendance, found that these groups led to significant increase in social activities (Geddes & Chamberlain, 1994). Nevertheless, some caution is needed in the interpretation of this result due to its small sample size and the use of a non-RCT design and more studies are needed in this area to see if there may be some benefit of involving the voluntary sector in future service planning.

1.12. Summary

Strokes are a disease of the elderly, which are projected to increase in incidence with the ageing population. The burden of stroke affects not only the stroke survivor and their ability to function independently. Preventive strategies aimed at reducing stroke have sought to control hypertension and vascular disease by identifying high risk individuals and by introducing population based behavioural programmes to reduce smoking and obesity and increase the level of physical exercise.

It is estimated that one third of all strokes will have residual disability requiring long term rehabilitation. The growing cost of health care has therefore focused attention on the need to provide treatments, which are both cost-effective and beneficial to stroke survivors' quality of life. Studies have illustrated the effectiveness of acute stroke units in providing better long-term outcomes for both functional disability and mortality rates. Studies have also showed that post-discharge rehabilitation managed by domiciliary stroke teams were more cost-effective than day hospital rehabilitation, but that both had little impact on survivors' psycho-social outcomes. The majority of studies in this area have mainly evaluated the effectiveness of these teams in urban environments, so more studies using teams working in rural or semi-rural environments are needed in order to generalise these findings. Finally, stroke affects both the physical and social aspects of a person's life, but most rehabilitation is geared towards the former, so further work is needed to evaluate interventions aimed at improving psycho-social outcomes.

CHAPTER 2: LITERATURE REVIEW ON STROKE CARERS

2.1. Chapter overview

This chapter aims to describe the main findings and criticisms of the literature, looking at the informal stroke carers in the following three areas; the impact of stroke on carers' 'quality of life', carers' ability to cope with the onset of stroke and the effectiveness of health services in improving carer outcomes. The final aim is to outline the development of the main hypotheses for this study.

2.2. The informal stroke carer

It is estimated that there are 270,000 people with stroke in Great Britain living in community households (Clark & Opit, 1994). A large proportion of these individuals will be physically independent six months post-onset of stroke (Wade, 1994; Ebrahim, 1990) and require very little assistance in activities of daily living. There will also be a significant number who will be unable to function independently as a result of the disability caused by their stroke and will require additional support to remain in the community. In common with other groups of people with a chronic disease, close family members such as spouses or their adult offspring provide the physical and emotional support required by the majority of these stroke survivors (Anderson et al, 1995; Wade et al, 1986). Frequently these individuals take on this supporting role without being formally employed or trained by statutory bodies and are commonly referred to as "informal carers".

These carers provide a valuable economic resource for the statutory bodies as they reduce the amount of primary health care and social services input required by the stroke survivor (Clark & Opit, 1994). Furthermore, they allow many of these survivors who would otherwise require either rest or nursing home placement, to remain in the community (Hancock & Jarvis, 1994). Hence, they play an important role in supporting stroke survivors in the community and studies involving a sample of both survivors and carers have illustrated the importance of these informal carers in maintaining the health status of stroke survivors. Such studies have found that stroke carers played an influential role in determining the success of survivors' rehabilitation (Evans et al, 1994; Anderson et al, 1985) and were important in maintaining their psychological well being. Those survivors who felt poorly supported by close family members were more likely to have higher depression levels than those who were well-supported (Norris et al, 1990; Morris et al, 1991).

2.3 Quality of life in stroke carers

Stroke research has traditionally concentrated on survivors' physical disability and this is understandable due to the devastating impact that stroke has on the functional independence of the affected individuals. Research has therefore been geared towards minimising the impact of stroke in the following three areas; stroke prevention, medical therapies aimed at reducing stroke pathology resulting from medical complications and an evaluation of different models of rehabilitation management. All these areas are aimed at reducing patients' physical disabilities resulting from the stroke. Nevertheless, there has been a growing recognition of the importance of the concept of quality of life (QoL), which seeks to address the issues of living with stroke on a long term basis once the patient has been discharged from hospital (Anderson, 1988).

Caring for a person with a chronic illness such as stroke can place a strain on a carers' physical and mental ability to cope (Anderson, 1988). There is now a growing recognition of the need to explore quality of life (QoL) issues for stroke carers, seeking to address the issues of living with stroke on a long term basis once the survivor has been discharged from hospital. QoL seeks to understand the significance of living with a chronic illness and the consequences for both the social and psychological domains of life. To date, there has been some debate as to what constitutes a quality of life measure, with clinicians focusing on physical outcomes and social scientists focusing on the interactions between the physical, psychological and social domain (Fallowfield, 1990). However, there is a growing consensus that in stroke outcome research, it is important to utilise a multi-dimensional approach which seeks to evaluate individuals' psychological health, physical health, functional status and social health (de Haan et al, 1992). In this study, using the framework outlined by de Haan et al (1992) and Fallowfield (1990), I defined quality of life as the interaction of physical, psychological and social domains.

2.4. Aims of literature review

The projected rise of stroke incidence in Western countries will see an increase in the numbers of people who will have moderate or severe disability. These people will require additional support to remain in the community (Malmgren et al, 1989), which in turn will see more close kin relatives becoming involved in the care of these survivors. Previous studies have already identified these informal stroke carers as being an important resource in the promotion of both successful health outcomes in stroke survivors and a more cost-effective use of health and social service resources as well as playing an important role in the care of many stroke survivors. However, caring for a person with a chronic illness such as stroke can adversely affect carers' quality of life by placing a strain on their physical and mental resources, though most studies have focused on stroke survivors' physical and functional outcomes. This literature review has therefore attempted to assess the type of studies that have been carried out with stroke carers and has focused on the following three objectives:

The first objective was to identify and review studies that have looked at the impact of caring for a stroke survivor on the carers' quality of life. It was important to clarify this impact and to identify any variables, which were found to affect quality of life.

The second objective was to identify and review studies, which looked at the ways stroke carers have coped and the type of support that have helped them to cope. It was important to identify areas of needs for these stroke carers so that support packages could be planned enabling these carers to continue with their supporting role.

The third objective was to identify studies looking at stroke carers' involvement with health services, focusing particularly on studies involving domiciliary stroke services. This theme was important as health services are often the first point of contact for many stroke carers and have a potential role in maintaining the health status and quality of life of this carer group. Furthermore, as one of the aims of health services is to promote a positive health outcomes, it is important to see how delivery of care is geared to support stroke carers and how effective this is.

2.5 Search strategies for reviewing literature

A literature search for the relevant articles was conducted using three electronic databases (BIDS-EMBASE, MEDLINE AND PSYCHLIT) for the period 1980-1997 in which the following keywords were employed: *carers, caregivers, stroke, quality of life, stroke services, delivery of health care*. These terms were exploded using the thesaurus option to obtain the initial source of references. This search was in particular interested in focusing specifically on stroke carers and the selection criteria (listed in section 2.5.1) were used to reduce the initial number of references.

2.5.1. Selection criteria

The following criteria were used to select the articles for review:

1. Articles must be written in English. Whilst there is an acknowledgement that some articles written in other languages may be missed, the problems and costs of obtaining a full translation for them outweighed the benefits as it was also felt that the majority of appropriate studies would still be identified.

2. Articles must be scientific papers satisfying two conditions: One, they must have been published in peer reviewed journals. Two, they must either be research studies or review papers. If they are research studies, they must have an introduction, a methodology and results section with a conclusion. All letters, comments and editorials were excluded from the review.

3. Articles must involve informal stroke carers. Whilst the ideal study was one in which the stroke carer was the main focus, any study which included the informal stroke carers as part of its sample was included. For this reason, this review was not interested in studies whose samples consisted of voluntary workers or those in the employment of statutory services.

4. Articles looking at informal carers' involvement with stroke-related health services. Whilst the main interest of the study was focused on the impact of post-discharge stroke rehabilitation services, any study which looked at stroke carers involvement with health services was included.

5. Articles must use a carer sample of elderly people with stroke over the age of 55 years. It is recognised that a minority of people with

stroke will be under the age of 55, but as stroke is predominantly a disease of the elderly (Wade, 1994), the focus of this review was on carers of older people with stroke who represent the majority of stroke carers. Studies compromising solely of carers of younger stroke studies were not included in the review as there would have been difficulties in comparing the experiences of carers of both younger and older people with stroke as the latter face unique problems associated with the ageing process.

2.5.2. Number of articles captured

Using the selection criteria outlined in section 2.5.1, a total of 31 studies were identified, of which 29 dealt exclusively with stroke carers and two involved both stroke and dementia carers. These two studies were included as results from both the stroke and dementia carers could be analysed separately. However, studies exclusively using carers of people with dementia were excluded. The researcher acknowledged that some parallels existed between stroke and dementia carers such as carers' age, problems of coping with the survivors' cognitive impairment, behavioural problems, mood disorder and communication difficulties. However, the impact of a stroke can be more sudden and dramatic giving a carer initially little time to adapt to the new circumstances unlike a carer of a person with dementia who may have some time to adapt to the deterioration. Likewise, numerous studies have been carried out on a diverse range of informal carers in areas such as HIV/AIDS and cancer care. Nevertheless, for this review, it would not have been appropriate to use literature from these fields as each group has to cope with unique issues affecting it, but not relevant to informal stroke carers.

2.6 Main findings of the literature review

2.6.1. Impact of a stroke on carers' quality of life

The main characteristics of these studies, including the main findings are summarised in Table 2.1. Generally, these have found that most studies looking at stroke carers have focused their research question on the psychological impact of caring for the individual with stroke, using the concept of psychological morbidity and carer burden. These studies have found that stroke carers have higher levels of perceived strain (Greveson, et al, 1991; Draper et al, 1992), and psychological morbidity when compared with the general population (Ross & Morris, 1988; Anderson et al, 1995). Nevertheless, results were mixed to the extent of this psychological morbidity; some studies have found cases of depression in their carer sample (Williams, 1993), whilst in others, depression levels in stroke carers were comparable with those of the normal population (Ross & Morris, 1988). Furthermore, a study by Macnarama et al (1990) showed that carers' anxiety was the only variable, which had increased concomitantly with time since the stroke.

Whilst there is still some debate about which variables are most important in predicting the degree of carers' psychological morbidity, studies have established the following points. One, cognitive and behavioural abnormalities caused by the patients' stroke were a predictor of carers' emotional dysfunction (Kinney et al, 1995; Anderson et al, 1995; Williams, 1993). In her study, Williams (1993) identified that carers' main sources of distress were dealing with stroke survivors' incontinence, their language impairment and demanding behaviour. Two, stroke survivors' physical disability i.e. their degree of mobility was related to carers' morale scores (Purk & Richardson, 1994) though many studies have also found no significant relationship between these variables (Macnarama et al, 1990). Three, carers' physical health was an important factor in determining their own psychological health (Hodgson et al, 1996). Four, carers' psychological status prior to the stroke and their level of optimism may determine their post-stroke psychological state (Schulz & Tompkins, 1990). Finally, the quality of the carers' relationship with the stroke survivor played an important role in maintaining carers' psychological well-being (Purk & Richardson, 1994). Thompson et al (1990) found that carers, who had a poor relationship with the survivor, often perceived their role to be more of a burden and had a more negative interpretation of their situation. Furthermore, longitudinal studies have shown how factors responsible for carers' psychological morbidity can vary with time (Schulz et al, 1988; Wade et al, 1986). At the initial stages of caring for a stroke, carers' psychological morbidity was related to factors such as the stroke survivors' own depression (Wade et al, 1986), stroke severity and concerns about future medical care (Schulz et al, 1988). At a later stage, other factors such as carers' own health, their own income and their age were more significant predictors (Schulz et al, 1988).

In comparison to the literature available on the psychological health of stroke carers, there were relatively fewer studies that have looked at the other dimensions of quality of life, such as social and physical health aspects. None have looked at the functional status of stroke carers and only one has used a multi-dimensional approach in evaluating the quality of life of stroke carers. Those which have looked into these issues have established that caring for someone with a stroke has a detrimental effect on social health, in which stroke carers experienced at least one lifestyle change (Periard & Ames, 1993) and a general disruption to their social life (Anderson et al, 1995). Furthermore, the physical impact of caring left stroke carers feeling isolated and exhausted (Anderson et al, 1995). Nevertheless, the psychological focus of these studies has meant that non-psychological outcome measures have mainly been used as a way of establishing their relationship with psychological outcome and not as a way of exploring quality of life issues.

Table 2.1: Studies looking at the impact of a stroke on carers' quality of life (n= 13)

Author	Study population	Study design	Outcome	Main results
	1) number of participants *2) carer definition* *3) sociodemographic details* *4) country of origin*		*a) psychological health* *b) carer burden* *c) physical health* *d) social health* *e) miscellaneous*	
Anderson, Linto & Stewart-Wayne (1995)	1) 84 2) Closest person responsible for maintaining stroke survivors in the community. 3) mean age = 58 yr.; 82% female; 59% spouses. 4) Australia	• longitudinal • quantitative	a) GHQ, HAD b) SBAS c) nil d) SBAS e) nil	Most carers report emotional ill-health and disruption to social life and expressed feelings of isolation and exhaustion, with behavioural abnormalities rather than physical disability, being predictive of emotional illness among carers
Draper, Poulos, Cole, Poulos & Ehrlich (1992)	1) 48 (and 51 dementia carers) 2) person who has been caring for a patient of > 60 yr. over the previous 6 months and co-resident with patient 3) mean age = 72 yr.; 48.5% female; 90% spouses. 4) Australia	• cross-sectional • quantitative	a) GHQ b) Relative Stress Scale c) Caregiver Health Scale d) n-s measure on quality of life; n-s measure on life satisfaction; n-s measure on social support e) nil	Carers experienced high degree of burden and psychological morbidity, which was associated with dissatisfaction with life activities.
Greveson, Gray, French & James (1991)	1) 44 2) not defined 3) not reported 4) UK	• cross-sectional • quantitative	a) nil b) CSI c) NHP d) nil e) nil	Carers had more problems with emotional reactions, sleep and social isolation than expected from age/sex matched group, in which 30% of carers suffered substantial strain
Kinney, Stephens, Franks & Norris (1995)	1) 78 2) person most responsible for assisting stroke survivor on a daily basis. 3) mean age = 60 yr.; 76% female; 74% spouses. 4) USA	• cross-sectional • quantitative	a) SCL-90-R b) Caregiving Hassles and Uplifts Scale c) nil d) Caregiver Social Impact Scale e) nil	Carers experienced more uplifts than hassles, in which stroke survivors' physical and cognitive characteristics were the strongest predictors of hassles or uplifts. Carers hassles were negatively associated with psychological well-being.

Keynotes:
GHQ - General Health Questionnaire
NHP - Nottingham Health Profile
HAD - Hospital Anxiety and Depression scale
BDI - Beck Depression Inventory
SBAS - Social Behavioral Assessment Schedule
PCGMS - Philadephia Geriatric Morale Scale
CSI - Caregiver Strain Index
n-s measure - non-standardised measure

Author	Study population	Study design	Outcome	Main results
	1) number of participants *2) carer definition* *3) sociodemographic details* *4) country of origin*		*a) psychological health* *b) carer burden* *c) physical health* *d) social health* *e) miscellaneous*	
Macnarama, Gummow, Goka & Gregg (1990)	1) 41 2) person co-resident with patient. 3) mean age = 59 yr.; 83% female; 83% spouses. 4) USA	• cross-sectional • quantitative and qualitative	a) Profile of Mood States b) CSI c) nil d) nil e) Open ended questions of carers experiences	Carers' anxiety, but not their depression, hostility or stress, was the variable which increased concomitantly with time since the stroke.
Periard & Ames (1993)	1) 20 2) Person responsible for providing direct care to stroke survivor 3) mean age = 67 yr.; 90% female; 65% spouses. 4) USA	• cross-sectional • quantitative and qualitative	a) nil b) nil c) nil d) structured and open-ended questions on lifestyle changes. e) nil	Most carers experienced at least one lifestyle change, precipitated by physical confinement or lack of time to engage in other activities, with the younger carer cohort (40-69) showing higher levels of 'carer strain' than the older cohort (70+).
Purk & Richardson (1994)	1) 44 2) not defined 3) all participants > 60 yr.; 67% female; 100% spouses 4) USA	• cross-sectional • quantitative	a) PCGMS b) nil c) nil d) nil e) nil	Patients' morale and functional score was positively related to carers morale score, in which a positive view of the caring situation associated with higher carer morale score.
Ross & Morris (1988)	1) 20 2) Person co-residing with stroke survivor and physically caring for them.. 3) mean age = 68 yr.; 60% female; 100% spouses 4) UK	• cross-sectional • quantitative	a) BDI; GHQ b) nil c) nil d) n-s measure on carer's situation e) nil.	Association found between negative changes in spouse's situation and psychological adjustment was strongest in relation to strain, increased dependency and decreased social interaction
Schulz & Tompkins (1990)	1) 150 2) not defined 3) see Schulz et al (1988) 4) USA	• longitudinal • quantitative	a) CES-Depression b) nil c) nil d) n-s measure on quality of social contacts e) n-s measure on structural social networks	Carers at risk from depression were likely to have higher initial depression scores, less optimistic, more likely to be married, named fewer network members and perceived poorer quality of social contacts.

Keynotes:
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Author	Study population	Study design	Outcome	Main results
	1) number of participants *2) carer definition* *3) sociodemographic details* *4) country of origin*		*a) psychological health* *b) carer burden* *c) physical health* *d) social health* *e) miscellaneous*	
Schulz, Tompkinson & Rau (1988)	1) 162 2) not defined 3) mean age = 56 yr.; 78% female; 51% spouses 4) USA	- longitudinal - quantitative	a) CES-Depression; Index of Psychological well-being; Level of Optimism scale b) Caregiver Burden Scale c) nil d) n-s measure on quality of social contacts e) n-s measure on structural social networks	Psychological well-being at acute stages were related to stroke severity whilst at later stages concerns about residual difficulties such as health, income and age were significant predictors of depression.
Thompson, Bundek & Sobolew-Shubin (1990)	1) 40 2) not defined 3) mean age = 56 yr.; 68% female; 80% spouses 4) USA	- cross-sectional - quantitative	a) Geriatric Depression Scale b) Questionnaire on Resources and Stress c) nil d) n-s measure e) n-s measure on control, meaning and hope	Carer depression was associated with greater patient physical disability, limited family opportunities, poorer family functioning, carers' negative perception of patient and carer loss of meaningfulness about life.
Wade, Legh-Smith & Langton-Hewer (1986)	1) 302 2) Person living in same house and most closely associated with the stroke survivor. 3) age and gender not reported; 85% spouse 4) UK	- longitudinal - quantitative	a) Wakefield Self-assessment depression inventory b) nil c) nil d) nil e) nil	Carer depression at 6 months was associated with both survivors' depression + low level of activities, though strength of this association decreased with time and no significant correlation was found by 2 years
Williams (1993)	1) 28 2) Primary carer whose responsibilities assistance with subsistence needs and financial matters. included direct physical care 3) mean age = 56 yrs, 72% female; 73% spouses. 4) USA	- cross-sectional pilot study - quantitative	a) Symptom Questionnaire b) n-s measure on carer burden c) n-s measure on global health; Cohen-Hoberman Inventory of Physical Symptoms	Most carers showed psychological distress with 45% showing signs of depression. The main source of distress was identified as dealing with cognitive + language impairment, demanding behaviour and incontinence.

Keynotes:

GHQ - General Health Questionnaire
NHP - Nottingham Health Profile
HAD - Hospital Anxiety and Depression scale
BDI - Beck Depression Inventory
SBAS - Social Behavioral Assessment Schedule
PCGMS - Philadephia Geriatric Morale Scale
CSI - Caregiver Strain Index
n-s measure - non-standardised measure

2.6.2 The coping ability of stroke carers

Caring for a stroke survivor is a stressful process challenging both the mental and physical resources of the individual carer (Anderson, 1992). This section was concerned with studies which look at the factors which enable stroke carers to cope with this stressful task (see Table 2.2). Many studies have concentrated on the psychological aspect of caring, so reflecting the general trend of research in this area. These have found that carers' own appraisal of their ability to cope with stress had an effect on their psychological well-being (Hodgson et al, 1996). Carers who used positive coping strategies such as self-control skills, reported fewer psychiatric symptoms with their spouses than those using passive avoidance strategies (Matson, 1994). Furthermore, carers taught the use of positive coping strategies had better outcomes on measures of family function and stroke knowledge than those allocated to either the control or education group (Evans et al, 1988). Nevertheless, whilst the use of positive coping strategies has some benefit to coping with stroke, other, more concrete measures such as post-discharge support, counselling, further information about strokes and practical help have been identified by stroke carers as improving long-term health outcome (Greveson & James, 1991). However, the provision of information prior to hospital discharge was by itself insufficient to bring about improvement either in coping or family adjustment (Casas, 1989).

Table 2.2: Studies looking at coping in stroke carers (n= 5)

Author	**Study population**	**Study design**	**Outcome**	**Main results**
	1) number of participants *2) carer definition* *3) sociodemographic details* *4) country of origin*		*a) psychological health* *b) carer burden* *c) physical health* *d) social health* *e) miscellaneous*	
Casas (1989)	1) 86 2) not defined 3) mean age not reported; 74% female; 57% spouses 4) USA	• cross-sectional • quantitative	a) n-s measure on coping b) nil c) nil d) nil e) n-s measure on stroke knowledge	No significant relationship was found to indicate that information provided prior to discharge contributed to either better coping or family adjustment.
Evans, Matlock, Bishop, Stranahan & Pederson (1988)	1) 188 2) principal supportive person living with stroke survivor 3) details reported as 3 separate groups 4) USA	• RCT (education v.'s counselling v.'s control) • quantitative	a) nil b) nil c) nil d) ESCROW profile; Family Assessment Device e) Stroke Care Information Test	Carers assigned to counselling group outperformed both control and educational groups on 4 out of 7 family function subscales, caregiver stroke knowledge and patient adjustment at 1 year, whilst control families had deteriorated in scores on healthy family problem solving
Greveson & James (1991)	1) 44 2) not defined 3) mean age = 62 yrs; 69% female; 66% spouses 4) UK	• cross-sectional • quantitative	a) nil b) CSI c) nil d) nil e) open ended questions on additional help	Carers outlined the following 3 themes in improving future outcome; better post-discharge support, more information about stroke and available resources, more practical help.
Hodgson, Wood & Langton-Hewer (1996)	1) 50 2) person providing physical, social and emotional support to patient following stroke 3) mean age = 63.4 yrs; 68% female; 66% spouse 4) UK	• longitudinal • quantitative	a) General Well-Being Index b) n-s measure on stress appraisal c) n-s measure on health d) Social Network Scale; Family functioning Chronic Illness Index e) n-s measure on satisfaction with health services	The following 3 variables, carer's physical health; carers' appraisal of stress and carers' satisfaction with service provision, accounted for 53% of variability in carers' well-being 12 months post-stroke.
Matson (1994)	1) 36 (and 37 dementia carers) 2) person living with patient since onset of stroke 3) mean age = 68 yrs; gender not reported; 89% spouses 4) UK	• longitudinal • quantitative	a) BDI b) Hassles Questionnaire c) Belloc Health Measure d) nil e) n-s measure on ways of coping	Carer stress and depression were positively associated with a) non-confronting coping, and b) current levels of behaviour disturbance. It was negatively associated with tactical coping to specific hassles.

Keynotes:
CSI - Caregiver Strain Index
BDI - Beck Depression Inventory
n-s measure - non-standardised measure

2.6.3. The impact of stroke services on carers' quality of life

The role of health services is the maintenance of health status for all members of society (Department of Health, 1997). They have a potentially important role in maintaining stroke carers' quality of life as they are often the first point of contact for this group if a stroke survivor is admitted into hospital. The objective of this section was to identify studies looking at the impact of stroke services on carers (see Table 2.3). A total of 13 studies were identified, the majority being predominantly UK based but with some US and Australian studies. Their focus of research has mainly concentrated on carers' perceptions of in-patient stroke services in two areas. These were carers' perceived needs for services (Pound et al, 1993; Rosenthal et al, 1993; McLean et al, 1991) and their satisfaction with them (Pound et al, 1993; Rosenthal et al, 1993; Wellwood et al, 1995). These studies have shown that carers were generally satisfied with most aspects of patient care (Pound et al, 1993; Wellwood et al, 1995). However, there was also dissatisfaction with at least one aspect of it (Wellwood et al, 1995), such as a lack of communication with nursing staff or discharge plans (Pound et al, 1993). A possible explanation to this variation in satisfaction level may be related to the different localities of stroke services, each operating with a separate care model and service philosophy and the diversity may be a reflection of the ability of some stroke services to satisfy carers' needs more than others.

These studies highlighted the shortcomings of stroke services in meeting carers' needs, mainly in the provision of sufficient information on issues such as allowance entitlements, post-discharge service needs, carers' domiciliary support and the provision of aids and adaptations (Pound et al, 1993). In particular, carers wanted information about reducing the chances of another stroke, though they often received less than they wanted (Van Veenendaal et al, 1996). Carers also felt inadequately supported by stroke services in tackling their emotional and personal problems (McLean et al, 1991), especially in dealing with both the lifestyle and role changes caused by the onset of a severe stroke (Rosenthal et al, 1993).

However, whilst health professionals may feel that patients were not receptive to all the information provided by them (Van Veenendaal et al, 1996), carers' psychological state did not hinder the uptake of their knowledge concerning stroke (Braithwaite & McGown, 1993).

Stroke carers play an important supporting role in the rehabilitation process, a role which may increase with a growing trend of providing stroke rehabilitation in survivors' own home once they have been discharged from hospital. However, there were relatively few studies looking at domiciliary delivery of stroke rehabilitation, and those available have focused on survivors' outcome with only one carer outcome measure used, this being on psychological health. These studies have generally found mixed results; some have showed no significant difference between domiciliary and day hospital stroke rehabilitation in either carers' psychiatric morbidity (Young & Forster, 1992) or their life satisfaction scores (Gladman et al, 1992). Equally, domiciliary rehabilitation did not seem to be detrimental to carer outcomes and any deterioration found in carers' perceived health status was temporary (Widen Holmqvis et al, 1996). One study, looking that the provision of enhanced Social Services OT, found that carers in the enhanced group had better psychological health than those in the control group (Logan et al, 1997). Nevertheless, this result did not indicate whether carers had shown any psychological improvement since baseline, so it was unknown whether the enhanced OT service had brought about this change or if carers in the enhanced group had better psychological health.

Interventions set up to deal with the psycho-social problems caused by stroke have also showed mixed results. One study looking at a specialist nurse team set up to promote both survivor social integration and alleviate carer stress found no improvement in carers' psychological health (Foster & Young, 1996). Likewise, another scheme based in Leeds using volunteers to support survivors through home visits found that it did not improve carers' psychological health (Geddes & Chamberlain, 1994). Furthermore, an intervention using a family social worker to meet with carer needs was shown to be effective in improving carer satisfaction with the services, but had minimal effect on their psychological health (Dennis et al, 1997).

Table 2.3: Studies looking at the impact of stroke services on carers' quality of life (n= 13)

Author	Study population	Study design	Outcome	Main results
	1) number of participants *2) carer definition* *3) sociodemographic details* *4) country of origin*		*a) psychological health* *b) carer burden* *c) physical health* *d) social health* *e) miscellaneous*	
Braithwaite & McGown (1993)	1) 37 2) not defined 3) mean age = 61 yrs; 81% female; 84% spouses 4) Australia	• cross-sectional • quantitative	a) n-s measure b) n-s measure c) nil d) nil e) n-s measure on stroke knowledge n-s measure on psycho-social loss	Carers' psychological state is not hinder in their quest for knowledge
Dennis, O'Rourke, Slattery, Staniforth & Warlow (1997)	1) 231 2) not defined 3) not reported 4) UK	• RCT (family social worker V's no additional support) • quantitative	a) GHQ, HAD b) n-s measure c) nil d) FAI, n-s measure on social adjustment e) n-s measure on carer satisfaction	Carers in treatment group had better outcomes than controls, but significant differences found only for mood symptoms.
Forster & Young (1996)	1) 139 2) resident main carer 3) not reported 4) UK	• RCT (specialist outreach nurse v.'s no additional support) • quantitative	a) GHQ b) nil c) NHP d) FAI e) nil	No significant difference found at psychological or physical health scores between both groups.
Geddes & Chamberlain (1994)	1) 27 2) not defined 3) not reported 4) UK	• longitudinal • quantitative	a) HAD b) nil c) nil d) nil e) nil	No significant difference in levels of anxiety or depression between carers in the Volunteer Stroke scheme or those receiving no additional support.
Gladman, Lincoln & Barer (1992)	1) 180 2) not defined 3) not reported 4) UK	• RCT (day hospital v's domiciliary physio/ OT) • quantitative	a) Life Satisfaction Index b) nil c) nil d)Brief Assessment of Social Engagement e) nil	No significant difference in carer social engagement and life satisfaction scores between domicilary and day hospital groups.
Logan, Ahern, Gladman & Lincoln (1997)	1) 55 2) not defined 3) not reported 4) UK	• RCT (enhanced v's usual OT services provided by Social Service) • quantitative	a) GHQ b) nil c) nil d) nil e) n-s measure to adjustment to stroke; n-s measure about stroke information.	Carers in intervention group had significantly better psychological outcomes than control group (p<0.01).

Keynotes:
GHQ - General Health Questionnaire HAD - Hospital Anxiety and Depression scale SIP - Sickness Impact Profile n-s measure - non-standardised measure

Author	Study population	Study design	Outcome	Main results
	1) number of participants *2) carer definition* *3) sociodemographic details* *4) country of origin*		*a) psychological health* *b) carer burden* *c) physical health* *d) social health* *e) miscellaneous*	
McLean, Roper-Hall, Mayer & Main (1991)	1) 20 2) person providing most of regular assistance with personal activities. 3) mean age = 55.5 yrs; 75% female; no data for relationship status. 4) UK	- cross-sectional pilot study - qualitative and quantitative	a) HAD b) nil c) nil d) nil e) semi- structured interview on carers' perceived needs.	Majority of carers unmet need identified in areas of personal-emotional advice.
Pound, Gompertz & Ebrahim (1993)	1) 99 2) person providing most of personal, practical or emotional help 3) mean age = 60 yrs; 73% female; 50.5% spouses. 4) UK	- cross-sectional - quantitative	a) nil b) nil c) nil d) nil e) n-s measure on satisfaction with in-patient services.	Most carers satisfied with both in-patient services and discharge plans, but main areas of dissatisfaction included lack of information on allowances and service needs post-discharge, provision of aids + adaptations and carer domiciliary support.
Rosenthal, Pituch, Greninger & Metress (1993)	1) 14 2) not defined 3) mean age = 60 yrs; 100% female; 100% spouses. 4) USA	- cross-sectional - quantitative	a) nil b) nil c) nil d) nil e) n-s measure on post-discharge needs.	Carers' perceived needs were not met by hospital staff with anger about insufficient information from health care providers on role change and financial issues.
van Veenendaal, Grinspun & Adriannse (1996)	1) 39 2) not defined 3) mean age = 62 yrs; gender & relationship status not reported 4) USA	- cross-sectional - quantitative	a) nil b) nil c) nil d) nil e) n-s measure on educational needs	Family members were most concerned with information about reducing incidence of another stroke occurring; then about information relevant to their specific situation
Wellwood, Dennis & Warlow (1995)	1) 114 2) next of kin/ main care provider 3) not reported 4) UK	- cross-sectional - qualitative	a) nil b) nil c) nil d) nil e) semi-structured interview on satisfaction with stroke services.	Most carers and bereaved carers satisfied with overall care, though 75% of carers expressed dissatisfaction with individual components of care

Keynotes:

GHQ - General Health Questionnaire

HAD - Hospital Anxiety and Depression scale

SIP - Sickness Impact Profile

n-s measure - non-standardised measure

Author	Study population	Study design	Outcome	Main results
	1) number of participants *2) carer definition* *3) sociodemographic details* *4) country of origin*		*a) psychological health* *b) carer burden* *c) physical health* *d) social health* *e) miscellaneous*	
Widen Holmqvist, de Pedro Cuesta, Moller, Holm & Siden (1996)	1) 8 2) family members 3) 100% spouses; age and gender not reported 4) Sweden	• longitudinal pilot study • quantitative	a) SIP b) n-s measure on carer burden c) SIP d) SIP e) nil	The impact on the home rehabilitation service showed a modest decrease in carers' subjective health which decreased over time.
Young & Forster (1992)	1) 63 2) not defined 3) not reported 4) UK	• RCT (day hospital v's domiciliary physio) • quantitative	a) GHQ b) nil c) nil d) nil e) nil	No significant difference between the two groups in carer stress scores

Keynotes:
GHQ - General Health Questionnaire HAD - Hospital Anxiety and Depression scale SIP - Sickness Impact Profile n-s measure - non-standardised measure

2.7. Methodological critique

2.7.1. Impact of stroke on carers' quality of life

A breakdown of the sample size for the 13 studies reviewed showed that the number of participating carers ranged from 20 to 302 with a median of 44. Most of these studies were able to identify the source of their carer sample, gave basic demographic information on the carer group such as gender, mean age and relationship status, and were able to give their definition of carer. However, the review also showed the diversity of this carer sample for whilst nearly all of these carers were recruited from stroke survivors who at some point had been admitted as in-patients, some studies mentioned that they recruited specifically from first time stroke survivors whilst others made no mention of the previous stroke history of their stroke survivors. This factor may be important as first time stroke carers will have different experiences to longer term carers, but only one study has mentioned the average time of caring.

The socio-demographic information revealed that carers involved in these studies were predominantly female, in their sixties and were either the spouse or the adult child of the stroke patient. Likewise, most studies centred their definition of an informal carer around the concept of one individual undertaking most of the care responsibility of that stroke survivor, though there were variations on this theme. However, there was a sizeable number of studies (n = 3) that did not provide either all the basic demographic information or the carer definitions (n = 5). These studies may present problems as it would not be easy to compare studies without this frame of reference about the type of carer used or their basic demographic information and would so prevent a comparison of results. Furthermore, in studies where socio-demographic details of carers were given about ethnic background and social class, it was identified that the majority of participating carers were predominately white and middle class, reflecting a under-representation of carers from either ethnic minority and working class background. This made it difficult to generalise the results from these studies to the wider population.

The majority of studies employed a cross-sectional design (n=9) which was useful in identifying associations between variables, but not in establishing causal relationships between them. The validity of the results in some of these cross-sectional studies were compounded by their small sample size. A breakdown of sample size used in these cross-sectional studies ranged from 20 to 78 with a median of 41, in which a sizeable number of studies (n=3) had less than 30 carers. The psychological angle adopted by these studies has meant that whilst standardised measures such as the General Health Questionnaire, the Beck Depression Inventory and the CES-Depression scales were used to investigate the psychological health of carers, other dimensions of quality of life, such as the social, functional and physical aspects (if they were measured) were often evaluated using non-standardised subjective measures such as self-reported responses. This use of non-standardised measures therefore reduced the validity of the results, especially when used in cross-sectional studies with small sample size. Longitudinal studies tended to measure the short term impact of caring for a stroke survivor with most studies being of one year's duration and only one study looking at a longer term two year post-stroke period.

2.7.2. Coping ability of carers

The five studies reviewed for this section had a sample size ranging from 36 to 188 with a median of 50 carers. The majority of these studies defined their carers as the principal person providing the majority of care for the stroke survivors. The carers in these samples were predominantly female, over the age of 60 and were married to the stroke survivor. However, many of these studies did not provide the basic demographic details, which made it more difficult to generalise these results to other stroke carers. Like the previous section, these carers were also recruited from stroke survivors who had contact with health services. A diversity of methodologies such as cross-sectional, longitudinal and randomised control trials (RCT), were used. Whilst there was an emphasis on measuring psychological outcomes, there was more interest in looking at physical health and social relationship, but this was offset by a greater use of non-standardised measures on all dimensions.

2.7.3. Carers and stroke services

The 13 studies reviewed for this section were subdivided and analysed into three main groups:

1) studies looking at carers' perceptions of inpatient stroke services and their own needs relating to service provision. The following studies were classified into this category: Braithwaite & McGowan (1993), McLean et al (1991), Pound et al (1993), Rosenthal et al (1993), van Veenendal et al (1996), Wellwood et al (1995).

2) studies looking at interventions dealing with patients' psycho-social issues. These were considered carer-orientated, for although their main aims were to improve patients' psycho-social outcomes, they were also partially orientated to help support carers. The following studies were classified into this category: Dennis et al (1997), Forster & Young (1996), Geddes & Chamberlain (1994).

3) studies looking at interventions dealing with patients' functional recovery. There were patient-orientated as their aims were to specifically improve patient functional outcome. The following studies were classified into this category: Gladman et al (1992), Logan et al (1997), Widen Homqvis et al (1996), Young & Forster (1992).

Studies looking at carers' perceptions (n=6) all utilised a cross-sectional design and employed smaller carer samples ranging between 14 to 114 with a median of 38 carers. Most of these studies gave basic socio-demographic details (n=5), which showed that these stroke carers were mainly female, over the age of 60 years and were married to the stroke patients. However, only two of these studies defined their carers as the main person providing the physical and emotional support and this lack of a proper definition made it difficult to compare the different results with each other. The main outcomes were mainly interested in carers' perceptions of health service delivery and very few studies measured quality of life. They generally used non-standardised measures which varied in their quality; some studies undertook to test the reliability and validity of their instruments whilst others were constructed without such consideration and the poor quality of some measures reduced the validity of their results.

Three studies looked at carer orientated interventions, of which two utilised a randomised controlled trial (RCT) design with a sample of 231 and 139 carers. Both these studies (Dennis et al, 1997; Forster & Young, 1996) utilised a range of standardised measures such as the Hospital Anxiety and Depression Scale (HAD), General Health Questionnaire (GHQ), Nottingham Health Profile and the Frenchay Activities Index, which encompass the psychological, physical and social aspects of Quality of life. Unfortunately, these two studies did not provide any information about their demographic details of carers or give any carer definitions, which may present problems in generalising these results. The third study (Geddes & Chamberlain, 1994) used a longitudinal design, had a sample size of 27 and used the HAD scale to evaluate psychological health. However, it provided no other details about the carer sample, which again made it hard to generalise the results.

Three of the studies looking at patient orientated interventions (Gladman et al, 1992; Logan et al, 1997; Young & Forster, 1992) all employed a RCT design with sample sizes of 180, 55 and 63. Only carers' psychological health was evaluated, but standardised outcome measures were used to evaluate this. Unfortunately none of these studies provided any carer definitions or demographic information. The fourth study identified (Widen Homqvis et al, 1996) was a pilot study, which provided carer definitions and gave basic demographic information, but only had a sample size of 8.

2.8. Conclusions of the literature review

Studies have shown that stroke carers have poorer psychological health than the general population, that factors such as the severity of the physical disability, the quality of the carer-survivor relationship and the extent of the cognitive and behavioural abnormality resulting from the stroke, were associated with this psychological morbidity. They have also highlighted that the use of positive coping techniques such as self-control skills contributed to better psychological outcome. Nevertheless, many criticisms can be levelled at these studies. One, their predominant use of cross-sectional studies coupled with their small sample sizes have reduced the validity of their results. Furthermore, cross-sectional studies can only be used to find associations between variables and not to establish a causal relationship between them. Two, these studies have concentrated their research questions on psychological morbidity on the assumption that the main burden of caring for a stroke is psychological, a trend influenced by the nature of previous studies and the research interest of their authors (Tyman, 1994).

Caring for a stroke survivor has a detrimental effect on psychological health, but there is a growing recognition of the importance of measuring quality of life in health care research. However, to date, there have been very few studies looking specifically at quality of life issues in stroke carers and those studies which have incorporated physical or social health, have often used non-standardised measures in their evaluation. More longitudinal studies are needed with each study employing a larger sample size. The research question needs to shift away from a purely psychological approach to the evaluation of a more global concept of quality of life, incorporating the physical, psychological and social domains that should be evaluated using standardised outcome measures for each dimension.

The bulk of studies on stroke services and carers have tended to be service evaluations looking at carers' perception of in-patient stroke care using non-standardised measures. These studies have found that carers were generally satisfied with most aspects of the service provided, though areas of dissatisfaction included the lack of information and post-discharge support. These studies have relied on the use of carers' self-reported satisfaction as their main outcome measure. Whilst satisfaction outcomes can highlight both service limitations in meeting carers' needs and areas for improvement, satisfaction measures can also be unreliable. There may be several reasons why carers were satisfied with services such as feeling obliged to give the socially desirable answer to show their appreciation of the care being provided. Satisfaction scores provide little information on the impact of health services on improving carers' quality of life (Hall & Dornan, 1990), although they may reflect real differences in the provision of care (Pound et al, 1999).

In comparison, the few studies looking at the impact of health services on carers can be sub-divided into two areas; one, the impact on carers' psychological health of different deliveries of stroke rehabilitation and two, different types of carer-directed interventions on their quality of life. In both these areas, there was little difference between the intervention and control groups on the carers' main outcomes. This could be interpreted in two ways; one, the new intervention treatment was ineffective in producing better outcomes than the control treatment. It may be that the interventions did not meet carers' needs as they were designed by health professionals without any consultation from stroke carers. Two, the new intervention was as effective as the control in preventing a deterioration of carer outcomes which may suggest that contact with health services was in itself sufficient in helping carers. However, within a health care setting, it would be difficult to evaluate this as it would be unethical to withhold health services input to stroke carers.

Methodologically, these service-based studies employed either a RCT or longitudinal design, using a sample size that provided sufficient statistical power in many cases. All these studies used standardised measures to evaluate their main carer outcomes and a broad range of psychological, social and physical measures were used in evaluating the effectiveness of carer-directed interventions. However, one major failing of these studies was the lack of information given about the carer sample. Very few gave any demographic details about their carers or how they defined them and in some cases, it was not clear what the sample sizes were. There may be several reasons for this. Traditionally, the focus of stroke research was still directed at stroke survivors, which may be reflected in some studies by the use of a solitary psychological measure on carer outcomes. However, this lack of carer detail made it difficult to allow these studies to be compared with each other and to generalise their results to a wider context.

A breakdown of the country of origin for each study showed that the bulk of studies originated from the USA, the UK and Australia with some contributions from other European countries. If these studies were sub-divided into the categories, impact-based and service-based studies, the majority of the impact-based studies would originate from the USA, whilst the UK studies would dominate the service-based studies. This dominance may make it difficult to generalise the results of these studies outside their context. For example, the lifestyle and culture of US carers may be so different from their counterparts from other Western societies that it may not be possible to apply these findings to non-US stroke carers. Likewise, as the British health service is different from many of its Western counterparts, being free at the point of delivery, problems may arise in the interpretation of the results from the service-based studies as the majority of these were from the UK and would been seen to be applicable only to similarly organised health care systems.

2.9. Directions and guidelines for future research

Future studies on stroke carers should move the research agenda away from looking solely at psychological health to exploring the wider quality of life issues, utilising a range of standardised outcome measures to evaluate the social and physical as well as the psychological aspects. Previous studies have used cross-sectional designs with small carer samples and frequent use of non-standardised measures and future studies should utilise a longitudinal design and have larger sample size, as this would make the results more statistically meaningful and allow causal relationships between variables to be established. One of the aims of health services is to enhance the quality of life for users and more studies are needed to evaluate the effectiveness of stroke services on improving carers' quality of life.

It is important to tighten up the methodological limitations of previous studies looking at both carer-directed and patient-directed interventions. Future studies looking at these interventions should ideally employ a RCT design. There should be more accurate and complete collection of carers' basic demographic details (age, gender, relationship status to stroke survivor, ethnic background, socio-economic status), sample size and a more precise definition of what was meant by a carer. Ideally, studies looking at stroke carers should recruit only the principal carer; that is, the individual identified as the main provider of the stroke survivor's emotional and physical support. Complete details of carer samples from each study enable comparisons to be made with other studies and allow results to be generalised.

2.10. Development of the research questions

Informal stroke carers are an important element in the care of stroke survivors, but the strain caused by caring for this group of individuals has a detrimental effect on their general quality of life. Whilst the majority of studies have been orientated to looking at stroke survivors, there is also a growing recognition of the need for health services to improve the quality of life in stroke carers. This study sought to address some of the limitations of previous studies by focusing the research question specifically to informal stroke carers. My focus of research was particularly interested in investigating the impact of post-discharge rehabilitation on stroke carers. This is because rehabilitation services play an important role as one of the major health service contacts for many carers once a survivor has been discharged from hospital. However, there have been relatively few studies looking at the effectiveness of rehabilitation services on improving carers' outcome, with most studies involving stroke carers and health services focusing on carers' perceptions of in-patient stroke services.

Furthermore, trends in health service policy have seen a decentralisation of health care delivery away from hospital to community settings. In post-discharge stroke care, this has led to the formation of domiciliary stroke teams in which multidisciplinary teams of therapists are employed to carry out rehabilitation in the survivors' own home instead of at a day hospital. This shift in health care delivery could see carers becoming more involved in the rehabilitation process, but little is known about what impact either the domiciliary team or the day hospital will have on carers' quality of life or on their ability to help carers cope with their role. It may be that greater contact between the stroke carer and the domiciliary rehabilitation staff will lead to more empowerment for stroke carers through greater involvement in the rehabilitation process of the stroke survivor and a better quality of life outcome. Conversely, day hospitals may provide an important respite role for the carer, which in turn leads to an improvement in the quality of life. However, the few studies evaluating the effectiveness of domiciliary services have generally found little difference in carer outcomes between the domiciliary and day hospital models, but these studies have only used psychological measures.

There has been no previous study, which has attempted to evaluate the impact of different models of post-discharge rehabilitation on stroke carers. This study is the first of its kind to do a complete investigation of the impact of different models of post-discharge rehabilitation on carers' quality of life. It aims to look at their effectiveness in bringing about change in carers' quality of life and if either of the rehabilitation models help stroke carers to cope better with their role.

My first research question was interested in evaluating the effectiveness of the different models of rehabilitation in improving carers' quality of life. I wanted to see if carers assigned to a domiciliary stroke team had any significant improvement in their quality of life when compared to those assigned to the day hospital group. I felt this was important as the results would have future implications for domiciliary stroke teams; in particular, any deterioration in carers' quality of life resulting from contact with domiciliary stroke team would need health services to rethink their policy of setting up such teams for the future. I was interested in evaluating quality of life using a wider range of measures incorporating social, physical as well as psychological domains unlike previous studies that have only used psychological health to measure carer outcome.

My second research question was interested in stroke carers' perceptions of the domiciliary stroke team and day hospital service. As a relatively new concept in health care, there have been few studies looking specifically in this area, but it is important for health services to cater for carers' needs. This question sought to provide a more qualitative evaluation of the different rehabilitation packages and to give some insight into which aspects of the rehabilitation package carers perceived as most useful in helping them to cope with the stroke. Likewise, any shortcomings in the different rehabilitation packages could potentially be used as a framework for future interventions to support stroke carers in their caring role.

My third research question was interested in investigating how stroke carers coped with their role as carers. This question arose from the lack of studies in this area, all of which have tended to focus on the use of specific psychological strategies in improving carers' ability to cope, but which provided little insight into how carers coped in their role. I felt it was important to identify the difficulties facing carers as this would provide a framework for supportive packages. For this purpose, I therefore wanted to gain an insight into the process which carers employed to cope with the onset of the stroke, their expectations of their role as carers and to identify the support structures available to them. Furthermore, I was also interested to explore the changes in their role occurring over a period of time.

My final research question was interested in investigating which survivor variables have an influence on the different domains of quality of life. Whilst previous studies have identified several factors which predict psychological morbidity, these studies have not looked at other domains of quality of life. I was therefore interested to see if there was any relationship between the main survivors' variables such as gender and level of disability with any of the carers' quality of life domains (i.e. physical health, social activities and psychological health).

CHAPTER 3: RESEARCH CONTEXT

3.1. Relationship of the Dorset Stroke Study with main carer study

There have been few studies in stroke research, which have looked at the impact of stroke services on informal carers. The Dorset Stroke Study (DSS) which was initially set up to evaluate the cost-effectiveness of different models of post-discharge rehabilitation, provided a unique opportunity for a researcher (J. Low) to conduct a detailed investigation on the impact of these different stroke rehabilitation models on informal carers. The researcher was able to recruit his carer sample from survivors participating in this stroke project and felt it was important to give some background information about its evolvement.

The key objectives of this chapter are to give an outline of the aims of the Dorset Stroke Study, to describe the structure of the health services involved in the DSS, and the methodology used to collect the data, and to present the results and their conclusions. The results described in this chapter focus specifically on outcomes relating to stroke survivors' physical, psychological and social functioning as it was felt this was important in trying to understand the impact of the different services on the carers involved in the study.

There was some debate as to what words could be used to describe a person with stroke. In this chapter and subsequent chapters, the term 'stroke survivor' was used instead of 'stroke patient'. It was considered more appropriate to use 'stroke survivors' as the emphasis of this study was on the stroke carers, not the person with the stroke. Thence, the use of 'stroke survivor' reflected this change in focus on the 'person with stroke' from someone receiving health care to someone who has survived the stroke and may need additional help from informal carers as a result of it. It was also acknowledged that the use of the word 'patient' may also have negative connotations associated about the passive role that these users have in the health service.

3.2. Dorset Stroke Study: Background information

The growing cost of health care has focused attention on the need to provide treatments, which are both cost-effective and beneficial to stroke survivors' quality of life. Strokes in particular are a growing health concern with the ageing population in the UK and the high costs of providing stroke care. The introduction of domiciliary stroke units in two studies have been shown to be a cost-effective method of delivering post-discharge rehabilitation in urban areas (Gladman et al, 1995), but there have been few studies showing its efficacy in rural or semi-rural areas. It was this lack of research, which prompted the Dorset Health Authority to evaluate the feasibility of introducing such a team into Dorset. The Dorset Stroke Study was therefore set up as a three year randomised control trial (RCT) through a South & West NHS Research and Development (R&D) grant. The prime aim of this study was to evaluate the cost-effectiveness of a domicilary stroke team with the service provided by day hospitals for the elderly in the delivery of post-discharge stroke rehabilitation. A multi-disciplinary steering group was set up to ensure the smooth running of the study and to investigate the following areas:

1) evaluating the effectiveness of the domiciliary stroke team in improving survivors' physical, psychological and social functioning compared to the day hospitals for the elderly.

2) an economic evaluation to determine if the cost of delivering domiciliary stroke rehabilitation was cheaper than providing this in the day hospital.

3) a subsidiary study to investigate 'the black box of stroke rehabilitation', looking at how therapy staff in the domiciliary team and day hospital spend their therapy time with stroke rehabilitation.

3.3. Service provider

3.3.1. Background to the main service provider

Poole Hospital NHS Trust is one of the two major providers of acute secondary health care in East Dorset, serving a population of 267,440 residing in the borough of Poole and the District Councils of East Dorset and Purbeck (Simons et al, 2000).

The Trust covers an area semi-rural in character, ranging from the East Dorset conurbation including Poole, the market towns of Wimborne Minister, Wareham and Swanage and remote rural areas such as the Purbecks (see Figure 3.1). This area also has a higher proportion of older people residing in it where 11% of the population are aged 75 years and older (Simons et al, 2000) compared with the national average of 7% aged 75 years and over (Office for National Statistics, 1998). This finding may be attributed to the fact that East Dorset is a popular retirement area and has an influx of older people moving into the region from other parts of the United Kingdom.

3.3.2. Organisation of stroke care for survivors in the catchment area of Poole Hospital NHS Trust.

The organisation of stroke care in Poole Hospital is generally determined by the person's age on admission. At the start of this study in 1995, there was no stroke unit at Poole Hospital so any stroke care was carried out in a generic environment. Younger stroke survivors (under 60 years) were admitted to an acute medical ward, where they receive both their treatment and rehabilitation. Any of these survivors requiring further rehabilitation on discharge were followed up in the out-patient departments of their nearest hospital. Older stroke survivors (60 years and older) were admitted to one of the three acute 'Care for the Elderly' wards for assessment until their medical condition stabilised when they were then transferred to their nearest local community hospital for the first stage of their rehabilitation. In some individual cases, survivors between 50-60 years have been admitted to a 'Care for the Elderly' unit as their clinical condition would benefit from the expertise provided by these units.

The community hospitals Alderney, Wimborne, Wareham, Swanage and St.Leonards are associated units with medical input from consultants based at Poole, but have separate management arrangements from Dorset Healthcare NHS Trust. Prior to the DSS commencing, many Poole residents were transferred to St. Leonards Hospital (12 miles from Poole) due to insufficient beds at Alderney, but this situation changed with the opening of two new rehabilitation wards (Kimmeridge and Lulworth) at Poole Hospital in October 1995.

Stroke survivors were discharged from secondary care either when they were able to function safely in the community with the appropriate level of social care input or when a suitable placement becomes available in a rest or nursing home. Discharged stroke survivors were only referred to their local day hospital if they had a residual disability, which would benefit from further rehabilitation.

3.3.3. Day hospitals involved in the Dorset Stroke Study.

The day hospital units participating in the Dorset Stroke Study were Studland, Woodlands (Alderney), Wimborne and St. Leonards. All except Studland (Poole Hospital NHS Trust) were managed by the Dorset Healthcare Trust.

Two changes occurred during the course of the study: 1) Studland Day Hospital was closed in December 1995 due to service re-organisation in Poole Hospital NHS Trust. 2) Wareham Day hospital, which was not initially included due to perceived travel problems for the domiciliary stroke team (i.e. heavy summer tourist traffic) was subsequently included into the study in October 1996 as the numbers of stroke survivors being recruited needed to be increased.

The underlying philosophy of these day hospitals was to provide co-ordinated health care in the rehabilitation of elderly survivors recently discharged from secondary health care. As in other parts of the UK, day hospitals in the Dorset Healthcare Trust operate in multi-disciplinary teams consisting of physiotherapists, occupational therapists and nurses with weekly speech therapy and medical input. Most referrals to the day hospital come mainly via the in-patient rehabilitation wards, but stroke survivors identified via General Practitioners are first seen by the consultant geriatrician (based at Poole Hospital) who will make a referral if appropriate.

Survivors were assessed on their first visit to evaluate the amount of therapy required. For each patient the number of day hospital visits varied from one to three times a week and was determined by the survivors' level of disability and their potential for recovery. Stroke survivors were booked for regular attendance until their maximum potential, as assessed by the team, was reached (this could take between one to three months).

Survivors were required to attend for the entire day (10.00AM to 3.00 PM) and were given individual sessions of physiotherapy and occupational therapy with some input from speech therapy if appropriate. Nursing and medical needs were also catered for during these visits. In most cases, ambulance transport was provided to and from the survivors' homes though some are brought in by private transport. Once survivors had reached their maximum potential for recovery and were considered for discharge, they were put on review for a month, re-assessed to monitor progress and if no further therapy was considered necessary by the multi-disciplinary team, they were discharged from the day hospital.

3.3.4. The domiciliary stroke team

The Dorset Health Authority set up a domiciliary stroke team in June 1995. Its aim was to provide home-based stroke rehabilitation to recently-discharged stroke survivors living in a designated catchment zone, which covered an area from Poole to Horton and Verwood in the north, Ringwood in the east and Wool in the west (see Figure 3.1).

Figure 3.1: Map of Dorset (taken from Dorset Health Authority website)

Key:

▨ area covered by domiciliary stroke team

This service consisted of one full time Senior I Physiotherapist and one half time Occupational Therapist who were responsible for stroke rehabilitation. Medical input was provided by monthly meetings with a consultant physician (from the Department of Medicine for the Elderly, Poole Hospital NHS Trust) to discuss individual cases. Survivors requiring any Speech therapy were referred directly to the Speech and Language Therapy Department at Poole Hospital.

The service philosophy of the domiciliary stroke team was to assess survivors' needs, devise an intervention programme and to provide therapy until maximum potential for recovery was reached. Once this had been achieved, stroke survivors were then placed on review for a period of a month and if no further therapy input was needed, survivors were discharged. Survivors were also transferred to a more appropriate service if the therapists felt that the person's disability was not stroke-related. Once discharged from the domiciliary stroke team, survivors could not be re-referred to this team; if further rehabilitation was needed, a new referral would be sent to either the day hospital or the domiciliary community teams for the elderly.

This latter team was set up in February 1996, as a consequence of service re-organisation, to provide a generic domiciliary rehabilitation service as a result of the closure of Studland Day Hospital. The philosophy of this team was to provide therapy to discharged survivors (except those with stroke) who would benefit from rehabilitation, but were unwilling or unable to attend the day hospital. Generally, there was little interface between the Dorset Stroke Study and the domiciliary community team, but there were brief weekly meeting between the researcher and the administrative staff from the latter to ensure that the community team was not treating potential stroke participants.

3.4. Dorset Stroke Study: Design

A randomised controlled trial (RCT) design was used in evaluating the effectiveness of the domiciliary stroke service compared to the traditional day hospital model. The advantage of the randomisation process is that it reduces the potential of selection bias occurring in the allocation of participants to intervention groups. Therefore, randomisation enables all confounding factors (known and unknown) to be evenly distributed by chance between the treatment groups, provided the sample is large enough (Hennekens & Buring, 1987). Hence, results from this type of study have high validity and RCTs are often considered 'gold standards' in medical research. Nevertheless, randomisation by itself cannot ensure an even balance of confounders in both the intervention and control groups, especially in a study with a relatively small sample such as the Dorset Stroke Study. Therefore, it was necessary to stratify the randomisation process for the following confounders; gender, age, baseline disability level (Barthel score) and day hospital catchment. These confounders were selected as previous studies have shown that they have an influence on either stroke epidemiology or recovery. Day hospital catchment was also selected as a potential confounder to ensure an even distribution between the two intervention groups in the different trial centres being used.

3.5 Participants

3.5.1 Source of participants

1) Acute stroke in-patients admitted into Poole Hospital or its associated community hospitals (Alderney, St. Leonards and Wimborne). Survivors from Wareham Hospital were included into the study in October 1996 provided they lived in the town of Wareham and its immediate environs (a distance of five miles from the centre of Wareham town). This area was considered geographically accessible to the domiciliary stroke team.

2) New stroke survivors identified in the community by their general practitioner or the consultant geriatrician during their domiciliary visits or outpatient appointments.

3.5.2 Eligibility criteria

The following eligibility criteria were used to decide which stroke survivors were suitable for inclusion into the Dorset Stroke Study:

a) person had a confirmed stroke diagnosis
b) person was 55 years or over
c) person was a resident of East Dorset at the time of discharge
d) person needed further rehabilitation for the disability caused by stroke
e) person was physically able to attend day hospital
f) person's pre-admission level of disability was not too severe to prevent further rehabilitation
g) person was not showing signs of advanced dementia, in that they had no loss of long and short term memory, and with clear comprehension of their environment and situation.

3.6 Procedure

Ethical approval was first obtained from the East Dorset Local Research Ethics committee. A stroke register was then set up between October 1995 to April 1997 to record all stroke survivors admitted to either a Poole Hospital geriatric rehabilitation ward or the following Dorset Healthcare Trust community hospitals (Alderney, St. Leonards and Wimborne). Wareham Hospital was included in the register in October 1996 (see section 3.3.3 for reason of Wareham's inclusion). Survivors were monitored on a weekly basis by the main researcher (J. Low - JL) and at the point of discharge from hospital, consultant geriatricans were asked to assess survivors' suitability for the study.

Eligible survivors were approached before discharge by JL with details of the study objectives (see Appendix I). Survivors agreeing to participate were asked to sign the Consent Form (see Appendix II) after which JL conducted the baseline assessments (see Appendix III) and survivors were then randomised. This was achieved by telephoning a central office where closed lists of randomisation schedules generated by computer were kept. Randomisation was stratified in blocks of four by gender, age, disability level (Barthel <10, 10-14, 14+) and the catchment area of the day hospital.

A referral to the appropriate service was made once survivors had been allocated to a treatment group and the researcher wrote to the participant, their principal carers (defined as the individual providing the majority of the survivors' emotional and physical support) and their general practitioner (GP) about their allocation. Participants who did not want to participate in the study were asked to give their main reason for non-participation, referred directly to the relevant day hospital and were not approached any further by the researcher. The procedure for recruiting stroke participants identified in the community was exactly the same as with acute in-patients except that participants were contacted directly at their homes when details were provided to the researcher.

Participants were followed up at three, six and 12 months using the Patient Follow-up Assessment (see Appendix IV). The three month assessment was conducted by JL, but a nurse researcher was employed to carry out the six and 12 month assessments. The employment of a nurse researcher, who was blind to the allocation of the study participants reduced the potential for observer bias and so increases the validity of the results. However, the nurse researcher was not employed for the 3 month results as there were no funds available in the South & West R&D bid to cover this period.

3.7 Main outcome measures (survivors)

3.7.1 Criteria for selecting outcome measures

The following criteria were used in selecting outcome measures to evaluate survivors' physical, psychological and social functioning:

i) standardised measures tested for validity and reliability.

ii) measures which were easy for both researchers to administer and DSS participants to understand.

iii) measures which had been used in previous stroke studies which allowed comparisons with other studies.

3.7.2 Outcome measures used

The following outcome measures were selected using the criteria listed in Section 3.7.1:

1. The Barthel Activities Index (BAI) was one of the measures used to evaluate physical functioning, looking specifically at personal Activity of Daily Living i.e. self-care ability such as bathing and toilet use (Wade, 1992). The BAI has the following scoring system; 20 indicates full independence, 15-19 minimal disability, 10-14 moderate disability and a score < 10 indicates severe disability.

2. Rivermead Mobility Index (RMI) was the other measure used to evaluate physical functional, looking specifically at a person's level of mobility (Collen et al, 1991). It is a 15 item questionnaire with a maximum score of 15 where a higher score indicates better mobility.

