University of Southampton

FACULTY OF MEDICINE, HEALTH & LIFE SCIENCES

School of Medicine

DOES AMOUNT AND SATISFACTION WITH COMMUNITY SUPPORT AFFECT OUTCOME FOR INFORMAL CARERS OF STROKE PATIENTS IN THE COMMUNITY?

by

Dr. Chantal Anne Else Simon

MA MSc BM BCh MRCGP DRCOG

Thesis for the degree of Doctor of Philosophy

January 2007

UNIVERSITY OF SOUTHAMPTON

ABSTRACT

FACULTY OF MEDICINE, HEALTH & LIFE SCIENCES

SCHOOL OF MEDICINE

Doctor of Philosophy

DOES AMOUNT AND SATISFACTION WITH COMMUNITY SUPPORT AFFECT OUTCOME FOR INFORMAL CARERS OF STROKE PATIENTS IN THE COMMUNITY?

by Chantal Anne Else Simon

Informal carers underpin community care policies of recent years. Many suffer both physical and psychological consequences due to their role. General Practitioners are the main point of access to the community support services for carers but general practitioners feel they have neither the time nor the training to perform that role. The aims of this thesis were to investigate: 1) health and social effects of caring on informal carers of stroke patients in the community at different points in time after stroke 2) relationship between health and satisfaction with care 3) relationship between satisfaction with care and level of service input.

A cohort study design was used. 105 new hands-on informal carers for stroke patients were interviewed using a fully structured, face-to-face questionnaire including measures of psychological health, physical health, lifestyle, social wellbeing, and formal community support provision. Interviews took place prior to discharge of the stroke patient home, six weeks after discharge, and 13 months after stroke. The carers' cohort was compared with a cohort of 50 matched non-carers over the same time period.

Results showed that carers had significantly higher psychological distress than non-carers which was present before the stroke patient was discharged home (CIS-R 11.16 vs. 7.52, t=2.405, p=0.018) and still present a year after discharge home (12.58 vs. 7.45, t=3.34, p=0.001, CI: 2.08-8.18). Early after stroke psychological distress was associated with perceived weight change since stroke and quality of informal social support. After a year caring, it was determined by previous low mood, alcohol consumption and low income. Physical health also deteriorated over the course of the study (number of health problems: 1.55 first vs.1.87 final interview, t=-2.02, p=0.046, CI: -0.64--0.002). Physical health was predicted by age early on. Later previous poor health, factors associated with increased workload, and support received to help with that workload became more important. All carers received input from the formal community services and 64% were satisfied with that support. Soon after discharge, amount of formal support was associated with level of handicap of the stroke patient, carers' self-rated health, number of supporters identified and other care commitments. Later on, in addition to level of handicap, quality of support and previous experience of care giving became more important factors. Soon after discharge, satisfaction with support depended on perceived quality of informal support and restriction of usual activities. A year later quality of the relationship between stroke patient and carer prior to discharge, age, psychological distress and cost of care were more important factors.

In conclusion, carers suffer physical and psychological health consequences as a result of care giving. These start very early on, before the stroke patient is discharged home. Carers with poor social support, and poor pre-existing relationships with the stroke patient, have more psychological distress. These factors should be taken into consideration when discharge planning. Further work is needed to establish whether identification of carers with psychological distress prior to discharge, and early interventions, in hospital or in the community, to improve quality of social networks, would improve outcome for carers long term.

Declaration of authorship

I, Dr. Chantal Simon, declare that the thesis entitled '*Does amount and satisfaction with community support affect outcome for informal carers of stroke patients in the community?*', and the work presented in it, is entirely my own work. This work was done wholly while in candidature for a research degree at this University. Reference to, quotation from, and discussion of the work of any other person has been correctly acknowledged within the work in accordance with the University guidelines for production of a thesis, and I have acknowledged all main sources of help. None of this work has been published before submission.

Signature: Chantal A. E. Simon

Date: 21.1.2007

List of contents

Page number

Appendices:

List of tables and illustrations:

Chapter 2: Literature review *Page number*

Tables:

Figures:

Chapter 3: Choice of study design

Tables:

Figures:

Chapter 11: Results from the first interview *Page number*

Tables:

Figures:

Chapter 12: Results from the second interview

Tables:

Figures:

Chapter 13: Results from the third interview

Tables:

Chapter 14: Limitations of the study *page number*

Tables:

Figures:

Chapter 15: Discussion of resultsaAaaaaa

Tables:

Figures:

Chapter 16: Conclusions

Table:

Figures:

Acknowledgements

This study was funded with a Research Training Fellowship from NHS R&D South East Region.

Thanks go to:

- My supervisors Professor Tony Kendrick and Dr. Satinder Kumar
- Dr. Damien Jenkinson and staff at the Christchurch stroke rehabilitation unit who helped recruit carers.
- Dr. Gill Turner and staff at the acute stroke unit, Southampton General Hospital who helped recruit carers.
- The stroke patients and carers who willingly volunteered their time to help.
- Professor Paul Little and Dr. George Lewith for providing feedback on this thesis.
- Dr. Peter Smith, reader in social statistics for advice on statistical matters.

Chapter 1: Introduction

Most General Practitioners undertake some work out of the practice to maintain their interests and skills. I worked one session a week at our local hospice. I could not help but notice that informal carers of patients who had been referred to the hospice were treated completely differently than carers of other sick, frail or disabled patients in the practice. They had a specialist carer support officer to help them; all their forms were filled in for them; information packs abounded and they had a hot line to the carer's officer if they needed any help. Other carers of non-cancer patients registered with my practice had none of this and yet often took on equally heavy and stressful burdens – frequently over periods of many years. There was a definite and marked inequality of care.

When the opportunity came to investigate a topic of relevance to general practice I decided to look into the effects of caring for someone with a disability on the carer, and interventions from the community and primary care services which provide support, with a view to finding ways to improve support for carers from the community services.

1.1 Definition of a carer:

Carer is a generic term used to describe someone who assumes a caring role. 'Caring' in this instance means doing something for someone that they cannot do for themselves. Carers (often referred to as 'informal' carers to distinguish them from 'professional' or 'formal' carers) are usually friends or relatives of the disabled person.

There is no standard definition of a carer. Carers UK, the leading national carer support charity uses the following definition on its website (Carers UK, 2004): "Carers look after family, partners or friends in need of help because they are ill, frail or have a disability. The care they provide is unpaid." This definition was used for the purpose of this study.

However, there are problems with this definition - when does a carer become a carer? How disabled does a person have to be before the person looking after them is termed a carer? Are people carers if they don't think they do anything special for someone who is frail or disabled?

"Carers are no more alike than women" was a comment made by a district nurse in a postal survey to determine current practice of GPs and district nurses with respect to carers (Simon C, Kumar S, & Kendrick T, 2002). The range of carers and problems they face is huge. To limit the scope of this study, the field had to be narrowed, so a decision was made to concentrate on carers of stroke patients. The reason for this was that the aftermath of stroke can have profound effects on both the individual and their family, carers often look after a stroke patient for many years, there is a definite point of "onset" of caring and this group is relatively neglected in the carers' literature.

1.2 Stroke as a cause of disability:

Stroke is characterised by rapidly developing clinical symptoms and signs of focal, and at times global, loss of cerebral function lasting more than 24 hours or leading to death, with no apparent cause other than that of vascular origin (Hatano S, 1976). Around 100,000 people suffer a first stroke each year in the UK (The Stroke Association, 2000) and stroke is the third most common cause of death in most developed countries (Bonita R, 1992). It is a worldwide problem: about 4.5 million people die from stroke each year and stroke can occur at any age, but half of all strokes occur in people over 70 years old (Bamford J et al., 1988).

At the time this study was carried out, thrombolysis was not routinely given to patients presenting with a diagnosis of stroke. Without thrombolysis, about 10% of all people with acute ischaemic strokes will die within 30 days (Bamford J et al., 1990). Of those who survive the acute event, about 50% will experience some level of disability after six months (Wade DT, 1987) making stroke the most common cause of adult-onset disability in the UK, and one of the biggest claims on health and social care resources. It is estimated that, in 2004, the cost of the aftermath of stroke to the NHS is £2.5 billion annually and, in line with population trends, stroke survivors are also becoming older and living longer in a disabled state so that figure is set to rise.

Stroke is a devastating condition. It usually has a sudden and unexpected onset and, in the early stages, it is very difficult to predict outcome whatever the severity of the initial event. However severe the stroke is, the lives of patients and all around them, instantly change forever.

Of those admitted from independent living with a diagnosis of stroke, who survive the initial event, 6-20% are discharged to institutions (Royal College of Physicians, 1998) but the rest return home - often cared for by relatives or friends (The Stroke Association, 2000). There are many potential role changes someone caring for a stroke patient might have to face. Returning someone who has had a stroke home can entail changes to both the structure and appearance of the home. Once home, caring for someone who has had a stroke may entail helping with communication, coping with new financial responsibilities and attending to tasks for which the carer has no previous knowledge or experience such as incontinence problems (Napoleoni L, 1994). A stroke can also severely limit the social life of both stroke patient and carer impacting on work, hobbies and family activities (Brocklehurst JC et al., 1981; Isaacs B, Neville Y, & Rushford I, 1976). Any situation in which there is such rapid and lasting change is likely to have health consequences.

1.3 Informal carers in society:

From General Household Survey data, there are six million carers in the UK with 23% spending more than 20 hours a week and 11% more than 50 hours per week on caring activities (Rowlands O & Parker G, 1998). However these are self-defined carers giving a positive response to a single question in the General Household survey asking if they regularly spend time looking after someone who is frail or disabled. Parker (1992) suggests that our efforts in supporting carers should be focussed on the 1.3 million "main" or "heavily involved" carers spending more than 20 hours per week on caring activities. This subset represents around one in 25 adults in an average area.

There have always been informal carers but the issue of formal care for carers has become more prominent in the last 20 years. There may be several reasons for this related to both social structure of our community and the role of health professionals within it.

First, the policy of care in the community has resulted in closure of many long-term residential care facilities. This is not a bad thing as there is good evidence that care in the home is both a cheaper and a better option for most patients (Chiu L, Shyu WC, & Chen TR, 1997). Compounding this, our population is ageing (Office for National Statistics, 2000) and more people survive illnesses that were previously fatal, being left frail or disabled and requiring help to live at home. There are therefore more disabled people in the community and more carers.

Citing a re-analysis of the General Household Survey, the Royal Commission on Long Term Care (HM Government, 1999b) notes that people aged 65 and over provide 35% of the care for people of that age and that spouses provide care for 51% of severely disabled older people. As carers are frequently spouses (Warner N, 1995), the carers themselves are becoming older and frailer too so require more assistance from the formal support services.

Second, improvements in transport and communications have resulted in loss of local community. Loss of the extended family (Office for National Statistics, 2000) has led to relatives often living too far away to be of practical help. Informal carers are probably more isolated than they have ever been and so rely more on formal support services.

Third, inpatient care is expensive and there is financial pressure for patients to be returned to the community within the shortest possible time (Beech R et al., 1999). This policy also has benefits for patients and there is good evidence supporting early discharge in several conditions (Mayo NE et al., 2000; Rudd AG et al., 1997). However it does mean that community services and informal carers take on the burden of care earlier and at a point where more input is required (Jones AL, Charlesworth JF, & Hendra TJ, 2000). Whether this leads to increased carer strain is controversial (Donnelly M et al., 2004; Jones AL, Charlesworth JF, & Hendra TJ, 2000; Teng J et al., 2003).

Lastly, there have been marked changes in the primary care system in the UK over the past 20 years. As a result of the shift from hospital to community-based care and increasing patient expectations, GPs and other members of the primary care team feel increasingly overburdened with work (Boseley S, 2003; Butler P, 2001). In an attempt to limit workload they are perhaps becoming more preoccupied with role definition. A GP is no longer the doctor in the community who will turn his hand to anything. The doctor's life is now fairly strictly bound in achieving Government driven targets (Department of Health, 2003c).

Carers have no formal medical diagnosis and do not suffer illness as we traditionally regard it. They are seen as having social rather than medical problems (Simon C & Kendrick T, 2001; Twigg J & Atkin K, 1994) and so are on the periphery of the GP's role – an area where general practice can absolve its responsibility. As the GP is the most frequent point of access to the primary care team (Henwood M, 1998), this will have an impact on the support other primary care team members can offer.

1.4 Carers and the primary health care team:

Approximately nine out of ten carers have seen their GP and half have seen a district nurse within the last year. When asked who has the most power to improve their lives, 72% of carers rank their GP top of the list (Henwood M, 1998). The Griffiths Report (Griffiths R, 1985) highlighted the importance of general practice in providing this support. Primary Care Services were envisaged to play a key role in supporting carers in the 1995 Carers Act (Department of Health, 1996) and the 1999 National Strategy for Carers (HM Government, 1999a) formally recognized that for many carers the most important initial point of contact is with their GP or another member of the primary care team.

At government level it is clearly regarded that GPs have a key role to play in supporting carers and influencing service providers in their local community. However, problems of interaction between GP and carer have been identified as a reason for delay in access to support services and a source of distress for carers (Bruce DG & Paterson A, 2000). National surveys of informal carers have shown that 71% feel their GP does not understand their needs (Warner L & Wexler S, 1998) and 40% think their GP could have done more for them (Henwood M, 1998). Moreover, most GPs do not feel it is their task routinely to support carers (Simon C & Kendrick T, 2001).

1.5 Public policy relating to carers:

1.5.1 National Strategy for Carers (1999): This Government policy document reviewed Carers' needs and set out a strategy and policy for supporting informal carers. It recognized that carers need support from statutory and/or voluntary services and that carers might miss out on services available to other sectors of the population as they have less opportunity to use those services due to their care commitments. It pledged to offer carers: freedom to have a life of their own; time for themselves; the opportunity to continue to work, if that is what they want to do; control over their life and over the support they need in it; better health and wellbeing; integration into the community; and, peace of mind.

1.5.2 Disabled persons' and carers' assessments

For stroke patients in hospital, under the *Community Care (Delayed Discharges) Act* 2003, if a patient is due for hospital discharge and the carer is concerned about how s/he will provide care in the home, the patient is entitled to a home assessment, which includes the caring role. This assessment should determine the need for aids, adaptations and home care, the latter being provided free of charge for a 6 week trial period.

Carers' assessments were first mentioned in the *Carers (Recognition and Services) Act* (1995). Any carer can ask for an assessment of their own needs from a social work or other health or social care professional, when the person they are caring for is having an assessment or re-assessment of their needs. Assessments for people with disabilities in the community are carried out under legislation introduced in the 1990 *NHS and Community Care Act* and look at the needs of the disabled person and decide what community care services are required to meet those needs. Many areas now use a "single assessment process" which is a joint assessment process for disabled people and their carers carried out by all the health and social care professionals involved in the situation.

In 2000, the *Carers and Disabled Children Act* took this a step further. It gives carers who provide or intend to provide regular and substantial care, the right to ask for an assessment of their own needs to help them continue to care, irrespective of whether the person being cared for has had or is having a needs assessment. This Act also allows social services departments to provide services directly to carers.

The *Carers Equal Opportunities Act* (2004) was implemented in April 2005. It placed a duty on social services departments to inform carers of their right to an assessment. It also changed the purpose of the assessment so that it is not only designed to help the carer to continue to care, but also includes discussion of the carer's employment, educational and leisure needs. Lastly, it enabled social services departments to refer carers to other public bodies, such as health services, for provision of services.

1.5.3 Carers and the GP contract:

The 2004 new GP Contract included provision for support for carers within its Quality and Outcomes Framework. Under Management Indicator 9, practices are awarded with three Quality points for having 'a protocol for the identification of carers and a mechanism for the referral of carers for social services assessment'. In most practices this simply means that carers are Read coded on the computer to enable identification and nothing else and this has done very little to support informal carers.

More recently the Scottish 'Services for Carers' Directed Enhanced Service (NHS Scotland, 2006) stressed that carers should be partners in care and rewarded practices for ensuring carers have been referred to appropriate support agencies. There is currently no equivalent Directed Enhanced Service for England, Wales or Northern Ireland.

1.5.4 National Service Frameworks and carers:

National service frameworks (NSFs) are long term strategies for improving specific areas of care. They set measurable goals within set time frames. Several NSFs, including the National Service Framework for older people (Department of Health, 2001), National Service framework for coronary heart disease (HM Government, 2000a) and National

Service Framework for Mental Health (Department of Health, 1999) contain guidance for involvement of carers in the care process, carer assessment and carer support. The National Service Framework for older people, in the context of stroke, also requires carers to be included in a multidiciplinary programme of secondary prevention and rehabilitation with the stroke patients they care for.

1.6 The need for more evidence:

The structure of general practice has changed enormously over the last ten years. Since the advent of primary care groups and, more recently primary care trusts, GPs have had far more control over provision and integration of community services than ever before. Modern technology can ensure effective inter-agency communication and make support of carers tied to the home easier (Goodman CC & Pynoos J, 1990; Zorowitz RD, 1999). This is an opportunity to develop co-ordinated services for groups such as carers who have fallen between traditional health and social services boundaries and thus have been relatively neglected in the past.

The National Service Framework for older people (Department of Health, 2001) proposes that more people will be cared for at home with the help of specialist services. It also explicitly demands that carers are involved in the rehabilitation of stroke victims as part of the team and demands that carers are consulted at local level about the services provided to them. However evidence about which strategies are helpful is lacking (Royal College of Physicians, 2000) and evidence is needed before scarce resources can be directed into this area.

Finding effective ways for the formal support services to help carers in the community is therefore an important topic which, until now, has been relatively under-explored and a decision was made to focus this research into that area.

Chapter 2: Literature review

2.1: Search strategy

The aim of this literature review was to ascertain what work had already been done about effects of caring on the carer, formal support of carers and specific interventions to support carers in order to focus in on suitable research questions for my PhD project. I searched both generally (all groups of carers) and specifically (carers of stroke patients) as there was only very limited information regarding carers of stroke patients. I confined the search to literature describing effects of caring on carers and community support for carers.

MeSH terms used for searching:

Carer terms:
Caregivers
Spouses
Family relations

Patient terms:
Homebound persons
Disabled persons

Effects of Caring:
Anxiety disorders
Depressive disorder
Morale
Life change events
Behaviour and behaviour mechanisms

Formal supporters of cares:
Nursing
Community health, nursing
Community workers
Community health services
Nursing care
Night care
Patient care
Palliative care
Home care agencies and services
Home nursing
Long term care
Hospice care
Respite care
Social welfare
Patient care team
Patient centred care

Disease specific terms:
Cerebrovascular accident
Parkinsons disease
Motor neurone disease
Terminal illness
Paraplegia
Alzheimer's disease
Dementia
Head injury
Amputee
HIV

Care Provision:
Patient care planning
Needs assessment
Community medicine
Community networks
Delivery of health care
Delivery of health care, Integrated

Table 2.1: MeSH terms used for literature searching

First, a list of MeSH terms/keywords to search with was constructed. These are listed in Table 1. EMBASE, MEDLINE, CINAHL and PSYCHLIT databases spanning 1990 to 2006 were searched with these terms. Generally I combined each "carer term" individually with each of the other terms listed. The exception to this rule was the term "cerebrovascular accident" which was searched in combination with each carer term individually and then was searched in combination with each of the other terms individually too.

These search terms were very wide due to lack of a specific term for informal carer, so it was possible to screen out a large proportion of the references accessed in this way just by their titles. Then abstracts of those which appeared relevant to the study were downloaded and, on the basis of these abstracts, decisions were made about which papers should be read in full and included in the review.

The reference sections of all papers identified in this way were also searched for additional papers missed on the database searches. Additionally, as much of the literature about carers has not been published in conventional journals but has been produced by charities supporting patient groups and/or carers, these groups were contacted directly to obtain any publications held and their websites were searched for publications and links to publications.

The Department of Health Website was used to obtain National Statistics (Statbase ®) and details of Government legislation relevant to this topic and a search of the National Research Register was made to ensure no similar work was underway elsewhere. Lastly the Citizen's Advice Bureau Website was searched to obtain details of help and services available to carers.

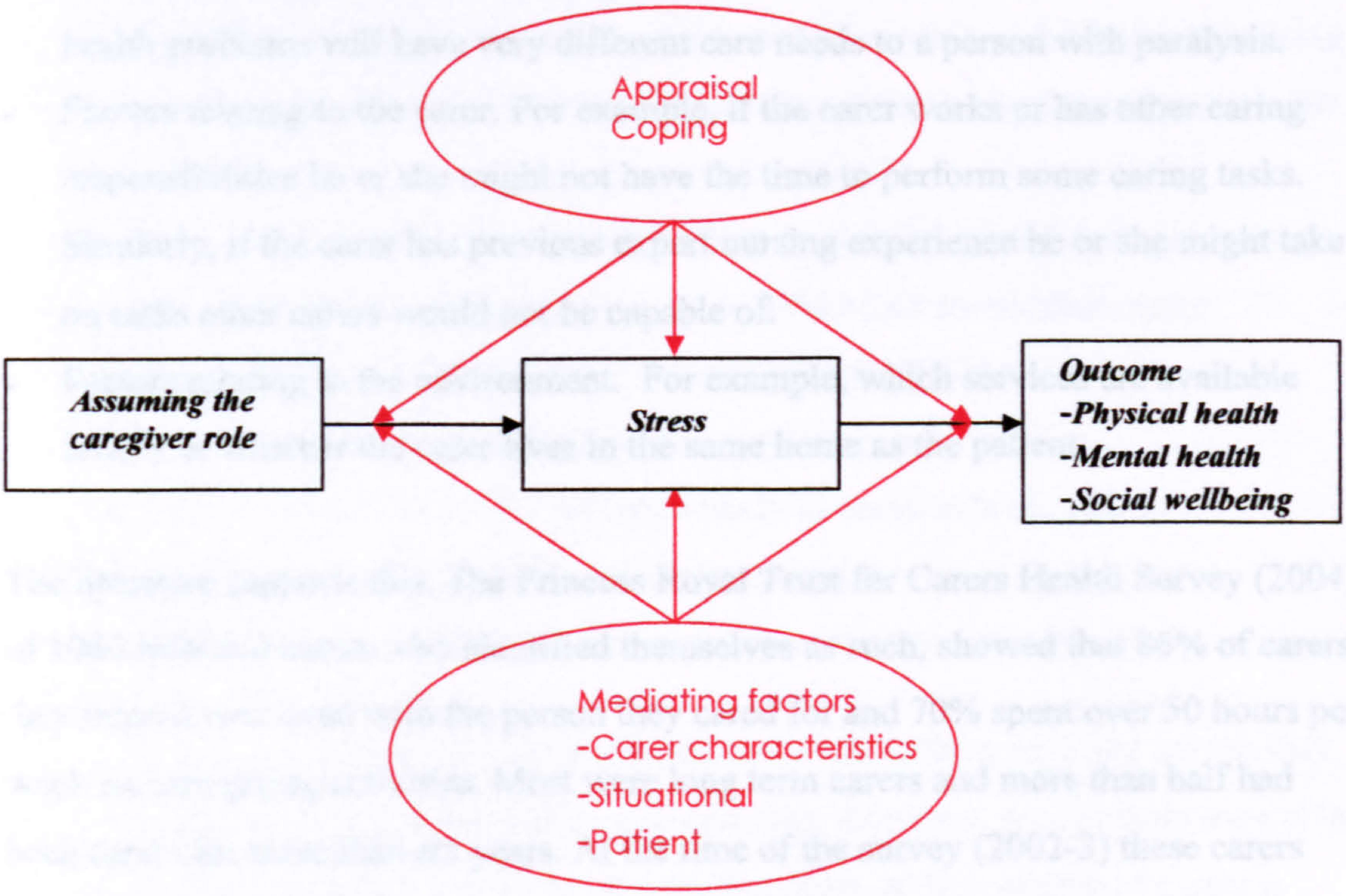
2.2: Theoretical basis for research on the effects of care giving

Most studies within the literature about carers generally have either explicitly or implicitly used the stress and coping theory in various formats as a basis for investigation (Lazarus RS & Folkman S, 1984; Nieboer A, 1996; Pearlin LI, 1990; Schulz R & Quittner AL, 1998). This model (see figure 2.1, page 11) was originally developed by Lazarus and Folkman (Lazarus RS & Folkman S, 1984) and then adapted for use in analysis of the caring role by other researchers (Pearlin LI, 1990).

In this model, a life-event causes stress which, in turn, affects the well-being of the individual from a physical, psychological and social perspective. The way in which an individual assesses and copes with the situation and the presence of other "mediating factors" determine the outcome for a given individual. These mediators fall into several groups:

1) Characteristics of the carer - age, gender, socioeconomic status, relationship to the person they care for (e.g. spouse, daughter etc.), education, personality, appraisal

Figure 2.1: A graphic representation of Lazarus and Folkmann's stress and coping theory as applied to the caring situation



of their role as carer, burden caused by caring and enjoyment of the positive aspects of caring.

2) Situational characteristics - social activities, social network, satisfaction with social support, previous quality of relationship with the person cared for, duration of caring, other life events.

3) Characteristics of the patient and their illness - suddenness of onset, number of tasks required, prognosis and degree of change of the patient, depression and behavioural disturbance.

Therefore care giving is a complex task. The way in which individuals respond to it will depend on the carer, the patient and their environment.

2.3: Caring tasks

One might also suspect that the tasks performed by carers will cover a huge range and depend on many factors including:

- Factors relating to the person being cared for. For example, a person with mental health problems will have very different care needs to a person with paralysis.
- Factors relating to the carer. For example, if the carer works or has other caring responsibilities he or she might not have the time to perform some caring tasks. Similarly, if the carer has previous expert nursing experience he or she might take on tasks other carers would not be capable of.
- Factors relating to the environment. For example, which services are available locally or whether the carer lives in the same home as the patient.

The literature supports this. The Princess Royal Trust for Carers Health Survey (2004) of 1066 informal carers who identified themselves as such, showed that 86% of carers they interviewed lived with the person they cared for and 70% spent over 50 hours per week on care giving activities. Most were long term carers and more than half had been carers for more than six years. At the time of the survey (2002-3) these carers did a wide variety of tasks:

- Over 80% cooked, shopped and ensured appointments were kept
- Over 70% dealt with medical staff and organised transport
- Over 60% administered medicines, managed money for the person they were caring for, did 'personal tasks', supervised medication, and did washing and ironing
- Over 50% did 'physical tasks', dealt with the DSS/Housing, got up in the night or coped with bizarre behaviour
- 44% dealt with verbal/emotional abuse and 28% with physical aggression/violence

However, this was a self-defined and self-selected group of informal carers largely in contact with carers organizations (which provided the questionnaire). Census data suggest only a third of informal carers perform care giving tasks for over 50 hours a week, a figure much lower than that reported in this survey, so the representativeness of the results is questionable. Another large study followed up 500 carers of older people in the community in London in the 1990's to discover which caring tasks were carried out by who (Bauld L et al., 2000). The authors found:

- 60% of carers looking after someone with critical interval needs (greater physical dependency requiring more frequent visits) and a cognitive impairment provide assistance with medical and toileting tasks, and just over one third of those caring for someone with critical interval needs and no cognitive impairment provide this form of help
- 85% of carers of people with critical interval need and a cognitive impairment provide assistance with personal care, as do 83% of all co-resident carers
- More female than male carers help with housework (61:51%)
- 84% of co-resident carers are involved in meal preparation
- Carers of less dependent users are more likely to assist with shopping
- 97% of informal carers provide company and leisure
- 70% of principal carers help the older person to manage their affairs.

In this study carers were identified by the professionals looking after the person they cared for and were not self-defined or self-selecting. However, many carers are not in contact with formal support services on a regular basis, so this sample of carers is skewed towards those who have been formally identified as carers and are in contact with the formal support services. This might affect the type of tasks performed.

Although both these methods of sampling to assess carer tasks have their limitations they do show that carers perform a large variety of tasks for the people they care for. These tasks range from housekeeping (such as shopping, cleaning, washing clothes and bedding), through personal care (for example washing or toileting the disabled person), and medical care (such as getting the person cared for to appointments and supervising medication), to entertainment and managing finances.

2.4: Carer stress or strain

Many studies have set out to measure levels of strain in carers. A much smaller number have looked at strain in carers of stroke patients.

A recent meta-analysis of studies involving informal carers looking after patients with any disability (Pinquart M & Sorensen S, 2003a) integrated findings from 228 studies on the association of six caring-related stressors and caring uplifts with burden. Care recipients' behaviour problems had the strongest associations with carer strain. In addition, amount of care provided and care receivers' physical impairments were related to burden for carers of non-demented older adults.

Most studies specifically looking at carers of stroke patients show they are also placed under strain by their roles. One study following carers through the early discharge period after stroke found at three months post discharge 35% of carers were under "considerable strain" and this figure remained the same after six months (Blake H, Lincoln NB, & Clarke DD, 2003). This figure is fairly consistent across studies (Blake H & Lincoln NB, 2000; Bugge C, Alexander H, & Hagen S, 1999; Greveson G et al., 1991).

Many different factors have been associated with carer strain amongst carers of stroke patients (table 2.2, page 15) however these studies are generally small and characterised by the use of many different measures. There were no studies identified which established any relationship between cause and effect.

2.4.1 Problems with the measurement of carer strain or burden:

2.4.1.1 Definition:

There are several problems with measurement of carer strain or burden. First the definition is not consistent. Definitions of carer strain or burden vary in their focus from emotional costs (such as feelings of embarrassment and overload) (Thompson E & Doll W, 1982) to financial difficulties, role strain and physical health deterioration (Robinson BC, 1983; Zarit S, Reever K, & Bach-Petersen J, 1980).

Carer strain is consistently related to psychological distress (Draper BM, 1992; Hodgson SP, Wood VA, & Langton-Hewer R, 1996; Nieboer A et al., 1998;Scholte op Reimer WJM et al., 1998; Wyller TB et al., 2003) so, is carer strain just an indirect way of measuring carer distress? This problem has been addressed in the literature (Fritz CL et al., 1997; Stuckey JC, Neundorfer MM, & Smyth KA, 1996; Stull DE, Kosloski K, & Kercher K, 1994) and burden scales seem to be measuring a different entity to carer "well-being" scales though they are closely related. However, if carer burden or strain cannot be defined, what do the results of measuring it mean?

2.4.1.2: Are the measures comparable?

Perhaps related to the problems with definition is this next problem. In the studies in table 2.2, six different measures are used. These measures overtly appear different from each other and, as no studies comparing measures directly against each other could be found, it is not clear that they are actually measuring the same thing.

Study	**Major findings:** ***Associations with strain***
Ross et al, 1988	Negatively related to family economics and communication functions and positively related to level of dependency.
Macnamara et al, 1990	Carer depression. Strain was not related to caring duration.
Draper et al, 1992	Carer burden was significantly associated with psychological morbidity. Psychiatric aspects of chronic disability rather than physical aspects were found to be more stressful for carers.
Elmstahl et al, 1996	Closer relationship but not to the living situation. Highest carer burden was found among patients showing the greatest improvements in activities of daily living. Patient degree of extroversion and quality of life were negatively correlated to carer burden.
Segal and Schall, 1996	Carer's life satisfaction is directly related to carer burden which, in turn, is related to patients' level of handicap.
Scholte op Reimer et al, 1998	Patients' disability (cognitive function, handicap and quality of life); Carer's characteristics – emotional distress (most important factor), loneliness, disability, amount of care provided, unmet demands for psychosocial care and unmet demands for assistance in activities of daily living
Bugge et al, 1999	Amount of time a carer spends helping a stroke patient, amount of time the carer spends with the patient, and the carer's health.
Blake and Lincoln, 2000	Carer well-being, patient everyday activities of daily living and negative affectivity.
Jones et al, 2000	Severity of stroke related disability
Thommessen et al, 2001	Cognitive function of the patient
van den Heuvel et al, 2001	Cognitive, behavioural and emotional changes in the patient; gender (women>men); younger carers; and, carers in poor health. High perceived self-efficacy, satisfaction with social support and using a confronting coping strategy are protective
Singh and Cameron, 2005	Lifestyle impact and emotional distress
Visser-Meily et al, 2005	Passive coping strategy of the caregiver and level of handicap of the stroke patient

Table 2.2: Summary of studies investigating factors which predict carer burden and/or strain amongst carers of stroke patients

2.4.1.3 Are the scales reliable and valid?

Another problem lies with the scales themselves. All the scales in table 2.2 have been developed to use with carers of patients who are very elderly (Poulschock SW & Deimling GT, 1984; Thornton M & Travis SS, 2003) and/or have Alzheimer's disease (Hebert R, Bravo G, & Preville M, 2000; Matsuda O, 1999; Novak M & Guest C, 1989; Vitaliano PP et al., 1991). They have not been validated for carers of stroke patients and thus any associations found in this group may not be real.

Vitaliano, Young and Russo (1991) critiqued ten measures of burden used with carers of individuals with dementia. They found measures had frequently been tested for reliability but very few reported content or criterion validity or sensitivity to change (see pages 49-52 for definition and explanations of these terms). Furthermore, scales used for measuring strain or burden have no established burden “cut off points” so classifying carers as “under a lot of strain” or “heavy burden”, as is done in many of the studies in table 2.2, are arbitrary classifications not comparable across studies. All the findings in table 2.2 should be interpreted with these reservations in mind.

2.4.1.3 What do the findings mean?

Finally, the last problem is that burden measures cannot be used on populations of non-carers so it is difficult to differentiate the impact of caring for the stroke patient from other factors, such as age, which might increase perceived burden over time. It is well established that depression increases with time after middle age (Mirowsky J & Ross CE, 1992; Osborn DP et al., 2003). As depression /psychological well-being and carer strain / burden are commonly related to each other (Draper BM, 1992; Hodgson SP, Wood VA, & Langton-Hewer R, 1996; Nieboer A et al., 1998; Scholte op Reimer WJM et al., 1998; Wyller TB et al., 2003), it is feasible that carer strain or perceived burden increases with time too.

2.5: Health effects of care giving upon informal carers

2.5.1 General effects of care giving:

Carers experience problems as a result of their role. UK Census data shows that of people aged 65 and over, more than a million (12%) are informal carers (498 000 men and 539 000 women). Of these, more than a third (382 000) care for at least 50 hours a week. Less than a third of older people with this heavy burden of care are themselves in good health and more than a quarter (103 000) rate their health as "not good" (Doran T, Drever F, & Whitehead M, 2003).

In the Princess Royal Trust Carers Health Survey (2004), 7% said their health was very good, 52% said their health was 'good', 37% said it was 'not very good' and 10% 'not at all good'. Specific activities perceived to cause ill health were:

- Getting up in the night (37%)
- Physical tasks such as lifting (27%)
- Coping with inconsistent/bizarre behaviour and dealing with verbal and mental abuse (27%)
- Physical aggression (16%)
- Dealing with benefit and housing problems and medical staff (both 16%)

2.5.1.1 Physical health:

The effects of informal caregiving on physical health are not entirely clear. In one postal survey 51% reported physical injury as a result of caring – mainly back and shoulder injuries (Henwood M, 1998). In the more recent survey by the Princess Royal Trust for Carers (2004), 61% of the 1066 carers who completed the survey reported currently feeling 'physically drained'. In addition, 20% reported back injury as a result of caring (mainly amongst carers doing heavy physical caring for those with physical disabilities) and 10% put their high blood pressure down to the stress of caregiving. However, these are survey data amongst self-defined and self-selected respondents. The research literature on physical effects of caregiving is more mixed.

Using self-reported ranking scales of health to measure physical health, George and Gwyther (1986) found that a group of carers of demented elderly patients ranked their health similar to that of age and sex matched non-carers. However, another study, using a similar group of carers, found the carers ranked their own health as worse than their matched controls (Haley WE et al., 1987).

When self-reports of chronic illness and/or medication usage are used as a measure of health the picture is also mixed with some studies showing no difference between carers and controls (Baumgarten M et al., 1992; Kiecolt-Glaser JK et al., 1991), and others showing carers have more chronic illness and/or use more medication than controls (George LK & Gwyther LP, 1986; Haley WE et al., 1987; Pruchno RA & Potashnik SL, 1989).

Use of health services is another way to measure health. The carer literature is mixed in this respect too. Some researchers report carers use more health services than matched controls (Haley WE et al., 1987; Kiecolt-Glaser JK et al., 1991; Pruchno RA & Potashnik SL 1989), others do not report such differences (Cattanach L & Tebes JK 1991; George LK & Gwyther LP 1986).

However, perhaps the most powerful evidence for a negative effect of caring on physical health comes from a large scale study in the United States. Schulz et al. (1999) showed an increased incidence of coronary heart disease and mortality amongst a mixed group of carers.

2.5.1.1.1 Meta-analysis: Meta-analysis findings support a negative effect of caring on physical health but the effect is smaller than for psychological health (see below). Vitaliano, Zhang and Scanlan (2003), performed a meta-analysis of 23 studies to compare the physical health of carers of dementia patients with demographically similar non-carers. When examined across 11 health categories, carers exhibited a slightly greater risk for health problems than did non-carers. Pinquart and Sorensen (2003b), in their meta-analysis of 84 studies comparing mixed carers with non-carers concluded that differences in the levels of physical health in favour of non-carers were statistically significant, but small.

2.5.1.2 Psychological health:

In a national postal survey of carers, 52% reported they had been treated for stress related illnesses since the onset of caring responsibilities (Henwood M, 1998). A more recent survey by the same organization (Princess Royal Trust, 2004) showed:

- 38% report stress/nervous tension
- 28% report depression (more likely in men aged 15-34) *and*
- 27% report anxiety (more likely amongst women and the elderly)

Lack of concentration, headaches, fear, panic attacks, and sexual problems were also common and currently being experienced by over a quarter of carers. This study also showed that informal carers experience a wide variety of negative emotions. The most frequent were:

- Feeling mentally/emotional drained (ever 77%; experienced nowadays 70%)
- Frustration (ever 74%; experienced nowadays 61%)
- Sadness for the person (ever 68%; experienced nowadays 56%)
- Disturbed sleep/sleep deprivation (ever 66%; experienced nowadays 57%))
- Stress/nervous tension (ever 65%; experienced nowadays 61%)
- Anger (ever 59%; experienced nowadays 41%)
- Loneliness (ever 54%; experienced nowadays 46%)
- Guilt (ever 53%; experienced nowadays 38%)

Results of research studies show a similar picture. A recent meta-analysis of 84 studies of effects of caring on carer health (incorporating studies of carers of patients of older adults with many different conditions) showed significant differences between carers and non-carers in perceived stress, depression, and general subjective well-being (Pinquart M & Sorensen S, 2003b).

Perhaps the best evidence of the harmful effect of caring on psychological health is a study by Hirst (2005). This study used data from the British Household Panel Survey and collected in the 1990s. Each participant had psychological well-being assessed at annual intervals using the General Health Questionnaire. Within the data collected was information on 3000 people who became carers, 2900 former carers, and 11,100 non-carers. Analysis of these data showed that informal carers providing long hours of care over extended periods had increased levels of distress, women more so than men. Compared with non-carers, risk for onset of distress increased progressively with the amount of time devoted to caregiving each week. Adverse effects on the psychological well-being of heavily involved carers were most pronounced around the start of caregiving episodes and when caregiving ended. Ongoing care increased susceptibility to recurring distress, and the adverse effects of caregiving were evident beyond the end of caregiving episodes.

2.5.2 Carers of stroke patients

Although most studies show that caring has a negative effect on psychological health which is comparable across conditions (Draper BM, 1992; Dura JR, Haywood-Niler E, & Kiecolt-Glaser JK, 1990; Matson N, 1995; Reese DR et al., 1994; Meagher-Stewart D, & Hart G, 2002), at least one study (Hooker K et al., 1998) and one meta-analysis (Pinquart M & Sorensen S, 2003b) show that carer effects differ depending on whether a carer looks after a patient with dementia or another condition. So, what *are* the health effects of caring for stroke patients' on their carers?

Carers of stroke victims are at particular risk due to the long-term nature of disability caused by stroke and the literature consistently shows that looking after someone who has had a stroke has a generally negative effect on health (Kinsella GJ & Duffy FD, 1979; Spackman A, 1991) which can be both physical and psychological (Fitzgerald G, 1989; McLean J et al., 1991; Reese DR et al., 1994; Young JB & Forster A, 1992). There is also some evidence to suggest that carers of stroke victims neglect their own health. In one study a significant number of carers reported a deterioration in health after one year of caring but there was not a corresponding increase in those receiving medical treatment (Brocklehurst JC et al., 1981).