3. Philadephia Geriatric Center Morale Scale (PGCMS) was used as a measure of psychological functioning looking specifically at a person's morale level (Working Group of the Royal College of Physicians, 1992). It has a maximum score of 17 where a higher score indicates a better level of morale.

4. The Short-Form 36 (SF-36), using the two dimensional scoring system (Ware et al, 1994) was employed in the DSS in which the Physical Component Score (PCS) was used to measure perceived physical health and the Mental Component Score (MCS) to measure perceived mental health status. Both these scales have a maximum score of 100 where a higher score is indicative of better health outcome and both have datasets for the general population. For the 75 year and over age group, median PCS and MCS scores are 37.9 and 50.4 respectively (Ware et al, 1994).

5. Frenchay Activities Index (FAI) was used to measure the level of social functioning (Holbrook & Skilbeck, 1983). It has a maximum score of 45 where a higher score indicates better levels of social functioning and a score of 30 is indicative of active social functioning (Turnbull et al, 2000). This measure was originally developed in stroke populations.

3.7.3. Timing of assessments

Table 3.1 shows the timing of each measure over the 12 month period. The three main measures used at all assessments were the BAI, PGCMS and RMI. The timing of each measure differed, partly due to their content. The SF-36 was not be used at baseline as it would have been recording patient health status during the initial recovery phase from stroke and so may have skewed the results. The FAI was excluded from the baseline and three month assessments as survivors would have been in hospital during the time span assessed and so would not provide an accurate score of their activity level either before or after the stroke.

Table 3.1: Timing of patient outcomes at baseline, three, six and 12 months

Outcomes	Time period			
	Baseline	3 months	6 months	12 months
BAI	✓	✓	✓	✓
PGCMS	✓	✓	✓	✓
RMI	✓	✓	✓	✓
SF-36	×	✓	✓	✓
FAI	×	×	✓	✓

3.7.4 Other details recorded.

The following details were collected on each patient during the baseline assessment: socio-demographic information (age, gender, previous occupation) and cognitive status which was measured using the Abbreviated Mental Test, a 10 item test recommended by the Working group of the Royal College of Physicians and the British Geriatrics Society (1992). Survivors' medical notes were used to obtain their pre-stroke medical history.

3.8 Data analysis

3.8.1 Data preparation

All items on each questionnaire were coded before being punched in by a data entry agency. The punched data were examined to check for any irregularities, cleaned up and formatted for use on an SPSS package.

3.8.2 Types of analyses used

The following analyses were carried out on the data using SPSS:

1) Reasons of ineligibility for stroke survivors admitted to Poole Hospital and associated community hospitals, calculated in frequency and percentages.

2) Reasons for eligible survivors not participating in Dorset Stroke Study, calculated in frequency and percentages.

3) Comparison of both domiciliary and day hospital groups on the following characteristics:
a) number and source of randomised survivors.
b) major sociodemographic details; gender, marital status, social class, age (calculated using mean and range), living arrangements, home and car owner.
c) clinical information; previous stroke, disability level (median, interquartile range, mean, standard deviation), cognitive status, length of hospital stay (median, interquartile range)

4) Descriptive statistics showing the median and interquartile range of all survivors outcome measures (Barthel, RMI, PGCMS, MCS, PCS and FAI) at baseline, three, six and 12 months.

5) Changes in score from baseline to 6 months and 6 to 12 months were calculated for the Barthel, the RMI and PGCMS. In addition, changes in score from 6 to 12 months were calculated for the MCS, the PCS and the FAI.

6) Independent t-tests were carried out to calculate t scores, p values and confidence intervals in comparing the mean score changes of the different outcome measures (BAI, RMI, PGCMS) between baseline and six months to see if there was any significant difference between the two groups on these measures.

7) Independent t-tests were carried out to calculate t scores, p values and confidence intervals in comparing the mean score changes of the different outcome measures (BAI, RMI, PGCMS, PCS, MCS and FAI) between six and 12 months to see if there was any significant difference between the two groups on these measures.

8) Non-parametric tests (Mann-Whitney U) were used to test for significant differences between the two groups for PCS, MCS and FAI at 6 months. Non-parametric tests were used as these frequency distributions were schewed.

3.9 Results

3.9.1 Patient recruitment

During the recruitment period (October 1995 to June 1997), 397 survivors with stroke were admitted to the rehabilitation wards of Poole Hospital and the four participating community hospitals. Of this sample, only 165 (42%) of these survivors were eligible.

A total of 232 out of 397 survivors were ineligible for the Dorset Stroke Study and the two main reasons for ineligibility were death or resolution of the stroke, which together accounted for 50% of the total. Of the 165 eligible survivors, 125 (76%) gave consent to participate in the study and were randomised together with 15 survivors who were recruited from community referrals. The remaining 40 survivors did not want to take part in the study and the main reasons for refusal were either a preference for one type of therapy (21/40) or an unwillingness to take part in the study (7/40).

An analysis of the age and gender distribution of the 40 non-participants was carried out to see if there was a difference between participating and non-participating survivors. This found that mean age of the non-participating survivors was 80.9 years and that 50% of this sample was male, characteristics similar to the participant group.

3.9.2 Baseline characteristics

The randomisation process allocated 66 participants to the domicilary team and 74 to day hospital care. Both groups were well matched for age, gender, marital status and social class. There was no difference between the groups in baseline Barthel score, the numbers with previous stroke, their length of time in hospital and the percentage with cognitive impairment.

3.9.3 Follow-up details (baseline to six months)

54 (84%) of domicilary participants and 58 (78%) of the day hospital participants had both baseline and six month outcome data. There were a few cross-overs: one patient was inappropriately assigned; five domicilary survivors switched to day care; two survivors switched over to the new domicilary scheme that was set up in part of the Poole area during the period of the study. Most withdrawals to follow-up were due to death, a recurrent stroke or the participant moving to a different area (19/26).

A further analysis showed no difference in the age or baseline Barthel between those remaining in the study and those lost to follow-up for non-clinical reasons. However, survivors who had died or had another stroke were older and had a poorer initial Barthel score (indicating a more severe stroke) that those who did not.

3.9.4 Survivors' outcomes at six months

The results referred to in this section are displayed in Appendix V.

3.9.4.1 Physical measures

At baseline, both domiciliary and day hospital survivors showed moderate functional disability (BAI scores of 14.0 and 13.0 respectively out of 20) and poor mobility (RMI scores of 6.0 and 6.0 respectively out of 15). An analysis of the mean change of the BAI and RMI (0 to 6 months) showed that both groups of survivors improved in physical functioning and mobility (see Appendix V). However, the domiciliary group had better functional (mean difference BAI 1.1; 95% C.I., –0.1, 2.3) and mobility improvements (mean difference RMI 0.9: C.I., 0.2, 2.0). In particular, the domiciliary group improved by 2 points (BAI), which shows clinically significant improvement in functional status. Nevertheless, none of these results reached statistical significance. In addition, median PCS scores of less than 37.9 at six months showed that most of the domiciliary and day hospital survivors had poorer physical health than the general population (Ware et al, 1994).

3.9.4.2 Psychological health

Both domiciliary and day hospital survivors had moderate level of 'morale' at baseline (median PGMS of 13.0 and 12.0 out of 17 for respectively). An analysis of the mean change from baseline to six months showed deterioration in the 'morale' scale for both groups, with the day hospital group having a larger but non-significant decrease (see Appendix V). Nevertheless, both the domiciliary and day hospital groups still had mental health status comparable to the general population at six months (median MCS of 57 in both groups) when compared to the general population median of 50.4 (Ware et al, 1994).

3.9.4.3 Social functioning

Survivors in both the domiciliary and day hospital group had poor social functioning (median of 12.0 and 7.5 respectively out of 45) and that they did not differ significantly from each other on this outcome at 6 months (see Appendix V).

3.9.5. Patient outcome at 12 months

The results referred to in this section are displayed in Appendix VI.

3.9.5.1 Physical measures

Both groups showed moderate functional disability in at 6 months (BAI scores of 14.0 and 13.0 respectively), reasonable mobility in the home environment (RMI scores of 9.5 and 8.0 respectively) and poorer physical health compared to the general population (PCS median scores of 36.1 and 31.6 respectively). An analysis of the mean change from six to 12 months of the BAI, RMI and PCS showed no further improvement in physical functioning, mobility or physical health in either group (see Appendix VI).

3.9.5.2 Psychological outcomes

Both domiciliary and day hospital survivors had moderate levels of morale at baseline (median PCGMS of 12.0 and 10.0 out of 17 for respectively). The mental health of both domiciliary and day hospital survivors at 6 months (median MCS score of 57.4 and 57.1 respectively) was comparable to the general population. An analysis of the mean change from six to 12 months of the PCGMS and the MCS showed little change in morale or mental health in either group of survivors (see Appendix VI).

3.9.5.3 Social functioning

Both the domiciliary and day hospital survivors had poor social functioning (median of 14.0 and 7.0 respectively out of 45). An analysis of the mean change from six to 12 months found little change in social functioning in either group (see Appendix VI). A one point difference in favour of the day hospital is clinically a very minor improvement on the FAI.

3.10. Summary of the main results from the Dorset Stroke Study (Baseline to 12 months)

Both domiciliary and day hospital groups made improvements in functional status and mobility from baseline to 6 months. At the same time, there was deterioration in survivors' morale. General trends from six to 12 months showed no change in any of the survivors' outcomes. None of the results reached statistical significance. These findings also showed that the domiciliary group had better improvements in physical outcomes and showed less deterioration in psychological outcomes than the day hospital group, but that these results did not reach statistical significance. No improvements were seen in social functioning in both groups, which was poor at 12 months. Clinically at 12 months, survivors in both groups had moderate to mild levels of disability and generally were mobile indoors. When compared with the general population, their physical health was slightly poorer, but their mental health was similar.

3.11. Economic evaluation

The Dorset Stroke Study was one of the few studies to carry out an economic evaluation of a domiciliary stroke service in a semi-rural area. Details of the methodology used to carry out the economic evaluation and a full description of the results can be found in Roderick et al (accepted). The main findings from this economic evaluation showed no significant difference in the cost per patient of the two rehabilitation services. A more detailed analysis showed that the direct costs of the domiciliary service were lower than the day hospital, but once the knock-on effects on social services were taken into account, it was more expensive although this result was not statistically significant.

However, this result did not take into account that the domiciliary service was not operating to full capacity (as number of survivors treated depended on study recruitment and patient allocation). A sensitivity analysis was therefore carried out to account for increased caseload in the domiciliary service and it showed that costs improved in favour of the domiciliary service. Whilst care must be taken to extrapolate these findings into policy recommendations, they did suggest that the introduction of a domiciliary stroke team would not lead to significantly greater costs in delivering stroke rehabilitation to older people after their discharge from hospital.

3.12. Investigative study into the black box of stroke therapy

The Dorset Stroke Study provided an opportunity for a sub-study to be carried out looking at the 'black box' of stroke therapy. The aims of this study was to understand what occupational therapists and physiotherapists do during their time in stroke therapy and to examine the variability between the domiciliary stroke team and the three day hospitals (Woodlands, St Leonards and Wimborne). It was led by Dr's Ann Ashburn and Claire Ballinger (University of Southampton), with support from the main researcher (JL) and Dr. Paul Roderick (University of Southampton). In this study, data on the activities of the therapists in both arms of the study were collected by asking therapists to record their activities in 15 minute periods for six 2 week periods during the study, using a classification scheme to describe the main activities undertaken.

The methodology and the results of this study were fully described by Ballinger et al (1999), but this sub-study highlighted two main findings. First, it showed that occupational therapists mainly carried out interventions on physical functioning, social/leisure and other tasks, whereas physiotherapists carried out interventions on walking, standing balance and upper limb movement. Second, it demonstrated the variability between the two methods of service delivery. It found that domiciliary therapists generally worked alone, whilst day hospital therapists had greater opportunity to deliver interventions in group settings. One question brought up by the main carer study was the potential impact of services on stroke carers. This sub-study showed that 2-3% of therapist time was spent educating the carer about therapy. Further analysis found that the percentage of time that domiciliary therapists spent in educating carers was greater than time spent by day hospital therapists (personal communication, A.Ashburn). These results suggested that domiciliary therapists may have better opportunities to provide carer education in their therapy sessions. On the other hand, day hospitals were better placed at carrying out both social and leisure therapy through the use of group work.

3.13. Conclusions

The domiciliary stroke team showed better short-term benefits in improving survivors' mobility and functional status, and in reducing the negative psychological impact of stroke when compared with the day hospital. A longer-term assessment found that neither the domiciliary or day hospital teams brought about any further improvements in physical or psychological outcomes. Furthermore, neither service delivery had any impact on social functioning at six or 12 months. Clinically, these results highlighted short-term benefits of the domiciliary stroke team in improving survivors' physical outcome after stroke. Whilst none of these results reached statistical significance, survivors' withdrawal from the study meant that only 112 survivors were available for analysis at 6 months. As 120 participants were required to achieve 80% power, the results at 6 months might have been slightly under-powered and so leading to a possibility of Type II errors. Furthermore, it can also be argued that the p value of 0.05 is only an arbitrary cut-off point for statistical significance. Hence, a p-value of 0.051 (as found in the 6 month analysis BAI) could also be considered statistical significant, bearing in mind the sample size and clinical significance of the result.

These findings indicated that whilst the beneficial impact of domiciliary stroke teams may need further assessment, survivor outcomes were no worse as a result of receiving domiciliary therapy than those receiving therapy at the day hospital. In addition, the economic evaluation showed that there was no cost advantage to either service in their delivery of post-discharge stroke rehabilitation. These findings indicated that the establishment of a domiciliary stroke team in a semi-rural area would be feasible. It would not lead to an increase in costs in the delivery of stroke rehabilitation after hospital discharge and would not adverse effect on survivors' physical outcomes and quality of life.

There is an increasing recognition to cater for the health needs of stroke carers. As Chapter 2 has established, informal carers are an important source of emotional and physical support for stroke survivors, but little is known on the impact that health services have on carers' quality of life. Hence, if a new type of health service intervention, such as a domiciliary service, is being considered on a national basis, it is important to know if it will have a detrimental impact on the informal carer. It may be that the reduced opportunities for respite, an indirect function of the day hospital, will have an adverse effect. On the other hand, increased opportunities at receiving education from the therapists as shown in the 'black box' study, may make the carer feel more involved and so may improve it. Therefore, the main carer study was carried out to address these issues by evaluating the impact of a domiciliary stroke team on carers' quality of life compared with the delivery of service from a day hospital. The findings from this study would also give a more rounded picture of the effect of different methods of service delivery, not only looking at survivors' outcomes and the cost implications, but also at the implications of domiciliary stroke teams for informal carers.

CHAPTER 4: METHODOLOGY

4.1 Methodological background

Health service research (HSR) is primarily concerned with "the relationship between the provision, effectiveness and efficient use of health services and the health needs of the population" (Bowling, 1997, p.6). It has developed from the need to shift the focus of research away from a purely clinical approach towards the evaluation of a more cost-effective and efficient use of health resources (Polgar & Thomas, 1995). Within this research agenda, quantitative methods have traditionally been used, as their methodological framework has been suitable to address whether an intervention is effective. This is because quantitative methodology, with its deductive approach, requires the researcher to formulate a hypothesis. To test out the hypothesis, numerical data are collected and analysed using rigorous statistical tests. These enable the relationship between the different variables to be established, from which the null hypothesis can either be accepted or rejected (Bowling, 1997).

However, there is now an increasing recognition of the need to focus research more on the health care needs of both patients and carers and the impact that health care has on them (Department of Health, 1997). At the same time, there is a realisation of the limitations of quantitative methodology to answer this type of research question (Pope & Mays, 1995). These limitations have centred on the assumptions made about quantitative methods and included the following points outlined by Guba & Lincoln (1994):

1. they encourage the researcher to adopt a neutral 'outsider' approach at the expense of the 'insider' perspective, which takes into account the social context.
2. they often ignore the meaning and purpose attached to human activity.

3. the variables extracted from quantitative studies are taken away from the context which gives them meaning.
4. the results obtained can often not be applied to individual cases.
5. the deductive framework of quantitative methodology prevents the emergence of new ideas as the hypotheses need to be pre-determined before the beginning of the study, using findings from existing work.

On the other hand, qualitative research provides a suitable framework in exploring service users' perceptions and beliefs about health service delivery. This is because it adopts an inductive approach in its analysis, in which data are used to determine the formation of theory or concepts (Henwood & Pigeon, 1992). Therefore, unlike quantitative methods, qualitative ones do not require hypotheses to be generated before data collection and this non-experimental approach encourages data collection in naturalistic settings with the researcher playing a central role in making sense of the data in the context of the relevant concepts (Creswell, 1994). In HSR, there is now a recognition that qualitative methodologies can provide a more valid means of exploring complex social phenomena within health research (Bowling, 1997) and Pope & Mays (1995) have suggested three ways in which qualitative methods can be used in HSR. The first is as an exploratory investigation of a phenomenon from which a quantitative study can be developed. The second is the supplementation of quantitative data by a method of triangulation, in which the results from both methods are used to enhance the validity of a study's results. The third is the exploration of complex phenomena that are inaccessible to quantitative methods.

4.2. Methodology used to answer the research questions.

There is a growing interest in HSR not only to evaluate if a health service intervention is effective, but also the processes of care that are responsible for this change. The research questions this study was interested in answering reflected this perspective. My first question sought to evaluate the impact of two different models of post-discharge stroke rehabilitation (a domiciliary therapy service versus the traditional day hospital) on carers' quality of life. The second question sought to investigate carers' perceptions of the social, physical and emotional difficulties they faced in providing care to stroke survivors. It also aimed to explore carers' expectations towards the therapy services and their own understanding of the therapists' role in the rehabilitation process.

The nature of the first question was interested in evaluating if carers of survivors allocated to the domiciliary arm had a better quality of life than those in the day hospital. Hence, quantitative methods were used to answer this question. To collect the numerical data, a questionnaire incorporating standardised outcome measures was used. The advantages of using questionnaires, is that it is a cheap and simple way of generating large amounts of quantitative data (Fife-Schaw, 1995). In addition, the availability of standardised outcome measures to evaluate QoL further enhances the reliability and validity of the data obtained in this study. These psychometric properties are important as they ensure that the measures replicate the same results under identical conditions i.e. reliability and that they measure what they purport to measure i.e. validity (Last, 1995), and so help to ensure the robustness of a study's results.

Nevertheless, the use of questionnaires has also been criticised for its inflexibility and the data obtained from them have sometimes lacked depth and detail (Pound et al, 1993). This may be due to their fixed response choices, which may not be sufficiently comprehensive and which present responders with a number of problems (Bowling, 1997). There may be a difficulty in identifying a response that reflects their true perceptions, which may in turn lead responders to choose an inappropriate response. The language used in a questionnaire may lead to misinterpretation and an inconsistency in how responders answer the question (Bowling, 1997). Whilst this can be overcome by using questionnaires, which have been extensively tested for reliability and validity and used in populations with specific diseases, it does not distract from the fact that many people feel that questionnaires are inflexible in recording their perceptions.

My second research question sought to explore carers' expectations towards the therapy services and their own understanding of the therapists' role in the rehabilitation process. It also aimed to investigate carers' perceptions of the social, physical and emotional difficulties they faced in providing care to stroke survivors. To answer these research questions, I felt that qualitative research methods were appropriate. Qualitative methods have an advantage over quantitative methods in situations where there is little pre-existing knowledge about a topic. In this study, qualitative methods were primarily used as a means of exploring complex phenomena, providing data, which was both descriptively rich and high in content validity. They were also used in a triangulation process, in which the data from the qualitative study was used to enhance the validity of the quantitative data. Hence, qualitative methods were used in two ways outlined by Pope & Mays (1995)

Quantitative methodology would not have been appropriate for this part of the study as there were no suitable standardised measures which would have directly addressed the questions I was interested in. There are generally very few measures which have been developed in this area of stroke carer research and those available have mainly looked at carers' perceptions of in-patient stroke services (Pound et al, 1993) which would have had low content validity in relation to my question. The use of an inappropriate measure would have in turn made the results invalid as I would not have addressed my area of interest.

Contrary to popular belief, qualitative methods reflect a wide range of different research paradigms with underlying assumptions, which specify the nature of reality and determine the way in which the data are analysed (Murray & Chamberlain, 1998). In this study, I used two types of qualitative analyses. I adopted 'content analysis' as one method of analysis as I was interested in getting a general overview of carers' perceptions and I felt that this approach, in which the researcher reduces data into categories was an appropriate method of analysis (Millward, 1995). In addition, I carried out an in-depth thematic analysis on a subset of my interview transcripts, as I was interested in exploring the above issues in greater depth. In both these analyses, I viewed the qualitative data as reflecting the true perceptions of how carers felt about caring for a stroke survivor and their expectations of the therapy services. However, I rejected a 'grounded theory' approach, as the aim of the research was not the generation of theory through the data. Likewise, 'discourse analysis' focuses on the structure of language and examines how people use language to construct versions of their worlds (Coyle, 1995). It was therefore considered inappropriate for this study as I viewed the use of language as a reflection of carers' thoughts and not as a way of constructing it.

4.3. Use of combined methodology

The diverse nature of the research questions could not be answered by using one methodology alone and the framework of this study was based on a combined approach using both quantitative and qualitative research methods. Combined methods are becoming increasingly popular within health care research to investigate the many different factors that influence health (Morgan, 1998). Their main advantage is the ability to yield data on different aspects of the research questions (Mason, 1994). Combined methodology was used in this study to utilise the different strengths of each method in obtaining data, which would help to complete a rounded picture of the impact that different stroke services have on carers' quality of life and their method of coping. This approach can fill the gaps of knowledge, which could not be completed by the reliance of one methodology alone. In this study, the quantitative data provided the tools to document the effects of system changes and so help policy makers to make decisions about health care whilst qualitative methods were used to understand the processes accompanying changes in health systems (Holm & Schmidt, 1997). In addition, qualitative data was also used in a triangulation process to further validate some of the quantitative findings.

However, the combining of different methodologies is fraught with difficulty and these problems may either be technical, or conflicts between the different paradigms due to the underlying differences of assumptions (Morgan, 1998). There is still a continuing debate about the use of combined methodologies and there are those who would argue that as both methodologies come from fundamentally diverse research paradigms, it would be inappropriate to use this combined approach. This group would say that the quantitative methodology involves a research process in which reality is seen as objective and value-free, where researchers act as impartial observers who maintain a distance from the carers and do not bring their own values into the study. This contrasts sharply from the qualitative paradigm where multiple realities constructed by the individual can exist in any one given situation. The researcher plays a central role in the study, both in interacting with the carers they are studying and making sense of the data in the context of the concept being explored (Creswell, 1994). Therefore, from a 'purist' stance, a barrier to using combined methodologies would stem from the fundamentally incompatible epistemological positions which quantitative and qualitative methods occupy and which should be seen as separate and mutually exclusive of each other (Bryman, 1988).

The 'pragmatic' schools of thought would disagree with this purist stance, claiming it to be inflexible and that the perceived dichotomy that exists between quantitative and qualitative methodologies is false. They would argue that an integration of both research traditions is needed to understand complex concepts (Creswell, 1994). Increasingly within health service research, there is a trend towards the use of combined methods as a way of investigating the complexity of the different factors influencing health, in which both methods are seen as a way of complementing each other (Pope & Mays, 1995). As a practical study that is trying to investigate the complex interaction surrounding health care, this study needed to utilise the best methodologies available to investigate them. However, I do not dispute the theoretical differences between quantitative and qualitative approaches, but recognise that it is possible to use a combination of methods (Morgan, 1998). Therefore this study viewed methodology as existing within a continuum framework with pure quantitative and qualitative methods occupying opposite dimensions. Using this frame of reference, it is possible to see that studies which employed a combined approach are situated somewhere on this continuum between the qualitative and quantitative dimensions. The use of this type of framework can explain a variety of different types of combined methods, such as studies using a predominantly quantitative approach, a predominantly qualitative approach and those in which quantitative and qualitative methodologies have equal status.

This study utilised a *dominant-less dominant design* in which one research paradigm dominates the main study, though a significant minor component of it is taken from the alternative paradigm. In this study, greater weighting was given to the quantitative study as I felt that my main question, which was geared towards evaluating if carers in the domiciliary group had significantly better quality of life than carers in the day hospital group, was best investigated using a quantitative approach. Therefore the structure of this study was designed to answer this question, but as I was also interested in exploring carers perceptions of health service delivery and their attitudes towards their caring role, qualitative methods were also included within the quantitative based structure of the study. The advantages of using *a dominant-less dominant design* is that a consistent paradigm picture is presented, in which additional data are drawn from the qualitative study to explain the findings from the quantitative study. Its disadvantage is that purists from either side of the quantitative-qualitative divide may feel that it is a misuse of their paradigm (Creswell, 1994).

Other types of combined methodologies were considered, such as the use of either two phase or mixed methodology designs. *In a two phase design*, both the qualitative and quantitative studies are carried out separately so there is no problem with distinguishing between the different research paradigms and this also presents a consistent paradigm picture, though there may also be difficulties in seeing the link between both studies (Creswell, 1994). In the *mixed methodology design*, both the quantitative and qualitative paradigms are mixed at various levels of the methodological process, allowing better integration between the qualitative and quantitative methods. Nevertheless, its main drawback is that it requires the researcher to be comfortable in working backwards and forwards between both research paradigms thus requiring intimate knowledge of both (Creswell, 1994).

Both these designs were rejected for the following reasons; the *mixed methodology design* would have been considered if there was equal weighting between the different methodologies, but was inappropriate for this study as there was greater weighting towards the quantitative side. The *two phase design* could have been considered if I was planning to use the results from one study to guide the structure of the other. For example, if I was interested in designing a questionnaire in a new area of research, a preliminary qualitative study would have been useful in generating themes or hypotheses to develop content for such a questionnaire. However, in this study, the results from both the quantitative and qualitative parts were trying to produce a general picture of the impact of the different services on stroke carers. It was therefore easier to incorporate the qualitative study with the structure of the dominant quantitative one rather than to set up a separate qualitative study.

4.4. Quantitative study

4.4.1. Quantitative design

Quantitative data can be collected using two types of studies; observational and experimental. As the quantitative element of this study was interested in evaluating the effectiveness of two systems of stroke rehabilitation in improving carers' quality of life, an experimental design was considered the most appropriate design to use. This is because an experimental design is concerned with the relationship between two variables, the independent and the dependent variable from which the researcher can manipulate the former and so measure its effects on the latter (Robson, 1994). In practical terms, the independent variable in this study was represented by the different experimental groups, the control group which represents either no or traditional treatment, and the experimental group which represents the new treatment. The researcher then measures the impact of the different groups on the dependent variable by the use of standardised outcome measures. As the researcher is interested in the relationship between the dependent and independent variable, data collection takes place in a controlled environment and any confounding variables i.e. participant characteristics which can affect the outcome, are controlled for either by randomised allocation methods or matching carers on confounding characteristics.

This study was an exploratory study, using a randomised controlled trial (RCT) design. As this study was nested in the framework of a larger RCT, the unit of randomisation was the paired association of the carer participant with the stroke survivors. An RCT enabled the impact of the intervention to be evaluated on several outcome measures using concepts such as carers' quality of life and psychological health. There are two main reasons for this; first, participants are randomly assigned to either the intervention (receiving the new treatment) or the control group (receiving the standard treatment), in which the latter acts as the comparison group. Second, data are collected at two or more different points in time, one being the baseline pre-intervention stage and the other at post-intervention. Carers are then followed over a period of time and any change in outcome can be evaluated between the different groups over time, assuming that both groups start with roughly equal experiences. Therefore, any improvement or deterioration in carers' outcomes can be attributed to the new treatment.

The randomisation process seeks to ensure that both the intervention and the control groups are equally balanced with respect to any known and unknown confounding variables. This reduces the potential for confounding as the confounders will be randomly allocated between both groups. It also seeks to prevent selection bias, which may occur if participation allocation was in the control of the researcher by a process of concealed allocation. However, there are also several drawbacks to the randomisation process: One, it is only effective in ensuring an equal balance between groups for larger sample sizes. Two, randomisation does not eliminate problems associated with the recruitment of a small group of self-selecting carers, such as the inability to generalise the results to other groups of carers.

Another potential problem localised to this study was that randomisation was achieved indirectly by the paired association of carers with stroke patients from the Dorset Stroke Study (see Chapter 3). It would have been preferable if carers could have been allocated randomly to the intervention or control group, but this would not have been possible as the initial intervention was centred on stroke patients. Hence, it was acceptable for carers to be randomised via this paired association as they were indirect recipients of this intervention. However, it was not possible to stratify the groups by potential confounders such as carers' age, gender, socio-economic status or their kin relationship with stroke survivors, so there is a risk of an imbalance for these confounders between the two groups.

A major problem of any follow-up study is sample attrition i.e. the loss of participants to follow-up which could occur in this study through a variety of different reasons. These include death of the carer or stroke survivor, a move out of the area, the occurrence of a new stroke in the survivor or the wish of carers to withdraw from the study on personal grounds. These losses have several knock-on effects such as potentially leaving the study with a more unrepresentative sample. This leads to a loss of statistical power in data analysis and an increase in the occurrence of false negatives (Type II error). In a RCT, this means that the null hypothesis can not be rejected as a true difference may exist between the experimental groups, which requires a larger sample size to identify it (Hennekens and Buring, 1987).

To minimise the effects of these losses, the following steps were taken; one, all carers were followed up at the different assessment times (3, 6 and 12 months). Two, the main statistical analysis was carried out using an 'intention to treat' analysis, which involves analysing all carers in the groups they were assigned to, irrespective of crossovers of their associated stroke survivor to the other treatment or subsequent withdrawal from the study (Lewis & Machin, 1993). This approach also reflects the real world where participants withdraw from studies for various reasons. 'Intention to treat' analysis would seem illogical compared with the alternative 'on-treatment' approach where only those who received treatment were analysed. Nevertheless, an 'on-treatment' analysis may produce a biased result by excluding participants who died or withdrew. Furthermore, many statisticians argue against this latter approach, indicating that analysis by treatment will disrupt the equal balance created by randomisation, leading to a problem of reduced sample size and consequent loss of power, and a undermining of the validity of significance testing (Lee et al, 1991).

Technical problems can also arise from a longitudinal study and one problem is "sampling conditioning" in which carers exposed to the same questionnaires over several occasions are aware of the nature of the study and may unintentionally provide answers which favour the researcher's hypotheses (Fife-Schaw, 1995). Likewise, carers may not be truthful with their responses, either because they do not personally like the researcher or they want to provide the socially acceptable answers e.g. they may want to give the impression of coping well. This would make the results appear to be more favourable than they actually are. Carers may also be influenced by their knowledge and beliefs of the different treatments, which can lead to information bias. An RCT tries to overcome this information bias by the blinding of both the carers (to avoid recall bias) and the researcher to the hypothesis (to avoid observer bias). In this study, it was not possible to keep both parties blind to the allocation of the stroke survivors for the following reasons: one, the investigator was the main co-ordinator to the Dorset Stroke Study and was responsible for the initial organisation of care for the stroke patients. Two, the closeness of the relationship between carers and stroke survivors would have made it impossible for the former not to be aware of the latter's group allocation.

4.4.2. Sample selection

4.4.2.1. Definition of informal carer

An informal carer was defined as the person identified by the stroke patient as providing the majority of that patient's emotional and physical support and who was not employed by a statutory organisation to provide that care.

4.4.2.2. Source of carers

The main carers as defined in section 4.3.2.1 were identified from the 140 stroke survivors participating in the Dorset Stroke Study (see Chapter 3).

4.4.2.3. Recruitment of carers

Recruitment of informal carers commenced in October 1995 and ended in June 1997. Informal carers were identified by asking each participating stroke survivor who their main informal carer was using the definition given in Section 4.3.2.1. Stroke survivors were asked if it was possible to contact their informal carer about participating in the study. Once their informal consent was given, each identified carer was sent a letter informing them about patients' participation in the study and the possibility of their involvement in the carers' study (see Appendix VII). Each carer was contacted by phone at least four times during different times of the day. Once contact was made, a meeting was arranged with them to discuss the purpose of the study in which they were provided with the summary sheet explaining the main objectives of the study (see Appendix I). This meeting also allowed carers to ask any questions concerning the study. Carers who agreed to participate were asked to sign a consent form (see Appendix II) whilst those who refused were asked their main reason for not wanting to take part. Carers who could not be contacted after four attempts were classified as the non-contact group.

4.4.3. Outcome measures

Outcome measures refer to instruments which enable changes in health status to be monitored as a result of either exposure to a disease or an intervention (Last, 1995). Often, standardised tests are used to measure changes in health status and this study employed a battery of standardised tests, which were incorporated in a questionnaire to measure carers' quality of life as a result of the impact of the different service deliveries. Within the context of health services research, outcome measures provide a scale by which individuals' health can be measured and there is much emphasis within health care to use standardised outcome measures to evaluate the effectiveness of treatment on individuals' health status.

Studies have indicated that quality of life in stroke is not a uni-dimensional concept which can be measured in a single item and incorporates a wide range of dimensions including physical, functional, psychological and social health (de Haan et al, 1992). Therefore, it was necessary to employ a wide range of measures to cover this range and the main criteria in selecting outcome measures for this study were:

1) each measure should demonstrate adequate validity and reliability.

2) easy for the carers to complete by themselves. This requires the measure to obey the following conditions;

i) the written language used has to be easily understood by the carer and the instructions for each measure should be easy to follow;

ii) the responses to each question should be straight-forward and require only one response to one question;

iii) each measure should be able to be completed in a short period of time (no more than 20 minutes) as too long measures can lead to fatigue and non-completion.

3) each measure must have been previously employed in studies involving either stroke survivors or their carers. This increases the validity of the measure and also provides the researcher with an opportunity to compare his carer sample with other studies.

4) each measure must be suitable for use with different age groups. This is because the carers, unlike the stroke survivors, have a diverse age range.

5) each measure must be written in the English language or have a standardised English translation. Each measure must be validated for the UK population, especially important when considering measures designed in the USA.

Using these criteria, the following measures were considered:

4.4.3.1 Carers' psychological health

The General Health Questionnaire (GHQ) is a 28 item questionnaire measuring psychiatric morbidity on a 4 point scale. A total possible score on this measure is 28, of which a score of five and above has been clinically recognised as an indication of psychological morbidity (Wade, 1992) and a higher score is indicative of increasing psychological morbidity. The GHQ was used in this study because it has been well validated and used in a large number of studies involving stroke carers (Anderson et al, 1995). This enables the results obtained in this study to be compared with other studies. Its main disadvantage is that a large component deals with physical symptoms, which many carers in this study may experience as a result of their age and not of their psychiatric morbidity.

The Hospital Anxiety and Depression Scale (HAD), a 13 item measure of depression and anxiety, was also considered for this study. Its main advantage is that it is simple to complete and it has no somatic items, which can be confused with the effects of old age. It has commonly been used as a psychological measure in oncology and has found to be appropriate for older people (Bowling, 1995). It has been used in stroke studies (Wade, Collen et al, 1992) and the British Stroke Research Group recommends the use of HAD (Wade, 1992). However, this measure was not used in this study because it was felt that more work was needed on its validity and reliability when this study commenced in 1995 (Bowling, 1991).

The Philadephia Geriatric Center Morale Scale (PGCMS) was also considered for this study, which looks at life satisfaction and self-esteem. It is a 17 item questionnaire which is recommended by the Working Group of the Royal College of Physicians (1992) as a measure to assess everyday subjective well-being. It is easy to complete and was developed for use specifically with elderly people with an optimal scale length allowing reliability without respondent fatigue. However, this measure was not considered as it would not have been appropriate for this carer sample, many of whom would be under the age of 65 years.

4.4.3.2 Carers' perceived health status

The Short-Form 36 (SF-36) was selected to measure carers' perceived health status as studies have showed its validity and reliability in detecting meaningful changes in health status (Brazier et al, 1992; Lyons et al, 1994; Garratt et al, 1994). Some problems have been identified in administrating the SF-36 to older people of 65-74 years. (Brazier et al, 1992; Hayes et al, 1995). Nevertheless, international studies seeking to validate the SF-36 may enable results to be compared across several countries and its measurement of several health domains may enable it to be a crude quality of life measure. The benefits of the SF-36 are its multi-dimensional evaluation of 9 facets of health; physical function, role limitation due to physical/emotional problems, social functioning, pain, general health perception, vitality, mental health and change in health. The SF-36 can also be combined to give a two dimensional physical and mental state score (PCS and MCS) using a weighted scoring system and for this study, the two health dimensional scoring system was employed, giving both a combined physical health score and a combined mental health score. It was felt that the use of this two dimension scoring would be less cumbersome than the 9 dimension score in the interpretation of the results (Ware et al, 1995). Whilst several population-based studies have established normative data sets for the UK population for the 9 health facets (Brazier et al, 1992), there are fewer UK studies using the combined two dimensional aggregation of physical and mental health (Jenkinson, 1998). Using the Jenkinson study (1998), the normative data for median mental and physical health score were 55.4 and 49.4 out of 100 respectively for the age group 55-64, where a higher score is indicative of a better health outcome.

4.4.3.3. Social functioning

The Frenchay Activities Index (FAI) was selected in this study as a measure of carers' social functioning. It has been tested for validity, reliability and sensitivity (Wade et al, 1985), used extensively in stroke studies to evaluate carers' social functioning since the onset of stroke (Dennis et al, 1997; Forster & Young, 1996) and is easy to administer. This instrument was initially designed to measure Instrumental Activities of Daily Living (I-ADL) in stroke patients (Holbrook & Skilbeck, 1983), a concept looking at more complex issues of domestic disabilities e.g. cooking and 'out of house' activities e.g. using public transport. The FAI contains 15 items relating to domestic chores, leisure/work and outdoor activities scored on a scale of zero to three. The total possible score on this measure is 45, in which a higher score indicates greater level of social activity. A validation study of this measure (Turnbull et al, 2000) showed that these scores could be classified into four groups; very active (median score = 31), active (median score = 30), fairly active (median score = 26) and not active (median score =13).

Nottingham Extended ADL Index (Nourri & Lincoln, 1987) was considered for this study, but was not selected for the following reasons: one, more studies are needed to show that this measure is both valid and reliable (Wade, 1992). Two, it is felt that this measure is not sensitive to patients' previous lifestyle and it assumes that survivors were engaged in all these items prior to the stroke e.g. "travel on public transport". Other items on this measure may be considered ambiguous and on one item "do your own shopping", a question can be raised about how one classifies the term 'your own shopping'.

4.4.3.4 Carer burden

Carer burden is an area in which there has been little development of a standardised measure and the Caregiver Strain Index (CSI) represents one of the few instruments available. The CSI (Robinson, 1983) is a 13 item measure with a 2 point scale, evaluating the level of carer burden as a result of caring for a person with a chronic illness. There is a possible total score of 13 where a higher score is indicative of greater carer burden. The CSI was selected as the main instrument to measure carer burden in this study as it has been used in some stroke-related studies (Macnarama et al, 1990; Greveson et al, 1991) and has been recommended by the British Stroke Research Group in the measurement of carer stress (Wade, 1992). The CSI was generally the best available quantitative measure in this area, but there were some disadvantages with using this measure; one was the lack of normative data corresponding to the scores and the second was the lack of validity testing. The Relative Stress Scale (Eagles et al, 1987) was considered for this study, but had similar problems of validity as the CSI and has only been used in one stroke carers' study (Draper et al, 1992).

4.4.4 Other measures

In addition to the above outcomes, sociodemographic data on carers' gender, age, social class, place of residence and kin relationship to the stroke survivor were recorded at baseline. The collection of this sociodemographic data would allow; a) comparison of both groups in terms of their characteristics, b) comparison of this carer sample with other studies.

4.4.5 Timing of measures

The following time points were selected in measuring carers' outcomes; baseline, three months, six months and twelve months. Whilst these points are standard and have been used in numerous studies (Gladman et al, 1992; Young & Forster, 1991), there was also a rationale for using these times. Baseline measures were employed as they provided information on carers' health status before intervention was implemented to assess the balance between the two groups. The three month assessment provided information on the immediate impact of health service intervention on carers. The six month measures reflected the effectiveness of the services in improving carers' quality of life, as most carers would have very minimal contact with health services, since the majority of stroke patients would have been discharged from secondary care. The 12 month assessment was a measure of the long term impact of the different service delivery on carers' quality of life. Whilst it would be ideal to have a longer follow-up period, the constraints of funds only permitted a one year period.

Table 4.1 shows the timing of each outcome measure used during the course of the year. Due to the content structure of some of these measures, it was only possible to use the SF-36 and the GHQ in all the assessments. It was not felt that the FAI was appropriate at 3 months, as some carers would have been visiting stroke survivors in hospital during the time span assessed, so making the score meaningless. However, unlike the survivor sample, carers were required to fill out the FAI at baseline to give their level of social functioning before the onset of the stroke, thereby providing a pre-stroke level as a useful comparison. It was felt that carers would not be suffering from confusion and so were able to give an accurate account. The CSI was not used at baseline because the burden of caring for a close person would not have been fully felt if the stroke patient was still in hospital.

Table 4.1: Timing of the different outcome measures over the one year period

Outcome measure	Baseline	3 months	6 months	12 months
SF-36	✓	✓	✓	✓
GHQ	✓	✓	✓	✓
FAI	✓	×	✓	✓
CSI	×	✓	✓	✓

4.4.6. Procedure

Once formal consent was obtained, carers were assessed at baseline using the Carers Baseline Assessment (see Appendix VIII). If possible, the researcher tried to do this baseline assessment within two weeks of the stroke patients' entry to the study. Carers were followed up at three, six and twelve months using the Carer Follow-up assessment (see Appendix IX) at approximately the same time as the stroke subjects. All these assessments comprised of a battery of outcome measures (see section 4.3.3) which was given to carers to complete. The researcher was on hand to help carers complete the assessment if they needed the support. In most cases, the assessments were conducted in the carers' own home, but in some cases, some preferred to go to the researcher base unit in Alderney Hospital, Poole. If both carers and stroke patients had assessment conducted at the same time and place, the researcher tried to ensure that the carers' assessment was carried out in a separate room.

Carers were free to withdraw from the study at any time and if they did, they were asked their main reason for withdrawing. Carers were also withdrawn if their associated stroke survivor had either died, had a new stroke or had decided to withdraw from the Dorset Stroke Study (see Chapter 3) for any other reason. The date and reasons for all withdrawals were recorded by the researcher. As this part of the UK has a very few people from ethnic backgrounds living in the region, it was anticipated that there would be few language problems related to ethnic background.

4.5. Data analysis (quantitative)

4.5.1. Preparation of data.

The data was prepared by sending the questionnaires to a data-punching agency for data entry, which was done due to the large volume of data collected during the three year period. The data was saved on a floppy disc and returned to the Medical Statistics Department (Southampton University) where it was then double-entered and checked for any missing data, nonsense data and errors in entry e.g. birth date.

4.5.2. Data analysis

A Statistical Package for the Social Sciences (SPSS) in Windows was used for the data analysis as it is the most comprehensible and robust software package for carrying out a whole range of statistical analysis, such as descriptive statistics, parametric and non-parametric tests, and regression analysis.

The following analyses were carried out on the data in the following categories:

1) Non-participation of eligible carers

a) Reasons for non-participation calculated in frequencies and percentages.

b) Breakdown of reasons for non-participation by carers' relationship in frequencies and percentages.

c) Comparison of stroke patients with and without a carer in frequencies and percentages.

d) Comparison of relationship status between carers and non-carers in frequencies and percentages.

2) Carers' sociodemographic details

a) Description of the certain sociodemographic details in frequencies and percentage (except age): gender, marital status, employment status, socio-economic status (SES), home ownership, car ownership, relationship status with stroke patient, living arrangements, age (given in means and standard deviation). This analysis was carried out to give the general characteristics of the sample group and enable a comparison of this sample with previous studies.

b) Comparison of the above sociodemographic details in frequencies and percentage (see 2 a) between the domiciliary and day hospital carers to ensure that both groups were well matched on these variables.

c) Details of carers who withdrew by six and 12 months by age, gender and relationship status in frequencies and percentages. This analysis was carried out to ensure that there was no obvious change in the distribution of these variables from baseline as a result of sample attrition.

3) Main outcome measures

a) Descriptive statistics showing the mean, median, standard deviation, interquartile range of all the carer outcome measures (the General Health Questionnaire, SF-36 mental health score, SF-36 physical health score, Frenchay Activities Index, Caregiver Strain Index) at baseline, three, six and 12 months (where applicable). These statistics were displayed both in tabular form and graphically using boxplots. Descriptive statistics were carried out to provide a distribution of scores for the various outcome measures.

b) The mean changes for each participant were calculated on each outcome measure using the following formula:

mean change = mean score at 6 months - mean score at baseline.

Mean changes provide information about treatment effects and enable the researcher to see how effective the intervention is. The period from baseline to six months was felt to represent the immediate impact of the intervention on the carers.

c) An independent t-test was carried out to calculate t scores, p values and confidence levels in comparing the mean changes over the six month for the following outcome measures (GHQ, SF-36 mental health, SF-36 physical health, FAI). This test was used to see if there were any statistical differences between the different groups at 6 months. An independent t test was used in this data analysis as the mean change scores were normally distributed and both groups (i.e. the domiciliary and the day hospital) did not contain the same sample of carers. It is justifiable that mean change scores for each of the outcome measures will be normally distributed. However, a frequency distribution of the mean changes for each outcome was carried out in which the results were presented graphically to check this was so.

d) Carers' mean change scores for each outcome measure were calculated for the period six month to 12 months using the following formula:

mean change = mean score at 12 months - mean score at 6 months.

The period six to 12 months was used as it was felt that it would be a good reflection of how well the effects of the intervention are sustained over a period of time once treatment has been stopped.

Once these scores were computed, the score distribution was checked to see if they were normally distributed (procedure described above in 3c). An independent t-test was then carried out to see if there were any statistical differences between the different groups at 6 months (procedure described above in 3d).

e) No in-depth analysis was carried out to evaluate mean change between baseline to three months, three to six months and baseline to 12 months. For the first two categories, it was originally thought that most stroke survivors would have finished their treatment by three months, so these two categories would have initially reflected the immediate impact of treatment and the subsequent short-term follow-up post-intervention. Unfortunately for many cases, treatment had not finished until six months, thereby making this analysis less relevant. Likewise, an analysis of the mean change between baseline and 12 months might have been interesting, but there would have been problems through larger losses to follow-up and the presentation of too much data.

f) One of my original questions was interested in investigating which survivors' variables may have an effect on carers' quality of life. A multiple regression analysis was considered in this study as a way of developing such a model, in which predictive variables for the main carer outcomes could be identified. However, there were many fundamental reasons why multiple regression was not used:

i) the study was designed to evaluate the impact on carers' quality of life of a domiciliary stroke service compared to a day hospital. To carry out regression analysis may require the collection of more information than was available in the study.

ii) regression analysis requires large sample sizes for the observations made to be considered reliable. The problem with small sample sizes is that any explanatory variables may have been identified by chance. As a guideline, Altman (1990) recommends that the number of variables, which should be explored in a regression analysis, is equal to n/10, where n is the sample size. Therefore, this study with a sample size of 60 would have only been able to use six exploratory variables in the regression.

g) Whilst randomisation should ensure that both the intervention and control groups are equally balanced with respect to any known and unknown confounding variables, there may be some imbalances between the two groups. A stratified analysis was used as a technique to control for confounding or imbalances in the analysis (Hennekens & Buring, 1987).

The first stage required a data inspection on the potential carer confounders (age, gender, socio-economic status, relationship status) and different survivor variables (level of functional ability, mobility, psychological morale, social functioning, mental health, physical health). A comparison was carried out between the two groups on the variables listed above at six and 12 months. A stratified analysis was then carried out if two conditions were met. The first was an imbalance of a particular variable between the domiciliary and day hospital group. The second was if there was a difference (clinical or statistical) between the two groups on a carer outcome.

In order to calculate the impact that a particular confounder/variables may have, it was necessary to calculate specific estimates separately. For example, if there was a clinical difference between the two groups in MCS score and there was imbalance of the social classes between the two groups, it was necessary to separate the MCS scores of the experimental groups into four separate categories: manual domiciliary carer, manual day hospital carer, non-manual domiciliary carer, non-manual day hospital carer. The scores from each category were then pooled together and presented in a 2x2 contingency table. Each score represented the trend for each category i.e improvement or deterioration in mental health.

4.6. Qualitative study

4.6.1 Qualitative design

The aim of qualitative research is to develop concepts that contribute to the understanding of social phenomena in natural settings. This is done by placing an emphasis on the values of the people being studied, using an inductive approach to data collection to generate them (Pope & Mays, 1995). Qualitative research represents a wide range of methods; each with their own assumptions and it is the nature of the research question that will influence what method is selected for a study. This qualitative study was concerned with exploring carers' perceptions of their social, physical and emotional difficulties in providing care to stroke survivors, their expectations towards the therapy services and their own understanding of the therapists role in the rehabilitation process.

The research interview was therefore selected as the main method in collecting qualitative data for the following reasons: one, interviews were the appropriate method of collecting data on perceptions and feelings (Britten, 1995). Interviews would not have been appropriate if the aims of the study were to understand how carers' behaviour interacted within their environment (Kvale, 1996). Two, interviews are flexible in that they can be used at any stage of the research process and hence it was possible to incorporate the interview within the structure of a quantitative study (Breakwell, 1995). Three, interviews provide a framework which allows information to be exchanged between the carers and the researcher and allows it to be collected in a systematic way. This is important as it maximises the chances of maintaining objectivity and achieving valid and reliable results (Breakwell, 1995).

Nevertheless, there are several drawbacks to the use of the research interview. One is the assumption that a person's response during interview is a true reflection of their perceptions (Smith, 1995), but it may be that the carers were not being truthful. Breakwell (1995) has identified this as the 'researcher effect', in which the characteristics of the researcher may influence the carers' willingness to either participate in the study or answer the questions accurately. Furthermore, the ethnic background of the researcher may have been an issue; the researcher was a male in his early thirties from an ethnic Chinese background whereas the majority of carers in this study were mainly middle-aged to elderly from a pre-dominantly white UK background. Whilst it would have been difficult to totally remove this effect, I tried to minimise this and ensure interviewer consistency by using myself as the principal researcher who conducted all the carers' interviews.

There was a choice of other qualitative methods, which were considered, but were not used in this study. One of these was observational methods, which involves the accurate watching and recording of behaviour as it occurs (Mays & Pope, 1995). Its main advantage is that much of the material produced occurs in 'real-life' situations with little interference from the researcher. However, observational methods were not considered for collection of qualitative data in this study for the following reasons: First, it would not address the question asked by the study. Second, the observational process would also be time consuming, labour-intensive with problems of external validity. Third, it would be both impractical and intrusive to carers as there would be little opportunity of observing carers and stroke survivors in their own home without infringing on their privacy. Fourth, observations would be extremely difficult to carry out for carers who did not live with the stroke survivor.

The other qualitative method considered was the use of focus groups. The aims of focus groups are to explore and clarify the views of a group of people in a way that would be less accessible to interview. Its advantages lie in its ability to tap into everyday forms of communication to obtain data which are sensitive to the cultural values of the group (Kitzinger, 1995). Whilst this method may have been useful in exploring carers' perceptions in the areas of interest, there were two main reasons why focus groups were not employed in this study. One, this study was interested in showing any qualitative change in the carers' perceptions of their role and the differential impact of the health service intervention over a six month period from the point they first entered the study. To assess this qualitative difference, it was felt that the qualitative interview was a more sensitive tool. Two, there would have been logistical problems in bringing all participating carers together such as co-ordinating their dates of availability, transportation and place of venue.

4.6.2. The research interview

The research interview provides a coherent framework of organising material in relation to specific research questions, in which the researcher is able to present a series of questions to carers with the aim of gathering data on them (Breakwell, 1995). This framework is known as the interview schedule and the type of schedule used determines the type of data collected. In research, there are three type of interview schedules available; structured, semi-structured and in-depth and this study selected the semi-structured interview as the most appropriate tool in exploring carers' perceptions. This type of interview consists of a series of loosely organised open-ended questions defining the area of interest (Britten, 1995). This provides carers with a focal point to the main interests of the researcher, but is also open enough to enable a detailed exploration of their views on the topic.

Thus, interviews provide an ideal mechanism for obtaining carers' subjective perceptions of a particular phenomenon and to explore areas where gaps have been identified. The semi-structured interview enables the researcher to empower carers by validating and publicising their views (Kvale, 1996). There is also a recognition that the format of the semi-structured interview facilitates better empathy with the carer, allows greater flexibility of material coverage and enables the interview to enter novel areas (Smith, 1995). Furthermore, as the semi-structured interview employs a framework of open questions to explore a specific topic which is used in each interview, the researcher is ensuring that the same topics are covered in each interview, which in turn increases the validity and reliability of the interview data (Breakwell, 1995).

I considered the use of both the structured and the in-depth interview, but these were not selected for the qualitative study. A structured interview involves the use of a fixed set of questions in which carers would be required to choose from a fixed set of responses. This is useful in the collection of socio-demographic information or in the administration of structured questionnaires (Britten, 1995), but the nature of data collected is limited due to this fixed format structure which would be unable to collect rich descriptive data and many may feel constrained by the choice limitation. Therefore, the structured interview would be inappropriate in trying to explore carers' perceptions in this study. An in-depth interview involves the coverage of one or two main issues in greater detail, in which further questions would be used to either clarify or probe for more details (Britten, 1995). The main advantages of this approach would be a potentially greater understanding of the topic under exploration, but in-depth interviews were not used in the qualitative study as it was felt they would not provide enough focus to understand the specific questions I was interested in tackling.

The research interview is an ideal tool to collect data on complex phenenoma, which can also have a beneficial effect on interviewees by providing them with an opportunity to discuss sensitive topics in a non-judgmental way. This may be because the techniques of the research interview, such as paraphrasing content and summarising, allows interviewees to clarify their thoughts (Coyle & Wright, 1996). However, there are ethical issues surrounding its use in sensitive issues such as in bereavement or caring for people with chronic illnesses, as by its very nature, it may restimulate painful memories amongst interviewees who may then become distressed and anxious (Coyle & Wright, 1996). For stroke carers in particular, the research interview may bring back memories of a lifestyle before the stroke and the thoughts of lost opportunities for the future. It would therefore be unethical for a researcher to conduct a research interview without being equipped to deal with any distress, which may result from it. I tried to address these ethical issues in the following ways. Firstly, I complied a list of the names, addresses and telephone numbers of various support organisations such as the Stroke Association and Carers Support, which I could supply to the carer if they requested this information. Secondly, I left a space of time at the end of the interview, 'a debriefing period' to provide carers with an opportunity to express any problems which were raised during the course of the interview.

4.6.3. Construction of the interview schedule

Smith (1995) has outlined the following issues that need to be considered before constructing an interview schedule. One, what are the main themes one is interested in? Two, what order will the themes be presented during the interview? Three, what questions will be used in relation to each theme? Four, what prompts or probes will the researcher use during the interview? In this study, I needed to construct an interview schedule for both the baseline and six month assessments. As I was interested in the qualitative changes that may occur from baseline to six months, it was important to set the themes around the baseline assessment. In devising these themes, my initial interest centred on exploring both carers' perceptions of caring for a stroke survivor and their attitudes towards the health services. I therefore identified five main themes for the baseline interview schedule using the following criteria: issues arising from both the stroke and general carers' literature, issues relating to the delivery of health care and areas that the researcher felt contributed to the greater understanding of carers' problems. These five themes are listed below, together with the rationale of why they were selected and presented in this order for the purpose of the schedule:

> *perception of health* - I felt it was important to tap into the health status of each carer as their level of health will affect their ability to provide care. Few studies looking at stroke carers have explored the subjective perceptions of how carers viewed their own health.
>
> *perception of the caring role* - the literature has looked at carers' coping behaviour in dealing with chronic illnesses. The aims of this theme were

to explore how carers came to terms with the stroke and their awareness of their future role.

perception of social support - many studies have indicated that the influence of social support from carers was an important determinant of the success of a stroke survivors' rehabilitation. Nevertheless, few studies have explored the support available for stroke carers. This theme was therefore geared to tap into who carers turned to for their emotional and physical support.

perception of service provision - previous studies on carers' perception of health services have centred on carers' satisfaction with in-patient services. This theme wanted to explore carers understanding of therapy and the roles of the different professionals in the rehabilitation process.

perception of the future - this theme focused on carers' perceptions of their future role as caregiver. There have been no studies in this area, though it was a theme that I thought was important.

Questions were then constructed around the nature of these themes, in which certain rules were employed. These have been described in numerous sources (Smith, 1995; Breakwell, 1995; Britten, 1995), but a summary of these rules are as follows; the use of simple sentences, the avoidance of leading questions or double negatives in a sentence, the use of neutral questions which are not value-laden, the avoidance of complex or jargon words. In constructing each question, it was important to remember that a large proportion of carers participating in this study were elderly, some with physical or cognitive impairments, so these questions were written in a language and a style which it was hoped they would be comfortable with. The first draft of the baseline interview schedule is displayed in Appendix X. I constructed around eight questions for the entire schedule with the aim that each question would take approximately three minutes to answer and it was anticipated that each interview schedule would take between 15 to 30 minutes to complete. This time period was initially felt to be adequate to obtain sufficient information on each theme and at the same time, not be too long so as to tire the older group of carers. The construction of the six month interview schedule used the same themes as the baseline schedule, but as I was interested in investigating any change in carers' perception during the corresponding six months, the questions were designed to illuminate this (see Appendix XI).

4.6.4. Recording the interview

Many workers have recommended the use of mechanical instruments to record each interview as it enables the contents of the interview to be fully recorded (Smith, 1995). Mechanical recording allows another person to check the accuracy of the any transcription, which in turn increases the data's reliability and robustness. There are two methods of mechanical recordings available; one is the use of video recording, which captures both the visual and verbal contents of an interview. This is useful if the nature of the research question entails looking at some aspect of non-verbal behaviour such as in a behavioural modification programme for people with learning disabilities. Unfortunately, the wealth of information produced using this medium is redundant if the researcher is only interested in the verbal content.

Therefore, in this study, I elected to use a tape recorder to capture only the verbal contents of the interview. Tape recorders are easy to use and provided the equipment is both adequate and reliable, the verbal contents of the interview should be fully recorded. This can then be transcribed at a later date ensuring as much detail as possible. Therefore, a tape recorder was used to record each interview in this study. This was mainly because I wanted a reliable method of recording the verbal contents of an interview as this study was interested in only the carers' perceptions. A small tape-recorder with an in-built microphone was purchased for this study as it was felt that many interviewees might feel intimated if a large machine with a plug-in microphone was placed in front of them.

An alternative to mechanical recording is to note down the verbal contents of the interview directly which has the advantage of being both cheap as no equipment needs to be purchased, and economical with time as no transcription of the interview is needed. However, there are several disadvantages; one, it is probable that not everything will be written down, thereby leaving the contents of the interview incomplete and open to accusations of interview bias (Breakwell, 1995). Furthermore, writing notes during the course of an interview is potentially distracting for both the interviewees, who could think that the interviewer was not paying them any attention, and the interviewer who may be unable to co-ordinate the interview and managed note taking at the same time. It was therefore decided that note taking would not an appropriate way to collect data.

4.6.5. Pilot study

The objectives of this pilot study were two-fold; one, to assess the suitability of both the baseline and six month interview schedules for this carer sample, to see what changes may be needed to the structure of the interview and to modify its structure accordingly. Two, to evaluate the face validity of the two schedules by checking that the interview questions were relevant to answering the study's question about carers' perceptions of caring and health services. If any part of the schedule was found to be irrelevant to the study questions, it would be then necessary to change and test them again. The pilot study was carried out in August 1996 with the recruitment of six carers; three of whom were used in the baseline pilot and the other three in the six month pilot. This baseline sample was selected from carers who had recently agreed to take part in the study and were awaiting their baseline assessments, whilst the six month sample was selected from participating carers who were currently approaching their six month assessments.

With both sets of carers, their verbal consent was first obtained before proceeding further after which, the researcher provided each carer with some verbal instruction about the aims of the pilot study with reassurances about confidentiality of information and asked if they objected to the interview being recorded. If the carers were happy to continue, the researcher placed a Dictaphone audio recorder between himself and the carer, and continued with the interview using the appropriate interview schedule constructed in section 4.3.3 with baseline and six month schedules being used for their appropriate groups. The 'Dictaphone' audio recorder was initially selected as the researcher felt it was small and so inconspicious to the carer, but at the same time would provide a clear recording of the whole interview. Unfortunately, a C-30 tape was the longest tape, which could be used on this machine. However, as each interview was expected to last for between 15 to 30 minutes, the use of this tape was considered adequate.

To evaluate the face validity of the questions in the interview schedule, I listened to carers' responses to each question and summarised the main points brought out by each carer (see Appendix XII). I then briefly analysed the content of these responses to check that the issues raised reflected the nature of the question. The findings from the pilot study suggested that carers experienced no problems with the format of the interview schedule or in understanding the contents of each question. Nevertheless, a number of issues were raised:

1) Carers understood the meaning of question 6 (baseline)/question 4 (6 months) on social support, but often distinguished different people as either sources of emotional or physical help.

2) Carers had difficulties with question 7 (baseline) as they considered going to the shops and going to the hospital as two separate situations requiring different strategies.

3) I wanted the question 8 (baseline) on service provision to deal with a wide range of issues such as perceptions of the services received, their understanding of therapy and definitions of a good service. Carers concentrated their answers on perceptions of services received.

Taking into account these issues and observations made by further consultation with academic colleagues that some alterations to the interview schedules were needed to improve clarity, the following changes were made:

1) A question was added about the carers' general health in the first section of the baseline schedule on health, together with the question on illnesses and disabilities.

2) Question 2, 3 and 9 (baseline) were rephrased as it was felt that the orginal questions were open to ambiguity.

3) Question 6 (baseline) was separated to give two questions; one on the sources of emotional support and the other on physical support.

4) Question 7 (baseline) was separated to give two questions; one on support for going to the shops and the other on support for going to the hospital.

5) More prompts about the understanding of therapy and definitions of a good service were added to question 8 (baseline) as a reminder to the researcher to cover these issues if they were not brought up by carers.

6) These changes highlighted above were made to the corresponding questions in the six month interview schedule. In addition, question 6 (6 month) on expectations was considered a bit ambiguous, so this question was rephrased to ask two questions, and the word 'therapy' was replaced by the term, physiotherapy and OT.

A final draft of the baseline and six month interview schedule, incorporating the above changes, were displayed in Appendix XIII and Appendix XIV respectively.

The pilot study was also used to test the quality of the tape-recording system and initial findings suggested no problems with the quality of the recordings. Nevertheless, the pilot study did establish that interviews ranged from 20 minutes to 40 minutes. Therefore, as it was necessary to record interviews longer than 30 minutes, the use of a C-90 tape was recommended for the main study and another advantage was that the whole of the interview could be recorded on one side without having to switch the tape over. To accommodate the use of a C-90 standard size audio tape, a standard 'Walkman' size tape recorder was purchased (Sanyo TRC-950C) and used for the main study instead of the 'Dictaphone'. This machine is small and compact, which gave good quality recordings when tested at this stage.

4.6.6. Procedure

The qualitative study commenced in October 1996 with the recruitment of two groups of carers; those who were already participating in the quantitative study and were approaching their six month assessments and those who had recently been identified and were happy to take part in the study from baseline. For the former group approaching their six month assessments, I explained that there was a qualitative study in which I was interested in asking them about issues on caring for stroke survivors and their views about the therapy service provided. Participation to this study would be on a voluntary basis and all information obtained would be confidential. For carers happy to participate in the qualitative study, I switched on the tape recorder, which was placed between the researcher and the carer, and began the interview using the amended six month interview schedule (see Appendix XIV).

The procedure for recruiting carers at baseline was similar to those recruited at six months except that the amended baseline schedule (see Appendix XIII) was used instead of the six month one. These carers were followed up at six months using the procedure described above except for those with associated stroke patient who had withdrawn from the Dorset Stroke Study due to either clinical or non-clinical reasons. Furthermore, carers who did not want to carry on with the study were asked their main reason for withdrawing. In both the baseline and six month assessments, each interview was carried out before the quantitative evaluation as I wanted to prevent any biased responses in the qualitative interview which may arise as a result of carers being first exposed to the structured questionnaire.

I played the role of an 'active listener' during the course of the interview. This involved reflecting on remarks made by the interviewees, probing and expanding on significant ideas relevant to the study question and finally giving a brief resume of interview content to allow carers to reflect on its accuracy. In addition, I had to use certain skills in order to keep the interview going smoothly. These have been listed by many qualitative workers (Britten, 1995) and included items such as making encouraging remarks and the use of eye contact when appropriate. When the final theme on the interview had been covered, I provided each participant with an opportunity to discuss any points they felt were not covered and to ask any questions after which the tape was switched off. It was not my role to give any medical advice and carers were recommended to contact their general practitioner or consultant physician on any medical matters. Nevertheless, I was prepared to answer questions related to the study and the nature of strokes. I also had a list of contact numbers prepared, such as various carer associations and voluntary organisations such as the Stroke Association, in case carers requested this information.

4.7. Data analysis (qualitative study)

4.7.1. Preparation of data

I decided to convert the verbal content of the interview into transcripts and sufficient funds were available for all the carer interviews (baseline and six months) to be transcribed. A transcript is defined as a piece of talk and as I was only interested in the content of the interviews and not its structure, the following rules were used for the transcription of each text; a) all verbal text on the tape was to be transcribed; b) missing data was defined as any piece of verbal text which could not be deciphered and was indicated as a series of dots i.e. **……** ; c) the transcriber was initially allowed to punctuate the text; d) no attempt was made to give a time period to any gaps in the text. Each transcript was saved on a floppy disc by the secretarial support and sent back to me and each transcript was given an appropriate identifying number, saved on the computer's hardware and converted into hard copies (paper). I went through each transcript whilst listening to the appropriate interview to check for reliability and any errors were then corrected on both the paper copy and the computer copies.

4.7.2. Analyses to be used

Both a content analysis and an in-depth thematic analysis were used in the analysis of the interview material. I used a content analysis as I was interested in identifying the issues which carers considered important in both providing care to the stroke survivor and their attitude to the therapy services. The benefit of this approach is its ability to reduce data to a manageable proportion, emphasising the main themes from the study which can be supplemented with selected quotations from the interviews to illustrate conclusions. In using this type of analysis, I assumed that the transcriptions were a true reflection of carers' perceptions of these issues and that it was the interview content that I wanted to analyse, not the temporal and social organisation of the text.

In addition to my content analysis, I decided to conduct an in-depth thematic analysis on a sub-set of my qualitative interview data. I used this approach as I was interested in exploring in greater depth the diversity of the range of issues related to quality of life and examining what impact the two different methods of stroke rehabilitation i.e. the domiciliary stroke team and the day hospital had on it.

4.7.3. Content analysis: Construction of the baseline and six month coding frame

Before content analysis of the interview data could start, it was necessary to construct a coding frame for the baseline and six month data. In order to construct this, I used the following procedure to generate the relevant categories, which would be used in the coding frames. I first assumed that each question on both my baseline (see Appendix XIII) and six month interview schedules (see Appendix XIV) represented a theme. I then labelled each theme by trying to summarise the nature of that question into a few words. I also felt that on closer inspection, some questions could be combined together to form a single theme as they were looking at a similar area. In the baseline interview schedules, I combined the responses from question 1 and 2 together to form a theme on "health problems" and I put in questions 8, 9 and 10 as part of the theme on "physical support". In the six month interview, I put together responses from question 5 and 6 as part of the theme on "physical support" and combined question 7 and 8 to form a theme on "expectations of service". The themes identified from the interview schedules at this stage are displayed in Table 4.2.

Table 4.2 shows that nine themes were identified from both the baseline and six months interviews schedules, from which there were seven shared themes in the following areas: role expectation, sources of physical support, sources of emotional support, service provision, difficulties in caring, impact on life. There were also themes, which were unique in both sets of interviews. Health problems and coping with the stroke only appears at baseline whereas at six months, the unique themes were 'expectation of therapy' and 'helpful support' in coping with the stroke. Once these themes had been identified, I then created files in a Word for Windows package for each theme listed in Table 4.2.

Table 4.2. Themes identified from the baseline and six month interview schedules

Baseline	Six months
Health problems	
	Helpful support in coping with stroke
Role expectation	Role expectation
Coming to terms with caring for stroke	
Impact of stroke	Impact of stroke
Difficulties in caring	Difficulties in caring
Source of physical support	Source of physical support
Source of emotional support	Source of emotional support
Service provision	Service provision
	Expectation of therapy
Future expectations of caring role	Future expectations of caring role

Generation of the categories was obtained as follows: I read through the full interview transcripts of the first four baseline (study number 5073, 5075, 5080, 5082) and six month interviews (study number 5033, 5036, 5042, 5045) to familiarise myself with the interview data. I used a total of eight interviews (four baseline and four six month interviews) as I felt that this amount of data would provide all the necessary categories needed for my coding frame to code all relevant material which may exist in the different interviews. Then, using the computer version of the transcript, I identified sections of each interview related to a particular theme and used the "cut" and "paste" functions to transfer the contents of each interview to the appropriate Windows file. Furthermore, there were some responses in the six month interview data which arose at the end of the interview sessions where carers were invited to add on any issues which they felt were important in caring for a stroke. These were initially categorised into a theme labelled "miscellaneous".

Once all the interview data from the eight transcripts had been “cut and paste” to their relevant themes, these data needed to be cleaned up. This was done by deleting the following type of sentences from the database; those with a simple yes/no response or general conversations not relevant to caring for a stroke eg. the weather. Once this task of cleaning all the theme data files was complete, the process of creating categories could begin. This was done by taking each sentence from a theme and condensing this piece of text into a description of a few words which outlined the inherent nature of the text (Weber, 1990). Whilst most of the text could be classified into categories, some of these categories needed to be sub-divided into sub-categories, especially if a category was broad-based in nature and had a wide range of different responses. This process of condensation was systematically carried out on all the sentences from the baseline and six month themes. I then used a Microsoft Excel spreadsheet to construct my coding frame, using the first column to input the name of the theme, the second column to input the names of the corresponding categories and the third to input any associated sub-categories. Version I of these coding frames are displayed in Appendix XV and XVI (baseline and six months respectively).

On inspecting the contents of both coding frames, I decided to combine the categories (and sub-categories) from the baseline and six month coding frame. I had two reasons for doing this: the first was that the themes in both the baseline and six months interviews covered similar areas (see Table 4.2). The second was that both baseline and six month coding frames shared many of the same categories. I therefore felt that combining the baseline and six month categories would give a more comprehensive list for the coding frame and so cover a wider range of situations. I also felt that the format of the coding frame (version I) was not user-friendly. To remedy this situation, I merged my original three columns into one column, with a group of categories being headed by a theme. To help aid the coding process for a future date, I numbered each of the categories in ascending order, except for those which had sub-categories associated with them, where I numbered these sub-categories instead. To distinguish these sub-categories from the main categories, I aligned them to the right of the column. These alterations were executed on the Excel spreadsheet to produce version II of the baseline (see Appendix XVII) and six month coding frames (see Appendix XVIII).

4.7.4. Testing the reliability of the coding frame

Once the two coding frames were constructed, I wanted to ensure that these frames had some degree of reliability so different raters would code the same material with the same categories. It is difficult to define the degree of reliability required as this is dependent on how and who will be using the coding frames as well as the nature of the research methodology. I accept that a high degree of inter-rater agreement (≈ 70%) is essential if other people were going to use the frames to code the interview data. However, as I would be solely responsible for the subsequent coding of the remaining baseline and six month interview data, I felt that a moderate level of concordance between the different raters was sufficient in demonstrating reliability of the coding frames in this case. Furthermore, the nature of this study was interested in the qualitative dimensions of carers' experiences, so the issue of coding frame reliability was seen as ensuring some level of inter-rater concordance and not a way of obtaining high inter-rater agreements.

Testing the reliability of the coding frame was necessary to allow the researcher to identify ambiguous categories that raters found difficult to use. To do this, the transcripts were distributed to myself (as the main researcher) and a group of two independent raters using coding frame (version II) as the instrument for coding. These responses were then analysed for inter-rater reliability and modifications to the coding frame were made resulting from the analyses of these responses. The modified coding frame was then given to two different raters and myself to code the same piece of text and these responses were analysed. It was anticipated that two sets of raters would be sufficient in testing and amending the coding frame to ensure sufficient reliability, but if it was felt that this was not achieved, the above procedure would be repeated until it was.

My sample of independent raters were university researchers involved in health-related research, but who were independent from the study. I felt it was important to use people who were familiar with research methods in health, but I did not feel that experience in content analysis and any forms of qualitative analysis was essential for this task. Each rater was given the following materials; Version II of the baseline (see Appendix XVII) and six month coding frame (see Appendix XVIII), four transcripts consisting of two baseline interviews (study number 5073, 5075) and two six month interviews (study number 5036, 5042) and an instruction sheet outlining the background of the study and the methodology to be used in doing the reliability testing (see Appendix XIX). Raters were asked to read through both the coding frames and the transcripts, after which they were instructed to go through all the sentence of the different transcripts and to code each one using the categories on the coding frame. Whilst most of the interview data should be codable using the coding frames, there were two types of data which may not fit into these categories. The first were sentences involving simple yes/no responses or referring to general conversations not related to caring for a stroke and I asked these responses to be coded as "n/a" - not applicable. The second revolved around text which could not be coded using the coding frame and in these cases, I asked raters to put a question mark (?) next to the relevant text and to suggest a category if possible.

The relevant material was given to two raters and myself who coded the interview transcripts using version II of the coding frame (see Appendix XX - Example of coded transcript) and this was known as phase 1. The codes given for each sentence were inputted into an Excel spreadsheet to show raters' responses (see Appendix XXI) and an analysis of these coding responses suggested seven possible combinations in which the three raters could code the same material:

For sentences that were coded, the following four combinations were possible:

1. FA: full agreement - main researcher agrees with both independent raters on the coding of the sentence.

2. PA: partial agreement - main researcher agrees with one of the independent raters on the coding of the sentence.

3. IRA: independent rater agreement - both independent raters, but not the main researcher, agree with each other on the coding of the sentence.

4. NA: no agreement among any of the raters on the coding of the sentence.

For sentences that were not coded, the following three combinations were possible:

1. U (FA): uncodable: full agreement - main researcher agrees with both independent raters that material is uncodable

2. U (PA): uncodable: partial agreement - main researcher agrees with one of the independent raters that material is uncodable.

3. U (IRA): uncodable: independent rater agreement - both independent raters, but not the main researcher, agree with each other that material is uncodable.

Each sentence was analysed for inter-rater reliability (see Appendix XXII) using one of these combinations and the total number for each combination is displayed in Table 4.3. This shows that in all the transcripts, a high proportion of coded sentences had either full rater (FA) or partial rater agreement (PA), ranging from 69% to 80%. Unfortunately, the proportion of material classified as uncodable was also high, ranging from 51% to 65% of the number of sentences in the transcript. This suggested that some further work was needed to clarify the instructions for using the coding frame. Furthermore, whilst the level of non-agreement (NA) and independent rater agreement (IRA) was low, it was still necessary to look at sentences which were classified in this way as these represented ambiguities within the coding frame itself. Hence, some difficulty was found in distinguishing the different types of categories between the themes on "impact" and "difficulties" of caring.

Table 4.3. Inter-rater agreement for Phase 1

	5073	5075	5036	5042
No of sentences in transcript	*71*	*41*	*55*	*37*
FA (%)	2 (7)	6 (30)	3 (16)	7 (47)
PA (%)	18 (62)	10 (50)	11 (58)	5 (33)
IRA (%)	1 (3)	1 (5)	1 (5)	1 (7)
NA (%)	8 (28)	3 (15)	4 (21)	2 (13)
Total no. coded	*29*	*20*	*19*	*15*
% of text coded	*41%*	*49%*	*35%*	*41%*
U(FA)	30	12	23	16
U(PA)	4	7	9	4
U(IRA)	8	2	4	2
Total no. uncoded	*43*	*21*	*36*	*22*
% of text uncoded	*61%*	*51%*	*65%*	*59%*

Furthermore, the two raters commented that they would have found it easier if;

a) the categories regarding emotional support and physical support were put in one theme
b) if the number sequencing for both coding frame were the same.

Taking into account the comments of the two raters and their coding responses (see Appendix XXI), I made the following changes to both sets of coding frames.

Major organisational changes for both coding frames included:
i) combining the sub-categories from the themes on "difficulties of caring" and "the impact of caring" into one major theme "difficulties/impact". This major theme was then sub-divided into three categories; "physical/behavioural issues", "psychological issues" and "social issues" from which the sub-categories were allocated to the most appropriate category. These categories were chosen to reflect my interest on the impact that stroke has on quality of life issues.
ii) using the categories on support structures to code both sources of emotional and physical support and including instructions on what is meant by physical and emotional support. In addition, the category "person mentioned, but not identified" was included to this theme from the recommendations of the raters.

iii) renumbering both baseline and six month coding frames to ensure that categories in both frames corresponded with each other as much as possible. Therefore, categories/sub-categories had the same numbers from 9 to 61.

Minor categorical changes for the baseline coding frame included:

i) the introduction of an additional category in the theme "health problems" to account for those with no chronic illness.

ii) the merging of the categories "acceptance" and "fatalism" to form a single category "acceptance".

iii) the addition of the category "some improvement" to the theme "future expectations".

Minor categorical changes for the six month coding frame included:

i) providing examples and a brief explanation for the theme "support structure" and defining what is meant by physical and emotional support.

ii) re-ordering the categories for the theme "service provision" to take into account the order they appear in the interview.

The above changes were made to Version II of the coding frame to give Version III (see Appendix XXIII for the baseline frame and Appendix XXIV for the 6 month one). Phase 2 was carried out in which the reliability of version III was tested using the procedure described earlier. As in phase 1, two different raters and myself were given the relevant material (including the same transcripts), but this time using version III to code the interview data. These codes were then inputted into an Excel spreadsheet to give raters' responses (see Appendix XXV) and each sentence was analysed for level of inter-rater reliability (see Appendix XXVI). The total number for each combination was calculated and displayed in Table 4.4.

Table 4.4. Inter-rater agreement for Phase 2

	5073	5075	5036	5042
No of sentences in transcript	*71*	*41*	*55*	*37*
FA (%)	13 (34)	6 (23)	12 (46)	7 (30)
PA (%)	18 (46)	14 (54)	8 (31)	14 (58)
IRA (%)	6 (15)	2 (8)	3 (12)	2 (8)
NA (%)	2 (5)	4 (15)	3 (12)	1 (4)
Total no. coded	*39*	*26*	*26*	*24*
% of text coded	*55%*	*63%*	*47%*	*65%*
U(FA)	23	7	16	10
U(PA)	6	6	12	3
U(IRA)	3	2	1	0
Total no. uncoded	*32*	*15*	*29*	*13*
% of text uncoded	*45%*	*37%*	*53%*	*35%*

A comparison of Table 4.4 with Table 4.3 illustrated the following points:

1) Improvement in achieving full inter-rater agreement from phase 1 to phase 2 in two transcripts (5073 and 5036).

2) Improvement in achieving partial inter-rater agreement from phase 1 to phase 2 in three transcripts (5075 and 5042).

3) A reduction in the level of non-agreement from phase 1 to phase 2 in three transcripts (5073, 5036, 5042) with no change in the level of non-agreement in one transcript (5075).

4) An increase in the level of independent rater agreement from phase 1 to phase 2 in all transcripts.

5) The number of items which were uncoded fell in all transcripts from phase 1 to phase 2.

The main points from this comparison showed that the combined figures for full agreement (FA) and partial agreement (PA) was greater at phase 2 than at phase 1, suggesting an improvement in the reliability of the coding frame (version III). A decrease in the proportion of items not coded would indicate that the new set of instructions and codes revised for phase 2 made it easier for most raters to give codes to each sentence. However, the increased level in independent rater agreement (IRA) at phase 2 compared to phase 1 may indicate some ambiguity in some of the categories in the coding frame. To deal with this problem, I decided to look at the sentences, which were rated IRA and see the responses of the independent raters to those sentences.

Overall, I felt these results demonstrated that version III of the coding frame had improved reliability when compared to version II. Some questions may be raised by the increase of independent rater agreement, which suggest some ambiguity with a few of the categories in the coding frame. I felt that version III of the coding frame was sufficiently reliable to enable myself (as the sole person responsible) to code the remaining baseline and six month interview data. I accept that more work would be needed if I was planning to use other researchers in the coding of the interview data.

4.7.5. Frequency analysis

The second stage of the analytic process involved doing a frequency count of the different categories and sub-categories from the baseline and six month coding frames. Before I could carry this out, I needed to code all my baseline and six month interview data using the appropriate coding frame. Once this task was complete, I could then do a frequency count of the different categories and sub-categories. The frequency of a particular category represented its level of importance, in which a larger number of ticks indicated greater importance compared to categories with fewer ticks.

To carry out this task, I created a tick chart in a Microsoft Excel programme, in which the study number of each interview was listed on the horizontal axis and the different themes (grouped by their relevant sections) were listed in the vertical axis (see Appendix XXVII). Then, using the coding frame to code every sentence from each interview, I inputted the number '1' (representing a tick) in the relevant box on the theme that was mentioned by that carer. Any categories/sub-category repeated by the same carer, were not inputted again. Sections that could not be coded were re-examined and given a new category name using the condensation process described in section 4.6.3. These categories were then incorporated into the coding frame, which were not numbered, were used in subsequent analysis of the interview data. This process was continued until the whole interview was analysed for its content and was repeated for all interviews. The frequency data for the whole sample was sub-divided by the groups the carers were randomised to, as I was also interested in the impact of the two different methods of service delivery (see Appendix XXVIII). Both sets of frequency data were then used to carry out a series of exploratory analysis (see section 4.4.6).

4.7.6. Analysis using frequency data.

My basic research questions were how stroke carers coped in their role and the impact of the different service deliveries on this role. Therefore, by relating the categories/sub-categories to their original theme, I could use the frequency data (obtained in section 4.4.5) to explore the following themes at baseline and at six months:

- identifying the advantages and disadvantages of the different methods of service delivery.
- initial expectations of what therapy would achieve (baseline only).
- understanding of the role of therapists in stroke rehabilitation.
- future expectation of the caring role.
- identifying the main difficulties faced by stroke carers.
- the role played as the main stroke carer.
- the mechanisms that carers used in coming to terms with the stroke.

- establishing the level of social support for each carer by examining who they could go to for their emotional and physical support.

I then carried out the following types of the analyses on the frequency data of the above themes:

1) Baseline and six month data for the above themes were compared to see if any qualitative differences existed between them.

2) Themes from paired baseline and six month data (ie. carers who had data available for both time periods) were examined for any changes which might have taken place over the time period.

3) Themes were compared with the quantitative variables (carer and patient), in which I was particularly interested in the following issues

    i) the relationship between the level of social support and carers' quality of life and carer burden.

    ii) the relationship between carers' socio-economic status and their degree of understanding of the role of therapist in stroke rehabilitation.

4.8. Issues of Reliability and Validity

4.8.1. Reliability

The term "reliability" has its roots in quantitative methodology to describe the consistency in which the same experimental design will produce the same result on subsequent occasions, using different samples (Davis, 1995). Within qualitative research, there has been some debate about the appropriateness of this concept. Some would argue that reliability is a redundant concept in qualitative research as knowledge is replicated through understanding different viewpoints of the same situation, not by reproducing consistent accounts (Banister et al, 1995). Others suggest that reliability is an important concept in collecting data in a consistent manner, assuming that the "social world" has stable properties which can be replicated (Silverman, 1993). In this study, I took the latter approach and defined reliability as the ability to ensure that data were collected in a consistent and systematic way. To increase the reliability of the qualitative data, I took the following steps; one, I conducted a pilot study in order to test the interview schedule to ensure that each item on the schedule was not producing a diverse range of answers. Two, the problems of interviewer reliability was reduced to the use of a single researcher co-ordinator as the only person conducting each of the interviews. Three, I ensure that inter-reliability checks on the coding of the answers to the open-ended questions were carried out, using three research-based colleagues from the Health Care Research Unit, Southampton University (see section 4.4.2).

4.8.2. Validity

There is now a general acceptance that validity is an important concept in ensuring rigour in qualitative research (Silverman, 1993; Mason, 1996) and within a qualitative framework, validity has a broader remit encompassing the degree to which the method used investigates what it is intended to investigate (Kvale, 1996). To reduce the sources of bias which reduce the validity of the results, validity check needs to be built into the research process to ensure the credibility, plausibility and trustworthiness of the findings (Kvale, 1996). In this study, I sought to increase the validity of my findings by justifying the use of my methodology and by tightening some of my methodological procedures. I originally decided to use a qualitative approach as I felt that this would be the most appropriate design in exploring an area where there was very little previous work.

In using qualitative methodology, I elected to use the research interview as the most appropriate qualitative tool in collecting data on carers' attitudes and perceptions. I needed to make the assumption that all carers' accounts would be honest. To ensure that I had recorded all accounts accurately during the interview, I played the role of an active listener, regularly feeding back pieces of oral text to the interviewee to ensure that I had interpreted the verbal context correctly. I checked that the contents of the two interview schedules would produce the answers I was interested in by carrying out a pilot study to check for face validity and making any necessary alterations arising from it (see section 4.3.5). Finally, I carried out frequency counts on category occurrences (see section 4.4.2) which would enable me to identify which themes were more relevant to the study questions.

4.9 In-depth thematic analysis

4.9.1. Sample selection

A sub-set of 15 transcripts was selected for the in-depth thematic analysis. As I was interested in how caring for a person with stroke may have affected quality of life, I decided to use only six month interviews as I felt this would provide the time necessary for carers to adapt to their role. The following criteria were used in determining which interviews were selected.

My main research question was concerned with the impact that the two different methods of stroke rehabilitation may have had on carers' quality of life. Hence, I decided to select 7 carers from one group and 8 from the other. It was not important which group had the extra carer, the decision being determined by level of independence (see criterion on disability). Gender was my next important criteria. Here, I wanted to balance two main issues, namely that: one, caring has been traditionally seen as a predominantly female activity and two, the lack of studies looking at caring from a male perspective. Hence, from each intervention group of seven, I decided to select four females and three males. I felt that this balance would reflect the fact that the majority of carers were female, but at the same time, provide enough material to look at caring and quality of life from a male perspective and address the paucity of research in this area.

My third criterion in the carers' selection was the level of disability in their associated survivors (as measured by their six month BAI score). This factor was selected as previous studies have shown a relationship between carers' psychological health and the levels of survivors' disability. Patient disability was sub-divided into three categories: severe (BAI score < 10), moderate (BAI score 10-14) and mild (BAI score 15-19). Ideally, I tried to ensure that there were at least two interviews per disability category except for people who were fully independent. In addition, I wanted to select one carer who was supporting a survivor who was fully independent (BAI score of 20), who could come from either the domiciliary or day hospital group. Within this framework, the following two factors were used in deciding which interviews to select; these were the carers' relationship with the survivors and social class. I wanted to ensure that I got a wide range of carers from different social classes. Likewise, I wanted to ensure that I got a wide range of different carer relationships, but also ensuring that numerically, the proportions were roughly in line with those of my main carer sample.

Using this procedure, I identified the following 15 carers from a pool of 31 carers who had transcribed six month interviews (see Appendix XXIX). The details of these 15 carers are presented in Table 4.5.

Table 4.5: Carers used in thematic analysis: Details of survivors' disability level, social economic status (SES) and relationship status

Domiciliary **Gender**	**Study no**	**Survivor 6 mth BAI**	**S.E.S.**	**Relationship**
Female	5036	20	III (non-manual)	Wife
	5114	17	IV	Wife
	5116	15	I	Daughter-in-law
	5084	8	II	Wife
	5066	4	III (manual)	Wife
Male	5102	19	II	Son
	5057	11	II	Brother
	5053	4	II	Husband
Day Hospital **Gender**	**Study no**	**Survivor 6 mth BAI**	**S.E.S.**	**Relationship**
Female	5100	19	II	Daughter
	5123	16	IV	Wife
	5033	12	II	Wife
	5096	7	III (non-manual)	Wife
Male	5052	16	II	Husband
	5126	12	I	Husband
	5131	8	IV	Husband

4.9.2. Methodology

An in-depth thematic analysis was carried out on a purposive sample of 15 interviews. To carry out this analysis, I read through the 15 transcripts to identify any emerging themes in two of the following areas: one, issues related to how caring for a person with a stroke may have affected the carer's quality of life; two, the qualitative differences that the two methods of stroke service rehabilitation had on carers' quality of life.

CHAPTER 5: RESULTS (QUANTITATIVE STUDY)

5.1 Chapter overview

This section aims to present the main findings from the quantitative study, looking at the characteristics of the recruited carer sample and an analysis of carers' main quality of life outcomes from baseline to six months and from six months to one year.

5.2 Carer recruitment

A sample of 140 stroke survivors participated in the Dorset Stroke Study. 32 of these patients did not have a carer and two withdrew from the study before contact could be established. This left 106 eligible carers to contact. A total of 60 carers were eventually recruited into the study whilst a further 46 refused to participate, giving a participation rate of 57%.

5.3 Comparison of participating and non-participating carers

5.3.1 Comparison of stroke participants with and without a carer.

Table 5.1 shows that the majority of survivors without a carer (26/32) were living alone before their stroke compared to survivors with a named carer (28/106) and that most survivors with carers (67/106) were living with their spouse before their admission into hospital.

Table 5.1: Comparison of pre-admission accommodation status of survivors with and without carers

Accommodation status	Patients with carer	Patients without carer	Total
Lives with spouse	67	1	68
Lives alone	28	26	54
Lives with non-relative	7	1	8
Lives with relatives	3	4	7
Missing	1	0	1
	106	32	138

5.3.2 Reasons for carer non-participation in study.

Table 5.2. shows the two main reasons identified for carer non-participation were either their unwillingness to participate in the study (31%) or the inability of the researcher to make contact with them (54%).

Table 5.2: Reasons for eligible carers not participating in study

Reasons for non-participation	**Number (%)**
Number of non-participating eligible carers	46
Unable to contact carer (after 3 telephone attempts)	25 (54)
Unwilling to participate in study	14 (31)
Unable to give consent	1 (2)
Patient doesn't want carer to be contacted	6 (13)

A further breakdown of the data, looking at the reason cited with relationship status are presented in Table 5.3. This shows that spouses made up the largest proportion of those unwilling to participate, whereas sons and daughters were the largest group whom the researcher was unable to contact. Stroke survivors were more likely to refuse consent for the researcher to approach the carer if that person was either a friend or a distant relative. Finally, there was one carer who was unable to give consent and so was not entered into the study. The survivor identified this person as his main carer, although the reality of the situation was that the survivor was supporting this person.

Table 5.3: Breakdown of figures illustrating carer relationship with reason for non-participation.

Relationship status	Unwilling to participate	unable to make carer contact	unable to give consent	Consent refused by patient	Total
Wife	8	4	1		13
Daughter		10			10
Husband	4	2		1	7
Son		5		1	6
step-daughter	1				1
daughter-in-law		1			1
son-in-law				1	1
Niece				1	1
other relatives		2			2
Friends	1	1		2	4
	14	25	1	6	46

5.3.3 Comparison of relationship status between participating and non-participating carers

Table 5.4 shows that the majority of participating carers consisted of close kin such as wives (45%), husbands (26%), daughters (18%) and same sex life partner (2%). Spouses and daughters also made up the majority of non-participating carers (65%) though the proportion was smaller than in the participating group. There was little representation of other relatives in the participating group and the presence of other male relatives was small with only the presence of one brother (2%) and one son (2%). There was a higher proportion of sons (13%) and friends (9%) in the non-participating group.

Table 5.4: The relationship of stroke patient between participating and non-participating carers.

Relationship status of carer	Participating carer Number (%)	Non-participating carer Number (%)	Participation rate by relationship (%)
Wife	27 (45)	13 (28)	27/40 (68)
Husband	16 (26)	7 (15)	16/23 (70)
Daughter	11(18)	10 (22)	11/21 (52)
Son	1 (2)	6 (13)	1/7 (14)
Daughter-in-law	3 (5)	1 (2)	3/4 (75)
Brother	1 (2)	0	1/1 (100)
life partner (same sex)	1 (2)	0	1/1 (100)
step-daughter	0	1 (2)	
Niece	0	1 (2)	
son-in-law	0	1 (2)	
other relatives (not specified)	0	2 (4)	
Friends	0	4 (10)	
Total	60	46	

5.4 Description of participating carers

5.4.1 Relationship status with stroke survivor

Details of the relationship status with the stroke survivor (also displayed in Table 5.4 above) shows that the majority of the study sample consisted of spouses or partners with 27 (45%) wives, 16 (26%) husbands and one (2%) same sex partner. Close female relatives made up the next largest group with 11 (18%) daughters and three (5%) daughter in laws. Other male relatives made up the smallest group with one (2%) brother and one (2%) son.

An analysis of the living status of stroke survivors with their spouses is presented in Table 5.5. This shows that the presence or absence of a spouse determined who would take on the main role as carer. Spouses/partners took on the responsibility of being the main carer if they were living with the stroke survivor. Likewise, if a stroke survivor did not have a spouse living with them, close family members, such as their adult children, took on the responsibility of being their main carer.

Table 5.5: Relationship of stroke survivors' living status with their spouses

	Living status of stroke survivors	
	Living with spouse*	Not living with spouse*
Spouse* as main carer	44	0
Other family member as main carer	0	16
Total	44	16

* Spouse also includes partners of long term relationships

A more detailed analysis of the different relations who took on the responsibility of caring is displayed in Table 5.6. This table shows that male stroke survivors (28/32) were more likely to be supported by their spouses or partners than female survivors (16/29). For female stroke survivors, husbands (16/29) were still the largest group of carers, but many adult children (12/29) such as daughters and daughters-in-law also took on the role as the main carer.

Table 5.6. The relationship status of stroke carers by gender.

	Gender of stroke survivor		
Carers relationship to survivor	Male	Female	
Spouse	27	16	43
same sex partner	1	0	1
Daughter	2	9	11
daughter in law	0	3	3
Son	1	0	1
Sibling	0	1	1
	31	29	60

5.4.2. Description of carers' socio-demographic details

Table 5.7 shows that the carer sample consisted of 41 (68%) females and 19 (32%) males and had a mean age of 67.9 years (s.d: 12.4 years). 50 (83%) participants were married, two (3%) were widowed, four (7%) were divorced and four (7%) were never married. The majority, 46 (76%) were retired, four (7%) were working full-time, four (7%) were working part-time, four (7%) were unemployed and two (3.3%) were keeping house.

Using social class coding from the Household Survey Classification, 39 (65%) carers fell into social classes I to III non-manual and were classified as non-manual. 21 (35%) carers fell into social class III manual to V and were classified as the manual group. Further details on home ownership showed that 52 (87%) were homeowners compared to five (8%) who rented their property. One (2%) person had other arrangements, whilst two (3%) did not give any information on this topic. Finally, 38 (63%) carers had access to car compared to 21 (35%) who did not.

Table 5.7: Comparison of carers' baseline socio-demographic characteristics

	Domiciliary	Day hospital	Combined Total
Number of participants	31	29	60
Mean age (s.d.)	67.2 (14.8)	68.6 (9.5)	67.9 (12.5)
Median age (IQR)	74.9 (63.1 – 78.7)	70.2 (62.9 – 75.1)	72.6 (62.9-77.8)
Gender			
Women (%)	22 (71)	19 (66)	41 (68)
Men (%)	9 (29)	10 (34)	19 (32)
Marital status			
Married (%)	24 (77)	26 (90)	50 (83)
Divorced (%)	3 (10)	1 (3.3)	4 (7)
never married (%)	3 (10)	1 (3.3)	4 (7)
Widowed (%)	1 (3)	1 (3.3)	2 (3)
Employment status			
Retired (%)	22 (72)	24 (83)	46 (76)
Working full-time (%)	2 (6)	2 (7)	4 (7)
Working part-time (%)	2 (6)	2 (7)	4 (7)
Unemployed (%)	4 (13)	0	4 (7)
keeping house (%)	1 (3)	1 (3)	2 (3)
Social class			
I (%)	1 (3)	1 (3)	2 (3)
II (%)	11(36)	10 (35)	21 (35)
III non-manual (%)	9 (29)	7 (24)	16 (27)
III manual (%)	6 (19)	7 (24)	13 (22)
IV (%)	3 (10)	4 (14)	7 (12)
V (%)	1 (3)	0	1 (1)
Ownership			
Home owner	27 (87)	25 (86)	52 (87)
Car owner	21 (68)	17 (59)	38 (63)
Relationship to patient			
Wife (%)	14 (45)	13 (45)	27 (45)
Husband (%)	7 (23)	9 (31)	16 (26)
Daughter (%)	6 (20)	5 (18)	11 (18)
Daughter-in-law (%)	2 (6)	1 (3)	3 (5)
Brother (%)	1 (3)	0	1 (2)
life partner (%)	0	1 (3)	1 (2)
son (%)	1 (3)	0	1 (2)
Living arrangements			
Living with spouse (%)	26 (84)	27 (93)	53 (88)
lives with other relative (%)	4 (13)	1 (3.5)	5 (8)
living alone (%)	1 (3)	0	1 (2)
lives with other non-relative (%)	0	1 (3.5)	1 (2)

5.4.3 Comparison of the domiciliary and day hospital groups at baseline

This section compares the baseline characteristics to ensure that the randomisation of carers via association with stroke survivor did produce an equal balance of the potential confounders between the two groups. Table 5.7 shows that both groups had a similar age and gender distribution and were well balanced with respect to social class, their relationship status with the survivor, employment status, home and car ownership. There was a slight imbalance in living arrangements of the groups, with a greater proportion of day hospital carers living with spouse (27/29) compared to domiciliary carers (26/31). Overall, the two groups were well balanced with respect to most of the important socio-demographic variables.

5.4.4 Comparison of associated stroke survivors' variables between groups at baseline

This section compares the baseline characteristics to ensure that the randomisation of carers via association with stroke survivor did produce an equal balance of the potential confounders between the two groups. Table 5.8 shows that both domiciliary and day hospital groups were evenly balanced on stroke survivor variables such as the levels of disability (measured by both the BAI and the RMI) and their psychological status (measured by the PCGMS). The mean ages of the associated stroke survivors were 78.1 years (s.d. 6.2 years) for the domiciliary group and 77.4 years (s.d. 6.5 years) for the day hospital group, indicating that the age distributions for both groups were also evenly balanced.

Median scores of 13.0 – 14.0 for the BAI and of 6.5 - 7.0 for the RMI indicated that both groups were caring for survivors with a moderate level of disability and immobility. Median scores of 13.0 for both groups on the PGCMS indicated that patients at baseline had a reasonable level of morale.

Table 5.8: Comparison of stroke survivor variables between the two groups at baseline.

Assessment	Intervention group	Median	IQR	range
BAI	Domiciliary	14.0	8.0 - 17.0	6.0 - 19.0
	day hospital	13.0	10.0 - 17.0	4.0 - 19.0
RMI	Domiciliary	6.5	3.0 - 8.0	0 - 12.0
	day hospital	7.0	2.5 - 9.5	1.0 - 13.0
PGCMS	Domiciliary	13.0	10.0 - 15.0	7.0 - 17.0
	day hospital	13.0	11.0 - 15.0	3.0 -17.0

5.4.5 Follow-up of participating carers.

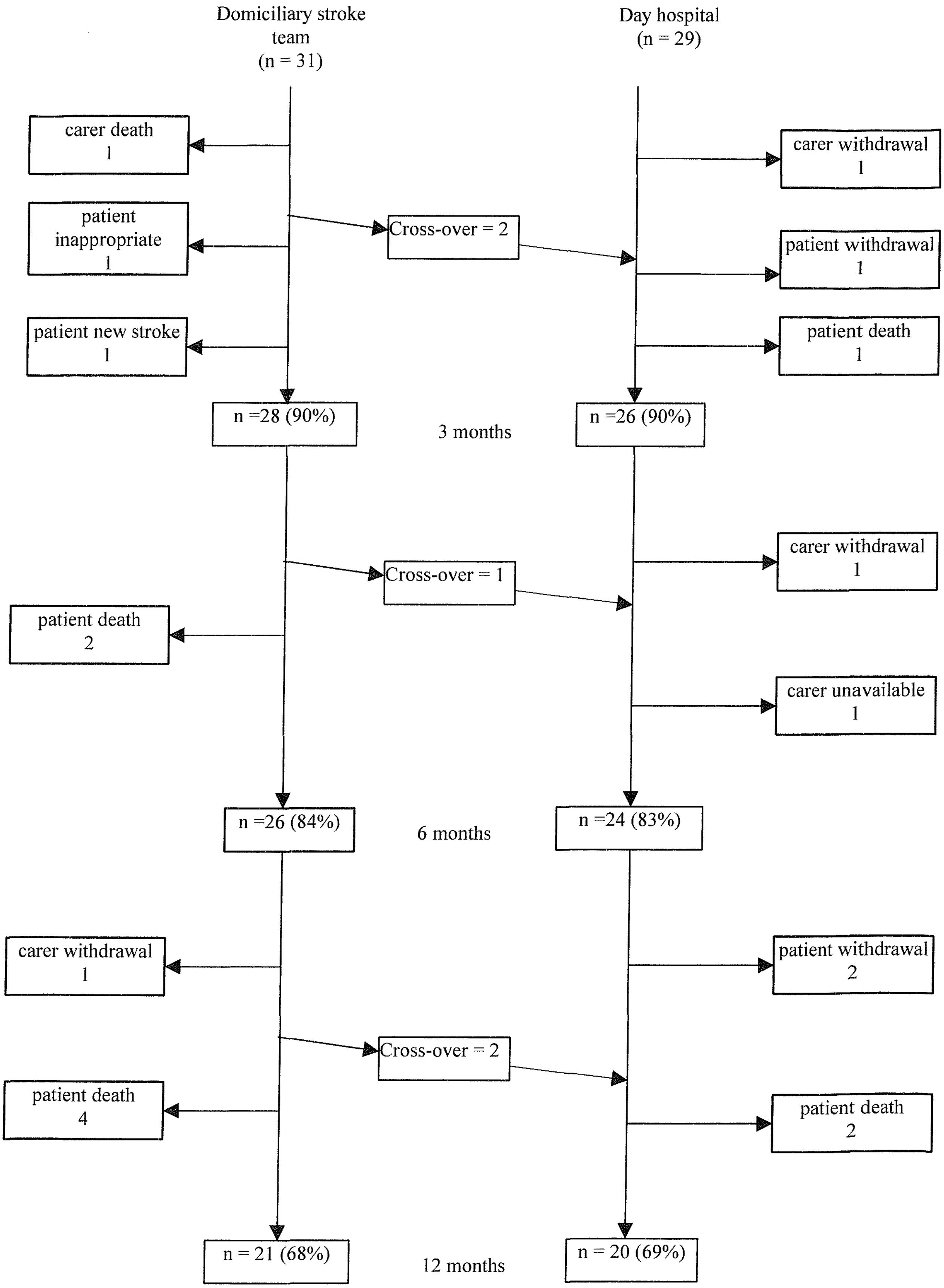
Figure 5.1 shows the numbers of carers followed up at three, six and 12 months and the details of withdrawals or cross-overs. These withdrawals included carers who died or did not want to continue participating in the study before the 12 month follow-up. Furthermore, a carer was also withdrawn if their associated survivor withdrew or died before the final assessment (12 months). Whilst withdrawals were not included in the follow-up analysis, the data from cross-over participants were analysed on 'an intention to treat' basis.

28/31 and 26/29 carers from the domiciliary and day hospital group were followed up respectively at three months, 26/31 and 24/29 carers respectively at six months and 21/31 and 20/29 carers respectively at 12 months. The follow-up rate for both domiciliary and day hospital were the same for all the assessment points with a 68-69% follow-up at 12 months.

A breakdown of the main reasons for carer withdrawal during the one year assessment period was given as; 9 from survivors' death, three from survivors' withdrawal, one from survivor extended CVA, three from carers' withdrawal, one from carer's death. Furthermore, one survivor was wrongly diagnosed as stroke and was subsequently withdrawn and one carer was unavailable during six months assessment and was not included in the analysis.

During the course of the 12 month follow-up of an intervention study, some survivors switched treatments period either through personal choice or other logistical difficulties. A total of three stroke survivors were transferred from the domiciliary to day hospital group for the following reasons. The first was transferred to day hospital as no domiciliary physiotherapy cover was available during the stroke survivor's entry to the study. The second was transferred due to deterioration of the stroke survivor's medical condition, which prompted ward staff to refer to day hospital on discharge and so over-ride the initial randomisation choice. The third was transferred to day hospital due to both carer and survivor preference after an initial six months of domiciliary care. Nevertheless, for the purpose of the analysis, these carers were analysed on 'an intention to treat' basis.

Figure 5.1: Diagram to illustrate withdrawals and cross-overs of carers at 3, 6 and 12 months



5.5 Carer outcomes: Baseline to six month analysis

Analysis of the data was carried out from baseline to six months to investigate the impact of the different service deliveries on carers' quality of life. In this section, only carers with data at 0, 3 and 6 months were included in the statistical analyses. It was initially planned that the UK normative scores obtained from Jenkinson (1998) would be used in the analyses of the MCS and PCS results. However, this was not possible as the sample in this study had a median age of 72.6 years (IQR: 62.9 – 77.8 years) and no normative data were available for people over 65 in the UK study. Hence, normative data for the 65-75 year age band of the US population were used instead (Ware et al, 1994). Some questions may be raised by the suitability of using US population data, but whilst health differences do exist between the US and the UK populations, there are also many similarities shared by both countries. To ensure suitability of the US normative data, a comparison of the PCS and MCS scores of both UK and US populations by age bands (18-65 years) was carried out. This found that both sets of data were very similar, so an assumption was made that the UK population would also have similar MCS and PCS scores in the 65-75 year age band. Therefore, the MCS and PCS scores used were 55.7 (25% & 75% IQ: 48.3, 59.1) and 46.2 (25% & 75% IQ: 35.0, 52.5) respectively.

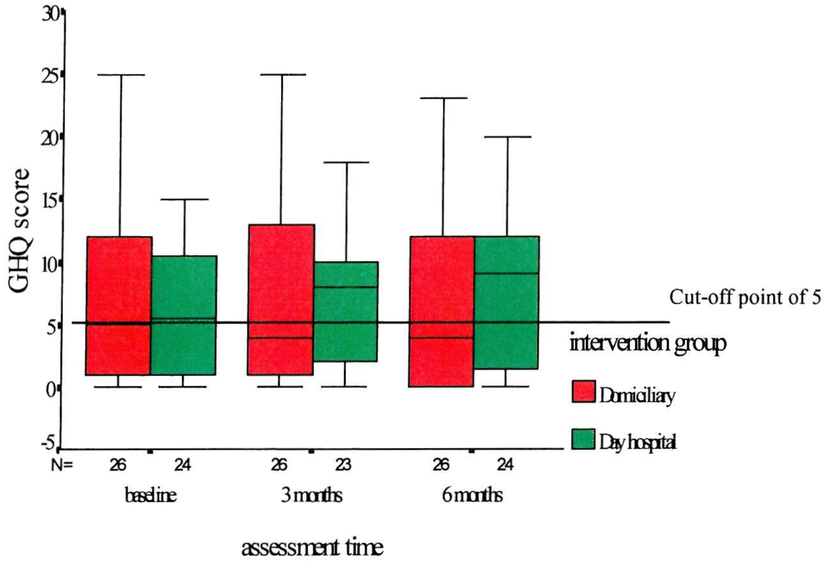
5.5.1 Psychological health

Psychological health was measured using two standardised measures; the General Health Questionnaire (GHQ) and the Mental Component Summary (MCS) of the SF-36. Both measures look at different aspects of this domain. The GHQ is a measure of psychological morbidity, often used as a screening tool in which a score of 5 or above is an indication of psychological morbidity in the sample population (Wade, 1992). The MCS is a measure of mental health, which has population data that can be used to evaluate the outcome of health interventions.

5.5.1.1. General Health Questionnaire

An analysis was carried out looking at the distribution of GHQ scores at baseline, three and six months by intervention groups and these results are presented in Figure 5.2. The cut-off point of 5 is also illustrated in this figure. These show median scores of 5.0 for the domiciliary group (IQR, 1.0 to 12.5; range, 0 to 25.0) and 5.5 for the day hospital group (IQR; 1.0 to 10.8; range 0 to 15.0), indicating that the majority of carers in both groups showed signs of psychological morbidity at baseline (see Figure 5.2). Fewer domiciliary carers showed psychological morbidity at 3 months (median 4.0; IQR 1.0 to 13.5; range 0 to 25) and 6 months (median 4.0; IQR 0 to 12.8; range 0 to 23.0). On the other hand, the proportions of day hospital carers with psychological morbidity had increased at both 3 months (median 8.0; IQR 1.0 to 11.0; range 0 to 18) and 6 months (median 9.0; IQR 1.3 to 12.0; range 0 to 20).

Figure 5.2. Boxplot to show distribution of GHQ scores by intervention group at baseline, three and six months.



Nevertheless, an analysis of the mean changes from baseline to six months (see Table 5.9 below) found no change in the GHQ scores of domiciliary carers, but an increase in the day hospital group. These results suggested that at six months, the domiciliary carers had a better outcome on psychological morbidity than the day hospital one with a mean difference of 2.3 (95% C.I.; -5.6, 1.0), though this difference was not statistically significant (t = -1.39, p = 0.172).

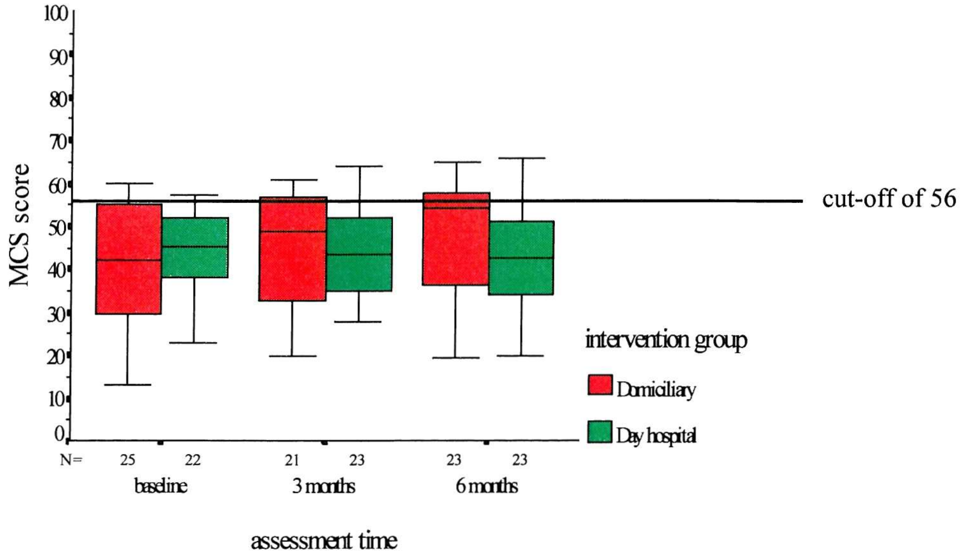
Table 5.9: GHQ mean and mean change scores from baseline to six months

	Dom: x (SD)	DH: x (SD)	Md (95%CI)	t	P
GHQ (0-6 mths)					
0 mth (group scores)	7.0 (7.4)	5.9 (4.9)			
3 mth (group scores)	7.4 (7.7)	7.0 (5.1)			
6 mth (group scores)	6.8 (8.0)	7.9 (5.9)			
Mean change 0 →6 mth	-0.3 (6.4)	2.0 (5.0)	**-2.3 (-5.6, 1.0)**	**-1.39**	**0.172**
n =	26	24			

5.5.1.2 Mental Component Summary (MCS) score

An analysis was carried out looking at the distribution of MCS scores at baseline, three and six months by intervention groups. These results are presented in Figure 5.3, in which the median MCS score of 54 points is illustrated in this figure. These show both domiciliary (median 42.1; IQR 29.4 to 55.3; range 13.2 to 60.2) and day hospital (median 43.7; IQR 36.1 to 52.3; range 22.9 to 57.5) carers had poorer mental health at baseline than a comparable section of the normal population (see Figure 5.3). However at three months, more domiciliary carers had better mental health (median 49.1; IQR 32.5 to 57.8; range 19.6 to 61.0) than at baseline. By six months, the majority of domiciliary carers had mental health status comparable to the normative population (median 54.1; IQR 36.0 to 58.3; range 19.2 to 65.1). In contrast, the proportion of day hospital carers with poor mental health did not change either at three months (median 43.6; IQR 34.4 to 52.8; range 27.8 to 63.9) or at six months (median 42.4; IQR 32.9 to 51.9; range 20.0 to 65.2).

Figure 5.3. Boxplot to show distribution of MCS scores by intervention group at baseline, three and six months.



These findings were supported by the mean change scores (see Table 5.10) which showed an improvement in the MCS scores of carers in the domiciliary group, but with minimal change in carers from the day hospital group. This finding has clinical significance as it showed that the domiciliary group had a better outcome on mental health status than the day hospital group with a mean difference of 6.0 points (95% C.I., -1.2 to 13.3) between the groups. A further analysis showed this difference was not statistically significant (t = 1.68, p = 0.101).

Table 5.10: MCS mean and mean change scores from baseline to six months

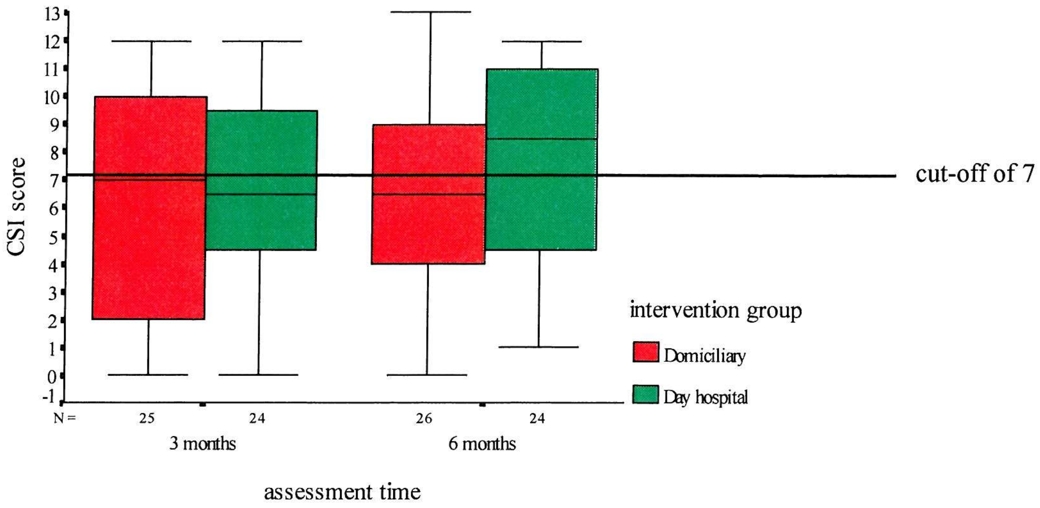
	Dom: x (SD)	DH: x (SD)	md (95%CI)	t	P
0 mth (group scores)	42.1 (14.4)	43.3 (1.6)			
3 mth (group scores)	45.3 (13.6)	44.0 (10.3)			
6 mth (group scores)	47.5 (13.0)	43.1 (11.7)			
Mean change 0 → 6 mth	5.2 (11.8)	-0.8 (12.3)	6.0 (-1.2, 13.3)	1.68	0.101
n =	23	22			

5.5.2 Carer burden

Carer burden was measured by the Caregiver Strain Index (CSI) in which a score of seven or more (out of 13) indicated greater carer burden (Robinson, 1983). An analysis was carried out, looking at the distribution of CSI scores at 3 and 6 months by intervention groups. These results are presented in Figure 5.4, in which the cut-off score of 7 is also illustrated.

The CSI was not used at baseline, but 3 month data indicated that both the domiciliary (median 7.0, IQR 2.0 to 10.0; range 0 to 12.0) and day hospital (median 6.5, IQR 4.3 to 9.8; range 0 to 12.0) carers showed high levels of carer burden (see Figure 5.4). At six months, domiciliary carers (median 6.5, IQR 3.8 to 9.3; range 0 to 13.0) had lower levels of carer burden than their day hospital counterparts (median 8.5, IQR 4.3 to 11.0; range 1.0 to 12.0). Nevertheless, a large proportion of carers in both the domiciliary and day hospital arm showed signs of carer burden at six months (see Figure 5.4).

Figure 5.4. Boxplot to show distribution of CSI scores by intervention group at three and six months.



An analysis of the mean change scores showed that there was no change in the burden level of domiciliary carers, whereas there was a slight deterioration with the day hospital group (see Table 5.11). Clinically, this suggested that the domiciliary group was better at maintaining the level of carer burden than the day hospital, but no statistical significance was found (t=-1.60, p=0.115).

Table 5.11: CSI mean and mean change scores from three to six months

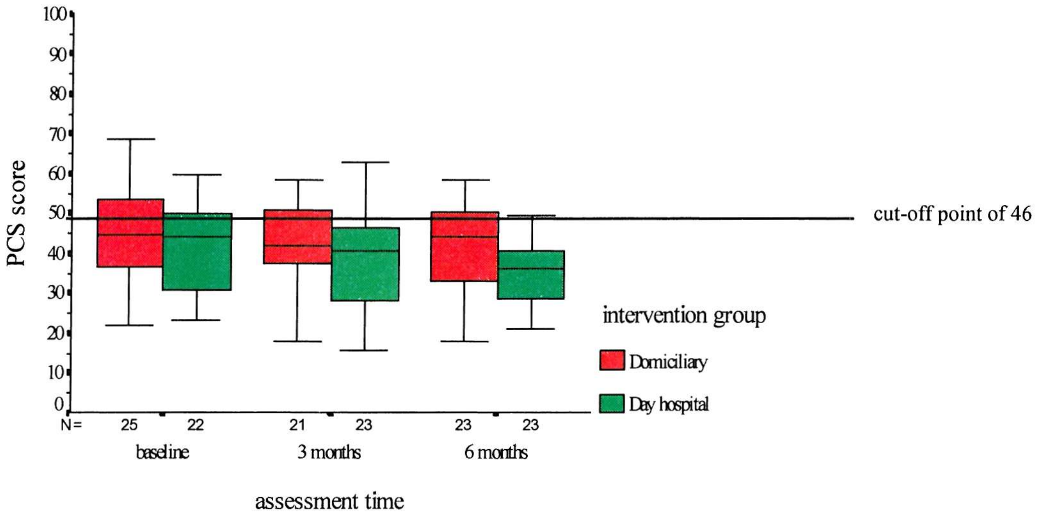
	Dom: x (SD)	DH: x (SD)	m.d (95%CI)	t	p
3 mth (group scores)	6.5 (4.1)	6.5 (3.2)			
6 mth (group scores)	6.2 (3.7)	7.5 (3.7)			
Mean change 3 → 6 m	-0.1 (2.7)	1.0 (2.2)	**-1.1 (-2.5, 0.3)**	**-1.60**	0.115
n =	25	24			

5.5.3 Physical health

Carers' physical health was measured by the Physical Component Summary (PCS) of the SF-36, in which a score of 46 (out of 100) was indicative of the standard physical health of the general population (aged 65-74 years) and a score greater than 46 indicated better physical health (Ware et al, 1994). Figure 5.5 shows the distribution of MCS scores at baseline and six months by intervention groups, in which the median PCS score of 46 is also illustrated.

The baseline median scores of 44.8 (IQR 35.1 to 54.4; range 21.8 to 68.4) and 44.3 (IQR 29.8 to 50.3; range 23.3 to 59.7) for the domiciliary and day hospital groups respectively, showed that both groups of carers had comparable physical health with the general population. The physical health status of the domiciliary carers at 3 months (median 42.1; IQR 36.6 to 51.3; range 18.0 to 58.7) and at 6 months (median 44.0; IQR 31.7 to 51.1; range 18.0 to 58.3) remained the same as at baseline. The physical health of day hospital carers showed a downward trend with more carers having poorer health status at 3 months (median 40.6; IQR 27.0 to 47.6; range 16.0 to 62.7) and at 6 months (median 36.1; IQR 28.0 to 41.3; range 21.3 to 49.3). Clinically, these results showed that domiciliary carers had similar physical health status as the general population, but day hospital carers had poorer physical health at three and six months.

Figure 5.5. Boxplot to show distribution of PCS scores by intervention group at baseline, three and six months.



Both the domiciliary and the day hospital groups showed deterioration in their physical health at six months, but with the deterioration in physical health being greater in the day hospital group (see Table 5.12). Clinically, this result suggested that the domiciliary stroke team may have been better than the day hospital at reducing the negative impact on carers' physical health (mean difference 3.9; 95% CI, -2.0, 9.8). Further analysis showed this difference was not statistically significant (t=1.32, p=0.193).

Table 5.12: PCS mean and mean change scores from baseline to six months

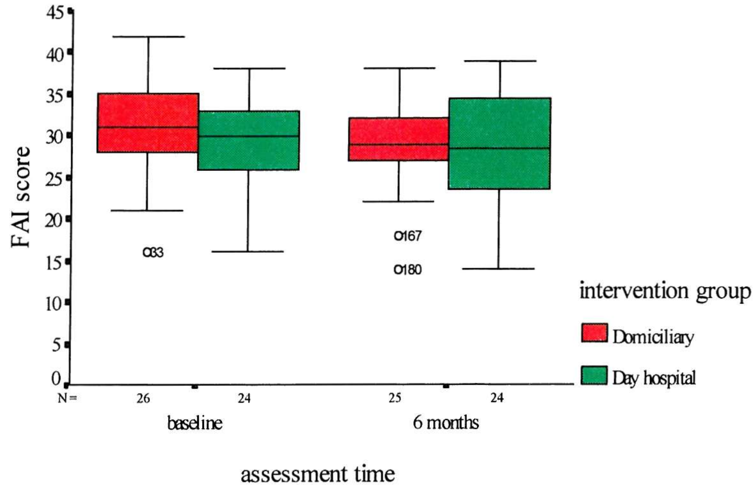
	Dom: x (SD)	**DH: x (SD)**	**md (95%CI)**	**t**	**p**
0 mth (group scores)	44.2 (12.9)	41.5 (11.9)			
3 mth (group scores)	42.1 (11.9)	37.6 (12.6)			
6 mth (group scores)	41.6 (12.2)	35.0 (8.6)			
Mean change 0 → 6 mth	-3.2 (8.9)	-7.1 (10.7)	3.9 (-2.0, 9.8)	1.32	0.193
N =	23	22			

5.5.4 Social functioning

Social functioning was measured using the Frenchay Activity Index (FAI), in which a higher score indicates higher social functioning. A recent validation study (Turnbull et al, 2000) has classified the scores into four distinct groups of social activity levels; very active = 31, active = 30, fairly active = 26; not active =13).