2.5.2.1 Effects on physical health of caring for a stroke patient:

A few studies have looked at associations with carers' physical health but none employed a non-carer control group, so it is difficult to know to what extent carer health is affected by caring for a stroke patient and to what extent physical health deteriorates due to other factors such as age.

- Four studies used a self-rating of physical health. These studies had mixed results with two showing a positive association between carer self-rated poor health and depression (Hodgson SP, Wood VA, & Langton-Hewer R, 1996; King RB et al., 2001) and the other two showing no association (Draper BM, 1992; Silliman RA et al., 1987)
- One study used a combination of self-rating and physical symptom scores (Schulz R, Tompkins CA, & Rau MT, 1988; Tompkins CA, Schulz R, & Rau MT, 1988). It showed that the presence of an association between carer depression and physical health depended on the measure being used - there was a positive association between poor physical health and depression when measured in terms of physical symptoms, but no association when measured with a self-report measure
- One study used physical symptoms alone (Carnwath TCM & Johnson DAW, 1987). It showed a positive association between carer depression and number of physical symptoms

- One study looked at immunological function (Reese DR, Gross AM, Smalley DL, & Messer SC, 1994). It compared a group of carers of stroke patients against a group of non-carers and a group of carers of patients with Alzheimer's dementia and found no differences between the groups

2.5.2.2 Psychological effects of caring for stroke patients:

A high incidence of anxiety and depression amongst carers of stroke patients has been noted by many investigators (Evans RL et al., 1989; Wade DT, Legh-Smith J, & Langton-Hewer R, 1986). Most estimate the level of depression amongst people caring for stroke victims to be in the region of 40% (Carnwath TCM & Johnson DAW, 1987; Coughlan AK & Humphrey M, 1982; Draper BM, 1992; MacKay A & Nias BC, 1979; Stein PN et al., 1992; Williams AM, 1993) compared to a background level of depression of 8-15% for this age group (Beekman AT et al., 1995; Copeland JR et al., 1999; Livingstone G, Manela M, & Katona C, 1997; Osborn DP et al., 2002).

However most of the carer studies fail to distinguish between clinical (major) depression and sub-clinical mood disturbance, creating uncertainty in what has actually been measured. General population studies of this age group, show that 20-30% screen positive for mood disturbance (Beekman AT et al., 1995; Cooper JE et al., 1977; Livingston G et al., 2000; Osborn DP et al., 2002).

The factors predicting depression among informal carers of stroke patients, have been investigated but findings are contradictory and are set out in tables 2.3, 2.4 and 2.5 (pages 22-26). Although the literature consistently suggests carers of stroke patients in the community have elevated levels of depression, there is little consensus about the correlates of depression (table 2.5, page 26). The most consistent correlations are that:

- Carers with more physical symptoms themselves tend to be more depressed
- Carers who employ certain coping mechanisms (suppression, avoidance and/or venting) tend to be more depressed
- Carers with less social support tend to be more depressed
- Carers of stroke patients who are more dependent, have abnormal or disruptive behaviour or are depressed are more likely to be depressed themselves.

Table 2.3: Summary of cross-sectional studies of factors predicting carer depression

Study no.	Authors	Date *Number of carers*	Country *Time after stroke*	Control group?	Findings
1	Grant et al (2004a)	2004 *74*	USA 1-2 days prior to discharge	No	Negative orientation towards problem solving, lack of carer preparedness and impaired social functioning
2	Wyller et al (2003)	2003 *54*	Norway *1 year*	Yes – elderly non-carers	No association was found between the relatives' emotional well-being and any characteristics of the patient. A strong relationship was detected between carer strain and emotional distress.
3	Bakas and Buergner (2002)	2002 *104*	USA *Not stated*	No	Low carer self-esteem, high task difficulty, and high threat appraisal are predictors of emotional distress.
4	van den Heuvel et al (2001)	2001 *212*	Netherlands *3.5 years*	No	Cognitive, behavioural and emotional changes in the patient are the main risk factors for carer 'burnout'. Women, younger carers and carers in poor health are also risk groups. Carers with high perceived self-efficacy, satisfied with social support and using a confronting coping strategy experience better mental well-being
5	Grant et al (2000)	2000 *52*	USA *Pre-discharge*	No	Carer depression is best predicted by lower life satisfaction, lower physical functioning, and a lack of tangible social support
6	Scholte op Reimer et al (1998)	1998 *115*	Netherlands *3 years*	No	Carer strain is associated with emotional distress
7	McClenahan and Weinman (1998)	1998 *86*	UK *>11 months*	No	Stroke severity variables and dysphasia do not account for carer distress. A significant amount of the variance of carer distress is explained by carer factors: generalised self-efficacy, illness perception factor timeline and use of coping strategies (venting and suppression).
8	Segal and Schall (1996)	1996 *38*	USA *6 months*	No*	Carers' life satisfaction was directly related to carer burden which in turn was related to patients' level of physical handicap
9	Bethoux et al (1996)	1996 *9*	France *17.6 ± 10.6 months*	No	Significant relationship between patients' functional impairment and disability, and carers' global quality of life.
10	Anderson et al (1995)	1995 *84*	Australia *1 year*	No	No significant relationship between emotional illness among carers and the degree of patients' physical disability but abnormal behaviours of stroke patients were significantly related to carer distress.
11	Kinney et al (1995)	1995 *78*	UK *Average 14.7 months*	No	When caring satisfaction outweighs caring stresses, carers report lower levels of distress.

* Comparison made with general population data

Table 2.3 (Continued):
Summary of cross-sectional studies of factors predicting carer depression.

Study no.	**Authors**	**Date** ***Number of carers***	**Country** ***Time after stroke***	**Control group?**	**Findings**
12	Matson (1995)	1994 *36*	UK *> 6 months*	Yes – carers for dementia patients	Behavioural disturbances of the stroke patient are significantly associated with depression and stress. Dependency behaviours are not related to depression. Non-confronting coping (keeping busy, confiding in someone else) is associated with increased depression; tactical coping (attempting to meet and balance the needs of both patient and carer) is associated with less depression.
13	Purk and Richardson (1994)	1994 *44*	USA *6 months – 4 years*	No	Morale of carers and care receivers was positively correlated. Functional independence of patients predicted patient and spouse morale levels. Impression of caring and morale of carers was positively correlated.
14	Stein et al (1992)	1992 *41*	USA *Not stated*	No	Depression is not related to gender, age or level of stroke survivor dependency
15	Draper et al (1992)	1992 *48*	Australia> *6 months*	Yes – carers for dementia patients	Psychological morbidity is associated with carer burden.
16	Macnamara et al (1990)	1990 *41*	USA *Average 14.63 months*	No	Carer anxiety increased with caring duration but carer depression was not related to caring duration.
17	Thompson et al (1989)	1989 *40*	UK *Average 9 months*	No	Carers' depression was not related to patients' depression and motivation.
18	Evans et al (1989)	1989 *80*	USA *13.8 ± 5.2 months*	No	Higher carer anxiety was associated with increased patient confusion and anxiety and with decreased patient depression and overall adjustment.
19	Ross et al (1988)	1988 *20*	USA *Not stated*	No	Level of depression in spouses was only significantly associated with problems of dependency.
20	Carnwath and Johnson (1987)	1987 *103*	UK *1-3 years*	Yes – matched community sample of non-carers	Level of depression is proportionate to level of disability and increases with time.
21	Silliman et al (1987)	1986 *89*	USA *11.1 (range 6-19) months*	No	Level of psychiatric distress is dependent on patient's functional status and the presence of additional life stresses.

Table 2.4: Summary of longitudinal studies of factors predicting carer depression

Study no.	Authors	Date *Number of carers*	Country *Time after stroke*	Control group?	Findings
22	van Puymbroeck & Rittman (2005)	2005 *127*	USA • *1 month* • *6 months*	No	Depression and quality of life is determined by ability of caregivers to mobilize their coping resources during periods of stress , functional status of the stroke patient and relationship of the carer to the stroke patient.
23	Visser-Meily et al (2005a)	2005 *187*	Netherlands • *At the start of rehab-ilitation* • *1 year*	No	Passive coping strategy of the carers predicted depression and life satisfaction. Level of handicap of the carer explained a small proportion of the variance in life satisfaction but not depression
24	Grant et al (2004b)	2004 *52*	USA • *1-2 days prior to discharge* • *5 weeks post-discharge* • *9 weeks* • *13 weeks*	No	Ethnicity (Caucasian four times more than African American), and burden predict depression. Increase in social belonging is protective.
25	King et al (2002)§	2002 *53*	USA • *In hospital* • *After 6 – 10 weeks at home* • *1 year* • *2 years*	No	Significant predictors of greater levels of depressive symptoms were lower levels of total support, finding meaning, avoidance coping and lower levels of family functioning and belonging support.
26	King et al (2001)§	2001 *136*	USA • *In hospital* • *After 6 – 10 weeks at home*	No	Depression at time of discharge, poor health, family functioning, and avoidance coping were the strongest of seven predictors of depression.
27	Dennis et al (1998)	1998 *246*	UK • *< 30 days* • *6months*	No	Carers were more likely to be depressed if the patients were severely dependent or emotionally distressed themselves. Female carers reported more anxiety than male carers. Carers suffered more emotional distress if the patients had been dependent before their strokes.
28	Kotila et al (1998)	1998 *125*	Finland • *3 months* • *12 months*	No	Level of handicap was related to carer depression 3 months after stroke. At 1 year after stroke, provision of an active stroke support programme reduced depression.

Notes:

§ Results from the same study published separately

Table 2.4 (Continued):
Summary of longitudinal studies of factors predicting carer depression.

Study no.	Authors	Date *Number of carers*	Country *Time after stroke*	Control group?	Findings
29	Nieboer et al (1998)	1998 *32*	Netherlands • *18 months prior to stroke* • *3 months* • *12 months*	Yes**	Increase in caring demands resulted in increased depression. Activity restriction was linked to depressive symptoms.
30	Hodgson et al (1996)	1996 *50*	UK • *3 months* • *12 months*	No	Carer's age, gender and caring responsibilities were not related to well-being 1 year post stroke. Well-being was associated with carer's physical health, appraisal of caring stress and satisfaction with service provision.
31	Schulz et al (1988)✝	1988 *162*	USA • *6.7 weeks (range 3-10 weeks)* • *7-9 months*	No	Prevalence of depressive symptoms was 2.5 – 3.5 times higher than in comparable populations of non-carers. Mean level of depression did not change over time, although level of optimism declined. Levels of depression were related to severity of stroke early after stroke. 7-9 months after stroke, health, income, and age were significant predictors of depression. Individuals who were older and who had good health and higher incomes were least depressed.
32	Tompkins et al (1988)✝	1988 *162*	USA • *6.7 weeks (range 3-10 weeks)* • *7-9 months* • *13-15 months*	No	Depression 6 months and 1 year after stroke can be predicted by depression in the early phase after stroke, reduced optimism about the future, concerns about future care, spouses, lower levels of social support. Additionally depression at 6 months could be predicted by low income and low satisfaction with social support.
33	Wade et al (1986)	1986 *302*	UK • *3 months* • *6 months* • *1 year* • *2 years*	No	Depression was dependent on the level of disability at one year post stroke but not at two years
34	Brocklehurst et al (1981)	1981 *97*	UK • *4-6 weeks* • *1 year*	No	Depression was not related to level of disability of the stroke patient. Carer's personality and relationship with the stroke patient were important factors.

Notes:

** Comparison group of non-carers from the original cohort of elderly people and comparison groups of carers for patients with hip fracture, congestive heart failure and myocardial infarction

✝ Results from the same study published separately

Table 2.5: Overview of findings of 34 studies investigating associations with depression amongst carers of stroke patients in the community.

Factors	Carer depression (number of studies)		
	Positive association	**Negative association**	**No association found**
Carer demographics			
Older age	0	1[4]	6[14-16,19,30,31]
Ethnicity (Caucasian > other)	1[24]	0	0
Higher income	0	1[31]	1[19]
Longer duration of caring	0	0	4[15,16,19,28]
Gender (M>F)	2[4,27]	0	3[14,22,30]
Relationship with patient	5[22,26,31,32,34]	0	0
Carer psychosocial factors			
Carer strain	8[2,6,8,15,22,24,29,30]	0	0
Carer self-esteem	0	1[3]	0
More concern for future care	3[3,31,32]	0	0
Less social support	7[1,4,24-26,31,32]	0	0
Carer physical health			
Poor self-rated health	3[4,26,30]	0	4[15,21,31,32]
More physical symptoms	3[20,31,32]	0	0
Stroke patient symptoms			
More physical disability / dependency	12[4,5,9,19-23, 27,28,31,33]	0	6[7,10,12,14,16,33]
More depression / demoralisation	5[13,15,20,27,33]	0	1[17]
Poor cognitive function	1[11]	0	2[10,33]
More abnormal behaviour	4[10-12,15]	0	0
Other factors			
Carer coping mechanisms	4[1, 12, 22,23]	5[4,7,12,25,26]	0
Carer self-efficacy	0	1[4]	0
Task difficulty	1[4]	0	0
Carer life satisfaction	0	1[5]	0
Good formal community support	0	2[28,30]	0
Activity restriction	1[29]	0	0
Preparedness	0	1[1]	0

Red suffixes are the numbers corresponding to study numbers in tables 2.3 and 2.4

Study	**Definition of "a carer"**
Dennis M et al, 1998 *Tompkins CA et al,1988*	Someone identified by the stroke patient as such
Carnwath and Johnson, 1987 *van Puymbroeck & Rittman (2005)*	Spouse of the stroke patient
Wade DT et al, 1986	A person living with the stroke patient
Scholte op Reimer W et al, 1998	Partner of the stroke patient
Brocklehurst, 1980	Person most totally involved in looking after the patient
Evans RL et al, 1989	A "significant other"
Anderson CS et al, 1995	Someone caring for the disabled patient
Hodgson SP et al, 1996	Primary Person providing physical, social and emotional support to the patient following stroke

Table 2.6: Definitions used for the term "carer" in different studies

Level of disability, adaptation to residual disability and coping strategies of carers change with time (Kelly-Hayes M, 1990; Schulz R, Tompkins CA, & Rau MT, 1988; Spencer K, Tompkins CA, & Schulz R, 1997), so one might predict depression levels would also vary with time after stroke. However many studies identified did not measure time after stroke at all (Carnwath TCM & Johnson DAW, 1987; Draper BM, 1992; Purk JK & Richardson RA, 1994). Those that did found overall depression levels were fairly constant but predictors of depression changed over time (Kotila M et al., 1998; Tompkins CA, Schulz R, & Rau MT, 1988; Wade DT, Legh-Smith J, & Langton-Hewer R, 1986). In each study the predictors were different and ranged from level of disability influencing early depression rates to presence of stroke support services protecting against later depression.

Caring for a stroke patient is not all bad and there are many positive aspects of care which carers identify but the influence of these is not clear. One study suggested depression occurs when the positive effects of caring are outweighed by the negative effects (Kinney JM et al., 1995). This sounds logical and warrants further investigation.

The influence of effects of stroke which might be more difficult to cope with - such as incontinence or dysphasia, is also not well studied. One study did look specifically at carers of patients with dysphasia however it was a very small scale (20 patients) cross sectional study with no control group (Ross S & Morris RG, 1988).

2.5.3 Problems with studies of carer health:

Methodological concerns about many of the studies looking at the health of carers of stroke patients make comparison between studies and synthesis into a coherent picture which applies to all carers of stroke patients challenging.

2.5.3.1 Definition of informal carer:

First, and perhaps most important, is a lack of a definition of a carer. Some of the studies listed do not give any definition of carer so it is not clear who the carers are (Draper BM, 1992; Matson N, 1995; McClenahan R & Weinman J, 1998). When the definitions in those studies that do give a definition are compared, it is clear how different the groups termed "carers" can be – table 2.6, page 26.

2.5.3.2 Lack of control groups:

Only five of the 34 studies found included a control group (17% - see tables 2.3 and 2.4, pages 22-25) – though one further study did include comparison with the general population norm (Segal ME & Schall RR, 1996). Of that five, only three had a control group of non-carers – the other two compared carers of stroke patients to carers of patients with Alzheimer's disease. It is necessary to compare carers and non-carers in order to differentiate unique stroke caring impacts. Without inclusion of non-carers it is not possible to define the extent of carer outcomes beyond those found in the general population (Reese DR et al., 1994).

2.5.3.3 Generalisability:

The groups studied varied enormously (table 2.7). Many of the variables (such as relationship to the stroke patient, gender, or age) may have had an impact on outcome (see table 2.5, page 26). Generalisation to other community populations and comparison across studies is therefore difficult.

2.5.3.4 Cross sectional studies:

Most of the studies listed (19 out of 29 – 66% - table 2.3, pages 22 - 23) are cross sectional. These studies can only explore associations between outcome measures and other factors thought likely to influence outcome. They cannot establish temporal relationship between factors and outcome. Therefore it is not clear whether a stroke patient with depression is a cause of a carer becoming depressed; the result of being

Table 2.7: Variation in groups of carers by selection criteria

Selection criteria	**Studies**
Place of recruitment	Community generated sample: 20,29,34 Admissions to hospitals or rehabilitation centres: 1,6,15,22-27,31,32 Outpatient departments, veterans groups or community services: 12,18 Patients in residential care excluded: 6,21,30,33
Gender	Female only: 18
Relationship with stroke patient:	Spouse only: 9,13,14 Co-habitant only: 21,33
Characteristics of the stroke patient:	First time stroke: 28,30,31,32 Older stroke patient only: 11,15,21 Co-existent conditions: 10

Red numbers correspond to study numbers in tables 2.3 and 2.4

cared for by a depressed carer; or whether there might be another factor leading to both (see pages 43 and 44 for further discussion of this point).

2.5.3.5 Measurement tools:

Measurement instruments used in these studies are very diverse and some commentators have raised concerns about their validity and reliability amongst this group (Spencer K, Tompkins CA, & Schulz R, 1997; Toedter LJ et al., 1995). In the studies listed in tables 2.3 and 2.4, 23 different measures of psychological distress alone are used (table 2.8). It is by no means clear whether or how these different measures relate to each other.

Table 2.8: Depression and life satisfaction measures used to measure carer psychological health in studies of factors predicting poor psychological health amongst carers of stroke patients

Measure	**Number of studies**
Pre-validated questionnaires:	
General Health Questionnaire	7[2,7,10,15,19,27]
Centre for epidemiologic studies depression scale	7[1,5,24-26, 31,32]
Beck depression inventory	3[12,14,28]
Hospital anxiety and depression scale	3[10,27,29]
Index of psychological well-being	2[31,32]
Level of optimism scale	2[31,32]
Life satisfaction index – Z	2[5,8]
Life satisfaction questionnaire	2[15,23]
SF-36 (mental well-being and vitality)	1[4]
Geriatric Depression Scale	1[22]
Goldberg depression scale	1[23]
COOP charts	1[6]
General Well-Being Index	1[30]
Loneliness questionnaire	1[6]
Montgomery and Asberg depression rating scale	1[9]
Philadelphia geriatric center morale scale	1[13]
Psychiatric assessment schedule	1[20]
State trait anxiety inventory	1[18]
Symptom rating test	1[12]
Wakefield self-assessment depression inventory	1[33]
Other measures:	
Use of antidepressants and tranquillisers	1[34]
Self-reported stress	1[34]
Non-standard questionnaire	1[19]

Red suffixes are the numbers corresponding to study numbers in tables 2.3 and 2.4

2.6: Community support of carers

2.6.1 Carers' views:

2.6.1.1 Qualitative work:

Qualitative work has focussed on interviewing carers to explore their views on what they want and need from the primary care services. A review of 23 qualitative studies (Murray J et al., 2003), which included approximately 500 patients and 180 carers, identified 203 problem areas, which were categorised into five domains: hospital experience; transfer of care; communication; services; and social and emotional consequences. The largest domain was the social and emotional consequences of stroke, representing 39% of all problem areas. These included problems relating to mood, social changes, attitudes to recovery, and changes in self-perception and relationships. Service deficiency, encompassing both health and social care, was the second largest domain, accounting for 29% of the problem areas.

Two studies in Scotland exploring the wants and needs of carers of stroke patients in the first year after stroke (Kerr SM & Smith LN, 2001 and Smith LN et al, 2004) identified several areas that carers felt the support services should address: physical preparation of carers for their caring role; emotional support; supply of information and advice; and provision of appropriate services (both social and health service provision). Data suggested that the physical and emotional toll associated with caring was great. Unfortunately, the help and support provided by the health and social services was often inadequate, inappropriate and poorly tailored to their individual needs. There was little evidence of a seamless flow of care between the secondary and primary care settings.

These findings are remarkably similar to our own qualitative work and pilot work done with carers between 2000 and 2001 (Simon C, 2003; Simon C & Kumar S, 2002). The findings are also very similar to a study done ten years previously in Birmingham (McLean J et al., 1991) suggesting that, despite community care reforms, in the interim, very little has changed.

2.6.1.2 Quantitative work:

Early quantitative work focussed on which services were provided to which stroke patients at various intervals after stroke (Ebrahim S & Nouri F, 1987; Greveson G, 1991; Legh-Smith J, Wade DT, & Langton-Hewer R, 1986; McLean J, Roper-Hall A, Mayer P, & Main A, 1991). These studies give a useful impression of the services available and service use though most were undertaken before community care reforms took place.

More recent quantitative work has been concerned with evaluation of specific interventions to support carers. Trials of specific interventions for use within primary care are numerous and varied, ranging from multimedia information provision (Hanson EJ, Tetley J, & Clarke A, 1999), through carer education (Grant JS et al., 2002) to specialist supporters or group support for patients and carers (Dennis M et al., 1997; Forster A & Young J, 1996; Lincoln NB et al., 2003; Mant J et al., 2000; van den Heuvel ET et al., 2002, Robinson L et al., 2005).

Unfortunately due to the variety of definitions of carer used and outcome measures employed, drawing comparison between studies can only be done with caution (Forster A et al., 2001; Thompson C & Briggs M, 2000). Moreover, many studies are statistically underpowered (Thompson C & Briggs M, 2000) and tend to lack adequate comparison groups (Han B & Haley WE, 1999), preventing conclusions being drawn. A systematic review of intervention studies to support carers of stroke patients was done in 2005 (Visser-Meily A., et al., 2005b). The authors concluded that no firm guidance could be given due to the reasons outlined here, but that counselling programmes appear to have the most positive outcomes.

2.6.2 Views of community and primary care supporters:

Studies of the views of GPs and other primary care team members reveal some of the problems that result in carers not getting the community support they want. Our own survey of 300 GPs and 280 District Nurses showed that most see themselves only in a reactive role - responding to problems as and when they occur (Simon C & Kendrick T, 2001; Simon C, Kumar S, & Kendrick T, 2002). Both groups considered they had insufficient time, resources and training to fulfil a more pro-active role and that other groups were better suited to the demands of that role. Our related qualitative study of the views of district nurses (Simon C, Kumar S, & Kendrick T, 2002) showed they felt they only had limited access to carers as they are often not directly their responsibility. Although they were sympathetic to carers' needs, they felt they did not have the time, resources or training to help carers unless a problem was specifically brought to them.

Qualitative research (Twigg J & Atkin K, 1994) with GPs suggests they naturally fall into one of three groups:

- Those that attempt to help carers – a small minority who actively try to provide carer support
- Those who are vaguely aware of carer issues and embarrassed that they are not doing more, but whose response to carers is ad hoc and arbitrary. This is the majority of GPs. Carers need to be in the right place at the right time to receive support. These GPs will not go out of their way to provide help or to seek help from sources they are unfamiliar with.
- Those for whom the issue of informal care is largely irrelevant – carers have no place in their frame of reference. Carers are unlikely to get any help from these GPs. GPs in this group do not feel that they are failing in their responsibilities towards carers as they do not have any.

Twigg and Atkin (1994) conclude that much of this is due to the biomedical stance of the GP and the lack of training GPs have received about social issues. GPs may either ignore or marginalise carers and their problems, or draw on personal experience and common sense to deal with the problems carers might face.

Twigg and Atkin (1994) used focus groups of GPs to obtain their data. This has some disadvantages. Firstly, GPs are busy people and recruiting GPs to take part in focus groups is a difficult task. It might be that those willing to take part are a self-selecting group not representative of the general population of GPs. Secondly, even those participating may not have given their own views due to worries about the image they might portray to fellow participants.

However, the results are remarkably consistent with those obtained from our own one in three sample of GPs in East and West Sussex surveyed about their attitudes and policies towards carers (Simon C & Kendrick T, 2001), which suggested that, despite changes in health and social care provision (Department of Health, 1990; Department of Health, 1996), emphasis about the care of informal carers (Department of Health, 1998; Department of Health, 2001; HM Government, 1999a; HM Government, 2000a) and guideline provision (Carers' National Association, 1998; Royal College of Physicians 2000), this view has remained remarkably static over time.

In our study, comments made on the questionnaire forms could largely be classified into the same three groups as those defined by Twigg and Atkin (1994). It could be argued that the 71% who returned the questionnaires were also self-selecting, but this is a much larger proportion of available GPs. For both studies though, there is a further drawback. GPs, worried about increasing workload (Boseley S, 2003; Butler P, 2001), might have given a politicized opinion designed to inform policy making decisions.

2.6.3 Effects of community support:

Although there has been an assumption in the literature that formal support from the primary care team is a mediator of the stress process and should improve outcome in terms of health of the carer, there has been little work done in this field. Carers' use of and satisfaction with primary care team has been investigated, but only two studies have made a link with outcome. One large study in Finland (Kotila M et al., 1998) showed that regions employing a specialist rehabilitation and support programme for their stroke patients in the community had lower levels of carer depression than those regions without such support programmes. However this was not a randomized controlled trial and other factors, such as locality, might account for these results.

However, a second small scale study in the UK (Hodgson SP, Wood VA, & Langton-Hewer R, 1996) has also made a link between satisfaction with carer community support and outcome. Patients admitted to a single secondary care centre with a history of first stroke were identified from patients' notes. Over an 11 month period 170 admissions due to stroke were identified of which 81 met the study criteria – living locally, discharged home after first stroke and having an identifiable carer. Sixty-six patients and carers agreed to participate in the study but 16 were subsequently lost to follow up. Reasons for loss to follow up were documented for all but two of the patient-carer dyads.

The main outcome measure was the carer's psychological well-being as measured using the General Well-Being Index (Hunt SM & McKenna SP, 1992). This measure has been specifically adapted from a well-used American measure for use with a British population. It consists of 22 questions, each scoring between one and five, with a high score indicating poor well-being and a low-score indicating good well-being.

The aim of the study was to identify factors which might predict poor well-being at one year post stroke. In order to do this patients and carers were assessed for a variety of factors which it was thought might influence outcome, in terms of general well-being, at one year post stroke. These factors included patient variables such as functional ability, memory, cognitive ability and depression, and carer variables such as physical health, perception of loss, family functioning, level of activity, environment, formal support and stress. Assessments were undertaken in the carers' and patients' homes at three, six and twelve months post stroke.

In order to assess the relationship between the hypothesized predictors and the outcome variable, a series of regression analyses were used. There is no record of any sample size calculation being done before the study commenced. The regression analysis identified three significant predictors of carers' well-being: carers' appraisal of caring stress; carers' physical health; and carers' satisfaction with service provision.

However, there were some problems with this study. First, this was a sample of carers from a single secondary care centre. It is not clear how representative of carers of stroke patients in the community this group is, and therefore how generalisable these findings are. Secondly, although well-validated measures were used to assess physical and cognitive abilities of and depression amongst the stroke patients, the measures used for the carers were not so robust. In fact the three significant predictors of carers' well-being were all quantified using unvalidated scales. Stress appraisal was measured using structured questions; carers' physical health was measured on a health index devised specifically for this study but no reliability or validity data was presented; and, satisfaction was measured with a single item global satisfaction question (Are you satisfied with the support you receive from formal services? Yes=0; No=1). Single item global satisfaction measures are difficult to interpret and will be discussed later (page 37). A further study using a larger, more varied population, assessed with better validated tools, is required before satisfaction with formal support services can be considered to be protective against depression in carers of stroke patients.

The caring literature in other groups, such as carers of victims of dementia or carers of the elderly, is fuller but gives a contradictory picture showing in some studies that level of care and satisfaction with care is linked with outcome and in others that it is not (Gilhooly MLM, 1984; Morris RG, Morris LW, & Britton PG, 1988; Stoller EP & Puglieski KL, 1989; Yates ME, Tennstedt S, & Chang B-H, 1999).

2.6.4 The role of consumer satisfaction:

While the prime focus of research is often the stroke survivor, not only the patient but also the carer is a service consumer. Two studies done in the early 1990's (Greveson G, 1991; Pound P, 1993) suggest significant carer dissatisfaction with services provided. These and other studies suggest that, not only were support services insufficient, but there was a lack of awareness of community services which caused carers problems (Anderson R ,1988; Geddes JML & Chamberlain MA, 1994; Greveson G, 1991; Hanger HC & Mulley GP, 1993; Silliman RA et al., 1987; Wolfe CDA et al., 1993; Woodhouse L &

Muller DJ, 1987). However, since these studies considerable reforms to community care provision have taken place.

2.6.4.1 What does carer satisfaction really mean?

For Hodgson's study (Hodgson SP, Wood VA, & Langton-Hewer R,1996) satisfaction was gauged by a single question "Are you satisfied with the support you receive from formal services". Responding carers were given the option of responding "yes" or "no".

Satisfaction is defined in the dictionary as "giving (a person) what he wants or demands or needs, to make pleased or contented; to demand no more than this, to consider that this is enough"(Oxford Paperback Dictionary, 1983). In the context of medical care, Ware et al. (1983) made the distinction between objective satisfaction i.e. reports about providers and care (e.g. waiting times for appointments), and satisfaction ratings which "attempt to capture a personal evaluation of care that cannot be known by observing care directly". It was the latter which Hodgson et al (1996) were attempting to capture. Thus satisfaction is an expression of an attitude based on the belief that care should possess certain attributes and the carer's evaluation of those attributes. It represents a synthesis between support provision and need from the perspective of the carer or, in other words, it is a measure of how the support provided is functioning in the real world.

2.6.4.2 Is satisfaction the right measure?

The importance of using the patient's point of view as a measure of quality of care is well established (Department of Health, 2003c; Harris LE, Swindle RW, & Mungai SM, 1999; Secretary of State for Health, 1998). For a chronic illness such as stroke, where carers play such a pivotal role, it would seem reasonable to seek a measure of the carer's point of view to assess quality of care.

2.6.4.3 Problems in measurement of satisfaction:

A common factor in many patient satisfaction surveys is that very few patients express dissatisfaction or are critical of their care (Abramowitz S, Cole AA, & Berry E, 1987; Hopton JL, Howie JGR, & Porter MD, 1993). In UK general practice, overall satisfaction rates of over 90% have been consistently reported over the last 30 years (Cartwright A, 1964; Khayat K & Salter B, 2001; Royal Commission on the National Health Service, 1979; Williams SJ & Calnan M, 1991).

As a result there is a tendency for satisfaction scores to respond poorly to change with researchers resorting to comparison of positive with more or less positive results. A way around this problem is the "discrepancy model"(Carr-Hill RA, 1992; Fox JG & Storms DM, 1981;Williams B, 1994). This shifts the focus to concentrating on areas of expressed dissatisfaction.

Most satisfaction studies, including those in the caring literature (Hodgson SP, Wood VA, & Langton-Hewer R, 1996), use single item global satisfaction questions (*How satisfied are you with care provided?)* to gauge satisfaction levels. However there is evidence that questions of a detailed and more specific nature reveal greater levels of dissatisfaction (Williams SJ & Calnan M, 1991) and there is considerable dissatisfaction regarding specific aspects of care such as communication and information provision (Williams SJ & Calnan M, 1991).

There has also been some concern that satisfaction levels reflect characteristics of the people interviewed and not the care provided. In other words a depressed carer might be expected to be less satisfied with care provided than a happy one. For this reason there is some debate about the meaning of satisfaction scores as outcome measures in healthcare settings (Lunnen KM & Ogles BM, 1997).

However, in the context of stroke care there is evidence with stroke patients that satisfaction is an independent outcome that does reflect real differences in provision of care and is independent of any associations with patient characteristics (Pound P et al., 1999). There has been no work done in this field with carers of stroke patients.

Another problem with measurement of satisfaction data is the validity and reliability of those measures. Sitzia (1999) examined 195 papers using satisfaction measures published in 1994 in 139 journals. He found that, with few exceptions, the instruments used for satisfaction rating demonstrated little evidence of reliability or validity with less than half reporting any validity or reliability data at all. For results of satisfaction studies to be credible, instruments with proven validity and reliability must be used.

2.7: Summary of the literature review

The theoretical basis underpinning much of the carer literature is the stress-coping theory (Lazarus RS & Folkman S, 1984) and variations upon it. Caring tasks are many and widespread and depend on factors relating to the person being cared for, the carer and the environment.

There is a general consensus that care giving, including care of stroke patients, has effects on the carer. Although the literature is hampered by methodological problems, care giving appears to have a marked effect on informal carer health with psychological health being affected more than physical health. Factors predicting which carers develop health problems are inconsistent between studies. Carers are also placed under considerable stress or strain though what this actually means is unclear.

As care giving occurs in the community and carers develop health problems, support from formal community support agencies might be expected to help. Community support of carers is less investigated but service deficiency, encompassing both health and social care, is a problem area which has been identified repeatedly. This is probably due to a combination of practical limitations such as inadequate funding, inadequate time and human resources, and attitudinal problems i.e. that it is someone else's job. This is compounded by the fact that there is very little evidence that formal support of carers affects outcome.

Two studies were identified which linked formal support to outcome. In one (Hodgson SP, Wood VA, & Langton-Hewer R, 1996), satisfaction with formal community support of informal carers resulted in better carer general well-being. Although this study was restricted to a single unit, had a small sample size and used an unvalidated measure of satisfaction, its findings are interesting and prompted a further look at the use of satisfaction (reflecting a synthesis between support provision and need from the perspective of the carer) as a measure to explore carer community support provision.

2.8: Conclusion

As a result of the literature review the project was focussed further to clarify:

1. What effect looking after a stroke patient at home has on the informal carer
2. What community support is currently provided
3. Whether the support provided meets the perceived needs of the carers
4. Whether satisfaction with support is related to carer health outcomes

The literature review also showed that a longitudinal approach would be needed to clarify cause and effect, well validated measures should be used wherever possible and a comparison group of non-carers should be employed in order to asses whether any changes seen were as a result of the caring role.

Chapter 3: Choice of study design

'Any given design is necessarily an interplay of measures, practicalities, methodological choices, creativity and personal judgement by the people involved' Patton, 1987

3.1: Aims of the project

The specific aims for this project were:

1. To investigate health and social effects of caring on informal carers of stroke patients in the community at different points in time after the stroke.
2. To investigate the relationship between health and satisfaction with care – where satisfaction is defined as the degree to which care received meets the wants and needs of the carer.
3. To investigate the relationship between satisfaction with care and level of service input.

3.2: Study design

Support of carers of stroke patients in the community is a "complex intervention" (MRC Health Services and Public Health Research Board, 2000). Complex interventions in healthcare comprise a number of separate elements which seem essential to the proper functioning of the intervention, though the "active ingredients" of the intervention that are effective are difficult to specify. Evaluation of complex interventions is difficult as they are built up of a number of different components which may act both independently and inter-dependently. The components usually include behaviours, parameters of behaviours (e.g. frequency, timing) and methods of organising and delivering those behaviours (e.g. types of practitioner, settings and locations).

A good example in stroke care is that of stroke units. Research evidence suggests stroke units work (Stroke Unit Trialists' Collaboration, 1997; Stroke Unit Trialists' Collaboration, 2002) but what exactly is a stroke unit? What are the active ingredients? Is it the skill mix or available technologies or even the organisational set up?

3.2.1 Feasibility of doing a randomized controlled trial:

The randomized controlled trial is the optimal study design to minimise bias and provide the best estimate of benefits of a complex intervention. However it is important that, before embarking on a randomised controlled trial, the vital elements of the intervention have been identified and the way in which those interventions will be used has been specified.

The literature review and our own previous work (Simon C, 2003; Simon C & Kumar S, 2002) had shown that informal carers of stroke patients living in the community were at risk of developing both physical and psychological health problems. There was evidence to show that satisfaction was a measure which reflected real differences in care and not just patient or carer characteristics, and one small study which suggested that increased satisfaction was related to better outcome in terms of carer health.

The Medical Research Council (MRC) recommends a stepwise approach to the investigation of complex interventions (MRC Health Services and Public Health Research Board, 2000) – see figure 3.1 (page 42). As a result of the literature review it was clear there was insufficient information about what care was provided currently to carers of stroke patients in the community and how this related to satisfaction and in turn to outcome to be able to define the complex intervention. A randomized controlled trial, while feasible, at this stage was not ideal in the absence of such information.

"Modelling is concerned with unravelling and distinguishing the key components of a complex intervention" (MRC Health Services and Public Health Research Board, 2000). This process can be paper-based, involve computer simulations and/or involve small-scale studies aimed at gathering more information about the relationship of elements of the intervention to outcome. This was the stage reached in the process of exploring the complex intervention of community support of informal carers of stroke patients.

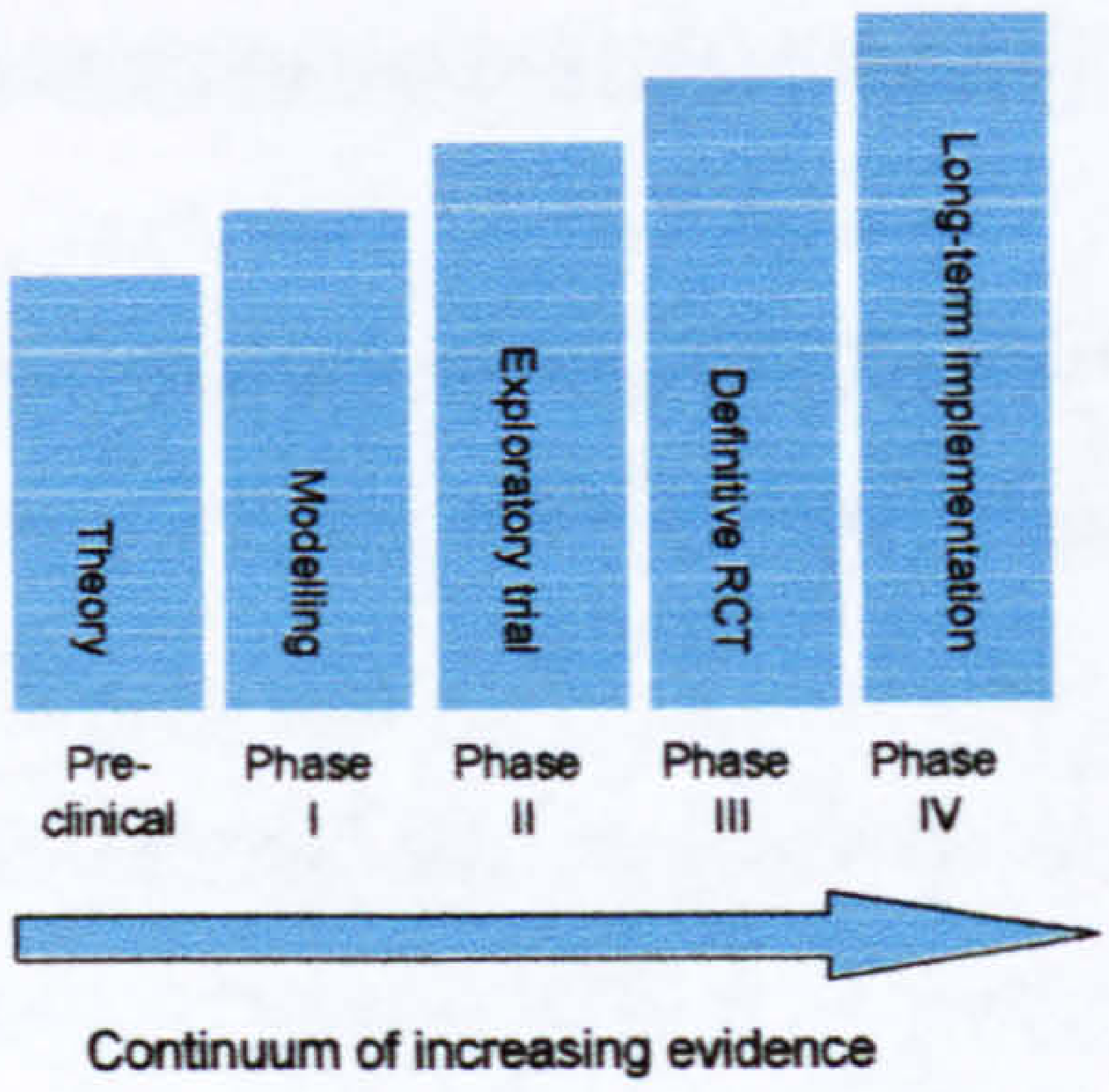


Figure 3.1: Step-wise investigation of complex interventions

Modelling aims to define the intervention – that is standardise the content –and delivery of the intervention by determining the critical components of the intervention and how they relate to and impact on each other. The critical components of the intervention had already been explored during our qualitative work for questionnaire development and the literature review. The next stage was to explore how they related to and impacted on each other. To do this an analytic study design was needed. There are two major types of analytic study design – the cohort study and the case-control study.