Figure 5.6 shows that both domiciliary carers (median 31.0; IQR 27.5 to 35.0; range 16.0 to 42.0) and day hospital carers (30.0; IQR; 26.0 to 33.0; range; 16.0 to 38.0) had active levels of social functioning at baseline. At six months, both sets of carers in the domiciliary (median 29.0; IQR 26.5 to 32.5; range 14.0 to 38) and day hospital (median 28.5; IQR 23.3 to 34.8; range; 14.0 to 39.0) groups had similar levels of social functioning as at baseline.

Figure 5.6. Boxplot to show distribution of FAI scores by intervention group at baseline, three and six months.



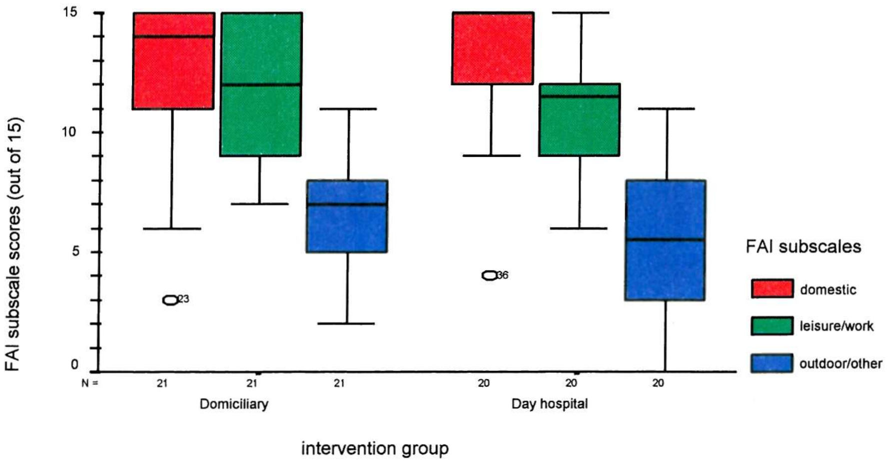
An analysis of the mean change scores from baseline to six months reflected the minimal impact that the different service deliveries had on carers' social functioning (see Table 5.13). Both groups showed a marginal decrease in social functioning. Whilst carers in the day hospital group did have a marginally better outcome than the domiciliary one, a mean difference of 0.3 (95% CI, -3.7 to 3.0) suggested that this result was neither clinically nor statistically significant (t = -0.20, p=0.841).

Table 5.13: FAI mean and mean change scores from baseline to six months

	Dom: x (SD)	DH: x (SD)	md (95%CI)	t	p
0 mth (group scores)	30.7 (5.7)	29.4 (5.0)			
3 mth (group scores)					
6 mth (group scores)	28.7 (5.6)	27.9 (7.7)			
Mean change 0 → 6 mth	-1.9 (6.4)	-1.6 (5.3)	-0.3 (-3.7, 3.0)	-0.20	0.841
N =	25	24			

These results suggest that carers had active levels of social functioning, which were unaffected by the impact of stroke. A further analysis was carried out in which the baseline FAI scores for both the domiciliary and day hospital carers were subdivided into the following three sub-scales; domestic, leisure/work and outdoor/other. These showed differences in the distribution of these sub-scale scores at baseline (see Figure 5.7). Both domiciliary and day hospital carers had the highest scores for domestic activity, but also had high scores for leisure/work work activities. Both groups of carers had low scores for outdoor functioning when compared to their scores on domestic activity.

Figure 5.7. Boxplot to show distribution of domestic, leisure and outdoor scores by intervention group at baseline.



The mean score changes from baseline to six months were analysed by intervention group with respect to the three sub-scales. These found no significant difference between domiciliary and day hospital carers' with respect to the change in their levels of domestic, leisure or outdoor functioning (see Table 5.7). Nevertheless, both groups of carers saw a 1-2 point increase in their levels of domestic activity, with a 1-2 point decrease in their levels of leisure and outdoor functioning.

Table 5.14: FAI subscales - mean and mean change scores from baseline to six months

Subscale	Time of assessment	Dom: x (SD)	DH: x (SD)	md (95%CI)	t	p
Domestic	0 mth (group scores)	12.0 (3.8)	12.5 (3.7)			
	3 mth (group scores)					
	6 mth (group scores)	13.8 (2.3)	13.3 (2.4)			
	Mean change 0 → 6 mth	1.8 (4.2)	0.8 (3.3)	-0.9 (-1.2, 3.1)	0.8	0.385
	N =	26	24			
Leisure/work	0 mth (group scores)	12.1 (2.9)	10.9 (2.6)			
	3 mth (group scores)					
	6 mth (group scores)	10.0 (3.2)	9.8 (4.4)			
	Mean change 0 → 6 mth	-1.9 (3.0)	-1.1 (3.5)	-0.8 (-2.7, 1.0)	-0.9	0.371
	N =	25	24			
Outdoor/leisure	0 mth (group scores)	6.6 (2.7)	6.0 (3.2)			
	3 mth (group scores)					
	6 mth (group scores)	4.9 (2.1)	4.8 (3.5)			
	Mean change 0 → 6 mth	-1.9 (2.3)	-1.3 (2.4)	-0.6 (-1.9, 0.8)	-0.8	0.406
	N =	26	24			

5.5.5 Comparison of the domiciliary and day hospital groups at six months

An analysis was carried out comparing the differences between the participating carers (used in the analysis above) and those who withdrew at six months on the main carer variables. Table 5.15 shows that at six months, both the domiciliary and day hospital groups were evenly balanced on the major socio-demographic variables of age and gender (female; 18/26 vs. 17/24 respectively). Generally, the majority of participating carers were either spouses or the adult children of the stroke survivors, but the domiciliary group had a larger proportion of carers in the other category (3/26) than the day hospital group (1/24). There was a slight imbalance on socio-economic status, with a higher proportion of carers from manual backgrounds in the day hospital group (10/24) than in the domiciliary group (8/26). There was also an age imbalance between participating carers (mean age 65.9 years) and withdrawers (mean age 73.8 years) in the domiciliary group, but further comparison of this imbalance was not possible due to the small numbers of withdrawers in both groups (n=5 for the domiciliary and n=5 for the day hospital).

Table 5.15. Comparison of the participating and withdrawing carers by intervention group at six months.

	Domiciliary		Day hospital	
	Participating	**Withdrawals**	**Participating**	**Withdrawals**
Number of carers	26	5	24	5
Mean age (s.d.)	65.9 (15.2)	73.8 (12.0)	68.5 (9.5)	69.2 (10.1)
Gender				
Female (%)	18 (69%)	4 (80%)	17 (71%)	2 (40%)
Male (%)	8 (31%)	1 (20%)	7 (29%)	3 (60%)
SES				
Non-manual (%)	18 (69%)	3 (60%)	14 (58%)	4 (80%)
Manual (%)	8 (31%)	2 (40%)	10 (42%)	1 (20%)
Relationship status				
Spouse (%)	17 (65%)	4 (80%)	19 (79%)	3 (60%)
adult children (%)	6 (23%)	1 (20%)	4 (17%)	1 (20%)
Others (%)	3 (12%)	0	1 (4%)	1 (20%)

As highlighted in Table 5.15, there was a slight social class imbalance between the two groups of carers at six months. To evaluate if this social class imbalance had any impact on carers' outcome, a stratified analysis was carried out looking at stratification of non-manual to manual classes on carers' mental health scores (see Table 5.16). These results showed that 'non-manual' carers, irrespectively of intervention group, improved in their mental health whilst 'manual' carers showed a deterioration. This result suggested that social class may be a predictor of change in carers' mental health.

Table 5.16: Stratified analysis to evaluate the impact of socio-economic status on the mean change in carers' MCS score (0 to 6 mths).

	Domiciliary (n=24)	Day hospital (n=21)
Non-manual (I - III n-m)	4.7 (0.5, 15.8)	3.3 (-8.6, 5.2)
Manual (III m – V)	-3.8 (-7.6, 0.3)	-11.5 (-13.2, 13.9)

5.5.6 Comparison of associated stroke survivors' variables between the groups at six months

The stroke literature has suggested that the certain survivor variables such as level of functional disability, mobility and social activities may have an impact on carers' quality of life. A comparison was therefore carried out between the domiciliary and day hospital group on the main psychological, physical and social outcomes of associated stroke survivors (see Table 5.17). This shows that both domiciliary and day hospital groups were evenly balanced on most of the different variables. These included physical health (median PCS score: 34.9 and 33.8 respectively), mobility (median RMI score: 9.0 and 8.0 respectively) and psychological status (median MCS score: 53.8 and 56.9; median PGCMS: 11 and 11 respectively). The mean ages of the associated stroke survivors were 77.3 years (sd. 6.2 years) for the domiciliary group and 77.4 years (sd. 6.5 years) for the day hospital group, indicating that the age distributions for both groups were also evenly balanced.

In summary, both groups were caring for stroke survivors with moderate levels of disability and immobility, poor physical health, inactive levels of social functioning and moderate psychological health. When the 6 month survivor sample was compared with the original baseline sample (see Table 5.6), the remaining sample i.e. those who had not withdrawn from the study, were less physically disabled on

Activities on Daily Living (ADL), more mobile and had poorer psychological health.

The domiciliary survivors had slightly better levels of social functioning than the day hospital ones (median FAI score of 12.5 compared with 8 respectively), but clinically both groups still had poor levels of social activity. There was also a 1.5 point difference in BAI score between both groups, with domiciliary stroke patients showing less disability. This difference could been important so a stratified analysis was carried out to investigate to evaluate the impact of this variable.

Table 5.17: Comparison of stroke survivor variables between groups at six months

Assessment	Intervention group	Median	IQR	Range
Barthel	Domiciliary	17.0	9.8 – 19.0	0 - 20.0
	day hospital	15.5	11.8 – 18.0	7.0 - 20.0
RMI	Domiciliary	9.0	4.5 – 13.0	0 - 15.0
	day hospital	8.0	5.5 – 10.5	3.0 - 15.0
PGCMS	Domiciliary	11.0	7.0 – 14.0	3.0 - 17.0
	day hospital	11.0	7.3 – 12.8	1.0 -16.0
FAI	Domiciliary	12.5	3.0 – 24.3	0 – 39.0
	day hospital	8.0	3.8 – 15.5	0 –36.0
MCS	Domiciliary	53.8	44.0 –61.7	30.2 - 66.8
	day hospital	56.9	50.0 – 62.9	22.9 - 75.5
PCS	Domiciliary	34.9	25.5 – 45.9	9.4 - 56.0
	day hospital	33.8	26.6 – 39.6	14.8 - 56.2

As highlighted in the Table 5.17, a 1.5 point difference in BAI score was found between survivors in the domiciliary and day hospital groups. To evaluate if this difference in functional ability had any impact on carers' outcome, a stratified analysis was carried out looking at stratification of BAI scores <15 and 15-20 (see Table 5.18). These results showed that survivors' functional ability (as measured by the BAI) might have confounded the effect, as improvement in MCS scores was seen in the BAI (15-20) group, but not the BAI (<15) one.

Table 5.18: Stratified analysis to evaluate the impact of stroke survivors' functional disability on the mean change in carers' MCS score.

	Domiciliary median (95% C.I)	Day hospital median (95% C.I)
BAI score (< 14)	1.2 (-1.4, 5.2)	-0.2 (-11.2, 4.9)
BAI score (15-20)	2.6 (-3.5, 17.5)	4.3 (-12.5, 8.5)

5.5.7. Summary of the quantitative results (0-6 months).

Table 5.19 shows that carers in the domiciliary arm had better clinical outcomes on mental health (MCS: m.d. = 6.0), psychological morbidity (GHQ: m.d. = 2.3) and carer burden (CSI: m.d. = 1.0). Both groups of carers showed deterioration in physical health from baseline to 6 months, but with carers in the domiciliary arm showing less deterioration (PCS: m.d. = 3.9). Both groups showed no change in their level of social functioning (FAI: m.d. = -0.3).

Table 5.19 shows that none of these results reached statistical significance. Whilst this may suggest that the domiciliary stroke teams were not effective in bringing about improvement in carers' psychological outcomes, the small sample size in this study increases the possibility of Type II errors occurring. The implication of this is that the null hypothesis can not be rejected. That is to say that a statistical difference between carers in both arms of the study may exist for both psychological and physical outcome, but would require a larger sample size to detect it.

Table 5.19 : Summary of mean change scores, mean differences and p values of all carer outcomes (0-6 months)

Outcomes	0-6 months			
	Domiciliary	Day hospital	m.d. (95% CI)	P
GHQ (max = 28)	-0.3	2.0	-2.3 (-5.6, 1.0)	0.17
MCS (max = 100)	5.2	-0.8	6.0 (-1.2, 13.3)	0.10
CSI* (max = 13)	-0.1	1.0	-1.1 (-2.5, 0.3)	0.12
PCS (max = 100)	-3.2	-7.1	3.9 (-2.0, 9.8)	0.19
FAI (max = 45)	-1.9	-1.6	-0.3 (-3.7, 3.0)	0.84

* mean change score 3 to 6 mth

5.6 Carer outcomes: Six month to one year analysis

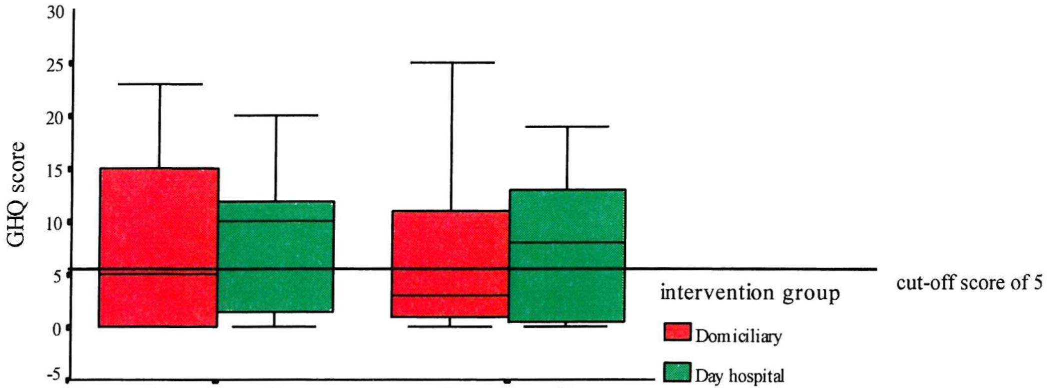
Data analysis from six to 12 months was carried out to evaluate the longer-term impact of either the domiciliary stroke team or the day hospital on carers' quality of life. In this set of statistical analysis, only carers participating at 12 months were included.

5.6.1. Psychological health

5.6.1.1. General Health Questionnaire (GHQ)

An analysis was carried out, looking at the distribution of GHQ scores at six and 12 months by intervention groups (see Figure 5.8). At 6 months, median scores of 5.0 for the domiciliary (IQR, 0 to 15.5; range, 0 to 23) and 10.0 for the day hospital (IQR, 1.3 to 12.0; range, 0 to 20) indicated that the majority of carers from both groups had signs of psychological morbidity (see Figure 5.7). By 12 months, the proportion of carers with psychological problems decreased in the domiciliary group (median 3.0; IQR 1.0 to 12.0; range 0 to 25), but increased in the day hospital group (median 8.0; IQR 0.3 to 13.5; range 0 to 19).

Figure 5.8. Boxplot to show distribution of GHQ scores by intervention group at six and 12 months.



To evaluate the impact of the two different services on psychological morbidity, the mean change of the GHQ scores from 6 to 12 months were calculated. Table 5.20 shows a decrease in GHQ scores for both the day hospital and the domiciliary groups with the former having a larger decrease than the latter. Nevertheless, whilst the day hospital carers showed a slight improvement in psychological morbidity, a mean difference of 0.6 (95%CI: -2.4, 3.7) between the two groups was neither clinically nor statistically significant (t = 0.41, p = 0.687). Furthermore, Figure 5.7 shows that the proportion of carers having psychological problems at 12 months was greater in the day hospital group than in the domiciliary one.

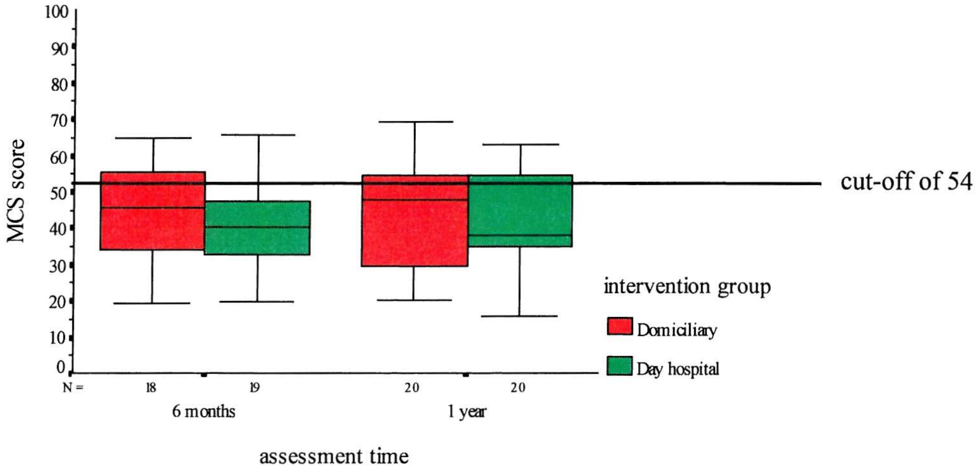
Table 5.20: GHQ mean and mean change scores from six to 12 months

	Dom: x (SD)	DH: x (SD)	md (95%CI)	t	p
GHQ (6-12 mths)					
6 mth (group scores)	7.6 (8.6)	7.6 (6.8)			
12 mth (group scores)	7.6 (8.6)	7.6 (6.8)			
Mean change 6→12 mth	-0.3 (3.8)	-0.9 (5.8)	**0.6 (-2.4, 3.7)**	**0.41**	**0.687**
n =	21	20			

5.6.1.2. Mental Component Score (MCS)

At six months, the majority of domiciliary carers (median 45.7; IQR 33.7 to 56.2; range 19.3 to 65.1) and day hospital carers (median 40.5; IQR 32.4 to 50.1; range 20.0 to 65.9) had poorer mental health than the general population (see Figure 5.9). There was no change in the mental health status of the two groups at 12 months with most domiciliary (median 48.1; IQR 29.1 to 60.0; range 20.5 to 68.4) and day hospital (median 38.1; IQR 34.4 to 56.0; range 20.5 to 69.4) carers still having poorer mental health than the general population (see Figure 5.9).

Figure 5.9: Boxplot to show distribution of MCS scores by intervention group at six and 12 months.



To evaluate the longer-term impact of the different services on carers' mental health, the mean change scores of carers MCS were calculated between 6 to 12 months. Table 5.21 shows no change in MCS scores of the domiciliary group by 12 months and only a very minimal improvement in the day hospital group. Whilst mental health in day hospital carers improved slightly compared to domiciliary carers (mean difference of 1.0; 95% CI, -8.7 to 6.6), this result was neither clinically nor statistically significant (t = -0.28, p=0.783). Furthermore, as Figure 5.9 illustrates, most carers from both groups still had poorer mental health than the general population.

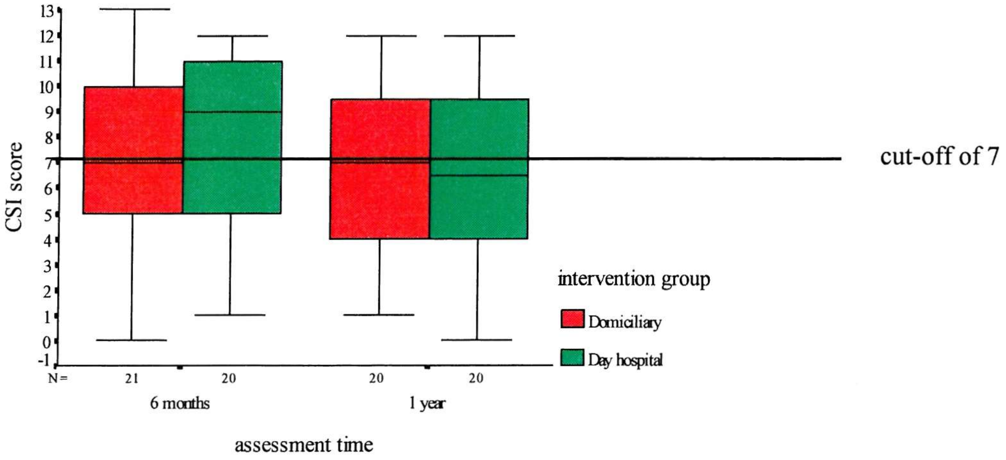
Table 5.21: MCS mean and mean change scores from six to 12 months

	Dom: x (SD)	DH: x (SD)	md (95%CI)	t	p
6 mth (group scores)	44.7 (13.4)	41.6 (12.0)			
12 mth (group scores)	44.0 (14.7)	42.2 (13.1)			
Mean change 6 → 12 m	-0.1 (9.8)	0.9 (12.4)	-1.0 (-8.7, 6.6)	-0.28	0.783
n =	17	19			

5.6.2. Carer burden

An analysis was carried out, looking at the distribution of CSI scores at six and 12 months by intervention groups. Figure 5.10 shows that most domiciliary (median 7.0, IQR 4.5 to 10.0; range 0 to 13.0) and day hospital (median 9.0, IQR 5.0 to 11.0; range 1.0 to 12.0) carers had high levels of carer burden at six months. There was no change in the proportion of domiciliary carers (median 7.0, IQR 4.0 to 9.8; range 1.0 to 12.0) with high levels of carer burden at 12 months, but there was a decrease in the numbers of day hospital carers (median 6.5, IQR 4.0 to 9.8; range 0 to 12.0). Nevertheless, these results showed that both carer groups still had clinically higher levels of carer burden when compared to the normal population.

Figure 5.10: Boxplot to show distribution of CSI scores by intervention group at six and 12 months.



To evaluate the longer-term impact of the different services on carers' burden, the mean change scores of carers' CSI were calculated. Table 5.22 shows that by 12 months, CSI scores in both groups show a decrease with the day hospital group having a greater improvement. However, a mean difference of 0.8 points (95% CI: -0.7, 2.4) in favour of the day hospital group was neither clinically nor statistically significant (t =1.10, p=0.279). Furthermore, Figure 5.10 shows that the level of carer burden in both the domiciliary and day hospital groups is still high.

Table 5.22: CSI mean and mean change scores from six to 12 months

	Dom: x (SD)	DH: x (SD)	md (95%CI)	T	p
6 mth (group scores)	6.9 (3.7)	8.0 (3.6)			
12 mth [group scores]	6.7 (3.3)	6.7 (3.4)			
Mean change 6 → 12 m	-0.5 (2.4)	-1.3 (2.5)	**0.8 (-0.7, 2.4)**	**1.10**	0.279
n =	20	20			

5.6.3. Physical health

An analysis was carried out, looking at the distribution of PCS scores at six and 12 months by intervention groups. Figure 5.11 shows that domiciliary carers had comparable physical health with the general population, both at six months (median 43.1; IQR 33.6 to 50.1; range 18.0 to 58.3) and at 12 months (median 45.3; IQR 28.0 to 50.2; range 17.8 to 60.0). On the other hand, the physical health of carers in the day hospital arm was poorer than the general population, both at six months (median 34.6; IQR 28.0 to 39.9; range 21.3 to 49.3) and 12 months (median 41.1; IQR 27.8 to 45.7; range 21.2 to 54.8).

Figure 5.11. Boxplot to show distribution of PCS scores by intervention group at six and 12 months

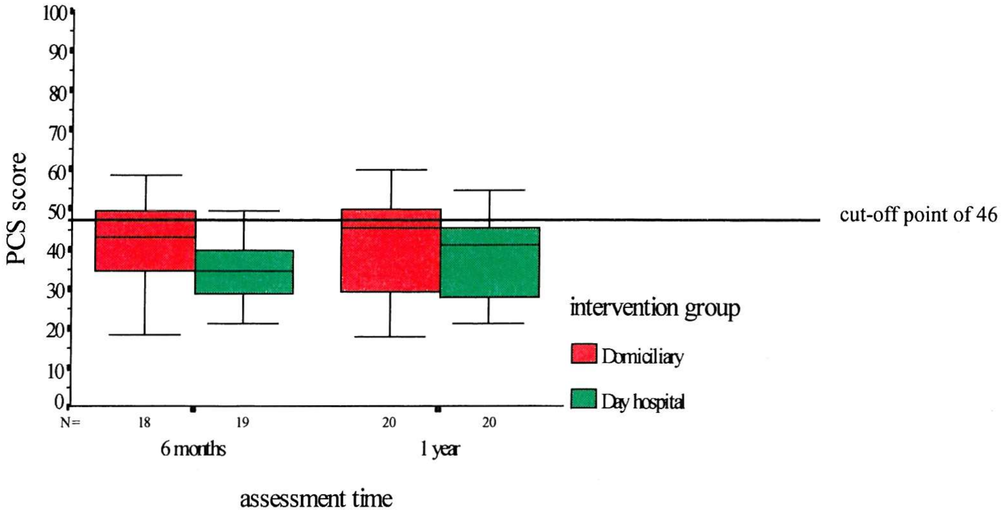


Table 5.23 shows an improvement in the physical health of day hospital carers, but a minimal deterioration in the physical health of domiciliary ones. A mean

difference of 4.3 MCS points (95% CI: -10.0, 1.4) in favour of the day hospital carers may be clinically significant, but as Figure 5.11 indicates, the physical health of day hospital carers was still worse than domiciliary carers at 12 months. No statistical difference was observed between the groups on physical health (t = -1.53, p = 0.136).

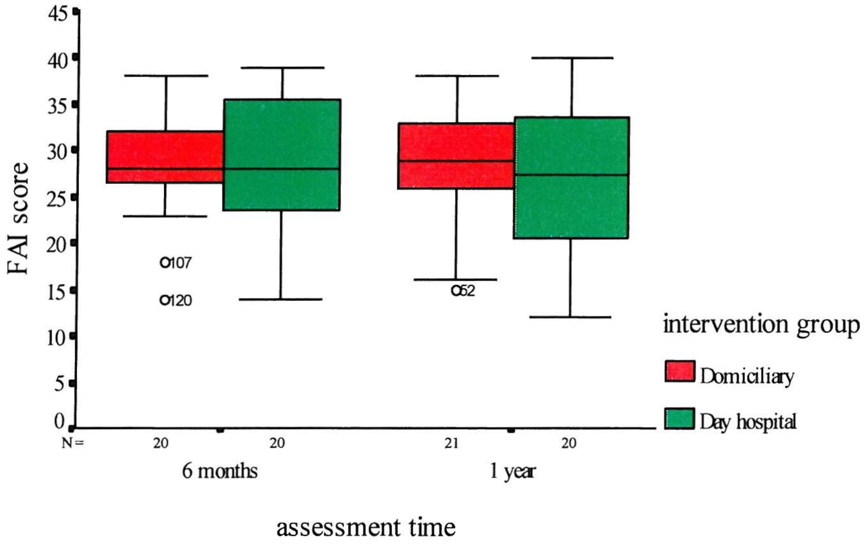
Table 5.23: PCS mean and mean change scores from six to 12 months

	Dom: x (SD)	DH: x (SD)	md (95%CI)	T	p
6 mth (group scores)	40.9 (11.9)	34.2 (7.9)			
12 mth (group scores)	40.0 (12.2)	38.0 (11.0)			
Mean change 6 → 12 m	-0.9 (7.7)	3.4 (8.9)	-4.3 (-10.0, 1.4)	-1.53	0.136
n =	17	19			

5.6.4. Social functioning

An analysis was carried out, looking at the distribution of FAI scores at six and 12 months by intervention groups. Figure 5.12 shows that both the domiciliary (median 28.0; IQR 26.3 to 32.0; 14.0 to 38.0) and day hospital (median 28.0; IQR 23.3 to 36.3; range 14.0 to 39.0) carers were engaged in active levels of social functioning at six months. There was little change to this level of social functioning at 12 months in both the domiciliary (median 29.0; IQR 26.0 to 33.0; 15.0 to 38.0) and day hospital carers (median 27.5; IQR 19.8 to 34.3; 12.0 to 40.0).

Figure 5.12. Boxplot to show distribution of FAI scores by intervention group at six and 12 months.



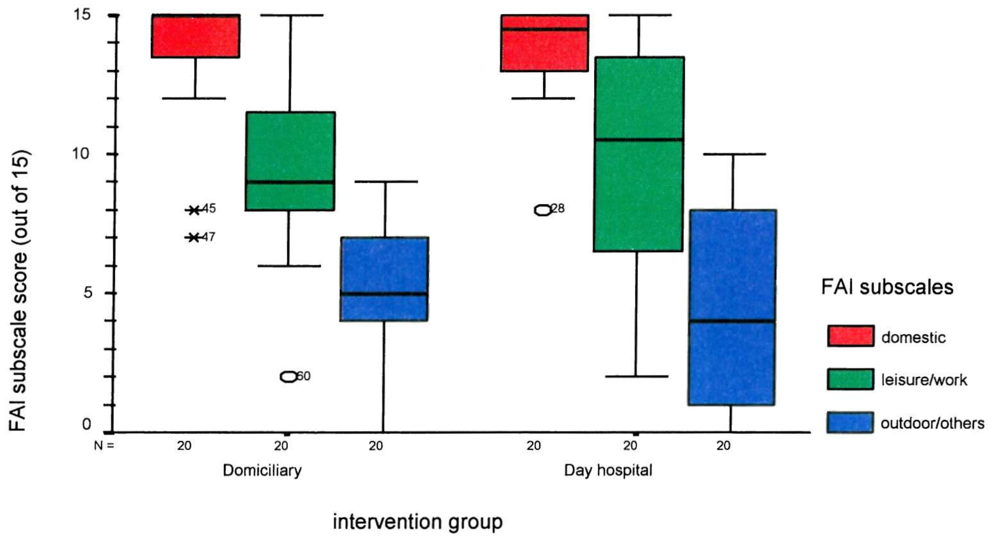
To evaluate the longer-term impact of the different services on carers' social functioning, the mean change scores of carers' FAI were calculated. Table 5.24 shows no change in social activity for the domiciliary group at 12 months whilst there was a slight deterioration in the day hospital group. The result may suggest that the domiciliary group was slightly better than the day hospital at maintaining its level of social activity. A mean difference of 0.9 FAI points (95% CI; -2.5 to 4.3) was not clinically significant and no statistical difference was observed between the groups (t = 0.53, p = 0.597).

Table 5.24: FAI mean and mean change scores from six to 12 months

	Dom: x (SD)	DH: x (SD)	Md (95%CI)	T	p
6 mth (group scores)	28.3 (5.6)	27.9 (7.7)			
12 mth (group scores)	28.3 (6.1)	27.0 (8.2)			
Mean change 6 → 12 m	-0.1 (5.6)	-1.0 (5.1)	0.9 (-2.5, 4.3)	0.53	0.597
n =	20	20			

Initial analysis of the global FAI scores suggested little change in carers' level of social functioning. A further analysis was carried out in which the six month FAI scores of both domiciliary and day hospital carers were divided into sub-scales of domestic, leisure/work and outdoor/other. Figure 5.13 shows that at six months, both domiciliary and day hospital carers had high scores in the domestic sub-scales and lower scores in the leisure and outdoor sub-scales.

Figure 5.13: Boxplot to show distribution of domestic, leisure and outdoor scores by intervention group at 6 months.



The mean change score from six to 12 months were analysed with respect to the three sub-scales. As with Table 5.14 looking at changes in the different FAI sub-scales from baseline to six months, Table 5.25 highlights similar findings. One, there was no significant difference between domiciliary and day hospital carers' with respect to their levels of domestic, leisure or outdoor functioning. Two, both sets of carers continued to show an increase in their domestic activity, but a decrease in their leisure and outdoor activities.

Table 5.25: FAI sub-scales - mean and mean change scores from baseline to six months

Subscale	Time of assessment	Dom: x (SD)	DH: x (SD)	Md (95%CI)	t	p
Domestic	6 mth (group scores)	13.8 (3.8)	13.8 (1.8)			
	12 mth (group scores)	13.3 (3.0)	13.7 (2.1)			
	Mean change 6 → 12 mth	1.5 (4.4)	0.5 (3.3)	1.1 (-1.4, 3.5)	0.9	0.384
	n =	21	20			
Leisure/work	6 mth (group scores)	9.5 (3.1)	9.8 (4.1)			
	12 mth (group scores)	10.4 (3.4)	9.1 (5.2)			
	Mean change 6 → 12 mth	-2.3 (3.2)	-0.8 (3.3)	-1.5 (-3.6, 0.6)	-1.5	0.154
	n =	20	20			
Outdoor/leisure	6 mth (group scores)	5.0 (2.2)	4.3 (3.5)			
	12 mth (group scores)	4.6 (2.3)	4.2 (3.2)			
	Mean change 6 → 12 mth	-1.9 (2.3)	-1.1 (2.4)	-0.8 (-2.3, 0.7)	-1.1	0.280
	n =	21	20			

5.6.5 Comparison of the domiciliary and day hospital groups at one year

An analysis was carried out comparing the differences between the participating carers and those who withdrew at six months on the main carer variables. Table 5.26 shows that both groups of carers participating at 6-12 months were evenly balanced with respect to the major socio-demographic variables of mean age (65.5 years vs. 68.0 years respectively), gender distribution (female; 15/21 vs. 16/20 respectively), socio-economic status (non-manual; 14/21 vs. 12/20 respectively) and relationship status (spouse; 15/21 vs. 15/20 respectively).

The increased number of withdrawals at 12 months (n=10 for the domiciliary and n=9 for the day hospital) enabled a comparison of both participating carers and withdrawals to be made on the basic socio-demographic variables. These found that participating carers and withdrawals were evenly balanced in socio-economic status. Participating carers in both the domiciliary and day hospital groups were younger than withdrawals. In the domiciliary group, both participants and withdrawals were evenly balanced with respect to gender distribution (female: 15/21 vs. 7/10 respectively), socio-economic (non-manual; 14/21 vs. 7/10 respectively) and relationship status (spouse; 15/21 vs. 6/10 respectively). More imbalances were seen in both gender distribution and relationship status within the day hospital group. Those who were more likely to withdraw were male (6/9 in withdrawal group compared to 4/20 in the participating one) and not the spouse/adult child of the survivor (3/4 in the withdrawal group compared to 1/3 in the participating group.

Table 5.26: Comparison of the participating and withdrawing carers by intervention group at 12 months.

	Domiciliary		**Day hospital**	
	participating	**Withdrawals**	**Participating**	**Withdrawals**
Number of carers	21	10	20	9
Mean age (s.d.)	65.5 (15.0)	70.7 (14.7)	68.0 (9.5)	70.0 (9.7)
Gender				
Female (%)	15 (71%)	7 (70%)	16 (80%)	3 (33%)
male (%)	6 (29%)	3 (30%)	4 (20%)	6 (67%)
SES				
non-manual (%)	14 (67%)	7 (70%)	12 (60%)	6 (67%)
Manual (%)	7 (33%)	3 (30%)	8 (40%)	3 (33%)
Relationship status				
Spouse (%)	15 (71%)	6 (60%)	15 (75%)	7 (64%)
adult children (%)	5 (24%)	2 (20%)	4 (20%)	1 (9%)
others (%)	1 (4%)	2 (20%)	1 (5%)	3 (27%)

5.6.6 Comparison of associated stroke survivors' variables between the groups at 12 months

A comparison was carried out between the domiciliary and day hospital group on the main psychological, physical and social outcomes of the associated survivors. Table 5.27 shows that both domiciliary and day hospital groups were evenly balanced on most of the stroke survivor variables. These included mobility (median RMI score: 9.5 and 7.0 respectively), physical health (median PCS score: 36.1 and 30.8 respectively), and psychological status (median MCS score: 55.5 and 58.5; median PGCMS: 12.0 and 10.0 respectively). The mean ages of the associated stroke survivors were 77.3 years (s.d. 6.2 years) for the domiciliary group and 77.4 years (s.d. 6.5 years) for the day hospital group, indicating that the age distributions for both groups were evenly balanced. However, associated survivors receiving domiciliary rehabilitation had higher levels of social activities (median FAI score: 15.0) than the day hospital (median FAI score: 8.0). They were also less physically disabled than survivors receiving day hospital care (median BAI score: 17.0 and 15), with a clinically significance difference of 2 points (BAI) between the two groups.

In summary, both groups were caring for stroke survivors with moderate levels of disability and immobility, poor physical health, low level of social functioning and moderate psychological health. When compared with the baseline sample (see Table 5.6), the remaining survivor sample at 12 months were less physically disabled on Activities on Daily Living (ADL), more mobile and had poorer psychological health. When this 12 month sample was compared to the six month one (Table 5.13), both time sample had similar levels of disability and psychological health.

Table 5.27: Comparison of stroke survivor variables between groups at 12 months.

Assessment	Intervention group	Median	IQR	range
Barthel	domiciliary	17.0	8.5 – 20.0	0 - 20.0
	day hospital	15.0	12.0 – 17.0	6.0 - 20.0
RMI	domiciliary	9.5	6.3 – 9.5	0 - 15.0
	day hospital	7.0	7.0 – 11.0	0 - 15.0
PGCMS	domiciliary	12.0	7.0 – 13.8	1.0 - 17.0
	day hospital	10.0	8.3 – 13.0	3.0 -17.0
FAI	domiciliary	15.0	6.5 – 21.0	0 - 36.0
	day hospital	8.0	4.0 – 19.0	0 - 36.0
MCS	domiciliary	55.5	45.4 – 60.8	32.3 - 72.1
	day hospital	58.5	54.4 – 63.6	30.2 - 69.7
PCS	domiciliary	36.1	28.1 – 45.2	12.7 - 54.5
	day hospital	30.8	25.0 – 39.0	15.7 - 50.1

As highlighted in Table 5.27, there was a 2 point difference in BAI score between carers in the domiciliary and day hospital groups. However, as both methods of service delivery had minimal impact on carers' psychological, social or physical health during the 6-12 month period, it was not necessary to carry out a stratified analysis on survivors' BAI.

5.6.7 Summary of quantitative results (6-12 months).

Whilst the 0-6 months showed clinical improvements in carers' psychological health in favour of the domiciliary team, Table 5.28 shows that little change was seen in either the domiciliary or day hospital group on carers' psychological or social outcomes between 6 to 12 months. An improvement in day hospital carers' physical health was seen at 12 months. This result may be clinically significant, but this has to be taken into context with the overall picture which shows that domiciliary carers still have better physical health than day hospital carers at 12 months (see Figure 5.10). No statistical difference was observed for any of the outcomes, though a small sample size raised the possibility of Type II errors occurring.

Table 5.28: Summary of mean change scores, mean differences and p values of all carer outcomes (6-12 months)

Outcomes	6-12 months			
	Domiciliary	Day hospital	m.d. (95% CI)	p
GHQ (max = 28)	-0.3	-0.9	0.6 (-2.4, 3.7)	0.69
MCS (max = 100)	-0.1	0.9	-1.0 (-8.7, 6.6)	0.78
CSI (max = 13)	-0.5	-1.3	0.8 (-0.7, 2.4)	0.28
PCS (max = 100)	-0.9	3.4	-4.3 (-10.0, 1.4)	0.14
FAI (max = 45)	-0.1	-1.0	0.9 (-2.5, 4.3)	0.60

CHAPTER 6: RESULTS (QUALITATIVE STUDY)

6.1 Chapter overview

The aims of this chapter are to present the results of the qualitative study in the following three areas: Firstly, to give the numbers of carers recruited in this arm of the study and a description of this sample. Secondly, to look at the differences in carers' perceptions of the domiciliary stroke teams and the day hospital and finally, to identify factors which were influential in determining carers' quality of life. In investigating these questions, both a content analysis approach and a thematic analysis were used. These are reported separately.

The first person singular was used in the sections dealing with the analysis and interpretations of the qualitative results. Whilst this study adopted a predominantly positivist framework, the researcher played an integral part in the design, execution and analysis of the interview data, so it was appropriate for the researcher to use the first person singular.

6.2 Carer recruitment to qualitative study

Of the 60 carers who initially took part in the quantitative study, 28 were recruited to the qualitative study at baseline, whilst another 18 were recruited at the six month stage. This gave a total of 46 carers involved in the qualitative study, leaving 14 non-participating carers. 23/28 carers seen at baseline were interviewed at six months. The five who withdrew did so for the following reasons; death of stroke survivor (3/5), occurrence of new stroke in survivor (1/5) and carer's wish to withdraw from study (1/5).

Table 6.1 shows that the main reasons for carer non-participation was that these carers, who were recruited before April 1996, would have already completed their six month assessments and so would have been too late to participate in the qualitative study.

Table 6.1: Reasons for non-recruitment to qualitative study

Reasons for non-recruitment	Number (%)
Number of non-recruited carers	14
Recruited to quantitative study before April 1996	10
Involved in qualitative pilot study	2
Withdrawal from carer quantitative study at 6 mth	2

6.3 Number of carers with audible interviews and the number of interviews available for transcription

Table 6.2 shows that 69 interviews were carried out with the 46 carers during the course of the qualitative study.

Table 6.2: Total number of interviews carried out in qualitative study

	Number of interviews
23 carers completed both baselline and 6 month interviews	46
5 carers completed baseline interviews only	5
18 carers completed followed up at six months	18
Total number of interviews =	69

Unfortunately, poor quality in the recording of some interviews meant that 14 were inaudible and could not be transcribed. Table 6.3 shows that 40/46 carers had audible interviews at baseline/6 months, which meant that six carers were removed from further descriptive analysis. In addition, Table 6.3 shows that these 40 carers had a total of 55 interviews available for transcription and analysis.

Table 6.3: Number of carers with audible interviews and number of interviews transcribed for analysis

	No. of carers with audible interviews	No. of interviews transcribed
Carers recruited at baseline with:		
audible interviews both at baseline & 6 months	15	30
audible interviews at baseline only	9	9
audible interviews at 6 months only	3	3
Total number at baseline	27	42
Carers recruited at six months with:		
audible interviews at 6 months	13	13
Total =	40	55

6.4 Description of participating carers

6.4.1 Description of carers' sociodemographic details

Table 6.4 shows that the carer sample in the qualitative study consisted of 29 (73%) females and 11 (27%) males and had a mean age of 68.7 years (s.d. 13.1 years). Using the social class coding from the Household Survey Classification, this sample was predominantly non-manual (27/40: 68%) with only 13 (32%) carers falling into manual category. The majority were retired (31/40: 78%), but of the carers of working age, three (8%) were full-time, two (4%) were part-time, three (7%) were unemployed and one (3%) was keeping house.

A comparison of the sociodemographic details in both sets of carers (see Table 6.4) found that both groups were evenly matched in terms of their gender distribution and employment status. The domiciliary group had proportionally more carers from a non-manual social background (18/24) than the day hospital group (11/22).

Table 6.4: Comparison of carer sociodemographic details by intervention group and combined total.

	Domiciliary	Day hospital	Combined Total
Number of participants	20	20	40
Mean age (s.d.)	67.7 (15.0)	69.7 (11.2)	68.7 (13.1)
Gender			
women (%)	14 (70)	15 (75)	29 (73)
men (%)	6 (30)	5 (25)	11 (27)
Social class			
Non-manual (%)	15 (75)	12 (60)	27 (68)
Manual (%)	5 (25)	8 (40)	13 (32)
Employment status			
retired (%)	15 (75)	16 (80)	31 (78)
in employment (%)	2 (10)	3 (15)	5 (12)
Unemployed (%)	3 (15)	0	3 (7)
keeping house (%)	0	1 (5)	1 (3)

6.4.2 Description of the relationship status, living arrangements and stroke survivors' disability levels

Details of the relationship status with the stroke survivor (see Table 6.5) shows that most of the carers in the qualitative study consisted of spouses/partners with 19 (48%) wives, nine (22%) husbands and one same sex partner. Close female relatives made the next largest group with 6/40 daughters and 3/40 daughter in laws. Male relatives included one son and one brother.

Table 6.5 also highlights the following findings. The first was that most carers (34/40) were living in the same household as the stroke survivor. The second was that the majority of carers (28/40) were supporting survivors with mild to moderate levels of residual disability at baseline, with a large minority of carers (12/40) supporting survivors with severe levels of disability. A comparison of the two sets of carers found that both groups were similar to each other in terms of their relationship status, their living status with survivors and in the distribution of survivors (with respect to their degree of disability) that carers had to support.

Table 6.5: Comparison of carers' relationship status by intervention groups and combined total.

	Domiciliary	Day hospital	Combined Total
Number of participants	20	20	40
Relationship to patient			
wife (%)	9 (45)	10 (50)	19 (48)
Husband (%)	5 (25)	4 (20)	9 (22)
same sex partner	0	1 (10)	1 (2)
Daughter (%)	2 (10)	4 (20)	6 (15)
Daughter-in-law (%)	2 (10)	1 (10)	3 (8)
other male relative (%)	2 (10)	0	2 (5)
Living arrangements			
living with survivor (%)	18 (90)	16 (80)	34 (85)
not living with survivor (%)	2 (10)	4 (20)	6 (15)
Patient BAI score (0 mth)			
severe: score <9	6	6	12
Moderate: score 10-14	7	8	15
mild: score 15-19	7	6	13

6.4.3 Comparison of the physical and mental health status of domiciliary and day hospital carers.

The carer sample in this qualitative study was comparable in physical health to an age-related sample in the general population, but had poorer mental health (median MCS and PCS for 65-74 year age group is 56 and 46 respectively; Ware et al, 1994). A comparison of the two groups showed that the domiciliary group had better physical and mental health than the carers in the day hospital (see Table 6.6).

Table 6.6: Comparison of the mental and physical health status between carers in the domiciliary and day hospital groups at baseline.

	Domiciliary median (IQR)	Day hospital Median (IQR)	All carers Median (IQR)
Number of participants	20	20	40
MCS score (0 mth)	51 (30-55)	46 (34-51)	47 (30-55)
PCS score (0 mth)	50 (36-56)	44 (35-49)	47 (34-54)
GHQ score (0 mth)	5 (1-10)	5 (1-10)	5 (1-10)

6.4.4. Summary description of the carers in the qualitative study

These results showed that this sample of stroke carers were mainly elderly and consisted predominantly of spouses and partners. They came from a mainly non-manual background, but were now retired. They were mainly female, with wives making up the majority, but with daughters and daughter-in-laws acting as the main carer in cases where no spouses were available. Most of the carers were living with the stroke survivors, who generally had mild to moderate residual disability, but with a large minority being severely disabled.

6.5. Qualitative data analysis (content analysis)

I carried out a content analysis on all the baseline and six month interview data available, using the coding frame described in Chapter 4. The results of these analyses were presented in Appendix XXVIII. I then immersed myself with these data and together with my experiences as the sole interviewer of each participant involved in the qualitative study, I was able to use this experience to make interpretations from the data. Using this method of analysis, I carried out a qualitative analysis on the following three areas: carers' perceptions of the two different services, the impact of the stroke on carers' quality of life, their roles as carers and the levels of social support available to them.

6.6. Carers' perceptions of the two methods of service delivery in stroke rehabilitation.

My main research question was concerned with identifying the qualitative differences between carers in the domiciliary group and the day hospital group in the way they perceived the different models of stroke rehabilitation. I was particularly interested in identifying the main themes, which emerged from carers about their perceptions of the advantages of the different therapies that their stroke survivor received. One of my research questions was to see if the domiciliary stroke team provided greater opportunities for carer education, so I carried out a sub-analysis to see if there was a difference between the domiciliary and day hospital carers on their understanding of what therapists do in stroke rehabilitation. Finally, I was interested in exploring carers' perceptions of what they felt constituted a good therapy service, their expectations of what the service should achieve and their fulfilment of their expectations. I felt it was important to understand carers' perceptions in these areas as a guide to potentially developing health services. In the analysis of the data, I looked at the perception of both domiciliary and day hospital carers separately, in which I used data from the content analysis (see Appendix XXVIII).

Figure 6.1 illustrates the major themes emerging from both the baseline and six month interview data about carers' perceptions of the advantages of receiving stroke rehabilitation either from a domiciliary team or at a day hospital. Both groups of carers saw the advantages of their respective therapies in terms of the social impact that it would have on their lives and not in terms of the contents of the therapy packages themselves. The perceptions of carers towards the different services were similar at both baseline and six months. However, at baseline, both groups of carers had pre-conceived ideas about what advantages each service would provide. By six months, these perceptions of the services were cemented by concrete experiences of being in receipt of them.

Figure 6.1: Stroke carers' perceptions of the main advantages of domiciliary and day hospital models of stroke rehabilitation

	Themes
Domiciliary	Comfort & convenience Carer education Therapy geared for home environment
Day hospital	Respite Opportunities for stroke survivors to mix with others Equipment & space

6.6.1. Advantages of the domiciliary stroke team

COMFORT AND CONVENIENCE

For carers in the domiciliary group, the following three themes emerged from the data: 1) the comfort and convenience of having therapy carried out at home, 2) greater opportunities for receiving advice and education from the therapist, and 3) the relevance of domiciliary therapy to the stroke survivor.

The majority of domiciliary carers identified the main advantages of the domiciliary stroke team as the convenience and comfort that they offered to both the stroke survivors and the carers themselves. For many carers, domiciliary therapy was convenient for them, as there was not the need to prepare the stroke survivor for the arrival of the ambulance to take them to day hospital.

it would be wonderful if it could be done at home. To me that's a lot simpler for him than in a chair, out, into an ambulance (5090, wife, baseline)

Carers also talked about the advantages of domiciliary care in terms of survivor convenience. Many carers perceived that stroke survivors would often prefer to have their therapy carried out in the safe confines of their home.

The very fact that he hasn't got to worry about moving out of the home you know is great, you know he seems to be responding very well to that because I suspect if he was less fear of trepidation I suppose about receiving somebody in your own home than there is about going to hospital and seeing somebody, you know its more congenial really. (5102, son, baseline)

This concept of survivor convenience could also be expressed in terms of the psychological distress that attending a day hospital would bring to some survivors, where carers would be aware that the survivor did not enjoy being in the social company of others.

he is not an outgoing man, some people absolutely love being picked up and taken to these places, but not him, it would be awful for him. (5042, daughter, 6 months).

Survivor empowerment was an issue raised by one carer who felt that having the therapy done at home had given his father more control in his treatment than if he had gone to the day hospital.

he felt that he could ask questions, say and do things, he had more control over events if even if they were in his own house. You know it wasn't just somebody else coming in, but you know he was the person inviting people to come in. (5102, son, 6 months).

CARER EDUCATION

Carer education was the second major theme to emerge from the data of domiciliary carers. The data suggested that home therapy brought the therapist in direct contact with carers, especially if the carer lived in the same residence as the stroke survivor. This in turn provided carers with more opportunities to become involved in the rehabilitation process and to learn directly from the therapist.

When (the physiotherapist name) is here sometime and she's dealing with him in the bedroom, I come and sit in here, other times I sit and watch what's going on ... Oh yes particularly with new movements because she showed me how I could help *during the week before she comes again. Things to do with his leg, rolling onto bed, lots of things she's taught me that I do. Jo will say, can you watch today or you know or are you available, or I say to her do you want me today she'll say or no. It's very pleasant, a pleasant relationship.* (5084, wife, 6 mths).

Many carers in turn felt that this opportunity to be on-hand to receive advice from the therapist gave them greater confidence to encourage the stroke survivors with their exercises and help in their rehabilitation.

I have been able to see what they do and what they expect her to do as an ongoing exercise pattern. If I hadn't have been there to see it, I wouldn't have been able to help her with that. (5091, daughter, baseline).

This is not to say that carers in the day hospital were not open to the opportunities on receiving education from the therapist about the survivors' treatment. One carer specifically felt that he had been well supported by the day hospital.

I've been up the hospital and the physiotherapists have shown me the correct way you know that [name of wife] should get off the bed, onto the chair and that. They worked in conjugation with me and showed me what [name of wife] and what I can do (5131, husband, 6 months).

Nevertheless, this particular carer was keen to be involved in all aspects of his wife's rehabilitation and made a special effort to get to the day hospital by public transport on the days his wife was there. This was a sign of determination as ambulance transport was only provided for day hospital patients and this carer did not have access to his own private car. Generally, the opportunities for receiving advice and education from the therapist were greater in the domiciliary team.

This point was further illustrated by an analysis of data looking at carers' level of understanding of therapist roles in stroke rehabilitation by group allocation, which was displayed in Table 6.7.

Table 6.7: The roles of therapists: the level of carers' understanding by group allocation.

	Domiciliary		Day hospital	
	0 mth	6 mth	0 mth	6 mths
No/little understanding	3	3	9	8
Some understanding	2	5	2	6
Good understanding	2	4	3	2
Total (n)	7	12	14	16

These data showed that the proportion of carers at baseline who had little understanding of the therapist role was higher in the day hospital group (9/14) compared to the domiciliary group (3/7).

No I don't understand the therapy I don't understand what therapy she is getting. (5080, husband, baseline)

Nevertheless, at six months, the proportion of carers who had at least some understanding of the therapist role in stroke rehabilitation was higher in the domiciliary group (9/12) compared to the day hospital group (8/16).

Yes, physiotherapists are moving your joints and muscles to get people back to as near normal as possible or to keep them supple ... I take it that now they're (referring to the Occupational therapist) involved with the movement as well, plus they're responsible for all the equipment, they come out of the house and see how you're managing ... manage up to the bed and his chair and how he's getting from the chair to the toilet and what sort of commode you would need, so to me they're responsible for practical things to keep him, you know as comfortable as possible (5112, wife, baseline)

One explanation may be the greater opportunities afforded to domiciliary carers in observing what therapists did during the rehabilitation sessions. Hence, many carers, whilst unable to give a technical definition of the therapist role, were able to give descriptive accounts of what they did.

She showed us how to get him in and out of the car, I mean I'm not in the right order now because she's been coming for a long time and that's only quite recently, she is going to have a kitchen, making tea and that sort of thing, it hasn't happened *yet but she shows him how to dress himself, wash himself and dress himself, what he done a bit in hospital but she's improved on it tremendously, absolutely wonderfully.* (5084, wife, 6 months, domiciliary)

Likewise, many day hospital carers did not have as many opportunities to meet directly with the therapist and so were unaware of their role.

No, I have never seen it. No, I don't know what they do. (5061, wife , 6 months)

RELEVANCE TO SURVIVORS' REHABILITATION

The third emergent theme showed that carers were aware that the domiciliary team could gear the rehabilitation process to deal specifically with problems relating to their home environment. They understood that whilst the day hospital had an array of equipment such as steps to practice stairs, space to practice walking or an assessment kitchen, these could not replicate the unique problems found within a home environment such as narrow stairwells or minimal space to manoeuvre a wheelchair.

And of course they can show a person their own environment to cope in their own home when people come to the house, they can show the patient how to cope (5132, wife, 6 months).

6.6.2. Advantages of day hospital

RESPITE

For the carers in the day hospital group, the most important theme to emerge was the issue of respite from the caring role. For many carers, the attendance of the stroke survivor at the day hospital provided the time opportunities for these carers had to have some space for themselves, a chance to go out and meet friends or even just to do the shopping.

Well yes because it gives you a chance you see to do things you can't do when you have someone else just sitting about here or sitting about in the lounge all the time, you can't do anything else (5096, wife, baseline).

Whilst there might be been some feelings of guilt about the stroke survivor going to the day hospital, these carers justified this respite by the fact that stroke survivors were going to the day hospital to receive professional assistance in helping them to recover some of their functional ability.

Oh yes because of the break it gave me and the fact that she was being looked after professionally and was getting assistance and help (5052, husband, 6 months)

OPPORTUNITIES TO MIX WITH OTHERS

Many carers also saw attendance at the day hospital as an opportunity for the stroke survivor to meet with other people with stroke. Some in particular felt that it was important for the stroke survivor not to be stuck inside the house and to have a change of scene.

that was the most important thing, that he got out of these four walls, a ride in the ambulance, meeting other people and having a laugh, silly as it might of been, and if you see your husband is happy, you are happy (5060, wife, 6 months)

Others stressed that the day hospital provided the opportunity for the stroke survivor to compare themselves with others who may be in a better or worse condition than themselves.

Well to go to the Day Hospital because it gets him away and he can see other people that are perhaps worse or better off (5110, wife, 6 months)

EQUIPMENT AND SPACE

Most carers identified social reasons as the main advantages of day hospital therapy. Nevertheless, a few carers felt that the day hospital provided better accessibility to a wider range of equipment and more space for therapy than was available with the domiciliary teams. One carer in particularly felt that medical care in the day hospital would be better co-ordinated as all the doctors, nurses and therapists were based in the same building and so would have better communication with each other.

my preference is for her to go to (name of day hospital) and have treatment there because she's got all the qualified staff there, she's got the OT's and the physiotherapists, she's got the complete bunch of staff around her there, everybody she needs. (5131, husband, 6 mths)

6.6.3. Carers' criticisms of the different methods of stroke rehabilitation

The interview data suggested a positive attitude was shown by carers about their experience of therapy, which was seen in terms of the advantages it brought to both themselves and the survivors. Nevertheless, there was also a recognition of the shortcomings of the different type of therapy. For the domiciliary team, this was the lack of access to equipment. One carer, who had recently asked to have her husband's therapy switched from the domiciliary therapy to day hospital, believed that the specialised equipment such as a tilting tray was needed to improve his functional recovery and felt that access to this equipment was better in the day hospital.

I mean the girls were absolutely excellent that came home but they could only do what one pair of hands could do. They've got no aids or help or anything, but they've got so much more (equipment) in the hospital which is why I asked to be transferred back (5066, wife, 6 mths)

Likewise, there were two criticisms levelled at the day hospital. The first was the inconvenience of preparing stroke survivors for the early morning pickup by the ambulance to the day hospital. Even carers who were generally enthusiastic about the day hospital found the necessity for preparing the survivor for the ambulance in the early hours of the morning a tiring process.

I used to be at her flat by 8 o'clock at the latest so that I could get her dressed and ready for when the ambulance came to pick her up at 9 o'clock or whatever time after that. But they stipulate you have to be ready for 9 o'clock because she never knew if she was going to be the first one to be picked, a lot of time she wasn't picked up until 9.30 am (5100, daughter, 6 mths).

The second was the lack of communication with health professionals at the day hospital, especially if the carer did not live in the same residence as the stroke survivor. Whilst one carer found it welcoming not to have the responsibility of her mother for a day, she would liked more feedback about her mother's progress from the day hospital.

it would have been helpful to hear something from the hospital about their expectations. What they expected her to manage and what they would like us to have encouraged her to do. (5062, daughter, 6 months).

In conclusion, the data suggested that there are elements of both the domiciliary and day hospital therapy that carers find beneficial. Carers appreciated the following elements from the domiciliary team; the convenience of having therapy carried out in the comfort of one's own home, the close contact with the therapists which in turn provided better communication and opportunities for the training and education of carers. Likewise, day hospitals provided carers with respite opportunities to have some time and space away from the routine of the caring. More importantly for carers, stroke survivors were receiving therapy to help them to recover, in the environment which enabled them to mix and compare themselves with others and with the availability of specialised equipment to help in this process.

6.6.4. Carers' perceptions of a good therapy service (Baseline)

The following three themes, physical improvement, practitioner skills and efficient delivery of health care, emerged from the content analysis (see Appendix XXVIII) and these are presented in Table 6.8.

Table 6.8: Themes identified from content analysis on perceptions of a good service by intervention group

	Domicilary (n=10)	Day hospital (n=14)	Total in theme (n=24)
Physical improvement	2	5	7
Practitioner skills	3	2	5
Efficient delivery of health care	4	3	7

First and most important, a good service was one which brought an improvement in physical functioning of stroke survivors. Many carers felt that having therapy was pointless if it could not achieve this goal.

Improvement, otherwise the therapy's a waste of time, isn't it? (5123, wife, baseline)

The practitioner skills of the therapists were recognised as paramount in the delivery of a good service. Carers expected therapists to have all the skills of competent practitioners; knowledgeable, punctual, empathetic to the needs of the stroke survivor and able to strike a good working relationship with them.

Well I think the first thing is the therapist and the patient have got to get on well together, that I think is vital ... And the other thing is you have got to feel that the physiotherapist knows what she is doing, and their competence that they know what they are doing. (5191, husband, baseline).

Finally, carers saw a good service as one in which health care was delivered efficiently and effectively. Nevertheless, carers' definition of what was important differed from each individual, depending on their experience. Some carers felt that frequent visits by the therapists and carer involvement with the rehabilitation process were important once the stroke survivor had been discharged from hospital. One carer felt that therapy should prepare survivors for a change in lifestyle and so provide interesting activities for them to engage in. Other carers highlighted elements of health care which they felt were missing from their survivor's own rehabilitation such as speech therapy and information on complementary therapy.

6.6.5. Carers' fulfilment about therapy at six months.

All carers had initial optimism that therapy would bring about both physical and functional improvements in stroke survivors. Therefore, the degree of carer fulfilment with therapy was determined by the level of perceived physical improvement in stroke survivor at six months. Hence, the most fulfilled carers were those who perceived that their stroke survivors had made some physical improvement.

Oh yes she has improved enormously even since she came home, it goes up and down you know, but basically I don't have to work anything like so hard moving her as I did so that is good (5057, brother, 6 months)

On the other hand, carers who felt that therapy made little impact on the physical condition of the stroke survivor had unfulfilled expectations of the therapy. This group of 'unfulfilled' carers could be further split into two sub-groups; a) those who externalised failure of survivor physical improvement to their level of disability, and b) those externalising failure to a lack of service provision.

Carers in the first sub-group accepted that progress with rehabilitation was slower either because of the severe level of survivors' disability or due to the survivors' intransigent personality.

No. Because I hope that they would be able to have got her a lot more mobile, a lot more confident in herself. She wasn't. It may not be their fault, it may be, it's probably some of my mum's fault. (5120, daughter, 6 months)

Carers in the second sub-group attributed the lack of rehabilitation progress to a failure of the health services to meet the needs of their stroke survivors. This carer sub-group outlined some of the problems they personally had with the health service, such as the non-availability of the domiciliary physiotherapist (due to her resignation at that time), a bad therapeutic relationship with the physiotherapist and the lack of therapy.

A day at the hospital, she gets a very limited amount of physio, got OT help in the kitchen, she had some, but it rather tailed off (5126, husband, 6 months, day hospital)

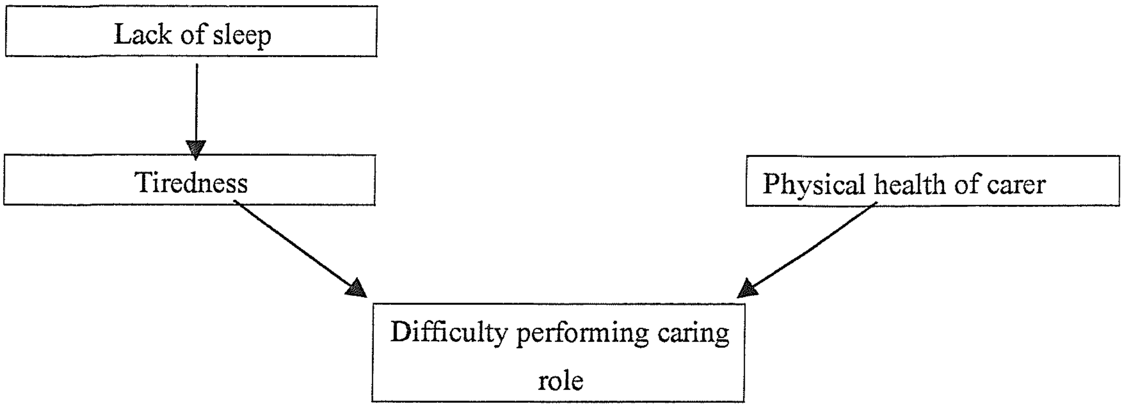
6.7. The impact and difficulties experienced by caring for a stroke survivor

The quantitative results showed no differences between the two carers' groups on the main psychological, social and physical outcomes, but indicated that carers, irrespective of treatment allocation, had high levels of psychological morbidity and had low levels of leisure activities than the general population. The content analysis (see Appendix XXVIII) showed that most carers experienced changes in lifestyle, impairments in their social life and felt that they had little time for themselves. Only 3/31 carers reported experiencing no difficulty as a result of caring after 6 months post-stroke.

6.7.1. Physical functioning

Quantitative results suggested that neither domiciliary nor day hospital methods of delivery had any impact on the physical health of carers. Nevertheless, my content analysis (see Appendix XXVIII) identified two main factors, carers' physical health status and interrupted sleep, which may determine carers' ability to carry out physical tasks associated with the caring role. The relationship of these two factors with their impact on physical functioning is displayed in Figure 6.2.

Figure 6.2: Relationship of the different factors on carers' physical functioning



The lack of sleep often left carers feeling tired the following day and so reduced their ability to function adequately.

You see because I get up three or four times in the night to attend the mrs, understand, that's what it is and when you get tired, all I want to do is keep sleeping in the daytime. (5073, husband)

Physical health status was an important factor as carers in poor physical health were more likely to have greater difficulties in carrying out their physical role and so often felt limited in what care they could provide to their stroke survivors.

Well I would find the main difficulty, getting him up, you see I would find it impossible, I was trying to do it before he went in and it was not very safe trying because you know of my own problems. (5132, wife, domiciliary).

To test this out, I identified 12 carers who had felt that their health problems had made it difficult to carry out the physical tasks required in their role and used their baseline PCS scores to compare their median and interquartile scores with those of the whole qualitative sample. This analysis showed that carers who identified some problems with the caring process as a result of their perceived health problems did have poorer physical health status than the whole carer sample (see Table 6.9).

Table 6.9: Comparison of baseline PCS scores (median and IQR) for carers with health problems and the whole qualitative care sample.

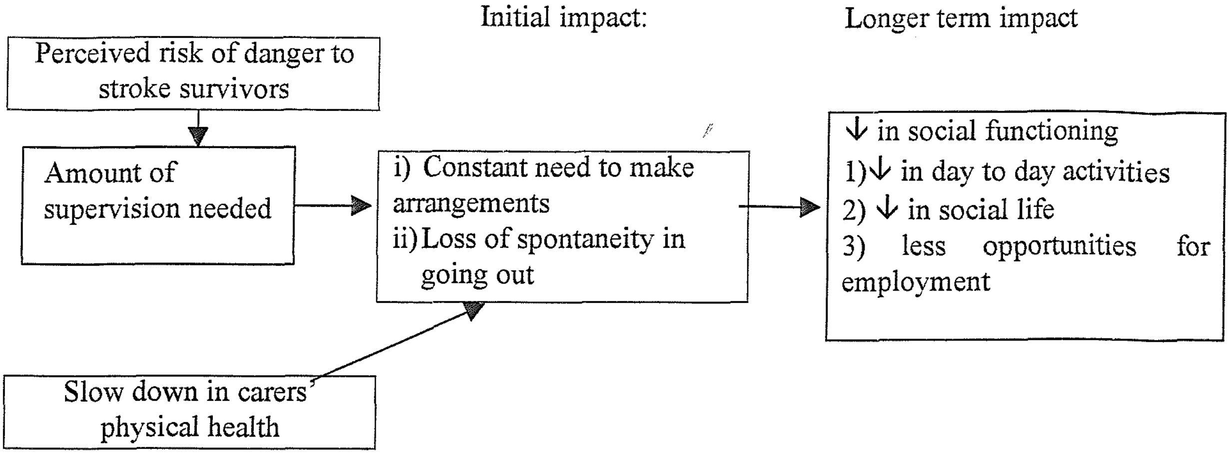
	Median scores (PCS)	IQR (PCS)
Carers with health difficulties	34	25-44
Whole qualitative carer sample	46	34-53

6.7.2. Social functioning

Content analysis showed that the main impact of caring for a person with a stroke was the restriction on social life, the difficulty of maintaining friendships and a restriction in marital relations (for spouse carers). In addition, it showed that the majority of carers (13/20) did not feel comfortable about leaving the stroke survivor unsupervised for more than one hour. Further inspection of these data showed no numerical difference between carers in the domiciliary or day hospital groups at either baseline or six months on these themes.

Using the data obtained from the content analysis, my knowledge of the interviews and my interpretative skills as a researcher, I identified two factors which influenced carers' level of social functioning. These were; a) carers' perceptions of the risk to survivors at home and b) carers physical health and Figure 6.3 outline the relationship that these factors had on carers' social functioning.

Figure 6.3: The relationship of the different factors on carers' social functioning.



Carers' perceived risk of danger to stroke survivors was important as it determined the level of supervision which carers felt was necessary to ensure the safety of the stroke survivor.

It's the moving when he moves about, I should think and of course I would not be able to go out and leave him, not at present anyway - he must not be left alone. (5096, wife, baseline).

Carers, who perceived that their stroke survivors were at greater risk, had to make arrangements to ensure the appropriate level of supervision was available during their absence. This may involve outsiders such as neighbours, relatives being asked to sit with the survivor, or to ensure that carers were aware of what to do.

It's reasonable, ain't it, you can't go out unless someone is here. When I do go out they stop in here for an hour or so, I go and get the rations, a bit of bread and stuff like that. (5075, husband).

This need for constant planning to ensure survivors' safety in turn has a limiting effect on what carers can do outside this 'caring role'. As these carers have to plan every movement in advance, this impairs social functioning as the opportunities for social life are reduced, leading to further restrictions in what carers can do outside their caring role, together with more routine task such as shopping. Furthermore, this loss of freedom also reduced the opportunities of finding employment for younger carers.

The level of supervision required may be related to the survivors' disability levels. To check this out, I carried out an analysis looking at survivors' level of disability at six months and cross-checked it with the amount of time that carers felt comfortable in leaving the stroke survivors at home by themselves. I used six month data as carers would settle into a routine by this period of time. This analysis showed that stroke survivors who were left by themselves for more than an hour had mild residual disability and were physically less disabled than those who were left alone for less than an hour (see Table 6.10). These results supported the finding that the amount of supervision given by carers was related to survivors' level of disability.

Table 6.10. Survivors' median BAI score by amount of time left alone.

Amount of time left alone	Number in group	Median BAI
no time (0 hr)	7	9
little of time (< 1 hr)	6	10
some of time (1-6 hr)	5	18
most of time (> 6 hr)	2	18.5
Total sample	20	

Nevertheless, other factors unrelated to the stroke may also lead to a reduction in social functioning. This includes a slow down in the lives of many carers, especially those in their seventies.

Yes we have adapted a quiet life because of his failing health really, we've enjoyed life in our own way and accepted the inevitable. (5130, female, domiciliary)

6.7.3. Psychological functioning

Content analysis showed that caring was a continual commitment, which left carers little time to spend on themselves. At the same time, some carers felt unwilling to involve other people in the caring process. An analysis of the patterns in these data suggested that proportionally more carers reported these subjective feelings at six months (19/31) than they did at baseline (5/24). A closer inspection of these data showed that at baseline, the proportions of domiciliary (2/10) and day hospital carers (3/14), who reported psychological problems were similar. By six months, the proportion of day hospital carers reporting psychological problems was higher than in the domiciliary carers (8/17 and 11/14 respectively). This may indicate that the carers in the day hospital group had poorer psychological health than domiciliary carers.

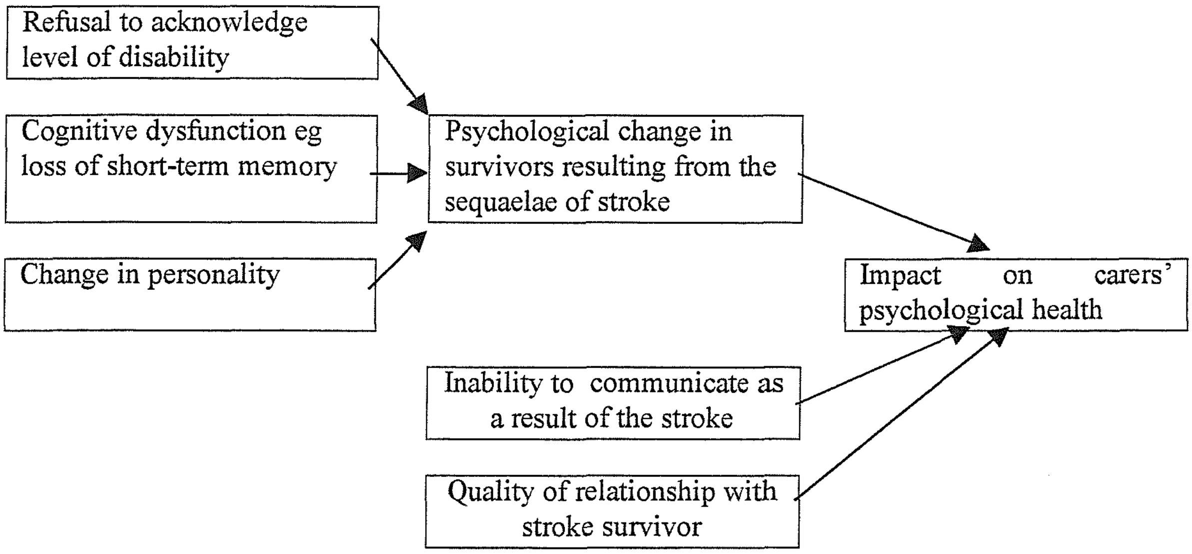
I wanted to see if carers who reported these feelings were in poorer psychological health than the rest of the carer sample. I carried out an analysis using the six month scores of the PCS, GHQ and CSI for carers who reported the following: 1) caring was a continual commitment, and 2) little time for themselves. This analysis found that carers, who either felt that caring was a continual process or felt that they had no time for themselves, had a lower MCS score and a higher GHQ and CSI score when compared with the scores of the whole carer sample (see Table 6.11). More importantly, a larger proportion of these carers scored more than 5 on the GHQ and 8 on the CSI, indicating that these carers showed higher levels of carer stress and psychological morbidity. Therefore, these data suggested that carers who felt that caring was a continual process had poorer psychological health.

Table 6.11. Psychological health of carers reporting a lack of time and space as a result of caring at 6 months.

Psychological outcomes	Continual (n=13)	no time (n=13)	Whole carer sample (n=48)
MCS median score (IQR)	39 (34-50)	37 (35-47)	41 (34-50)
GHQ median score (IQR)	10 (1-12)	11 (7-15)	9.5 (2-12)
CSI median score (IQR)	9 (7 -11)	10 (8-11)	9.5 (5-11)
no of carers scoring GHQ > 5	9 (69%)	12 (92%)	14 (29%)
no of carers scoring CSI > 7	10 (77%)	8 (62%)	12 (25%)

Content analysis had identified several themes, which had an influence on carers' psychological health.The relationship of these different themes in influencing carers' psychological health is displayed in Figure 6.4. This illustrates that three themes were related to this ability to cope, these being; a) the degree of psychological change in survivors resulting from the sequaelae of stroke, b) the inability to communicate as a result of the stroke and c) the quality of the relationship with the stroke survivor.

Figure 6.4: The relationship of the different factors on carers' psychological health



The first two themes arose as a result of stroke-related deficits affecting the survivors and of these themes, carers were in particular affected by psychological changes resulting from the stroke, such as changes in personality, loss of short-term memory and a refusal to acknowledge their level of disability. These changes may hit carers the hardest as they also contribute to a loss in survivors' independence and so increase dependency on carers.

he does need those little memory jolts, otherwise he cannot think forward, he cannot plan forward, you have go to say to him, if you take the chicken pie out of the freezer you must defrost it before you cook it, he would ignore that unless you *told him. So it does play on your mind a tremendous amount so you can't really enjoy yourself if you are away* (5042, daughter, 6 mths).

Furthermore, the changes in personality, for example may be difficult for carers to accept as the survivor may bear no resemblance to what they were like before the stroke. In particular, carers of people with dysphasia were frustrated by the survivors' inability to communicate with them.

My mum died as far as I am concerned when she had her first stroke. This lady is not the same person. The stroke has completely changed her and there are odd little bits sometimes that I recognise. So that is the hardest part (5082, daughter, 6 mths)

6.7.4. Coming to terms with stroke (baseline)

Folkman & Lazarus (1991) proposed that coping consists of a series of cognitive and behavioural strategies that a person employs to manage stressful situations. In this study, fatalistic acceptance was expressed by most carers as the way they coped with the onset of the survivors' stroke. There was a feeling amongst carers of the fact that once the stroke had occurred, there was little one could do, but accept the situation and to get on with the caring process.

Cope the best that you can there is nothing else you can do (5082, husband, baseline)

Nevertheless, fatalism by itself did not account solely for the mechanism which carers employed to come to terms with the stroke. Further data analysis identified that three main factors were beneficial to carers in helping them to come to terms with the stroke; these were a) the knowledge of how a stroke can affect carers' lives, b) survivor-related characteristics and c) social networks. These factors are displayed in Table 6.12, which further sub-divided each theme to specific categories.

Table 6.12: Illustration of the themes and their associated categories of coming to terms with the stroke.

Main themes	Specific categories
Knowledge of the impact of stroke on life	Experience of previous stroke Experience through professional training Experience of other chronic illnesses
Stroke survivors characteristics	Personality level of physical improvement
social networks	friends & neighbours
not coming to terms with stroke	

Knowledge of how a stroke affects carers' lives was useful for carers in that it prepared them for what to expect when supporting someone with a stroke as well as some of the uncertainties. Hence, this knowledge may be important in giving carers some control of events in their lives. In the majority of cases, this knowledge was acquired by experience of caring for a person with a stroke previously. Nevertheless, many carers who had spent a large period of their lives supporting a person with other chronic conditions felt they were also well equipped to deal with being a stroke carer.

As my husband has been ill really off and on for the past 50 years I got used to being his sole carer, I have had to learn to be nurse and doctor, but you do that because it's your husband or your family (5075, wife, baseline)

Knowledge obtained by nursing or other health professional training was another way in which some carers became knowledgeable about strokes. Often this structured training would provide both knowledge about the stroke prognosis and nursing skills to handle any practical problems arising from the stroke.

I find because of my nursing experience that I can accept it, what's happening (5112, wife, baseline)

The second factor identified in influencing carers' coming to terms with the stroke was survivor-related characteristics. This comprised of two elements; the first was the level of survivor recovery from stroke, in which good physical recovery in stroke survivors helped carers to cope with the stroke better.

It has been encouraging that recovery has been so relatively quick. All the experts have expressed the same opinion that she is doing remarkably well, so that is encouraging - that helps to keep one going and at the back of one's mind, one's got the feeling that this isn't something that is going to go on for ever (5094, husband, baseline)

The second was related to the personality of the stroke survivor, in which carers were often able to cope better if their survivors had either a positive attitude to recovery or had a cheerful outlook to their life situation

She's very determined to get better ... she has got a good sense of humour, that helps tremendously, she was not sorry for herself, which is another burden for a carer (5099, daughter-in-law).

Social networks such as friends and neighbours were identified by some carers as essential in helping them to come to terms with the stroke by providing both physical and emotional support.

Well with the help of wonderful neighbours, quite well I should think ...well they would come in everyday. They took me to hospital every day, my neighbours would come in the evening - that sort of thing, so I never felt I was on my own. (5096, wife)

Whilst the above factors (displayed in Table 6.7) were identified as some of the mechanisms helped carers cope with the stroke, there were a small proportion of carers who felt that they had not come to terms with their survivors' stroke.

I don't suppose really I have come to terms with it because I you know, sometimes I feel I don't want to do anything, don't want to do anything at all, I just get really down in the dumps. (5105, husband)

6.7.5. The main role of carers

Content analysis identified the different roles that stroke carers played in the care of their stroke survivor, which is displayed in Table 6.13. This table highlights the diverse role played by carers in caring for a stroke survivor. This involves a wide range of activities, such as looking after their personal care and medical/nursing needs, doing their domestic chores and their shopping, encouraging them with their social activities and activities of daily living and sorting out their financial affairs.

Carers predominantly saw their roles in terms of the physical aspects of care, ensuring that the survivors' needs in personal care and domestic tasks were met. This emphasis on the provision of physical care also reflected traditional ideas of a carer's role. Nevertheless, at six months, carers also played an increasingly important role in encouraging survivors with their daily activities and organising their social activities.

Table 6.13: Frequency of the different roles played by carers at baseline and 6 months

	Baseline	Six months
Total sample in group =	23	31
Personal care	14	25
Domestic tasks	19	22
Shopping	12	13
Medical and nursing care	7	9
Financial affairs	7	9
Encouragement		
- activities of daily living	6	16
- social activities	2	10

6.7.6. Social support

Content analysis (see Appendix XXVIII) showed that family members were often the source of emotional and physical support for these stroke carers. Close family members, such as adult children of the older carers or spouses for the younger ones, were associated with providing both emotional and physical support for stroke carers. Other family members were more likely to provide physical support for the stroke carer.

Non-family members were generally associated with providing physical support for stroke carers, in which neighbours and paid workers were identified as the largest source of physical support. Nevertheless, whilst non-familial support tended to be physical, friends and neighbours were two sources which some carers felt they could go to for emotional support.

There were other sources of support, which carers had accessed and those in close contact with Health Services and Social Services personnel often identified these individuals as a source they could turn to for emotional support. Furthermore, some carers still identified the stroke survivor as the source of their emotional support. Nevertheless, there were a sizeable number of stroke carers who were unable to identify a person for either emotional or physical support.

These results may be related to the degree of social support available to carers. It may be that stroke carers who have lived in East Dorset for most of their working lives and have family and friends within the local area have greater sources of support than carers who initially came down to East Dorset with their partner. This is an important issue as many in my sample came down to the area to retire and may be lacking their network of family and friends. Therefore, I carried out an analysis on sub-groups of carers (at baseline and six months); those who identified family members as sources of both physical and emotional support and those who could not identify an individual and looked at their 'residential status' and availability of children in East Dorset (ED).

This analysis (see Table 6.14) shows that stroke carers who had lived in East Dorset with close family living nearly (9/13) were more likely to have an individual, usually a close family member, who could provide them with both physical and emotional support. Likewise, carers who had retired (4/11) or had recently moved into East Dorset (2/11) without close family were less likely to identify an individual who could provide them with emotional or physical support. This supported the theory that those who have lived in East Dorset for most of their working lives and had family and friends within the local area had greater sources of support than carers who initially came down to retire with their partner.

Table 6.14: Comparison of the residential status of stroke carers by perceived level of social support and availability of close family.

	Person identified for both physical and emotional support	No person identified for emotional or physical support	Total
Local, Family in ED	9	4	13
Retired, No family in ED	3	4	7
New, No family in ED	0	2	2
Local, No family in ED	0	1	1
	12	11	23

Key:
Local – person who has lived in East Dorset during the working life
Retired – person coming to East Dorset specifically to retire
New – person of employable age coming to East Dorset.
Family – close family member living in East Dorset.

6.7.7. Helpful support for the future

An analysis was carried out to check on the types of support identified by carers as being useful in the future, which shows that additional support would not have helped many carers (9/26) to cope with the stroke (see Table 6.15). For those carers who felt that future help would be beneficial, five categories of help were identified. These were; physical help, social support, information, respite and input from the primary health care teams.

Table 6.15: Types of support identified as useful by carers at six months.

Type of support identified	Frequency (n)
Total in sample	26
No help needed	9
Physical help	
- *housework*	*7*
- *support with survivors' personal care*	*3*
- *gardener*	*1*
Social opportunities	4
Information	
- *stroke*	*3*
- *complementary therapy*	*1*
Respite	3
Input from primary health care team	1

Physical help was identified by the largest numbers of carers (11/26). This consisted mainly of additional help for housework, though some carers felt they would have liked assistance in carrying out personal care tasks for the survivor such as bathing or toiletting. The chance to provide stroke survivors with opportunities for some social contact or outings was identified by carers (4/26).

The information needs of some carers were still not being met (4/26). In most of these cases, this was related to the need for more information about the effect of a stroke although one carer would have liked some information on complementary medicine to weigh up their advantages and disadvantages.

My other solution is that something be given out of time about alternative medicines, options being acupuncture for stroke victims and things like that where it's not necessarily stroke victims to make a choice, but that those are around to be aware there are other options of care available (5116, daughter-in-law, 6 months).

The opportunities for some respite would have been appreciate by carers (3/26).

Well a break, I will have to get away from her and that sounds terrible, it's not the way I mean it ... But it has gone on just day after day after day and it is getting very wearying. That's the only way I can express myself by saying that, I am not getting fed up with it but I am beginning to feel the cost, you know physically of continually looking after her. (5052, husband, 6 months)

Finally, a few carers felt unsupported by their local general practitioner and would have liked the surgery to initiate some contact with them.

Well I think it would be nice if the medical people kept in touch with us a bit more, yes. I mean its usually me initiates it and I think they now and again pop in and see if everything is all right. I mean they might get me on a good day, they might get me on a bad day, at least I feel they're aware of us (5036, wife, 6 months)

6.7.8. Future expectation of caring role

At six months, most carers (19/28) were not optimistic that their caring role would improve with time. A further analysis suggested that the carers' level of optimism about the future was related to the degree of recovery seen in stroke survivors at six months. Optimistic carers perceived that the stroke survivor had made significant improvement by six months and in a few cases, had even reached their pre-stroke morbidity levels.

Definitely, I think he'll gradually get back to normal and take a bit of me. I mean even now he can wash up, cups, saucers and plates. (5036, wife, survivor 6 mth barthel - 20)

Likewise, non-optimistic carers felt that the deterioration in survivors' physical health would in turn lead to an increase in the workload of the caring role and hence, a worsening of their role.

Well I'm afraid its going to be worse because he's got this bad heel and it's spread right round ... because he's diabetic that it will be gangrene set in there you see, because it's black right round the back of the heel, of course the doctor when he came on Wednesday, I said to him about it, he said it's all caused by pressure. (5096, wife, survivor 6 mth Barthel score - 7)

It may be that optimistic carers were supporting stroke survivors who were less disabled than non-optimistic carers. To investigate this theme, I carried out an analysis of the six month Barthel scores with the four different categories of optimism/non-optimism identified by content analysis. This analysis (see Table 6.16) shows that the optimistic carers were more likely to care for survivors who were less disabled (median BAI: 17; IQR; 15-19) than the other non-optimistic group of carers. This further supported the finding that carer optimism for the future was affected by the disability level of stroke survivors.

Table 6.16: Comparison of the median scores and inter-quartile ranges of survivors' 6 months Barthel score (BAI) between optimistic carers, no improvement carer, pessimistic carers and uncertain carers (n=28)

Group	Number in group	Median	IQR
Optimistic	9	17	15-19
no improvement	6	9.5	5-11.75
Pessimistic	7	15	10.5-17
Uncertain future	6	16	14.5-18.25
Total sample	28		

6.8. The relationship between the qualitative (content analysis) and quantitative data

The use of combined methods enabled me to explore two different aspects of the same area. The quantitative results showed that the different methods of service delivery had little impact on carers' quality of life. My qualitative results, by exploring the process of health care, helped me to understand why these services had minimal impact on carers' quality of life. My results highlighted carers' appreciation of the services and identified many advantages of both the domiciliary stroke teams and the day hospitals for themselves. Nevertheless, carers ultimately viewed the main goals of therapy services as improving survivors' functional outcomes and not in meeting their own needs. This may in turn explain why neither method of service delivery had much impact on carers' quality of life.

Combined methods also enabled me to use the quantitative data to support my qualitative results in a process of triangulation in a number of areas. I showed that carers reporting difficulty with physical tasks were in poorer physical health (using PCS scores). I established that survivors' level of disability (using the Barthel Activities Index) influenced both carers' expectations for the future and the amount of time the survivors could be left unsupervised. Finally, I found that carers who reported that caring was a continual commitment with little time for themselves had poorer mental health (using the MCS of the SF-36), greater psychological morbidity (GHQ) and greater carer strain (Carer Strain Index).

6.9. In-depth thematic analysis.

I carried out an in-depth thematic analysis on a sub-set of the qualitative data. This process is described in Chapter 4. Three main themes emerged from the data, which may have a potentially important influence on how the impact of caring for a person with stroke affects carers' quality of life. The first theme was the degree of disruption to carers' life, whilst the second was the loss of shared activities with the stroke survivor, a theme more relevant to carers who were married to the stroke survivor. The third theme is social support, in which family, friends and neighbours may also play an important role in helping carers both physically and emotionally, though the degree of this support may be affected by geographical and psychological factors. In addition, my analysis identified the main themes which carers from both domiciliary and day hospital arms found useful in helpng them cope with caring for a person with stroke. Finally, my analysis identified types of future help which may support carers in their caring role.

6.9.1. Disruption to carers' life

The degree of disruption to the carer's life was a theme, which affected all groups of carers. This degree of disruption may in turn be influenced by survivors' functional status. It may be that survivors who were physically more disabled required more support from their carers in areas of personal care such as toiletting and bathing. These tasks are both physically demanding and time consuming and may challenge the coping mechanism of carers. Hence, the time carers' spend in their caring role was partially related to the functional disability caused by the stroke. Carers of survivors with severe levels of disability were therefore more likely to be involved in the physical aspects of care such as toiletting and bathing when compared with other types of carers. This in turn reduces the amount of time that carers have for themselves and leads to an adverse effect on their quality of life. At one extreme, carers found it stressful if they had spent their whole day geared towards organising the care organisation of the survivor with little or no time for themselves or their own interests.

life isn't my own now it belongs to him. I've got to, everything I do has got to be revolved round him. I can't go out unless he's gone to a Day Centre ... I can't get things done indoors because he takes up so much time. For instance, it takes me at least 2 hours from the time of him waking up to when he finally finished all his toiletries and washing and dressing and everything in the morning. Again at night *is a good hour by the time he's been washed and changed and into bed (5066, domiciliary, wife, survivor BAI - 4).*

On the other hand, many carers supporting survivors with little residual disability found that their caring role had little impact on their lives. These role changes were mainly administrative such as dealing with the finances, picking up the pensions from the post office and other paperwork matters and these carers found that their life had not significantly altered to what it was like before the stroke.

it's just been not a lot of difference except that there's different little things that I have to do that he doesn't do now because he's not able to, like writing the cheques, paying the bills (5036, domiciliary, wife, survivor BAI - 20)

Nevertheless, whilst the level of functional disability in the survivor may be important in determining the nature of the caring role, functional disability per se may not be the over-riding factor in influencing the impact on carers' quality of life. More important factors may be carers' perception of the survivors care needs and the level of support that carers thought they needed to provide for survivors. Further analysis suggested that there were no general trends determining this and that these perceptions were dependent on the individuals concerned. One daughter had provided her mother with much of her personal and domestic care needs, although this person had a mild disability as a result of her stroke. She also felt anxious about leaving her mother alone due to the recent falls she has had.

Yes I do, not because I'm saying she expects it from me, I just feel that I should be there because, well because I worry about her. I do worry about her because she's so unsafe now ... she's had a good many falls you know, so I feel if I'm with her, at least she's not falling over. Yes it has affected my private life. (5100, day hospital, daughter, survivor BAI - 19)

Likewise, differences in individual carers may exist in the way they feel about their caring role. Whilst many carers had talked about caring in negative ways, such as the restrictions that caring imposed on their life, one carer talked about his caring role in positive terms. He was happy to be providing his wife with good quality care, which in turn increased his confidence with his new role.

I didn't feel too sure of myself at first, but now I can see how well I am doing, I'm quite proud at the way my wife is looking, she's very happy at the way I'm taking care of her (5131, day hospital, husband, survivor BAI – 8)

6.9.2 Shared life themes

The ability to share life together was particularly relevant for carers married to the stroke survivor. This may stem from the belief that marriage was a partnership where couples strive to work together, expressed by sharing in activities or both being involved in the decision making process.

We go together, well we're married aren't we and if it can be, I think you should do things together ... Maybe it's an old fashioned way of thinking, I don't know but that's how we work it. (5123, wife, day hospital, survivor BAI @ 6 mths - 12).

Quality of life for these carers may be related to the degree that they were able to share life together with their partners following the stroke. Data analysis identified two aspects of the relationship, which may be important in determining the effect on carers' quality of life. These were the loss of shared decision-making and the ability to share activities together.

6.9.2.1. Loss of shared decision-making:

Decision sharing forms an integral part of any marriage relationship. Any event which reduces the capacity of one partner to be involved in the decision-making process potentially puts more pressure on the remaining person, who has to shoulder that responsibility. An event, such as a stroke, can lead to cognitive dysfunction of the survivor. This cognitive dysfunction can take many forms, either a loss of short-term memory or an inability to communicate with others (either expressive or receptive dysphasia), all of which affects survivors' ability to take part in the decision-making process. Carers of survivors with dysphasia in particular expressed their difficulties in coming to terms with their inability to communicate with their partners.

I'm finding it more and more difficult the days when I'm completely on my own because his speech, you know if he wants me to do something you can't immediately understand, it's frustrating, you know (5084, domiciliary, wife, survivor BAI – 8)

It may be that the added responsibility of making all the decisions by themselves, may further compound the problems facing carers. One wife described how she and her husband used to share all the decision-making, but since the stroke, all the decisions had been left entirely on her shoulders.

Another thing I find very difficult if you've got no-one really to have a conversation with, discuss things with, sort of choosing birthday, Christmas, things like that it's all down to you ... Well when you've have 45 years, 46 years of doing it together, it comes a bit hard. I mean I've always helped. It's always been discussed and everything and after all that time it comes a bit difficult. (5066, wife, domiciliary, survivor's BAI - 4).

6.9.2.2. Ability to share activities together

It may be important for carers to be able to share some of the activities that they used to do together before the stroke occurred. There may be a combination of several reasons why the joint participation of social activity by both carers and survivors may have a positive effect on the former. It may indicate progress being made by the survivor, a potential reduction in the caring role for carers or a gradual return to pre-stroke lifestyle. Hence, the opportunities for married couples to take part in some form of shared activity after the stroke may reduce the negative impact of caring for a stroke. One carer, a husband caring for a wife with a severe disability, was pleased about the fact that they were both able to go out for a social evening and compared it to the type of life he shared with his wife before the stroke.

She used to do a lot of dancing, she can't do that now but I take her to watch and I'm taking her out tonight to the Caledonian Society where she can watch all the people dancing ... I'm taking her out tonight and we're going to the Stroke Club tomorrow afternoon, so we're leading a social life again and there's a friend of ours picks us up every Sunday morning and takes us to Church so we're leading very much the same sort of life now (5131, husband, day hospital, survivor BAI - 8)

Likewise, sharing social activities may be a way for carers to enjoy some of the things they used to do with the survivor. The inability to do these things and to restrict their life together in terms of providing care for the survivor may cause some bitterness in carers. One husband described his disappointment at not being able to go on holiday with his wife, an activity that he had always done with his wife.

I have been trying to get her to go on holiday, I mean I do like to go away to the sun and so does she. We used to go on holiday regularly every year, sometimes twice a year if we can afford it and I have been looking forward to getting away this winter, because we usually go in October and I asked her about a holiday. She says I am not able to go on holiday now, "I wouldn't want to go", so, I mean, this is going to be a bit of a blow if I can't even get a holiday with her (5052, husband, day hospital, survivor BAI - 16).

6.9.3. Social support

The term 'social support' was used in this study to signify any additional person or group of people (not paid directly by the carer) who provided support for the carer in caring for the survivor. For many carers, this additional network of family and/or friends supported the carer in two ways. The first was in a physical capacity, such as helping with the shopping, other domestic chores or providing a sit-in service if the carer needed to pop out for an hour or so. The second was in an emotional capacity, providing carers with the knowledge that someone was around to talk with if needed. Many carers found this source of support useful in helping them to cope with the stroke.

I'm more confident now than I was a few weeks ago when I just thought I'm fighting a battle here alone and then my children came round and they said, "Dad we're right here behind you, if you need any help or want us, we'll be here", and my daughter comes over several times a week, from (name of village) and she helps me a lot (5131, day hospital, husband, survivor BAI – 8).

The composition of this network varied. Adult children tended to provide the bulk of this support for older carers (mainly spouses of the stroke survivor), but other sources of support from neighbours and friends were available if required. Carers without any close relatives living in the area could sometimes rely on their neighbours to do tasks like shopping and sitting in with the survivor. Younger carers (mainly the adult children of the survivor) tended to rely on their partners for this support (if they were married) and generally did not have any physical problems with their health.

Social support was not restricted solely to blood kin and friends. Many carers identified health professionals or Social Service personnel as great sources of support. This may be for several reasons: many carers were appreciative of the care that they were getting on behalf of the survivors, especially if they (the survivors) were making physical improvement. One carer mentioned that speaking with a health professional, helped her get her problems off her chest instead of being bottled up. Another carer found it useful to have a helpful contact at the Housing Office, who would go through the forms and help them to relocate to more appropriate housing in the near future.

For some carers, the main factor limiting the availability of social support was the location of where the carer lived in relation to other people who could provide this support. In particular, physical support of a temporary nature may be difficult to provide if the carer did not live nearby to the children and they did not have close links with the neighbours. This may be a particular issue for areas such as East Dorset and the whole South West of England where many carers moved down to retire, but leave their social networks behind.

There's family, they don't live locally. They come as much as they can. Two daughters and son. My daughter live in Sussex and my son lives in Plymouth (5126, day hospital, husband, BAI –12).

Even if this support was nearby, there may be psychological barriers why carers were reluctant to involve others with this care. One carer knew that she could rely on the support of her children who lived locally to her, if there was an emergency. However, she was reluctant to involve them further because she felt that they had their own families to worry about. Furthermore, she was also unwilling to discuss any problems concerning caring for her husband, because she felt it would have been awkward discussing problems about their father.

they just say, well I once if anything like that goes wrong again, just phone and let us know and we'll come round, you know. But it's a bit difficult to sort of say things about their father, do you know what I mean (5033, day hospital, wife, survivor BAI – 12).

Whilst most carers could identify some social support, there were a few who did not have any social support available to them. A daughter caring for her mother, did not feel if she was able to share any problems with her husband, whom was a busy man running a business.

I think my husband's got enough worries and responsibilities with running his business and that. When he comes home from work at night, he doesn't want to hear me you know, either having a grizzle or a mutter about it, so I don't really discuss it with anybody...It's all held in here (pointing to herself) (5100, day hospital, daughter, survivor BAI – 19).

On a different angle, there were couples who both shared in the care of the stroke survivor. In my study, an example of this comes from a daughter-in-law and her husband, who was the survivors' son. Both share in the care of their mother, but both play different roles. The daughter-in-law was responsible for organising the day to day general supervision, including social activities and meals, whilst the son was responsible for the legal and financial matters concerning her mother.

6.9.4. The impact of the different methods of service delivery on carers' quality of life.

The quantitative results suggested that there was little difference in any of the quality of life outcomes between the domiciliary and the day hospital groups. The in-depth analysis found that carers benefited from both methods of the different service deliveries they received.

6.9.4.1. Domiciliary stroke teams

Carers receiving indirect contact from the domiciliary stroke team, saw the main benefits mainly in terms of education and in greater convenience. Carers, especially those living with the survivor, stressed the importance of being involved in the therapy, gaining knowledge from the therapist and having the opportunity to ask questions.

Well it's better at home I would think, I mean I can see what's being done and know what's being done whereas if he was at Alderney or anywhere, I wouldn't know much about it (5114, domiciliary, wife, survivor BAI – 17)

In addition, carers in the domiciliary group found it more convenient and comfortable for both themselves and their survivors to have the therapy done at home. Carers perceived that survivors would not like the disruption of preparing to go to the day hospital.

it's easier for us because we didn't have to turn out and it was more relaxed for him, you know he did, he felt that he could ask questions, say and do things, he had more control over events if even if they were in his own house. (5102, domiciliary, son, survivor BAI – 19)

6.9.4.2. Day hospital

Carers receiving indirect contact from the day hospital saw the benefits mainly in terms of social benefits of the day hospital. Carers in particular appreciated the respite elements of the day hospital. They saw the day hospital as a legitimate form of respite, which provided an opportunity for many carers to have some time for themselves and to catch up with things like the shopping or the household.

it was nice for me because I knew she, when they picked her up until they dropped her off, she was in safe hands, so it was a relief for me because I haven't, that day is what I call my day until she came home because I didn't have to worry about her (5100, day hospital, daughter, survivor BAI – 19)

Respite was particularly appreciated by carers who felt restricted because of the large amount of time spent caring for the survivor. One carer, whose survivor was initially receiving domiciliary care, but decided to switch to day hospital after 5 months because of the perception of better equipment, was pleased to have the opportunity to have half a day to herself. This person could therefore see the advantages that both the domiciliary and day hospital services could provide her, but ultimately decided that she appreciated the respite time more.

Freedom for a few hours and that is precious. That is the advantage (5066, day hospital, wife, survivor BAI – 4)

Another element of day hospital care that carers appreciated was the opportunity for stroke survivors to mix with others in a similar situation, the chance for them to share experiences with each other and to encourage each other to improve their rehabilitation outcomes. Many had felt that the day hospital had given some purpose in life back to the survivor.

Going there, she meets other people in a similar situation which helps when you're on your own, the only person with this disability so she enjoys meeting people at the day hospital, talks a lot with particular friends from the village (5126, day hospital, husband, survivors' BAI – 12).

Nevertheless, many carers expressed the main drawback of day hospital was getting the survivor ready for the early morning pick-up.

if she's having to do something for a certain time, she gets herself in a state and then her hands start shaking and she can't do her buttons up or whatever, so I used to be at her flat by 8 o'clock at the latest so that I could get her dressed and ready for when the ambulance came to pick her up at 9 o'clock or whatever time after that (5100, day hospital, daughter, survivor BAI – 19).

6.9.5. Future help

There were two main categories of future help identified by carers. These were respite care and physical support. In addition, individual carers identified issues such as the need to be better informed about the nature of strokes and the importance of being followed up by primary care teams.

6.9.5.1. Respite care

This theme was identified by a group of carers, who were experiencing high levels of stress as a result of caring for their stroke survivor. These carers, supporting stroke survivors with severe functional or cognitive dysfunction, often felt that they had little time for themselves. Hence, carers whose lives were severely disrupted by the stroke tended to feel that they needed respite more than carers who were relatively unaffected. Carers in this situation often looked forward to the next period of respite for the survivor. For them, respite was an opportunity for them to have some time for themselves, whilst other people took on the main physical caring tasks.

Yes, I was able to go to bed when I wanted to in the evening. In the old days I used to always go to bed first. Now I can't. It was such a joy, sometimes I'd be asleep when they put him to bed, sometimes I wouldn't but it was such a joy to just be able to go, I'd just be on my own for a bit and then to bed (5084, domiciliary, wife, survivor BAI – 8).

6.9.5.2. Physical support

In an ideal world, carers would like to have additional physical support to help with odd jobs around the house as it would leave them to spend more time with the survivor.

it's only if you're well off and you could say to somebody, oh come in and do all the housework and I'll just sit with him (5036, domiciliary, wife, survivor BAI – 20).

Most commonly, it was domestic jobs like gardening which people required additional help for. The garden had been the responsibility of one person until the stroke had prevented them from continuing with it. Nevertheless, there was a pride amongst many carers to carry out maintenance work to keep the garden looking neat. Carers did not have a problem paying money for tasks like gardening, but had misgivings about the high costs and finding a reliable person.

there's one coming tomorrow, it's going to cost me £60 odd to get my garden in order, you know so I don't want anything for nothing but I think that's a lot of money (5123, day hospital, wife, survivor BAI – 16).

Another emergent theme was the importance of how this physical help should be delivered to carers and survivors. Many carers entitled to home help felt unsatisfied with the way that this care was delivered by Social Services. This dissatisfaction centred on the inconvenient times that the home help were sent to the carers, which were geared to fit in more with service needs as opposed to providing convenience for the carer. Hence, carers often found these packages of greater inconvenience, especially those organised in the morning, than help and often discontinued them as soon as they felt comfortable to do so.

when he first came out of hospital, the very first time I was having a carer to get him up and put him to bed but it wasn't successful. I couldn't get them to come at times that suited me or him, so once the physio said that I could manage to transfer him and get him in and out of bed, then I'd dismissed them and I've managed on my own ever since (5066, day hospital, wife, survivor BAI – 4).

6.9.5.3. Other forms of help

Most carers in this sample were relatively new to the caring role as this was the survivors' first stroke. Hence, not much can be said about the long-term needs of these carers. However, some insight can be gathered by the experiences of one carer, whose husband had had his first stroke four years previously. Her main complaint was the lack of contact she had with the local General Practitioner, which made her feel isolated. Whilst she accepted that they were busy people, she felt that some contact initiated by them would have been very supportive to her.

I think it would be nice if the medical people kept in touch with us a bit more, yes. I mean it's usually me initiates it ... I know they're busy, I think you know, every so often, somebody should phone up and say about once in every three months or so, but they make the initiative and come see me (5033, day hospital, wife, survivor BAI – 12).

6.10. Summary of the qualitative data

My results showed that carers saw three main advantages of domiciliary stroke teams: a) the comfort and convenience they provided for both survivor and carer, b) the opportunity for carers to be better informed and educated about the therapy process and c) designing a therapy programme specifically for the home environment. In particular, domiciliary stroke teams may have improved carers' understanding of therapy and carers in particular, felt it was important for them to be involved in the therapy process. On the other hand, the strengths of day hospitals were seen in terms of respite time, the opportunity for stroke survivors to meet other people with stroke and the centralised provision of health care. In particular, carers stressed the importance of having some time to themselves for their quality of life, an opportunity for them not to think about their caring role. However, carers saw the ultimate aim of these services as improving survivors' functional outcomes and hence, carers' satisfaction with services was ultimately dependent on survivors' level of recovery.

My analysis did not show any qualitative differences between the two groups of carers in regards to the impact that caring had on their quality of life, but identified several themes, which were common to both the domiciliary and day hospital carers. Firstly, the level of survivor's disability may determine the amount of time that carers could leave them. This, in turn may influence the impact on carers' level of social functioning. Survivors' disability may also have an impact on carers' expectations for the future, in which carers had poor expectations of the future if the survivors had moderate levels of disability at six months. Secondly, the way carers initially came to terms with the stroke may depend on the amount of knowledge they had concerning the effects of a stroke, the manner in which the survivor dealt with the stroke and the degree of social support available. Carers' longer term ability to cope with the caring role may be affected by three factors; one, psychological changes in the survivor as a result of the stroke, two, the quality of the relationship with the survivor and three, the inability to communicate with the survivor.

Furthermore, in-depth analysis has shown that the impact of caring for a stroke on carers' quality of life may be dependent on: a) the level of disruption to carer's own life and, b) the ability of both carer and survivor to share together some aspects of their life (the second theme may only be applicable to carers married to the stroke survivor). Survivor variables in turn may play an important role in influencing these factors. Survivors' functional disability may influence the amount of support that carers need to provide, whilst survivors' cognitive dysfunction may influence the degree to which they can participate in joint decision-making with the carers. Nevertheless, other individual carer characteristics, such as the quality and nature of the relationship between survivor and carer, and carers' own perception of what survivors' needs are, also have an influential effect.

Carers played a diverse role in supporting survivors with a wide range of needs. They predominantly saw their role as providing for the physical aspects of care, but were also playing an important role in encouraging them with their daily activities and social life by six months. Many carers had a social network of close family, friends and neighbours who provided a mixture of social and emotional support. A breakdown of this support showed that close family members tended to provide social and/or physical support, whilst non-familial support tended to be physical help. The availability of close family was dependent on carers' personal circumstances of whether they had come to retire in East Dorset or if they had lived there during their working life. In-depth analysis also illustrated that this source of support was greatly appreciated in helping many with their role as carers.

Finally, many carers did not feel that any future help was needed to help them cope, but those who did mainly identified physical help. Respite care was also identified by a small group of carers supporting survivors with severe cognitive and functional disabilities. This group of carers felt it was important to have this care available to provide them with a break to recoup both the physical and mental strength to enable them to continue with their caring role. Regular contact with a member of the primary health care team may also be an important source of support in considering the long term needs of stroke carers.

CHAPTER 7: DISCUSSION

7.1. Outline of chapter

The aim of this chapter is to deal with the following five areas: firstly, to summarise the main findings from this study, to compare the results with previous studies and to highlight the contributions this study has made to the overall literature on stroke carers. Secondly, to highlight the strengths and limitations of the methodologies used in this study and the problems of using a combination of quantitative and qualitative methodologies. Thirdly, the ways in which future research on stroke carers could be carried out. Fourthly, the implications that this study has for future health policy and possible developments for the delivery of care to stroke carers and finally, a summary is given of the main points raised.

7.2 Highlights of the main findings

7.2.1. The impact of the two methods of care provision on carers' quality of life

This exploratory study was one of the few to date that has specifically looked at the impact of health service interventions on carers' quality of life. It had, unlike the previous ones looking at domiciliary and day hospital stroke rehabilitation (Gladman et al, 1992; Young & Forster, 1991), evaluated not only carers' psychological health, but other dimensions of their quality of life (QoL). Hence, the first research question was concerned with whether the domiciliary stroke team brought about any significant improvement in carers' quality of life compared to the day hospital. Quantitative results have suggested that neither method of service delivery brought about any long-term clinical improvement in carers' quality of life. A detailed analysis of carers' different QoL domains showed that the domiciliary team brought about some short-term clinical improvements in psychological health and may have a buffering effect in reducing the deterioration in physical health at six months. The 12 month results showed no subsequent improvement in the psychological health of these two groups of carers, with a slight improvement in physical health in favour of the day hospital. Both services had only a minimal impact on carers' social functioning. Furthermore, none of the differences between the two groups reached statistical significance.

These results may support the null hypothesis which suggested that both methods of service delivery had limited impact in bringing about clinical improvements in carers' QoL, and so supported other studies (Gladman et al, 1992; Young & Forster, 1991), which found no long-term impact on carers' psychological health. Furthermore, these results would suggest that caring for a person with a stroke has its main impact on the psychological health of carers, with less impact on their physical health and social functioning. One explanation to the lack of improvement in QoL may be attributed to the aims of these service interventions, which was directed at the rehabilitation of stroke survivors, not the improvement of carers' QoL. This is not to say that the occupational therapists and physiotherapists responsible for delivery of this health care did not have the therapeutic skills to bring about improvement in carers' QoL, but the philosophy of these services centred on stroke rehabilitation for the survivors.

This study has suggested that neither the domiciliary stroke team nor the day hospital brought any change in carers' QoL. One question this raises is the possibility that indirect therapist contact may be beneficial in preventing a deterioration of carers' QoL. It was not the aim of this study to evaluate this research question, but a recent trial (Walker et al, 1999) has looked at the provision of occupational therapy (OT) for stroke patients not admitted to hospital. These findings showed that whilst having OT was beneficial for improving patients' activities of daily living, there was no significant difference in the psychological health of their associated carers' between those receiving or not receiving therapy. These results would suggest that carers' contact with health services do not act as a buffer against the deterioration of psychological health.

Alternatively, the small sample size increases the likelihood that this study was under-powered. This in turn increased the possibility of a Type II error occurring, which means that the null hypothesis cannot be rejected, as a statistical difference between the two groups may exist if the study had greater power. This is an important issue for the 0-6 month findings, as clinical differences in psychological health were found between the domiciliary and day hospital groups. It may be that a statistical difference also exists between the two groups in psychological health, but would require the study to have greater power to detect it.

7.2.2. Carers' perceptions of the different methods of service delivery

The qualitative study highlighted the elements of care from the two different services which carers found beneficial. Domiciliary care was convenient to both carers and survivors, as both parties did not have to prepare to go out to the day hospital. This result supported parallel findings by Stephenson & Wiles (2000), who reported that patients receiving domiciliary therapy found it convenient and comforting. In addition, this study found that domiciliary care also provided carers with greater educational opportunities to meet regularly with therapists. In turn, this transference of skills increased carers' confidence in supporting and encouraging stroke survivors with their rehabilitation. Hence, this study indicated that domiciliary stroke teams might have provided carers with the confidence and skills to support stroke survivors in their rehabilitation and could have provided carers with some degree of empowerment. These results ran parallel to findings by Ballinger et al (1999), which showed that domiciliary therapists saw it as one of their functions to educate carers in the rehabilitation process. Nevertheless, this increased confidence and knowledge did not extend to improving carers' ability to cope with their caring role.

Day hospitals, on the other hand, played an important social function, providing many carers with much-needed opportunities for respite away from the caring process and the chance to have some time to themselves. Whilst this was valued by all carers, the respite element was particularly appreciated by carers supporting survivors with severe cognitive and functional disability and who were finding their caring role stressful. Furthermore, carers viewed day hospitals as venues for stroke survivors to mix with other people with stroke. Many felt this would encourage survivors to compare with each other and improve their rehabilitation outcome. Nevertheless, whilst this respite was appreciated by carers by providing time to themselves, these findings showed that day hospitals did not bring about any improvements in terms of carers' QoL or the way they coped.

The qualitative study enabled carers to identify elements of care, which they found useful from both methods of service delivery. Day hospitals provided carers with respite opportunities i.e. to have a regular period of time to themselves. Domiciliary stroke teams provided carers with greater educational and training opportunities and this in turn facilitated better understanding of the rehabilitation process and may increase survivor adherence with the rehabilitation exercises. Hence, this qualitative study was able to give a more detailed description of the important components of service delivery, one of the few studies to date which have attempted to describe the diverse nature of health service interventions. Carers were also appreciative of the services their stroke survivors were getting, a finding similar to a study by Dowswell et al (1997) looking at specialist nurse intervention. Nevertheless, carers ultimately saw the main aims of stroke therapy as improving the physical and functional status of stroke survivors and not their own needs. Hence, carers' satisfaction with the service provided was related to the degree of physical improvement made by their stroke survivor and not the benefit that it might have brought to them, further evidence that neither method of service delivery was geared to the needs of carers.

These results also indicated that health care needs to be directly delivered to carers if it is going to tackle some of the psychosocial issues facing them. Nevertheless, the few studies which have specifically looked at various carer interventions such as a designated family social worker (Dennis et al, 1997) or a community support worker (Forster & Young, 1996), have found these have generally not been effective in improving carers' QoL.

7.2.3. Factors influencing carers' quality of life

The qualitative data was analysed in two ways. The first was the use of a triangulation process to understand the processes and factors affecting QoL. This involved using the qualitative data from the content analysis as a way of explaining the findings from the quantitative results and the results were analysed by three domains of QoL. The second was the use of an in-depth thematic analysis to gain a deeper insight on how the factors may interact with each other in influencing QoL.

7.2.3.1. Social functioning

Initial data from the quantitative study suggested that carers had active levels of social functioning at one year. A closer analysis of the different sub-scales (of the Frenchay Activities Index) showed a slightly different picture, with carers becoming increasingly involved in domestic tasks and shopping, but with a reduction in the amount of leisure activities they engaged in. These findings were consistent with Anderson et al (1995) which showed that caring for a stroke survivor has a detrimental effect on social life. This study, like Periad & Ames (1993), indicated that carers, especially those who lived with the survivor, were more likely to take the leading role on domestic chores as a result of the survivors' disability.

In addition, qualitative data suggested that carers' social functioning may be related to the amount of supervision that carers felt stroke survivors needed to remain safely at home. Hence, carers felt more restricted if survivors required more supervision than those who needed less. The results also suggested that the degree of supervision required may be related to survivors' degree of disability. Hence, this study supported findings by Purk & Richardson (1994), who found a relationship between carers' morale and survivors' physical disability. Nevertheless, supervision was not the only factor influencing carers' levels of social functioning. Many older carers attributed a reduction in their social life as a sign of a general slow-down in their life due to old age.

7.2.3.2. Physical health

Quantitative data showed that carers' physical health were similar to an age-related sample of the general population at one year post-stroke. This finding, together with Forster & Young (1996) study on a specialist out-reach nurse intervention, suggested that these interventions had no impact on carers' physical health. However, whilst caring may have little impact on carers' physical health, the physical health status of carers was important in determining how able carers were in carrying out roles that carers were expected to do. A recent study by Bugge et al (1999) has shown that carers' health was significantly associated with carers' stress. This study has shown that carers in poor physical health often found it difficult to carry out the more physical aspects of caring such as bathing and transfers, an important fact if their survivors had severe residual disability. Hence, as the physical health status of carers was often related to the carers' age and as many carers in this study were spouses aged 70 and over, so many experienced difficulties with caring. It may be that inability to carry out these physical tasks has an adverse psychological impact on these carers. Furthermore, this study, like Greveson et al (1991), found large proportions of carers reporting inadequate sleep, a factor identified as contributing to the physical difficulty of the caring process.

7.2.3.3. Psychological health

The quantitative study may have shown a slight improvement in carers' psychological health at six months in favour of the domiciliary stroke teams. These findings still showed that carers (irrespective of the type of rehabilitation received) had greater psychological morbidity, higher levels of carer stress and poorer mental health status when compared to the general population. This finding supported previous studies (Ross & Morris, 1988; Anderson et al, 1995*)* and further illustrated the psychological impact that caring had on stroke carers.

Qualitative data suggested that carers' psychological ability to cope may be related to three main factors:

1) survivors' degree of cognitive impairment following the stroke, in particular factors, such as short-term memory loss, personality changes and dysphasia.
2) the quality of the relationship between carers and survivors before the stroke
3) survivors' refusal to acknowledge their level of disability.

Data triangulation showed that carers who reported subjective feelings of continual commitment and little space as a result of the caring process may have poorer mental health, greater levels of stress and higher levels of psychological morbidity than carers who did not report these experiences.

7.2.3.4. Other factors identified in thematic analysis

There have been few studies, which have specifically looked at the qualitative impact that caring for a stroke has on carers' QoL. This was one of the few studies to tackle this issue. Hence, my in-depth thematic analysis was aimed to complement the content analysis in providing a different perspective on how caring for a person with stroke may affect carers' QoL. This analysis suggested that carers' QoL may have been affected by two factors: a) the disruption caused to carers' own life as a result of the stroke and, b) the inability of carers and survivors to share aspects of their lives together, a theme more relevant to carers married to the stroke survivor. Within this framework, survivors' variables, such as the level of their physical and cognitive dysfunction, may be influential on these factors, although other individual issues, such as the quality of carers' relationship with the survivors, may also play an important role.

7.2.4. Factors identified in how stroke carers cope

Previous studies have tended to look at the use of psychological interventions to identify if these improved carers' ability to cope (Low et al, 1999). This study took one step back by identifying the factors that helped carers to cope in their role as carer. It identified four main themes: fatalism about the stroke, knowledge about the impact of stroke, social networks and the degree of survivors' recovery from stroke. In addition, many carers did not identify any additional resources that they felt would have helped them. Of the carers who did, the most common themes were the need for physical help, greater opportunities to go out socially and more information. The findings on information supported previous studies (Greveson & James, 1991), but interventions aimed at improving carers' knowledge about stroke have had little impact in improving health outcomes (Rodgers et al, 1999; Casas, 1989). This result may suggest that it is only by having previous practical experience of caring for a person with stroke, that carers have the confidence to know what to do in certain situations and so feel more in control. However, other factors, such as social networks and the degree of survivors' disability, also contributed to how well carers coped. This study found that carers who were less optimistic for the future were those caring for survivors with severe to moderate levels of functional disability.

7.2.5. The impact of survivor variables on carers' quality of life.

One of my research questions was interested in investigating which survivor variables have an influence on the different domains of carers' quality of life. I initially considered using a regression analysis as a way of developing a predictive model to look at this question. It was not possible to use this method of analysis in this study due to the small sample size (for full explanation, see Section 4.5.2, p.102). Nevertheless, the qualitative study (see Section 7.2.3.1, p.208 and Section 7.2.3.3, p. 209) highlighted several interesting findings. One, the level of survivors' disability may influence the degree of supervision which carers gave to them. This in turn affected carers' social life and their ability to go out. Two, carers' psychological ability to cope may be affected by the degree of survivors' cognitive impairment, the quality of their relationship and survivors' acceptance of their disability as a result of the stroke, findings which were supported by Anderson (1992).

7.2.6. Carer sample

The carer sample recruited in this study was identified from stroke survivors participating in the Dorset Stroke Study (see Chapter 3). Hence, this sample was not representative of all stroke carers, and meant that the findings were only applicable to carers of survivors with moderate to severe levels of disability requiring post-hospital stroke rehabilitation. In other respects, the sample from this study was similar to those found in other studies who identified carers as the main provider of emotional and physical support (Low et al, 1999). This study, like Anderson (1992) found that carers saw their role mainly in supporting survivors' needs in personal care and domestic tasks. This study found that the majority of carers consisted of spouses and partners (73%) and was predominantly female in its gender distribution (68%). Furthermore, as these carers were recruited from a community sample, the problems of bias associated with volunteer groups were not a major issue. The problem with volunteer groups are that they are unrepresentative of the general carer population as they tend to be highly motivated and determined individuals.

When compared to other studies looking at carers and stroke services, this study was one of the few to give a full demographic description of the carer sample used and a definition of what was meant by an 'informal' carer. A sample size of 60 in this study was also higher than most studies looking at the impact of stroke (number of studies n=13; median sample size = 44), studies looking at coping (n=5, median = 50) and studies looking at carers' perceptions of stroke services (n=6, median = 38). The sample size was similar to the number of carers recruited to both the Bradford (Young & Forster, 1991) and the DOMINO (Gladman et al, 1992) studies and only the two psychosocial interventions (Dennis et al, 1997; Young & Forster, 1996) recruited more than 100 carers.

The findings of this study showed a hierarchy of which relatives became the main carer, with spouses and partners seeing themselves as firstly responsible for the main care of a survivor. The gender imbalance between husbands and wives may reflect the demographic trends of women living longer than men. When no spouse or partner was available, the female adult children of the stroke survivor, such as daughters and daughters-in-law took on this caring role. There were very few male carers (other than husbands and partners) in this sample, a trend reflected in other carer studies (Low et al, 1999). It may be that males of working age do not traditionally see themselves as carers. This may partly be due to the lack of their free time outside work. The two males who were in this study were not employed. The social class bias in the sample (65% of all carer participants came from social class I to III non-manual) may highlight the fact that people from non-manual background were more likely to take part in a research study than those from lower social classes. Unfortunately, very few studies on stroke carers have given details of their participants' social class. However, this social class bias may have implications for the generalisation of the quantitative results, as there are unique differences in the way the different social classes utilise health service resources.

This study showed that carers who had lived in East Dorset during their working life and had close family living in the area were more likely to have additional social support for themselves than carers who had retired to East Dorset. These non-local carers were less likely to identify an individual who they could turn to for support. The issue of support structures is an important one as the UK population is becoming older and with social trends showing the move of older people away from the major cities towards retirement areas such as the South Coast of England. Hence, many of these people face social isolation with this move away from close family and friends if they become future carers. This has potential social policy implications as additional resources may be needed to support these carers, especially in areas such as East Dorset, which has a higher proportion of people over 65 years compared to the national average.