3.2.2 The feasibility of a case-control study:

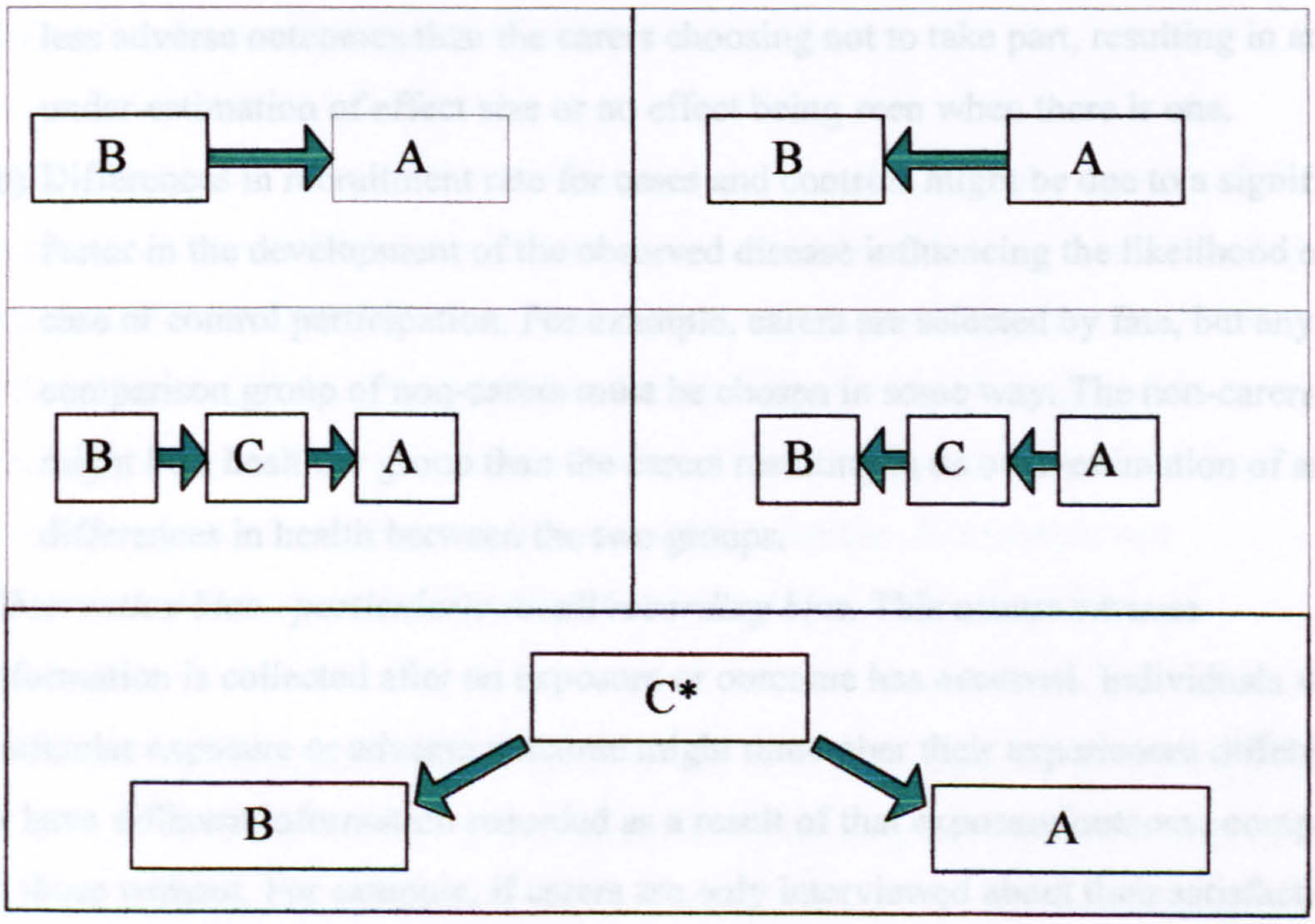
A case-control (or cross-sectional) study is a type of observational analytic investigation in which subjects are selected on the basis of whether they do (cases) or do not (controls) have the condition under study (Hennekens CH & Buring JE, 1987). The groups are then compared with respect to the proportion having a history of exposure or characteristic of interest.

Case control studies have been used extensively to investigate the effects of becoming a carer (see table 2.3, pages 22 and 23). A group of carers is identified and physical and mental health measures performed. In that way the proportion with depression (or any other measure used) can be determined and individuals with and without depression identified. The investigators then look at carer / patient characteristics and backwards in time to assess exposure to potential risk factors to identify associations between outcome (in this case depression) and characteristics / exposure.

The advantage of this type of study in this situation is that it is cheap and relatively quick to perform. However there are several major problems with this study design:

1) *Both exposure and disease have already occurred at the time the participants enter the study.* This means that the relationship between cause and effect cannot be determined. Associations between the outcome measure (in this case depression) and patient/carer characteristics or previous exposures can be made but there is no evidence of causality (see figure 3.2).
2) *Confounding.* Confounding occurs when an observed association (or lack of one) is a mixing of effects between the exposure/characteristic, the outcome and a third factor associated with the exposure and independently associated with the outcome (see figure 3.2). Confounding can lead to either the observation of apparent differences

Figure 3.2: Mechanisms by which outcome A can be associated with factor B (where C is an unknown factor)



**In this case C is a confounding factor* between study groups when they do not exist or, conversely, the observation of no differences when they do exist. For example, if satisfaction with community services and carer well-being were measured, and it was found that satisfaction with formal support was associated with better carer well-being, that could be because better formal support led to more carer well-being or because there was a third factor involved. For example, carer depression might influence both of these factors and result in both dissatisfaction with formal support services and poor general well-being.

3) *Selection bias.* Selection bias occurs when the way in which participants are selected into the study differs for cases and controls (Hennekens CH & Buring JE, 1987). There are several ways in which this can occur.
    (a) The relationship between the exposure and disease observed amongst those who participate in the study might be different from that for individuals who are eligible for the study but have been unwilling to participate, or those who are not selected by the investigator. For example, carers who agree to participate in a study might be those who are more motivated and less likely to have adverse health outcomes. Compared to a comparison group of non-carers, they may have less adverse outcomes than the carers choosing not to take part, resulting in an under-estimation of effect size or no effect being seen when there is one.
    (b) Differences in recruitment rate for cases and controls might be due to a significant factor in the development of the observed disease influencing the likelihood of case or control participation. For example, carers are selected by fate, but any comparison group of non-carers must be chosen in some way. The non-carers might be a healthier group than the carers resulting in an over-estimation of any differences in health between the two groups.
4) *Observation bias - particularly recall/recording bias.* This occurs because information is collected after an exposure or outcome has occurred. Individuals with a particular exposure or adverse outcome might remember their experiences differently or have different information recorded as a result of that exposure/outcome compared to those without. For example, if carers are only interviewed about their satisfaction with formal support a year after stroke, those carers for whom the care giving

situation has broken down where the stroke patient has been admitted to residential care, might consider the formal support services were inadequate when in reality no more could have been done to prevent that adverse outcome.

The primary aim of this study was to investigate health and social effects of caring for a stroke patient at home, and how community support affects those outcomes. This involves not just demonstrating an association between outcome and exposure but establishing a temporal relationship. A case-control study was not a suitable choice of tool for doing this.

3.2.3 Feasibility of a cohort study:

An alternative study design is the cohort study. A cohort is a group of people who have something in common when they are first assembled and who are then observed for a period of time to see what happens to them. The cohort is thus defined on the basis of presence or absence of exposure to a situation that is a suspected risk factor for a disease. In this study the exposure would be becoming a carer of a stroke patient and the disease depression and/or decrease in physical and/or social health. Other names for cohort studies are longitudinal, prospective or follow-up studies.

Cohort studies can be prospective or retrospective depending on the temporal relationship between the initiation of the study and the occurrence of the disease (Hennekens CH & Buring JE, 1987). In retrospective studies both the exposures and outcomes of interest have already occurred. In a prospective cohort the exposure may or may not have occurred when the study begins but the outcomes have not yet happened. Participants are followed into the future to assess incidence rates of disease. Advantages and disadvantages of cohort studies are listed in table 3.1 (page 46).

A prospective cohort study seemed a good choice of study design. Stroke is a condition which has a definite point of onset and therefore, by limiting the study to first time stroke patients and their carers, it would be easy to identify carers who had been carers for different durations. Incidence of disease compared to a matched population of non-carers

Table 3.1: Advantages and Disadvantages of Cohort Studies

Advantages	Disadvantages
▪ Can measure incidence of disease directly ▪ Can be used to assess the effects of rare exposures as cohort is defined by exposure ▪ Can evaluate the relationship between exposure and disease ▪ Allows for the examination of multiple effects of a single exposure ▪ Minimises the potential for selection bias	▪ Inefficient because many more subjects are recruited than will develop the disease. ▪ Cannot be used if the disease is rare ▪ Expensive – often need to observe many people over a long period ▪ Results are often not available for a long time ▪ Validity can be seriously affected by loss to follow up

could then be measured at different points in time after onset of caring responsibilities. Assuming the two groups were well matched at the baseline, any differences between the two groups at follow up would probably be due to the care giving experience.

Potential disadvantages are the effects of non-participation and any loss to follow-up. In any cohort study, only a proportion of those eligible to participate will agree to do so. It is probable the group who agree to participate differ in important respects (e.g. attitudes to health care) from those who decline. However as the population is defined by exposure and the outcome has not yet occurred this will not affect the internal validity of the results but may affect their external validity or generalisability.

The potential effects of loss to follow up are more of a concern. In any cohort study, a number of exposed individuals will be lost to follow up by the end of the study. The reasons for loss to follow up are very important as, if reason for loss to follow up is related both to the exposure and to the outcome (e.g. if carers who become depressed are more likely to move closer to their families and thus be lost from the study), a biased estimate of the association might result. For this reason, it would be important to make every effort to determine reasons for loss to follow up during this study.

3.2.4 Would additional qualitative data help inform the results?

Support of carers in the community is complex and there are many factors to be taken into consideration. Any cohort study measuring all these factors would be likely to generate a large amount of data. Interpreting the results might be helped through qualitative work with focus groups of carers and/or health professionals. However, it is very difficult to get groups of carers together to form focus groups as they have care responsibilities, so any focus group of carers would be likely to include only those carers looking after the least disabled stroke patients, or those carers with the most help who are able to leave the stroke patient to attend the group. The opinions generated by such groups might be skewed and misleading. Generating focus groups of healthcare professionals is also difficult without resources to pay for their time. Therefore, the idea of focus groups to inform the results was considered but rejected.

3.3 Summary

Support of carers in the community is a complex intervention consisting of many component parts. The MRC framework for investigation of complex interventions was used as a basis for choice of study design (MRC Health Services and Public Health Research Board, 2000). A randomized controlled study design was rejected due to a lack of definition of the key components to be included. A case-control study design was excluded due to the inability of this design to determine the temporal relationship between outcome and exposure.

A cohort design was finally chosen as stroke has a definite point of onset. If a group of new carers and matched controls were followed through from the time of stroke, any differences between the groups would be likely to be due to the impact of care giving on the carer. It was recognized that this study design has drawbacks too. In particular those caregivers not recruited to the study might be a different group from those willing to participate and thus the findings might not be generalisable to all carers of stroke patients. Secondly, there could be an important factor resulting in loss to follow up which might falsely alter estimates of association.

Chapter 4: Theoretical basis for choice of measurement instruments

From the literature search, certain criteria were identified which had to be met when selecting outcome measures and measurement instruments:

- Wherever possible pre-validated (or standardised) instruments would be used to enable comparison with other studies and/or normative population data.
- Outcome measures must be concerned with the health and well-being of the carers – particularly psychological health. Reduction in psychological health is the most consistent effect of caring seen in the literature (Carnwath TCM & Johnson DAW, 1987; Coughlan AK & Humphrey M, 1982; Draper BM, 1992; MacKay A & Nias BC, 1979; Stein PN et al, 1992; Williams AM, 1993).
- The study would include a measure for all the major factors identified as influencing outcome for carers in the literature search
- The satisfaction questionnaire developed for the purpose of this study (Simon C, et al., 2003) would be used alongside a global satisfaction measure to enable further validation of the new measure, examination of the interaction between carer satisfaction, support and health outcomes and elements of community support provision important for the carers to be identified.

Donabedian (1980), in his work on assessing quality of health care, identifies three major processes in evaluating health care which focus on "structure", "process" and "outcome". Structure refers to the relatively stable features of care such as care providers and organisation; process refers to what actually happens; and, outcome denotes those aspects of well-being which can be linked to care provided. In addition to the measures above, we aimed to include measures to encompass all three of these processes.

4.1 Method of administration:

During piloting work (Simon C, 2003) a self-administered questionnaire was tried but gained very poor response rates. This is not a unique finding. Another study investigating carers' views recently achieved a similar response rate with a self-administered questionnaire (Peckham S & Wilson A, 2001). However during piloting, high response rates were achieved using face-to-face interviews. Therefore whichever instruments were chosen, a face-to-face interview technique would be best.

4.2 Use of standardised instruments:

A standardised instrument is one which has been tested and validated scientifically on the population with which it is to be used. This ensures that test results are:

- Representative (they test and show accurately what they are meant to show - which is established by comparing them with other lines of evidence) *and*
- Reproducible (i.e. that the same results will be obtained in the same patient by another assessor or by the same person upon re-test).

4.2.1 The validity of a questionnaire:

How do we know that an instrument measures what we think it measures? Measurement validity means the extent to which an instrument measures what it is claimed to measure (Punch KF 1998). There are three main types of validity which are commonly assessed:

4.2.1.1 Face and content validity:

This is a subjective judgement that the instrument is measuring what it sets out to measure. Face validity refers to whether items on a questionnaire superficially appear to be relevant and make sense with respect to the objective of the measurement instrument. It is equally important that the items or questions cover the full range of the issue or attitude being measured. Assessment of items of an instrument in this respect is termed content validity. There are various methods of assessing face and content validity such as review by expert panels, use of qualitative data to clarify areas which should be covered by a questionnaire and literature review to ensure aspects identified in other research and by other experts in the field are included. Face and content validity remain a subjective measure of the instrument however.

4.2.1.2 Criterion and construct validity:

This refers to how well an instrument corresponds with gold standard measures or measures of the same construct in which the researcher has confidence (Kumar R, 1996).

There are two types of criterion validity. Concurrent validity involves measuring with the instrument to be tested and with the gold standard instrument at the same time. If there is good agreement between the two then the instrument being tested is said to be valid. Predictive validity is where the criterion variable will not occur until later. An example is an instrument to predict examination grades. Comparing the scores obtained in advance on the instrument being tested with the actual scores achieved for the examination gives an idea of how valid the instrument being tested is. Construct validity refers to how well an instrument confirms expected hypotheses or theoretical expectations.

4.2.2 Reliability of a questionnaire:

Reliability refers to the ability to produce consistent results. There are three aspects of reliability commonly tested: test-retest reliability (agreement between responses following administration of the test on two separate occasions under the same circumstances); inter-rater reliability (agreement between responses following administration of the test by two different raters); and internal consistency (measurement of the same concept by different scale items).

4.2.2.1 Test-retest and inter-rater reliability:

The test-retest reliability checks the ability of a test to obtain the same response time and time again when everything remains the same. Inter-rater reliability checks the ability of a test to obtain the same response when administered by two different assessors. Some factors affecting reliability are:

- *The wording of questions:* any slight ambiguity can affect the test-retest reliability as an individual may interpret that question differently on different occasions;
- *The physical setting:* any change in setting may affect responses given and thus reliability;
- *The respondent's mood:* any change in mood may affect the responses obtained. This is particularly important for attitudinal questionnaires like ours.
- *The nature of interaction:* the way the interviewer and respondent interact with each other may well be different on the first test and a subsequent test as the nature of their relationship has changed;

- *The regression effect of an instrument:* respondents often respond strongly on first administration of an instrument

The most commonly used measure of inter and intra-rater reliability is Cohen's Kappa coefficient (Cohen J, 1960). This is a statistical technique used to evaluate the extent of agreement between two or more independent evaluations of a categorical variable. Kappa takes into account the extent of agreement that could be expected on the basis of chance. Weighted Kappa is a refinement of the kappa coefficient that takes into account the "seriousness" of disagreement among raters. For example a difference between raters of one point is not as "serious" as a disagreement between raters of ten points.

Landis and Koch (1977) suggest the following guidelines for interpretation of kappa values:

Kappa Value	**Interpretation**
Below 0.00	Poor
0.00-0.20	Slight
0.21-0.40	Fair
0.41-0.60	Moderate
0.61-0.80	Substantial
0.81-1.00	Almost perfect

4.2.2.2 Internal consistency:

The most frequently used measure of internal consistency of a scale in which several numerical items are added together to form a composite score is Cronbach's alpha (Kuder GF & Richardson MW, 1937). It may be interpreted as the average correlation between the two halves of a multi-item instrument if that instrument were to be split into all possible combinations of two halves. Alpha values lie between 0 and 1. A high alpha indicates good internal consistency and suggests that there is at least one fairly homogeneous dimension underlying the scores on the instrument.

4.2.3 Sensitivity of a questionnaire:

This is the ability of an instrument to detect true differences. This can take two forms - sensitivity to change and discriminant sensitivity. Sensitivity to change reflects the ability of the instrument to pick up and measure differences for a given individual if there has been a real change. Discriminant sensitivity is the ability of an instrument to detect real differences between different individuals.

4.3 Choice of background data to include

A list of demographic variables commonly collected for carer-related studies was made and commonly encountered items were used to make a background information or enrolment questionnaire. These included address, age, gender, ethnicity, relationship to the person being cared for, socio-economic status (measured by housing type, level of education and income), employment status, other caring responsibilities and previous caring experience – see Appendix 2.

Several of these variables have been shown to impact on carer health. Using gender as an example, Vitaliano, Zhang and Scanlan (2003) found female carers report more physical health related symptoms than male carers; Hirst (2005) found female carers were more prone to distress than male carers; Bookwala and Schulz (2000) indicated that caring husbands experience fewer stressors and depressive symptoms than their female counterparts; and, in one meta-analysis gender and mean age of the carer were important variables predicting health effects (Pinquart M & Sorensen S, 2003b).

4.4 Choice of primary outcome measures

4.4.1 Measurement of psychological health:

There are many instruments which measure psychological health. These range from quality of life measures to indices of psychotic illness.

Most previous studies in this field have used non-specific measures of psychological distress (Bakas T & Burgener SC, 2002; Draper BM, 1992; Hodgson SP, Wood VA, & Langton-Hewer R, 1996; McClenahan R & Weinman J, 1998; Purk JK & Richardson

RA, 1994; Wyller TB et al., 2003). Those which have used more specific measures have shown that anxiety and depression occur at different times after the onset of caring responsibilities (Dennis M et al., 1998; Grant JS et al., 2000; Macnamara SE et al., 1990; Tompkins CA, Schulz R, & Rau MT, 1988).

Therefore any measure employed must be able to distinguish between anxiety and depression, and must have reliability data and validity data for the community sample of the UK population it would be used with.

4.4.1.1 The Revised Clinical Interview Schedule:

The literature suggests carers suffer from a variety of neurotic symptoms. The Clinical Interview Schedule (CIS) (Goldberg DP et al., 1970) has been widely used as a standardised interview for assessing minor psychiatric disorders within the spectrum likely amongst carers. It was originally designed for use in general practice but has also been used in community surveys and occupational studies. As the Clinical Interview Schedule is specifically intended for use in a "community" setting, the threshold for case definition corresponds roughly to the point at which a general practitioner (GP) would become concerned about a patient's mental health. This scale would measure in real terms when carers were becoming depressed or anxious to the point at which they would benefit from GP intervention.

The revised Clinical Interview Schedule (CIS-R) (Lewis G et al., 1992) is an updated version of the CIS. The reasons for the changes from the CIS were to increase standardization of the interview to such an extent that it is not necessary for an experienced mental health physician to administer the interview. Therefore it would be suitable for the purposes of this study. The CIS-R is reproduced in Appendix 3.

The CIS-R contains 14 sections. Each deals with a particular type of neurotic symptom. A final section establishes the overall effect of these neurotic symptoms on the affected person's life. Each section has a variable number of mandatory questions which act as a gate to more detailed assessment of the symptoms. Each section is scored over the past

Table 4.1: Comparing the results of the CIS-R with others using standardised interviews. Results given are mean weighted kappas (or other agreement index) across symptoms. The figures in brackets are the kappas for agreement on 'cases'.

Study	**Interview**	**Observer rating design**	**Re-interview design**
Kendell et al (1968)	Present state examination (PSE)	0.73	0.41
Goldberg et al (1970)	Clinical Interview Schedule (CIS)	0.71	-
Wing et al (1977)	PSE	0.52*	0.34 (0.37)
Cooper et al (1977)	PSE	0.67	0.38
Sturt et al (1981)	PSE	0.60 (0.43)*	-
Rodgers and Mann, (1986)	PSE	0.71 (0.61)*	-
Lewis et al (1992)	CIS-R	-	0.55 (0.72)
Lewis et al (1992)	CIS-R	0.87 (0.87)	-
Lewis (1994)	Computerised CIS-R	-	0.63 (0.70)

* Audiotapes of interview assessed

Reproduced from: University of Bristol website: http://www.bris.ac.uk/Depts/Psychiatry/rtheme5.html

seven days and rated on a 0-4 scale. Estimates of the reliability of the CIS-R compare favourably with the results of studies of other standardised interviews (Lewis G et al., 1992). In addition, lay interviewers are as reliable as psychiatrists and do not show any bias in their use of the CIS-R (Lewis G et al., 1992) - see table 4.1.

The CIS-R has been extensively validated in UK community samples (Hotopf M, Sharp D, & Lewis G, 1998; Lewis G et al., 1992) and normal population data are available for people in the UK using this measure from the National Psychiatric Morbidity Study in which the CIS-R was used to assess neurotic symptoms (Jenkins R et al., 1997; Jenkins R et al., 2003a; Jenkins R et al., 2003b). A score of 12 or more indicates the presence of significant neurotic symptoms, while a score of 18 or more indicates symptoms of a level likely to require treatment (Lewis G et al., 1992).

The drawbacks of using the CIS-R are that it is a relatively long interview schedule and thus increases the total length of carer interviews. Carers are busy people due to their caring responsibilities and this might reduce the number of people willing to take part.

Also the CIS-R UK population data and all the validation data available for the CIS-R were based on population samples aged 16-75 years of age. Although most carers involved in this study were likely to be under 75 years of age, it was possible that a few might be older. However scales developed to measure psychiatric distress in older populations would certainly not be valid for some of the younger carers likely to be enrolled into the study.

When contacted about the validity of the CIS-R in populations older than 75 years, the author of the scale, Glyn Lewis, replied that the CIS-R had been used in older populations without problems as long as the older person was not significantly cognitively impaired. He also commented that cognitive impairment was a problem when using the scale with younger people too. It would be unlikely that any of the carers in this study would have significant cognitive impairment due to their responsibilities as carers. However it would be important to include a simple measure of cognitive function with the CIS-R to ensure this was the case.

Another potential problem with the CIS-R is that the ability of the CIS-R to map onto ICD-10 diagnostic criteria has been questioned. One study has found poor concordance between the CIS-R and Schedules for Clinical Assessment in Neuropsychiatry (SCAN), a standard, semi-structured, clinical assessment for any ICD-10 neurotic disorder and for depressive disorder (Brugha TS et al., 1999). However, as mentioned above, the CIS-R was not designed to record major psychiatric illness but to classify symptoms usually seen in the community by whether they are severe enough to warrant GP action. As long as this fact was taken into consideration when interpreting results, the results should still be meaningful.

4.4.2 Measurement of physical health:

There are numerous ways of measuring physical health. These range from full clinical questionnaire and physical examination, through examination of medical records or records of medication (with number of drugs taken being an estimate of health status) and symptoms scores, to self-perceived health measures. The carers in this study would not be "patients" and therefore it was felt they might be reluctant to divulge too much about their own health or be subjected to a physical examination. Instead self-perceived health was the method chosen to test physical health status.

Self-perceived health is a commonly used measure in which the participant is asked: "Would you say that in general your health is: excellent, very good, good, fair, or poor?"(Hagan HC et al., 1994). A review of 27 studies has shown that this simple measure of self rated health has strong predictive validity for mortality, independent of other physiological, behavioural, and psychosocial risk factors (Idler EL & Benyamini Y, 1997). Furthermore, it has been shown in longitudinal studies that self rated health predicts the onset of disability (Farmer MM & Ferraro KF, 1997; Ferraro KF, Farmer MM, & Wybraniec JA, 1997; Idler EL & Kasl S, 1995; Wilcox VL, Kasl S, & Idler EL, 1996). Self-rated health has also been used in other studies of carers of stroke patients (Draper BM, 1992; Silliman RA et al., 1986) so using this measure would enable a direct comparison to be made.

However there is evidence that carers may neglect their own health (Brocklehurst JC et al., 1981). How this might affect a self-report health measure was unknown. Therefore the self-perceived health measure was combined with two traditionally-used objective measures of health – the number of drugs being taken on a regular basis and the number of chronic conditions the person is suffering from. Reasons for any changes between interviews were also recorded. The physical health questionnaire used is included in Appendix 5.

4.5: Choice of secondary measures

4.5.1 Cognitive function:

This measure was included to ensure carers in the study were able to understand the questions in the CIS-R. It was only administered once during the initial interview and used to screen out carers unable to participate due to poor cognitive function. For this reason, the simplest and quickest measure available was used.

Box 4.1: The Abbreviated Mental Test Score

The 10 items of the AMTS:

1. Age
2. Time (nearest hour)
3. Year
4. Name of place
5. Recognition of 2 persons
6. Date and month of birth
7. Date of the first world war
8. Queen's name
9. Count from 20-1 backwards
10. 5 minute recall: full street address

The Abbreviated Mental Test Score (AMTS) (Hodkinson HM, 1972) is the most widely used test of cognitive function in the UK – both in clinical and research settings. It was derived from the Roth-Hopkins test which correlates well with pathological brain changes at autopsy (Blessed G, Tomkinson BE, & Roth M, 1968). It was first tested using 700 patients aged over 65 years and showed a good correlation with the Roth-Hopkins Test. A summary of reliability and validity data is presented in table 4.2.

The AMTS is composed of ten test questions (box 4.1). Each correct item scores one mark and the items are totalled. The maximum score is 10 implying completely normal cognition. Various cut offs have been used to imply "impairment of cognition" but I chose to use a cut off of a score of less than eight, as this correlates well with cognitive impairment documented in medical records (Jitapunkul S, Pillay I, & Ebrahim S, 1991).

Table 4.2: Reliability and validity data for the Abbreviated Mental Test Score.

	Agreement index
Test-retest reliability and inter-rater reliability (weighted kappa)[1]	0.79-0.86*
Comparison with Roth-Hopkins test[2]	0.87 -0.96**
Internal reliability (Cronbach's alpha)[3]	0.89

* Patients included community samples an institutionalized patients

** Patients included elderly patients with normal cognition, psychogeriatric day patients and institutionalized patients

1 Little A et al. 1987; Qureshi KN & Hodkinson HM 1974; Thompson P & Blessed G 1987; Vardon VM & Blessed G 1986
2 Hodkinson HM 1972; Qureshi KN & Hodkinson HM 1974; Thompson P & Blessed G 1987
3 Jitapunkul S, Pillay I, & Ebrahim S 1991

Scores on the AMTS correlate well with scores on other cognitive function tests (Qureshi KN & Hodkinson HM, 1974; Thompson P & Blessed G, 1987) and clinical assessments of cognitive function (Vardon VM & Blessed G, 1986). The AMTS also shows good inter-rater reliability and repeatability (Little A et al., 1987; Qureshi KN & Hodkinson HM, 1974; Thompson P & Blessed G, 1987; Vardon VM & Blessed G, 1986).

4.5.2 Smoking, alcohol consumption and weight change:

For smokers, the amount smoked varies according to stress levels (Lindenthal JJ, Myers JK, & Pepper MP, 1972). These increases are usually not maintained beyond the period of stress (Schneider NG, & Houston JP, 1970). Therefore the amount smoked by smokers is an indirect measure of acute stress.

A similar pattern is seen with respect to alcohol consumption (Steptoe A et al., 1996) and eating behaviour (Geliebter A, & Aversa A, 2003). People who drink alcohol tend to drink more at times of stress. Likewise, non-obese individuals tend to eat less at times of stress whilst obese individuals tend to eat more.

ABOUT YOUR LIFESTYLE:

- How much do you smoke?

9	Non-smoker	
1	Pipe smoker	.... oz / week
2	Cigarette smoker	.... cigarettes / day
3	Cigar smoker	.... cigars per day

- How much alcohol do you drink in a week?

9	Teetotaller	
1	Wine	.........Wine-glasses/week
2	Beer or cider	.... Pints / week
3	Sherry	.... Sherry-glasses/week
4	Spirits	.... spirit-measures/week

- Have you lost or gained weight recently? If yes, how much weight have you lost?

1	No	☐
2	gained weight	☐
3	lost weight	☐
4	lost more than ½ stone	☐
5	trying to lose weight or on a diet	☐

Box 4.2: Information about smoking and drinking patterns and weight change

These factors were measured as it is easy to do, quick, and might reveal stress carers were reluctant to report directly for fear of upsetting the stroke patient or appearing to have "failed". Questions used to gauge tobacco and alcohol consumption and weight change are shown in box 4.2, page 58.

4.5.3 Measurement of quality of life:

As many of the studies of carers in the community were done using general well-being or quality of life measures, a quality of life or general well being measure was included alongside the CIS-R to enable a broader comparison with these studies too. However quality of life is a very broad concept and this study was specifically interested in general psychological well-being rather than this broader concept. There are several well validated measures of general psychological well-being in common usage (see table 2.8, page 29).

The Philadelphia Geriatric Center (PGC) morale scale (reproduced in Appendix 4 - Lawton MP, 1975; Morris JN & Sherwood S, 1975) was chosen for use in this study because it has been used with carers in the past (Purk JK & Richardson RA, 1994), is designed for use with an older population (though age limits are not defined and the scale has been used over a wide age range), is simple to administer as all the questions in the scale have simple dichotomous answers (most yes-no) and it has been extensively validated world-wide (table 4.3).

Table 4.3: Reliability and validity data for the PGC morale scale.

	Agreement index
Test-retest reliability[1]	0.75* - 0.91**
Split half reliability[1]	0.79
Comparison with independent ranking of morale[2]	0.47-0.74***
Internal reliability (Kuder-Richardson)[3]	0.81

* Weighted kappa after 5 weeks;
** Weighted kappa after 3 months

***Comparison with a single item morale measure; the Life satisfaction index and Life Satisfaction Index-Z

1 Lawton MP 1972
2 Kozma A & Stones MJ 1987; Lawton MP 1972
3 Morris JN & Sherwood S 1975

Factors shown to be related to high morale as measured on the PGC morale scale in other studies include: continued mobility and feeling well; having an adequate income; not spending too much time alone; being able to expect care when ill from an informal carer and having a locally integrated or wider community focused support network (Weinger GC, Davies, & Shahtahmasebi S, 1995).

4.5.4 Measurement of social factors:

Social support may modify the impact of illness on patients (Cohen S & Wills TA, 1987; Ganster CD & Victor B, 1988) and there is some evidence that social support is a factor in the development of depression amongst carers of stroke patients (King RB et al., 2001; King RB et al., 2002; Schulz R, Tompkins CA, & Rau MT, 1988; Tompkins CA, Schulz R, & Rau MT, 1988).

Social support is a function not only of the size and quality of social network available to the carer but also of the support the stroke patient gives the carer. This is in turn related to the quality of relationship with the stroke patient (Brocklehurst JC et al., 1981; King RB et al., 2001; Schulz R, Tompkins CA, & Rau MT, 1988; Tompkins CA, Schulz R, & Rau MT, 1988) and support gained from pursuing normal, enjoyable activities (Nieboer A et al., 1998). Ideally a measure was needed which would accommodate each of these areas.

4.5.4.1 The social support questionnaire:

The social support questionnaire (Appendix 6) is intended to measure the availability of and satisfaction with social support. It focuses on emotional support and was designed as a research instrument. It can be used with any type of respondent. It was originally developed using a sample of 602 students. Factor analysis repeatedly shows that each score (availability and satisfaction with social support) is underpinned by a single factor accounting for over 70% of the variance in each case (Daniels LR, 2003; McCormick IA, Siegert RJ, & Walkey FH, 1987; Sarason IG et al., 1983).

The length of the questionnaire was an issue as carers do not have a great deal of spare time, so the 6-item abbreviated version described by Sarason, Sarason and Shearin in

Table 4.4: Reliability and validity data for the Social Support Questionnaire.

	Agreement indices	
	Availability of support	**Satisfaction with support**
Test-retest reliability (kappa) [1]	0.90	0.83
Comparison with personality scores [2]	-0.33 - -0.63*	-0.23 - -0.63*
Correlation with depression [3]	-0.22	-0.43
Comparison with other social support measures [4]	0.28-0.53 **	0.24 -0.66**
Internal reliability (Cronbach's alpha) [5]	0.97	0.94

*Shyness and loneliness

**Inventory of socially supportive behaviours, Social network list, Family environment scale, Interpersonal support evaluation list and Perceived social support

1 Sarason IG et al 1983; Sarason IG, Sarason BR, & Shearin EN 1986
2 Sarason BR et al. 1987; Sarason IG et al 1983
3 Jitapunkul S, Pillay I, & Ebrahim S 1991
4 Sarason BR et al 1987; Tardy CH 1985
5 Sarason IG et al 1983; Tardy CH 1985

1987 was chosen for this study. For each of the six items respondents are asked to list people who provide support and then rate their satisfaction with support for each item on a scale of 1-6 (very satisfied to not very satisfied). A measure of amount of support is gained by totalling the number of people listed and dividing by six. A measure of satisfaction with support is obtained by totalling satisfaction scores and dividing by six in the same way.

Both the full version and abbreviated version have been extensively tested for reliability and validity – see table 4.4. Using this scale would give a measure both of actual amount of informal support, who that support was being provided by (as the questionnaire asks respondents to name each person and state relationship to the respondent), and how adequate the carer perceived that support to be.

4.5.5 Measuring quality of relationship with the stroke patient:

The three-question "quality of relationship" measure used by Motenko (1989) (Box 4.3. page 62) was chosen to measure quality of relationship between the stroke patient and carer. This measure is very simple, does not depend on the relationship between carer and patient as being a spouse-spouse relationship and is phrased in terms carers can easily understand. Its drawback is that it has no published validity or reliability data.

Box 4.3: Quality of relationship scale

I am now going to ask you about your relationship with the person you look after:				
How would you describe your relationship with (insert name of the stroke patient)?				
Excellent	Good	Indifferent	Bad	Terrible
Do you feel appreciated by the person who has had the stroke?				
Very much	A bit	Not sure	Not really	Definitely not
Do you argue with the person who has had the stroke?				
Very infrequently	Very occasionally	From time to time	Often	All the time
How close do you think your relationship with the stroke patient is?				
Very Close	Close	In between	Distant	Very distant

4.5.6 Measuring activity restriction:

The Activity Restriction Scale was developed in the Netherlands to look at whether prevention of doing activities usually enjoyed by the person and prevented by illness and/or bereavement, affected outcome (Nieboer A, 1996; Nieboer A et al., 1998). It involves giving the carer an extensive picking list of activities at the earliest possible time (in this study the carers would be asked to pick the activities they engaged in prior to the stroke whilst the patient was still in hospital). The carers are then asked to pick the six items they would miss the most. At subsequent interviews they are asked whether they do those activities more or less and why there has been a change, to give a measure of "activity restriction".

Apart from its use in the studies for which it was developed, there are no validity or reliability data for this scale. This is a potential problem, however the scale has been used to investigate carers of stroke patients in the community before (Nieboer A, 1996; Nieboer A et al., 1998) and its use would enable a direct comparison of results. Moreover there is no other similar questionnaire available. See Appendix 7 for a full list of activities and the activity restriction questionnaire.

4.5.7 Measurement of degree of impairment of the stroke patient:

A variety of different measures of impairment of the stroke patient have been used in the caring literature including the Barthel Index (Carnwath TCM & Johnson DAW, 1987; Draper BM, 1992; Hodgson SP, Wood VA, & Langton-Hewer R, 1996), Oxford Handicap Scale (Anderson CS, Linto J, & Stewart-Wynne EG, 1995), Frenchay Activities Index (Anderson CS, Linto J, & Stewart-Wynne EG, 1995; Carnwath TCM & Johnson DAW, 1987; Hodgson SP, Wood VA, & Langton-Hewer R, 1996), Clifton Assessment Procedure for the Elderly (CAPE)(Matson N, 1995), Functional Independence Measure (FIM)(Segal ME & Schall RR, 1996) and Craig Handicap Assessment and Reporting Technique (Segal ME & Schall RR, 1996).

4.5.7.1 The Barthel Index:

Initially, the Barthel index (Mahoney FI & Barthel DW, 1965) was the preferred measure of functional ability of the stroke patient. The advantage of this was that it has been used widely in the caring literature (Carnwath TCM & Johnson DAW, 1987; Draper BM, 1992; Hodgson SP, Wood VA, & Langton-Hewer R, 1996) and is routinely collected in hospital.

During early work in preparation for this project it became clear that it would be impossible to do this. Many of the stroke patients would be discharged home indirectly, spending a period of time either in a community hospital or a nursing or rest home before returning home. Barthel scores were not routinely collected in these establishments. Even for patients discharged directly home the Barthel scores in the notes were frequently out of date and carer and stroke patients alike had noticed considerable improvements since the time of the last score.

An alternative would be to perform an assessment of the stroke patient as part of the study. However, the carers not the stroke patients would have consented to take part in the study. Moreover, carers frequently would choose to be interviewed when the stroke patient was out or otherwise occupied. A direct assessment would be impossible too.

Box 4.4: The Oxford Handicap Scale

Oxford Handicap Scale Grades:

0 = No symptoms
1 = Minor symptoms which do not interfere with lifestyle
2 = Minor handicap: Symptoms that lead to some restriction in lifestyle but do not interfere with the patient's capacity to look after him or herself
3 = Moderate handicap: Symptoms that significantly restrict lifestyle and prevent totally independent existence
4 = Moderately severe handicap: symptoms that clearly prevent independent existence though not needing constant attention
5 = Severe handicap: totally dependent patient requiring constant attention day and night

4.5.7.2 The Oxford Handicap Scale:

The Oxford Handicap Scale (Box 4.4 - Bamford J et al., 1988) is an alternative to the Barthel index. Handicap is defined as "a physical, mental, or emotional condition that interferes with an individual's normal functioning" or "reduction in a person's ability to perform a social role as a consequence of impairment" (On-line medical dictionary, 2004) and handicap scales assess participation from an outsider's perspective (Wade DT & de Jong BA, 2000). The Oxford Handicap Scale has been used widely (Anderson CS, Linto J, & Stewart-Wynne EG, 1995; Carlsson GE, Moller A, & Blomstrand C, 2003; Rodgers H et al., 1997) and has good validity and inter-rater reliability – see table 4.5.