Selection bias in this study may have arisen from the low response rate of 60 participating carers out of the potential sample of 106. These results showed that the majority of the 46 non-responders were not contactable, which suggested that this group of carers were at work when the telephone calls were made to try and establish contact. These findings suggested two possible explanations: the first was that this study was not identifying carers who were in employment and would not be at home during the researcher's working hours of 9:00AM to 6:00PM. It may be that this study, like previous studies were neglecting an important sub-group of carers who were in employment. A second explanation could be related to the fact that many of the non-participating carers were not technically 'informal carers', but were named in this role because they were the adult children of these survivors, who were recognised as the next of kin. The researcher set about minimising this potential problem, by providing each participant from the Dorset Stroke Study a definition of what he meant by an informal carer. There is also the issue that we assume there is a 'main carer', but in some circumstances, responsibility for caring is more diffuse and complex, with both family and friends involved in the provision of care.

7.3. Critique of the methodology

7.3.1. Quantitative study

This study contained several features that enhanced validity and reliability and so made it compare favourably to previous studies looking at stroke carers. The first feature was the use of a randomised control trial design, which enabled potential confounding variables to be evenly distributed amongst the intervention groups and so reduces the risk of bias in the results. This in turn, makes randomised control trials one of the most robust methods to evaluate the effectiveness of treatment (Altman, 1991). An analysis of the domiciliary and day hospital groups showed good internal validity, with both being well balanced in the major demographic variables and having similar drop-out rates.

The rigour of quantitative results are further enhanced by the use of standardised outcome measures, which have been tested for validity and reliability on stroke-related populations. Whilst many workers in rehabilitation may argue that these measures are insensitive to the changes experienced by both stroke survivors and carers, the use of standardised measures can be used to monitor global changes over a period of time. In particular, they can also be used to compare the results of this study with those of other related studies. Hence, all the outcome measures used in this study were standardised, with psychometric properties of validity and reliability. All have been used in previous stroke-related studies and some have been recommended by the British Stroke Research Group (Wade, 1992). The use of such outcome measures further increased the reliability and validity of the results obtained in this study.

The main difficulty of using a randomised controlled trial for this study was its small sample size. With a recruitment of 60 participants, there was a high probability that the results were statistically under-powered. So, whilst this study showed that neither methods of service delivery brought any overall change in carers' quality of life, the null hypothesis cannot be rejected, as a larger sample may have found a statistical difference in carers' quality of life in favour of the domiciliary group. Therefore, it would have been better to calculate the sample size needed to obtain 80-90% statistical power (Altman, 1991). In this study, it would have been difficult to achieve this for two main reasons: first, it was not the main intention of these different services to address issues on carers' quality of life. Secondly, the maximum numbers of carers that could have been recruited for this study was 102 carers as the sample was restricted to the stroke survivors (with an identified informal carer) participating in the Dorset Stroke Study. Furthermore, a 41% non-participation rate meant that there could have been some selection bias in carer recruitment, which could restrict the generalisation of these results.

The researcher experienced some limitations in using the Short Form-36 (SF-36) and the Frenchay Activities Index (FAI). The first problem involved the use of the mental health (MCS) and physical health (PCS) summary scores in the SF-36, which arose from the fact that normative scores for the UK population covered the age bands of 18-65 (Jenkinson, 1998). However, as this carer sample had a mean age of 68 years (s.d. 12.5 years), normative scores for the age band 66-75 years would have been more appropriate. To overcome this problem, normative scores from the U.S. population were used (Ware, 1994) as the U.S. population showed similar trends to the UK population between the ages of 18-65 years. However, some caution was needed in the interpretation of these results as the U.S. and the UK have different health problems and issues. Secondly, the main problem in using the FAI with stroke carers was the inappropriateness of some questions. For example, questions on domestic tasks/chores may be inappropriate, as many stroke carers would have to take on these tasks even if they did not do them before the onset of the survivors' stroke. Nevertheless, the breakdown of the FAI into the three sub-categories of domestic, community and leisure activities has enabled these unique categories to be monitored separately as well as giving a global score (Turnbull et al, 2000).

The nature of this carer sample meant that these results could only be generalised to the carers of stroke survivors with moderate to severe levels of disability, who were also receiving rehabilitation for the stroke. Nevertheless, as this sample was a community-based one and not one identified from voluntary groups, these results could be generalised to a relevant sample of stroke carers.

7.3.2. Qualitative study

Methodological rigour refers to the ability of the study's methods to supply the data necessary for a comprehensive analysis of the research question and is an issue which is as important in qualitative studies as it is in quantitative ones. However, the huge diversity in methods used in qualitative research has meant that the evaluation of rigour is influenced by the methodology employed (Yardley, 2000). Qualitative research was used in this study, as it was the most appropriate method to explore carers' subjective experiences of the services provided for stroke survivors. The collection of qualitative data was used to understand processes in health care and to explain some of the quantitative results, so this qualitative study was very much integrated within the framework of the quantitative study. So, whilst qualitative methods provided the ideal tools to explore carers' subjective experiences, the aims of the qualitative data in this study were to identify important themes and this was done in two ways. Firstly, the frequencies with which carers identified these themes were counted, the assumption being that the most frequently identified themes were the important ones. Secondly, an in-depth thematic analysis was carried out to get a deeper understanding of how these themes may influence quality of life. As this study took a predominantly 'positivist' approach in the collection, analysis and interpretation of the data, this meant that the methodological rigour of this study needed to be assessed in these terms.

I took the following steps to ensure rigour in the collection of the qualitative data. I used interview schedules to provide a framework with which to conduct the interview with carers. In my procedure, I carried out the semi-structured interview first before going through the questionnaire with carers. I also conducted all interviews in carers' own home, in surroundings which I hoped they felt more comfortable in. Nevertheless, I accepted that there were many aspects of the interview which I had little control over. The quality of my first interviews may not have been as good as my subsequent ones. This might partly be due to improved technique as a result of continual practice of doing more interviews. Hence, I was more confident in carrying out the later interviews and in using prompts more effectively, but this may have meant that the quality of these later interviews were better.

Furthermore, I found some interviews easier to do than others. I enjoyed interviewing carers who were both informative and direct to the point. On the other hand, I found it difficult to do the interviews with carers who were often diverted from the focus of the question and talked about a different topic. Whilst I felt that it was important for carers to feel comfortable during the interview and to be open with what they said, I sometimes did find it difficult to concentrate on what was being said if the interviewee was long-winded. The most difficult interviews were with carers who were very guarded and did not say more than a couple of sentences to each question. At the end of each interview, most interviewees would ask a question about the study and sometimes, carers would talk about their previous life experiences. I found these anecdotal accounts interesting to listen to, especially those relating to the Second World War, life in inter-war Britain or urban developments in the local area.

I had decided to adopt a professional look, wearing a jacket, tie and non-casual trousers. I felt that according to the social mores, my carer sample would have expected me to be smart and look professional. However, this 'professional' look may have contributed to a 'power divide' between myself and the carers, in which they may have viewed me as a person 'in authority'. Many carers had indeed asked if I was a trainee doctor, especially as they had previously seen me in the hospital. This perception of myself as a 'medic' may have influenced some carers into giving 'socially-desirable' responses during the interview, which were not too critical of the health services. They may have perceived that by being critical, they would then be labelled as unappreciative. This, they felt, may have a negative effect on their future medical care. There may also be another explanation on why carers provided 'socially-desirable' responses. For many older carers, this may be related to the life experiences of their generation, growing up without a National Health Service and living through the deprivation of the Second World War. These carers may have been brought up with a culture of paying for medical care, so have little to compare with and hence, have low expectations of what health care provides. Therefore, they may be appreciative of any medical care provided free by the National Health Service.

There were a number of limitations with using content analysis. The main assumption is that carers would only bring up important themes salient to themselves during the interview, but this ignores the many reasons why certain themes were not raised during the research interview. One, carers tend to concentrate only on themes which are salient to them at the time of the interview. Two, carers may not recognise a particular theme as being important, until someone brings it to their attention. Three, during the course of a research interview lasting 45 minutes, it is easy for interviewees to get carried away with their initial thoughts and forget to mention other themes. Four, content analysis is not sensitive to the subtlety of non-verbal language like the tone of voice and body language, cues which people often use with spoken language to express how they feel. Therefore, as content analysis is only interested in the verbal content of what people say, it may be possible that some of the analysed text could have been misinterpreted and taken out of the context it was said in. There is also some debate about the concept of inter-reliability as there are questions as to whether two people interpret the same code in the same way.

Many qualitative studies use a process of selective sampling by which a sample of participants are purposefully selected to represent the diverse nature of the group. This method was not used in the content analysis, as its primary interest was to identify themes using frequency data. Instead, all eligible carers were invited to take part in this study, but left the possibility that the data may have come from a biased carer sample. To check this, an analysis of demographic details showed that this sample consisted of a wide range of carers, all with varying degrees of physical and psychological health and supporting stroke survivors with mild to severe disability. Furthermore, it was necessary to ensure that the subjective experiences of both majority and minority of carers were highlighted. This was done by selecting quotes, which represented both the subjective experiences of the majority perceptions of carers as well as highlighting the perceptions of the minority.

However, one criticism of content analysis may be the lack of depth in explaining why certain themes may influence carers' quality of life. An in-depth thematic analysis was therefore carried out to address these limitations by providing a more in-depth description of these important themes and how they may affect carers' quality of life. To ensure that a wide range of carers' perceptions were accounted for, a purposive sample of 15 carers were selected using the criteria of type of services received, gender, relationship status with the survivor, the degree of survivors' functional disability and social class. As with the content analysis, quotes were selected, which represented both the majority and minority of carers' subjective experiences.

7.3.3. Use of a combined methods approach

This study has attempted to investigate two questions, which have not been addressed by previous studies looking at stroke carers: the first was the effectiveness of the different services on improving carers' quality of life. The second was to uncover 'the black box' of service delivery and identify which components of service delivery were considered important for carers. Both questions have equal importance, as there is a growing awareness in health service research not only to know if a new method of service delivery is effective, but also what aspects of the services were considered beneficial. Therefore, this study employed both quantitative and qualitative methodologies, in which the quantitative was used to document the effects of system changes while the qualitative was used to understand the process accompanying the health change. Hence, both arms of the study seek to investigate the impact of the two services by looking at it from different angles.

The problem with combined methods was the difficulty in linking both the qualitative and quantitative datasets with each other. This problem of data compatibility arises from the fact that both qualitative and quantitative methods come from different research paradigms; quantitative data requires statistical analysis to be carried out on it whilst qualitative data requires the researcher to become involved in the analytic process. Hence, this difference between the two sets of data may suggest that each method was exploring a different concept. This study did not disagree with this, but ultimately viewed combined methods as a way of using different approaches to explore the same theme. This meant that the unique nature of the different datasets were recognised as answering their specific questions, but at the same time, it may be that one dataset can be used to support the other. For example, in this study, qualitative data (which looked at process of health care) was used to explain differences between the two services in carers' quality of life. In addition, there were certain occasions when qualitative data were directly used in a triangulation process to further provide support for the quantitative data. Whilst this combined approach may be at odds with the purists stance, health service research often requires pragmatic frameworks to investigate issues in the real world.

7.3.4. General critique of the study

Previous studies looking at stroke carers have had many methodological limitations such as the use of small sample sizes, cross-sectional designs and the use of non-standardised outcome measures (Low et al, 1999). Generally, most studies have concentrated on the impact of caring for a stroke survivor, with very few looking at the impact of different methods of service delivery on carers' quality of life. In comparison, this study has attempted to address some of these methodological problems by employing a randomised control study design, a statistically robust method for comparing outcomes in two intervention groups (Altman, 1991). It has used well-validated outcome measures and has recognised the use of qualitative methods, in addition to the quantitative ones, as a means of investigating the processes influencing health care.

This study was also an opportunistic study, which was initially developed from the Dorset Stroke Study (see Chapter 3) through this researcher's interest in stroke carers. As a result, it was not possible to develop the methodology of this study earlier than the start of the Dorset Stroke Study. Hence, there were several methodological constraints, the main one being the 11 month gap between the commencement of the quantitative study and the qualitative study. This gap existed because it was easier to incorporate the quantitative arm of this study into the Dorset Stroke Study protocol once the outcome measures had been selected for use in the study. The qualitative arm required more time in which to develop the protocol and interview schedules and to conduct a pilot study to test for face validity. This time gap meant that more carers were recruited into the quantitative arm, leaving it open to the criticism that the carer sample in the qualitative arm was less representative of the general carer sample and so reducing the generalisation of the findings. However, the results showed little variation between the carers participating in the quantitative and qualitative study in terms of main demographic characteristics and survivors' level of disability.

Ideally, it would have been better if both the quantitative and qualitative arms of the study had started at the same time. In the real world where funding is limited, funding bodies have to allocate resources where they consider it appropriate. As the emphasis in health care is predominantly patient-centred, most funding in stroke research has been focused on studies aimed at bringing about improvements in patient outcomes. Hence, the difficulties of obtaining funding for carer-related studies is one of the reasons why the Dorset Stroke Study was used as the vehicle to investigate the impact of different methods of service delivery on carers quality of life. Whilst this was not the perfect solution from a research perspective, it reflects the practical problems of conducting research in the real world and devising pragmatic solutions to make the best of the situation.

7.3.5. Impact of the research interview on carers

Anecdotal comments by carers showed that many found it either reassuring or a relief to talk through their problems, whilst others found they thought more deeply about the topic in question and a few felt it had changed their attitudes. This finding highlighted previous studies (Oakley, 1981), which have shown that involvement with a research study does have an influence on the majority of participants involved. It was not the initial intention of this study to record the impact of the research interview on the participants and the tape recorder was switched off when all issues were covered. In all interviews, the researcher maintained his social distance and only prompted participants on relevant topics.

At the end of the recorded interview, many carers expressed a sense of relief at having been able to talk through their problems and to reflect on them. Many also said they were glad to have taken part in the study. In addition, many participants asked questions relating to the study, the stroke or the organisation of the health service. The latter two comments may reflect the following explanations: one, carers were still unsure about what a stroke was; two, carers were unsure which health professional to discuss problems concerning the different aspects of the stroke. Unfortunately, none of this information was recorded on tape as the formal interview had ended, so it was not possible to carry out a content analysis of these data. With hindsight, the inclusion of this information would have provided an even richer source of data. This point further illustrates that the quality of the content analysis is dependent on the material that is recorded. Instead of switching the tape off after the last question, it should have been left running until the point where the "informal" interview had reached its natural conclusion.

7.3.6. Equipment limitations

The main problem centred around the tape recorder, which had difficulty in picking up the voices of softly spoken individuals or distinguishing the verbal content of the interview from loud external noises such as the sound of a washing machine or outside traffic. A plug-in microphone was not used as it was felt that: 1) it would be intrusive to participants; 2) the in-built microphone would adequately record the interviews. Early sound checks suggested that the interviews were audible, but when the tapes were sent to an independent secretarial service for transcribing, it was discovered that several were inaudible. Measures were then taken to improve the sound quality by; a) ensuring the tape recorder was placed between the researcher and the interviewee, b) requesting potential source of noise to be switched off during the interview.

Nevertheless, this resulted in several interviews not being transcribed due to their poor sound quality, which in turn meant that less data were available for content analysis. The researcher's responsibility was to ensure that participants' time was used to the best advantage. Hence, the loss of data through faulty equipment could be considered unethical, as participants were required to be open about their role; a process which some carers found an emotional experience. The lessons learnt were as follows; a) studies requiring the collection of interview data should use a tape recorder in which a microphone can be plugged into it. This would increase the sound quality of the interview and so make transcribing the interviews easier as voices would be clearer. b) it is important to check each recording soon after the interview has been completed to ensure that the recordings are still clear.

7.4. Ways forward for future research

7.4.1. Carer-based interventions

The few interventions aimed at improving carers' psychosocial outcomes have met with limited success. Likewise, interventions aimed at increasing carers' knowledge about stroke had little impact in improving health outcomes (Rodgers et al, 1999). These findings posed two interesting questions. The first was, do these interventions meet the real needs of carers? It may be that the nature of these interventions, with health service planners taking a top-down approach in deciding what type of health care was needed, may not address the psychosocial needs of stroke carers. It may be that health services need to adopt a bottom-up approach and involve stroke carers in the planning of future services. One possible way in which such a bottom-up approach could be developed and evaluated is through the use of action research. This type of methodology has been used by both health and Social Services professionals to define the needs and problems of a particular group and to devise methods in dealing with these problems and so improve services. The aim of action research is the development of organisation structures which will empower survivors to be active participants in decision-making process (Bowling, 1997). In action research, the needs of the study population would be assessed and goals would be set. These goals would then be implemented and evaluated for effectiveness. The cycle of research, action and assessment would be constantly carried out and any action changed to take into account the perceptions of the study population.

7.4.2. Studies using qualitative methods

The second question raised by the lack of success attributed to the carer-directed intervention may be a lack of sensitivity that standardised measures have in evaluating meaningful goals for stroke carers. Indeed, previous studies have predominantly used quantitative outcome measures to evaluate the impact of stroke on carers. Whilst it is important for health services to evaluate the impact of their services on health outcomes and standardised quantitative measures play an important role in determining effectiveness, these measures on their own may not be sensitive in detecting subtle changes which may occur within individuals. Furthermore, the delivery of health care is not a unitary concept, but consist of several different elements which need to be considered such as the experience and training levels of health care personnel, the philosophy of the unit and aims of the treatment. For example, studies (Stroke Unit Trialists' Colaboration, 1997) have illustrated the effectiveness of stroke units in reducing the degree of mortality and morbidity caused by a stroke without increasing the length of hospital stay. However, little is known about why stroke units are effective. Is it because of the high level of co-ordinated care (between the different health professionals) that survivors receive? Is it due to specialised training that stroke physicians and nurses may receive or is it due to the enthusiasm of the stroke physician or is it a combination of all three? There is little knowledge of why some methods of health care work and there is a growing recognition within health service research of the importance of unwrapping this 'black box', to try and identify the elements of service provision which help users to benefit.

Previous qualitative studies (Dowswell et al, 1997) have shown that carers appreciated the input that they received from health services and this qualitative study showed that carers played an important role in encouraging survivors to carry out their rehabilitation exercises. This input from carers may be important as quantitative results from the Dorset Stroke Study did show that survivors' receiving domiciliary therapy had better physical improvement than those going to day hospital, but that this difference was both clinically and statistically insignificant. This study showed that qualitative research methods were able to explore the underlying processes behind the provision of health service delivery. Future studies evaluating the effectiveness of these models could incorporate qualitative methods as part of their methodology to identify the aspects of health care which carers find helpful. At present, there are few studies which have looked into this, so the findings from these studies could then contribute to the literature on stroke carers and be used as guidelines for the organisation of services.

7.4.3. Summary of suggestions for future research

The primary objective of any health care intervention is to promote or maintain the health status and quality of life of health service users. The use of standardised quantitative outcomes can enable health researchers to evaluate the effectiveness of a new method of health care compared with established health care practices. Nevertheless, quantitative data on their own can only evaluate one aspect of care, namely, was the new intervention effective or not? There may however, be other questions that health service researchers need to ask such as what aspects of the intervention were identified as helpful or useful to health service users. It may be important to know these perceptions as a guideline to future service developments, although they may not contribute to an improvement in outcome. This is in particular important in research involving stroke carers, as this group of people are often the indirect recipients of any health care intervention, but little is known what impact these interventions have. Even when interventions are directed at stroke carers, I still feel it is important to understand what aspects of care were identified as important.

Future studies evaluating the effectiveness of different methods of stroke rehabilitation should incorporate some qualitative methods within the framework of the study methodology as there are still very few studies involving stroke carers. Such studies have already highlighted interesting concepts about the helpfulness of different methods of service delivery, which can also serve as guidelines to how services could develop. Previous carer-directed interventions have adopted top-down approach with little consideration to whether these address carers needs and have had limited success at helping carers. Future studies therefore could aim to assess the needs of stroke carers and involve stroke carers in designing the intervention, which would require constant evaluation. Action research, which originates from social work, is one method that could be used to evaluate such questions.

7.5. Future policy implications

7.5.1. The development of domiciliary stroke teams

The limited resources available in health care, coupled with an ageing population utilising more health care, has led to a growing need for health services to develop methods of care delivery which has to be both cost effective and evidence-based. Stroke rehabilitation is no exception and this strive for greater cost-effectiveness has seen the move away from day hospital delivery towards domiciliary care. Previous studies have shown that the introduction of domiciliary stroke teams are a feasible option in providing post-discharge stroke rehabilitation when compared with current delivery methods such as day hospitals, in terms of both rehabilitation outcome and cost-effectiveness. The Dorset Stroke Study, carried out in a mixed urban/semi-rural setting, supported these findings and highlighted the feasibility of using domiciliary stroke teams in the delivery of post-hospital stroke rehabilitation, with patient functional recovery shown to be as effective as the day hospital (Roderick et al, submitted).

This study, which was one of the few to carry out a more detailed analysis on the impact of two different methods of delivering stroke rehabilitation on carers' quality of life, showed that domiciliary stroke teams had little impact, a finding which could be interpreted in two ways. One, domiciliary stroke teams were primarily designed to bring about functional improvements in stroke survivors. Hence, this finding showed that these methods of rehabilitation could not be seen as bringing about an improvement in carers' quality of life. At the same time, the fact that carers quality of life did not show a deterioration also emphasised that the introduction of a domiciliary stroke team did not have an adverse effect on carers' quality of life when compared with other methods of stroke rehabilitation.

These findings showed that policy makers could not expect the domiciliary stroke team or the day hospital to bring about an improvement in carers' quality of life, but at the same time, neither method of service delivery brought a deterioration in carers quality of life. Hence, the implications of these findings suggested that the introduction of a domiciliary stroke team in replacement of the day hospital would have no adverse effect on carers' quality of life. Indeed, domiciliary service would meet some of the National Clinical Guidelines for Stroke in improving patient rehabilitation management by providing carers with more opportunities to receive training in transferring and supporting survivors with their activities of daily living (The Intercollegiate Working Party for Stroke, 2000). Nevertheless, this study would suggest domiciliary stroke teams would have little impact on improving carers' QoL.

7.5.2. Feasibility of a mixed method of health service delivery

The Dorset Stroke Study suggested that a mixed method of service delivery incorporating both domiciliary and day hospital elements could be an appropriate way forward in the delivery of stroke rehabilitation for survivors (Roderick et al, submitted). The findings of this study suggested that both domiciliary and day hospital delivery of stroke rehabilitation brought indirect advantages to carers. Domiciliary care provided carers with both greater convenience and better educational opportunities to be involved in the rehabilitation process, which in turn, may bring about greater survivor adherence. On the other hand, day hospitals provided advantages for carers such as respite opportunities to have time to themselves and to provide social contact for stroke survivors to meet each other.

Hence, the possibility of developing a shared model incorporating a mixture of both domiciliary and day hospital rehabilitation, would enable the best aspects of care identified in both the domiciliary and day hospital model to be combined into one care package. This package would provide carers with greater educational input from therapists whilst providing them with respite opportunities away from the caring role. In turn, this mixed care package will enable stroke carers to be additional vehicles in supporting survivors, so leading to better adherence of the latter with the rehabilitation regimes and providing stroke carers with time to themselves.

This mixed package of care may be a feasible mode of delivering stroke rehabilitation to survivors. The introduction of such a service is also unlikely to lead to deterioration in carers' quality of life. Nevertheless, whilst this package does combine elements of care which carers have identified as useful, such as the ability to be both involved in the rehabilitation process and to have some respite time to themselves, the findings from this study do not suggest that it will help in improving their quality of life. Therefore, the implication for policy makers is that a shared care package will not bring an improvement in carers' quality of life.

7.5.3. The development of carer-directed interventions

The informal stroke carer is an important source of emotional and physical support for stroke survivors. They are also an important economic asset for statutory bodies as these carers often take on the responsibility of supporting these survivors in the community, many of whom have had a severe residual disability and would otherwise require nursing or rest home care. At the same time, stroke carers suffer from poorer psychological health and a disruption to their social life as a result of the caring process. Nevertheless, there had been little official recognition of the needs of this group until a recent White Paper (Department of Health, 1999) stipulated that health policy makers were responsible for catering for the unique needs that informal carers (including stroke carers) may have.

This study has highlighted some important findings that need to be taken into consideration when planning future interventions for stroke carers. Whilst most carers expressed little need for additional help to cope with their caring role, the availability of respite care was important for a sub-group of carers who found their caring role stressful. Often these carers would have severe disruption to their lives as a result of caring for a person with stroke. The provision of physical help may also be helpful in providing more time for carers to spend socially with the survivor instead of on other caring tasks. Nevertheless, this support would need to be directed to suit carers' needs as opposed to service led ones.

Nevertheless, there has generally been little in the way of carer-directed interventions aimed at improving stroke carers' QoL. This trend is slowly changing with the recommendation by the National Clinical Guidelines for Stroke (2000) that a liaison health professional should be available for advice, especially after survivors' discharge from hospital. Such interventions, using health professionals such as social workers or specialist nurses, have aimed to help stroke carers access a wide range of items which include information, community facilities or health facilities. Studies have shown that these health professionals were more empathetic to the needs of both carers and survivors, who in turn valued these services (Dowswell et al, 1997). Carers were also more satisfied that their information needs were being met by these services (Dennis et al, 1997). Increased satisfaction could reflect a real difference of care provision in favour of these interventions (Pound et al, 1999). However, these interventions, whilst appreciated by carers, had limited success on improving their health outcomes (Forster & Young, 1996; Dennis et al, 1997).

There may be several reasons for their lack of success in improving QoL. One, the quantitative measures used to measure QoL may be insensitive to evaluating the aims of these interventions. Two, it may be that these interventions did not reduce the demands of the caring process, which would then overwhelm the coping ability of carers. Hence, these interventions, whilst achieving their objective in meeting the immediate needs of carers post-stroke, were not sufficient in themselves to improve carers' QoL. Health service planners need to consider the long-term interventions aimed at improving QoL, using a bottom-up approach in the development, execution and evaluation of such a service to incorporate the views of carers. This is not to say that carers' views were not considered in the planning of the interventions, but as Dowswell et al (1997) admit, their intervention was aimed at the short-term needs of carers. One possibility is the use of action research (as described in section 7.4.1.) which would adopt this bottom-up approach.

Three, these results could be a reflection that whilst the majority of carers showed little or no improvement following intervention, there was a small sub-group of carers who saw some improvement in their health outcomes. It may be that health service planners need to identify these groups of stroke carers and to target resources at them. Such an approach would enable health services to utilise funds more efficiently by aiming interventions at groups who would benefit from it the most. Dennis et al (2000) suggested that it was possible to identify stroke survivors who were more likely to suffer from depression. On a similar vein, it may be that health services need to identify specific vulnerable carers who were not coping with their role as the main informal carer, though such a move may appear more controversial as it could set the prerogative for the rationing of health care.

In summary, these studies showed that the use of liaison health professionals soon after discharge were useful sources of practical and emotional support, which met the immediate needs of stroke carers, but studies did not show these interventions were effective in improving QoL. Whilst these results may be partially due to the insensitivity of the measures used, it may be that health service planners need to develop strategies to identify a sub-group of vulnerable carers who would benefit from psycho-social intervention. Health service planners also need to develop services to deal with the long-term needs of these carers.

7.5.4. Development of Primary Care Groups in delivery of health services to stroke carers

The health needs of stroke carers are often neglected as the focus of treatment has centred on the functional recovery of survivors. Nevertheless, the recent White

Paper on Carers acknowledges that this group of individuals have specific health issues that need to be met. Within the health service framework, primary care teams, in the form of General Practice could play a potentially important role in the delivery of health care to these carers. This is because these teams have several advantages: One, they are ideally situated in the community they serve, thereby increasing patient convenience. Two, as gatekeepers to acute services, they are often the first point of contact for most people seeking health care and advice; thence they have the potential to identify individual carers with psychological problems who may need further input. Three, they provide a continuity of care for survivors by keeping up-to-date health records and so are often aware of their long-term health status.

Nevertheless, despite the unique position of general practices within the community, stroke carers often find that primary care seemed ill-equipped to support them in their long term needs. This finding was further highlighted by this study, which found that several carers felt isolated from their local General Practice. This problem may be further accentuated with problems in General Practitioner (GP) recruitment which is likely to see an increase in the workload of the remaining GPs, a lack of suitable training to deal with the psycho-social issues associated with carers as well as a lack of experience in recognising a person with psychological problems.

The development of primary care groups (PCG) and the introduction of primary care trusts (PCT) with the first wave implemented in April 2000, could give General Practices the opportunity to develop partnerships with secondary care and social services within a multi-disciplinary setting and so provide a wide range of specialist health care. Kendrick & Hilton (1997) described the development of two such services, one looking at a practice in Chertsey wanting to develop a service for people with learning disabilities, and the other based in practices in Wandsworth (inner south west London), which has seen the set-up of extended primary care services. Within the framework of PCG, general practices could develop primary health care groups to form partnerships with clinical psychologists, occupational therapists, physiotherapists, social workers and community nurses. These teams could then work to deliver health care to both stroke survivors and carers and in addition, these teams could cater for the longer-term needs of stroke carers and their survivors. These teams may be a more cost-effective way of delivering health care as they have fewer overheads and capital costs than hospital-based care. Hence, primary care has the potential to screen and monitor the health status of carers, to deliver health care when necessary and to maintain their quality of life.

7.5.5. Service provision for carers of people with long term severe disability

Whilst improvements in the management of acute care and rehabilitation have led to better outcomes for people with stroke, it is still estimated that 35% of all people with new strokes will be severely disabled and require additional support to remain in the community. Furthermore, as the stroke incidence in the UK is set to increase with the ageing population, more informal carers will be needed to provide long term support for these stroke survivors. There have been no studies which have evaluated the long-term impact, though longitudinal studies of one year duration (including this one) showed that stroke carers had poorer psychological health and more disruptions to their social life than their counterparts in the general population. In addition, increased geographical mobility e.g. the migration of retired people to the South West and the South Coast of England, has meant that many carers live away from close family members and have reduced access to additional social support.

Health services need to cater for the long-term health needs of these groups of stroke carers. Nevertheless, post-rehabilitation follow-up of health care is infrequent not only for stroke carers, but also their survivors with any subsequent health care, such as health check-up with the local practice or the annual review with the consultant physician being directed at stroke survivors. Nevertheless, anecdotal data from a study recently commissioned by the Stroke Association, (looking at the unmet needs of young people with stroke) found that some people still had unmet health needs 3-5 years after their stroke. Primary care, with its continuity of care with survivors and its proximity to them, may offer the most feasible approach in monitoring carers' health status and delivering care to this group (see section 7.5.4. - Development of Primary Care Groups in delivery of health services to stroke carers)

7.6. Conclusion

1) The introduction of a domiciliary stroke team to deliver post-discharge stroke rehabilitation will not have any adverse impact on carers' quality of life when compared to day hospital delivery. Domiciliary teams provide carers with greater opportunities for education to increase their knowledge of stroke rehabilitation. This in turn may promote survivors' adherence with therapy and so improve their rehabilitation outcome. At the same time, day hospitals serve a useful respite function for many carers, who see them as providing survivors with opportunities to mix with each other.

2) Neither the domiciliary nor the day hospital methods of health care delivery can be considered appropriate on its own if a secondary objective of the health intervention is to improve the quality of life in stroke carers. Mixed methods incorporating elements of both domiciliary care and day hospital may confer the benefits of education and respite. Nevertheless, if health services are interested in dealing with the psycho-social issues resulting from caring, they need to tackle these issues directly.

3) The emphasis of stroke rehabilitation has mainly focused on survivors' functional recovery. Few interventions have directly tackled the psycho-social issues affecting carers and those which have, were not shown to be effective in improving carers' outcomes. This may be due to several reasons; quantitative measures used to measure health status change may not be sensitive enough in

detecting change which carers perceive as being meaningful; these interventions were initiated by health service perceptions of what they thought carers' needs were (a top-down approach).

4) This study reaffirmed the findings of previous studies, which highlighted the adverse effect that caring for a person with stroke has on a carer's psychological health and social functioning. Nevertheless, the impact of caring varies with individual carers and is dependent on the amount of supervision that the stroke survivor needs to be safe at home and survivors' degree of cognitive impairment as a result of the stroke. Whilst physical health was not affected by caring, carers' physical health status was important in determining the ability of carers to carry out the physical aspects of their caring role, such as bathing and transfers.

5) Little is still known about what impact different methods of health care delivery have on carers' quality of life. Nevertheless, carers play an important role in stroke rehabilitation, often acting as a valuable source of emotional and physical support for survivors and aiding them in their rehabilitation. Future research needs to assess the impact of interventions on stroke carers. Therefore, all interventions involving carers either directly or indirectly, should incorporate some measures to evaluate quality of life. Moreover, the incorporation of qualitative methods into a study would enable an understanding of the elements of health service delivery considered useful. An approach using a combined quantitative and qualitative methodology would enable researchers to both evaluate the effectiveness of different interventions in improving quality of life and also to understand the processes of health care, which might have contributed to an improvement.

6) Future policy implications suggest the following points:

i) domiciliary stroke teams improve carers knowledge about the rehabilitation process, which may improve stroke survivors' rehabilitation outcome.

Domiciliary teams would also have no adverse impact on carers' quality of life if they replaced day hospitals, but would not bring an improvement in it.

ii) a mixed method of health care delivery incorporating both day hospital and domiciliary care would provide carers with both greater educational opportunities from therapists and the chance for respite for the caring process. Nevertheless, whilst conferring these benefits to carers, the focus of this care package was patient-centred.

iii) Carer-directed interventions are needed to tackle both the psychosocial issues affecting carers and to improve their quality of life. This may require a multi-level approach. On the lowest level, a named health professional with experience with stroke care could act as a liaison support worker, initially helping carers (and survivors) with their information needs or accessing health or community facilities. Respite care should be made available for all stroke carers who identify a need for it. On a higher level, a bottom-up approach may be needed in the planning, delivery and evaluation of services to cater for individual carers who were not coping with their role. The latter could be delivered through the framework of primary care groups, who would be ideally situated to identify individual carers and also to provide for their long-term health needs.

7. The rise in stroke incidence with the ageing population will see more informal carers become involved in the long term care of stroke survivors with severe physical disability. Health services have to prepare to meet the needs of this group of long term carers.

Appendix I - Summary sheet given to patients/carers

DORSET STROKE STUDY
DS2

SUMMARY SHEET

Dorset Health Commission have set up a new service for stroke patients in Poole. It provides physiotherapy and occupational therapy in the patient's own home. We do not know whether this is an improvement on current practice which involves attendance at one of the local day hospitals. This study is a randomised trial which aims to compare the new home service with the day hospital care.

The study will involve patients who are referred to the day hospital after having a stroke. They could be referred by their GP or at discharge from hospital. They will be assessed by a doctor from the day hospital. Those who are suitable and agree to take part in the study will be allocated randomly to attend the day hospital or to receive home care. Their GP will be informed which care has been allocated. Patients who do not want to take part in the study will receive care in their local day hospital as is current practice.

At the start of the study there will be an interview with a trained researcher to find out how the stroke has affected the patient's ability to perform everyday tasks and their quality of life. The patient will then receive day hospital or home care as allocated. There will be similar interviews at 3, 6 and 12 months after entry. Details of the patient's contact with health and social services will be collected during this period. If there is a carer at home they will also be interviewed at the same times to find out the effects of looking after a stroke patient. There will be no invasive tests such as blood tests as part of the study and there is no risk to either the patient or carer from taking part in the study.

Patients and their carers are free not to enter the study without giving a reason or to withdraw at any time. This will not effect their current or future medical care in any way.

If you require further information about the study, please contact:

Dr Richard Day
Consultant Geriatrician,
Poole General Hospital

Tel: 01202 442916

Dr Paul Roderick
Senior Lecturer in Public Health Medicine
Institute of Public Health Medicine
Southampton General Hospital

Tel: 01703 796532

Appendix II - Consent Form for patients/carers

DORSET STROKE STUDY
DS4

Study number ☐☐☐☐

CONSENT FORM

	Please cross out as necessary
Have you read the Patient Information and Summary sheet ?	**YES/NO**
Have you had an opportunity to ask questions and discuss this study?	**YES/NO**
Have you received satisfactory answers to all of your questions?	**YES/NO**
Have you received enough information about the study?	**YES/NO**

Who have you spoken to? Dr/Mr/Mrs..

Do you understand that you are free to withdraw from the study: **at any time,** **without having to give a reason for withdrawing** **and without affecting your future medical care?**	**YES/NO**
Do you agree to take part in this study?	**YES/NO**

Signed .... Date ....

(NAME IN BLOCK LETTERS):...

Appendix III: Patient baseline assessment

Patient Baseline Assessment

☐☐☐☐
1 4

☐ 5
0 1
6 7

Dorset Health Commission have set up in a new service for stroke patients in Poole, which provides physiotherapy and occupational therapy in the patient's own home. We do not know whether this is an improvement on current practice which involves attendance at one of the day hospitals. Little is also known on how this will affect patients' life. The purpose of this study is to understand the impact of the different services on patient's daily lives, so that we can improve health services for both stroke patients and carers.

An important part of this study involves looking at both the patients' quality of life and to monitor any functional or mobility improvements. In today's assessment, I will be asking you some details about yourself, how well you can move around and how the stroke has affected your life.

All the information that you give during the interview will be strictly confidential and in order to protect your privacy, a confidential study number rather than your name will be used on all forms.

Your participation in this study is important to us. Thank you for your help.

Section 1 Demographic

B1. Gender:

Female...1
Male..2 8

B2. Date of birth (day/month/year) ____/____/___ 9 - 14

B3. Are you currently:

Married...1
Widowed (how long?______)........................2
Divorced..3
Separated..4 15
Never married..5
Other..6

B4. During the last 30 days, were you:

Working full-time...1
Working part-time..2
Unemployed, laid off or looking for work......3
Retired..4 16
Disabled..5
Keeping house...6
None of the above..7

B5. Out of the past 12 months, how many months did you work for pay at least 15 hours a week?

0 months	1
1-3 months	2
4-6 months	3
7-9 months	4
10-12 months	5

17

B6. Are you now able to work:

	Yes	No	
a. Part-time	1	2	18
b. Full-time	1	2	19

B7a. (During your working life), what is (was) your main occupation?

☐ NA; Does not work outside the home OR

Full job title ________________________________

In which industry/business was this? ____________________

Were you
manager ☐
foreman ☐
employee ☐

B7b. (During his working life), what is (was) your husband/partner main occupation?

☐ 21

☐ NA; Does not work outside the home OR

Full job title ________________________________

In which industry/business was this? ________________

Were you
manager ☐
foreman ☐
employee ☐

B8. Type of accommodation occupied by this household: (Code from observation if in doubt ask informant).. ☐☐ 22-23

(1=Whole house, bungalow, detached; 2 = whole house, bungalow, semi-detached; 3= whole house, bungalow, terraced/ end of terrace; 4= Purpose-built flat or maisonette in block with lift; 5 = Purpose-built flat or maisonette in block without lift; 6 = part of house/converted flat or maisonette in block without lift; 7 = part of house/converted flat or maisonette/rooms in house without lift; 8 = dwelling with business premise; 9= caravan/houseboat; 10= other (specify _________)

B9. Is your residence owned or rented?

Owned..1
Rented..2 24
Other (specify________________)...............3

B10. Is your accomodation sheltered housing or a specialised flat for elderly people?

Yes, sheltered housing 1
Yes, specialised flat for elderly people...........2 25
No 3

B11a. Before your stroke, were you a car driver?

Yes 1 26
No 2

B11b. How many cars did you own before your stroke?

None..1
One..2 27
Two or more...3

B12. Which of the following people live in the same household with you?

Lives alone...1
Lives with husband/wife or significant
other person...2 28
Lives with other relatives 3
Lives with other non-relatives 4

B13. Who would you identify as your main carer?

spouse 1
daughter 2
son...3
other relative..4 29
other non-relative..5
n one..6

B14a. How many children do you have?

None..1
One..2 30
Two and above 3

B14b. How many of these live in the local area (i.e. East Dorset)?

None..1
One..2 31
Two and above 3

Now I would like to ask you a few general questions before starting the interview.

		Incorrect	Correct
1.	Age	0	1
2.	Time (to nearest hour)	0	1
3.	Address for recall at end of test - this should be repeated by the patient to ensure it has been heard correctly: *10 North Road*	0	1
4.	Year	0	1
5.	Name of institution/hospital/road youlive on	0	1
6.	Recognition of two persons (doctor, nurse etc)	0	1
7.	Date of birth (day and month sufficient)	0	1
8.	Year of First World War	0	1
9.	Name of present monarch	0	1
10.	Count backwards 20 to 1	0	1

B15. Total AMT Score.. [ ][ ] 32-33

☐☐☐☐
1 4

☐ [0][3]
5 6 7

SECTION 2

I would like to ask you a few questions about how you feel at this moment.

P1. Do things keep getting worse as you get older?

Yes 0
No 1 8

P2. Do you have as much energy as you did last year?

Yes 1
No 0 9

P3. Do you feel lonely much?

Yes 0
No 1 10

P4. Do you see enough of your friends and relatives?

Yes 1
No 0 11

P5. Do little things bother you more this year?

Yes 0
No 1 12

P6. As you get older do you feel less useful?

Yes 0
No 1 13

P7. Do you sometimes worry so much you can't sleep?

Yes 0
No 1 14

P8. As you get older are things better than expected?

Yes 1
No 0 15

P9. Do you sometimes feel that life isn't worth living?

Yes 0
No 1 16

P10. Are you as happy now as you were when you were younger?

Yes 1
No 0 17

P11. **Do you have a lot to be sad about?**

Yes 0
No 1 18

P12. **Are you afraid of a lot of things?**

Yes 0
No 1 19

P13. **Do you get angry more than you used to?**

Yes 0
No 1 20

P14. **Is life hard for you most of the time?**

Yes 0
No 1 21

P15. **Are you satisfied with your life today?**

Yes 1
No 0 22

P16. **Do you take things hard?**

Yes 0
No 1 23

P17. **Do you get upset easily?**

Yes 0
No 1 24

P18 **Total score** ☐☐ 25 - 26

☐☐☐☐
1 4
☐ 0 4
5 6 7

The next set of questions is concerned with different aspects of your mobility. Please answer the following questions with a 'yes' or a 'no'.

R1. Do you turn over from your back to your side without help?

Yes 1
No 0 8

R2. From lying in bed, do you get up to sit on the edge of bed on your own?

Yes.. 1 9
No 0

R3. Do you sit on the edge of the bed without holding on for 10 seconds? [sitting balance]

Yes.. 1 10
No 0

R4. Do you stand up (from any chair) in less than 15 seconds (using hands, and with an aid if necessary)? [sitting to standing]

Yes.. 1 11
No 0

R5. Observe standing for 10 seconds without any aid. [standing unsupported]

Yes.. 1 12
No 0

R6. Do you manage to move from bed to chair and back without any help? [transfer]

Yes.. 1 13
No 0

R7. Do you walk 10 metres, with an aid if necessary, but with no standby help? [Walking inside, with an aid if needed]

Yes.. 1 14
No 0

R8. Do you manage a flight of stairs without help? [stairs]

Yes.. 1 15
No 0

R9. Do you walk around outside, on pavements without help. [Walking outside (even ground)]

Yes.. 1 16
No 0

R10. Do you walk 10 metres inside with no caliper, splint, or aid, and no standby help? [Walking inside, with no aid]

Yes 1
No 0 17

R11. If you drop something on the floor, do you manage to walk 5 metres, pick it up and then walk back? [Picking off floor]

Yes 1
No 0 18

R12. Do you walk over uneven ground (grass, gravel, dirt, snow, ice, etc.) without help? [Walking outside (uneven ground)]

Yes 1
No 0 19

R13. Do you get in/out of bath or shower unsupervised and wash self? [Bathing]

Yes 1
No 0 20

R14. Do you manage to go up and down four steps with no rail, but using an raid if necessary? [Up and down four steps]

Yes 1
No 0 21

R15. Do you run 10 metres without limping in four seconds (fast walk is acceptable)? [Running]

Yes 1
No 0 22

R16. Total Rivermead score ☐☐ 23-24

☐☐☐☐
1 4

☐ 0 5
5 6 7

The next set of questions are concerned with various activities of daily living, for example, self-care and feeding.

BA1. BLADDER

Incontinent, or catheterised and unable to manage 0
Occasional accident (max. once per 24 hours) 1
Continent (for more than seven days) 2 8

BA2. BOWELS

Incontinent.......... 0
Occasional accident (once a week).......... 1 9
Continent.......... 2

BA3. GROOMING

Needs help with personal care: face, hair, teeth shaving.... 0 10
Independent (implements provided).......... 1

BA4. TOILET USE

Dependent.......... 0
Needs some help but can do something alone.......... 1 11
Independent (on and off, wiping, dressing).......... 2

BA5. FEEDING

Unable.......... 0
Needs help in cutting, spreading butter etc.......... 1 12
Independent (food provided within reach).......... 2

BA6. TRANSFER

Unable - no sitting balance.......... 0
Major help (physical, one or two people), can sit.......... 1
Minor help (verbal or physical).......... 2 13
Independent.......... 3

BA7. MOBILITY

Immobile.......... 0
Wheelchair independent, including corners etc.......... 1 14
Walks with help of one person (verbal or physical).......... 2
Independent.......... 3

BA8. DRESSING

Dependent.......... 0
Needs help but can do about half unaided.......... 1 15
Independent (including buttons, zips, laces etc).......... 2

BA9. STAIRS

Unable.......... 0
Needs help (verbal, physical, carrying aid).......... 1 16
Independent up and down.......... 2

BA10. BATHING

Dependent.......... 0
Independent (Bath: must get in and out unsupervised and wash self. Shower: unsupervised/unaided).......... 1 17

BA11. Total Barthel score = ☐☐ 18-19

Appendix IV: Patient follow-up assessment

DS14

☐☐☐☐ 1 4

☐ 5 0 3 6 7

Patient Follow-up Assessment

Today's assessment will be similiar to the format of the previous assessment and I will be asking you some details about how the person's stroke has affected your life.

All the information that you give during the interview will be strictly confidential. Once again, thank you for your help.

I would like to ask you a few questions about how you feel.

P1. Do things keep getting worse as you get older?

Yes 0
No 1 8

P2. Do you have as much energy as you did last year?

Yes 1 9
No 0

P3. Do you feel lonely much?

Yes 0
No 1 10

P4. Do you see enough of your friends and relatives?

Yes 1 11
No 0

P5. Do little things bother you more this year?

Yes 0 12
No 1

P6. As you get older do you feel less useful?

Yes 0 13
No 1

P7. Do you sometimes worry so much you can't sleep?

Yes.. 0
No... 1 14

P8. As you get older are things better than expected?

Yes.. 1
No... 0 15

P9. Do you sometimes feel that life isn't worth living?

Yes.. 0
No... 1 16

P10. Are you as happy now as you were when you were younger?

Yes.. 1 17
No... 0

P11. Do you have a lot to be sad about?

Yes.. 0 18
No... 1

P12. Are you afraid of a lot of things?

Yes.. 0 19
No... 1

P13. Do you get angry more than you used to?

Yes.. 0 20
No... 1

P14. Is life hard for you most of the time?

Yes.. 0 21
No... 1

P15. Are you satisfied with your life today?

Yes 1
No 0

22

P16. Do you take things hard?

Yes 0
No 1

23

P17. Do you get upset easily?

Yes 0
No 1

24

P18. Total Score = ☐☐

25 - 26

☐☐☐☐
1 4

☐ 0 4
5 6 7

The next set of questions is concerned with different aspects of your mobility. Please answer the following questions with a 'yes' or a 'no'.

R1. Do you turn over from your back to your side without help?

Yes 1
No 0

8

R2. From lying in bed, do you get up to sit on the edge of bed on your own?

Yes 1
No 0

9

R3. Do you sit on the edge of the bed without holding on for 10 seconds? [sitting balance]

Yes 1
No 0

10

R4. Do you stand up (from any chair) in less than 15 seconds (using hands, and with an aid if necessary)? [sitting to standing]

Yes 1
No 0

11

R5. Observe standing for 10 seconds without any aid. [standing unsupported]

Yes 1
No 0

12

R6. Do you manage to move from bed to chair and back without any help? [transfer]

Yes 1 13
No 0

R7. Do you walk 10 metres, with an aid if necessary, but with no standby help? [Walking inside, with an aid if needed]

Yes 1 14
No 0

R8. Do you manage a flight of stairs without help? [stairs]

Yes 1 15
No 0

R9. Do you walk around outside, on pavements without help. [Walking outside (even ground)]

Yes 1 16
No 0

R10. Do you walk 10 metres inside with no caliper, splint, or aid, and no standby help? [Walking inside, with no aid]

Yes 1 17
No 0

R11. If you drop something on the floor, do you manage to walk 5 metres, pick it up and then walk back? [Picking off floor]

Yes 1 18
No 0

R12. Do you walk over uneven ground (grass, gravel, dirt, snow, ice, etc.) without help? [Walking outside (uneven ground)]

Yes 1 19
No 0

R13. Do you get in/out of bath or shower unsupervised and wash self? [Bathing]

Yes 1 20
No 0

R14. Do you manage to go up and down four steps with no rail, but using an raid if necessary? [Up and down four steps]

Yes 1
No 0 21

R15. Do you run 10 metres without limping in four seconds (fast walk is acceptable)? [Running]

Yes 1
No 0 22

R16. Total Rivermead score = ☐☐ 23 - 24

☐☐☐☐
1 4

☐ 05
5 6 7

The next set of questions are concerned with various activities of daily living, for example, self-care and feeding.

BA1. BLADDER

Incontinent, or catheterised and unable to manage........... 0
Occasional accident (max. once per 24 hours).................. 1
Continent (for more than seven days).............................. 2 8

BA2. BOWELS

Incontinent.. 0
Occasional accident (once a week)................................. 1
Continent.. 2 9

BA3. GROOMING

Needs help with personal care: face, hair, teeth shaving.... 0
Independent (implements provided)................................ 1 10

BA4. TOILET USE

Dependent 0
Needs some help but can do something alone 1
Independent (on and off, wiping, dressing) 2 11

BA5. FEEDING

Unable 0
Needs help in cutting, spreading butter etc 1
Independent (food provided within reach) 2 12

BA6. TRANSFER

Unable - no sitting balance 0
Major help (physical, one or two people), can sit............. 1
Minor help (verbal or physical)...................................... 2
Independent... 3 13

BA7. MOBILITY

Immobile 0
Wheelchair independent, including corners etc 1
Walks with help of one person (verbal or physical)........... 2
Independent 3 14

BA8. DRESSING

Dependent 0
Needs help but can do about half unaided......................... 1
Independent (including buttons, zips, laces etc)............... 2 15

BA9. STAIRS

Unable 0
Needs help (verbal, physical, carrying aid)........................ 1
Independent up and down 2 16

BA10. BATHING

Dependent 0
Independent (Bath: must get in and out unsupervised and wash self. Shower: unsupervised/unaided)............................... 1 17

BA11. Total score = ☐☐ 18 - 19

First of all, I would like to ask you some questions about your general health.

☐☐☐☐
1 4

SF1. In general, would you say your health is:

☐ 06
5 6 7

(Circle one)

Excellent.. 1
Very Good.. 2
Good.. 3 8
Fair.. 4
Poor 5

SF2. <u>Compared to one year ago</u>, how would you rate your health in general <u>now</u>?

(Circle one)

Much better now than one year ago 1
Somewhat better now than one year ago 2 9
About the same as one year ago 3

Somewhat worse now than one year ago.. 4

Much worse now than one year ago.. 5

SF3. The following questions are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

(Circle one number on each line)

Activities	Yes, limited a lot	Yes, limited a little	No, not limited at all	
a. **Vigorous activities**, such as running, lifting heavy objects, participating in strenuous sports	1	2	3	10
b. **Moderate activities**, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	1	2	3	11
c. Lifting or carrying groceries	1	2	3	12
d. Climbing **several** flights of stairs	1	2	3	13
e. Climbing **one** flight of stairs	1	2	3	14
f. Bending, kneeling, or stooping	1	2	3	15
g. Walking **more than a mile**	1	2	3	16
h. Walking **half a mile**	1	2	3	17
i. Walking **one hundred yards**	1	2	3	18
j. Bathing or dressing yourself	1	2	3	19

SF4. During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

(Circle one number on each line)

	YES	NO	
a. Cut down on the **amount of time** you spent on work or other activities	1	2	20
b. **Accomplished less** than you would like	1	2	21
c. Were limited in the **kind** of work or other activities	1	2	22
d. Had **difficulty** performing the work or other activities (for example, it took extra effort)	1	2	23

SF5. During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

(Circle one number on each line)

	YES	NO	
a. Cut down on the amount of time you spent on work or other activities	1	2	24
b. Accomplished less than you would like	1	2	25
c. Didn't do work or other activities as carefully as usual	1	2	26

SF6. During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbours, or groups?

(Circle one)

Not at all	1	
Slightly	2	
Moderately	3	27
Quite a bit	4	
Extremely	5	

SF7. How much bodily pain have you had during the past 4 weeks?

(Circle one)

None	1	
Very mild	2	
Mild	3	28
Moderate	4	
Severe	5	
Very Severe	6	

SF8. During the <u>past 4 weeks</u>, how much did <u>pain</u> interfere with your normal work (including both work outside the home and housework)?

(Circle one)

Not at all 1

A little bit 2

Moderately 3 29

Quite a bit 4

Extremely 5

SF9. These questions are about how you feel and how things have been with you <u>during the past 4 weeks</u>. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during <u>the past 4 weeks</u> -

(Circle one number on each line)

	All of the time	**Most of the time**	**A good bit of the time**	**Some of the time**	**A little of the time**	**None of the time**	
a. Did you feel full of life?	1	2	3	4	5	6	30
b. Have you been a very nervous person?	1	2	3	4	5	6	31
c. Have you felt so down in the dumps that nothing could cheer you up?	1	2	3	4	5	6	32
d. Have you felt calm and peaceful?	1	2	3	4	5	6	33
e. Did you have a lot of energy?	1	2	3	4	5	6	34
f. Have you felt downhearted and low?	1	2	3	4	5	6	35
g. Did you feel worn out?	1	2	3	4	5	6	36
h. Have you been a happy person?	1	2	3	4	5	6	37
i. Did you feel tired?	1	2	3	4	5	6	38

SF10. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc)?

(Circle one)

All of the time.. 1
Most of the time 2
Some of the time 3 39
A little of the time.. 4
None of the time.. 5

SF11. How TRUE or FALSE is each of the following statements for you?

(Circle one number on each line)

	Definitely true	**Mostly true**	**Don't know**	**Mostly false**	**Definitely false**	
a. I seem to get ill more easily than other people	1	2	3	4	5	40
b. I am as healthy as anybody I know	1	2	3	4	5	41
c. I expect my health to get worse	1	2	3	4	5	42
d. My health is excellent	1	2	3	4	5	43

☐☐☐☐
1 4
☐ ☐☐
5 6 7

In this section, I will ask you how your stroke has affected you in your daily life.

In the last 3 months, have you done any of the following activities:

F1. Prepared main meals (involving organisation, preparation and cooking)

never 0 8
under one week.. 1
1-2 times a week.. 2
most days.. 3

F2. **Washed up**, such as washing, wiping and putting away.

never 0
under one week.............................. 1 9
1-2 times a week............................ 2
most days...................................... 3

F3. **Washing clothes.** This includes organising of washing and drying clothes.

never 0
1-2 times in 3 months..................... 1 10
3-12 times in 3 months................... 2
at least weekly 3

F4. **Light housework,** such as dusting, polishing or tidying small objects.

never 0
1-2 times in 3 months..................... 1 11
3-12 times in 3 months................... 2
at least weekly 3

F5. **Heavy housework** including bed making, cleaning floors or moving furniture.

never 0
1-2 times in 3 months..................... 1 12
3-12 times in 3 months................... 2
at least weekly 3

F6. **Local shopping** i.e. playing substantial role in organising and buying shopping.

never 0
1-2 times in 3 months..................... 1 13
3-12 times in 3 months................... 2
at least weekly 3

F7. **Social occasions** such as going out to clubs, church activities, cinema, theatre, drinking, dinner with friends, in which you take an active part.

never 0
1-2 times in 3 months..................... 1 14
3-12 times in 3 months................... 2
at least weekly 3

F8. Walking outside > 15 mins

never	0	
1-2 times in 3 months	1	15
3-12 times in 3 months	2	
at least weekly	3	

F9. Actively pursuing hobby, requiring some 'active' participation and thought.

never	0	
1-2 times in 3 months	1	16
3-12 times in 3 months	2	
at least weekly	3	

F10. Driving a car or travelling by bus

never	0	
1-2 times in 3 months	1	17
3-12 times in 3 months	2	
at least weekly	3	

In last 6 months, have you done any of the following

F11. Travel outings/car rides to some place for pleasure (not routine journeys. This must involve some organisation and decision making by patient)

never	0	
1-2 times in 6 months	1	18
3-12 times in 6 months	2	
at least weekly	3	

F12. Gardening outside

never	0	
light (occasional weeding)	1	19
moderate (regular weeding, pruning)	2	
heavy (all necessary work)	3	

F13. Household/car maintenance

never	0	
light (repairing small items)	1	20
moderate (some painting/decorating/routine car maint)	2	

heavy (most necessary household/car maint) 3

F14. **Reading books** (not magazines, periodials, papers)

none	0	
1 in 6 months	1	
Less than 1 a fornight	2	21
over 1 a fornight	3	

F15. **Gainful work** (paid work, not voluntary)

none	0	
up to 10 hours/week	1	
10-30 hours/week	2	22
over 30 hours/week	3	

F16 **Total score =** ☐☐ 23 - 24

Appendix V: Outcome changes between domiciliary and day hospital groups at 6 month follow-up for physical, psychological and social outcomes.

	Domiciliary	Day Hospital	md (95%CI)	t value	p value
Physical					
BAI					
Median (IQR)					
0 mth	14.0 (9.3, 16.0)	13.0 (9.0, 17.0)			
3 mth	16.5 (10.0, 18.8)	14.5 (10.0,18.0)			
6 mth	17.0 (10.8, 19.0)	15.5 (9.0, 18.0)			
Mean change 0→ 6 mth	**1.8 (3.0)**	**0.7 (3.1)**	**1.1 (-0.1, 2.3)**	**1.97**	**0.051**
n =	**54**	**58**			
RMI					
Median (IQR)					
0 mth	6.0 (3.0, 8.0)	6.0 (2.0, 9.0)			
3 mth	8.0 (5.0, 12.0)	7.0 (3.0, 10.0)			
6 mth	9.00 (6.0, 13.0)	8.0 (3.3, 11.0)			
Mean change 0→ 6 mth	**2.8 (2.8)**	**1.9 (3.0)**	**0.9 (-0.2, 2.0)**	**1.57**	**0.119**
n =	**52**	**56**			
PCS					
Median (IQR)					
3 mth	29.7 (23.1, 35.7)	27.7 (22.3, 34.1)			
6 mth	35.2 (26.5, 43.7)	32.7 (26.8, 39.2)		-1.22*	0.223*
n =	49	50			
Psychological					
PGCMS					
Median (IQR)					
0 mth	13.0 (9.0, 15.0)	12.0 (9.0, 15.0)			
3 mth	12.0 (8.3, 14.0)	10.0 (7.0,13.0)			
6 mth	11.0 (7.0, 14.0)	10.0 (6.0, 12.0)			
Mean change 0→ 6 mth	**-1.1 (3.7)**	**-2.2 (3.9)**	**1.1 (0.4, 2.6)**	**1.41**	**0.161**
n =	**49**	**51**			
MCS					
Median (IQR)					
3 mth	51.6 (44.7, 58.7)	49.9 (42.5, 58.1)			
6 mth	57.4 (49.9, 62.9)	57.1 (50.6, 63.0)		-0.01*	0.989*
n =	49	50			
Social					
FAI					
Median (IQR)					
6 mth	12.0 (3.0, 25.3)	7.5 (3.0, 16.5)		-1.67*	0.094*

*non-parametric test (Mann-Whitney U)

Appendix VI: Outcome changes between domiciliary and day hospital groups at 12 month follow-up for physical, psychological and social outcomes.

	Domiciliary	Day Hospital	mean difference (95%CI)	t value	p value
Physical					
BAI					
Median (IQR)					
6 mth	17.0 (11.0, 19.0)	16.0 (9.0, 18.0)			
12 mth	17.0 (10.0, 20.0)	14.0 (10.5,17.0)			
Mean change 6→ 12 mth	**-0.2 (1.7)**	**-0.4 (2.2)**	**0.2 (-0.6, 1.0)**	**0.46**	**0.646**
n =	**47**	**50**			
RMI					
Median (IQR)					
6 mth	9.5 (6.0, 13.0)	8.0 (4.0, 11.0)			
12 mth	10.0 (6.0, 13.0)	8.0 (4.0, 10.5)			
Mean change 6→ 12 mth	**-0.2 (1.9)**	**-0.8 (2.2)**	**0.6 (-0.2, 1.5)**	**1.54**	**0.127**
n =	**46**	**48**			
PCS					
Median (IQR)					
6 mth	36.1 (23.8, 43.8)	31.6 (26.9, 39.1)			
12 mth	36.7 (29.1, 43.6)	30.1 (29.3, 39.1)			
Mean change 6→ 12 mth	**0.5 (8.8)**	**0.1 (9.2)**	**0.4.(-3.6, 4.4)**	**0.20**	**0.840**
n =	**41**	**40**			
Psychological					
PGCMS					
median (IQR)					
6 mth	12.0 (8.0, 14.0)	10.0 (7.0,11.5)			
12 mth	11.0 (7.0, 14.3)	9.5 (7.0, 12.8)			
Mean change 6→ 12 mth	**-0.2 (2.9)**	**0.7 (2.9)**	**-0.9 (-2.2, 0.5)**	**-1.27**	**0.208**
n =	**37**	**35**			
MCS					
median (IQR)					
6 mth	57.4 (50.3, 62.3)	57.1 (50.6, 62.9)			
12 mth	56.8 (48.3, 63.5)	56.9 (49.1, 63.5)			
Mean change 6→ 12 mth	**-0.5 (8.9)**	**0.9 (11.9)**	**-1.5 (-6.1, 3.1)**	**-0.64**	**0.526**
n =	**41**	**40**			
Social					
FAI					
median (IQR)					
6 mth	14.0 (3.0, 26.0)	7.0 (3.0,16.8)			
12 mth	15.5 (6.3, 23.0)	9.0 (3.5, 17.5)			
Mean change 6→ 12 mth	-0.4 (5.2)	0.8 (4.5)	-1.2 (-3.2, 0.8)	-1.17	0.246
n =	44	48			

Appendix VII - Letter sent to carers about patient randomisation and participation in study.