Table 4.5: Reliability and validity data for the Oxford Handicap Score

	Agreement index
Inter-rater reliability (Kappa)[1]	0.72-0.91
Comparison with the Barthel index[2]	0.87

[1] Bamford J et al. 1989; van Swieten JC et al. 1988; Wolfe CD et al. 1996
[2] Celani MG et al. 2002

Although it is a much cruder index of disability than the Barthel Index, the carers would be able to give a rating of the stroke patient's handicap without the patient being present. There is some evidence carers are good proxy judges of stroke patients' abilities and disabilities (Segal ME, Gillard M, & Schall RR, 1996). Moreover the carer's opinion might be coloured by the way the carer views the stroke patient's level of functioning – in other words a more accurate reflection of their own perception of the stroke patient's level of handicap.

4.5.8 Service provision:

As discussed in chapter 2, this study aimed to explore the relationship between formal community support and carer well-being. There are two aspects of support which needed to be measured – quantity of support and whether the carer was satisfied with that support. For the purposes of this study the satisfaction model proposed by Ware (Ware JE et al., 1983) was adopted and a definition of satisfaction with health care as being a measure of the degree to which the care received meets the needs, wants and expectations of the carer.

4.5.8.1 Quantity of support:

Community services received by older people living in the community (Jones DA & Vetter NJ, 1985; Salvage AV, Jones DA, & Vetter NJ, 1988) and after stroke (Garraway WM et al., 1981; Legh-Smith J, Wade DT, & Langton-Hewer R, 1986; McLean J, Roper-Hall A, Mayer P, & Main A 1991) have been documented in several studies. Using this information a questionnaire was constructed to record which services the carer-patient unit were receiving, and also the amount of time they were receiving those services for and the service provider. This questionnaire was designed to be administered by an interviewer and was piloted in an earlier study done by us (Simon C et al, 2003). Box 4.5 (page 66) shows the items used and format of the questionnaire.

The accuracy of carer recall about services provided is unknown but stroke patients are known to be unreliable reporters of rehabilitation services they receive (Luther A, Lincoln NB, & Grant F, 1998). Therefore, wherever possible reports about services

Box 4.5: Quantity of formal community support

We are interested only in the care you have received from the community services – not the care received whilst X was in hospital.

Have you, or the person you care for, been in contact with any of the following people or services in the past 6 weeks?

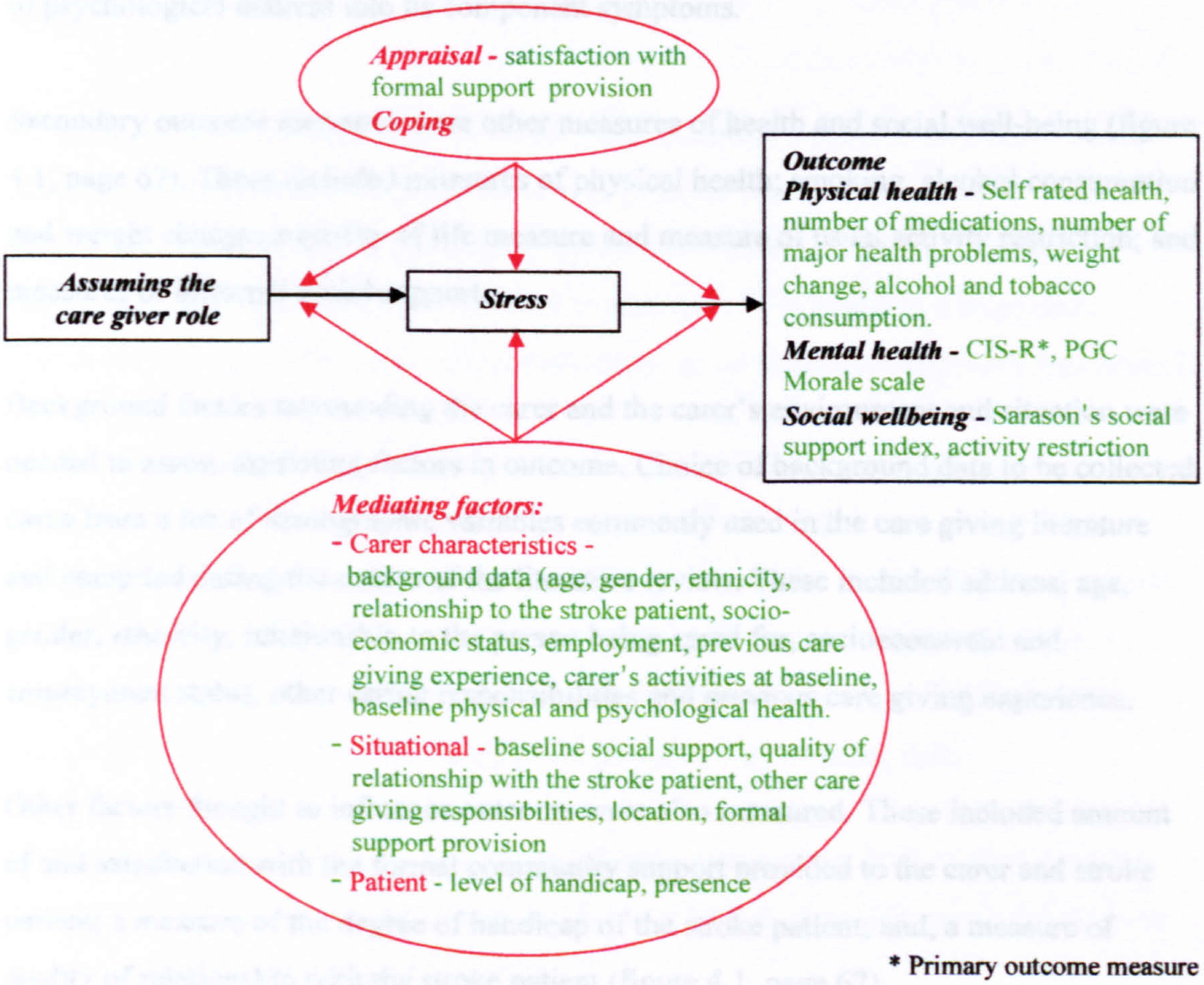
Service	*Yes*	*No*	*Don't Know*	*Number of times*		*Length of encounter*	
				You	*Stroke patient*	*Ave*	*Max*
GP	☐	☐	☐				
District nursing team	☐	☐	☐				
Social services	☐	☐	☐				
Occupational therapist	☐	☐	☐				
Physiotherapist	☐	☐	☐				
Home carers	☐	☐	☐				
Counsellor	☐	☐	☐				
Voluntary groups e.g. stroke association, Crossroads	☐	☐	☐				
Day Hospital or day centre	☐	☐	☐				
Hospital Out-patients	☐	☐	☐				
Community psychiatric team	☐	☐	☐				
Other							
State:	☐	☐	☐				
....	☐	☐	☐				

received were corroborated with official records (e.g. district nurse notes, GP records). However, due to the range of services provided and diversity of service providers it would be impossible to corroborate all reports. The counter side of that argument is that it would be impossible to record services provided by going directly to service providers without obtaining information from the stroke patient or carer first as there are so many different providers and no central record of care. The cost of care provided could then be calculated using published unit costs of healthcare (Curtis, L. & Netten, A., 2005).

4.5.8.2 Satisfaction with service provision:

The degree to which services provided meet the needs, wants and expectations of the carers was recorded with the Carer Satisfaction with Community Support (CSCS) a questionnaire specifically developed for this project (Simon C et al., 2003). The full questionnaire is included in Appendix 1. As piloting only provided provisional validity and reliability data for the new scale, a single-item global satisfaction measure was included alongside this questionnaire to enable further validation and comparison with other studies ("Overall are you very satisfied, satisfied, neither satisfied nor dissatisfied, dissatisfied or very dissatisfied with the support you have received from the hospital and community services since X came home?").

Figure 4.1: Relationship of the measures chosen to the stress-coping model underpinning the proposed research



* Primary outcome measure

4.6 Summary

The literature review provided the criteria for choice of measurement instruments. Face-to face interviews, as opposed to self-administered questionnaires, were preferred due to the higher response rates found during piloting. Standardised instruments with published validity and reliability data were used wherever possible.

As the effect of care giving on health is the most consistent effect of care-giving seen in the literature, this was chosen as the primary outcome measure. Health can be divided into psychological and physical health. Care giving has a greater effect on psychological health, so this was chosen as the primary outcome measure (figure 4.1, page 67) and the instrument chosen to gauge it was the CIS-R. This measure was designed for use by untrained researchers on community samples, it has extensive published validity and reliability data, there are normative population data available, and, it enables breakdown of psychological distress into its component symptoms.

Secondary outcome measures were other measures of health and social well-being (figure 4.1, page 67). These included measures of physical health; smoking, alcohol consumption and weight change; a quality of life measure and measure of usual activity restriction; and measures of informal social support.

Background factors surrounding the carer and the carer's environment and situation were needed to assess mediating factors in outcome. Choice of background data to be collected came from a list of demographic variables commonly used in the care giving literature and compiled during the course of the literature review. These included address, age, gender, ethnicity, relationship to the person being cared for, socioeconomic and employment status, other caring responsibilities and previous care giving experience.

Other factors thought to influence outcome were also measured. These included amount of and satisfaction with the formal community support provided to the carer and stroke patient; a measure of the degree of handicap of the stroke patient; and, a measure of quality of relationship with the stroke patient (figure 4.1, page 67).

Chapter 5: Choice of study groups and timing of interviews

A cohort design had been chosen. It was then necessary to decide how to obtain a study group, how to select a suitable comparison population and how often and at what intervals to follow those groups up.

5.1 Choice of study group

The study aimed to look at support provided and health effects at set points after carers began their caring responsibilities in order to look at early and later effects of caring. Therefore carers would need to be identified early in their caring careers and ideally before becoming carers. Studies like this have been done in which cohorts of carers have been constructed from large populations already being studied for other reasons (Nieboer A et al., 1998; Schulz R & Beach SR, 1999). However there were no such populations available for use.

As incidence of first stroke is about 2/1000/year (Bamford J et al., 1988), constructing a general population cohort of sufficient size to generate enough new carers for stroke patients during the duration of my study would involve recruiting over 125,000 individuals – assuming all affected agreed to take part. This would be a huge and impossible task given time and budget restrictions so an alternative approach was needed.

The easiest approach was to identify carers through the stroke patients they would be caring for. Stroke is common in the community and over 80% of stroke victims are admitted to hospital at the time of their stroke. By limiting the study to carers of patients who had suffered their first stroke, the caring experience would be new to the carers. Identifying stroke patients via hospital records and then contacting their main carer as identified in the hospital records seemed the simplest way of doing that.

However it did have several disadvantages. Firstly, carers of the 20% of stroke victims not admitted to hospital would be omitted. Little is known about this group but they are:

- patients who have milder strokes;

- patients with uncertain diagnosis that later, after out-patient investigation, turn out to have suffered a stroke; or,
- very frail patients already in nursing home care.

The latter two groups would not be suitable for the study anyway as those found later to have suffered a stroke could not be included as an estimate of carer health soon after stroke would be needed, and those already in residential care are not likely to be discharged from residential care after the stroke (and residents of care establishments were excluded from the study population - see below). Therefore only the first group – the carers of patients not admitted to hospital after mild strokes (less than 10% of all suitable stroke victims) – would be missed by this method.

Including carers of stroke patients not admitted to hospital has drawbacks too as often diagnosis of stroke in the community has not been made with immediate imaging support, risking misclassification errors i.e. including carers of patients who later turned out not to have suffered a stroke. Secondly this group would be very difficult to recruit early in the course of stroke as recruitment would require GPs to notify the stroke to the project co-ordinator. Since caring for a stroke patient in the community without hospital admission is now a relatively rare event, this would involve a lot of GPs notifying very few cases and would be unlikely to happen.

A further disadvantage of recruiting carers via stroke patients is that the stroke has already occurred. This will have immediate effects on the carers which might affect assessment of their psychological health. However, immediate affects of stroke on the carer might have a bearing on later changes in their health so could provide a new and interesting perspective. For example, could we predict which carers would do well or badly from assessment of carer state pre-discharge?

5.1.2 Inclusion criteria for carers:

The Carer's UK definition of a carer was used for the purposes of recruitment (page 1). Suitable patients were identified from admission and stroke unit records (as this ensured patients admitted with another diagnosis and later found to have stroke were included). Potential carers were then identified by ward staff from information about social situation routinely collected about in-patients. Carers could be considered for inclusion if they had stated they were fit enough and intended to look after the stroke patient should he or she return home from hospital.

Next, only those stroke patients with co-habitant carers or carers who saw the stroke patient on a daily basis were included. This was due to the difficulty in deciding when a carer becomes a carer. Is a carer living a day's drive away still a carer? Is someone in another country who telephones once a month a carer? By confining this study to co-habitant carers, i.e. the person living in the same home as the stroke patient and having the major responsibility for his or her care, and those seeing the person they care for on a daily basis, this definition was effectively limited to those providing face to face care. However, this policy might result in problems only non-cohabitant carers have going undetected (e.g. additional stresses of running two households or stress of being at a distance when something goes wrong). A summary of inclusion criteria is included in table 5.1.

Table 5.1: Inclusion criteria for exposure and comparison groups

Inclusion criteria for carers *A carer who ………*	***Inclusion criteria for comparison non-carers*** *A non-carer who ………*
▪ Intends to look after a stroke patient, after first stroke, on discharge home from hospital. ▪ Is fit enough to look after the stroke patient on return home. ▪ Lives with the stroke patient or will care for him/her on a daily basis ▪ Can understand the interviewer-administered questionnaire. ▪ Has given written informed consent to take part. ▪ Has the permission of the consultant in charge of the stroke patient to take part in the study. ▪ Can be interviewed before the stroke patient returns home	▪ Does not currently care for anyone with any chronic infirmity ▪ Can understand the interviewer-administered questionnaire. ▪ Has given written informed consent to take part.

5.2 Choice of comparison group

Once the source of exposed subjects had been decided, the next consideration was the selection of an appropriate comparison group. The choice of this group is very important. The groups being compared should be as similar as possible with respect to all other factors that might be related to the disease except the determinant under question (Hennekens CH & Buring JE, 1987). In that way, if there really is no association between exposure and disease, the disease rates in the populations being compared should be essentially the same.

For this study a comparable group of non-exposed individuals or "non-carers" was needed. Initially we aimed to do that by asking GPs in the catchment areas of the two hospitals used for recruitment to identify patients in the 50-70 year age group who did not currently care for anyone with ongoing infirmity and who would be "fit" in their opinion to take on a caring role if ever placed in that position. In this way there would be a degree of fitness selection as there is when making a decision that a stroke patient can go home. Several GPs agreed to do this but in practice it soon became apparent that the GPs seemed to be highly selecting the individuals thought suitable. Carers of stroke patients are selected by fate and tend to come from a much broader range of backgrounds than the "non-carers" who were selected by GPs on the basis that the GP felt they would be co-operative and good study subjects. In addition GPs were not enthusiastic about recruiting "controls" and very few potential candidates were nominated.

An alternative group of "non-carers" would be needed. In order to obtain the same spread of social backgrounds, carers already involved in the study would be asked to nominate a friend, relative or neighbour without caring responsibilities, living within the catchment area of the study and of similar age to the carer (within 10 years). This proved a much more successful strategy as these "non-carers" were much more enthusiastic and co-operative about taking part as they had a personal interest in the study. The disadvantage of using this group as a comparison group is that, if the non-carer was a close contact of the carer, he or she might also assume some of the caring responsibility and thus be affected by the same factors as the carer thereby lessening the difference between exposure and non-exposure groups. The net effect of this would be to make the comparison more conservative.

Another potential disadvantage of this method is that not all the carers recruited nominated non-carers. Therefore those with controls are a self-selected group. As friends or relatives within our catchment area were specified, those who did not nominate controls could be more socially isolated than those who did. Again one might expect that those more socially isolated would have less support in their caring activities and suffer more health and social consequences (King RB et al., 2001; King RB et al., 2002; Schulz R, Tompkins CA, & Rau MT, 1988; Tompkins CA, Schulz R, & Rau MT, 1988). This might again have the effect of lessening differences between carers and controls and making the comparison more conservative. Inclusion criteria for comparison "non-carers" are included in table 5.1, page 71.

5.3 Timing of carer interviews

Time interval since stroke is a crucial measure in any outcome research concerning stroke patients or their carers (Kelly-Hayes M, 1990). Overall, the majority of recovery after stroke occurs in the first 11 weeks, with the largest amount occurring in the first 4.5 weeks (Jorgensen HS et al., 1995; Jorgensen HS et al., 1999; Wade DT, 1987). A similar trajectory of stroke recovery is seen in a wide range of deficits including motor, visual, and behavioural deficits. The time course of recovery varies with stroke severity but there is unlikely to be any great improvement after a year (Skilbeck C et al., 1983). In addition stroke patients and their carers receive more input from hospital and community services early after discharge (Legh-Smith J, Wade DT, & Langton-Hewer R, 1986; Simon C, 2003). This input reduces over time (Simon C, 2003).

One of our primary outcomes was psychological health. Previous studies (table 5.2, page 74) have shown that psychological well-being of carers of stroke patients varies with time. These studies used an early measurement three months or less after stroke and further measurements later on. It was important that this study measured psychological health of carers early after the onset of caring and again later on but due to manpower,

Table 5.2: Change in psychological well-being of carers over time after stroke.

Study	**Time interval after stroke**	**Findings**
Wade et al (1986)	3 months, 6 months, 1 year and 2 years	Carer depression is significantly related to patient's disability and depression up to six months post stroke, and patient disability up to one year after stroke. After that time carer depression is not related to any patient factors.
Schulz et al (1988) and Tompkins et al (1988)	3-10 weeks, 7-9 months and 13-15 months	Early after stroke depression is related to functional impairments of the stroke patient, relationship with the patient and concern about future care; after 7-9 months depression is related to patient's personality change, carer's age and perceived load. Carers depressed at 13-15 months post stroke had less social support.
Kotila et al(1998)	3 months and 12 months.	Level of handicap is related to carer depression at 3 months; lack of a formal support programme was associated with depression at one year after stroke.

budget and time considerations the maximum number of follow ups that could be done in this study was three for each carer with a time span ranging over one year.

Finally this study aimed to investigate the relationship between satisfaction with care and level of service input. Stroke patients and their carers receive more input from hospital and community services early after discharge (Legh-Smith J, Wade DT, & Langton-Hewer R, 1986; Simon C, 2003). This input reduces over time (Simon C, 2003). It was important to follow carers up at a point soon after discharge and again later on.

As a result of these considerations, carers were recruited soon after stroke and the first interviews were carried out as soon as possible after recruitment to give a baseline level of physical and psychological health. Each carer was then followed up twice more.

It was decided that time from stroke was not a good way to decide the timing of the second interview. This was because there is wide variation in the length of time patients spend in hospital. If a time for the second interview designed to capture carer experience in the early phase post-discharge was fixed based on average hospital stay, some patients would have been home, and their carers would have been 'hands-on' carers for a considerable time, while other patients would still be in hospital. One of the aims of the project was to look at the effect of the formal support services and so all carers needed to have been exposed for about the same time to their formal support services to be able to give comparable opinions.

A time post discharge seemed the most appropriate measure. From clinical experience, carers find the first few weeks after discharge a very busy time with numerous visitors preventing them from readjusting to their new situation and settling down to any form of routine. Interviews during this time might add to carer burden and were more likely to be refused by carers. Since average hospital stay is 34 days (Royal College of Physicians, 2002), a time interval of six weeks post discharge was chosen for the first follow up interview. This should have meant that the average time after stroke of the second interview would be approximately 10 weeks making results comparable with the studies listed in table 5.2, page 74.

All the studies in table 5.2 (page 74) used a follow up point of about a year after stroke. However, for this study a period of 13 months post stroke was chosen for the second follow-up interview to avoid interviewing around the anniversary of the stroke in case of any short-term adverse effect that might have on psychological wellbeing of the carers.

5.4 Timing of non-carer interviews

Initial interviews were done with comparison non-carers when they were identified. Only one follow up interview was performed with non-carers. This was done 13 months after the initial interview. It was not possible to do a follow up interview equivalent to the six weeks post-discharge interview. The discharge date varied considerably from carer to carer. Since non-carers had no discharge date, there was no such point in the non-carer's life on which to base the timing of the "six-week follow up" interview.

5.5 Summary

Taking into consideration practical constraints, a decision was made to recruit carers of stroke patients to the study cohort via the stroke patients they planned to look after on a daily basis. The intervention group was limited to carers of patients who had suffered their first stroke and were still in hospital following that event. After an unsuccessful trial of recruiting a comparison non-carer group via general practitioners, an alternative strategy of recruiting non-carers by asking carers already involved with the study to nominate a friend or relative of similar age, without caring responsibilities, and living within the catchment area of the study was employed.

Timing of interviews was based on information from the literature about recovery after stroke and other longitudinal studies of carers of stroke patients. It was decided that carers would be interviewed once whilst the stroke patient was still in hospital; once six weeks after discharge to detect the early effects of caring and record the community support received at this stage; and once again just over a year after the stroke when maximum recovery from stroke had occurred and the short-term community support provided immediately after discharge had gone. The comparison non-carers would be interviewed just twice - once at baseline and then again after 13 months - as there was no comparable point to the carers' six-week post-discharge interview.

Chapter 6: Ethical considerations

"The dignity, rights, safety and well-being of participants must be the primary consideration in any research study." Department of Health, 2003b

6.1 The Research Governance Framework for Health and Social Care

The Research Governance Framework for Health and Social Care (Department of Health, 2003b) was originally developed by the Department of Health in 2001. It aims to promote good quality research and protect participants. The standards in the framework apply to all research concerned with health and social care systems in the UK. Standards relevant to this project include:

- All research involving patients, service users, care professionals or volunteers, should be reviewed independently to ensure it meets ethical standards.
- All studies must have appropriate arrangements for obtaining consent.
- All those involved in research must be aware of their legal and ethical duties in the use and protection of patient data.

Box 6.1: The four principles of biomedical ethics (Beauchamp T & Childress J, 2001):

1. Autonomy	*Respect for the person - a notion of human dignity* – Does my action impinge on an individual's personal autonomy? – Do all relevant parties consent to my action? – Do I acknowledge and respect that others may choose differently?
2. Beneficence	*Benefit to the research participant* – Who benefits from my action and in what way?
3. Non-maleficence	*Absence of harm to the research participant* – Which parties may be harmed by my action? – What steps can I take to minimise this harm? – Have I communicated risks involved in a truthful and open manner? – In the event of a disaster, how can I avert the possible harm caused?
4. Justice	*Equal distribution of risks and benefits between communities* – Have I identified all vulnerable groups that may be affected by my action? – Is my proposed action equitable? – How can I make it more equitable?

6.2 Ethical considerations in the context of this study

Before starting this project ethical approval was sought and gained from Southampton and South West Hampshire Local Research Ethics Committee (LREC), Portsmouth and South East Hampshire LREC and East Dorset LREC. There were several difficult ethical considerations in relation to this study which were resolved taking into consideration the four principles of biomedical ethics (Box 6.1, page 77 - Beauchamp and Childress, 2001).

6.2.1 Access to patient data:

I was not a hospital clinician working on the stroke units involved, so there would not be automatic right of access to the notes of patients on the stroke units. However, access to these notes without prior consent of the patients would be needed to be able to recruit the sample of carers. Respect for confidentiality is an essential requirement for the preservation of trust between patient and doctor, so should information be passed on for research purposes, especially if the person whose information is being used is not the subject of the study?

The Department of Health has published guidelines for healthcare staff about disclosure of information (Box 6.2, page 79 - Department of Health, 2003a) and there are several pieces of legislation which protect the confidentiality of patients:

- *The Human Rights Act (1998):* Establishes a right to 'respect for private and family life' and creates a general requirement to protect the privacy of individuals and preserve confidentiality of their health records.
- *Common law of confidentiality:* Built up from case law where practice has been established by individual judgments. The key principle is that information confided should not be used or disclosed further, except as originally understood by the confider, or with their subsequent permission, except in exceptional circumstances.
- *Data Protection Act (1998):* Imposes constraints on processing of personal information. It also requires personal data to be protected against unauthorised/ unlawful processing and accidental loss, destruction or damage.

*Box 6.2: Caldicott Principles for disclosure of patient information**

Caldicott Principles for disclosure of patient information:

- *Justify the purpose:* Patients may voluntarily agree to identifiable information about themselves being released to specific individuals for known purposes. Implied consent occurs when a patient who is aware their personal information may be shared and of their right to refuse, but makes no objection. Patients must have had a realistic opportunity to refuse. If patients refuse, it should be clearly documented and respected.
- *Don't use patient identifiable information unless it is absolutely necessary:* It is not necessary to seek consent to use anonymous information.
- *Use the minimum necessary patient identifiable information.*
- *Access to patient identifiable information should be on a strict "need to know basis".*
- *Everyone should be aware of their responsibilities.*
- *Understand and comply with the law.*

*Department of Health, 2003a

Taking this into consideration, an honorary contract was obtained for from the NHS Trust responsible for one of the participating stroke units for CS, the researcher. She was then technically a member of staff for the duration of the study. The hospital authorities at the hospitals participating in the studies stated at the time that it was only necessary to have one contract and there was no need for separate contracts with each of the participating hospitals.

The study also gained approval from the hospital authorities of both hospitals involved and the consultants directly responsible for the stroke patients' care. Research is a clinical activity and, as such, limited access to patient notes was granted to us. However, access was kept to the minimum needed to assess whether a patient's carer was suitable for the study. In all cases the ward clerk or a ward nurse was asked to supply the front sheet of the nursing index which usually contained all the information required for the study. If not, the patient's responsible nurse could usually supply missing any information.

Finding patients not on the stroke unit was more of a problem. However, in all cases the ward clerk accessed the hospital computer system on our behalf, and extracted only the information needed to know how to locate the patient.

Data on stroke admissions were provided by the hospitals in anonymized format. This meant that the project was supplied with a figure for the total number of patients admitted with a diagnosis of stroke during the time the project was running. There was no way of cross referencing that figure to the records obtained from the wards.

6.2.2 Carer considerations

Carers are a potentially vulnerable group. Many are elderly and frail themselves. Moreover, we would be approaching them to take part in this study at a time when a close family member of friend had just had a stroke. In a study like this it would be easy for a carer to feel coerced into taking part due to a fear that not participating might affect the care the stroke patient was receiving in hospital or the community support available after discharge.

In order to do avoid this, carers were supplied, where possible, with full information about the project (Appendix 8) before I contacted them. The information was in terms an elderly person could easily understand and information sheets were provided in large font type to enable those with poor eye sight to read them. Carers unable to read or understand the information sheets were given extra time with the researcher in order that the study could be explained fully.

In all cases, whoever supplied the information about the project, carers were given time to discuss the matter with friends or family and consider whether to take part, and an opportunity to discuss any worries about their participation in the project with the researcher. In all cases it was stressed to carers that help and support would be available whether or not they agreed to take part and would continue if they decided to withdraw from the study.

It was also felt that taking part in a study like this might place unnecessary additional burdens on carers already under strain. To minimize the burden on carers, carer's wishes with respect to timing and venue of interviews were accommodated as far as possible.

6.2.3 Confidentiality:

As carers might be afraid that if they said anything in criticism of the support received, it might adversely affect their care, it was stressed to carers that the researcher was independent from both the hospital they had been recruited from and their GP or other community services they would be involved with. Confidentiality was promised. Carers were told that nothing they said to the researcher would be passed on to their service providers except in summarised, anonymous and unidentifiable format.

6.2.4 Stroke patient considerations:

Support for carers cannot be viewed in isolation. Most formal support is provided for the person cared for and carer as a unit. Therefore discussing support provided to a carer often involves sharing information about the person being cared for too. Should the stroke patient be asked for consent too?

There are problems with asking for consent from stroke patients as well as carers. First this might exclude some of the carers likely to be under most stress – such as those with poor relationship with the person they cared for, or carers looking after stroke patients with cognitive or speech and language problems who could not understand sufficiently to give consent. Also some of the carers specifically wanted to be interviewed alone – asking for consent from the stroke patient would make that much more difficult.

After some deliberation a combination of strategies was used to get around this problem:

(a) Explaining the study to the stroke patient (wherever possible) before asking the carer to take part.

(b) Encouraging the carer to discuss the project with the stroke patient before consenting to take part.

(c) Allowing the stroke patient to be present at interviews if desired

(d) Excluding the carer from the study group if at any point the stroke patient objected to his or her participation in the study.

(e) Not including any questions about confidential information relating to the stroke patient

(f) Not including any direct assessments of the stroke patient.

6.2.5 Role conflict:

Although this was an observational study, it would be unethical not to act to help a carer or stroke patient if significant risk of harm (either mental or physical), which was not already being dealt with, was detected by the researcher during the course of the research work. To address this potential dilemma, a phrase was added to the consent form to allow the researcher to contact the carer's GP or social worker with the carer's permission, should this scenario arise.

As the researcher, CS was also an experienced general practitioner with additional experience in this field, another difficult ethical problem was the conflict between the researcher-role and doctor-role. Carers were not told that CS was a doctor in order that responses were not biased towards answers the carers thought a GP would like to hear. However, CS was likely to identify areas of care which could be improved to make the carer's life easier during the course of the interviews. Except where the carer was at risk of harm, it was decided that CS would just record the agreed observations during the study and inform the carer about additional benefits, information or services which might help after the final interview.

6.3 Summary

Carers are a potentially vulnerable group, as are the stroke patients they care for. This study raised several difficult ethical issues which needed to be addressed before it began, taking into consideration legislation in place at that time. Issues of concern included the right to access stroke patients' notes to recruit carers, worries about carers feeling coerced to take part in the study for fear of receiving a poorer standard of care or support if they did not, worries about asking carers about the health and support provided to the stroke patients they were caring for, worries that carers might not feel free to criticize care provided if they thought that the care providers would have access to the information they gave, and finally, worries about the dual role of the researcher as doctor and researcher.

These issues were resolved through:

- Ensuring CS had an honorary contract with the organizations involved with recruitment. As a staff member she was then able to access patient notes. The minimum amount of information needed was accessed in order to recruit carers.
- Providing full information to carers before they agreed to participate. Carers were then given time to make a decision about whether or not to take part. The information included a reassurance that not taking part in the study would not affect care or support received. It also included a reassurance that all information provided by the carer during the course of the study would be confidential and would not affect the care or support received.
- Obtaining written consent from each carer taking part.
- Defining the limits of the doctor and researcher roles of the researcher, taking into account potential problems identified in advance, in order to minimize problems with role conflict.

Ethical approval for the study was obtained from the Local Ethics Research Committees covering the area of the study.

Chapter 7: Sample size calculation

A crucial question in the planning stage of a study is how many subjects are needed.

7.1 The importance of the sample size calculation

Sample size calculations are important to ensure that if an effect deemed to be clinically or biologically important exists, then there is a high chance of it being detected, i.e. that the analysis will be statistically significant. If the sample is too small, even if large differences are observed, it may be impossible to show that these are due to anything more than sampling variation.

In the past many studies have been carried out with sample sizes too small to detect the effect they were designed to investigate. A study done in 1994 showed that roughly a quarter of published trials in major journals had "negative" results (Moher D, Dulberg CS, & Wells GA, 1994). Less than half of these trials had large enough sample sizes to detect clinically meaningful differences (Frieman JA et al., 1978; Moher D, Dulberg CS, & Wells GA, 1994). A good example is thrombolysis for acute myocardial infarction. Seventeen of the first twenty-two trials had non-significant results but subsequent meta-analysis showed a 19% reduction in early mortality (Lau J, Schmid CH, & Chalmers TC, 1995).

If this occurs, research time, participant effort and support costs invested in the study are wasted. It is therefore unethical to recruit patients into a study that does not have a large enough sample size for the trial to deliver meaningful information and ethics committees, major funding bodies (Medical Research Council, 2000) and major research guidelines (Altman DG et al., 2001; Department of Health, 2003b) all demand a clear statement of sample size together with justification of how that sample size was arrived at.

7.2 Which variables should be included in the sample size calculation?

The sample size calculation should relate to the study's primary outcome variable. If the study has secondary outcome variables which are also considered important, the sample size should also be sufficient for the analyses of these variables too. Separate sample size calculations should ideally be provided for each important variable.

This study was designed to investigate if there was a significant difference in psychological health between the carers of stroke patients in the community and matched non-carers. It also aimed to explore whether those carers satisfied with their formal community support differed in terms of psychological health from those dissatisfied with that support. Therefore in this study the primary outcome measure is the psychological health of the carer as measured on the CIS-R and sample size should be based on this measure.

7.3 Null and alternative hypothesis

Many statistical analyses involve the comparison of two treatments, procedures or subject types. The numerical value summarising the difference of interest is called the effect. Usually, the *null hypothesis* states that there is no effect (e.g. the difference is zero; the relative risk is one; or the correlation coefficient is zero). The opposite or *alternative hypothesis* states that there *is* an effect.

In this study the main outcome was the psychological health of the carers. Therefore the hypothesis was that there was a difference in psychological health between the groups being compared (carers and comparison non-carers in the first instance, those satisfied with care and those dissatisfied with care in the second instance). The null hypothesis was that there was no difference between these groups.

7.4 Probability value (p-value)

The p-value is the probability of obtaining the effect observed in the study (or one stronger) if the null hypothesis of no effect is actually true. It is usually expressed as a proportion (e.g. $p=0.03$).

7.5 Significance level

The significance level (α) is a cut-off point for the p-value, below which the null hypothesis will be rejected and it will be concluded that there is evidence of an effect. In other words it sets the likelihood of detecting an effect when no effect exists (leading to a "false-positive" result). Results with a p-value above the threshold lead to the conclusion that an observed difference may be due to chance alone, while those with a p-value below the threshold lead to rejecting chance and concluding that the factor in question - in this case being a carer - has a real effect.

The significance level is most commonly set at 5%. The significance level, although a p-value, is usually expressed as a percentage: $p=5\%$ is equivalent to $p=0.05$. This means the investigator is prepared to accept a 5% chance of erroneously reporting a significant effect or obtaining a “false-positive” result.

7.6 Power

Power $(1-\beta)$ is the probability that the null hypothesis will be correctly rejected i.e. rejected when there is a real difference or association. It can also be thought of as "100 minus the percentage chance of missing a real difference". Therefore, the higher the power is, the lower the chance of missing a real effect. By convention, power should not be less than 80%. However, a study power set at 80% accepts a likelihood of one in five of missing a real difference or obtaining a “false-negative” result.

7.7 Type I and type II errors

A Type I error occurs when the null hypothesis is rejected even though it is true (table 7.1). The probability of making a type I error is equal to the p-value and significance level. Using the most common situation in which significance level is 5%, if the p-value

Table 7.1: Type I and type II errors

		True state	
		Null hypothesis true	*Hypothesis true*
Decision based on statistical test	*Null hypothesis accepted*	Correct $(1-\alpha)$	Type II error (β)
	Null hypothesis rejected	Type I error (α)	Correct $(1-\beta)$

from a statistical test is less than 0.05, then the probability of making a Type I error is considered acceptably small.

A Type II error (β) occurs when the null hypothesis is not rejected even though the alternative hypothesis is true (table 7.1, page 86). One minus this error (1-β) gives the power of the statistical test.

7.8 Effect size

The effect size (δ) is a subjective measure - it is the difference the study aims to discover and therefore will vary according to the nature of the study. However, wherever possible a clinically meaningful effect size should be justified with evidence from past research or expert opinion (Burnand B, Kernan WN, & Feinstein AR, 1990). This study was aiming to examine whether being a carer has a clinically meaningful effect on the subjects exposed to it, so the effect size is the minimum relevant difference in outcome in terms of psychological health as measured on the CIS-R. The sample size should be set so that if such a difference exists, then it is very likely a statistically significant result would be obtained.

7.8.1 Comparing the carer group to the non-carer group:

When comparing the carer group to a population of non-carers this study wanted to detect a difference in the proportions classified as having poor psychological health, defined by a CIS-R score of greater than 12 (Lewis G et al., 1992), in each group. This is a binary measure – in other words participants either have a score greater than 12 or they don't.

From other studies of carers of stroke patients, 40% of carers of stroke patients are classified as having "poor psychological health"(Carnwath TCM & Johnson DAW, 1987; Coughlan AK & Humphrey M, 1982; Draper BM, 1992; MacKay A & Nias BC, 1979; Stein PN et al., 1992;Williams AM, 1993). From the National Psychiatric Morbidity Surveys of Great Britain (Jenkins R et al., 2003b; Meltzer H & Jenkins R, 1994) approximately 15% of the general population aged 16-64 years have a CIS-R score greater than 12. This is the *underlying population event rate.*

Although this study population would have a mean age older than this and depression does tend to increase with advancing age (Mirowsky J & Ross CE, 1992), similar proportions have been found in other community surveys of elderly people (Beekman AT et al., 1995; Copeland JR et al., 1999; Livingstone G, Manela M, & Katona C, 1997; Osborn DP et al., 2002).

Therefore the study needed to detect a difference of 25 percentage points between the two study populations of carers and comparison non-carers. In view of the fact that the normative population data for the CIS-R were based on a younger population and a higher proportion of non-carers might have CIS-R scores of greater than 12 in this study, sample size was calculated to detect a difference of 40% versus 20% (i.e. 20% difference or 0.2) between the two groups.

7.8.2 Comparison of the group of carers satisfied and dissatisfied with community support:

For comparison between groups of carers satisfied with their community support and dissatisfied with their community support, it was necessary to decide what degree of difference in scores between the two groups is clinically relevant. In other studies a difference in CIS-R score (as a continuous measure) of five or more points has been deemed of clinical significance (Jenkins R et al., 2003b; Meltzer H & Jenkins R, 1994).

7.9 One-sided and two-sided tests of significance

In a two-sided test, the null hypothesis states there is no effect, and the alternative hypothesis (often implied) is that a difference exists in either direction. In a one-sided test the alternative hypothesis does specify a direction. Two-sided tests should be used unless there is a very good reason for doing otherwise (Bland JM & Altman DG, 1994b).

In the context of this study there is considerable evidence that carers suffer poor psychological health as a result of their caring activities (see pages 16-29). The effect is unilateral. Therefore a one-sided test of significance was chosen to estimate sample size when comparing the psychological health of the carers with that of the controls.

On the other hand, it is unclear whether community support reduces or increases psychological distress of carers. Therefore in the sample size calculation for this comparison, a two-sided t-test was used.

7.10 Allowing for response rates and other losses to the sample

The sample size calculation should relate to the final, achieved sample of evaluable patients. Therefore, the initial numbers approached in the study may need to be increased in accordance with the expected response rate, loss to follow up, lack of compliance, and any other predicted reasons for loss of subjects. The link between the initial numbers approached and the final achieved sample size should be made explicit.

For the purposes of this study, it was likely some carers would be lost as a result of the stroke patient not returning home. Ten percent of stroke patients die within 30 days of their stroke (Bamford J et al., 1990). Most of these do not return home before death. Therefore a 10% drop out rate was included to allow for carers of patients in this group.

In addition, 80% of stroke patients who survive return home (Royal College of Physicians, 1998). In other words 80% of the 90% surviving 30 days will return home – 72% of the number whose carers had been potentially recruited. So a drop out rate of approximately 30% should be expected between identification of the carer and the first follow up interview after discharge home. This could be accommodated by continuing recruitment until the required number of stroke patients had gone home to be with their carers.

After return home, further carers would continue to be lost. There are many possible reasons for this – for example house moves, work or time pressure, illness, subsequent death of the carer or stroke patient or simply because they had changed their minds about participating. A further 10% of those admitted with a diagnosis of stroke will die more than 30 days post stroke in the year following stroke (Wolfe CD et al., 2000). Other factors which might result in loss of carers are hard to quantify but an estimate that a further 10% of carers would be lost for other reasons was made. So there would be an estimated loss of 20% of carers between the six week and thirteen months interviews for the purposes of sample size calculation.

7.11 Sample size calculation

Formal statistical advice about sample size calculation for this project was sought from Peter Smith, Professor in Social Statistics, Southampton University. In order to calculate sample size one assumes that the null hypothesis is false – in other words that an alternative hypothesis is true.