DORSET STROKE STUDY

Woodlands
Alderney Community Hospital
Ringwood Road
Parkstone
Poole
BH12 4NB.

Tel: (01202) 735537 Ext279 Fax (01202)718763

Joanne Minett	**Joe Low**	**Amanda Moore**
Senior Physiotherapist	Researcher	Senior Occupational
Therapist		

Date:

Dear

Re: Notification of patient's entry into the Dorset Stroke Study

As you may know, ... has agreed to participate in the Dorset Stroke Study.

I am writing to inform you that he/she has been allocated into the **DOMICILIARY TEAM / DAY HOSPITAL (______________________).**

The **domiciliary team/day hospital** has been informed of this and will contact him/her about plans for OT & physiotherapy treatment when he/she has been discharged from hospital.

Furthermore, we are doing a carers' study looking at the impact of caring of a person with a stroke in which your help would be most appreciated. I will be phoning you about this at a later date.

If there are any problems, please do not hestitate to contact me, Joseph Low, either on 01703-798926 or 01202-735537 Ext 279.

Yours sincerely

Joseph Low
(Researcher)

Appendix VIII: Carer baseline assessment

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CARER BASELINE QUESTIONNAIRE

Dorset Health Commission have set up in a new service for stroke patients in Poole, which provides physiotherapy and occupational therapy in the patient's own home. We do not know whether this is an improvement on current practice which involves attendance at one of the day hospitals. Little is also known on how this will affect carers' life. The purpose of this study is to understand the impact of the different services on carer's daily lives, so that we can improve health services for both stroke patients and carers.

An important part of this study involves looking at the quality of life of carers and the impact that caring for a relative with a stroke has. Today's assessment will be divided into two parts; in the first part, I will be asking you some details about yourself and how the person's stroke has affected your life. In the second part of today's assessment, I will give you the questionnaire to complete.

All the information that you give during the interview will be strictly confidential and in order to protect your privacy, a confidential study number rather than your name will be used on all forms.

Your participation in this study is important to us. Thank you for your help.

From Interviewee

B1. Gender:

Female 1
Male 2 8

B2. Date of birth (day/month/year) ___/___/___ 9-14

B3. Are you currently:

Married 1
Widowed (how long?______) 2
Divorced 3
Separated 4 15
Never married 5
Other 6

B4. During the last 30 days, were you:

(Circle one number)

Working full-time 1
Working part-time 2 16
Unemployed, laid off or looking for work 3

Retired	4
Disabled	5
Keeping house	6
None of the above	7

B5. Out of the past 12 months, how many months did you work for pay at least 15 hours a week?

0 months	1	
1-3 months	2	17
4-6 months	3	
7-9 months	4	
10-12 months	5	

B6. Are you now able to work:

	Yes	No	
a. Part-time?	1	2	18
b. Full-time	1	2	19

B7a. (During your working life), what is (was) your main occupation?

☐ NA; Does not work outside the home OR

Full job title ____________________

In which industry/business was this? ____________________

Were you
manager ☐
foreman ☐
employee ☐

☐ 21

B7b. (During his working life), what is (was) your husband/partner main occupation?

☐ NA; Does not work outside the home OR

Full job title ____________________

In which industry/business was this? ____________________

Were you
manager ☐
foreman ☐
employee ☐

B8. Type of accommodation occupied by this household: (Code from observation if in doubt ask informant) ☐☐ 22 - 23

(1=Whole house, bungalow, detached; 2 = whole house, bungalow, semi-detached; 3= whole house, bungalow, terraced/ end of terrace; 4= Purpose-built flat or maisonette in block with lift; 5 = Purpose-built flat or maisonette in block without lift; 6 = part of house/converted flat or maisonette in block without lift; 7 = part of house/converted flat or maisonette/rooms in house without lift; 8 = dwelling with business premise; 9= caravan/houseboat; 10= other (specify__________)

B9. Is your residence owned or rented?

Owned.. 1
Rented... 2 24
Other (specify__________________)...................... 3

B10. Is your accomodation sheltered housing or a specialised flat for elderly people?

Yes, sheltered housing 1
Yes, specialised flat for elderly people............... 2 25
No 3

B11a. Are you a car driver?

Yes 1 26
No 2

B11b. How many cars do you own?

None... 1
One.. 2 27
Two or more.. 3

B12. Which of the following people live in the same household with you?

Lives alone 1
Lives with husband/wife or significant
other person... 2 28
Lives with other relatives 3
Lives with other non-relatives 4

B14a. How many children do you have?

None.. 1
One.. 2 30
Two and above 3

B14b. How many of these live in the local area (i.e. East Dorset)?

None.. 1
One.. 2 31
Two and above 3

☐☐☐☐
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In this section, I will ask you how (the person's name) stroke has affected you in your daily life.

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5 6 7

In the last 3 months, have you done any of the following activities:

F1. Preparing main meals (involving organisation, preparation and cooking)

never 0
under one week.. 1 8
1-2 times a week.. 2
most days.. 3

F2. Washing up, such as washing, wiping and putting away.

never 0
under one week.. 1
1-2 times a week.. 2 9
most days.. 3

F3. Washing clothes. This includes organising of washing and drying clothes.

never 0
1-2 times in 3 months.. 1 10
3-12 times in 3 months.. 2
at least weekly 3

F4. Light housework, such as dusting, polishing or tidying small objects.

never 0
1-2 times in 3 months.. 1 11
3-12 times in 3 months.. 2
at least weekly 3

F5. **Heavy housework** including bed making, cleaning floors or moving furniture.

never 0
1-2 times in 3 months.......... 1
3-12 times in 3 months.......... 2 12
at least weekly 3

F6. **Local shopping** i.e. playing substantial role in organising and buying shopping.

never 0
1-2 times in 3 months.......... 1
3-12 times in 3 months.......... 2 13
at least weekly 3

F7. **Social occasions** such as going out to clubs, church activities, cinema, theatre, drinking, dinner with friends, in which you take an active part.

never 0
1-2 times in 3 months.......... 1 14
3-12 times in 3 months.......... 2
at least weekly 3

F8. **Walking outside > 15 mins**

never 0
1-2 times in 3 months.......... 1 15
3-12 times in 3 months.......... 2
at least weekly 3

F9. **Actively pursuing hobby**, requiring some 'active' participation and thought.

never 0
1-2 times in 3 months.......... 1 16
3-12 times in 3 months.......... 2
at least weekly 3

F10. **Driving a car or travelling by bus**

never 0
1-2 times in 3 months.......... 1 17
3-12 times in 3 months.......... 2
at least weekly 3

In last 6 months, have you done any of the following

F11. Travel outings/car rides to some place for pleasure (not routine journeys. This must involve some organisation and decision making by patient)

never	0	
1-2 times in 6 months	1	18
3-12 times in 6 months	2	
at least weekly	3	

F12. Gardening outside

never	0	
light (occasional weeding)	1	
moderate (regular weeding, pruning)	2	19
heavy (all necessary work)	3	

F13. Household/car maintenance

never	0	
light (repairing small items)	1	
moderate (some painting/decorating/routine car maint)	2	20
heavy (most necessary household/car maint)	3	

F14. Reading books (not magazines, periodials, papers)

none	0	
1 in 6 months	1	21
Less than 1 a fornight	2	
over 1 a fornight	3	

F15. Gainful work (paid work, not voluntary)

none	0	
up to 10 hours/week	1	
10-30 hours/week	2	22
over 30 hours/week	3	

F16. **Total Score** = ☐☐ 23-24

Now, I would like to ask you for your views about your health. This information will help keep track of how you feel and how well you are able to do your usual activities.

1 4

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5 6 7

At this point, hand questionnaire over to the carer.

Please answer every question by marking the answer as indicated. If you are unsure about how to answer a question, please give the best answer you can. I will be at hand to help if there is any you do not understand.

SF1. In general, would you say your health is:

(Circle one)

Excellent.. 1
Very Good.. 2
Good.. 3 8
Fair.. 4
Poor.. 5

SF2. Compared to one year ago, how would you rate your health in general now?

(Circle one)

Much better now than one year ago.. 1
Somewhat better now than one year ago.. 2
About the same as one year ago.. 3 9
Somewhat worse now than one year ago.. 4
Much worse now than one year ago.. 5

SF3. The following questions are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

(Circle one number on each line)

Activities	**Yes, limited a lot**	**Yes, limited a little**	**No, not limited at all**	
a. **Vigorous activities**, such as running, lifting heavy objects, participating in strenuous sports	**1**	**2**	**3**	10
b. **Moderate activities**, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf.	**1**	**2**	**3**	11
c. Lifting or carrying groceries	**1**	**2**	**3**	12
d. Climbing several flights of stairs	**1**	**2**	**3**	13
e. Climbing one flight of stairs	**1**	**2**	**3**	14

Activities	Yes, limited a lot	Yes, limited a little	No, not limited at all	
f. Bending, kneeling, or stooping	1	2	3	15
g. Walking more than a mile	1	2	3	16
h. Walking half a mile	1	2	3	17
i. Walking one hundred yards	1	2	3	18
j. Bathing or dressing yourself	1	2	3	19

SF4. During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

(Circle one number on each line)

	YES	NO	
a. Cut down on the **amount of time** you spent on work or other activities	1	2	20
b. **Accomplished less** than you would like	1	2	21
c. Were limited in the **kind** of work or other activities	1	2	22
d. Had **difficulty** performing the work or other activities (for example, it took extra effort)	1	2	23

SF5. During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

(Circle one number on each line)

	YES	NO	
a. Cut down on the **amount of time** you spent on work or other activities	1	2	24
b. Accomplished less than you would like	1	2	25
c. Didn't do work or other activities as carefully as usual	1	2	26

SF6. During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbours, or groups?

	(Circle one)	
Not at all	1	
Slightly	2	
Moderately	3	27
Quite a bit	4	
Extremely	5	

SF7. How much bodily pain have you had during the past 4 weeks?

	(Circle one)	
None	1	
Very mild	2	
Mild	3	28
Moderate	4	
Severe	5	
Very Severe	6	

SF8. During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?

	(Circle one)	
Not at all	1	
A little bit	2	
Moderately	3	29
Quite a bit	4	
Extremely	5	

SF9. These questions are about how you feel and how things have been with you <u>during the past 4 weeks</u>. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during <u>the past 4 weeks</u> -

(Circle one number on each line)

	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time	
a. Did you feel full of life?	1	2	3	4	5	6	30
b Have you been a very nervous person?	1	2	3	4	5	6	31
c. Have you felt so down in the dumps that nothing could cheer you up?	1	2	3	4	5	6	32
d. Have you felt calm and peaceful?	1	2	3	4	5	6	33
e. Did you have a lot of energy?	1	2	3	4	5	6	34
f. Have you felt downhearted and low?	1	2	3	4	5	6	35
g. Did you feel worn out?	1	2	3	4	5	6	36
h. Have you been a happy person?	1	2	3	4	5	6	37
i. Did you feel tired?	1	2	3	4	5	6	38

SF10. During the <u>past 4 weeks</u>, how much of the time has your <u>physical health or emotional problems</u> interfered with your social activities (like visiting with friends, relatives, etc)?

(Circle one)

All of the time.. 1

Most of the time.. 2

Some of the time.. 3 39

A little of the time.. 4

None of the time.. 5

SF11. How TRUE or FALSE is <u>each</u> of the following statements for you?

(Circle one number on each line)

	Definitely true	Mostly true	Don't know	Mostly false	Definitely false	
a. I seem to get ill more easily than other people	1	2	3	4	5	40
b. I am as healthy as anybody I know	1	2	3	4	5	41
c. I expect my health to get worse	1	2	3	4	5	42
d. My health is excellent	1	2	3	4	5	43

In this next section, we would like to know if you have had any medical complaints and how your health has been over the past few weeks. Please answer *all* the following questions by marking the answer which you think most nearly applies to you. Remember that we want to know about present and recent complaints, not about those you have had in the past.

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Have you recently:

GHQ 1.	**Been feeling perfectly well and in good health?**	*Better than usual* 0	*Same as usual* 0	*Worse than usual* 1	*Much worse than usual* 1	8
GHQ 2.	**Been feeling in need of a good tonic?**	*Not at all* 0	*No more than usual* 0	*Rather more than usual* 1	*Much more than usual* 1	9
GHQ 3.	**Been feeling run down and out of sorts?**	*Not at all* 0	*No more than usual* 0	*Rather more than usual* 1	*Much more than usual* 1	10
GHQ 4.	**Felt that you are ill?**	*Not at all* 0	*No more than usual* 0	*Rather more than usual* 1	*Much more than usual* 1	11
GHQ 5.	**Been getting any pains in your head?**	*Not at all* 0	*No more than usual* 0	*Rather more than usual* 1	*Much more than usual* 1	12
GHQ 6.	**Been getting a feeling of tightness or pressure in your head?**	*Not at all* 0	*No more than usual* 0	*Rather more than usual* 1	*Much more than usual* 1	13
GHQ 7.	**Been having hot or cold spells?**	*Not at all* 0	*No more than usual* 0	*Rather more than usual* 1	*Much more than usual* 1	14

Have you recently:

GHQ 8.	**Lost much sleep over worry**	*Not at all* *0*	*No more than usual* *0*	*Rather more than usual* *1*	*Much more than usual* *1*	15
GHQ 9.	**Had difficulty staying asleep once you were off?**	*Not at all* *0*	*No more than usual* *0*	*Rather more than usual* *1*	*Much more than usual* *1*	16
GHQ 10.	**Felt constantly under strain?**	*Not at all* *0*	*No more than usual* *0*	*Rather more than usual* *1*	*Much more than usual* *1*	17
GHQ 11.	**Been getting edgy and bad tempered?**	*Not at all* *0*	*No more than usual* *0*	*Rather more than usual* *1*	*Much more than usual* *1*	18
GHQ 12.	**Been getting scared or panicky for no good reason?**	*Not at all* *0*	*No more than usual* *0*	*Rather more than usual* *1*	*Much more than usual* *1*	19
GHQ 13.	**Found everything getting on top of you?**	*Not at all* *0*	*No more than usual* *0*	*Rather more than usual* *1*	*Much more than usual* *1*	20
GHQ 14.	**Been feeling nervous and strung-up all the time?**	*Not at all* *0*	*No more than usual* *0*	*Rather more than usual* *1*	*Much more than usual* *1*	21

Have you recently:

GHQ 15.	**Been managing to keep yourself busy and occupied?**	*More so than usual* *0*	*Same as usual* *0*	*Rather less than usual* *1*	*Much less than usual* *1*	22
GHQ 16.	**Been taking longer over things you do?**	*Quicker than usual* *0*	*Same as usual* *0*	*Longer than usual* *1*	*Much longer than usual* *1*	23
GHQ 17.	**Felt on the whole you were doing things well?**	*Better than usual* *0*	*About the same* *0*	*Less well than usual* *1*	*Much less well* *1*	24
GHQ 18.	**Been satisfied with the way you've carried out your task?**	*More satisfied* *0*	*About same as usual* *0*	*Less satisfied than usual* *1*	*Much less satisfied* *1*	25

GHQ 19.	**Felt you are playing a useful part in things?**	*More so than usual* *0*	*Same as usual* *0*	*Less useful than usual* *1*	*Much less useful* *1*	26
GHQ 20.	**Felt capable of making decisions about things?**	*More so than usual* *0*	*Same as usual* *0*	*Less so than usual* *1*	*Much less than usual* *1*	27
GHQ 21.	**Been able to enjoy your normal day-to-day activities?**	*More so than usual* *0*	*Same as usual* *0*	*Less so than usual* *1*	*Much less than usual* *1*	28

Have you recently:

GHQ 22.	**Been thinking of yourself as a worthless person?**	*Not at all* *0*	*No more than usual* *0*	*Rather more than usual* *1*	*Much more than usual* *1*	29
GHQ 23.	**Felt that life is entirely hopeless?**	*Not at all* *0*	*No more than usual* *0*	*Rather more than usual* *1*	*Much more than usual* *1*	30
GHQ 24.	**Felt that life isn't worth living?**	*Not at all* *0*	*No more than usual* *0*	*Rather more than usual* *1*	*Much more than usual* *1*	31
GHQ 25.	**Though of the possibility that you might make away with yourself**	*Definitely not* *0*	*I don't think so* *0*	*Has crossed my mind* *1*	*Definitely have* *1*	32
GHQ 26.	**Found at times you couldn't do anything because your nerves were too bad?**	*Not at all* *0*	*No more than usual* *0*	*Rather more than usual* *1*	*Much more than usual* *1*	33
GHQ 27.	**Found yourself wishing you were dead and away from it all?**	*Not at all* *0*	*No more than usual* *0*	*Rather more than usual* *1*	*Much more than usual* *1*	34
GHQ 28.	**Found that the idea of taking your own life kept coming into your mind?**	*Definitely not* *0*	*I don't think so* *0*	*Has crossed my mind* *1*	*Definitely have* *1*	35

GHQ29. **Total score =** ☐☐ 36 - 37

Appendix IX: Carer follow-up assessment

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CARER FOLLOW-UP QUESTIONNAIRE

Today's assessment will be similiar to the format of the previous assessment and will be divided into two parts; in the first part, I will be asking you some details about how the person's stroke has affected your life. In the second part of today's assessment, I will give you the questionnaire to complete.

All the information that you give during the interview will be strictly confidential. Once again, thank you for your help.

In this section, I will ask you how (the person's name) stroke has affected you in your daily life.

In this section, I will ask you how your stroke has affected you in your daily life.

In the last 3 months, have you done any of the following activities:

F1. Preparing main meals (involving organisation, preparation and cooking)

never 0
under one week........ 1
1-2 times a week........ 2
most days........ 3

8

F2. Washing up, such as washing, wiping and putting away.

never 0
under one week........ 1
1-2 times a week........ 2
most days........ 3

9

F3. Washing clothes. This includes organising of washing and drying clothes.

never 0
1-2 times in 3 months........ 1
3-12 times in 3 months........ 2
at least weekly 3

10

F4. Light housework, such as dusting, polishing or tidying small objects.

never 0
1-2 times in 3 months........ 1
3-12 times in 3 months........ 2
at least weekly 3

11

F5. **Heavy housework** including bed making, cleaning floors or moving furniture.

never 0
1-2 times in 3 months.................................. 1 12
3-12 times in 3 months................................ 2
at least weekly 3

F6. **Local shopping** i.e. playing substantial role in organising and buying shopping.

never 0
1-2 times in 3 months.................................. 1 13
3-12 times in 3 months................................ 2
at least weekly 3

F7. **Social occasions** such as going out to clubs, church activities, cinema, theatre, drinking, dinner with friends, in which you take an active part.

never 0
1-2 times in 3 months.................................. 1 14
3-12 times in 3 months................................ 2
at least weekly 3

F8. **Walking outside > 15 mins**

never 0
1-2 times in 3 months.................................. 1 15
3-12 times in 3 months................................ 2
at least weekly 3

F9. **Actively pursuing hobby**, requiring some 'active' participation and thought.

never 0
1-2 times in 3 months.................................. 1 16
3-12 times in 3 months................................ 2
at least weekly 3

F10. **Driving a car or travelling by bus**

never 0
1-2 times in 3 months.................................. 1 17
3-12 times in 3 months................................ 2
at least weekly 3

In last 6 months, have you done any of the following

F11. Travel outings/car rides to some place for pleasure (not routine journeys. This must involve some organisation and decision making by patient)

never 0
1-2 times in 6 months.................................... 1 18
3-12 times in 6 months.................................. 2
at least weekly 3

F12. **Gardening** outside

never 0
light (occasional weeding).............................. 1 19
moderate (regular weeding, pruning).................... 2
heavy (all necessary work) 3

F13. **Household/car maintenance**

never 0
light (repairing small items)............................ 1 20
moderate (some painting/decorating/routine car maint) 2
heavy (most necessary household/car maint) 3

F14. **Reading books** (not magazines, periodials, papers)

none 0
1 in 6 months.. 1 21
Less than 1 a fornight.................................... 2
over 1 a fornight 3

F15. **Gainful work** (paid work, not voluntary)

none 0
up to 10 hours/week 1 22
10-30 hours/week... 2
over 30 hours/week 3

F16. **Total score =** ☐☐ 23 -24

In the next section,I am going to read a list of things which other people have found to be difficult when helping someone who has an illness. I would like you to give me a 'yes' or 'no' answer to these questions.

☐☐☐☐
1 4

☐ 0 9
5 6 7

CS1. **Sleep is disturbed (e.g. because............is in & out of bed or wanders around at night)**

Yes.. 1 8
No.. 0

CS2. **It is inconvenient (e.g. because helping takes so much time or it's a long drive over)**

Yes.. 1 9
No.. 0

CS3. **It is a physical strain (e.g. because of lifting in & out of a chair, effort or concentration is required**

Yes.. 1 10
No.. 0

CS4. **It is continuing (e.g. helping restricts free time or cannot go visiting)**

Yes.. 1 11
No.. 0

CS5. **There have been family adjustments (e.g. because helping has disrupted routine, there has been no privacy).**

Yes.. 1 12
No.. 0

CS6. **There have been changes in personal plans (e.g. had to turn down a job, could not go on holiday)**

Yes.. 1 13
No.. 0

CS7. **There have been other demands on my time (e.g. from other family members).**

Yes.. 1 14
No.. 0

CS8. There have been emotional adjustments (e.g. because of severe arguments).

Yes.. 1
No... 0 15

CS9. **Some behaviour is upsetting (e.g. because of incontinence:........................ has trouble remembering things. .... accuses people of taking things.**

Yes.. 1
No... 0 16

CS10. It is upsetting to find .... has changed so much from his/her former self (e.g. he/she is a different person than he/she used to be)

Yes.. 1
No... 0 17

CS11. There have been work adjustments (e.g. because of having to take time off)

Yes.. 1
No... 0 18

CS12. It is a financial strain

Yes.. 1
No... 0 19

CS13. Feeling completely overwhelmed (e.g. because of worry about................, concerns about how you will manage).

Yes.. 1
No... 0 20

CS14. **Total Score =** ☐☐ 21 - 22

Now, I would like to ask you for your views about your health. This information will help keep track of how you feel and how well you are able to do your usual activities.

☐☐☐☐
1 4

☐ 0 6
5 6 7

I will now give you the questionnaire to complete by yourself. There are two assessments to fill out.

For the first assessment, please answer every question by marking the answer as indicated. If you are unsure about how to answer a question, please give the best answer you can

SF1. In general, would you say your health is:

(Circle one)

Excellent.. 1

Very Good.. 2

Good.. 3 8

Fair.. 4

Poor.. 5

SF2. <u>Compared to one year ago</u>, how would you rate your health in general <u>now</u>?

(Circle one)

Much better now than one year ago.. 1

Somewhat better now than one year ago.. 2

About the same as one year ago.. 3 9

Somewhat worse now than one year ago.. 4

Much worse now than one year ago.. 5

SF3. The following questions are about activities you might do during a typical day. Does <u>your health now limit</u> you in these activities? If so, how much?

(Circle one number on each line)

Activities	**Yes, limited a lot**	**Yes, limited a little**	**No, not limited at all**	
a. **Vigorous activities**, such as running, lifting heavy objects, participating in strenuous sports	**1**	**2**	**3**	10
b. **Moderate activities**, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	1	2	3	11
c. Lifting or carrying groceries	1	2	3	12
d. Climbing several flights of stairs	1	2	3	13
e. Climbing one flight of stairs	1	2	3	14
f. Bending, kneeling, or stooping	1	2	3	15

Activities	**Yes, limited a lot**	**Yes, limited a little**	**No, not limited at all**	
g. Walking more than a mile	1	2	3	16
h. Walking half a mile	1	2	3	17
i. Walking one hundred yards	1	2	3	18
j. Bathing or dressing yourself	1	2	3	19

SF4. During the <u>past 4 weeks</u>, have you had any of the following problems with your work or other regular daily activities <u>as a result of your physical health</u>?

(Circle one number on each line)

	YES	NO	
a. Cut down on the amount of time you spent on work or other activities	1	2	20
b. Accomplished less than you would like	1	2	21
c. Were limited in the kind of work or other activities	1	2	22
d. Had difficulty performing the work or other activities (for example, it took extra effort)	1	2	23

SF5. During the <u>past 4 weeks</u>, have you had any of the following problems with your work or other regular daily activities <u>as a result of any emotional problems</u> (such as feeling depressed or anxious)?

(Circle one number on each line)

	YES	NO	
a. Cut down on the amount of time you spent on work or other activities	1	2	24
b. Accomplished less than you would like	1	2	25
c. Didn't do work or other activities as carefully as usual	1	2	26

SF6. During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbours, or groups?

	(Circle one)	
Not at all	1	
Slightly	2	
Moderately	3	27
Quite a bit	4	
Extremely	5	

SF7. How much bodily pain have you had during the past 4 weeks?

	(Circle one)	
None	1	
Very mild	2	
Mild	3	28
Moderate	4	
Severe	5	
Very Severe	6	

SF8. During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?

	(Circle one)	
Not at all	1	
A little bit	2	
Moderately	3	29
Quite a bit	4	
Extremely	5	

SF9. These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks -

(Circle one number on each line)

	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time	
a. Did you feel full of life?	1	2	3	4	5	6	30
b Have you been a very nervous person?	1	2	3	4	5	6	31
c. Have you felt so down in the dumps that nothing could cheer you up?	1	2	3	4	5	6	32
d. Have you felt calm and peaceful?	1	2	3	4	5	6	33
e. Did you have a lot of energy?	1	2	3	4	5	6	34
f. Have you felt downhearted and low?	1	2	3	4	5	6	35
g. Did you feel worn out?	1	2	3	4	5	6	36
h. Have you been a happy person?	1	2	3	4	5	6	37
i. Did you feel tired?	1	2	3	4	5	6	38

SF10. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc)?

(Circle one)

All of the time	1	
Most of the time	2	
Some of the time	3	39
A little of the time	4	
None of the time	5	

SF11. How TRUE or FALSE is each of the following statements for you?

(Circle one number on each line)

	Definitely true	Mostly true	Don't know	Mostly false	Definitely false	
a. I seem to get ill more easily than other people	1	2	3	4	5	40
b. I am as healthy as anybody I know	1	2	3	4	5	41
c. I expect my health to get worse	1	2	3	4	5	42
d. My health is excellent	1	2	3	4	5	43

For the next assessment, we would like to know if you have had any medical complaints and how your health has been over the past few weeks. Please answer *all* the following questions by marking the answer which you think most nearly applies to you. Remember that we want to know about present and recent complaints, not about those you have had in the past.

☐☐☐☐
1 4

☐ 0 8
5 6 7

<u>Have you recently:</u>

GHQ 1.	**Been feeling perfectly well and in good health?**	*Better than usual* *0*	*Same as usual* *0*	*Worse than usual* *1*	*Much worse than usual* *1*	8
GHQ 2.	**Been feeling in need of a good tonic?**	*Not at all* *0*	*No more than usual* *0*	*Rather more than usual* *1*	*Much more than usual* *1*	9
GHQ 3.	**Been feeling run down and out of sorts?**	*Not at all* *0*	*No more than usual* *0*	*Rather more than usual* *1*	*Much more than usual* *1*	10
GHQ 4.	**Felt that you are ill?**	*Not at all* *0*	*No more than usual* *0*	*Rather more than usual* *1*	*Much more than usual* *1*	11
GHQ 5.	**Been getting any pains in your head?**	*Not at all* *0*	*No more than usual* *0*	*Rather more than usual* *1*	*Much more than usual* *1*	12
GHQ 6.	**Been getting a feeling of tightness or pressure in your head?**	*Not at all* *0*	*No more than usual* *0*	*Rather more than usual* *1*	*Much more than usual* *1*	13

GHQ 7.	**Been having hot or cold spells?**	*Not at all* *0*	*No more than usual* *0*	*Rather more than usual* *1*	*Much more than usual* *1*	14

Have you recently:

GHQ 8.	**Lost much sleep over worry**	*Not at all* *0*	*No more than usual* *0*	*Rather more than usual* *1*	*Much more than usual* *1*	15
GHQ 9.	**Had difficulty staying asleep once you were off?**	*Not at all* *0*	*No more than usual* *0*	*Rather more than usual* *1*	*Much more than usual* *1*	16
GHQ 10.	**Felt constantly under strain?**	*Not at all* *0*	*No more than usual* *0*	*Rather more than usual* *1*	*Much more than usual* *1*	17
GHQ 11.	**Been getting edgy and bad tempered?**	*Not at all* *0*	*No more than usual* *0*	*Rather more than usual* *1*	*Much more than usual* *1*	18
GHQ 12.	**Been getting scared or panicky for no good reason?**	*Not at all* *0*	*No more than usual* *0*	*Rather more than usual* *1*	*Much more than usual* *1*	19
GHQ 13.	**Found everything getting on top of you?**	*Not at all* *0*	*No more than usual* *0*	*Rather more than usual* *1*	*Much more than usual* *1*	20
GHQ 14.	**Been feeling nervous and strung-up all the time?**	*Not at all* *0*	*No more than usual* *0*	*Rather more than usual* *1*	*Much more than usual* *1*	21

Have you recently:

GHQ 15.	**Been managing to keep yourself busy and occupied?**	*More so than usual* *0*	*Same as usual* *0*	*Rather less than usual* *1*	*Much less than usual* *1*	22
GHQ 16.	**Been taking longer over things you do?**	*Quicker than usual* *0*	*Same as usual* *0*	*Longer than usual* *1*	*Much longer than usual* *1*	23
GHQ 17.	**Felt on the whole you were doing things well?**	*Better than usual* *0*	*About the same* *0*	*Less well than usual* *1*	*Much less well* *1*	24
GHQ 18.	**Been satisfied with the way you've carried out your task?**	*More satisfied* *0*	*About same as usual* *0*	*Less satisfied than usual* *1*	*Much less satisfied* *1*	25

GHQ 19.	**Felt you are playing a useful part in things?**	*More so than usual* *0*	*Same as usual* *0*	*Less useful than usual* *1*	*Much less useful* *1*	26
GHQ 20.	**Felt capable of making decisions about things?**	*More so than usual* *0*	*Same as usual* *0*	*Less so than usual* *1*	*Much less than usual* *1*	27
GHQ 21.	**Been able to enjoy your normal day-to-day activities?**	*More so than usual* *0*	*Same as usual* *0*	*Less so than usual* *1*	*Much less than usual* *1*	28

<u>Have you recently</u>:

GHQ 22.	**Been thinking of yourself as a worthless person?**	*Not at all* *0*	*No more than usual* *0*	*Rather more than usual* *1*	*Much more than usual* *1*	29
GHQ 23.	**Felt that life is entirely hopeless?**	*Not at all* *0*	*No more than usual* *0*	*Rather more than usual* *1*	*Much more than usual* *1*	30
GHQ 24.	**Felt that life isn't worth living?**	*Not at all* *0*	*No more than usual* *0*	*Rather more than usual* *1*	*Much more than usual* *1*	31
GHQ 25.	**Though of the possibility that you might make away with yourself**	*Definitely not* *0*	*I don't think so* *0*	*Has crossed my mind* *1*	*Definitely have* *1*	32
GHQ 26.	**Found at times you couldn't do anything because your nerves were too bad?**	*Not at all* *0*	*No more than usual* *0*	*Rather more than usual* *1*	*Much more than usual* *1*	33
GHQ 27.	**Found yourself wishing you were dead and away from it all?**	*Not at all* *0*	*No more than usual* *0*	*Rather more than usual* *1*	*Much more than usual* *1*	34
GHQ 28.	**Found that the idea of taking your own life kept coming into your mind?**	*Definitely not* *0*	*I don't think so* *0*	*Has crossed my mind* *1*	*Definitely have* *1*	35

GHQ29. **Total score =** ☐☐ 36 - 37

Appendix X: - Baseline interview schedule (first draft)

Interview Schedule for carers' study (baseline)

Carers' perception of health

1. Do you had any illnesses or disabilities at present?

Carers' perception of their role

2. In what way have you coped with (patient's name) stroke?

3. What role do you think you will play as (patient's name) main carer?

4. What do you think will be the main difficulties in caring for your (patient's name)?

5. How do you think caring for your (patient's name) will affect your own life?

prompts *(social*
(physical
(emotional

Carers' perception of social support

6. Who gives you most of your emotional and physical support?

7. If you wanted to go to the shops or the hospital, who would you ask?
- how often could you ask them

Carer's perception of service provision

8. What expectations do you have about the therapy that (patient's name) will receive at home/day hospital?
- preferential treatment – reasons why?
- issues of respite
- education and involvement of carers in rehab process

Carers' perception of the future

12. How do you think your role as a carer might change in another 6 months from now?

jtsl/dss/carer
25.09.96

Appendix XI: Six month follow-up interview schedule (first draft)

Interview Schedule for carers' study (follow-up)

Carers' perception of their role

1. What role have you played as (patient's name)'s main carer over the last 6 months?

2. How has caring for (patient's name) affected your own life?

3. What have been the main difficulties in caring for (patient's name)?

Carers' perception of social support

4. Where have you got most of your emotional and physical support from?

5. Over the last 6 months, if you had wanted to go out e.g. the shops, who have you asked?

Carers' perception of service provision

6. How have the expectations that you had about the therapy been fulfilled?

7. How has having (the patient's name) therapy done at home/the day hospital affected your life?

   - what were the good things about it for you?
   - what were the bad things about it for you ?

8. What other kind of help would you have found useful in coping with (the patient's name) stroke?

Carers' perception of the future

9. What are your expectations of your caring role over the next year?

Appendix XII: Summary of pilot interviews

DSS 5023. Date of interview: 06.08.96. 6 month.

Caring role

To feed him a proper diet and arranging doctor if he had problems as husband got confused. Important role was to keep husband calm and not agitated. Also helped husband in exercising, going for short walks. Freq depended in time of year; in summer, approx 4x/week, in winter, husband occupied himself in shed.

Life affected by caring

husband restricted in his activities. Subject gives husband extra attention not to strain himself. Generally, caring hasn't affected social life.

Main difficulties

just keeping him calm. Only time when subject is distressed is when husband doesn't look too good.

Emotional support

Most of emotional support provided through faith (Jehovah Witness) and prayer. Some support may come through her daughter, husband and friends.

Physical support

Subject has a number of friends from her faith who take both her and her husband out. Subjects feels that these friends will offer help all the time. If going shopping, can ask friends, who will offer help at any time.

Expectations about OT/PT

wasn't aware of what it would involve.

Feelings post PT/OT

Helped her alot as it gave the feeling that he can get better, imparticularly finding out what was wrong. They helped her with his writing. She didn't know that he had a problem with writing.

Therapy at home

Not so upsetting as he couldn't drive . Got on friendly terms with staff and looked forward to therapist coming.

Additional help

No additional hrlp needed.

Expectations of caring

Hope he will improve. If husband got worse, it would pull her down and would not find it easy to cope

DSS 5025 Date of interview: 15.08.96. 6 months.

Main role as carer
Visiting, bringing down and doing clothes washing, shopping. No personal care, but mainly time consuming tasks.

Affect on own life
Interruption to normal routine and visiting places that she didn't have to go before mother's stroke. Also having to go in her mother's home every day, so had to curtail certain things that she would have usually have done. Changes to life have been minor and mamnage to juggle her time.

Main difficulties
Juggling time. No major physical problems to do things. Generally able to cope.

Emotional support
Uses her own resources. Sister lives away. Her 2 sons (late teens and early 20's) not much use.

Physical support
Prama care provide this.

Expectations of physio/OT
mininal amount - what she expected to happen, happened.

Effects of therapy at home
No effect on herself. Had mother not been able to get out, she would have preferred mother to go to DH, but as she was, no difference and it would have probably been better to have had therapy at home. One less hassle of going out.

What other help useful
None except a 24hr carer.

Expectation of future caring role
Mother's leg is getting worse. She feels her role will be more involved. More contact as she would feel duty bound to do more than what she does now. Over the year, her input will increase. Her mother may go into an active rest home.

DSS 5026 Date of interview: 16.08.96. 6 months.

Role in last 6 months

Housework, cooking, shopping and looking after her eg. washing her ie. helping her to get in and out of the bath, dressing. Mother had previously shared these tasks before her stroke. At this point, mother is able to do more and can dress herself.

Affected life

No time for herself and got very tired. Things are getting better - mother keen to do more for herself and able to go out more. For the first 2-3 months, she had no life. Now able to have more of life. She didn't feel that the health professionals didn't tell her what to expect.She can leave her mother for longer periods of time, but still needs to prepare vegetable and to plan ahead. Before the stroke, she had her own life and job, but this was turned upside down.

Main difficulties

Helping with personal care and cooking (having never cooked). Also clearing up after two brothers.

Emotional support

Boyfriend and an older lady friend (who took her under her arm). Needed time to be on her own and to go out for a couple of hours. Sometimes used to get angry. Boyfriend has been there all the time. Had to go out, otherwise she would have cracked up.

Physical support

No other support. None from mother's family. Dad helpful in getting on with his own life and doing his own things.

When going to shops, initallyasked dad to keep a eye on mother. After a while, she usually told her motherthat she was going out for a couple of hours.

Expectations of therapy

Thought they (the therapists) would do a lot at home. Overall, she felt that her mother would have had a lot more physio (once a fornight was not adequate). she had the impression that her mother was left to get on with it, though physio was supportive. She wasn't happy and would have preferred her mother to have gone to DH - she was on her own, no-one to compete with (more motivated in a group) and she (the daughter) would have had a day free. At DH, both would have had a break.

Other help

someone to talk to; she felt isolated, it was an effort to make contact with the stroke club.Mother didn't make the progressshe thought she would and it would have been nice to have had a person eg. counsellor who had initated the first contact, was in the background.

Future expectations.

Expects mother to make gradual progress, so that she (the daughter) can slowly get back to her own life. If mother takes a turn for the worse, she couldn't take it again and she wouldn't stay at home. Would have liked more information about mother's other medical conditions ie. diabetes as she felt unprepared.

DSS 5060 Date of interview: 02.08.96. Baseline.

Physical
Not good. Suffer from arthritis, angina and has suffered from heart attack in 1991. Over the last month, it has been worse and she is also suffering from stress. Slightly worse, but coping.

Coming to terms with husband's strokes
had to accept it. Very sorry for him. Nobody's fault. Had to accept it as a fact of life. Nothing I could have done about it.

Expectations
Wants to help him in every way possible. She wants to do the personal and practical help.

Main difficulties
Her husband's weight would present one problem. She would not be able to help him struggling out of bed, but maybe able to steady him. She wouldn't have the strength to push him in the wheelchair up the hill.

Coping with difficulties
Will push herself as far as she can. She has been given help to dress him in the morning and to put hi in bed at night as both activities require a lot of bending which she is not good at. If he can walk, she will do all practical jobs, except these heavy ones.

If his mind wanders and he forgets that he has had a stroke, it is difficult to remain calm as she doesn't want him to see him cry.

How will caring for your husband affect your life
Don't know. Doesn't see a great problem inside the house and hopes that he will get a bit better. He is losing his eyesight, frustrating for both of them as they have led busy lives and now, he can't read. Her social life has already been affected due to her poor health. Don't go out, but quite content.

Emotional support
Can speak to Minister openly about anything - get alot of guidance. Also has a lady friend that she got to know through the church, but she wouldn't go to many people for help. For physical health, she would go to the doctor.

Physical support
Nobody as neighbours are both elderly and family is 100's miles away. If she wanted to go to the shops, husband could be left on his own for a short time (about 1.5 hr). If it was for a few hours, she would ask friends, maybe lady next door, but would mainly not bother people except if she was away for more than 2 hours. There would be enough friends in the church and Rotary to draw from.

Expectation about therapy
She would prefer DH cos:-1) husband is stuck in house. By going to DH, he is uplifted by seeing and meeting different people and can share worries and can share problems, instead of only seeing just her. Husband has always been a social person. DH will also give her a little break in the knowledge that he is in good hands and can do what she wants to do, even if it is only sleeping. It is bound to be good for him to get out rather than be surrounded by these four walls.

How much would you like to be involved in rehab process
Not at all. Taking care of him is as much as she can cope with. She doesn't think she can give more physical help due to the state of physical health. However, would like to know how to handle him properly and also so that she doesn't hurt herself. OT and physios coming from hospital - she wants to know what moods he has to do - getting out of bed.

Role change
Hopes that he will get better. If it gets worst, will first speak to doctor.

DSS 5062. Date of interview: 02.08.96. Baseline.

Health
Good. No illnesses or disabilities at present.

Coping with mother's stroke
Has been preparing as there has been a gradual deterioration in her mother's abilities to do day to day things. She has organised her life to suit the circumstances.

Role
Care for her mother is divided into 3 people; herself, her nephew & partner and her sister. Her role is to cover everyday needs such as washing, to help prepare meals and to see if she is eating OK. Mother is also having meals on wheels. She is going in 3 times/ week. Nephew is providing overnight cover and sister is providing remaining cover.

Main difficulties
1) Making mother understand her own limitation as she still wants to do things her own way, but can't perform these tasks.
2) Fitting it into existing family committment and trying to balance the time between her own family and fitting this with caring for her mother.

Affecting life
Mother's stroke was the immediate cause of her giving up her full-time job, but will need to return to part-time work to help support her son in college.

Physical problems
None

Emotional problems
Painful to see an independent person, the one who cared for you, have the situation reversed.

Emotional support
mainly husband as sons are too busy leading their lives and she is not close to her sister.

Physical support
neighbours of mother say they are willing to help her with her mother when necessary.

Expectations
She hopes that therapy will improve mother's mobility and give a chance for practicing speech. Also feels that day hospital will give mother a chance for 'social therapy' as her mother enjoys talking to others and there will be a chance to talk with others.
She would prefer her mother to go to DH as it would give her a spare day and time to think of her own family instead of the caring role.
Helping her to do the things that she can do. However, she would not like to be involved in the rehab process, rather leaving that to the professionals and generally feels that enough information has already been given.

Role change
It could go either way. If mother got worse, it wouldn't be possible to give her more care than she is already providing. If further care was necessary, it would have to be provided by home care or rest home.

DSS 5064 Date of interview: 16.08.96. Baseline.

Health
gets tired more often, but generally all right. No illness to date.

Coping
Married to husband for 43 years and never parted. Generally doesn't panic and copes well

Role as carer
Often dresses husband and washes his back, gets breakfast and meals. Once dressed, just sits there.
Generally doing what's she's been doing for 43 y, except washing and dressing him.
Shock of stroke knocked her over.

Main difficulties
Now improving, though his peg is his main difficulty - when he was getting a blockage in his water though he is improving on that, but can call district nurse on that.

Affect on own life
Had to give up work earlier than anticipated though at 76 y, she couldn't have gone working forever. Never usually goes out often, only to the local pub. Used to visit sister, but since stroke, they visit her at her home. Apart from that, life is the same.

Problems for physical tasks
None, but getting more tired. Husband is more mobile than others.
No need for additional help, but has got a neighbour who would help and can also call a district nurse.

Physical support
No-one.
Only goes shopping if husband goes up to the DH - she uses husband's visits as respite, but if husband stops going to DH, wouldn't know who to ask (perhaps neighbours or son in an emergency).

Expectations about therapy
Doesn't know what he's having done.and on going on what she is told. Wouldn't like further involvement as she wants him to mix with others so little involvement. Rather he went on his own.

Role change
Don't know though he is improving. Doesn't know what to think if he gets worse.

Appendix XIII: Baseline interview schedule (final draft)

Interview Schedule for carers' study (baseline)

Carers' perception of health

1. How has your health been over the last month?

2. Do you have any illnesses or disabilities at present?

Carers' perception of their role

3. How have you come to terms with (patient's name) stroke?

4. As (patient's name) main carer, what do you expect to do?

5. What do you think will be the main difficulties in caring for your (patient's name)?

6. How do you think caring for your (patient's name) will affect your own life?

(social
prompts *(physical*
(emotional

Carers' perception of social support

7. Who gives you most of your emotional support?

8. Who gives you most of your physical support?

9. If you wanted to go to the shops, who would you ask?
- how often could you ask them

10. If you wanted to go to the hospital, who would you ask?

Carer's perception of service provision

11. What expectations do you have about the therapy that (patient's name) will receive at home/day hospital?

(what is their understanding of the therapy provided?
(what do they define as a good service?
ie in your opinion, what would you call a good service?

Prompts (which treatment would you prefer the patient to have - why?
- issues of respite
- education and involvement of carers in rehab process

Carers' perception of the future

12. How do you see your role changing in the next 6 months?
- will it get better/worse? Why?

jtsl/dss/carer
25.09.96

Appendix XIV: Six month follow-up interview schedule (final draft)

Interview Schedule for carers' study (follow-up)

Carers' perception of their role

1. What role have you played as (patient's name)'s main carer over the last 6 months?

2. How has caring for (patient's name) affected your own life?

3. What have been the main difficulties in caring for (patient's name)?

Carers' perception of social support

4. Where have you got most of your emotional support from?

5. Where have you got most of your physical support from?

6. Over the last 6 months, if you had wanted to go out e.g. the shops, who have you asked?

Carers' perception of service provision

7. What expectations did you have about the physiotherapy /OT.
   - *what is their understanding of the therapy provided?*

8. Have these expectations been fulfilled?
   -If yes, ask how?
   -If no, ask why?

9. How has having (the patient's name) therapy done at home/the day hospital affected your life?
   - *what were the good things about it for you?*
   - *what were the bad things about it for you ?*

10. What other kind of help would you have found useful in coping with (the patient's name) stroke?

Carers' perception of the future

11. What are your expectations of your caring role over the next year?

Appendix XV - Baseline coding frame (Version I)

Baseline

Main theme	**Categories**	**sub-categories**
Health problems	presence of chronic illnesses	
Role expectation	care organisation	social activities personal self-care domestic tasks
Support structure (physical & emotional)	family	daughter son sibling
	friends	
	neighbour	
	Social Service worker	
	external paid worker	
coming to terms with the stroke	acceptance	
	fatalism	
	experience: previous stroke	
	experience: other illnesses	
	physical support	
difficulties/impact of stroke	lack of time for oneself	
	organisation of care post-work	
	constant need to be supportive	
	problems associated increasing age	
	interrupted nights	
	loss of previous life together	
	role reversal	
	no social life	
future expectations	no improvement	
	uncertain of future	
	dependent on recovery from stroke	
service provision	understanding of therapy	
	expectation of therapy	
	advantage/disadvantages of day hospital	
	advantages/disadvantages of domiciliary	
	understanding of good service	
	professional status	

Appendix XVI - 6 month coding frame (Version I)

6 months

Main themes	**Categories**	**sub-categories**
Role of main carer	care organisation	social activities personal self-care domestic tasks medical care encouragement and support financial/paperwork
Support structure (physical & emotional)	family	daughter son sibling
	neighbour Social Service worker external paid worker carers groups no person identified	
	more respite greater contact with primary care more physical help (general or specific)	
difficulties/impact of stroke	lack of time for oneself	
	physically tiring process loss of previous life together inability to talk to close kin 'not to be a burden' bureaucratic difficulties with payments complex medications physical difficulties inability to invite friends need to organise care if leaving survivor by themselves loss of routine difficulty of maintaining friendships limited transport facilities if survivors was main driver problems associated increasing age loss of job	

	role reversal	
	no improvement	
	uncertain of future	
	dependent on recurrance of another stroke	
	optimistic about future	
	not easy with increasing age	
service provision	understanding of therapy	
	expectation of therapy	hoping for improving no expectations help to consolidate skill base acceptance of professional dominant role
	advantage/disadvantages of day hospital	good for survivor to mix with others space and rooms to carry out therapy respite from daily routine of care tasks
	advantages/disadvantages of domiciliary	convenient and more comfortable carer support during therapy carer education during therapy
	understanding of good service	
	acceptance of dominant status of therapists	
miscellaneous	uneasiness of leaving husband at home	
	unfair system of spending savings on care	
	unwilling to involve family further.	

Appendix XVII: Baseline coding frame (Version II)

Cat No.	
	Health problems
1	presence of chronic illness
	coming to terms with the stroke
2	acceptance
3	fatalism
4	experience: previous stroke
5	experience: other illnesses
6	physical support
7	support network (friends, relatives, others)
8	involvement in other activities (ie. watching TV)
	Role expectation
9	organise care from outside services
10	social activities
11	personal self-care
12	domestic tasks
13	medical care
14	encouragement (and support)
15	shopping
16	financial/paperwork
	difficulties of caring for stroke
17	no real difficulties
	general issues
18	lack of time for oneself
19	organising care when tired
20	physically tiring process
21	difficulty of maintaining friendships
22	age-related health problems
23	constant need to be supportive
24	loss of routine
	specific issues
25	interrupted nights
26	bureaucratic difficulties (payments)
27	complex medications
28	physical difficulties
29	limited transport if survivors was main driver
	Impact of stroke
30	loss of job
31	inital impact but no real change
32	role reversal
33	loss of previous life together
34	no social life
35	loss of energy

amount of time left unsupervised (if going out)
36 none of the time
37 a little of the time (up to 1 hour)
38 some of the time (1-6 hours)
39 most of the time (> 6 hours)
40 never free from 24 hr caring comittment

Support structure (emotional)
family
41 daughter
42 son
43 sibling
44 other relatives
45 stroke survivor
46 neighbour
47 friends
48 Social Service worker
49 external paid worker
50 carers groups
51 no person identified

Support structure (physical)
family
52 daughter
53 son
54 sibling
55 other relatives
56 stroke survivor
57 neighbour
58 friends
59 Social Service worker
60 external paid worker
61 carers groups
62 no person identified

service provision
understanding of therapy
63 no/little understanding
64 some understanding (OT/PT involved in rehab)
65 good understanding (OT/PT definitions)

expectation of therapy
66 no expectations
67 specific physical improvement (eg. limb movement)
68 general physical improvement
69 help to consolidate skill base

advantages/disadvantages of day hospital
70 good for survivor to mix with others
71 space and rooms to carry out therapy
72 respite from daily routine of care tasks
73 equipment is more accesible

advantages/disadvantages of domiciliary
- 74 convenient and more comfortable
- 75 carer support during therapy
- 76 carer education during therapy

77 acceptance of professionals dominant role

understanding of good service
- 78 no hassles with transport

involvement with therapy
- 79 some involvement
- 80 no involvement

future expectations of caring role

81 no improvement
82 uncertain of future
83 dependent on recovery from stroke

others

84 unwilling to involve close kin for more help
85 inital confusion when stroke occurred

Appendix XVIII: 6 month coding frame (Version II)

Cat. No.	Categories
	Role of main carer
1	organise care from outside services
2	social activities
3	personal self-care
4	domestic tasks
5	medical care
6	encouragement (and support)
7	shopping
8	financial/paperwork
	difficulties of caring for stroke
9	no real difficulties
	general issues
10	lack of time for oneself
11	organising care when tired
12	physically tiring process
13	difficulty of maintaining friendships
14	age-related health problems
15	constant need to be supportive
16	loss of routine
	specific issues
17	interrupted nights
18	bureaucratic difficulties (payments)
19	complex medications
20	physical difficulties
21	limited transport if survivors was main driver
	Impact of stroke
22	loss of job
23	inital impact but no real change
24	role reversal
25	loss of previous life together
26	no social life
27	loss of energy
	amount of time left unsupervised (if going out)
28	none of the time
29	a little of the time (up to 1 hour)
30	some of the time (1-6 hours)
31	most of the time (> 6 hours)
32	never free from 24 hr caring comittment

Support structure (emotional)

family

33 daughter
34 son
35 sibling
36 other relatives
37 stroke survivor
38 neighbour
39 friends
40 Social Service worker
41 external paid worker
42 carers groups
43 no person identified

Support structure (physical)

family

44 daughter
45 son
46 sibling
47 other relatives
48 stroke survivor
49 neighbour
50 friends
51 Social Service worker
52 external paid worker
53 carers groups
54 no person identified

Service provision

understanding of therapy

55 no/little understanding
56 some understanding (OT/PT involved in rehab)
57 good understanding (OT/PT definitions)

expectation of therapy

58 no expectations
59 specific physical improvement (eg. limb movement)
60 general physical improvement
61 help to consolidate skill base

fulfilment of expectation

62 fulfilled
63 not fulfilled
64 unable to comment

advantages/disadvantages of day hospital
- 65 good for survivor to mix with others
- 66 space and rooms to carry out therapy
- 67 respite from daily routine of care tasks
- 68 equipment is more accesible
- 69 convenient and more comfortable
- 70 carer support during therapy
- 71 carer education during therapy

72 acceptance of professionals dominant role

Helpful support

73 more respite
74 greater contact with primary care
75 more physical help (general or specific)
76 more information from health professionals

Future expectation of caring role

- 77 no change
- 78 less role
- 79 worsening role
- 80 uncertain future

Other

81 unfair system of spending savings on care
82 unwilling to involve family further.

number of strokes
- 83 first
- 84 > 2 strokes
- 85 not mentioned

Appendix XIX: Instruction sheet to raters

Title: Testing the Validity and Reliability of two sets of coding frames to be used in the content analysis of baseline and six month interviews

Background: A study looking at the impact of two different models of stroke rehabilitation on carers' quality of life was carried out between May 1995 - March 1998. As part of this study, qualitative methods were used to explore carers perceptions on different themes involving coping and caring for a person with stroke and stroke services.

To analyse these qualitative interview data, it was decided to use content analysis. The first stage of analysis involves the construction of two coding frameworks, one for the baseline and the other for the six month interviews. Categories for each schedule was obtained by going through the transcripts of the first four people interviewed both at baseline and at six months, selecting categories from different part of the text and describing these in a few words. These categories were then grouped together in underlying themes. The initial list of categories forming the framework for baseline and six months were compared to enable categories from some themes to be amalgamated together to produce a comprehensive list of categories.

These schedules will initially be given to two researchers and the author to assess their inter-rater reliability and using these results, the schedules will be modified and given to another two researchers. This process will continue until concordance between the three raters is 60%, but it is anticipated that two sets of analysis should be sufficient to achieve 60% concordance. These coding schedules, once they have been checked for validity and reliability, will be then used in the coding of the remaining interviews.

Aims: To test the reliability and validity of the two coding frameworks designed by a health services researcher to analyse interview data from baseline and six month interview data.

Sample: A minimum of four researchers working in the field of health services research, but independent of this carer study were asked to take part in the testing.

Materials:

Two transcripts of interviews conducted at baseline (participants 5073, 5075).

Two transcripts of interviews conducted at six months (participants 5036, 5042).

One coding schedule to analyse the baseline interviews.

One coding schedule to analyse the six month interviews.

Procedure:

1) Go through both coding schedules to familiarise yourself with the different themes and categories. Each theme is listed numerically and I have tried to arrange them in sequential order to correspond to the order that it should appear in the interview, though it may not happen in many cases.

   In both schedules, I have tried to keep the same numbers for the same themes, but please note the following three points

   i) Six month coding schedule starts at category no. 9
   ii) the theme numbers of both baseline and 6 months coding schedules differ at category number 61.
   iii) Please note the instructions for coding the section "Social Structures"; category no 46 - 55.

   I have also combined the sections on "difficulties on caring" and "impact of caring" together into one section, following responses from the first set of analysis. I have sub-divided this section into physical, social, psychological and amount of time left unsupervised. I would appreciate any comments you have about these new codes i.e. appropriateness of sub-categories.

2) Starting from the beginning, read through each interview and code every sentence in bold text (representing carer's perceptions), using the categories from the appropriate coding schedule i.e. use the 6 month schedule to code the 6 month interview data.

   Coding is done by selecting a category for a particular text and writing down the number and name of the category in the left hand column of the transcript (see example sheet). Please note that some sentences may have more than one category.

3) Hopefully, most of the transcript text can be coded using the schedule. However, there will be sentences which are either irrelevant or non-codable using the any of the categories. In these situations, the following instruction apply.

   For text which is not relevant e.g. general conversation, the weather etc, please code as N/A
   on the left hand column.

   For text which cannot be coded using the schedule, please code as ? and suggest a theme for it if possible.

4) Each interview should take about 30 minutes to code. I would appreciate it if you could return this as soon as possible, preferable by Friday, 16 July 1999.

I appreciate your help in taking part in the validation and reliability exercise. Thank you very much.

Meanwhile, if there are any comments you may have about the coding frame or analysis in the way it may be improved, please do not hesitate to contact me.

Joe Low
Research Fellow
Health Care Research Unit
Southampton University.

11/07/99

Appendix XX: Example of coded transcript (5073)

5073 24.10.96. Baseline

Patient (P) in same room, but initally asleep

Q. How has your health been over the past month?

A. Well not too bad considering not too bad but I get very tired. You see because I get up three or four times in the night to attend the misses understand, that's what it is and when you get tired all I want to do is keep sleeping in the daytime. I sleep in the afternoon. Now this morning I got up at 5.30 and she wanted to come and sit in the chair so I put her in the chair but I went to sleep in the end for an hour until about 7. Then I made myself a cup of tea but even then, even now I still feel tired - it does affect you don't it? understand? if you don't get a proper rest or sleep it will affect you because I am getting a bit old now.

Q. Do you have any illnesses or disabilities at the present?

A. No, well I had the flu last week and I felt rough but since then it seems to have worn off now. It's not too bad.

Q. Well do you think you have any disabilities, other disabilities?

A. Well I don't think I have.

Q. Your wife has had a stroke recently, how have you come to terms with it?

A. Well I don't know how do you mean? worry about it or what?

Q. No, come to terms with your wife's stroke; no, how have you dealt with your wife's stroke?

A. Well I have had to deal with it because I am the only one here understand I am the only one here to help her. I give her some porridge this morning, and dinner time the lady next door she comes in and makes her a bit of a sandwich or something like that but she doesn't eat a lot doesn't eat much.

Q. But in terms of cope - I mean like obviously

A. I can't go out and do my gardening because I can't leave her - see what I mean

Q. How have you dealt with the fact that your wife has had a stroke within yourself - how have you coped?

A. **Well I have had to cope haven't I?**

Q. How long have you done that?

A. **Well by just looking after her see what I mean. I mean I don't go out at all unless there is somebody here see what I mean?**

All right, yes

Q. As your wife's main carer what do you expect to do?

A. **Well do everything really, to look after her, to feed her and look after her, you can't just leave a person like that, now you see you can't go out can I, you can't go out because she is in here, the only time I can go out is when the woman comes in next door and she sits with her a looks after her, other than that I am in here like a prisoner - a prisoner of war.**

Q. So that you are saying in terms of what you do you do everything.

A. **Well I don't do everything - I mean I sometimes do a bit of washing up now and again. But I have another woman that comes in who tidies up, hoovers around that's what she does.**

Q. How often does this woman come in?

A. **Well she comes in - now she might be in today about 4 o'clock when she finishes work see. She comes in for an hour or so and then goes home again because they have there own life to live haven't they? You don't expect the woman to keep coming in here. Well she comes in she is very good - I pay her - I have to give her a few bob. Well, these people don't come in for nothing, you know, so I have to give her some money. It's a bit of a problem, (   ) you see, I can't go out and leave her on her own so I am stuck in here.**

Q. So in terms, that you said you did everything.

A. **Mostly, a bit of grub through my stomach.**

Q. You do a bit of cooking

A. **I do a bit of cooking.**

Q. Do you do any other things for your wife?

A. **Well I keep taking her to the toilet when she wants to go there's nobody else I have to take her to the toilet and bring her back. Well she goes to the toilet half a dozen times a day - she has those water tablets - she's been taking them of course what it amounts to she wants to go to the toilet, so I'm here to take her to the toilet and bring her back again - it's a full time job, see what I mean.**

Q. See if I have got this right. So basically you help with a bit of cooking, you help with a bit of washing and take your wife to the toilet. Do you help to bath your wife or not?

A. **No I don't like to, the woman that comes in does that - I've got a shower and theygo in and give her a shower. They came in yesterday afternoon and gave her a shower. So she wasn't too bad like that, she's reasonably clean.**

Q I have mentioned the four things earlier on, is there any thing else that you do?