7.11.1 Sample size needed to compare carers with comparison non-carers:

The statistical test used to test for the association between two binary variables is the Pearson χ^2 test. The sample size required detecting a difference in proportions between two proportions p_1 and p_2 with power 1-β is calculated with a formula based on the Pearson χ^2 test. The z statistic resembles the χ^2 test, with one important difference: the z statistic can be one- or two-tailed, whereas the χ^2 test is always two-tailed. The sample size required to detect a difference between two proportions p_1 and p_2 with power 1-β using a one-sided test with significance level α is:

$$n = \frac{\{z_\beta \sqrt{p_1(1-p_1) + p_2(1-p_2)} + z_\alpha \sqrt{2\bar{p}(1-\bar{p})}\}^2}{(p_1 - p_2)^2}.$$

Where:

- n is the number in each group
- $\bar{p} = \frac{p_1 + p_2}{2}$
- z_α and z_β are the upper α and β percentage points of standard normal distribution (available from statistics tables and computer software packages).

From this formula it was calculated that 49 carers and 49 comparison non-carers would be needed to detect a difference in psychological health between the groups.

7.11.2 Sample size needed to compare satisfied and dissatisfied carers:

In a two group comparative study where the outcome measure is a continuous variable which is normally distributed, a two sample unpaired t test for comparison of means would be the statistical test used in the final analysis. Therefore a t-test is also used to estimate sample size (Campbell MJ, Julious SA, & Altman DG, 1995).

The sample size required for different values of the standardised difference d (where d is the effect size required (δ) divided by the standard deviation (σ), using a two-sided t-test is given by the formula:

$$n = \frac{2\sigma^2 (z_\beta + z_{1/2\alpha})^2}{(\mu_1 - \mu_2)^2}$$

Where:

- n is the number of subjects required in each group for a two sided significance (alpha) and power 1-ß.
- σ is the standard deviation of the scale
- μ_1 and μ_2 are the means of the two groups being compared
- z_β is the value that is exceeded by the proportion ß and $z_{1/2\alpha}$ is the value which is exceeded by a proportion 1/2α of a standard normal distribution.

The value of z terms can be found in tables or statistical packages. A level of 80% for the power of the study was selected for pragmatic reasons of manpower and time. This means that the study should have had a 4 in 5 chance of finding an effect if there was one. The significance level was set at 5%, meaning that the study should have a 1 in 20 chance of finding an effect when there was not one. For a two-sided t-test with 80% power and 5% significance levels:

- $z_{1/2\alpha} = 1.96$
- $z_\beta = 0.84$

In a UK sample, the standard deviation (σ) of scores on the CIS-R is 9.41 (Lewis G et al., 1992) and mean score is 13.1 (Lewis G et al., 1992). Using this formula and an effect size of 5 points ($\mu_1 - \mu_2 = 5$), 28 carers would be required in each group. However, for a given total sample size the maximum power is achieved by having equal numbers of subjects in the two groups (Campbell MJ, Julious SA, & Altman DG, 1995). In this study it would be unlikely that the same number of carers would be satisfied and dissatisfied. This is a less efficient design and an adjustment to sample size dependent on the allocation ratio must be made to accommodate it (Woodward M, 1992).

Hodgson (1996) found 84% of carers of stroke patients in the community were satisfied with formal support provision. However this was using a very crude measure of satisfaction (see page 37). Piloting data of the global satisfaction question being used for this study suggested 63% of carers are satisfied with their care. Other large scale surveys of mixed groups of carers give similar figures (Henwood M, 1998; Warner L & Wexler S, 1998).

Using the allocation formula (Campbell MJ, Julious SA, & Altman DG, 1995):

$$n_1 = \frac{n\,(r+1)}{2r}$$

Where:

- n_1 is the number of subjects required in group 1
- r is the allocation ratio (in this case 35/65 = 0.54)
- n is the number required in each group if group sizes were equal (in this case 28 carers)

The number required in the bigger group is 40 carers (i.e. the group satisfied with care) and the number required in the smaller group is 22 carers (i.e. the group dissatisfied with care). This gives a total sample size required of 62 carers. Allowing for 20% drop out in the carer group over the first year of follow up, the study should aim to recruit until 75 stroke patients went home to their carers. This would entail identifying 98 suitable carers from the hospitals involved. Applying a drop out rate of 10% to the comparison non-carers too, a total of 55 comparison non-carers would be needed.

7.12 Summary

For any study, it is important to ensure the sample size is large enough to detect the differences expected. For this study two sample size calculations were performed to ensure the sample size of both carers and comparison non-carers recruited was large enough to detect the main outcomes of interest. In both the significance level was set at 5% (i.e there would be a one in twenty chance of erroneously reporting a significant difference or 'false-positive') and the power was set at 80% (i.e. the chance of missing a real difference or reporting a 'false-negative' would be one in five).

The primary outcome measure was the psychological health of carers. Two aspects were of particular interest and a sample size calculation was performed for each. First, was there a difference in psychological health of carers and non-carers at different points during the caregiving experience? Second, was there a difference in psychological health between carers satisfied and dissatisfied with the community support received?

Based on the reported properties of the CIS-R and expected differences derived from information in other studies, 49 carers and 49 comparison non-carers would be required to asses a difference in psychological health between these two groups. However, 40 carers satisfied with community support and 22 dissatisfied with community support would be required to compare the group satisfied and dissatisfied with care, so a total of 62 carers would need to complete the study. To allow for the expected drop out rate from the cohort, it was estimated that 98 carers would need to be recruited from the hospitals involved and 55 comparison non-carers.

Chapter 8: Method

8.1 Recruiting carers:

Carers of stroke patients were identified through patient records from two major South Coast stroke units – Southampton acute stroke unit and Christchurch stroke rehabilitation unit. The ward clerks obtained a list of all those admitted to Southampton General Hospital and the Royal Bournemouth Hospital with a diagnosis of stroke in the previous two weeks. Each hospital was visited to view the list on alternate weeks – Southampton General Hospital one week, Christchurch Hospital the next.

This method of identification did not include patients admitted with a diagnosis other than stroke (such as collapse or fitting). Therefore the list of admissions to the stroke units involved was also checked on each visit and anyone admitted to the stroke unit who was not on the hospital admissions list was also included.

As only 36% of patients nationally with a diagnosis of stroke are admitted to a stroke unit (Intercollegiate stroke working party, 2002), patients not admitted to a stroke unit needed to be identified too. In Southampton the ward clerk has a list of "outliers" with a diagnosis of stroke who needed to be assessed by a member of the stroke team for suitability for admission to the stroke unit. This list was also checked. Unfortunately because the acute stroke unit is located in a different hospital in Bournemouth it was not possible to do the same there.

From the ward computers the ward clerk could immediately exclude all those who had died or were already discharged home and locate each patient. Once all the patients had been located, the front sheet of their nursing notes (in Southampton) or the admissions book (in Bournemouth) was checked to establish final diagnosis, whether this was a first stroke or not and whether there was an identifiable carer. At this stage it was possible to exclude those patients who:

- were not expected to survive their stroke
- had already had a stroke previously (i.e. this was not their first stroke)

- had their diagnosis changed after admission to something other than stroke
- had no identifiable carer

After checking care plans and discussion with ward staff it was then possible to exclude a further group who would not be going home as planning was already in progress for admission to residential care.

A letter was then addressed to each carer. This letter invited the carer to take part in the project. Enclosed with the letter were the information sheets about the project and a self-complete questionnaire recording "background information" (Appendices 8 and 2 respectively). A week after giving the carers the letter, the carers were telephoned and asked if they were willing to take part in the study. Carers were invited to ask questions about the study at this point.

If the carer agreed then an appointment was made for the first interview either at the carer's home or in the hospital. The carer was also reminded to fill in the background information questionnaire as this would be collected at the first interview. A further group of carers was excluded at this point because:

- the stroke patient had been discharged home between the letter being delivered and the phone call
- the stroke patient had died
- plans were underway to place the stroke patient into residential care on discharge
- the carer did not want to participate in the study

8.2 Carer consent

Written consent to take part in the study was obtained from each participating carer immediately before the first interview. By that stage the carer had usually had the information sheets for more than a week and had also had an opportunity to discuss the study on the telephone. Further opportunities for questions about the study were given before the consent form (Appendix 8) was signed.

8.3 Recruitment of comparison non-carers

Once carers were enrolled in the study and had completed their first two interviews, they were sent a request to identify a comparison non-carer (Appendix 8). This consisted of a letter to the carers asking them to think of a suitable control non-carer, an introduction letter and a copy of the background information questionnaire to pass on to the non-carer identified (Appendix 2), and a form for the carer to complete and return to the study headquarters (a pre-addressed stamped envelope was included for this purpose) providing contact details of the non-carer identified (Appendix 8). As the study needed a third more carers for the comparison of those satisfied and those dissatisfied with formal support, than were needed for the comparison of carers with non-carers, it was only necessary for two-thirds of the carers to identify a non-carer. The effects of this will be discussed later (pages 186 - 188).

Once details of comparison non-carers were received, the non-carers were telephoned and, if they agreed to take part, an appointment was arranged for the first interview. Written consent to take part in the study was obtained from each participating non-carer immediately before the first interview as for the carers.

8.4 Carer interviews

8.4.1 First carer interview:

Interviews were arranged by telephone as described on pages 94 - 95. At the first interview, the background information (enrolment) questionnaire (Appendix 2 and page 52) was collected. Some carers had difficulty filling it in and so, if carers had forgotten or were unable to do it, the questionnaire was completed with the carer.

The first interview, conducted whilst the stroke patient was still in hospital, was a fully structured face-to-face interview. Items included in the first questionnaire are indicated in table 8.1. All interviews took place either at the carer's home or in the hospital in which the stroke patient was an in-patient. In all but one case, when the carer requested an interview by the stroke patient's bedside, the stroke patient was not present during the interview. The whole interview together with the consent process took about an hour to complete. Responses were filled in on the questionnaire by the interviewer (in all cases this was me). Consent forms, background information questionnaires and first interviews were then collected together and filed in a brown envelope allocated to that carer in order to keep them together.

The CIS-R and PGC morale scale were included at this point to allow a pre-discharge measure of psychological morbidity to be recorded. The abbreviated mental test score was included to screen out carers with sufficient cognitive deficit to make them ineligible for participation. The social support questionnaire and relationship questionnaire were included to establish anticipated level of social support when the stroke patient went home and a measure of the relationship between the carer and stroke patient before the realities of "hands on" care had been able to alter it.

8.4.2 Six weeks after discharge follow up carer interview:

The second carer interviews, carried out six weeks after the stroke patients were discharged home from hospital, took place at the carers' homes and took 60-90 minutes to complete. The method of arranging these interviews varied between recruitment centres. In one centre it was easy to identify when the stroke patient went home as patients always go straight home from the ward. The carer was then telephoned four weeks after the stroke patient had been discharged to arrange the follow up appointment six weeks after discharge.

In the other centre it was much more difficult. There is no stroke rehabilitation unit at that centre so stroke patients may return straight home from the acute stroke unit or go on to specialist neurological rehabilitation units or peripheral community hospitals before eventually going home. Therefore carers recruited from that centre were contacted by telephone six weeks after the initial contact and asked what was happening. Often the carer was then able to give some indication of when the stroke patient was expected home so that an appointment could be arranged. If that was not possible, a further telephone call to update on progress was booked.

	Carers				Non-carers		
Questionnaire	***When enrolled***	***1st interview***	***2nd interview***	***3rd interview***	***When enrolled***	***1st interview***	***2nd interview***
Background information[1]	✓				*		
CIS-R[2]		✓	✓	✓		✓	✓
PGC Morale Scale[3]		✓	✓	✓		✓	✓
Lifestyle measures[4]		✓	✓	✓		✓	✓
Physical health measure[5]		✓	✓	✓		✓	✓
Cognitive function[6]		✓				✓	
Social support questionnaire[7]		✓	✓	✓		✓	✓
Quality of relationship questionnaire[8]		✓	✓	✓			
Activity restriction questionnaire[9]			✓	✓			
Oxford handicap scale[10]			✓	✓			
Quantity of formal support questionnaire[11]			✓	✓			
Global satisfaction question[12]			✓	✓			
Carer satisfaction with community support questionnaire[13]			✓	✓			

* Background information on age, gender and address was collected for non-carers

Notes:

1 page 51 and Appendix 2
2 page 51-54 and Appendix 3
3 page 58-59 and Appendix 4
4 page 57-58
5 page 55 and Appendix 5
6 page 56
7 page 59-60 and Appendix 6
8 page 61
9 page 61-62 and Appendix 7
10 page 63-64
11 page 64-65
12 page 66
13 page 66 and Appendix 1

Table 8.1: Questionnaires included in each interview

Questionnaires included in the interview are shown in table 8.1 (page 98). These measures were chosen so that early impact of caring on health could be documented. Social support and relationship measures were repeated to record how these had altered since the pre-discharge measures and the activity restriction questionnaire showed how usual activities had changed. The Oxford handicap scale measured the level of disability of the stroke patient, and whether the stroke patient was dysphasic or not was recorded based on carer report. Both the quantity and satisfaction with community support early after discharge were measured at this time point too.

8.4.3 Thirteen month after stroke follow up carer interviews:

Final interviews were carried out in the same way as six week follow up interviews. Carers were contacted 13 months after the anniversary of the stroke to arrange final interviews. Interviews took place in the carers' homes or any other suitable venue by agreement (two interviews were done at carers' places of work and one in a hospital ward where the carer had been admitted with a broken ankle). The interview was identical to that used at the six week follow up (table 8.1, page 98). The same measures were chosen to allow a direct comparison to be made with the carer's situation six weeks post discharge and 13 months post stroke.

8.5 Non-carer interviews

Initial interviews were performed at the homes of the non-carers and were very similar to the carers' first interviews. Non-carers were asked for their consent to take part and the background information questionnaire collected. Interviews took about one hour to complete. Questionnaires included are listed in table 8.1, page 98. The follow up interviews, performed 13 months after the initial interviews, were identical to the initial interviews with the omission of the abbreviated mental test score (which was included only to ensure the CIS-R could be used).

The social support questionnaire was included to allow a comparison in social support between carers and those not caring for anyone with a disability. The CIS-R, PGC morale scale and physical health measures were the main outcome measures for the study in terms of the health of the carer. A direct comparison between these measures for the carers and non-carers was needed to enable us to determine if any changes in health of the study population of carers was due to caring. If there was a similar change in health of the non-carers then the changes would be unlikely to be due to caring responsibilities and probably due to a common factor affecting both groups – for instance due to the aging process.

8.6 Data entry

When interviewing was complete each carer was allocated a number. Questionnaire data was entered onto computer using an Excel spreadsheet (Microsoft, 2003). Carers were not identified on the computer by name to ensure confidentiality. Subsequently appropriate parts of the data were transferred into the Statistical Package for Social Sciences (SPSS) version 11.5 (SPSS Inc., 2003) for data analysis.

Chapter 9: Analysis

9.1 Choice of statistical tests for analysis

In selecting a statistical test, the most important question is "what is the main study hypothesis?" In this case the main study hypotheses were:

1. Carers have poorer health than non-carers
2. Carers satisfied with their support have better health than those dissatisfied
3. Satisfaction with support is higher if there is more support

9.1.1 What types of data were being measured?

The statistical tests used should be determined by the data. Data can be split into quantitative variables ("how much?") and categorical variables ("what type?") (Swinscow TDV, 2002)

9.1.1.1 Quantitative variables:

Quantitative variables can be *continuous* or *discrete* according to whether the variable can take on all the values within the limits of the variable. In this study, the Oxford Handicap Scale is a discrete variable as responses can only take on the values 0, 1, 2, 3, 4, and 5 - the variable cannot have the value 1.7. Carer's age is a continuous variable as it can take on any value (e.g. 72 years 4 months).

9.1.1.2 *Categorical variables:*

Categorical variables may be *nominal (unordered)* or *ordinal (ordered)*. The difference between them is defined by whether or not the order of the categories is arbitrary. If there is no ordering, the variable is nominal, for example, the housing categories used for this study (1=flat, 2=bungalow, 3=house, 4=other). The order of the categories is arbitrary. Ordinal data are categorical data where there is a logical ordering to the categories, for example, the Likert scale used for the satisfaction survey in this study (1=Strongly disagree; 2=Disagree; 3=Neither agree nor disagree; 4=Agree; 5=Strongly agree). Quantitative variables can be converted into categorical variables using cut off points (e.g. ages 30-50 years; ages 50-70 years; older than 70 years – an ordinal variable).

9.1.2 Describing data

9.1.2.1 Quantitative variables:

Quantitative variables can be described in terms of *median, mean* and *standard deviation.* Median and mean are measures of location. The median (or mid point) is the point which has the property that half the data are greater than it, and half the data are less than it. The main advantage of using the median as a measure of location is that it is "robust" to outliers. The mean (or average) is the total of observed values divided by the number of observed values. A major disadvantage of the mean is that it is sensitive to outlying points.

In addition to measures of location, measures of range and spread are needed. The range is the difference between the smallest and largest value (usually recorded as smallest value – largest value). However this does not give any indication of where points lie within this range. When the population from which the data arise have a distribution that is approximately "normal", then the standard deviation provides a useful basis for interpreting the data in terms of probability. A range covered by one standard deviation above the mean and one standard deviation below it (±1SD) includes about 68% of the observations; a range of two standard deviations above and two below (±2SD) includes about 95% of the observations; and of three standard deviations above and three below (±3SD) about 99.7% of the observations.

9.1.1.3 *Categorical variables:*

Categorical data are described in terms of frequency of occurrence in each category. Certain statistical concepts are meaningless for nominal data. For example it would be inappropriate to ask what are the mean and standard deviation for type of housing. While computation of a median is justifiable for ordinal data, some statisticians have reservations about computing a mean for ordinal data (Swinscow TDV, 2002).

9.1.3 Are the data independent?

As a rule of thumb, results on the same individual, or from matched individuals, are not independent. Thus in this study the sequential results on individuals were not independent variables nor were the differences between subjects and matched controls. However differences between groups defined by another parameter (e.g. level of satisfaction) were independent.

9.1.4 Comparison of means

9.1.4.1 Independent sample t-test

The independent sample t-test compares means for two groups of cases using the same measure (. It assumes that means for the two groups are the same. The procedure involves calculating a test statistic called "t" which is a measure of how far apart the means of the two groups are in standard error units. The larger the t value the less likely it is that the means are the same i.e. the more likely it is that the groups are different in respect to that measure. In this study it was used to compare groups of carers split into two groups on the basis of another variable such as satisfaction with support, or gender.

9.1.4.2 The paired sample t-test

The paired-samples t-test compares the means of a given variable for related groups. It computes the differences between values of the two variables for each pair of cases and tests whether the average differs from zero. In this study it was used to compare variables for individual carers over time.

9.1.4.3 Ranked score tests

The t-tests described above assume that data are distributed normally. In general population studies the CIS-R is not normally distributed. It is slightly positively skewed (Lewis G et al., 1992). Therefore the data analysed with t-tests were also analysed using non-parametric tests to ensure any conclusions were valid. Wilcoxon and Mann and Whitney described rank sum tests used to do this. They have since been shown to be the same but convention has now ascribed the Wilcoxon test to paired data and the Mann-Whitney U test to unpaired data (Swinscow TDV, 2002).

9.1.5 Measures of association:

9.1.5.1 The chi-square test (χ^2 test)

A contingency table is a table showing the frequency of responses to each category of one variable as a function of another variable. For example, for each type of housing recorded (categorical variable 1), the number of people classified as smokers and non-smokers (categorical variable 2). Chi squared tests of independence are used to explore whether there is any relationship between the two (for example, is there a relationship between the type of housing and number of smokers?). The null hypothesis is that there is no relationship between row and column frequencies (Lewick P & Hill T, 2005).

The first step in computing the chi square test of independence is to compute the expected frequency for each cell under the assumption that the null hypothesis is true. The general formula for expected cell frequencies is:

$$E_{ij} = \frac{T_i \times T_j}{N}$$

Where:

- Eij is the expected frequency for the cell in row i and the column j,
- Ti is the total number of subjects in the i,
- Tj is the total number of subjects in the column j, and
- N is the total number of subjects in the whole table.

The difference between the observed values in each cell (O) and Expected value in each cell (E) can then be used to calculate the χ^2 statistic using the formula:

$$\chi^2 = \Sigma \frac{(E - O)^2}{E}.$$

The number of independent pieces of information that go into the estimate of a parameter is called the degrees of freedom (df). In the case of a contingency table as described above the number of degrees of freedom is equal to the number of rows minus one, multiplied by the number of columns minus one.

Using the χ^2 statistic and the degrees of freedom the probability of there being no association between the row and column frequencies can be calculated. If this probability is very low then the probability of there being an association is high. A variant of the χ^2 test is the McNemar test which compares paired categorical variables to determine association.

9.1.5.2 Correlation

Correlation denotes linear association between two continuous quantitative variables - one variable increases or decreases a fixed amount for a unit increase or decrease in the other. Degree of association is measured by a correlation coefficient (r), sometimes called Pearson's correlation coefficient. The correlation coefficient is measured on a scale that varies from + 1 through 0 to - 1. Complete correlation between two variables is expressed by either + 1 or -1. When one variable increases as the other increases the correlation is positive; when one decreases as the other increases it is negative. Complete absence of correlation is represented by zero (Lewicki P & Hill T, 2005). If a plot of the data reveals outlying points well away from the main body of the data, which could unduly influence the calculation of the correlation coefficient, or if the data are ordered categorical or discrete quantitative variables, a non-parametric procedure – the Spearman rank correlation should be used instead (Swinscow TDV, 2002).

9.1.5.3 Regression

The other technique that is often used in these circumstances is regression, which involves estimating the best straight line to summarise the association (Bland JM & Altman DG, 1994a). If two variables are related it means that when one changes by a certain amount the other changes on an average by a certain amount. If y represents the dependent variable and x the independent variable, this relationship is described as the regression of y on x. The independent variable can predict the dependent variable, but the dependent variable cannot be used to predict the independent variable.

Box 9.1: The regression equation

$$y_i=b_0+b_jx_{ij}+\ldots+b_px_{ip}+e_i$$

Where:

y_i is the value of the i^{th} case of the dependent scale variable
p is the number of predictors
b_j is the value of the j^{th} coefficient, $j=0,\ldots\ldots,p$
x_{ij} is the value of the i^{th} case of the j^{th} predictor
e_i is the error in the observed value for the i^{th} case

The regression equation (box 9.1), representing how much y changes with any given change of x, can be used to construct a *regression line* on a scatter diagram, and in the simplest case this is assumed to be a straight line (linear regression). The direction in which the line slopes depends on whether the correlation is positive or negative. Linear regression is therefore used to model the value of the dependent scale variable based on its linear relationship to one or more predictors.

It is possible that there is more than one independent variable related to the dependant variable. In such a case the method of predicting the value of the dependant variable based on the independent variable is known as multiple regression. So, multiple regression is used when the researcher wants to determine what variables contribute to the explanation of the dependent variable and to what degree. For this study, multiple regression was used to explore which (if any) background measures or patient measures were associated with satisfaction and later on with health of the carer.

In forward stepwise regression, independent variables are entered one at a time to the model. An R^2, multiple correlation statistic, is generated on each occasion. This represents the percentage of variance in the dependent variable explained collectively by all of the independent variables in the model. Since stepwise regression adds one variable at a time to the regression model, generating an R^2 value each time, subtracting each R^2 from the prior one gives the R^2 increment.

Partial correlation is the linear correlation between the proposed predictor (independent variable) and the dependent variable after removing the effect of the current model. Independent variables are added one by one in order of partial correlation with the dependant variable until the R^2 increment is no longer significant. Significance of R^2 increments are tested by the F-test. If $F < 0.5$ then the model is significantly better than would be expected by chance and the null hypothesis of no linear relationship of the dependent variable to the independent variable is rejected (Lewick P & Hill T, 2005).

9.2: Plan of analysis for this study

Data analysis was done using SPSS v. 11.5 and later SPSS v.13. Analyses are summarised in tables 9.1, 9.2, and 9.3.

9.2.1 Background questionnaire:

Background questionnaire data were simply described (table 9.1, page 108). Two financial measures were included in the background questionnaire – whether carers' finances were sufficient for their needs and approximate net monthly income. Correlations between these measures were explored as, if they correlated highly, only one measure would be used in subsequent analyses.

Information about type of housing was originally intended as a measure of social class. However, probably due to the nature of the population which tended to be elderly, the vast majority of carers, whatever their level of deprivation or income, owned their own homes. Therefore it was decided not to use this measure as a social index, but instead to use postcode data. Presence or absence of a warden was, however, still used in subsequent analyses.

Instead, deprivation data from the Department of the Environment, Transport and the Regions (2000) were used. These provided an index of multiple deprivation score (IMD).

Table 9.1: Plan of analysis of data collected from the background questionnaires.

Data	Planned analysis	Test used	Reason for analysis
Recruitment data	*Enumeration of:* • Admission figures to the hospitals concerned • Number of patients/carers recruited • Reasons for non-participation • Geographical spread • Reasons for failure to follow up	Enumeration	To describe the sample
Background questionnaire data	*Description of:* • Age of stroke patients • Age of carers • Gender of carers • Relationship of carers to stroke patients • Ethnicity • Education level • Self-reported income • Housing • Deprivation • Other caring responsibilities	Mean, median, range and standard deviation where appropriate (see page 102)	
	Association of: Self-reported family income and whether finances were sufficient for needs	Chi-square test – page 104-105	To confirm these measures were related.

It is based on scores collected for different areas in the subject areas:

- income (25%),
- employment (25%),
- health deprivation and disability (15%),
- education, skills and training (15%)
- housing (10%)
- geographical access to services (10%)

Figures in brackets denote the percentage each factor contributes to the final index score. Data are presented at ward level but it is a relatively simple procedure to convert postcode data to wards using the National Statistics on-line full geographic search facility (National Statistics, 2004). Using this method it was possible to allocate a deprivation score for each carer interviewed. As in many wards there was just one carer, presenting data at ward level brought up issues of confidentiality. Therefore data were broken down into major postcode areas (i.e. the first half of each postcode - SO16, BH6 etc.) and a summary of deprivation scores was calculated for each area.

9.2.2 First interview (pre-discharge):

Information collected at the first interview was analysed as described in table 9.2, page 110. As weight is something women tend to be more conscious of than men, data were additionally examined for a relationship between self-reported weight change and gender.

9.2.2.1 Factors independently associated with physical and psychological health:

As many factors might influence physical and/or psychological health of carers, a stepwise multiple regression technique (page 105-107) was used to explore which of the measures recorded might have an influence on carer health and the degree to which each of these contributed. Items were included one by one if they had been identified previously as factors which might influence carer health from the carer literature (see chapter 2). These items included: place of recruitment, gender, age of carer, deprivation score, smoking status, alcohol consumption, reported weight change, social support quality and quantity, and quality of relationship with the stroke patient.

9.2.3 Second interview (six weeks post discharge):

The plan of analysis for data collected at the second interview is presented in table 9.3, page 114. Data on self-reported smoking, alcohol consumption, weight change and social support were described again. A comparison was made between these measures pre-discharge and six weeks post discharge to see if there had been any change. For cigarette and alcohol consumption there was unlikely to be any change for those who did not drink or were teetotal. Therefore changes were examined only for the groups who did smoke or did drink alcohol at either time point. Data from other measures not used in the first interview were presented and plots made to demonstrate distribution where appropriate.

9.2.3.1 Level of handicap of the stroke patient:

As using carer report of level of handicap of the stroke patient is a slightly unorthodox way of measuring handicap (see pages 64 - 66), whether length of hospital stay of the

Table 9.2: Plan of analysis of data collected at the pre-discharge (first) interview.

Data	Planned analysis	Test used
Description of: • Smoking habits of carers • Alcohol consumption of carers • Reported weight change of carers	Provides direct and indirect measures of carer stress - see pages 58-59.	Mean, median, range and standard deviation where appropriate for carers and non-carers (where applicable) - see page 102
Association of: Reported weight change and gender	To confirm suspicions that these two measures would be associated	Chi-square test – page 104-105
Description and graphic representation of: • Social support questionnaire indices • Relationship scores • Physical health scores • Psychological health scores	To describe the sample and demonstrate parametric or non-parametric distribution of the data.	Mean, median, range and standard deviation where appropriate - see page 102
Comparison of carers and non-carers: • Physical health scores • Psychological health scores	To examine the effect of being a carer	• Independent t-test for continuous data – see page 103 • Mann Whitney U test for non-parametric data or ordered categorical data – see page 103 • Chi-squared tests for nominal categorical data – see pages 104-105
Comparison of carers recruited from different centres: • Physical health scores • Psychological health scores	To examine the effect of in-patient stroke care	
Comparison of male and female carers: • Physical health scores • Psychological health scores	To examine the effect of gender of the carer on health	
Examination of factors predicting health: • Physical health • Psychological health	To determine which measures are associated with carer health.	• Pearson's R or Spearman's rho for association of continuous variables –see page 105 • Independent t-test for comparing groups – see page 103 • Chi-square test for association of categorical variables – see pages 104-105 • Stepwise multiple regression analysis (page 105-107) –see page 109 for reasons for including variables within the models.

stroke patient correlated with level of handicap was examined. Length of stay is a crude measure of severity of stroke and thus should correlate with the reported level of handicap. If it did, it would give some additional legitimacy to this method of assessing handicap i.e. the measure was behaving as one would predict it would.

9.2.3.2 Amount and satisfaction with formal support provision:

Formal support levels were recorded both in terms of number of services involved (by counting the number of services mentioned on the questionnaire) and hours of involvement (calculated by totalling the number and length of encounters over the six weeks since discharge). In calculating the total amount of input in terms of time, hospital treatment was excluded if there was an overnight stay, as this was not community support and often provided for reasons which had nothing to do with support of the carer. Respite care was included in the time calculation as it was a service provided to support the carer.

Satisfaction with formal support was measured with both a global satisfaction question and the Carers satisfaction with community support services (CSCSS) questionnaire for reasons described on page 67. Results obtained using both measures were presented together with responses to individual items in the CSCSS questionnaire. This enabled areas of support provision which could be improved to be identified.

9.2.3.2.1 Effect of place of recruitment: The sample was split into those recruited in each of the recruitment centres and the two groups were compared to look at the effect of pre-discharge planning and location on service provision. The differences in individual service provision between the two recruitment centres were also examined to clarify this point further.

9.2.3.2.2 Effect of gender: As an additional analysis, the effect of gender on individual service provision was examined. This was done to corroborate or refute a chance finding in the pilot study, that district nurse support was more likely to be provided to male rather than female carers (Simon C., 2003).

9.2.3.2.3 Differences between carers satisfied and dissatisfied with community support: Using the global satisfaction scores, the study population was split into those satisfied with the care they received (i.e. saying they were satisfied or very satisfied) and those who did not say they were satisfied (i.e. those who were neither satisfied nor dissatisfied, dissatisfied, or very dissatisfied). The reason why this point was taken to split the study population was because there is a positive skew in responses towards a more satisfied response in all satisfaction studies. Therefore any deviation from this response suggests a degree of dissatisfaction (see pages 37 - 38).

The two groups created in this way were compared in terms of variables which might contribute to satisfaction – namely place of recruitment, age of carer, education level, income, availability of a warden, other care commitments, social support, activity restriction, quality of relationship with the stroke patient, level of handicap and amount of formal support.

9.2.3.2.4 Factors independently associated with provision of and satisfaction with community support: As many factors might influence the amount of support provided, a stepwise multiple regression technique (page 105 - 107) was used to find out which measures had an influence on the amount of service provision and the degree to which each of these contributed. Items were included in the model if the carer literature suggested that they might have an influence on support provision (see chapter 2). These included: age of carer and patient, level of education, income, deprivation, previous experience of care giving and other care commitments, quality of relationship with the stroke patient, activity restriction, social support quality and quantity, formal support quantity and cost, physical and psychological health of the carer, and level of disability of the stroke patient.

The same technique was used to create a regression model of factors predicting satisfaction score (as measured with the CSCSS questionnaire). Factors included were the same as those thought to be predictive of support provision.

9.2.3.3 Factors independently associated with physical and psychological health:

A stepwise multiple regression technique was used to explore which of the measures recorded might have an influence on carer health and the degree to which each of these contributed as for the pre-discharge interview (page 109). All the factors used in that model were included again with the addition of further items which had not been available previously - level of handicap of the stroke patient and provision of, and satisfaction with, care.

9.2.4 Third interview (13 months post discharge):

Data collected at the third interview were analysed in the same way as data collected at the second interview (table 9.3, page 114). Repeated measures were compared with those measures recorded at the second interview (and where relevant) at the first interview. In this way it was possible to build up a picture of change in social support, level of handicap and formal support over time and factors which might influence those parameters at given time points.

9.2.5 Further validation of the Carer satisfaction with community support services questionnaire:

As stated in chapter 4, this questionnaire was developed for this study and had only undergone a preliminary assessment of validity and reliability during the piloting phase. Therefore, data from this study were further analysed (as described in my MSc document – Simon C., 2003) to provide more evidence of validity, reliability and factor structure. Since these data do not have any direct bearing on the results of this study they are presented separately, together with information about the new questionnaire, in Appendix 1.

Table 9.3: Plan of analysis of data collected at the six weeks post discharge (second) interview and 13 months post stroke (third) interview.

Planned analysis	Reason for analysis	Test used
Description of and comparison with previously recorded: • Smoking habits of carers • Alcohol consumption of carers • Reported weight change of carers • Social support questionnaire indices • Relationship scores • Physical health cores • Psychological health scores	To describe the sample and examine change in indirect measures of stress and social support levels for carers (and controls where applicable) over time.	• Paired t-tests for continuous variables – page 103 • Marginal homogeneity test (an extended form of the McNemar test – page 105) for nominal categorical variables. • Wilcoxon signed ranks test for ordinal categorical variables – page 103
Description and graphic representation of[§]: • Activity restriction • Level of handicap • Amount and cost of formal support • Satisfaction with formal support	To describe the sample and demonstrate parametric or non-parametric distribution of the data.	Mean, median, range and standard deviation where appropriate (see page 102)
Comparison of carers recruited from different centres: • Amount and cost of formal support • Satisfaction with formal support • Individual service provision • Depression scores • Physical health scores	To examine the effect of pre-discharge planning and location on service provision	• Independent t-test for continuous data – see page 103 • Mann Whitney U test for non-parametric data or ordered categorical data – see page 103 • Chi-squared tests for nominal categorical data – see page 104-105
Comparison of carers and non-carers: • Depression scores • Physical health scores	To examine the effect of caring for a stroke patient	
Comparison of male and female carers: • Amount and cost of formal support • Satisfaction with formal support • Individual service provision • Depression scores • Physical health scores	To examine the effect of gender of the carer on service provision	
Comparison of carers satisfied and not satisfied with formal care: • Place of recruitment • Age of carer • Age of stroke patient • Education level • Income • Presence of a warden • Deprivation • Other care commitments • Social support questionnaire indices • Relationship scores • Activity restriction • Level of handicap • Amount and cost of formal support • Physical health scores • Psychological health scores	To examine demographic differences and differences in social support, disability (carer) load and amount of formal support between these two groups.	

Table 9.3 (Cont.): Plan of analysis of data collected at the six weeks post discharge (second) interview and 13 months post stroke (third interview).

Planned analysis	Reason for analysis	Test used
Examination of factors predicting provision of formal support services: • Amount of formal support • Cost of formal support • Satisfaction with formal support	To find out which measures have an influence on amount of service provision and the degree to which each of these contribute.	• Pearson's R or Spearman's rho for association of continuous variables –see page 105 • Independent t-test for comparing groups – see page 103 • Chi-square test for association of categorical variables – see page 104-105 • Stepwise multiple regression analysis (page 105-107) –see text for reasons for including variables within the models.
Examination of factors predicting health: • Physical health • Psychological health	To find out which measures have an influence on carer health and the degree to which each of these contribute.	• Pearson's R or Spearman's rho for association of continuous variables –see page 105 • Independent t-test for comparing groups – see page 103 • Chi-square test for association of categorical variables – see page 104-105 • Stepwise multiple regression analysis (page 105-107) –see text for reasons for including variables within the models.

§ For data collected from the third interview using these variables, there was no graphic representation and results using these measures were compared with results obtained using the same measures at the previous interview. Level of handicap was also correlated with length of hospital stay during analysis of second interview data as this is an indirect measure of disability and would lend validity to my disability measure.

Chapter 10: Recruitment and background data results

10.1 Recruitment

During the period of recruitment (November 2001 to November 2002), 593 patients were admitted either to the Royal Bournemouth Hospital or to Southampton General Hospital with a diagnosis of stroke. This figure does not include patients admitted with another diagnosis who subsequently received a diagnosis of stroke, but does include some patients admitted with a diagnosis of stroke which subsequently proved incorrect.

Of those patients admitted, 147 had carers who were suitable for inclusion and agreed to take part in the project. Table 10.1 shows the total number of patients identified during the recruitment phase of the project and reasons why they were not recruited. Nothing further is known about carers who were excluded or refused to participate.

Table 10.1: Stroke patients identified and reasons for non-inclusion in the study.

	Number	Percentage
Total number of stroke patients identified	*745**	*100%*
Reason for non-inclusion in the study:		
Patient factors:		*26.8%*
Dying or dead	79	10.6%
Diagnosis other than stroke	6	0.8%
Second or subsequent stroke	115	15.4%
Administrative factors:		*12.8%*
Discharged home before contacted	81	10.9%
Ward staff felt contact was inappropriate	3	0.4%
Unable to find the patient	7	0.9%
Unable to find the patient notes	4	0.5%
Residence factors:		*10.1%*
Admitted from residential care	56	7.5%
Discharge planned to residential care	17	2.3%
Patient and carer lived outside the study area	2	0.3%
Carer factors:		*30.6%*
No identifiable carer	71	9.5%
Distant carer identified (i.e. non-cohabitant)	83	11.1%
Patient or carer refused to participate	42	5.6%
Unable to contact the carer	21	2.8%
Carer unable to participate due to cognitive deficit / deafness	9	1.2%
No English	2	0.3%
Number recruited	*147*	*19.7%*

**This figure totals more than the admissions due to stroke as it includes additionally patients admitted with a diagnosis other than stroke (including transient ischaemic attack, collapse, fall, fractures, subdural haematoma, confusion, off legs and many others) who subsequently were diagnosed with stroke.*

Table 10.2: Carers who agreed to take part but were not interviewed

Reason for not being interviewed	Southampton	Christchurch
Stroke patient died	9	4
Stroke patient not going home	6	10
Discharge before interview	7	5
Other	1	
Total	*23*	*19*

Of the 147 carers who agreed to take part in the study, 105 underwent initial interviews. Figure 10.1, page 118 is a flow chart describing carer participation and losses to follow up. Of the 105 who underwent the initial interview, 47 (44.8%) were recruited from the Bournemouth Hospital system and 58 (55.2%) were recruited through Southampton Hospitals. Table 10.2 shows reasons why carers agreed to take part and then did not undergo their first interviews.

10.1.1 Geography:

The geographic spread of participants is recorded in Figure 10.2, page 119. All carers came from the BH and SO postcode sectors. Post code data were used to calculate deprivation scores (see page 107-109). Most participants recruited from Southampton came from the area immediately around the city. Patients recruited from Bournemouth came from a wider geographic area. There was some overlap of catchment areas of the two hospital systems in the New Forest.

Originally the intention was to look at Primary Care Group areas too, to investigate variation in community care services between them, but due to mergers into Primary Care Trusts and boundary changes over the period of the study, this proved impossible. Seven different social services departments covered the same area (three under direction of Dorset county council and four run by Hampshire County Council).