A. **Well all I do more or less is look after her stop indoors that's all I can do isn't it?**

Q. What are the main difficulties in caring for your wife?

A. **The main difficulties?**

Q. What do you think is difficult in looking after her?.

A. **Well I am getting a bit old to look after anybody understand? But other than that I don't know how to work that one out. Things are difficult when you have got somebody just sitting down all day long, understand, and they can't help themselves - see what I mean. I have got to be here every day. The woman next door came in this morning and had a little chat - now shes gone again, they don't come in for long, see how things are then they are gone. It's a bit of a problem really.**

Q. This next question I am going to ask you how do you think caring for your wife will affect your own life? you mentioned somethings like you can't go out

A. **Well you can't go out, can I. It's reasonable, ain't it, you can't go out unless someone is here. When I do go out they stop in here for an hour or so, I go and get the rations, a bit of bread and stuff like that.**

Q. You talk about getting the rations, what do you mean by getting the rations?

A. **Well I have to get bread and the milk things like that for the day, the next day - I have to go and get it nobody else does. I have to go to Tesco and get the rations.**

Q. You said that you have to take your wife to the toilet?

A. **I do take her to the toilet all day, mostly all day. She goes to the toilet about six times a day understand - so I am here all the time when she wants to go to the toilet. Now she's been to the toilet this morning, the nurse washed her - washed her face. Now about every half hour/hours time she wants to go to the toilet again, so I'm lumbered I have to keep taking her to the toilet so that's it.**

Q. Is there any other physical tasks?

A. **No No.**

P. In the night

A. **Well in the night she wants to go in the night, we don't have anyone in the night, but she's calling out for a neighbour about 2 o'clock in the morning "come and help me", I can hear her in the next bedroom so I had to go in and she wants to sit up out of bed.**

P. I was in great pain last night

A. **She has been in pain in her foot and her ankle, had the cramp, so I give her that deep spray**

Q. Can I ask who gives you most of your emotional support? Does anybody? What do I mean by emotional support?

A. **How do you mean emotional support?**

Q. Basically if you feel you want to cry or you feel lonely

A. **Oh no I'm not like one of them am I?**

Q. Or if you feel that you need

A. **I can put up with, put up with it actually speaking, I can put up with these things**

Q. Or if you feel down in the dumps let's say who would you go to.

A. **I can't go to nobody, you carry on don't you**

P. Your emotional support come from your brother.

A. **What do you mean**

P. Reg

A. **Well, my brother, he phones up from Canada about 3 or 4 days ( ) just to find out how she is, but that's all.**

Q. Is there anyone else you can go to for emotional support.

A. **No No, it isn't a case .... I can't understand what you mean**

Q. OK is there anyone else if you felt down in the dumps.

A. **Oh I'm always down in the dumps, aren't I? (laughs)**

Q. You talked about helping your wife go to the toilet, let's say if you had to lift her ?

A. **well I don't, she fell on the floor twice and I sent for the ambulance, she was sitting here one day and she slipped on the bed, she thought she was in bed on the floor - so I called the ambulance - they have been a couple of times. She was in the seat one day and she fell over the floor so I called the ambulance. The nurse came a fortnight ago I don't see any of those people, know what I mean, you don't see them. The nurse, if they came once a week it would be all right, but they have not been in this week and today's Thursday. If they come in to see how she was it would be a different thing wouldn't it. Now the Social Services they came in to see me and they said they would get me a girl to come in the morning - now the girl she comes in for half an hour you understand, she's only here for half an hour looks at her she took her to the toilet give her a little wash and she's finished - she's away and gone. You can't do much in half an hour.**

Q. So basically, for help like that, it's Social Services, Social Services sent someone in.

A. **Yes, they did**

Q. Is there anyone apart from Social Services, is there anyone local who may help, anyone who lives nearby you?

A. **This is what I say, well the woman who comes in here, she goes to work, and she comes in about 11.30-12.00 to see how things are and then she goes**

home, because she has her own family to look after see, they are not in here all day - they come in for an hour or so and then they are gone.

Q. If you needed any physical help would you ask?

A. **I don't know about physical help.**

P. Chris ( )

A. **Oh physical help, guys that are physical help and working.**

Q. Yes, if you needed some physical help to do the gardening

A. **Oh yes I have an old friend of mine he is an old pensioner, he is 74 and if I wanted anything to be done he would come and do it for me, but I manage to do most things myself.**

Q. If you wanted to go to the shops would you have to ask anyone, you talk about going to get the rations, do you have to ask anyone to stay here with your wife?

A. **Oh yes, I can't go rations unless there is someone here**

Q. Who would you ask?

A. **Well this woman, my neighbour next door - Betty next door - she comes in if I say I want to get the rations and they stay here with her and they say they will be here half an hour or so and I go and get the rations.**

Q. How often would you ask?

A. **Well you don't ask them too much do you.**

Q. Well how often would you ask them

A. **What in the week?**

P. Well she comes in and she says she is going shopping ( ).

A. **Sometimes she might bring in some stuff.**

P. Sometimes she stays here while he ( )

A. **There always has to be someone here to look after her. You can't just leave her on her own. The telephone rings or someone comes to the door. I have got to be here.**

Q. So basically if you want to go out to the shops you have to rely on someone being here and ask someone next door to stay here and someone do the shopping for you. And how often could you ask them, about once a week or more than that.

A. Yes more than once a week ( ),and this woman's, the next door's, the husband's been ill and in hospital, understand, he was a prisoner of war, he has got to have an operation on his stomach or something or other, so she can't leave him too long, understand, ( ) what's why she can't leave him too long because he's a bit of an invalid and he's 78 so she's more or less indoors all the time, just pops in now and again to see how things are and then she's back home.

A. Just say you had to go to the hospital who would come in.?

A. Well I would have to ask someone here to look after her

Q. Would it be the same person?

A. Sometimes or the other one who comes in an does a bit of hoovering and cleaning she would stay for an hour.

P. Your sister?

A. My sister-in-law who lives in Wareham, but the last time we saw her was 3 weeks ago. She doesn't come down, it's too far to travel. Well, she's over 80 so it stands to reason she is not a young woman she comes up to see you, perhaps tomorrow she comes to see her.

Q. So basically if you had to go to hospital?

A. I would have to ask someone to look after her while I am out.

Q. And that someone else would be your next door neighbour or the other one that does a bit of cleaning for me.

A. Yes, that's right.

Q. Do you remember the girls in the blue trousers and the green trousers?

A The nurses you mean?

Q. Not nurses they are health workers, but they wear green trousers and blue trousers and white tunics.

A. No this woman came in here Social Services and she came in here about fortnight ago or 3 weeks ago and they got a night nurse to come here for 3 nights.

Q. I am more talking about, do you remember Amanda and Therese. Girls, woman, early 30's

A. What is she physiotherapist, was she a young girl?

Q. Yes

A. Yes she came in here last week

Q. What expectations do you have about the physiotherapy and occupational therapy that your wife receives at home?

A. Well she hasn't had nothing yet

Q. Well what expectations did you have beforehand?

P. well I expected it would be massages.

A. well if she could have given her massage or something like that but these girls they just come in and say well how are you getting on - oh yes try the thing and then they are just gone again.

Q. What do you understand they would be doing?

A. You can't give her a massage, can you

Q. What do you think they should be doing?

A. Well I don't know myself don't know much about this physiotherapy

P. Massage the knees, exercise on the shoulder I am having trouble with.

A. you see these people, they just come in, spent half an hour and have a little chat to you, very nice, tries this out see if she can be walk about and then go home - that's all they do.

Q. I mean what would you call a good service?

A. **There is no service at all is it - yes I know what you mean.**

P. *The girl that came at nights she was very good then they send you the bill for £85(*

A. **They send me a bill now the Social Services, the woman that come in here about 3 weeks ago for 3 nights - a nurse.**

P. *She was very good*

A. **Social Services said that you only have enough for 3 nights but I am going to send you a bill for £18 - I said to mum, what because I have to pay for that girl coming here? - understand? It's unusual - I don't mind the £18 but that finishes at there, at the end of the month.**

Q. That's one issue but what would you call a good service?

A. **Well I can't see any good service here to tell you the truth, none at all.**

Q. Well what would you call a good service from the physiotherapy and occupational therapy - what would you expect?

A. **I don't expect anything really, because what it amounts to is not for me to say - these girls that come in they have a chat to you, see how you are, they take her to the toilet, that's it, finished. I suppose they are here about half an hour and then they are gone but they don't do nothing at all, they just have a little chat - but the service there is no service at all really. The nurse, she came here about 3 weeks ago, the nurse with the blue what the name and she had a chat - how are your keeping and that's about as far as it went, so I wouldn't say you have any service, would you.**

Q. Well I think I am only just talking about the physiotherapy and occupational therapy, just interested in that service.

Q. If you had a choice would you prefer having the treatment done at home?

A. **If I had a choice, and I won the lottery I would put her in a home - a care home or something like that - it's the only way. If I had the money I could afford to put her in a home. But this care centre, they are supposed be taking her to a care centre but when, I don't know. If they put her in a care centre just for the morning that would give me a break. If they could pick her up and put her in the care centre for the morning or the afternoon as the case may be, I could go out then?**

Q. So you would prefer if you wife had treatment in the day hospital?

A. **If she had treatment in the day centre, it would be all right.**

Q. Because you could go out?

A. **Yes, I could go out couldn't I?**

Q. Do you in anyway want to be involved in your wife's exercises or not - being shown how to do the exercises.

A. **I don't know about exercise - I don't know what exercise she can do because she can only just about walk - so what exercise can she do?**

Q. How do you see your role changing in the next six months?

A. **In six months well I don't know, I shall be in the box in 6 months. I used to belong to the Woolwich but I don't know. I drew the money out of the Woolwich to buy the shower so I am not skint, but I have only got a few shillings to get by. I think I can stand this - yes. I was in the army for 6 years and that didn't kill me so I can manage this.**

Q. Do you think it will get worse - the caring role that you do?

A. **I can't see it getting any better - she is no better now than when she came out of hospital - see what I mean. She's swearing more, carries on at me - get me down - but you have got to be a bit thick skinned you know - I take it as it comes.**

Q. I mean have you got anything else you want to add?

A. **No not much - so you have got that all sorted out have you?**

Q. Ending interview now.

Appendix XXI: Raters' response (Phase 1)

5073 - Baseline										
	P.1 sent 1	*P.1 sent 2*	*P.1 sent 3*	*P.1 sent 4*	*P.1 sent 5*	*P.1 sent 6*	*P.1 sent 7*			
JL	?	n/a	?	n/a	2	18	2			
Rater 1 (DW)	20, 25				2	18	2			
Rater 2 (LB)	25				3, 12, 57		3			
	IRA	U (FA)	U (FA)	U (FA)	PA	PA	PA			
	P.2 sent 1	*P.2 sent 2*	*P.2 sent 3*	*P.2 sent 4*	*P.2 sent 5*	*P.2 sent 6*	*P.2 sent 7*			
JL	36	11, 18	12	60	n/a	12	11			
Rater 1 (DW)	23	23		60		12	20			
Rater 2 (LB)	18, 36	12, 46/57	12	60		12	11			
	PA	NA	PA	FA	U(FA)	FA	PA			
	P.3 sent 1	*P.3 sent 2*	*P.3 sent 3*	*P.3 sent 4*	*P.3 sent 5*	*P.3 sent 6*	*P.3 sent 7*			
JL	50	?	n/a	18	?	15	?			
Rater 1 (DW)	51			22	15, 18		28			
Rater 2 (LB)	60	34		33, 46	34	15	11			
	NA	U (PA)	U (FA)	NA	NA	PA	NA			
	P.4 sent 1	*P.4 sent 2*	*P.4 sent 3*	*P.4 sent 4*	*P.4 sent 5*	*P.4 sent 6*	*P.4 sent 7*	*P.4 sent 8*	*P.4 sent 9*	*P.4 sent 1*
JL	n/a	25	13	n/a	51	51	51	n/a	n/a	n/a
Rater 1 (DW)								44		
Rater 2 (LB)		14	13					43		
	U (FA)	NA	PA	U (FA)	U (IRA)	U (IRA)	U (IRA)	NA	U (FA)	U (FA)
	P.5 sent 1	*P.5 sent 2*	*P.5 sent 3*	*P.5 sent 4*	*P.5 sent 5*	*P.5 sent 6*	*P.5 sent 7*	*P.5 sent 8*		
JL	n/a	?, 59	59	60	n/a	n/a	58	36		
Rater 1 (DW)		28, 48, 59		59						
Rater 2 (LB)		59		60			58	36		
	U (FA)	PA	U (IRA)	PA	U (FA)	U (FA)	PA	PA		
	P.6 sent 1	*P.6 sent 2*	*P.6 sent 3*	*P.6 sent 4*	*P.6 sent 5*	*P.6 sent 6*	*P.6 sent 7*	*P.6 sent 8*	*P.6 sent 9*	
JL	57	n/a	n/a	n/a	36	57	n/a	60	n/a	
Rater 1 (DW)	46				57, 58					
Rater 2 (LB)	46/57				36			60		
	PA	U (FA)	U (FA)	U (FA)	PA	U (IRA)	U (FA)	PA	U (FA)	
	P.7 sent 1	*P.7 sent 2*	*P.7 sent 3*	*P.7 sent 4*	*P.7 sent 5*	*P.7 sent 6*	*P.7 sent 7*	*P.7 sent 8*	*P.7 sent 9*	
JL	n/a	57, 60	n/a	n/a	n/a	n/a	?	?	n/a	
Rater 1 (DW)										
Rater 2 (LB)								67		
	U (FA)	U (IRA)	U (FA)	U (FA)	U (FA)	U (FA)	U (FA)	U (PA)	U (FA)	
	P.8 sent 1	*P.8 sent 2*	*P.8 sent 3*	*P.8 sent 4*	*P.8 sent 5*	*P.8 sent 6*	*P.8 sent 7*			
JL	63	63	?	n/a	n/a	n/a	?			
Rater 1 (DW)	63									
Rater 2 (LB)		63								
	PA	PA	U (FA)	U (FA)	U (FA)	U (FA)	U (FA)			
	P.9 sent 1	*P.9 sent 2*	*P.9 sent 3*	*P.9 sent 4*	*P.9 sent 5*	*P.9 sent 6*	*P.9 sent 7*			
JL	72	72	72	80	n/a	?	n/a			
Rater 1 (DW)				82						
Rater 2 (LB)			72		16	81				
	U (IRA)	U (IRA)	PA	NA	U (PA)	U (PA)	U (FA)			
5075 - Baseline										
	P.1 sent 1	*P.1 sent 2*	*P.1 sent 3*	*P.1 sent 4*	*P.1 sent 5*	*P.1 sent 6*				
JL	1		1		5	5				
Rater 1 (DW)	1, 2				2, 5	5				
Rater 2 (LB)	1, 12			1	31, 5					
	PA	U (FA)	U (IRA)	U (PA)	PA	PA				
	P.2 sent 1	*P.2 sent 2*	*P.2 sent 3*	*P.2 sent 4*						
JL	48									
Rater 1 (DW)	62									
Rater 2 (LB)	6, 47, 49									
	NA	U (FA)	U (FA)	U (FA)						
	P.3 sent 1	*P.3 sent 2*	*P.3 sent 3*	*P.3 sent 4*	*P.3 sent 5*	*P.3 sent 6*				
JL		11		?	53					
Rater 1 (DW)		11			53	22, 23				
Rater 2 (LB)		11			53, 58, 60					
	U (FA)	FA	U (FA)	U (FA)	PA	U (PA)				

	P.4 sent 1	*P.4 sent 2*	*P.4 sent 3*	*P.4 sent 4*	*P.4 sent 5*					
JL	34	60	36	36	51					
Rater 1 (DW)	21	15		36	21					
Rater 2 (LB)	34	49		36	34					
	PA	NA	U (IRA)	FA	NA					
	P.5 sent 1	*P.5 sent 2*	*P.5 sent 3*	*P.5 sent 4*	*P.5 sent 5*					
JL	21	35	67	63	n/a					
Rater 1 (DW)	47	?	67	63						
Rater 2 (LB)	47	35	67		63					
	IRA	PA	FA	PA	U (PA)					
	P.6 sent 1	*P.6 sent 2*	*P.6 sent 3*	*P.6 sent 4*	*P.6 sent 5*	*P.6 sent 6*	*P.6 sent 7*			
JL	n/a	?	n/a	70	72	73	79			
Rater 1 (DW)	13/18		8	70	78	73	79			
Rater 2 (LB)				70	72	73	79			
	U (PA)	U (FA)	U (PA)	FA	PA	FA	FA			
	P.7 sent 1	*P.7 sent 2*	*P.7 sent 3*	*P.7 sent 4*	*P.7 sent 5*	*P.7 sent 6*	*P.7 sent 7*			
JL	79	n/a	?	81	n/a	n/a	n/a			
Rater 1 (DW)	79			83	2		42, 53			
Rater 2 (LB)				81						
	PA	U (FA)	U (FA)	PA	U (PA)	U (FA)	U (PA)			
	P.8 sent 1									
JL	n/a									
Rater 1 (DW)										
Rater 2 (LB)										
	U (FA)									
5036 - 6 months										
	P.1 sent 1	*P.1 sent 2*	*P.1 sent 3*	*P.1 sent 4*	*P.1 sent 5*	*P.1 sent 6*	*P.1 sent 7*	*P.1 sent 8*	*P.1 sent 9*	
JL	8	52	23	?	23	23	23	n/a	n/a	
Rater 1 (DW)	8	?	8	?						
Rater 2 (LB)	8, 4	52					23			
	FA	PA	NA	U (FA)	U (IRA)	U (IRA)	PA	U (FA)	U (FA)	
	P.2 sent 1	*P.2 sent 2*	*P.2 sent 3*	*P.2 sent 4*	*P.2 sent 5*	*P.2 sent 6*	*P.2 sent 7*	*P.2 sent 8*		
JL	n/a	n/a	21	n/a	n/a	9	23	n/a		
Rater 1 (DW)	?	?	21	?	?	9	9	?		
Rater 2 (LB)			23							
	U (FA)	U (FA)	PA	U (FA)	U (FA)	PA	NA	U (FA)		
	P.3 sent 1	*P.3 sent 2*	*P.3 sent 3*	*P.3 sent 4*	*P.3 sent 5*	*P.3 sent 6*	*P.3 sent 7*			
JL	n/a	33	33	n/a	44	n/a	n/a			
Rater 1 (DW)	?	33	33		44	?				
Rater 2 (LB)		33, 36			44, 47					
	U (FA)	FA	PA	U (FA)	FA	U (FA)	U (FA)			
	P.4 sent 1	*P.4 sent 2*	*P.4 sent 3*	*P.4 sent 4*	*P.4 sent 5*	*P.4 sent 6*	*P.4 sent 7*			
JL	n/a	n/a	?	58	n/a		64			
Rater 1 (DW)				58	?		60			
Rater 2 (LB)			33,34,44,47	56, 59			56			
	U (FA)	U (FA)	U (PA)	PA	U (FA)	U (FA)	NA			
	P.5 sent 1	*P.5 sent 2*	*P.5 sent 3*	*P.5 sent 4*	*P.5 sent 5*	*P.5 sent 6*	*P.5 sent 7*			
JL	n/a	?	62	62, 6	n/a	69	?			
Rater 1 (DW)	?	?			62					
Rater 2 (LB)			62	62			69			
	U (FA)	U (FA)	PA	PA	U (PA)	U (IRA)	U (PA)			
	P.6 sent 1	*P.6 sent 2*	*P.6 sent 3*	*P.6 sent 4*	*P.6 sent 5*	*P.6 sent 6*	*P.6 sent 7*	*P.6 sent 8*		
JL	69	n/a	?	69	n/a	70	n/a	n/a		
Rater 1 (DW)	?			69	69	69				
Rater 2 (LB)	69, 70		72			69	70, 71			
	PA	U (FA)	U (PA)	PA	U (PA)	IRA	U (PA)	U (FA)		
	P.7 sent 1	*P.7 sent 2*	*P.7 sent 3*	*P.7 sent 4*	*P.7 sent 5*	*P.7 sent 6*				
JL	n/a	75	n/a	78	?	?				
Rater 1 (DW)				77						
Rater 2 (LB)		75		8	78	68				
	U (FA)	PA	U (FA)	NA	U (PA)	U (PA)				

	P.8 sent 1	*P.8 sent 2*	*P.8 sent 3*							
JL	n/a	47	n/a							
Rater 1 (DW)										
Rater 2 (LB)			78							
	U (FA)	U (IRA)	U (PA)							
5042 - 6 months										
	P.1 sent 1	*P.1 sent 2*	*P.1 sent 3*	*P.1 sent 4*	*P.1 sent 5*	*P.1 sent 6*	*P.1 sent 7*			
JL	2,4,5,6		31	8	n/a	?	22			
Rater 1 (DW)	4, 7			8			22			
Rater 2 (LB)	4, 7			8			22			
	PA	U (FA)	U (IRA)	FA	U (FA)	U (FA)	FA			
	P.2 sent 1	*P.2 sent 2*	*P.2 sent 3*	*P.2 sent 4*	*P.2 sent 5*	*P.2 sent 6*				
JL	?	n/a	n/a	n/a	?	?, 26				
Rater 1 (DW)	84				?	?				
Rater 2 (LB)	84	21			41	26				
	IRA	U (PA)	U (FA)	U (FA)	U (PA)	PA				
	P.3 sent 1	*P.3 sent 2*	*P.3 sent 3*	*P.3 sent 4*	*P.3 sent 5*	*P.3 sent 6*				
JL	?	?	n/a	43	52	2				
Rater 1 (DW)	?	?		43	53	?				
Rater 2 (LB)			30	43	52	26				
	U (FA)	U (FA)	U (PA)	FA	PA	NA				
	P.4 sent 1	*P.4 sent 2*	*P.4 sent 3*	*P.4 sent 4*	*P.4 sent 5*	*P.4 sent 6*	*P.4 sent 7*	*P.4 sent 8*		
JL	n/a	30	n/a	n/a	?	?	58	n/a		
Rater 1 (DW)		30					58			
Rater 2 (LB)		30					58			
	U (FA)	FA	U (FA)	U (FA)	U (FA)	U (FA)	FA	U (FA)		
	P.5 sent 1	*P.5 sent 2*	*P.5 sent 3*	*P.5 sent 4*	*P.5 sent 5*					
JL	57	69, ?	69	69	69					
Rater 1 (DW)	57	69		69	?					
Rater 2 (LB)	57			69	53					
	FA	PA	U (IRA)	FA	NA					
	P.6 sent 1	*P.6 sent 2*	*P.6 sent 3*	*P.6 sent 4*	*P.6 sent 5*					
JL	?	?	n/a	77	n/a					
Rater 1 (DW)				77						
Rater 2 (LB)			77	80						
	U (FA)	U (FA)	U (PA)	PA	U (FA)					

Appendix XXII – Inter-rater reliability (Phase 1)

5073 – baseline

	Page									
	1	2	3	4	5	6	7	8	9	Total
FA		2								2
PA	3	3	1	1	4	3		2	1	18
IRA	1									1
NA		1	4	2					1	8
U(FA)	3	1	1	4	3	5	7	5	1	30
U(PA)			1				1		2	4
U(IRA)				3	1	1	1		2	8
	7	7	7	10	8	9	9	7	7	71

5073 - baseline

	Page								
	1	2	3	4	5	6	7	8	Total
FA			1	1	1	3			6
PA	3		1	1	2	1	2		10
IRA					1				1
NA		1		2					3
U(FA)	1	3	3			1	3	1	12
U(PA)	1		1		1	2	2		7
U(IRA)	1			1					2
	6	4	6	5	5	7	7	1	41

5036 – 6 months

	Page								
	1	2	3	4	5	6	7	8	Total
FA	1		2						3
PA	2	2	1	1	2	2	1		11
IRA						1			1
NA	1	1		1			1		4
U(FA)	3	5	4	4	2	2	2	1	23
U(PA)				1	2	3	2	1	9
U(IRA)	2				1			1	4
	9	8	7	7	7	8	6	3	55

5042 – 6 months

	Page						
	1	2	3	4	5	6	Total
FA	2		1	2	2		7
PA	1	1	1		1	1	5
IRA		1					1
NA			1		1		2
U(FA)	3	2	2	6		3	16
U(PA)		2	1			1	4
U(IRA)	1				1		2
	7	6	6	8	5	5	37

Appendix XXIII Baseline coding frame (Version III)

Cat No.

Health problems

1 presence of chronic illness eg. cardio-vascular disease, arthiritis
2 absence of chronic illness

coming to terms with the stroke

3 acceptance
4 experience: previous stroke
5 experience: other illnesses
6 physical support
7 support network (friends, relatives, others)
8 involvement in other activities, keeping busy

Main role as stroke carer

9 personal self-care i.e. feeding, toiletting, bathing
10 domestic tasks i.e. cooking, hoovering, other household jobs
11 shopping
12 financial/paperwork
13 medical/nursing care eg. handling drug prescriptions, minor first aid
14 transporting survivors at various places/activities/events
15 encouragement (and support)
16 organise care from outside services
17 social activities

difficulties/impact of caring for stroke

18 no real difficulties/change

physical/behavioural issues

19 organising care when tired
20 physically tiring process
21 difficulties with physical tasks
22 loss of energy
23 age-related health problems
24 interrupted nights
25 dealing with complex medications

psychological issues

26 lack of time for oneself
27 caring is a continual committment (requiring constant planning and support relating to caring)
28 feelings of guilt
29 loss of routine
30 unwillingness to involve others
31 role reversal

social issues
- 32 restriction in social life or other activities
- 33 difficulty of maintaining friendships
- 34 unable to share tasks/life together
- 35 poor transport facilities
- 36 loss of employment
- 37 bureaucratic difficulties (i.e. payments)

amount of time left unsupervised (if going out)
- 38 none of the time
- 39 a little of the time (up to 1 hour)
- 40 some of the time (1-6 hours)
- 41 most of the time (> 6 hours)

Support structure

When using these sets of codes, please add P for physical support and E for emotional suppo after category code. For example, if daughter provides emotional support, please code as 41E. Likewise, in text where neighbour provided physical support, please code as 46P

Physical support can range from tasks such as sitting with stroke survivor to DIY rasks. Emotional support refers to any activity which helps carers cope emotionally. This can include telephone contact.

family
- 42 daughter
- 43 son
- 44 sibling
- 45 other relatives
- 46 stroke survivor

47 neighbour
48 friends
49 carers groups
50 Social Service worker
51 Health service worker
52 external worker (paid)
53 person mentioned, but not identified
54 no person identified for physical/emotional support

service provision

expectation of therapy
- 55 no expectations
- 56 specific physical improvement (eg. limb movement)
- 57 general physical improvement
- 58 help to maintain current levels of daily living skills eg. mobility, transferring

understanding of the role of OT or physiotherapy in stroke rehabilitation
- 59 no/little understanding eg. don't know, OT - basket weaning.
- 60 some understanding - recognition that physio and OT play an important role in rehab.

61 good understanding - able to define physio and OT role in stroke rehab

advantages of day hospital
62 good for stroke survivor to mix with others
63 space and rooms to carry out therapy
64 respite from daily routine of care tasks
65 equipment is more accesible

advantages/disadvantages of domiciliary
66 convenient and more comfortable
67 carer support during therapy
68 carer education during therapy

involvement with therapy
69 some involvement
70 no involvement - no specified reason
71 no involvement - professionals know what they are doing

future expectations of caring role
72 no improvement/same as it is now
73 some improvement
74 role worsening
75 uncertain of future

Appendix XXIV: 6 month coding frame (Version III)

Cat No.

Main role as stroke carer
9 personal self-care i.e. feeding, toiletting, bathing
10 domestic tasks i.e. cooking, hoovering, other household jobs
11 shopping
12 financial/paperwork
13 medical/nursing care eg. handling drug prescriptions, minor first aid
14 transporting survivors at various places/activities/events
15 encouragement (and support)
16 organise care from outside services
17 social activities

difficulties/impact of caring for stroke
18 no real difficulties/change

physical/behavioural issues
19 organising care when tired
20 physically tiring process
21 difficulties with physical tasks
22 loss of energy
23 age-related health problems
24 interrupted nights
25 dealing with complex medications

psychological issues
26 lack of time for oneself
27 caring is a continual committment (requiring constant planning and support relating to caring)
28 feelings of guilt
29 loss of routine
30 unwillingness to involve others
31 role reversal

social issues
32 restriction in social life or other activities
33 difficulty of maintaining friendships
34 unable to share tasks/life together
35 poor transport facilities
36 loss of employment
37 bureaucratic difficulties (i.e. payments)

amount of time left unsupervised (if going out)
38 none of the time
39 a little of the time (up to 1 hour)
40 some of the time (1-6 hours)
41 most of the time (> 6 hours)

Support structure

When using these sets of codes, please add P for physical support and E for emotional suppo after category code. For example, if daughter provides emotional support, please code as 41E Likewise, in text where neighbour provided physical support, please code as 46P

Physical support can range from tasks such as sitting with stroke survivor to DIY rasks. Emotional support refers to any activity which helps carers cope emotionally. This can include telephone contact.

- family
  - 42 daughter
  - 43 son
  - 44 sibling
  - 45 other relatives
  - 46 stroke survivor

- 47 neighbour
- 48 friends
- 49 carers groups
- 50 Social Service worker
- 51 Health service worker
- 52 external worker (paid)
- 53 person mentioned, but not identified
- 54 no person identified for physical/emotional support

service provision

- expectation of therapy
  - 55 no expectations
  - 56 specific physical improvement (eg. limb movement)
  - 57 general physical improvement
  - 58 help to maintain current levels of daily living skills eg. mobility, transferring

- understanding of the role of OT or physiotherapy in stroke rehabilitation
  - 59 no/little understanding eg. don't know, OT - basket weaning.
  - 60 some understanding - recognition that physio and OT play an important role in rehab.
  - 61 good understanding - able to define physio and OT role in stroke rehab

- fulfilment of expectation
  - 62 fulfilled
  - 63 not fulfilled
  - 64 carer unable to comment

- advantages of day hospital
  - 65 good for stroke survivor to mix with others
  - 66 space and rooms to carry out therapy
  - 67 respite from daily routine of care tasks
  - 68 equipment is more accesible

- advantages/disadvantages of domiciliary
  - 69 convenient and more comfortable
  - 70 carer support during therapy

71 carer education during therapy

involvement with therapy

72 some involvement

73 no involvement - no specified reason

74 no involvement - professionals know what they are doing

Helpful support

75 more respite

76 greater contact with primary care

77 more physical help (general or specific)

78 more information from health professionals

79 no further help beneficial

future expectations of caring role

80 no improvement/same as it is now

81 some improvement

82 role worsening

83 uncertain of future

Appendix XXV: Raters' response (Phase 2)

5073 - Baseline										
	P.1 sent 1	*P.1 sent 2*	*P.1 sent 3*	*P.1 sent 4*	*P.1 sent 5*	*P.1 sent 6*	*P.1 sent 7*			
JL	24, 20	2	2	n/a	3, 12, 47P	32	3			
Rater 3 (DC)	9,19,24,29	n/a	n/a	n/a	9	26, 27				
Rater 4 (PK)	24,20,9	n/a	2	n/a	9, 47P	26	3			
	PA	U (IRA)	PA	U (FA)	PA	IRA	PA			
	P.2 sent 1	*P.2 sent 2*	*P.2 sent 3*	*P.2 sent 4*	*P.2 sent 5*	*P.2 sent 6*	*P.2 sent 7*			
JL	38	9, 32	10, 53P	52P, 32	n/a	10	9			
Rater 3 (DC)	26	9,10,27,26	16, 52P	27	?	10	9			
Rater 4 (PK)	6?, 38	9,38,47,32	10,52P	52P, 38	10	10	9, 27			
	PA	PA	PA	PA	U (PA)	FA	FA			
	P.3 sent 1	*P.3 sent 2*	*P.3 sent 3*	*P.3 sent 4*	*P.3 sent 5*	*P.3 sent 6*	*P.3 sent 7*			
JL	53	32	n/a	23, 27	30	11	30, 37			
Rater 3 (DC)	52P	?	?	47E	32,26,11	11	9, 51P			
Rater 4 (PK)	52P	n/a	n/a	27,32,47E	27,30,53	11	9, 51			
	IRA	U (IRA)	U (FA)	PA	PA	FA	IRA			
	P.4 sent 1	*P.4 sent 2*	*P.4 sent 3*	*P.4 sent 4*	*P.4 sent 5*	*P.4 sent 6*	*P.4 sent 7*	*P.4 sent 8*	*P.4 sent 9*	*P.4 sent 1*
JL	n/a	24	13	n/a	?	?	54E	n/a	45E	n/a
Rater 3 (DC)		24	13	n/a	?	?	?	?	45E	?
Rater 4 (PK)		24, 9	13	n/a	n/a	n/a	54	n/a	45E	n/a
	U (FA)	FA	FA	U (FA)	U (FA)	U (FA)	PA	U (FA)	FA	U (FA)
	P.5 sent 1	*P.5 sent 2*	*P.5 sent 3*	*P.5 sent 4*	*P.5 sent 5*	*P.5 sent 6*	*P.5 sent 7*	*P.5 sent 8*		
JL	n/a	51P, 50P	n/a	52P	n/a	n/a	48P	38		
Rater 3 (DC)	?	50P	?	52P	?	?	48P	38		
Rater 4 (PK)	n/a	51, 50	50	53	n/a	n/a	48P	38		
	U (FA)	FA	U (PA)	PA	U (FA)	U (FA)	FA	FA		
	P.6 sent 1	*P.6 sent 2*	*P.6 sent 3*	*P.6 sent 4*	*P.6 sent 5*	*P.6 sent 6*	*P.6 sent 7*	*P.6 sent 8*	*P.6 sent 9*	
JL	47P	?	n/a	?	38	n/a	38	52P	n/a	
Rater 3 (DC)	47P/E	?	?	?	38	47E	?	?	45P/E	
Rater 4 (PK)	47P/E	n/a	n/a	47P	38, 27	47, 30	n/a	52P		
	FA	U (FA)	U (FA)	U (PA)	FA	IRA	U (IRA)	PA	U (PA)	
	P.7 sent 1	*P.7 sent 2*	*P.7 sent 3*	*P.7 sent 4*	*P.7 sent 5*	*P.7 sent 6*	*P.7 sent 7*	*P.7 sent 8*	*P.7 sent 9*	
JL	38	n/a	n/a	n/a	n/a	n/a	?	56	n/a	
Rater 3 (DC)	38	?	?	50?, 51?	?	51P	?	?	?	
Rater 4 (PK)	n/a	n/a	n/a	50	n/a	n/a	n/a	59	n/a	
	PA	U (FA)	U (FA)	IRA	U (FA)	U (PA)	U (FA)	NA	U (FA)	
	P.8 sent 1	*P.8 sent 2*	*P.8 sent 3*	*P.8 sent 4*	*P.8 sent 5*	*P.8 sent 6*	*P.8 sent 7*			
JL	59	59	?	n/a	n/a	n/a	n/a			
Rater 3 (DC)	59	?	?	?	?	?	55			
Rater 4 (PK)	59	59	?	50	?	?	55, 59			
	FA	PA	U (FA)	U (PA)	U (FA)	U (FA)	IRA			
	P.9 sent 1	*P.9 sent 2*	*P.9 sent 3*	*P.9 sent 4*	*P.9 sent 5*	*P.9 sent 6*	*P.9 sent 7*			
JL	64	n/a	64	70	n/a	72	n/a			
Rater 3 (DC)	?	?	64	?	74?	74	?			
Rater 4 (PK)	64	n/a	64	59, 70	72	72	n/a			
	PA	U (FA)	FA	PA	NA	PA	U (FA)			
5075 - Baseline										
	P.1 sent 1	*P.1 sent 2*	*P.1 sent 3*	*P.1 sent 4*	*P.1 sent 5*	*P.1 sent 6*				
JL	1	n/a	1	n/a	5, 13	26				
Rater 3 (DC)	5	5	5	?	?	26, 27				
Rater 4 (PK)	1, 20		1	1	5,6,13	?				
	PA	U (PA)	PA	U (PA)	PA	PA				
	P.2 sent 1	*P.2 sent 2*	*P.2 sent 3*	*P.2 sent 4*						
JL	6, 54	n/a	n/a	n/a						
Rater 3 (DC)	53P	n/a	n/a	n/a						
Rater 4 (PK)	27, 26	53P, 53P								
	NA	U (PA)	U (FA)	U (FA)						
	P.3 sent 1	*P.3 sent 2*	*P.3 sent 3*	*P.3 sent 4*	*P.3 sent 5*	*P.3 sent 6*				
JL	n/a	9	n/a	34	43P	32				
Rater 3 (DC)	3, 18	?	n/a	53	43P, 53P	29				
Rater 4 (PK)	n/a	9, 21	n/a	53	43P, 53P	?				
	U (PA)	PA	U (FA)	IRA	PA	NA				
	P.4 sent 1	*P.4 sent 2*	*P.4 sent 3*	*P.4 sent 4*	*P.4 sent 5*					
JL	32, 26	53P	53P, 39	38	35, 33					
Rater 3 (DC)	32	53	?	26?	32,33,35					
Rater 4 (PK)	2,43E,26,6	53P	53P, 39	38	33, 32					
	PA	FA	PA	PA	PA					

	P.5 sent 1	*P.5 sent 2*	*P.5 sent 3*	*P.5 sent 4*	*P.5 sent 5*				
JL	33	22	56	59	59				
Rater 3 (DC)	54E	22	?	59	?				
Rater 4 (PK)	32	54,22,10	56	59	n/a				
	NA	PA	PA	FA	U (IRA)				
	P.6 sent 1	*P.6 sent 2*	*P.6 sent 3*	*P.6 sent 4*	*P.6 sent 5*	*P.6 sent 6*	*P.6 sent 7*		
JL	13	n/a	n/a	62	64	65	69		
Rater 3 (DC)	?	?	?	62	64	?	69?		
Rater 4 (PK)	13	n/a	n/a	62	64	65	69		
	PA	U (FA)	U (FA)	FA	FA	PA	FA		
	P.7 sent 1	*P.7 sent 2*	*P.7 sent 3*	*P.7 sent 4*	*P.7 sent 5*	*P.7 sent 6*	*P.7 sent 7*		
JL	69	?	72	72	?	?	30, 2		
Rater 3 (DC)	69?	?	?	?	?	n/a	22		
Rater 4 (PK)	69	75	75	n/a	n/a	43E	22, 10		
	FA	U (PA)	NA	U (IRA)	U (FA)	U (PA)	IRA		
	P.8 sent 1								
JL									
Rater 3 (DC)									
Rater 4 (PK)									
	U (FA)								
5036 - 6 months									
	P.1 sent 1	*P.1 sent 2*	*P.1 sent 3*	*P.1 sent 4*	*P.1 sent 5*	*P.1 sent 6*	*P.1 sent 7*	*P.1 sent 8*	*P.1 sent 9*
JL	10	53	12	?	?	?	18	n/a	18
Rater 3 (DC)	12, 10	10, 53P	18	n/a	18	18	n/a	n/a	18
Rater 4 (PK)	12, 10	53P	12	n/a	n/a	n/a	10	12,10?	18
	PA	FA	PA	U (FA)	U (PA)	U (PA)	NA	U (PA)	FA
	P.2 sent 1	*P.2 sent 2*	*P.2 sent 3*	*P.2 sent 4*	*P.2 sent 5*	*P.2 sent 6*	*P.2 sent 7*	*P.2 sent 8*	
JL	n/a	?	?	?	n/a	18	9	18	
Rater 3 (DC)	18?	n/a	35,32	n/a	n/a	18	9, 53P	32	
Rater 4 (PK)	n/a			n/a		18	9, 21	n/a	
	U (PA)	U (FA)	U (PA)	U (FA)	U (FA)	FA	PA	NA	
	P.3 sent 1	*P.3 sent 2*	*P.3 sent 3*	*P.3 sent 4*	*P.3 sent 5*	*P.3 sent 6*	*P.3 sent 7*		
JL	n/a	42E	42E	n/a	42P	n/a	?		
Rater 3 (DC)	n/a	42E,45E		n/a	42P, 45P	?	?		
Rater 4 (PK)	n/a	2P,42E,45I	n/a	n/a	42P,45P	n/a	n/a		
	U (FA)	PA	U (IRA)	U (FA)	PA	U (FA)	U (FA)		
	P.4 sent 1	*P.4 sent 2*	*P.4 sent 3*	*P.4 sent 4*	*P.4 sent 5*	*P.4 sent 6*	*P.4 sent 7*		
JL	?	45P	30	55	n/a	n/a	59		
Rater 3 (DC)	?	?	45E	55	?	60	62		
Rater 4 (PK)	42, 45	45	42E, 45E	57	63	60	60		
	U (PA)	PA	IRA	PA	U (PA)	IRA	NA		
	P.5 sent 1	*P.5 sent 2*	*P.5 sent 3*	*P.5 sent 4*	*P.5 sent 5*	*P.5 sent 6*	*P.5 sent 7*		
JL	n/a	n/a	n/a	62	62	69	69		
Rater 3 (DC)	n/a	?	62	?	62	69	69		
Rater 4 (PK)	n/a	n/a	n/a	62, 15	62	69	69		
	U (FA)	U (FA)	U (PA)	PA	FA	FA	FA		
	P.6 sent 1	*P.6 sent 2*	*P.6 sent 3*	*P.6 sent 4*	*P.6 sent 5*	*P.6 sent 6*	*P.6 sent 7*	*P.6 sent 8*	
JL	69	?	?	69	n/a	70	?	n/a	
Rater 3 (DC)	69	n/a	n/a	69	n/a	69, 70	n/a	?	
Rater 4 (PK)	69, 70	n/a	n/a	69	n/a	70	72	n/a	
	FA	U (FA)	U (FA)	FA	U (FA)	FA	U (PA)	U (FA)	
	P.7 sent 1	*P.7 sent 2*	*P.7 sent 3*	*P.7 sent 4*	*P.7 sent 5*	*P.7 sent 6*			
JL	n/a	77	n/a	81	81	?			
Rater 3 (DC)	?	77?	77	81	81	?			
Rater 4 (PK)	n/a	77	n/a	81	81	65			
	U (FA)	FA	U (PA)	FA	FA	U (PA)			
	P.8 sent 1	*P.8 sent 2*	*P.8 sent 3*						
JL	n/a	45P	n/a						
Rater 3 (DC)	?	81	n/a						
Rater 4 (PK)	n/a	43P, 81	81						
	U (FA)	IRA	U (PA)						

5042 - 6 months										
	P.1 sent 1	*P.1 sent 2*	*P.1 sent 3*	*P.1 sent 4*	*P.1 sent 5*	*P.1 sent 6*	*P.1 sent 7*			
JL	10, 11, 14	n/a	?	12	n/a	n/a	36			
Rater 3 (DC)	14,10,11	?	?	37	n/a	?	26,29,36			
Rater 4 (PK)	10,11.14	n/a	?39/40/41	12, 15	n/a	n/a	36			
	FA	U (FA)	U (PA)	PA	U (FA)	U (FA)	PA			
	P.2 sent 1	*P.2 sent 2*	*P.2 sent 3*	*P.2 sent 4*	*P.2 sent 5*	*P.2 sent 6*				
JL	n/a	n/a	n/a	?	32	32,52,27,32				
Rater 3 (DC)	?	?	?	?	26,29	27, 32				
Rater 4 (PK)	n/a	n/a	n/a	15	32	2,16,10,32,33				
	U (FA)	U (FA)	U (FA)	U (PA)	PA	PA				
	P.3 sent 1	*P.3 sent 2*	*P.3 sent 3*	*P.3 sent 4*	*P.3 sent 5*	*P.3 sent 6*				
JL	32	27	n/a	54E	52	17				
Rater 3 (DC)	32, 30	28	28	54E	?52P	?				
Rater 4 (PK)	?	10,28	n/a	54	52	17				
	PA	IRA	U (PA)	FA	FA	PA				
	P.4 sent 1	*P.4 sent 2*	*P.4 sent 3*	*P.4 sent 4*	*P.4 sent 5*	*P.4 sent 6*	*P.4 sent 7*	*P.4 sent 8*		
JL	n/a	40	27	?	28	28	55	n/a		
Rater 3 (DC)	?	41	?	?	28	28	55	?		
Rater 4 (PK)	n/a	40	10	n/a	28	?	55	n/a		
	U (FA)	PA	NA	U (FA)	FA	PA	FA	U (FA)		
	P.5 sent 1	*P.5 sent 2*	*P.5 sent 3*	*P.5 sent 4*	*P.5 sent 5*					
JL	61	69	69	69	69					
Rater 3 (DC)	61	69	?	69	?					
Rater 4 (PK)	60	?	69	69,14	69					
	PA	PA	PA	FA	PA					
	P.6 sent 1	*P.6 sent 2*	*P.6 sent 3*	*P.6 sent 4*	*P.6 sent 5*					
JL	69	79	n/a	82, 28	n/a					
Rater 3 (DC)	?	79	80	28	?					
Rater 4 (PK)	69	79	80	83						
	PA	FA	IRA	PA	U (FA)					

Appendix XXVI: Inter-rater reliability (Phase II)

5073 - baseline

	Page									
	1	2	3	4	5	6	7	8	9	Total
FA		2	1	3	3	2		1	1	13
PA	4	4	2	1	1	1	1	1	3	18
IRA	1		2			1	1	1		6
NA							1		1	2
U(FA)	1		1	6	3	2	5	3	2	23
U(PA)		1			1	2	1	1		6
U(IRA)	1		1			1				3
	7	7	7	10	8	9	9	7	7	71

5075 - baseline

	Page								
	1	2	3	4	5	6	7	8	Total
FA				1	1	3	1		6
PA	4		2	4	2	2			14
IRA			1				1		2
NA		1	1		1		1		4
U(FA)		2	1			2	1	1	7
U(PA)	2	1	1				2		6
U(IRA)					1		1		2
	6	4	6	5	5	7	7	1	41

5036 – 6 months

	Page								
	1	2	3	4	5	6	7	8	Total
FA	2	1			3	3	3		12
PA	2	1	2	2	1				8
IRA				2				1	3
NA	1	1		1					3
U(FA)	1	3	4		2	4	1	1	16
U(PA)	3	2		2	1	1	2	1	12
U(IRA)			1						1
	9	8	7	7	7	8	6	3	55

5042 – 6 months

	Page						
	1	2	3	4	5	6	Total
FA	1		2	2	1	1	7
PA	2	2	2	2	4	2	14
IRA			1			1	2
NA			0	1			1
U(FA)	3	3		3		1	10
U(PA)	1	1	1				3
U(IRA)							0
	7	6	6	8	5	5	37

Appendix XXVII: Tick chart used for content analysis (sample)

Baseline coding schedule

Cat No.		5073	5075	5080
	Health problems			
1	presence of chronic illness		1	1
2	absence of chronic illness	1		
	coming to terms with the stroke			
3	acceptance	1		1
4	experience: previous stroke			
5	experience: other illnesses		1	
6	physical support		1	
7	support network (friends, relatives, others)			
8	involvement in other activities, keeping busy			
	Main role as stroke carer			
9	personal self-care	1	1	
10	domestic tasks	1		1
11	shopping	1		1
12	financial/paperwork	1		
13	medical/nursing care	1	1	
14	transporting survivors at various places/activities/events			
15	encouragement (and support)			
16	organise care from outside services			
17	social activities			
	difficulties/impact of caring for stroke			
18	no real difficulties/change			
	physical/behavioural issues			
19	organising care when tired			
20	physically tiring process	1		
21	difficulties with physical tasks			
22	loss of energy		1	
23	age-related health problems	1		1
24	interrupted nights	1		
25	dealing with complex medications			
	psychological issues			
26	lack of time for oneself		1	
27	caring is a continual committment	1		
28	feelings of guilt			
29	loss of routine			
30	unwillingness to involve others	1	1	
31	role reversal			1
	social issues			
32	restriction in social life or other activities	1	1	
33	difficulty of maintaining friendships		1	
34	unable to share tasks/life together		1	
35	poor transport facilities		1	
36	loss of employment			

Appendix XXVIII: Content analysis (whole data set by intervention group).

Baseline coding schedule

Cat No.		Dom (n=10)	DH (n=14)	Total (n=24)
	Health problems			
1	presence of chronic illness	4	9	13
2	absence of chronic illness	6	5	11
	coming to terms with the stroke			
3	Acceptance	5	9	14
4	experience: previous stroke	0	2	2
5	experience: other illnesses	3	1	4
6	physical support	1	1	2
7	support network (friends, relatives, others)	0	3	3
8	involvement in other activities, keeping busy	0	1	1
	not as bad as expected	4	0	4
	Survivors positive personality	2	2	4
	Improvement in stroke survivors	0	3	3
	hasn't come to terms with stroke	1	1	2
	Previous good times together	0	1	1
	length of acquitance with stroke survivor	1	0	1
	Respite	1	0	1
	carer previous work experience	0	1	1
	survivor returning home	0	1	1
	life experiences	1	0	1
	Main role as stroke carer			
9	Personal self-care	5	9	14
10	Domestic tasks	10	9	19
11	Shopping	6	6	12
12	financial/paperwork	5	2	7
13	medical/nursing care	4	3	7
14	Transporting survivors at various places/activities/events	1	1	2
15	Encouragement (and support)	4	5	9
16	Organise care from outside services	0	2	2
17	social activities	1	1	2
	Maintain independence and dignity of survivor	1	0	1
	catering for survivor needs	0	1	1
	Identified as needing help	0	1	1
	difficulties/impact of caring for stroke			
18	no real difficulties/change	2	1	3

Cat No.		Dom (n=10)	DH (n=14)	Total (n=24)
	stroke patient related			
	patient's acceptance of physical limitation/home environment	0	2	2
	loss of memory	0	1	1
	survivor personality (negative aspects)	0	1	1
	patient's psychological problems	1	0	1
	limited functional ability	1	0	1
	demanding behaviour	1	0	1
	non-encroachment of patients' independence	1	0	1
	personality change	0	0	0
	physical/behavioural issues			
19	Organising care when tired	0	2	2
20	Physically tiring process	4	0	4
21	difficulties with physical tasks	3	5	8
22	loss of energy	0	1	1
23	age-related health problems	2	3	5
24	interrupted nights	2	1	3
25	dealing with complex medications	0	0	0
	time management	1	0	1
	coping with caring if ill	0	2	2
	psychological issues			
26	lack of time for oneself	0	2	2
27	caring is a continual committment	2	2	4
28	feelings of guilt	0	0	0
29	loss of routine	0	1	1
30	unwillingness to involve others	1	4	5
31	role reversal	0	2	2
	social issues			
32	restriction in social life or other activities	7	8	15
33	difficulty of maintaining friendships	1	2	3
34	unable to share tasks/life together	2	4	6
35	poor transport facilities	0	3	3
36	loss of employment	1	0	1
37	bureaucratic difficulties (i.e. payments)	1	0	1
	limited social support	1	0	1
	amount of time left unsupervised (if going out)			
38	none of the time	3	6	9
39	a little of the time (up to 1 hour)	4	4	8
40	some of the time (1-6 hours)	0	3	3
41	most of the time (> 6 hours)	1	1	2

Cat No.		Dom (n=10)	DH (n=14)	Total (n=24)
	Support structure*	E,P, E&P	E,P, E&P	E,P, E&P
	Family			
42	Daughter	2,2,3	1,2,2	3,4,5
43	Son	0,1,1	1,1,3	1,2,4
44	Sibling	0,1,0	0,1,1	0,2,1
45	Other relatives	1,2,0	1,2,0	2,4,0
46	Stroke survivor	1,0,0	2,0,1	3,0,1
	Spouse	0,0,2	0,0,0	0,0,2
47	Neighbour	0,4,0	0,3,3	0,7,3
48	Friends	0,2,1	3,2,3	3,4,4
49	carers groups	0,0,0	0,0,0	0,0,0
50	Social Service worker	0,3,0	0,3,0	0,6,0
51	Health service worker	0,1,0	0,0,0	0,1,0
52	External worker (paid)	0,3,0	0,3,0	0,6,0
53	person mentioned,not identified	0,2,0	0,4,0	0,6,0
54	no person identified	2,0,0	2,0,0	4,0,0

* E – emotional support only, P – physical support only, E&P – joint emotional and physical support

	Service provision			
	Expectation of therapy			
55	No expectations	1	1	2
56	Specific physical improvement	3	7	10
57	General physical improvement	2	4	6
58	Help to maintain current levels of daily living skills	1	1	2
	Understanding of good therapy service			
	Physical improvement			
	improvement in patient physical condn	1	4	5
	to restore patient to pre-stroke status quo	1	0	1
	getting maximum level of recovery	1	0	1
	Practitioner skill			
	encouragement and attitude	2	0	2
	Empathy	1	1	2
	competent as practitioner	2	0	2
	Reliability	1	0	1
	increase confidence	0	1	1
	good working relationship	1	0	1
	Providing interesting activities for patients.	0	1	1

Cat No.		Dom (n=10)	DH (n=14)	Total (n=24)
	Efficient delivery of health care			
	more time spent in therapy	0	1	1
	regular visits determined by patients capabilities	1	0	1
	good follow-up	1	0	1
	involvement of carers	0	1	1
	information provision	1	0	1
	involvement of speech therapist	1	0	1
	Frequent visits	0	1	1
	more time spent in therapy	0	1	1
	Psychological improvement	1	0	1
	Understanding of the role of OT/PT in stroke rehabilitation			
59	no/little understanding	3	9	12
60	some understanding	2	0	2
61	good understanding	2	3	5
	advantages of day hospital			
62	good for stroke survivor to mix with others	4	9	13
63	space and rooms to carry out therapy	0	1	1
64	Respite from daily routine of care tasks	3	11	14
65	Equipment is more accesible	0	2	2
	advantages/disadvantages of domiciliary			
66	Convenient and more comfortable	7	3	10
67	carer support during therapy	2	0	2
68	carer education during therapy	3	0	3
	involvement with therapy			
69	some involvement	0	2	2
70	no involvement - no specified reason	1	0	1
71	no involvement – professionals know what they are doing	0	1	1
	Social Service provision			
	lack of punctuality	0	1	1
	Inconvenient timings	1	1	2
	future expectations of caring role			
72	no improvement/same as it is now	4	6	10
73	some improvement	3	3	6
74	role worsening	0	0	0
75	uncertain of future	2	4	6

Six months coding schedule

Cat No.		Dom (n=14)	DH (n=17)	Total (n=31)
	Main role as stroke carer			
9	personal self-care	11	14	25
10	domestic tasks	8	14	22
11	Shopping	6	7	13
12	financial/paperwork	5	4	9
13	medical/nursing care	3	6	9
14	transporting survivors at various places/activities/events	2	1	3
15	Encouragement (and support)	8	8	16
16	organise care from outside services	2	2	4
17	social activities	6	4	10
	Companionship	1	0	1
	supervisory role	0	1	1
	difficulties/impact of caring for stroke			
18	no real difficulties/change	3	0	3
	Patient related			
	personality change	1	3	4
	unmotivated (to do exercises)	1	3	4
	loss of memory	2	1	3
	personality (negative aspects)	1	1	2
	inability to communicate/poor communication skills	1	1	2
	demanding behaviour	2	0	2
	Incontinence	0	2	2
	psychological problems	1	0	1
	survivor despondency	1	0	1
	survivor's attitude to carer	0	1	1
	survivor's lack of appreciation	0	1	1
	slower reactions	0	1	1
	physical/behavioural issues			
19	organising care when tired	1	1	2
20	physically tiring process	3	4	7
21	difficulties with physical tasks	4	2	6
22	loss of energy	2	5	7
23	age-related health problems	3	4	7
24	interrupted nights	3	5	8
25	dealing with complex medications	0	1	1
	time management	1	2	3
	constant need for carer to be nearby	1	2	3
	unpleasantness of toiletting	1	0	1
	increased workload	0	1	1

Cat No.		Dom (n=14)	DH (n=17)	Total (n=31)
	psychological issues			
26	lack of time for oneself	4	10	14
27	caring is a continual commitment	4	9	13
28	feelings of guilt	1	4	5
29	loss of routine	0	1	1
30	unwillingness to involve others	1	4	5
31	role reversal	1	1	2
	emotionally tiring process	0	1	1
	need to be patient	0	1	1
	change in role within relationship	1	0	1
	social issues			
32	restriction in social life or other activities	7	7	14
33	difficulty of maintaining friendships	1	1	2
34	unable to share tasks/life together	2	3	5
35	poor transport facilities	0	3	3
36	loss of employment	2	2	4
37	bureaucratic difficulties (i.e. payments)	0	1	1
	less time with other family members	0	1	1
	amount of time left unsupervised (if going out)			
38	none of the time	2	5	7
39	a little of the time (up to 1 hour)	5	1	6
40	some of the time (1-6 hours)	3	2	5
41	most of the time (> 6 hours)	1	1	2
	Support structure	E,P, E&P	E,P, E&P	E,P, E&P
	family			
42	Daughter	2,0,5	3,2,1	5,2,6
43	Son	3,1,2	2,2,0	5,3,2
44	Sibling	1,1,0	1,0,0	2,1,0
45	other relatives	2,6,1	0,1,0	2,7,1
46	stroke survivor	2,0,0	0,0,0	2,0,0
	Spouse	0,0,3	0,0,1	0,0,4
47	Neighbour	0,2,1	0,4,1	0,6,2
48	Friends	2,1,0	1,3,1	3,4,1
49	carers groups	0,0,0	0,1,0	0,1,0
50	Social Service worker	0,2,0	3,3,0	3,5,0
51	Health service worker	2,0,0	0,1,0	2,1,0
52	external worker (paid)	1,6,0	0,4,0	1,10,0
53	person mentioned, but not identified	0,2,0	0,2,0	0,4,0
54	no person identified for physical/emotional support	2,1,0	2,2,0	4,3,0
	church members	0,0,0	1,0,0	1,0,0

* E – emotional support only, P – physical support only, E&P – joint emotional and physical support

Cat No.		Dom (n=14)	DH (n=17)	Total (n=31)
	other carer issues			
	sense of duty	1	4	5
	unfair to spend savings on care	0	2	2
	service provision			
	expectation of therapy			
55	no expectations	2	2	4
56	specific physical improvement	3	7	10
57	general physical improvement	4	4	8
58	help to maintain current levels of daily living skills	0	3	3
	type of expectations from therapy			
	exercise provision	2	0	2
	aids provision	1	0	1
	mental stimulation	1	0	1
	receiving therapy is important	1	0	1
	skillful/knowledgeable therapist	1	0	1
	good interdisciplinary contact	1	0	1
	understanding of the role of OT/PT in stroke rehabilitation			
59	no/little understanding	3	8	11
60	some understanding	4	4	8
61	good understanding	3	2	5
	fulfilment of expectation			
62	Fulfilled	4	7	11
63	not fulfilled	4	5	9
64	carer unable to comment	1	1	2
	advantages of day hospital			
65	good for stroke survivor to mix with others	3	12	15
66	space and rooms to carry out therapy	0	1	1
67	respite from daily routine of care tasks	2	15	17
68	equipment is more accessible	3	3	6
	in safe hands	0	3	3
	comparison of patients with others	1	1	2
	lack of information	1	1	2
	inconvenience of preparing survivor for day hospital	0	1	1
	lack of understanding about older person's needs	0	1	1
	getting out of house	0	1	1
	carer education	0	1	1
	interdiscplinary team on one site	0	1	1
	limited amount of therapy available	0	1	1
	Advantages/disadvantages of domiciliary			
69	convenient and more comfortable	12	2	14
70	carer support during therapy	4	0	4
71	carer education during therapy	6	0	6
	therapy designed for home environment	2	1	3

Cat No.		Dom (n=14)	DH (n=17)	Total (n=31)
	General issues involving interventions			
	lack of continuing therapy	0	2	2
	increasing confidence	0	1	1
	Social Services provision			
	inconvenient times	1	2	3
	hassles with organising Day Centre care	0	1	1
	involvement with therapy			
72	some involvement	1	0	1
73	no involvement - no specified reason	0	0	0
74	no involvement – professionals	0	0	0
	Helpful support			
75	More respite	1	2	3
76	Greater contact with primary care	0	1	1
77	More physical help (general or specific)	3	8	11
78	more information from health professionals	2	1	3
79	no further help beneficial	5	4	9
	social contact for survivor	1	2	3
	social outing	0	2	2
	arranging holiday together	0	1	1
	info on alternative therapies	1	0	1
	future expectations of caring role			
80	no improvement/same as it is now	5	2	7
81	some improvement	6	3	9
82	role worsening	1	6	7
83	uncertain of future	2	4	6

Appendix XXIX Demographic details of the 31 carers from the 6 month qualitative interviews.

Study no	Group	Gender	pat. BAI (6 mth)	Relationship	S.E.S.
5036	Domiciliary	Female	20	wife	III-nm
5049	Domiciliary	Female	20	wife	II
5042	Domiciliary	Female	19	daughter	III-nm
5114	Domiciliary	Female	17	wife	IV
5116	Domiciliary	Female	15	daughter-in-law	I
5132	Domiciliary	Female	9	wife	II
5084	Domiciliary	Female	8	wife	II
5066	Domiciliary	Female	4	wife	III-m
5085	Domiciliary	Female	4	daughter-in-law	II
5059	Domiciliary	Male	19	husband	III-nm
5102	Domiciliary	Male	19	son	II
5094	Domicilary	Male	18	husband	II
5057	Domiciliary	Male	11	brother	II
5053	Domiciliary	Male	4	husband	II
5110	Day hospital	Female	20	wife	III-nm
5100	Day hospital	Female	19	daughter	II
5075	Day hospital	Female	18	wife	III-nm
5062	Day hospital	Female	17	daughter	III-m
5045	Day hospital	Female	16	wife	II
5123	Day hospital	Female	16	wife	IV
5082	Day hospital	Female	15	daughter	III-nm
5099	Day hospital	Female	15	daughter-in-law	III-m
5061	Day hospital	Female	14	wife	IV
5033	Day hospital	Female	12	wife	II
5120	Day hospital	Female	11	daughter	III-nm
5122	Day hospital	Female	10	wife	III-nm
5060	Day hospital	Female	7	wife	II
5096	Day hospital	Female	7	wife	III-nm
5052	Day hospital	Male	16	husband	II
5126	Day hospital	Male	12	husband	I
5131	Day hospital	Male	8	husband	IV

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