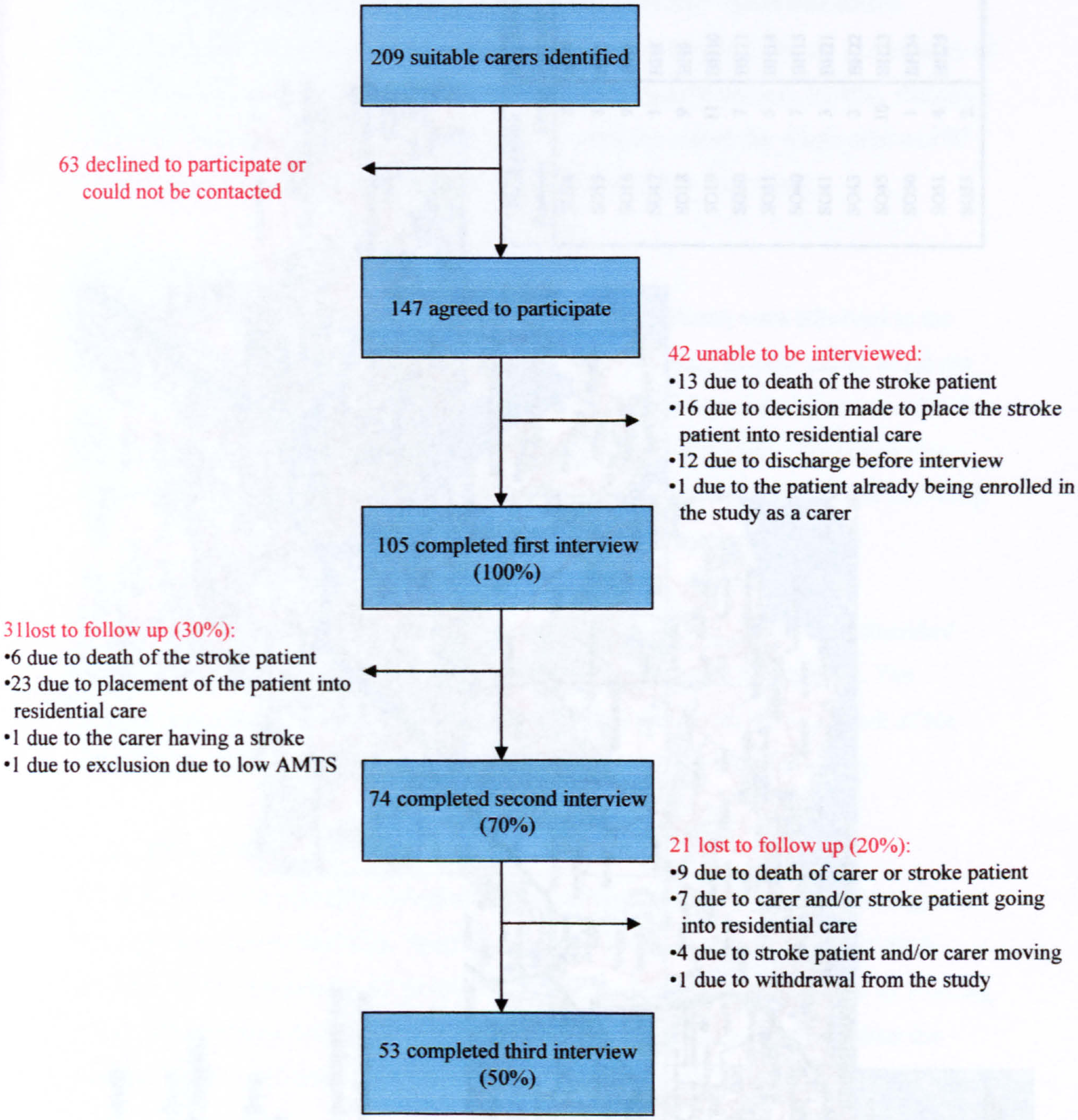


Figure 10.1: Flow chart of carer participation in this study

Figure 10.2: Study area map

▲ Participants recruited from Southampton General Hospital

▲ Participants recruited from Christchurch Hospital

▲ Carers who agreed to participate but did not undergo the initial interview

Southampton		*Bournemouth*	
Postcode	**Count**	**Postcode**	**Count**
SO14	3	BH4	1
SO15	8	BH5	1
SO16	9	BH6	2
SO17	1	BH8	2
SO18	9	BH9	4
SO19	11	BH10	4
SO30	7	BH11	6
SO31	5	BH14	1
SO40	7	BH15	1
SO41	3	BH21	1
SO43	3	BH22	4
SO45	10	BH23	12
SO50	1	BH24	12
SO51	4	BH25	12
SO53	2		

10.2 The self-complete "background information" questionnaire

The background information questionnaire was completed by 105 carers. A summary of results is included in table 10.3. Most carers were spouses (96 carers - 92.4%). Patients and carers were registered with 76 different GP practices across the whole area and 97 different GPs. No practice or GP was represented more than four times.

10.2.1 Ethnicity:

During the entire study period only five non-Caucasian patients were admitted to the study hospitals with a diagnosis of stroke. Two were excluded as their carers could not speak English, two were included and one died. One of the carers included was of Indian origin (Sikh); the other was of Chinese ethnicity but born in the UK. Only three carers interviewed were born outside the UK. This will be discussed later (see pages 185-186).

10.2.2 Employment:

As can be seen from table 10.3, most of the carers were retired. Those who classified themselves as unemployed were, in all cases but one, long-term housewives. The husband who classified himself as unemployed had given up his job as a result of his wife's illness in order that he could take care of her when she returned home.

10.2.3 Education:

The wording of the education question proved difficult for the carers due to changes in the education system over time. Most of the carers interviewed had completed their education before the advent of "O-levels" and "A-levels" and were confused by wording which included these terms. However, all but three carers eventually did answer the question – some after asking for clarification first. The results are recorded in table 10.3.

10.2.4 Finances:

The majority (81 carers – 77.5%) felt their finances were sufficient for their needs prior to the stroke. Self reported net monthly incomes are shown in table 10.3, page 120. As might be expected, there was a relationship between the carers' self-reported income and whether they felt their finances were sufficient for their needs (χ^2=7.319; df=2; p=0.026).

Table 10.3: Background information about carers undergoing first interview

Background variable		
Age	*Carers*	66.8 years (range 22 – 91; SD 12.4)
	Stroke patients	71.6 years (range 30-89; SD 10.9)
Gender	*Carers*	77 (73.3%) female: 28 (26.7%) male
	Stroke patients	29 (27.6%) female: 76 (72.4%) male
Relationship of carers to stroke patients	*Wife*	69 (65.7%)
	Husband	28 (26.7%)
	Child[a]	5 (4.8%)
	Other (partner, friend, sister)[b]	3 (2.9%)
Do the patient and carer see the same GP?	*Same practice, same GP*	70 (66.7%)
	Same practice different GPs	24 (22.9%)
	Different practice, different GPs	6 (5.7%)
Ethnicity	*Caucasian*	103 (98.1%)
	Sikh	1 (1%)
	Chinese	1 (1%)
	Born outside UK	3 (2.9%)
Employment	*Full time*	8 (7.6%)
	Part time	17 (16.2%)
	Retired	74 (70.5%)
	Unemployed	6 (5.7%)
Education	*No formal qualifications*	60 (57.1%)
	Basic qualifications; left school at 16y.	18 (17.1%)
	Higher level qualifications; left school at 18y.	14 (13.3%)
	Diploma	7 (6.7%)
	Degree	3 (2.9%)
Net family income	*<£1000 / month*	44 (41.9%)
	£1000-£2000/month	43 (41.0%)
	>£2000/month	12 (11.4%)
	Missing data	6 (5.7%)
Previous experience of caring?	*Yes*	33 (31.4%)
	No	72 (68.6%)
Other care commitments?	*Yes – other disabled adult*	7 (6.7%)
	Yes – child < 16y.	6 (5.7%)
	No	98 (93.3%)

[a] 2 daughters; 1 daughter-in-law

[b] 2 partners; 1 sister

Type of accommodation	*Warden*	*Owner occupied*	*Rented from local authority or housing association*	*Privately rented*	***Total***
House	0	55	2	0	**57 (54.3%)**
Bungalow	0	21	2	0	**23 (21.9%)**
Flat or maisonette	14	12	9	3	**24 (22.9%)**
Mobile home	0	1	0	0	**1 (1.0%)**
Total	**14 (13.3%)**	**89 (84.8%)**	**13 (12.4%)**	**3 (2.9%)**	

Table 10.4: Carer accommodation

At the time of recruitment, in seven cases the major breadwinner was the person who had the stroke. One carer, who was the major breadwinner, had already given up his job to look after his wife at the time of interview.

10.2.5 Accommodation:

Carers lived in a variety of different types of accommodation – see table 10.4.

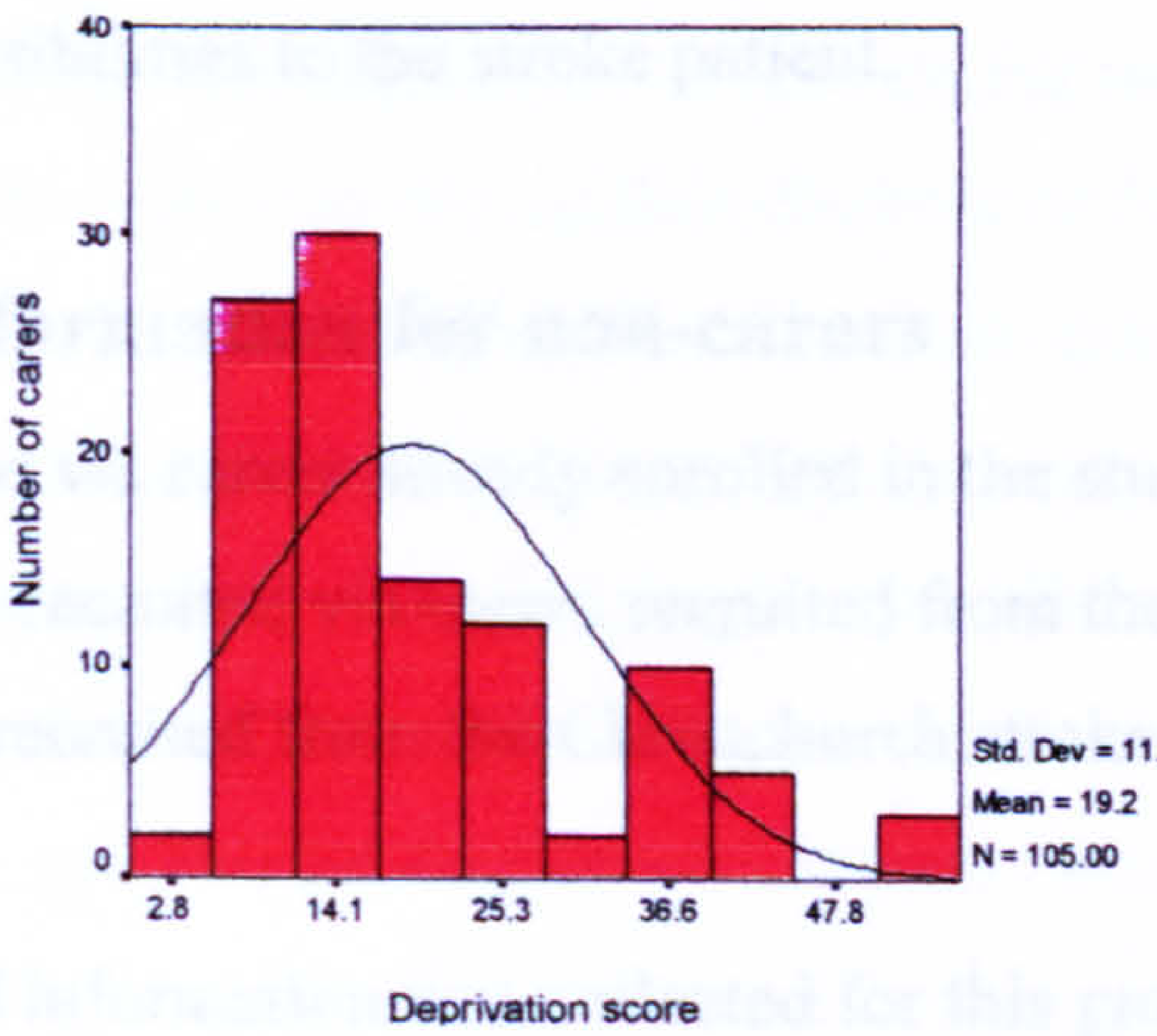


Figure 10.3: Deprivation score data for carers at the time of the first interview showing normal distribution of scores

10.2.6 Deprivation:

National data show that the average deprivation score for the whole of England and Wales using the Index of Multiple Deprivation (IMD) is 21.70 (range 1.16 – 83. 77 with lower numbers indicating less deprivation; SD 15.39) (Department of the environment, trade and the regions, 2000). Based on postcode data collected during interviewing (see Figure 10.2), the mean deprivation score for this sample was 19.18 (range 3.16-53.79, SD 11.55). Deprivation scores were normally distributed (see Figure 10.3, page 122)

10.2.7 Other caring responsibilities:

Of those that did have previous experience of caring, four (3.8%) had gained that experience in a professional capacity (as a nurse or home carer) and the rest (29 carers – 27.6%) had previously looked after a friend or relative with a disability or chronic illness.

Eighty-nine carers (85.6%) had children and 15 carers (14.3%) did not. The large majority (93 carers – 88.6%) no longer had their children living with them. Of those that did still have children living with them, nine carers (8.6%) had one child still living with them; two carers (1.9%) had two children in residence and one carer had three children in the home. Thirteen carers (12.4%) had either an ongoing commitment to child care or an ongoing commitment to caring for another sick or disabled person in addition to their impending caring responsibilities to the stroke patient.

10.3 Background information for non-carers

Non-carers were recruited via carers already enrolled in the study. Of the 50 non-carers recruited, 31 (62%) were recruited via carers recruited from the Southampton stroke unit, and 19 (38%) via carers recruited from the Christchurch stroke unit.

Only limited background information was collected for this group as many questions such as those about the quality of relationship with the stroke patient and previous care giving responsibilities did not apply. Table 10.5, page 124, is a summary of background data collected for the non-carers and their matched carers. There was no significant

Table 10.5 Background data collected for non-carers and their matched carer group

	Non-carer	**Carer**
Age	65.3 years (range 31-86 years; SD 12.56)	66.3 years (range 32-88 years; SD 11.90)
Gender	13 male (26%); 37 female (74%)	14 male (28%); 36 female (72%)
Deprivation scores	17.8 (range 3.16-53.79; SD 10.67)	19.6 (range 5.73-53.79; SD 12.43)

difference between the carer and non-carer groups in terms of age (t=0.425, p=0.672), deprivation scores (t=0.766, p=0.445) or gender (χ^2=0.051, df=1, p=0.822).

10.4 Summary

During the period of recruitment (November 2001 to November 2002), 593 patients were admitted to the recruitment centres with a diagnosis of stroke. Of those patients admitted, 147 had carers who were suitable for inclusion and agreed to take part in the project and 105 of those underwent the first interview.

The carers came from a wide geographical area and were registered with 76 different GP practices across the whole area and 97 different GPs. The vast majority (98%) were Caucasian and most (70.5%) were retired. Other care giving responsibilities were held by 12.4% of carers - either for a child or for another disabled or frail adult. Income was sufficient for needs for 77.5% prior to the stroke. Postcode data were used to calculate deprivation scores and this showed that the sample had a mean IMD score of 19.18 compared to a National mean IMD score for England and Wales of 21.70. Comparison of carers with their controls showed that the control group was well-matched with no significant differences in age, gender or deprivation scores between the two groups.

Chapter 11: Results from the first interview

Average time between admission and first interview was 54.4 days (range 9 – 146 days; SD 28.6 days) – see Figure 11.1, page 126. There were many reasons for this delay. First many stroke patients spent some time on other wards or even in other hospitals before being identified as having a stroke and/or being referred to the stroke unit. For example one stroke patient spent nearly three months in a specialist neurological unit before being referred to the stroke unit; another suffered his stroke abroad.

Secondly the recruitment procedure introduced a considerable delay. Carers were only identified in each location once every two weeks. If they were not available on the ward at that time, information was left with ward staff to be passed on to the carers when they did come in to see the stroke patient. This could take some time. Then, once carers had received the information, the carers were contacted to arrange an appointment if they wished to participate. Contacting carers could also be difficult as the carers were frequently out for much of the day visiting the hospital.

Lastly, once carers had been contacted and agreed to participate, there was often still further delay. As CS was the only interviewer, and the carers were often busy with appointments with many other health professionals in relation to the stroke, it was common for there to be no mutually convenient time slot for a meeting for several weeks.

11.1 Pre-existing disability of the stroke patient

Nine carers reported that the stroke patient had significant pre-existing disability which had required care from the carer before the stroke. Their conditions were:

- Dementia
- Liver disease
- Severe angina and valvular heart disease
- Amputation of a leg
- Severe ulcerative colitis
- Bowel cancer (with colostomy)
- Severe vertigo causing unsteadiness
- Severe asthma
- Blindness

Figure 11.1: Timing of interviews relative to stroke, discharge home and each other

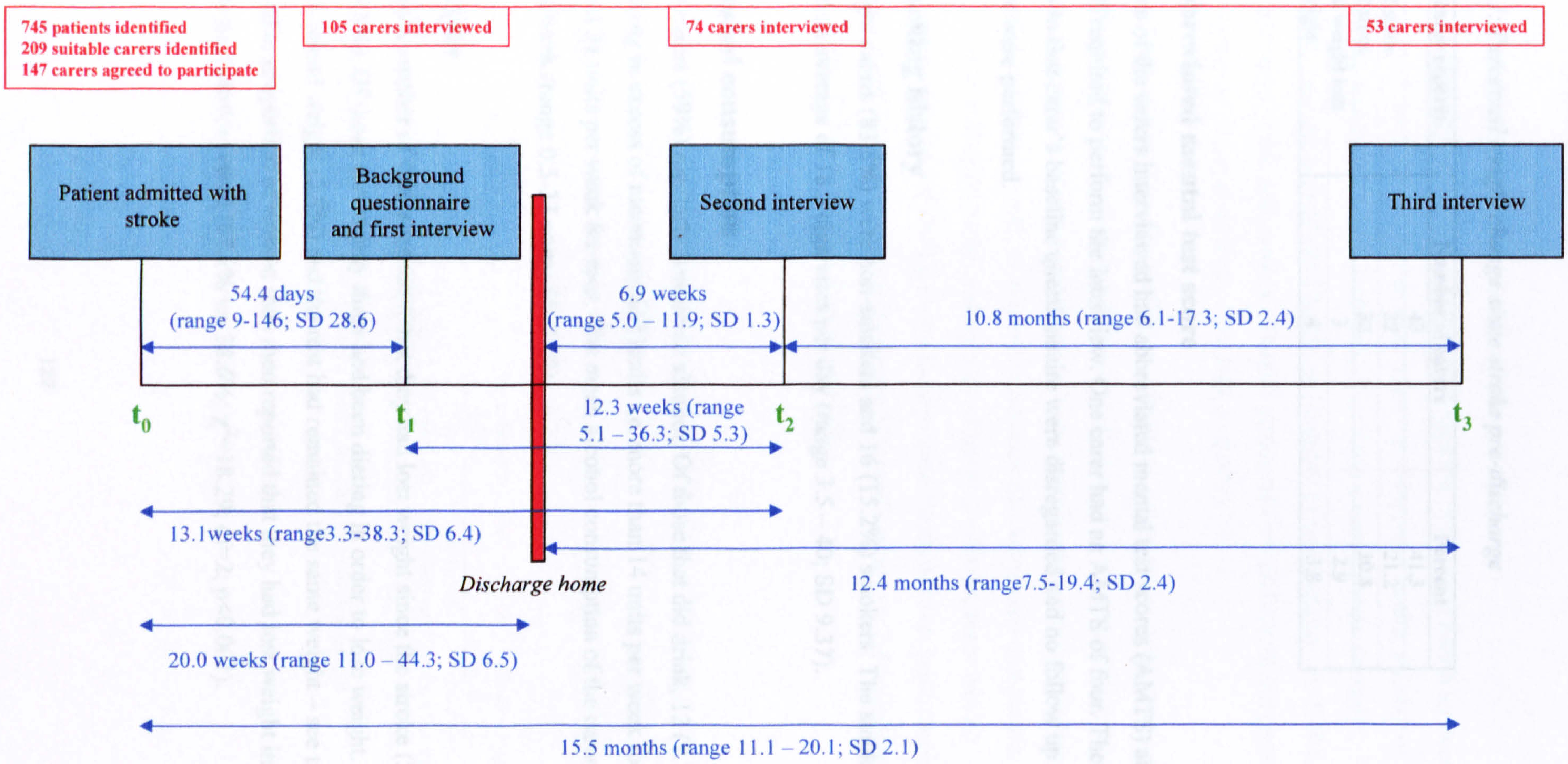


Table 11.1: Perceived weight change since stroke pre-discharge

Weight (carer report)	Number of carers	Percent
Same	43	41.3
Lost < 1/2 stone	22	21.2
Lost > 1/2 stone	32	30.8
Intentional weight loss	3	2.9
Gained weight	4	3.8

11.2 Abbreviated mental test score

All but one of the carers interviewed had abbreviated mental test scores (AMTS) above the cut-off required to perform the interview. One carer had an AMTS of four. The responses to that carer's baseline questionnaire were disregarded and no follow up interviews were performed.

11.3 Smoking history

Eighty-eight carers (83.8%) were non-smokers and 16 (15.2%) smokers. The smokers consumed an average of 18.5 cigarettes per day (range 3.5 – 40; SD 9.37).

11.4 Alcohol consumption

Sixty-one carers (59%) regularly consumed alcohol. Of those that did drink, 12 (7.7%) were drinking in excess of recommended limits i.e. more than 14 units per week for women and 21 units per week for men. The mean alcohol consumption of the carers was 5.84 units/week (range 0.5-33 units; SD 7.07).

11.5 Weight

A substantial number of carers reported that they had lost weight since the stroke (57 carers; 54.8%). Of those carers only three had been dieting in order to lose weight. Four carers had gained weight (3.8%) and the rest had remained the same weight – see table 11.1. A higher proportion of women than men reported that they had lost weight in the immediate post-stroke period (67.1% vs. 28.6%; $\chi^2=18.29$; df=2; p<0.001).

11.6 Physical health

Before the study it was difficult to select a valid measure of physical health so three different measures were run alongside each other - self-reported health, number of medications and number of health problems. The three measures were strongly correlated with each other (self-rated health and number of medications - r=-0.408, p<0.001; self-rated health and number of health problems - r=-0.410, p<0.001; number of health problems and number of drugs - r=0.609, p<0.001).

At baseline there was no significant difference between carers and matched non-carers in terms of any measure of physical health (table 11.2). Amongst the carers, there was also no difference in physical health according to which centre they were recruited from (Southampton or Bournemouth) or whether or not they had nominated comparison non-carers. In terms of self-rated health and number of health problems, there was no difference between male and female carers though male carers were on more medications on average at baseline than female carers (mean 3.39 medications vs. 2.04 medications, t=2.670, p=0.008, 95% CI: 0.409-2.298) at baseline.

	Mean score for carers (SD)	**Mean score for non-carers (SD)**	**Effect of being a carer**	**Effect of gender**	**Effect of place of recruitment**
Self-rated health	3.45 (1.056) *Range 1-5*	3.42 (1.357) *Range 1-5*	t=0.336 *(2-tailed sig. 0.737)*	t=-1.158 *(2-tailed sig. 0.249)*	t=-0.735 *(2-tailed sig. 0.464)*
Number of medications	2.40 (2.23) *Range 0-12*	2.20 (2.29) *Range 0-8*	t=0.217 *(2-tailed sig. 0.829)*	t=2.843 *(2-tailed sig. 0.005)*	t=-1.523 *(2-tailed sig. 0.131)*
Number of health problems	1.66 (1.26) *Range 0-5*	1.68 (1.54) *Range 0-6*	t=-0.496 *(2-tailed sig. 0.621)*	t=-0.593 *(2-tailed sig. 0.555)*	t=-0.638 *(2-tailed sig. 0.525)*

Table 11.2: Physical health scores for carers and non-carers pre-discharge

Note: Results highlighted in red denote significant results (p<0.05).

Figure 11.2: Distribution plots for the three physical health measures used in this study

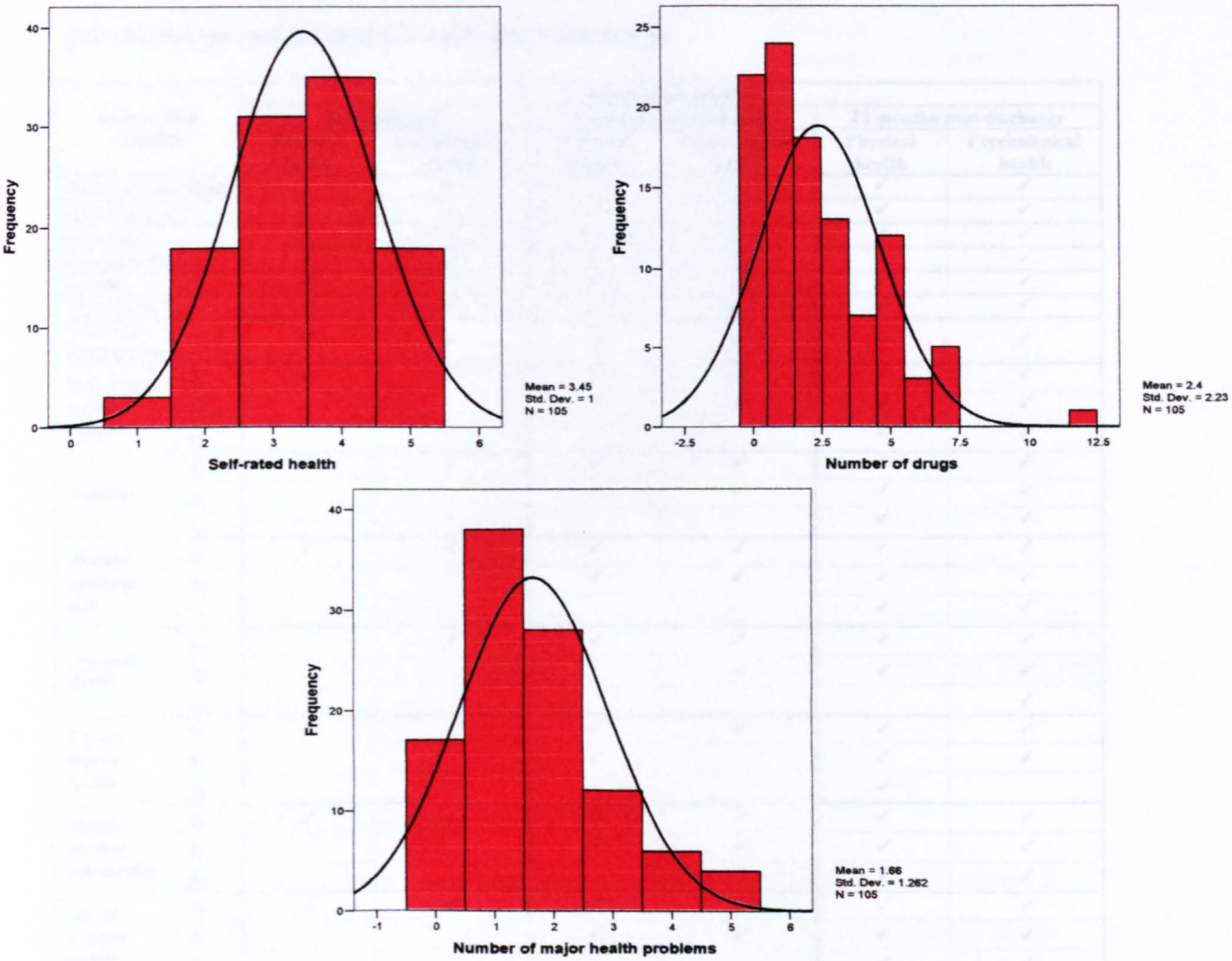


Figure 11.3: Distribution plots for the psychological health measures used in this study

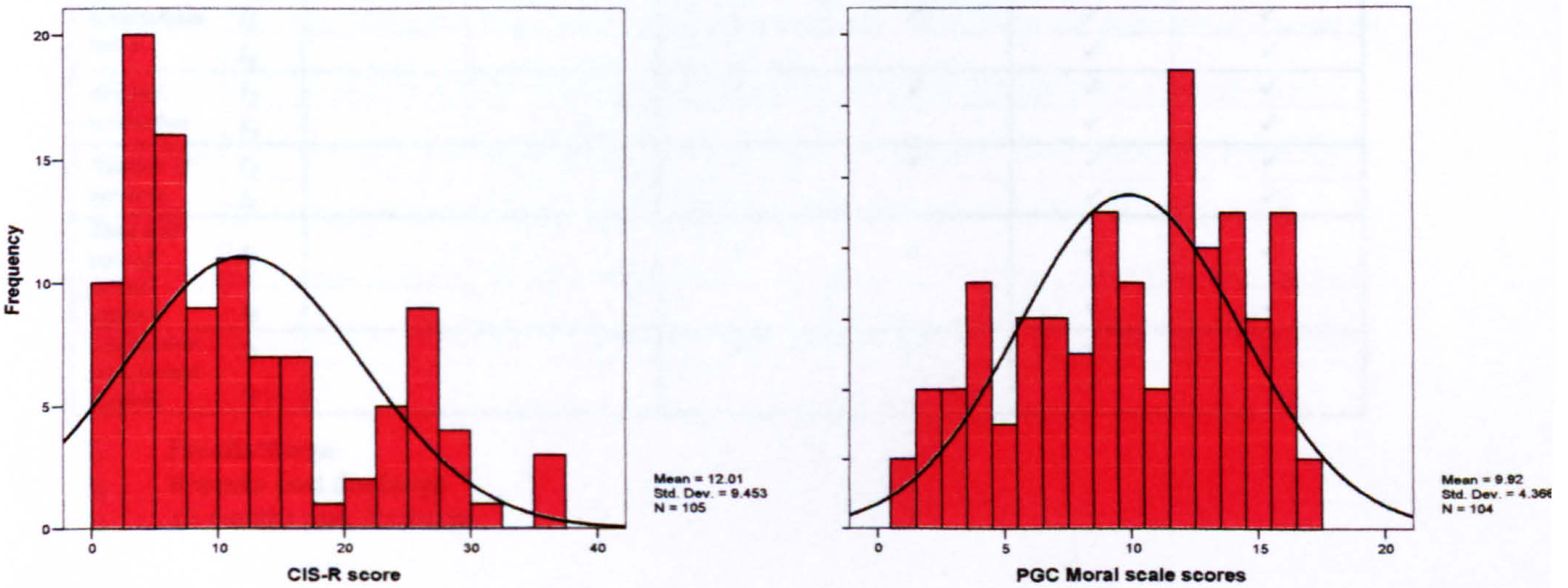


Table 11.3: Independent variables entered into the regression models for health of carers pre-discharge and six and 13 weeks post-discharge

Independent variables		Dependent variables					
		Pre-discharge		6-weeks post-discharge		13 months post-discharge	
		Physical health	Psychological health	Physical health	Psychological health	Physical health	Psychological health
Place of recruitment		✓	✓	✓	✓	✓	✓
Gender of carer		✓	✓	✓	✓	✓	✓
Carer age		✓	✓	✓	✓	✓	✓
Education level		✓	✓	✓	✓	✓	✓
Income		✓	✓	✓	✓	✓	✓
Deprivation		✓	✓	✓	✓	✓	✓
Other care commitments		✓	✓	✓	✓	✓	✓
Perceived weight change	t_1	✓	✓	✓	✓	✓	✓
	t_2			✓	✓	✓	✓
	t_3					✓	✓
Smoking	t_1	✓	✓	✓	✓	✓	✓
	t_2			✓	✓	✓	✓
	t_3					✓	✓
Alcohol consumption	t_1	✓	✓	✓	✓	✓	✓
	t_2			✓	✓	✓	✓
	t_3					✓	✓
Physical health	t_1		✓	✓	✓	✓	✓
	t_2				✓	✓	✓
	t_3						✓
Psychological health	t_1	✓		✓	✓	✓	✓
	t_2			✓		✓	✓
	t_3					✓	
Social support availability	t_1	✓	✓	✓	✓	✓	✓
	t_2			✓	✓	✓	✓
	t_3					✓	✓
Social support quality	t_1	✓	✓	✓	✓	✓	✓
	t_2			✓	✓	✓	✓
	t_3					✓	✓
Total relationship score	t_1	✓	✓	✓	✓	✓	✓
	t_2			✓	✓	✓	✓
	t_3					✓	✓
Activity restriction	t_2			✓	✓	✓	✓
	t_3					✓	✓
Number of services	t_2			✓	✓	✓	✓
	t_3					✓	✓
Time and cost of formal support	t_2			✓	✓	✓	✓
	t_3					✓	✓
satisfaction with formal support	t_2			✓	✓	✓	✓
	t_3					✓	✓

t_1 Pre-discharge
t_2 6 weeks post discharge
t_3 13 months post discharge

Table 11.4: Psychological health scores for carers and non-carers pre-discharge

	Mean score for carers (SD)	**Mean score for non-carers (SD)**	**Effect of being a carer**	**Effect of gender**	**Effect of place of recruitment**
CIS-R score	12.01 (9.45) *Range 0-36*	7.52 (5.548) *Range 0-23*	t=2.405 *(2-tailed sig. 0.018)*	t=-2.571 *(2-tailed sig. 0.018)*	t=1.364 *(2-tailed sig. 0.175)*
PGC Morale Scale	9.92 (4.37) *Range 1-17*	11.02 (4.42) *Range 2-17*	t=0.170 *(2-tailed sig. 0.866)*	t=2.335 *(2-tailed sig. 0.021)*	t=-1.021 *(2-tailed sig. 0.310*

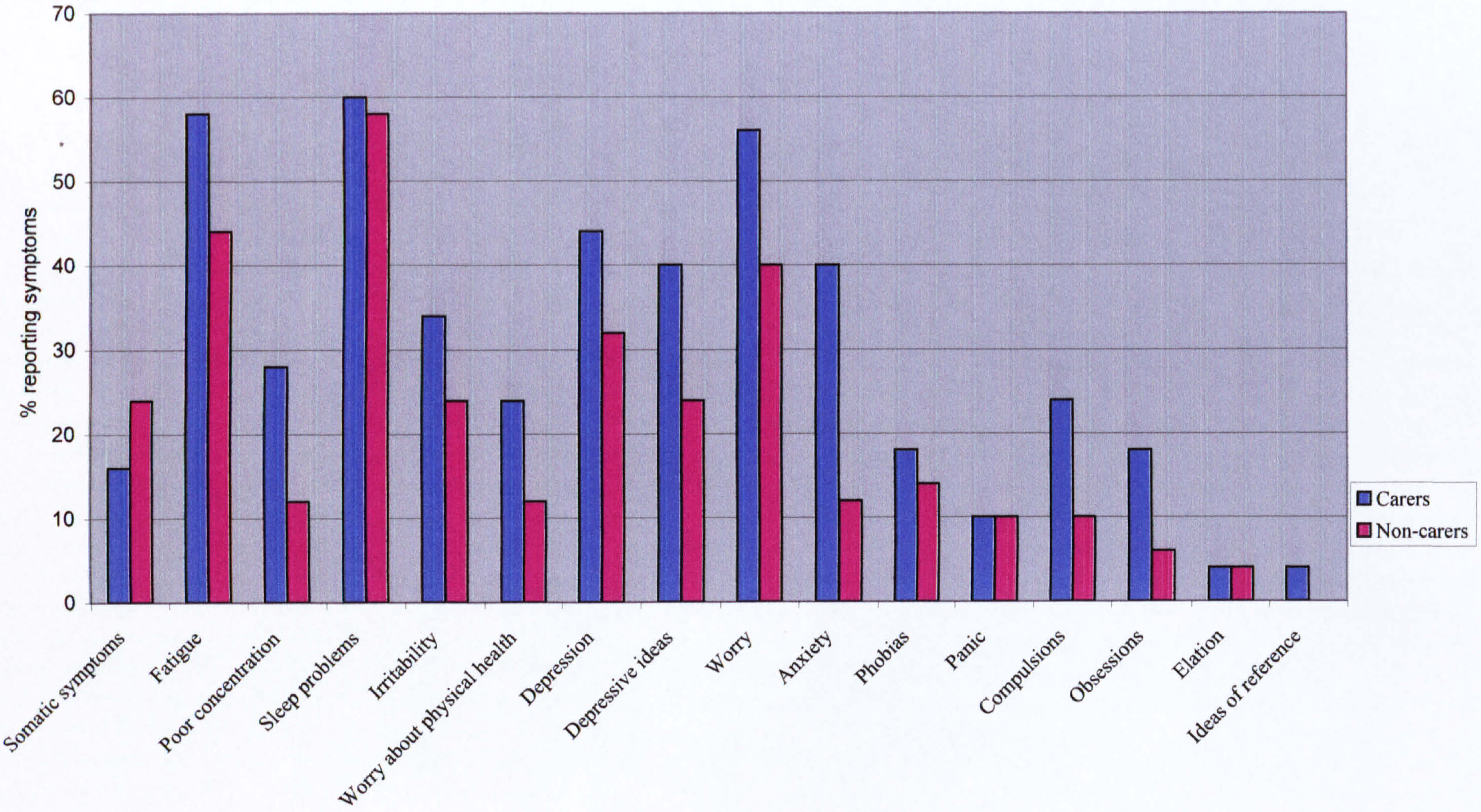
Note: Results highlighted in red denote significant results ($p<0.05$).

Stepwise regression analysis entering the variables listed in table 11.3 (page 130) revealed that the age of the carer was the only predictor of self-rated physical health status, number of drugs and number of major health problems accounting for 4.2% ($R^2=0.042$, F=4.168, p=0.044), 14.8% ($R^2=0.148$, F=16.268, p<0.001) and 8.7% ($R^2=0.087$, F=8.920, p=0.004) of the variance respectively. For all three measures, the older the carer, the worse the physical health (r=-0.279, p=0.004; r=0.390, p<0.001; and, r=0.352, p<0.001 respectively).

11.7 Morale and psychological health

At baseline there was already a difference between carers and matched non-carers in terms of psychological health (table 11.4) with the carers having significantly higher CIS-R scores indicating greater psychological distress (mean 11.16 vs. 7.52, t=2.405, p=0.018, CI: 0.628-6.652) than the matched non-carers. Thirty-seven percent of carers as opposed to 16% of non-carers had significant psychological distress (i.e. CIS-R score >12) and 24% of carers as opposed to 15% of non-carers had CIS-R scores in the range which would suggest they require treatment for their distress (i.e. CIS-R score >17). There was no significant difference in CIS-R scores between carers who had nominated non-carers and those who had not (mean CIS-R scores 11.16 vs. 12.78 respectively, t=-0.877, p=0.382).

Figure 11.4: Distribution of psychological symptoms in carers and comparison non-carers at baseline



The CIS-R scores and PGC Morale scores were strongly correlated ($r=-0.730$, $p<0.001$) but there was no difference in PGC morale scale scores (mean 11.02 vs. 11.16, $t=0.170$, $p=0.886$) at baseline between carers and matched non-carers. However, carers who had nominated comparison non-carers had significantly higher morale than those who had not (mean morale scores 11.16 vs. 8.78 respectively, $t=2.877$, $p=0.005$, CI: 0.740-4.025)

The distribution of psychological symptoms amongst carers and matched controls is shown in Figure 11.4. The symptoms reported more commonly amongst carers compared to controls, ranged from depressive symptoms including fatigue, poor concentration, irritability, depression and depressive ideas, to anxiety symptoms including worry, anxiety and obsessions and compulsions. Although many carers complained of sleep problems, this complaint was equally common amongst the matched controls.

Amongst the carers, there was no difference in psychological health according to which centre they were recruited from. Male carers tended to have lower CIS-R scores and higher PGC Morale scale scores than female carers, indicating less psychological distress (mean 8.18 vs. 13.40, $t=-2.571$, $p=0.018$, 95% CI: -9.254 - -1.194 and mean 11.54 vs. 9.33, $t=2.335$, $p=0.021$, 95% CI: 0.332 - 4.081 respectively). As it was known that the CIS-R data were slightly positively skewed (see figure 11.3, page 129 for the distribution plots for the data in this study), all these analyses were repeated using non-parametric tests but this made no difference to the findings.

Stepwise regression analysis using the same parameters as for physical health (see table 11.3, page 130) revealed that perceived weight change since stroke and quality of social support were the only factors independently associated with the CIS-R and PGC Morale score. Perceived weight change since stroke accounted for 11.1% of the variance in CIS-R ($R^2=0.111$, $F=11.715$, $p=0.001$) and 13.3% of the variance in PGC Morale score ($R^2=0.133$, $F=14.446$, $p=<0.001$). Carers reporting weight loss had a mean score of 14.26 on the CIS-R compared to 9.04 for carers not reporting weight loss, and a mean score of 8.75 on the PGC Morale scale compared with a score of 11.32 for carers not reporting weight loss.

Quality of social support accounted for 8.5% of the variance in CIS-R (R^2=0.085, F=9.879, p=0.002) and 5.1% of the variance in the PGC morale score (R^2=0.051, F=5.867, p=0.017). The higher the quality of social support reported, the lower the CIS-R score (r=-0.247, p=0.011) and the higher the morale of the carer (r=0.198, p=0.045).

11.8 Social support

The social support availability index was calculated by dividing the sum of the number of informal helpers identified in response to each question in the questionnaire by the number of questions answered. Since the maximum possible number of persons that a carer could identify in response to any question was nine, this meant that the potential range of scores on this index was 0 – 9 with nine representing a high level of available informal support. Results are presented in table 11.5.

Table 11.5: Social support at the first interview

	Availability of support index				**Quality of support index**			
	All carers	*Carers without controls*	*Carers with controls*	*Controls*	*All carers*	*Carers without controls*	*Carers with controls*	*Controls*
Range	0.17-5.00	0.17-4.33	0.33-5	0.33-6	2.33-6.00	2.33-6.00	2.83-6.00	2.33-7.20
Mean	1.59	1.49	1.70	1.35	5.36	5.11	5.62	5.33
Median	1.37	1.33	1.55	1.17	5.83	5.33	6.00	5.80
Standard deviation	0.94	0.94	0.95	0.99	0.89	0.92	0.78	1.05

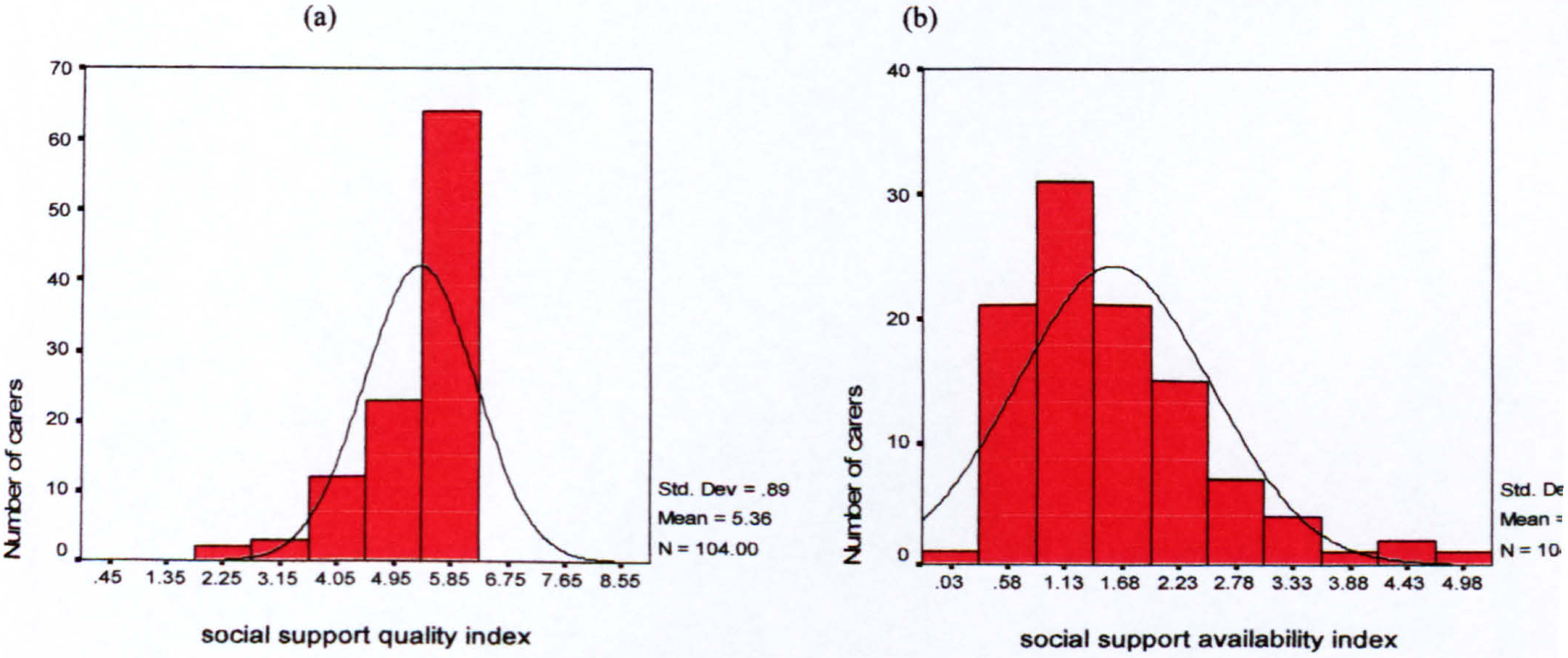
The quality of support index was calculated by dividing the total quality of support score by the number of questions answered. Thus the minimum score on the quality of support index was zero and the maximum six, where a score of six implied a high quality of informal support from the carer's perspective. The results are presented in table 11.5.

The method employed by Sarason et al. (1983) was used to deal with missing values. This involved dividing the total number of people listed and quality scores by the number of questions answered (rather than by six as would happen if all six questions were answered). This has the effect of giving the questions the carer chose to answer more weight. Missing responses are assumed to have the same value as the questions answered. However, if the carer chose not to answer a question for fear of giving a negative response (and possibly offending someone), this method of handling missing values could have the effect of making the social support number or quality seem higher, and thus imply more support, than was actually the case. The distribution for both the availability index and social support index approximated to a normal distribution (Figure 11.5).

Overall, these figures suggest that carers perceived that they had very few available informal supporters (on average they would call on only one or two other individuals for help) but they believed the quality of the help that they received on those occasions (judged by whether the response met their needs) was high.

Comparison using the t-test of those carers who had nominated comparison non-carers, and those carers who had not, showed that the number of supporters identified was not significantly different between the two groups, but the carers who had nominated controls

Figure 11.5: Distribution histograms for the availability (a) and satisfaction (b) indices of the social support questionnaire.



perceived that they had significantly better quality of social support (mean 1.7 vs. 1.49, t=2.956, p=0.004, CI: 0.163-0.829). There was no significant difference in either availability or quality of social support between the carers who had nominated comparison non-carers and the comparison non-carers themselves.

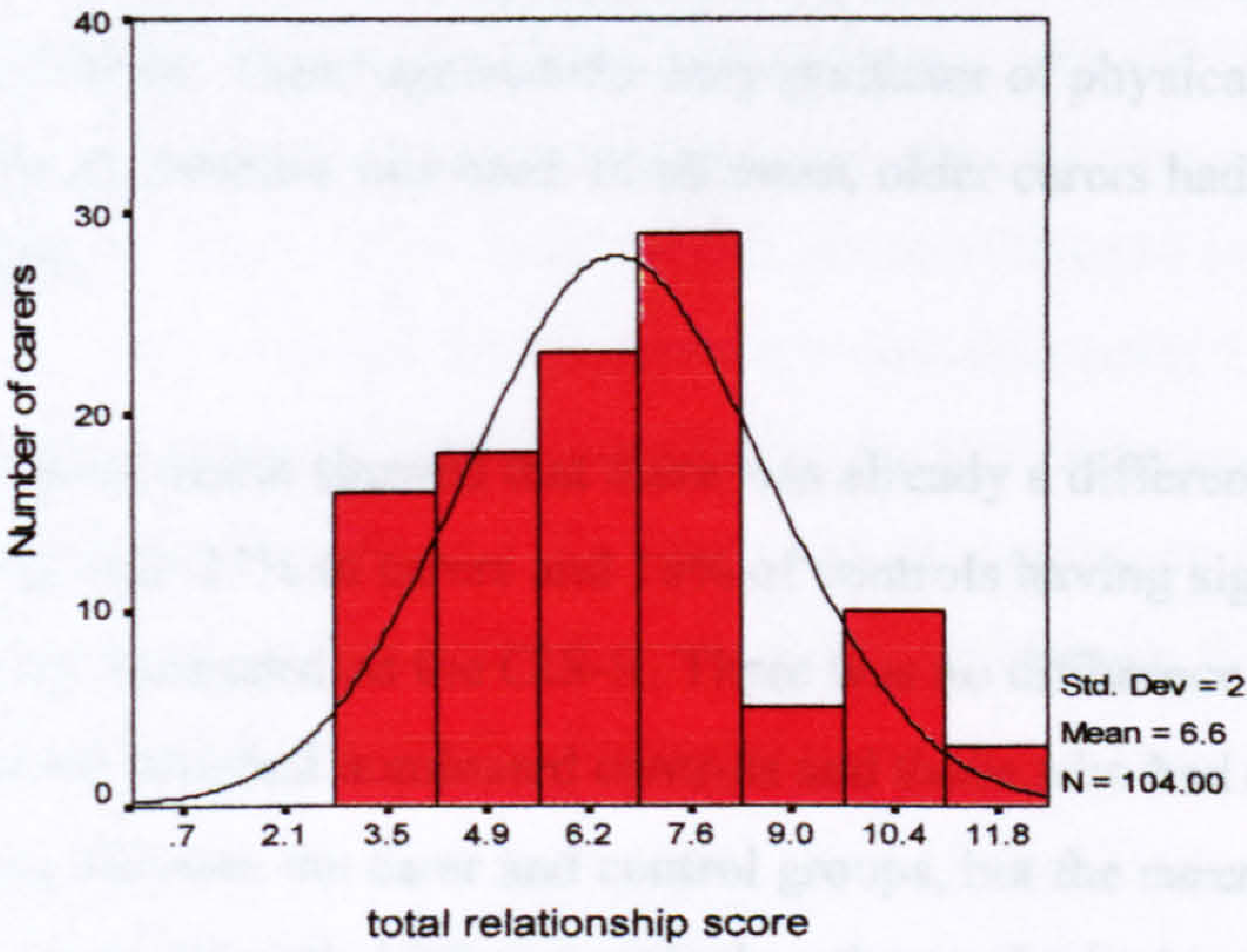
11.9 Relationship quality

Most of the carers considered that they had good relationships with the stroke patient (see table 11.6). Cumulative relationship scores followed an approximately normal distribution (Figure 11.6, page 137) with a range of four to 12 (where four is the best possible relationship and 16 the worst possible relationship); mean of 6.63 and standard deviation of 2.07. There was no significant association between either the gender of the carer, or the nature of the relationship between the carer and stroke patient (i.e. spouse or child), and any of the four relationship questions, or the cumulative relationship score.

Table 11.6: Relationship of carer and stroke patient pre-discharge

		Number of carers	**Percent**
How would you describe your relationship?	Excellent	71	68.3
	Good	30	28.8
	Indifferent	3	2.9
Do you feel appreciated?	Very Much	69	66.3
	A bit	26	25.0
	Not sure	4	3.8
	Not really	4	3.8
	Definitely not	1	1.0
Do you argue?	Very infrequently	28	26.9
	Very occasionally	27	26.0
	From time to time	39	37.5
	Often	6	5.8
	All the time	4	3.8
How close is your relationship?	Very close	67	64.4
	Close	27	26.0
	In between	9	8.7
	Distant	1	1.0

Figure 11.6: Distribution of relationship scores



11.10 Summary of results from the first interview

One hundred and five carers underwent a first interview, on average of 54.4 days after the stroke. All but one of the carers had an abbreviated mental test score above the cut-off point required to take part in the study. Most carers reported they had a good quality of relationship with the stroke patient prior to the stroke and for all but nine of the carers, caring for the stroke patient once discharged from hospital would be a new experience.

The average carer could identify only one or two informal supporters that they could rely on to help them. They generally felt that the help they would receive would be of high quality. There was no difference in either quality or quantity of social support between the carers and comparison non-carers. However, carers who had nominated comparison non-carers had a higher quality of social support than those who had not.

A substantial number of carers (54.8%) - more male than female - reported that they had lost weight since the stroke. Baseline measures of physical health showed no significant differences between carers from the two recruitment centres, between carer and control groups, or between carers who had nominated controls and those who had not. Comparison of male and female carers showed that the male carers were on significantly more medications than the female carers, but there was no apparent reason for this as self-perceived health and the number of reported health problems were the same whether the carer was male or female. Carer age was the only predictor of physical health whichever physical health measure was used. In all cases, older carers had poorer self-reported physical health.

Measures of psychological health showed that there was already a difference between the carer and control group with 37% of carers and 16% of controls having significant psychological distress as measured on the CIS-R. There was no difference in CIS-R scores between the carers who had nominated controls and those who had not. There was no difference in morale between the carer and control groups, but the carers who had nominated controls had significantly higher morale than those who had not.

Male carers had significantly less psychological distress and higher morale than female carers. Factors independently associated with both psychological distress and morale were reported weight change since stroke and quality of support, with the carers reporting weight loss having higher levels of psychological distress and lower morale, and the carers reporting a higher quality of support having lower psychological distress and higher morale.

Chapter 12: Results from the second interview

Six week post-discharge interviews were done with 74 carers – 54% (40 carers) recruited from Southampton and 46% (34 carers) from Christchurch. The average age of carers interviewed was 65.9 years (range 31-91 years; SD 13.36) and 73% (54 carers) were female. Note, there were no non-carers for comparison at this time point for reasons outlined on page 74. All those who dropped out between the first and second interview were accounted for (see figure 10.1, page 118). There was no significant difference in terms of any of the health measures or social support measures between those who continued in the study and those carers who dropped out.

12.1 Timing of interviews

The mean time interval between discharge of the stroke patient and interview was 6.9 weeks (range 5.0-11.9 weeks; SD 1.3weeks) – see Figure 11.1, page 126. Several interviews were late due to the patient being discharged to another hospital prior to being discharged home. This meant that no information was received when the patient was discharged home. Regular checks with the carers revealed when these carers came home but introduced a delay.

12.2 Smoking history

Sixty-four carers (86.5%) were non-smokers and ten (13.5%) smokers. Smokers consumed an average of 16.9 cigarettes per day (range 3.5 –25.0; SD 7.1). Using a paired sample t-test, there was no significant difference in the amount smokers smoked pre-discharge and at six weeks post discharge (t=1.681; p=0.124; 95% CI: -1.407 – 10.043).

12.3 Alcohol consumption

Thirty-nine carers (52.7%) regularly consumed alcohol. Of those that did drink alcohol, five carers (6.8%) drank more alcohol than recommended and the mean alcohol consumption was 9.0 units/week (range 0.5-49.0 units; SD10.6). Using a paired sample t-test there was a significant difference in the amount of alcohol consumed by carers who

Table 12.1: Carer weight change since discharge of the stroke patient

Weight (carer report)	Number of carers	Percent
Same	37	50.0
Lost < 1/2 stone	12	16.2
Lost > 1/2 stone	17	23.0
Intentional weight loss	0	0
Gained weight	8	10.8

drank alcohol pre-discharge and six weeks post-discharge (3.49 vs. 4.74 units/week respectively, t= -2.529; p=0.015; 95% CI: -3.488 - -0.389).

12.4 Weight

Exactly half the carers thought that their weight had remained steady since the stroke patient had returned home, 39.2% thought they had lost weight and 10.8% felt they had gained weight – see table 12.1. The relationship between weight loss and gender seen pre-discharge had disappeared (χ^2=0.568; df=2; p=0.75). The marginal homogeneity test (an extended form of the McNemar test) and Wilcoxon signed rank test both showed that there was a significant difference in the weight change reported pre-discharge and post discharge with significantly less weight loss being reported post discharge (standard MH statistic=-2.772; p=0.006 and z=-2.695; p=0.007 respectively).

Table 12.2: Comparison of pre- and post-discharge physical health of carers

	Mean score for carers pre-discharge (SD)	Mean score for carers 6 weeks post-discharge (SD)	Comparison of pre-discharge and post-discharge values
Self-rated health	3.54 (1.011) *Range 1-5*	3.35 (1.119) *Range 1-5*	paired t = 1.542 *(2-tailed sig. p=0.127)*
Number of medications	2.30 (2.150) *Range 0-12*	2.49 (2.241) *Range 0-12*	paired t = -2.112 *(2-tailed sig. p=0.038)*
Number of health problems	1.57 (1.171) *Range 0-5*	1.74 (1.159) *Range 0-5*	paired t = -2.075 *(2-tailed sig. p=0.042)*

Note: Results highlighted in red denote significant results (p<0.05).

12.5 Physical health

There was a significant increase in both the number of drugs carers were taking and the number of major health problems (paired t=-2.112, p=0.038, 95% CI:-0.368 - -0.011 and paired t=-2.075, p=0.042, 95% CI:-0.344 - -0.007), but no significant difference in self-rated health between the pre-discharge and six week post-discharge interviews (table 12.2, page 140) .

Six weeks post-discharge, there was no difference in physical health according to which centre the carers were recruited from, or the gender of the carers (table 12.3). The earlier disparity in the number of medications between male and female carers had disappeared. Carers who had lost weight in the period immediately after stroke had significantly worse self-rated health than those who had not (mean 3.07 vs. 3.72, t= -2.565, p=0.012, CI: -1.150 - -0.144).

Stepwise regression analysis was then performed entering independent variables into the model as listed in table 11.3, page 130. Results are recorded in table 12.4, page 142. The major factors independently associated with each measure of physical health status post-discharge, were the pre-discharge health status measures. Self-rated health, the most

Table 12.4: Effect of gender and place of recruitment on physical and psychological health scores for carers post-discharge

	Mean score for carers (SD)	**Effect of gender**	**Effect of place of recruitment**
Self-rated health	3.35 (1.119) *Range 1-5*	t=1.411 *(2-tailed sig.0.163)*	t=0.553 *(2-tailed sig.0.582)*
Number of medications	2.49 (2.241) *Range 0-12*	t=1.444 *(2-tailed sig.0.153)*	t=-1.360 *(2-tailed sig.0.178)*
Number of health problems	1.74 (1.159) *Range 0-5*	t=-0.871 *(2-tailed sig. 0.387)*	t=-0.804 *(2-tailed sig. 0.424)*
PGC Morale scale	9.25 (4.223) *Range 1-17*	t=0.359 *(2-tailed sig. 0.721)*	t=1.210 *(2-tailed sig. 0.231)*
CIS-R	13.97 (9.819) *Range 1-43*	t=0.173 *(2-tailed sig.0.863)*	t=-0.140 *(2-tailed sig. 0.889)*

Table 12.4: Factors independently associated with physical health of carers six-weeks post-discharge

	Predicted by:	**% variance:**	**Statistics:**
Self-rated health	Self-rated health pre-discharge	20.1%	R^2= 0.201, F=16.06, p<0.001
	Number of cigarettes smoked	10.6%	R^2= 0.106, F=11.034, p=0.002
	Weight change immediately after stroke	9.6%	R^2= 0.096, F=8.612, p=0.005
	Gender of the carer	6.1%	R^2= 0.061, F=7.546, p=0.008
	Satisfaction with formal support	4.9%	R^2= 0.049, F=5.454, p=0.023
	Oxford Handicap scale score	3.9%	R^2= 0.039, F=5.170, p=0.027
	Amount of social support pre-discharge	3.3%	R^2= 0.033, F=4.577, p=0.037
Number of medications	Number of medications pre-discharge	83%	R^2= 0.830, F=313.476, p<0.001
	Social support quality pre-discharge	1.3%	R^2= 0.013, F=5.238, p=0.025
Number of health problems	Number of health problems pre-discharge	61%	R^2= 0.830, F=100.058, p<0.001
	Self-rated health pre-discharge	2.4%	R^2= 0.830, F=4.057, p=0.048

subjective of the physical health measures used, was associated with more factors than the other two physical health measures, perhaps reflecting the fact that carers' judgment of their own health may be influenced by many factors.

12.6 Morale and psychological health

Six weeks post-discharge there was no difference in morale or psychological health according to which centre carers were recruited from or gender (table 12.4). There was a significant reduction in morale, as measured with the PGC morale scale, amongst carers between the pre-and post-discharge interviews (paired t = 3.765, p<0.001, CI=0.763-2.484).

Table 12.5: Comparison of pre- and post-discharge psychological health of carers

	Mean score for carers pre-discharge (SD)	**Mean score for carers 6 weeks post-discharge (SD)**	**Comparison of pre-discharge and post-discharge values**
PGC Morale scale score	10.87 (3.831) *Range 2-17*	9.25 (4.223) *Range 1-17*	paired t = 3.765 *(2-tailed sig. p<0.001)*
CIS-R score	11.53 (9.540) *Range 0-36*	13.97 (9.819) *Range 1-43*	paired t = -2.244 *(2-tailed sig. p=0.028)*

Note: Results highlighted in red denote significant results (p<0.05).

Six weeks after the stroke patient was discharged home, 54% of carers (40 carers) had CIS-R scores of more than 12, and 24% (18 carers) scores greater than 17, suggesting significant psychological distress amongst this group. Table 12.5 (page 142) shows that there was a significant worsening in CIS-R scores and hence increase in psychological distress measured pre-discharge and post-discharge (paired $t=-2.244$, $p=0.028$, CI=-4.618 - -0.274). Repeating the analysis of the CIS-R score results with non-parametric measures produced the same results.

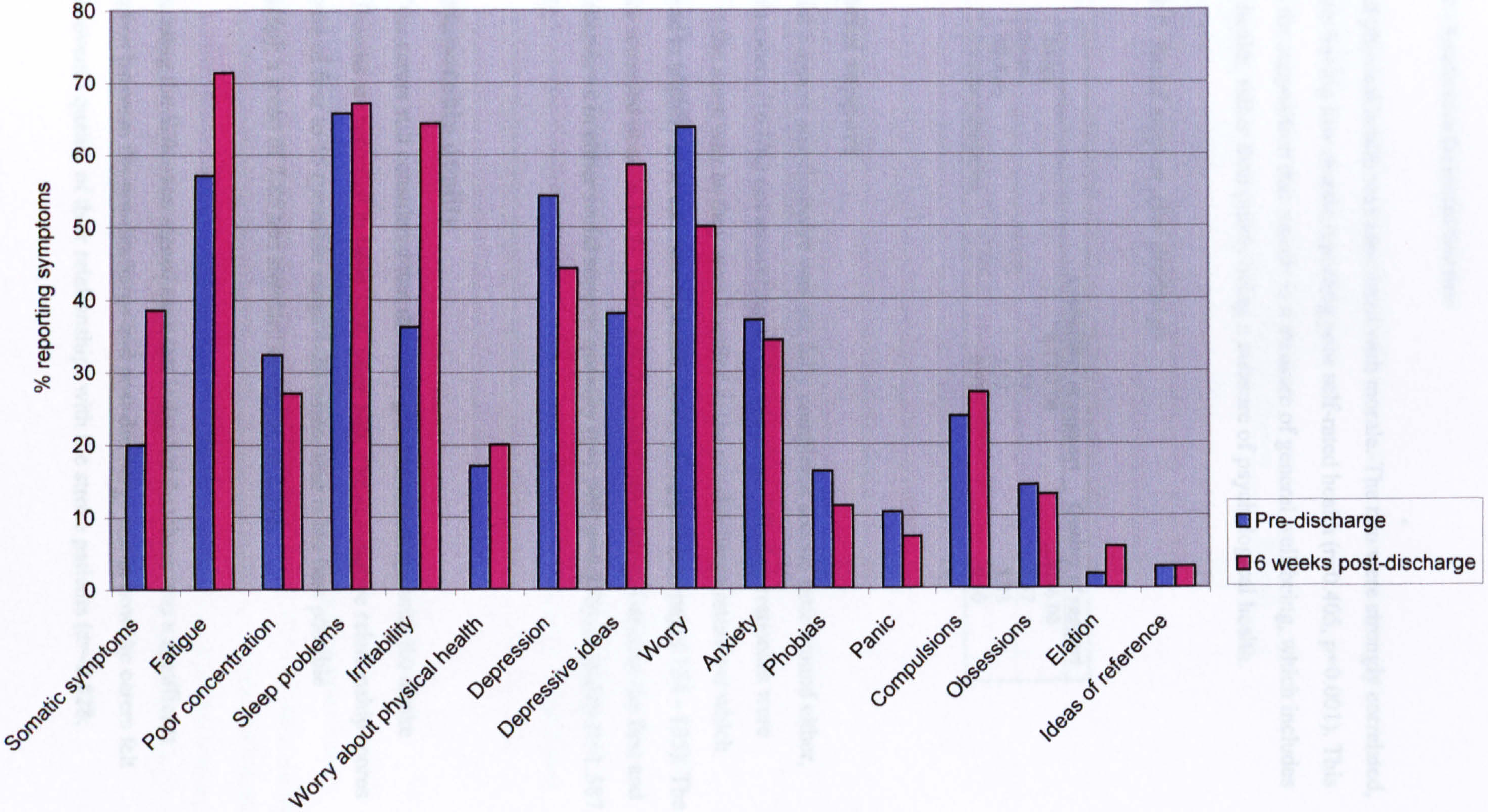
The distribution of psychological symptoms is shown in figure 12.1, page 144. There were marked increases in the percentage of carers reporting fatigue, irritability and depressive ideas post-discharge compared with the percentage reporting those symptoms pre-discharge, but a reduction in worry and depression.

Table 12.6: Factors independently associated with psychological health of carers six-weeks post-discharge

	Predicted by:	**% variance:**	**Statistics:**
PGC Morale scale	PGC Morale score pre-discharge	36.4%	$R^2= 0.364$, $F=36.654$, $p<0.001$
	Quality of social support after discharge	9.7%	$R^2= 0.097$, $F=11.363$, $p=0.001$
	Self-rated physical health post-discharge	9.2%	$R^2= 0.092$, $F=12.729$, $p=0.001$
	Quality of social support pre-discharge	7.4%	$R^2= 0.074$, $F=12.120$, $p=0.001$
CIS-R	CIS-R score pre-discharge	23.7%	$R^2= 0.237$, $F=20.793$, $p<0.001$
	Quality of social support post-discharge	10.6%	$R^2= 0.106$, $F=10.691$, $p=0.002$
	Quality of social support pre-discharge	7.2%	$R^2= 0.072$, $F=7.965$, $p=0.006$
	PGC Morale score pre-discharge	4.7%	$R^2= 0.047$, $F=5.542$, $p=0.022$

Stepwise regression analysis using the parameters listed in table 11.3, page 130 was then performed. The findings are listed in table 12.6. As for physical health the major factors independently associated with both the PGC morale score and CIS-R score post-discharge, were the pre-discharge scores. However, in both cases, the quality of social support both before and after the stroke patient was discharged, was also an important factor. The better the perceived quality of social support, the higher the PGC morale score and the lower the CIS-R score ($r=0.366$, $p=0.002$ and $r=-0.416$, $p<0.001$ respectively).

Figure 12.1 Comparison of reported psychological symptoms in the pre-and post-discharge interviews



Self-rated physical health was associated with morale. The two were strongly correlated, with carers having low morale reporting poor self-rated health (r=0.405, p=0.001). This supports the supposition that morale is a measure of general well-being, which includes physical health, rather than purely being a measure of psychological health.

Table 12.7: Social support after discharge

	Availability of support	Quality of support
Range	0.17-5.00	2.83-6.00
Mean	1.53	5.32
Median	1.33	5.83
Standard deviation	0.97	0.90

12.7 Social support

The Social Support questionnaire was not fully completed second time around either, with eight carers (10.8%) not answering all the questions. Missing responses were handled in the same way as they were handled in the pre-discharge interview which would tend to slightly over-estimate reported levels of support (see pages 134 - 135). The results are recorded in table 12.7. There was no significant change between the first and second interviews in either social support quantity (t=1.098, p=0.276) or quality (t=1.587, p=0.117).

12.8 Relationship quality

Most of the carers still considered that they had good relationships with the stroke patient. Results are recorded in table 12.8, page 146. The cumulative relationship scores had a range of four to 15 (possible range 4-20 where four is the best possible relationship); a mean of 7.85 and standard deviation of 2.778.

Analysis using the Wilcoxon signed rank test indicated that there was a significant deterioration between the pre-discharge and post-discharge test in how the carers felt about the overall quality of their relationships with the stroke patients (z=-2.828;

Table 12.8: Relationship quality of the carer and stroke patient in the immediate post-discharge period

		Number of carers	Percent
How would you describe your relationship?	Excellent	39	52.7
	Good	26	35.1
	Indifferent	8	10.8
	Bad	1	1.4
Do you feel appreciated?	Very Much	41	55.4
	A bit	20	27.0
	Not sure	5	6.8
	Not really	5	6.8
	Definitely not	3	4.1
Do you argue?	Very infrequently	16	21.6
	Very occasionally	13	17.6
	From time to time	27	36.5
	Often	14	18.9
	All the time	4	5.4
How close is your relationship?	Very close	37	50.0
	Close	21	28.4
	In between	12	16.2
	Distant	3	4.1
	Very distant	1	1.4

p=0.005); the stroke patients' appreciation of their efforts (z=-2.108; p=0.035); and the closeness of their relationships (z=-3.157; p=002). The frequency of arguments was unchanged. Using a paired sample t-test, there was a significant increase in the total relationship scores pre-discharge and six weeks post-discharge, indicating a significant deterioration in relationship (mean 6.81 vs. 7.85, t= -3.502; p=0.001; 95% CI: -1.63 - -0.45).

12.9 Activity restriction

Carers' activities were altered in all but four cases. The activity restriction score has a range of -6 to +6 where -6 means that the carer has reduced the amount he or she is doing all six activities identified as those that would be missed most prior to the onset of "hands on" caring. A score of +6 means that the carer is doing all the activities more and a score of 0 means that overall the carer is spending as much time as usual on those activities.

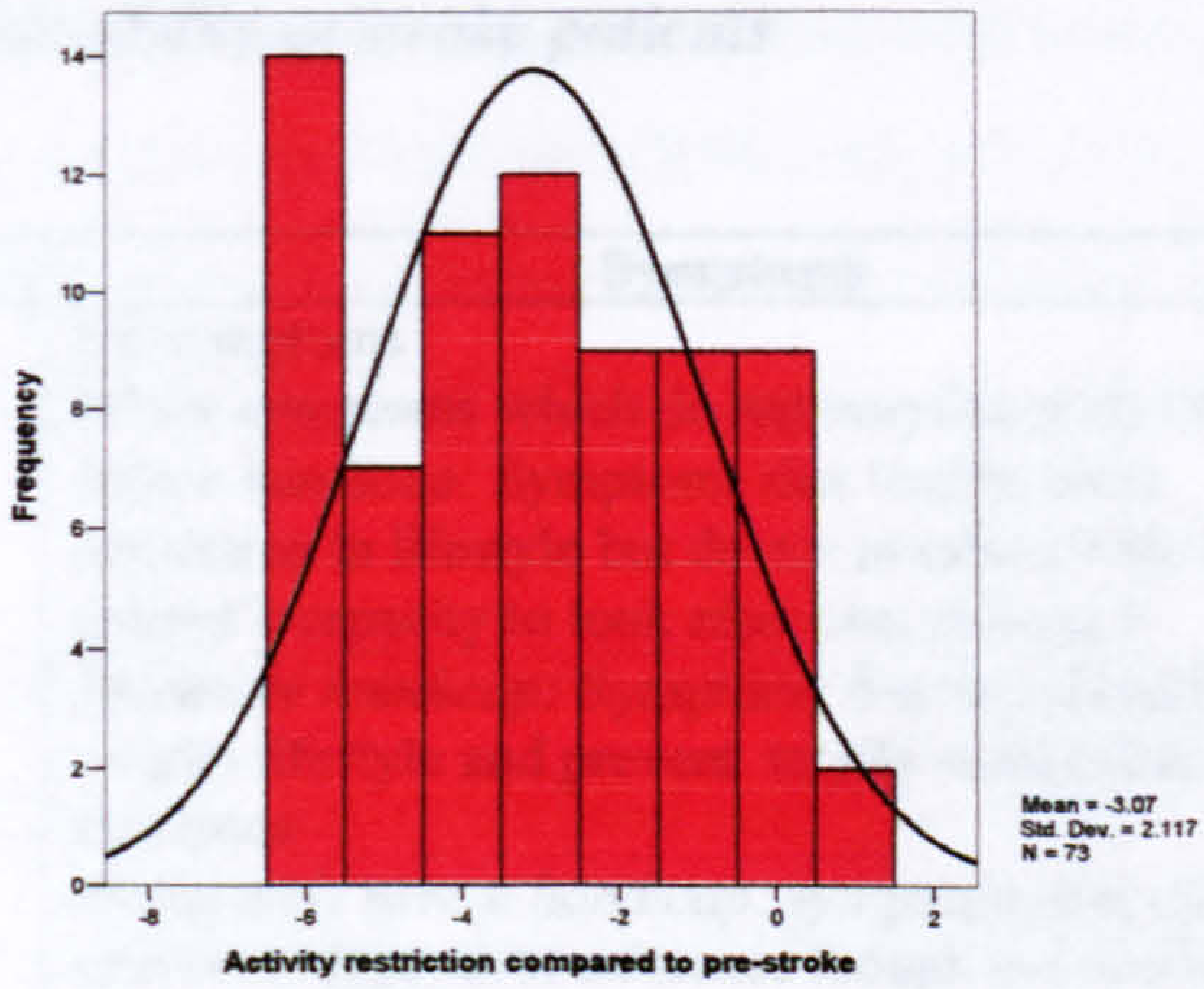


Figure 12.2: Distribution of activity restriction scores

Only 11 carers (15%) did not report an overall reduction in their usual activities. Mean activity restriction score was -3.07 (median -3.00; range -6 - +1; SD 2.12) which suggests that carers had their usual activities significantly curtailed, with more than half their usual activities reduced, in the six weeks after the stroke patient was discharged from hospital.

The distribution of the activity restriction scores are shown in Figure 12.2. Reasons given for the restriction of usual activities included the stroke (87.8%), changes in the carers' health (1.4%) and other unrelated factors such as the season of the year (4.1%).

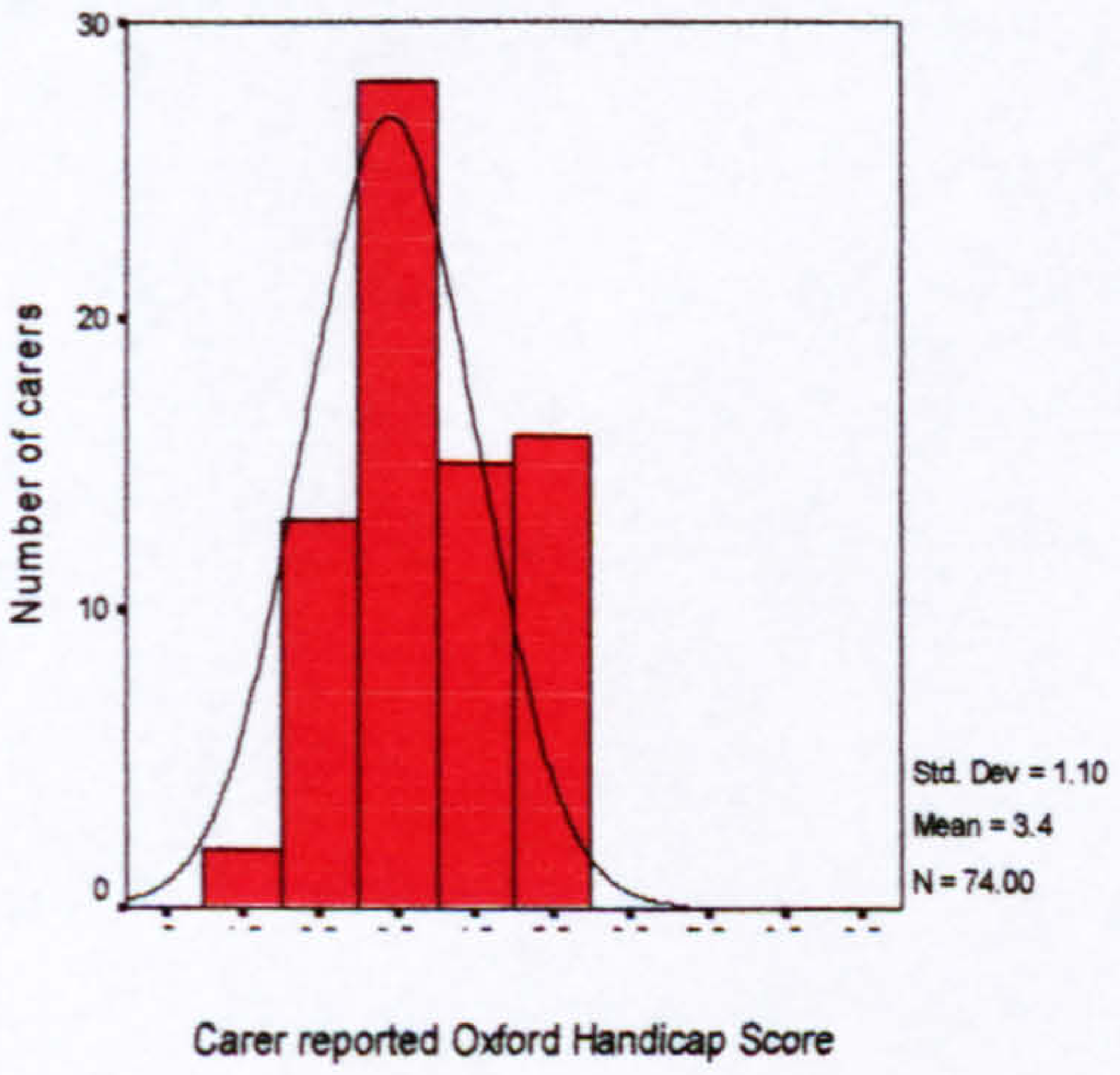
12.10 Level of disability

Carer reports of levels of disability of the stroke patients are recorded in table 12.9 (page 148). The mean Oxford handicap score was 3.41 (median=3.00; SD=1.097). This meant that the stroke patients looked after by the carers taking part in this study generally had significant levels of handicap when they were discharged home. With these levels of handicap, most would require a great deal of input from their carers as they would not be able to cope in the community alone. The carers reported that 31 stroke patients (42%) had some form of speech deficit following stroke. Distribution of the Oxford Handicap scores is depicted in Figure 12.3 (page 148).

Table 12.9: Level of disability of stroke patients

Disability measure		**Symptoms**	**Number *(%)***
Oxford Handicap Scale	***0***	No symptoms	0 *(0)*
	1	Minor symptoms which do not interfere with lifestyle	2 *(2.7)*
	2	*Minor handicap:* Symptoms that lead to some restriction in lifestyle but do not interfere with the patient's capacity to look after him or herself	13 *(17.6)*
	3	*Moderate handicap:* Symptoms that significantly restrict lifestyle and prevent totally independent existence	28 *(37.8)*
	4	*Moderately severe handicap:* symptoms that clearly prevent independent existence though not needing constant attention	15 *(20.3)*
	5	*Severe handicap:* totally dependent patient requiring constant attention day and night	16 *(21.6)*
Dysphasia	***Yes***	Some impairment of language due to stroke	31 *(41.9)*
	No	No impairment of language	43 *(58.1)*

Figure 12.3: Distribution of carer reported Oxford Handicap Scale scores



The length of hospital stay was strongly correlated with level of handicap as assessed by the carers of the stroke patients (Pearson's R=0.542, p<0.001; Spearman's rho=0.499, p<0.001). This suggests that carers reports of stroke patients' handicap is a reasonable way to measure stroke patients' level of handicap in this type of study.

12.11 Quantity and cost of formal service provision:

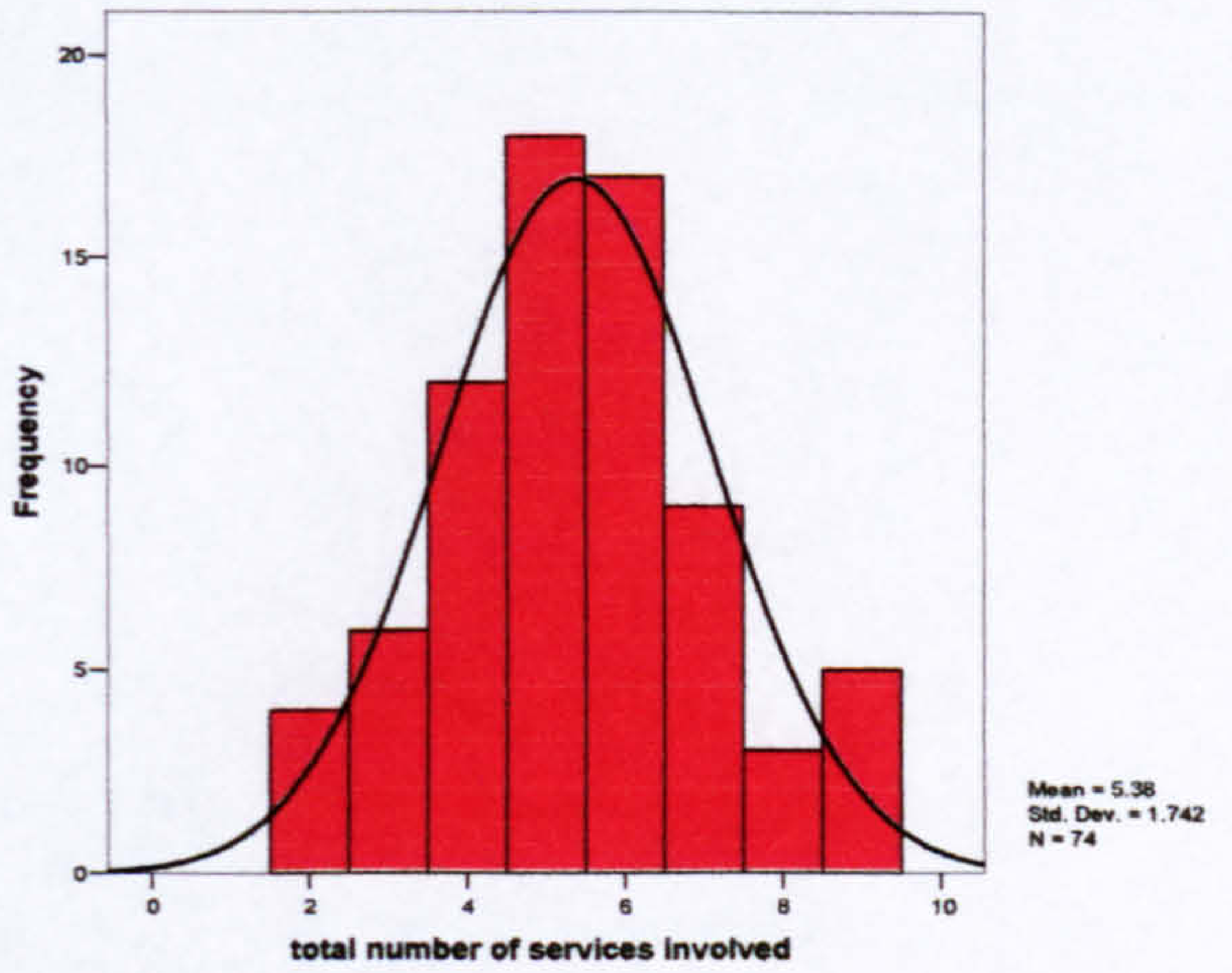
The cost of service provision was calculated using published unit costs for health and social care (Curtis, L. & Netten, A., 2005) where possible. Costs for the services provided to carers in this study are listed in table 12.10, page 151. For items where there was no published unit cost an estimate was made using the unit costs of a comparable service. There were some difficulties doing this as the carers were often not specific about the service provider. The number of formal support services involved followed a normal distribution but total hours of formal support received and costs of formal care did not (Figure 12.4, page 150).

All the carers received some input from formal support services in the first six weeks after discharge (mean number of services involved = 5.38; range 2-9 services; SD = 1.742) – see table 12.10, page 151. The amount of time formal support services spent with carers and stroke patients varied considerably from a minimum of a quarter of an hour over the six week period to a maximum of nearly 341 hours (mean=43.78 hours; median=32.4 hours; range 0.25-340.83 hours; SD=58.82 hours).

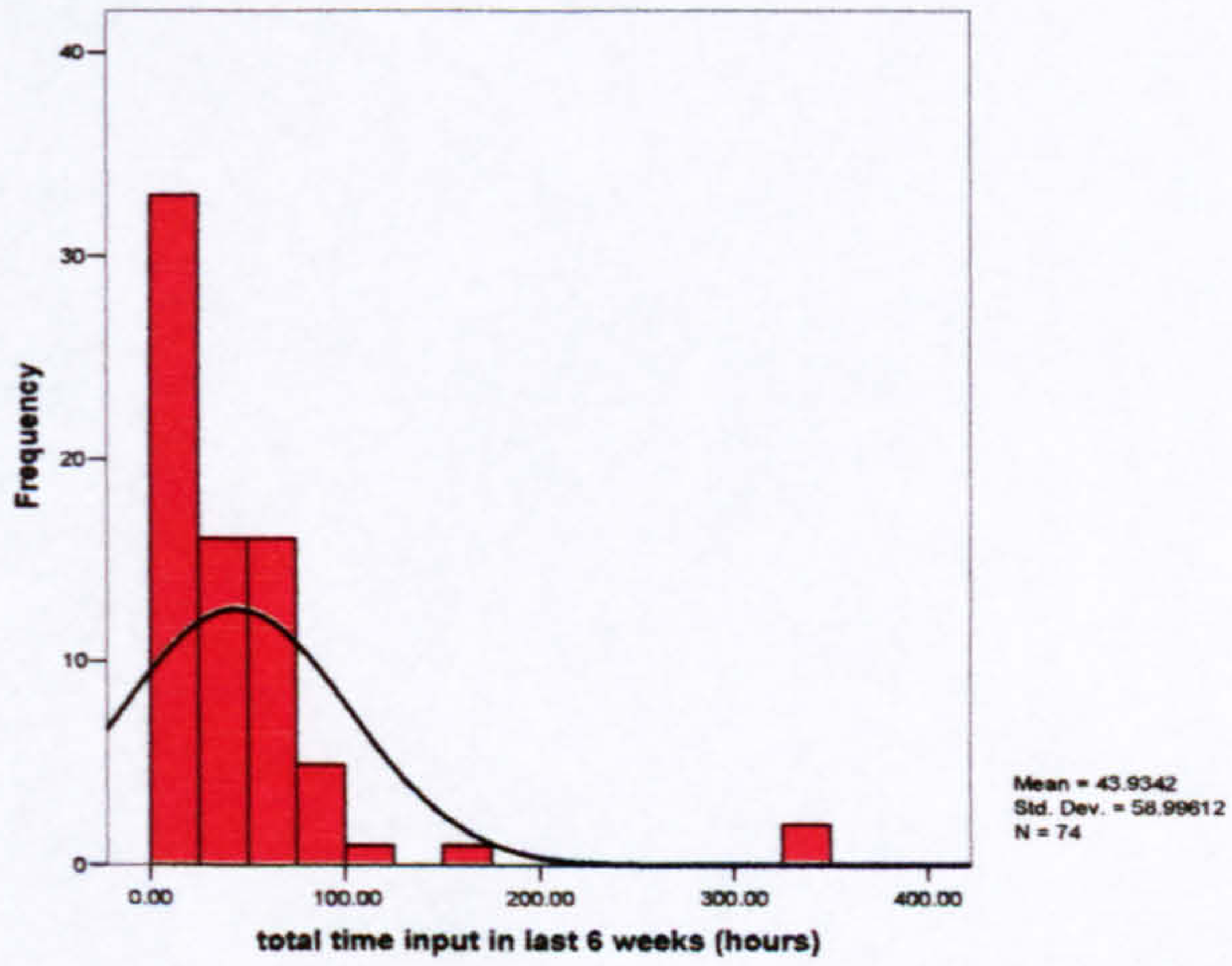
The minimum cost of care in the six weeks following discharge was £40 and the maximum £4234 (mean £609.55, median £468.00, SD £709.72). As might be expected, the cost of care was strongly correlated with both the time allocated to the carer-patient dyad by the formal support services and the number of services involved (Spearman's rho = 0.960, p<0.001 and Spearman's rho = 0.703, p<0.001 respectively).

Figure 12.4: Distribution histograms for both formal support measures and cost of care

(a) Total number of services involved



(b) Total amount of time provided by formal support services



(c) Cost of community care

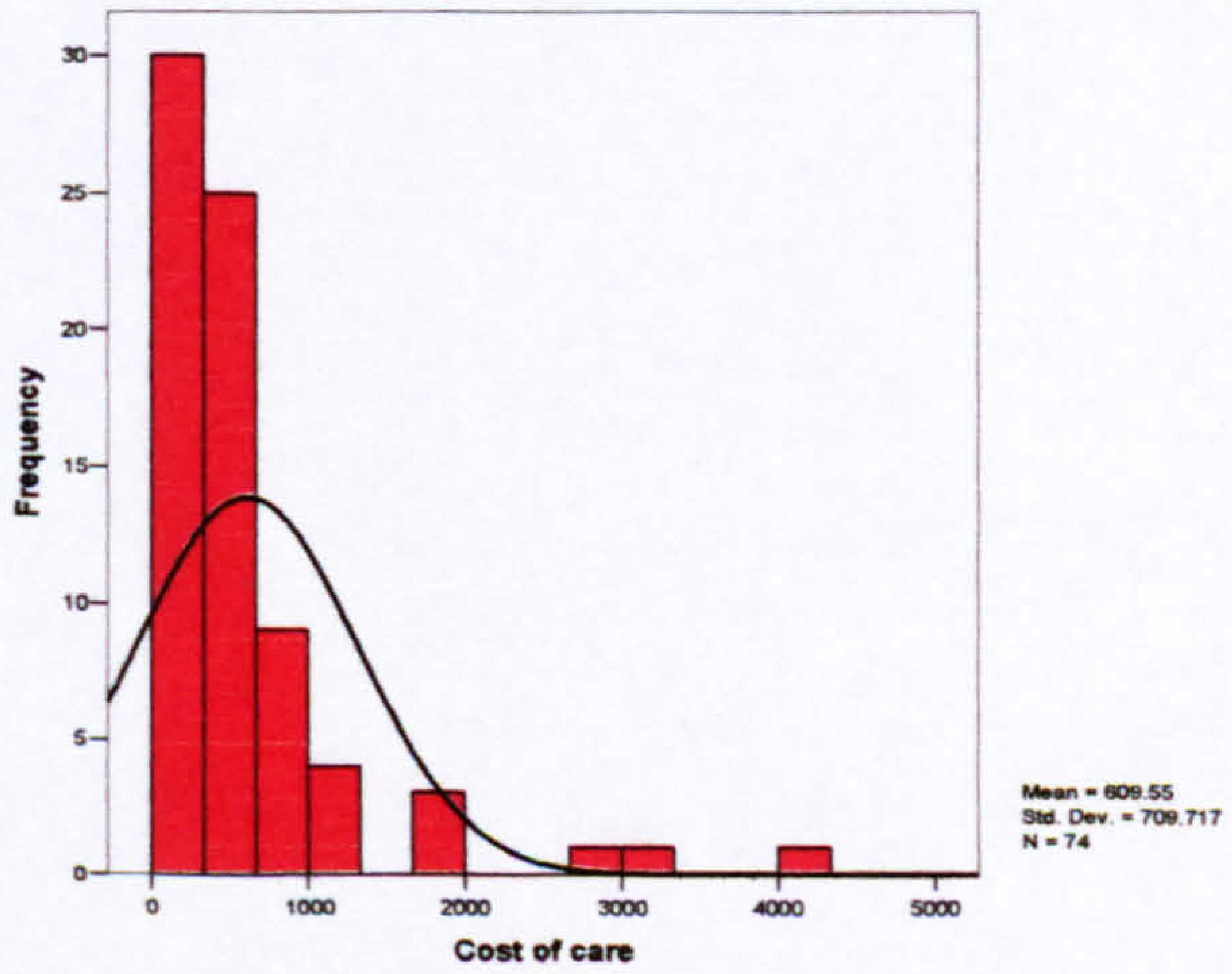


Table 12.10: Formal support services involved after discharge and their unit costs

Service	**Estimated unit costs for each service**	**Number *(%)* in contact since discharge.**		
		Total	*Southampton*	*Christchurch*
General practitioner	£108/hour	67 *(90.5)*	37 *(93)*	30 *(88)*
Community nurse	£53/hour	54 *(73.0)*	30 *(75)*	24 *(71)*
Social services	£31/hour	31 *(41.9)*	16 *(40)*	15 *(44)*
Physiotherapist	£45/hour	47 *(63.5)*	23 *(58)*	24*(71)*
Occupational therapist	£46/hour	40 *(54.1)*	18 *(45)*	22*(65)*
Home carers	£12.50/hour	35 *(47.3)*	24 *(60)*	11 *(32)*
Counsellor	£39/hour	1 *(1.4)*	1 *(3)*	0
Voluntary support groups	Not costed	13 *(17.6)*	5 *(13)*	8 *(24)*
Day centre or day hospital	£30/day - voluntary day care £54/day - local authority day care £78/day - day hospital	23 *(31.1)*	1 *(3)*	22 *(65)*
Hospital outpatients	£88/hour	27 *(36.5)*	10 *(25)*	17 *(50)*
Community psychiatric nurse	£71/hour	3 *(4.1)*	2 *(5)*	1 *(3)*
Other services (not on the original list):				
- speech therapist	£41/hour	15 *(20.3)*	10 *(25)*	5 *(15)*
- specialist stroke support nurse	£71/hour	15 *(20.3)*	8 *(20)*	7 *(21)*
- in-patient care / respite	In-patient - £204/day Respite - £395-£509/week	4 *(5.4)*	3 *(8)*	1 *(3)*
- other specialist hospital nurse	£71/hour	2 *(2.7)*	0	2 *(6)*
- health visitor	£72/hour	1 *(1.4)*	0	1 *(3)*
- phlebotomy	£20/hour	2 *(2.7)*	0	2 *(6)*
- chiropody	£23/hour	2 *(2.7)*	1 *(3)*	1 *(3)*
- dentist	£45/visit	2 *(2.7)*	1 *(3)*	1 *(3)*
- breast screening	£45/screen	1 *(1.4)*	0	1 *(3)*
- NHS drop in centre	£52/hour	1 *(1.4)*	1 *(3)*	0
- sitter	£12.50/hour	1 *(1.4)*	1 *(3)*	0
- art therapy	£41/hour	1 *(1.4)*	1 *(3)*	0
- citizen's advice bureau	£30/hour	1 *(1.4)*	0	1 *(3)*
- solicitor	£150/hour	1 *(1.4)*	0	1 *(3)*
- shopper	£12.50/hour	1 *(1.4)*	1 *(3)*	0
- cleaner	£12.50/hour	4 *(5.4)*	2 *(5)*	2 *(6)*

Total number of carers = 74

Number of carers recruited from Southampton = 40

Number of carers recruited from Christchurch = 34

Unit costs are from 'Unit costs for health and social care', Curtis, L. & Netten, A., 2005

Note: Results highlighted in red denote results significantly different ($p<0.05$) between recruiting centres.

12.11.1 Effect of place of recruitment:

There was no significant difference in overall quantity or cost of formal support provision between the two recruitment centres as measured with the independent t-test for the number of services provided ($t= -1.928$, $p=0.058$) and with the Mann Whitney U test for time allocation and cost of formal support services ($U=615.5$, $p=0.484$ and $U=564.5$, $p= 0.210$ respectively). However, when individual service provision was examined, there were significant differences between the carers recruited from each of the two centres (table 12.10, page 151). Sixty percent of those recruited from Southampton were discharged with home care provision as opposed to 32% of those recruited from Christchurch ($\chi^2= 5.636$, df=1, $p=0.018$). There was no significant difference in handicap levels (as measured with the independent t-test) to account for this.

Day hospital or day centre care provision also differed between the two centres with 3% of those recruited from Southampton as opposed to 69% of those recruited from Christchurch receiving day centre or day hospital support ($\chi^2= 33.2$, df=1, $p<0.001$). This difference is probably due to the specialist stroke rehabilitation facility at Christchurch which had day centre facilities. There was no equivalent facility in Southampton. Finally, out-patient follow up varied between the two centres. Fifty percent of stroke patients and carers recruited from Christchurch had been reviewed in out-patients since discharge as opposed to 25% of those recruited from Southampton ($\chi^2=4.957$, df=1, $p=0.026$).

12.11.2 Effect of the carer's gender:

Overall, there was also no significant difference in quantity or cost of formal support provision for male and female carers as measured with the independent t-test for the number of services provided ($t = 0.664$, $p=0.509$), and with the Mann Whitney U test for time allocation and cost of formal support services ($U=460.5$, $p=0.333$ and $U=459.5$, $p=0.327$ respectively). However, when individual service provision was examined there was a significant difference in service provision between male and female carers with 75% of male carers but only 46% of female carers receiving occupational therapy input

Table 12.11: Independent variables entered into the regression models for provision and satisfaction with services

Independent variables		**Dependant variables**					
		6 weeks post discharge			**13 months post stroke**		
		Number of services	**Time allocated by formal services**	**Carer satisfaction**	**Number of services**	**Time allocated by formal services**	**Carer satisfaction**
Place of recruitment		✓	✓	✓	✓	✓	✓
Gender of carer		✓	✓	✓	✓	✓	✓
Patient age		✓	✓	✓	✓	✓	✓
Carer age		✓	✓	✓	✓	✓	✓
Registered with same practice?		✓	✓	✓	✓	✓	✓
Education level		✓	✓	✓	✓	✓	✓
Income		✓	✓	✓	✓	✓	✓
Deprivation		✓	✓	✓	✓	✓	✓
Previous experience of caring		✓	✓	✓	✓	✓	✓
Other care commitments		✓	✓	✓	✓	✓	✓
Oxford Handicap score	t_2	✓	✓	✓	✓	✓	✓
	t_3				✓	✓	✓
Physical health	t_1	✓	✓	✓	✓	✓	✓
	t_2	✓	✓	✓	✓	✓	✓
	t_3				✓	✓	✓
Psychological health	t_1	✓	✓	✓	✓	✓	✓
	t_2	✓	✓	✓	✓	✓	✓
	t_3				✓	✓	✓
Social support availability	t_1	✓	✓	✓	✓	✓	✓
	t_2	✓	✓	✓	✓	✓	✓
	t_3				✓	✓	✓
Social support quality	t_1	✓	✓	✓	✓	✓	✓
	t_2	✓	✓	✓	✓	✓	✓
	t_3				✓	✓	✓
Total relationship score	t_1	✓	✓	✓	✓	✓	✓
	t_2	✓	✓	✓	✓	✓	✓
	t_3				✓	✓	✓
Activity restriction	t_2	✓	✓	✓	✓	✓	✓
	t_3				✓	✓	✓
Number of services	t_2			✓			✓
	t_3						✓
Time allocated by formal support services	t_2			✓			✓
	t_3						✓
Cost of care	t_2			✓			✓
	t_3						✓

t_1	pre-discharge interview
t_2	six weeks post-discharge interview
t_3	thirteen month post stroke interview

Table 12.12: Correlation between the quantity of formal service involvement and Oxford Handicap Scale

	Correlation of Oxford Handicap scores with measures of formal service involvement	
	Pearson's R	**Spearman's rho**
Number of services involved	0.392*	0.404**
Time allocated	0.533**	0.632**
Cost of care	0.558**	0.620**

*p=0.001 ** p<0.001

(χ^2=4.842, df=1, p=0.028). This is interesting bearing in mind the similar gender discrepancy seen in the piloting data (Simon C, 2003).

12.11.3 Factors predicting amount or cost of formal service provision:

The presence of dysphasia increased the number of services involved (5.87 vs. 5.02 services, t= 2.182; p=0.032; 95% CI: 0.076 – 1.679) but not the quantity of services in terms of hours of input. As might be expected more stroke patients with dysphasia had speech therapy support (χ^2=10.724, df=1, p=0.001). When speech therapy was removed there was no significant difference between the number of services involved with dysphasic and non-dysphasic patients. The level of handicap on the Oxford Handicap Scale was also strongly correlated with the amount of formal support provision and cost of care (table 12.12). The more handicapped the stroke patient the more support was provided, and the higher the cost of care.

Entering amount and cost of formal support into the stepwise regression model (described on page 112) as the dependent variable, with the independent variables listed in table 12.11 (page 153), revealed 3 factors independently associated with the number of services, 3 factors independently associated with time input from formal services and 3 factors independently associated with cost of care (table 12.13, page 155). The level of handicap was the strongest predictor for all three measures confirming that the level of handicap is the most important factor predicting provision of formal support early after stroke.

Table 12.13 Factors independently associated with of formal support provision and cost of care six-weeks post-discharge

	Predicted by:	% variance:	Statistics:
Number of services	Oxford Handicap score	13.0%	R^2= 0.130, F=9.525, p=0.003
	Place of recruitment	10.8%	R^2= 0.108, F=8.947, p=0.004
	Self-rated health prior to discharge	8.6%	R^2= 0.086, F=7.857, p=0.007
Time allocated	Oxford Handicap score	26.5%	R^2= 0.265, F=23.027, p<0.001
	Presence of other care commitments	9.8%	R^2= 0.098, F=9.674, p=0.003
	Quantity of social support post-discharge	6.8%	R^2= 0.068, F=7.375, p=0.009
Cost of care	Oxford Handicap score	28.4%	R^2= 0.284, F=25.407, p<0.001
	Presence of other care commitments	13.1%	R^2= 0.131, F=14.165, p<0.001
	Quantity of social support post-discharge	4.8%	R^2= 0.048, F=5.530, p=0.022
Satisfaction with care	Quality of informal support post-discharge	10.8%	R^2=0.108, F=7.746, p=0.007
	Restriction of usual activities	8.4%	R^2=0.084, F =6.527, p=0.013

The place of recruitment accounted for a further 10.8% of the variance in number of services provided (R^2 change= 0.108, F change =8.947, p=0.004), suggesting that services provided soon after discharge do depend upon the unit from which the stroke patient is discharged. The influence of the carer's self-rate health on the number of services provided (R^2 change = 0.086, F change =7.857, p=0.007), suggests that either carer self-rated health is taken into consideration when planning formal support, or that carers who perceive themselves to have poorer health, seek more support.

The same factors were independently associated with both the amount of time allocated by the formal support services to support the carers and stroke patients, and the cost of care. This is not surprising considering how strongly correlated these measures are. Apart from the level of handicap, the other two factors independently associated with both were the quantity of informal support available (R^2 change = 0.098, F change =9.674, p=0.003and R^2 change = 0.131, F change =14.165, p<0.001 respectively) and the carer's other care commitments (R^2 change = 0.068, F change =7.375, p=0.009 and R^2 change = 0.048, F change =5.530, p=0.022 respectively). Carers with other care commitments reported a mean of 95.8 hours formal support in the preceding six weeks while carers without other caregiving responsibilities reported a mean of 34.9 hours formal support during that time (t=3.381, p=0.001, CI: 25.02-96.92). This suggests that other demands on the carers' time, and other sources of support with caregiving duties, are taken into consideration when planning formal support provision, and thus also cost of care, for the immediate post-discharge period.

12.12 Satisfaction with service provision:

Using the global satisfaction question, 23 carers (31.1%) stated that they were very satisfied overall with the community support services received; 24 carers (32.4%) said they were satisfied; 9 carers (12.2%) that they were neither satisfied nor dissatisfied; 9 carers (12.2%) that they were dissatisfied; and 9 carers (12.2%) that they were very dissatisfied.

In total there were 11 missing responses to individual questions on the satisfaction with carer support questionnaire. These were spread across the questionnaire as shown in table 12.14 (page 157). Four carers missed one question – in all cases because they felt they had no experience to allow them to give an opinion about the question asked. One carer

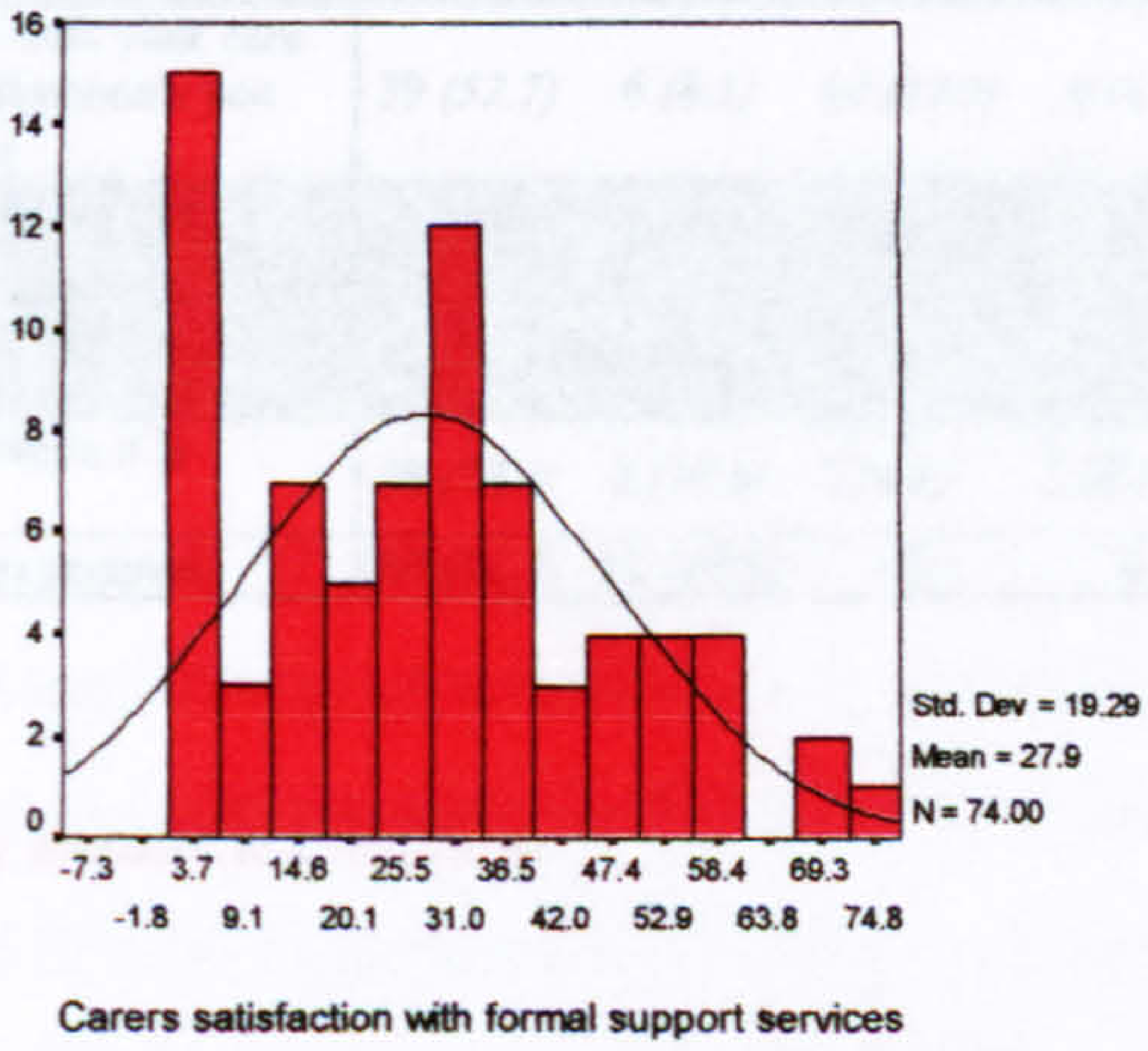


Figure 12.5: Distribution of carer satisfaction scores

Question	**Number *(%)***					
	Strongly agree	*Agree*	*Neither agree nor disagree*	*Disagree*	*Strongly disagree*	*Missing*
You are satisfied with the total amount of help provided to you (include in this help to allow you time to do what you want to do and time off)	33 *(44.6)*	18 *(24.3)*	6 *(8.1)*	6 *(8.1)*	11 *(14.9)*	0
You are confident that services provided to you would adapt if your situation were to change (for example if you were ill or had an accident and were unable to do what you do now for the person you care for)	20 *(27.0)*	18 *(24.3)*	6 *(8.1)*	9 *(12.2)*	21 *(28.4)*	0
You are satisfied with information you have been given about help available from the community services for you (include health, social and voluntary services)	39 *(52.7)*	3 *(4.1)*	1 *(1.4)*	7 *(9.5)*	24 *(32.4)*	0
Services and equipment provided to you are usually of good quality	63 *(85.1)*	6 *(8.1)*	3 *(4.1)*	1 *(1.4)*	1 *(1.4)*	0
You are confident you would know whom to contact from the community services if you had a problem	49 *(66.2)*	6 *(8.1)*	0	0	19 *(25.7)*	0
You are satisfied with information you have been given about your role as a carer	20 *(27.0)*	5 *(6.8)*	7 *(9.5)*	4 *(5.4)*	38 *(51.4)*	0
You have been given enough training for the tasks (such as lifting or bathing) you need to do for the person you look after	34 (45.9)	6 *(8.1)*	7 *(9.5)*	2 *(2.7)*	23 *(31.1)*	2 *(2.7)*
You are satisfied with information you've been given about stroke	43 *(58.1)*	11 *(14.9)*	3 *(4.1)*	3 *(4.1)*	14 *(18.9)*	0
You are satisfied with information you have been given about what to expect of someone who has had a stroke	29 *(39.2)*	7 *(9.5)*	4 *(5.4)*	19 *(25.7)*	15 *(20.3)*	0
You are confident you would know where to get information about any matter related to stroke or looking after someone who has had a stroke if you needed it	53 *(71.6)*	9 *(12.2)*	0	2 *(2.7)*	10 *(13.5)*	0
You are satisfied with help you've received from the community services when you've had a problem	49 *(66.2)*	2 *(2.7)*	9 *(12.2)*	3 *(4.1)*	8 *(10.8)*	3 *(4.1)*
The professionals involved with your care seem as concerned about you as the person you look after	37 *(50.0)*	5 *(6.8)*	3 *(4.1)*	5 *(6.8)*	24 *(32.4)*	0
You feel your opinion is ignored in making decisions about the person you care for	11 *(14.9)*	5 *(6.8)*	7 *(9.5)*	1 *(1.4)*	49 *(66.2)*	1 *(1.4)*
You are satisfied about information you have been given about financial help you might be entitled to (including benefits)	36 *(48.6)*	10 *(13.5)*	1 *(1.4)*	10 *(13.5)*	16 *(21.6)*	1 *(1.4)*
Given the choice, there are tasks you do now as a carer that you would rather not do	14 *(18.9)*	5 *(6.8)*	1 *(1.4)*	5 *(6.8)*	47 *(63.5)*	2 *(2.7)*
Services involved with your care lack co-ordination or don't work together	13 *(17.6)*	11 *(14.9)*	8 *(10.8)*	3 *(4.1)*	39 *(52.7)*	0
You could have been consulted more about the person you look after	19 *(25.7)*	9 *(12.2)*	1 *(1.4)*	10 *(13.5)*	35 *(47.3)*	0
As far as you can tell, the professionals involved with your care (doctors, nurses, social workers or any other professionals you see) seem to understand what being a carer is like	39 *(52.7)*	6 *(8.1)*	10 *(13.5)*	6 *(8.1)*	13 *(17.6)*	0
You would have liked more help applying for benefits and services	30 *(40.5)*	4 *(5.4)*	1 *(1.4)*	6 *(8.1)*	32 *(43.2)*	1 *(1.4)*
Essential changes to equipment, housing or services have been made too slowly	23 *(31.1)*	1 *(1.4)*	1 *(1.4)*	7 *(9.5)*	41 *(55.4)*	1 *(1.4)*
Services provided to you are at times of the day when it is convenient to have them	58 *(78.4)*	8 *(10.8)*	3 *(4.1)*	3 *(4.1)*	2 *(2.7)*	0
Information you have received has generally been accurate	60 *(81.1)*	11 *(14.9)*	0	0	3 *(4.1)*	0

▨ *Marks negatively worded questions*

Figures in red indicate a predominantly dissatisfied response

Table 12.14: Answers to the satisfaction with community service questionnaire

missed five questions. Missing values were replaced with the mean of scores for that carer to calculate total scores, as replacement of missing values by the mean for the carer has least effect on the overall response of that carer (Simon C., 2003a).

The mean satisfaction score on the satisfaction questionnaire was 27.88 (range 1-73; SD=19.292). Scores were normally distributed (see Figure 12.5, page 156). Individual scale items and responses are listed in table 12.14, page 157.

12.12.1 Comparison by recruitment centres and by gender of the carer:

There was no significant difference in satisfaction with formal support service provision between the two recruitment centres measured either with the global satisfaction question (U=657.5; p= 0.800), or the CSCSS questionnaire (t=-0.700, p=0.486). There was also no significant difference in satisfaction between male and female carers (U=430.0; p= 0.165 and t=1.176; p=0.244 respectively).

12.12.2 Comparison of carers satisfied and not satisfied with formal care:

In order to make this comparison, subjects were split between a group who expressed satisfaction for the formal care provided using the global satisfaction measure (i.e. responded that they were very satisfied or satisfied), and a group that did not. Reasons for splitting the sample in this way are discussed on page 112.

Four factors were associated with significant differences between those satisfied and dissatisfied with formal support services:

- Pre-discharge total relationship scores (mean score in the satisfied group was 6.43 against 7.48 in the dissatisfied group (t=-2.217, p=0.037, CI: -2.045- -0.066))
- Social support quality scores pre-discharge (mean 5.63 in the satisfied group and 5.14 in the dissatisfied group), and post-discharge (mean 5.53 in the satisfied group and 4.92 in the dissatisfied group) (t=2.371, p=0.020, CI: 0.767 - 0.888 and t=2.920, p=0.005, CI: 0.193-1.026 respectively), *and*

- CIS-R score post-discharge (mean score of 11.72 amongst those satisfied with support provided and 17.89 amongst those dissatisfied with support provided (t=-2.711, p=0.008, CI: -10.699 - -1.632)).

Therefore better social support through either the relationship with the stroke patient or a wider social network seems to be associated with greater satisfaction. The difference in CIS-R scores between those satisfied and dissatisfied with care, could indicate that carers with significant psychological distress were more likely to be dissatisfied with support, or that poor support causing dissatisfaction also caused psychological distress. There was no difference in the amount of formal support or cost of care between the groups satisfied and dissatisfied with care.

12.12.3 Examination of factors contributing to satisfaction with community support:

Stepwise linear regression using the satisfaction score as the dependent variable and the variables listed in table 12.11 (page 153) as the independent variables yielded two factors independently associated with satisfaction scores, together accounting for a total of 19.2% of the variance of the satisfaction scores. These factors (also listed in table 12.13, page 155) were the quality of informal social support post discharge (R^2 change = 0.108, F change = 7.746, p=0.007) and the level of restriction of usual activities (R^2 change=0.084, F change =6.527, p=0.013).

Both these measures were significantly correlated with satisfaction scores, the higher the satisfaction score (and thus more dissatisfied the carer was), the lower the social support quality score (r=-0.267, p=0.022; rho=-0.278, p=0.016), and the higher the satisfaction score, the more restricted were the carer's usual activities (r=-0.291, p=0.013; rho=-0.275, p=0.019). This implies that satisfaction levels early in the care experience are influenced by social factors and not by the quantity of care or physical or psychological health of the carer.

12.13 Summary of results from the second interview

Seventy-four carers underwent the second follow up interview six weeks after the stroke patient was discharged from hospital. There was significantly less weight loss reported by carers at this time point but alcohol consumption had risen significantly between the pre- and post-discharge interviews.

Physical health measures showed that there was a significant deterioration in carer health between the pre-discharge and early post-discharge interviews as measured by the number of medications and number of health problems reported. There was no significant change in self-rated health. The major factors independently associated with all three health measures were the carers' pre-discharge physical health scores.

Psychological health measures also showed a significant deterioration between the pre-discharge and early post-discharge interviews with a significant increase in CIS-R scores, indicating an increase in psychological distress, and a reduction in morale scores. Six-weeks after the stroke patient was discharged home, 54% of carers had a CIS-R score indicating significant psychological distress. As with physical health, the strongest factors independently associated with early post-discharge measures of psychological health were the pre-discharge scores. However, for both psychological distress and morale, the quality of social support was also an important factor - the higher the quality of social support, the lower the CIS-R score and higher the morale.

The amount and quality of social support available to the carers did not significantly change between the pre-discharge and early post-discharge interviews, however there was a significant deterioration in the relationship between the stroke patients and carers. Most of the stroke patients were discharged home with significant handicaps, with only 15% judged by the carers to be able to cope without carer support. All the carers received some support in the early post-discharge phase from the formal support services with a mean of 5.38 services involved per carer. There were no significant differences in quantity of support provision or satisfaction with that support between the recruiting centres, or male or female carers, though there were differences in individual service provision between these groups.

The stroke patient's level of handicap was a factor predicting both the number of hours of formal support provision and the number of services provided. The greater the incapacity of the stroke patient, the more formal support was provided. In addition, the number of services was predicted by the carer's self-rated health and place of recruitment with carers with poorer self-rated health receiving more services. Number of hours of formal support was also predicted by the carer's other care commitments, and the number of social supporters identified. Carers with other commitments received more support, and those carers who identified more informal social supporters, receiving less formal care.

As well as CIS-R scores, pre-stroke relationship scores and social support quality scores differed between carers satisfied and dissatisfied with formal support provision. This suggests better social support, either through the carer's relationship with the stroke patient or wider social network, is associated with greater satisfaction. Factors independently associated with satisfaction scores included quality of social support and activity restriction, which would seem to support this.

Chapter 13: Results from the third interview

Final follow up interviews were carried out for 53 carers – 27 (51%) recruited from Southampton and 26 from Christchurch. Reasons for carers dropping out of the cohort are recorded in figure 10.1 on page 118. Of the carers remaining in the cohort, 39 (73.6%) were female and 14 (26.4%) male. The average age of the carers was 65.64 years (range 31-88 years; SD 12.12 years). There was no significant difference in terms of any of the health or social care measures between those carers who continued in the study and those who dropped out. Only one of the comparison non-carers failed to complete the second interview, leaving 49 comparison non-carers in the study.

13.1 Timing of interviews

The mean time interval between the stroke and the third interview was 15.5 months (range 11.1 – 20.1 months; SD 2.1 months) – see Figure 11.1, page 126.

13.2 Smoking history

Forty-six carers (86.8%) were non-smokers and seven (13.2%) smokers. Three smokers had given up during the course of the study, one before the six week post-discharge interview and the other two between the six-week interview and final interview. Smokers consumed an average of 17.4 cigarettes per day (range7.0 -30.0; SD 7.6). Using a paired sample t-test, there was no significant difference in the amount smokers smoked at six weeks post discharge and at the time of the final interview (t=1.898, p=0.094). However there was a significant reduction in the amount smokers smoked between the pre-discharge interview and the final interview (19.6 vs. 12.2 cigarettes / day respectively, t=3.050, p=0.014, 95% CI 1.91 – 12.89).

13.3 Alcohol consumption

Twenty-three carers (43.4%) regularly consumed alcohol. Of those that did drink, the mean alcohol consumption was 9.76 units/week (range 0.50-42.00 units; SD11.41). Three carers (5.6%) were consuming a weekly amount of alcohol in excess of recommended limits. Analysis using a paired sample t-test showed that there was no significant difference in the amount of alcohol consumed by carers at six weeks post-discharge and at the time of the final interview (t=1.036, p=0.310) or prior to discharge and at the time of the final interview (t=-0.545, p=0.590).

Table 13.1: Carer weight change since discharge of the stroke patient

Weight (carer report)	**Number of carers**	**Percent**
Same	25	47.2
Lost < 1/2 stone	5	9.4
Lost > 1/2 stone	12	22.6
Intentional weight loss	0	0
Gained weight	11	20.8

13.4 Weight

Weight change figures at the time of the final interview were very similar to those recorded at the time of the six week interview - see table 13.1. The marginal homogeneity test and the Wilcoxon signed ranks test both showed there was a significant change in perceived weight loss between the pre-discharge interview and the final interview (standard MH statistic=-2.951; p=0.005 and z=-2.839; p=0.005 respectively) but no significant change in the weight changes being reported between the second and final interviews (standard MH statistic=-1.200; p=0.230 and z=-1.184; p=0.237 respectively).

13.5 Physical health

Over a year post-discharge, there was no difference in physical health according to which centre carers were recruited from, or according to the gender of carers (table 13.2). For

	Mean score for carers (SD)	**Effect of gender**	**Effect of place of recruitment**
Self-rated health	3.15 (1.063) *Range 1-5*	t=-0.323 *(2-tailed sig.0.748)*	t=1.552 *(2-tailed sig.0.127)*
Number of medications	2.55 (2.470) *Range 0-12*	t=1.579 *(2-tailed sig.0.121)*	t=-1.319 *(2-tailed sig.0.193)*
Number of health problems	1.87 (1.387) *Range 0-6*	t=0.189 *(2-tailed sig. 0.851)*	t=-0.677 *(2-tailed sig. 0.502)*

Table 13.2: Effect of gender and place of recruitment on physical health scores for carers more than a year post-discharge

Table 13.3: Comparison of physical health measures for carers throughout the study

Health measure	**Mean score at first interview (SD)**	**Mean score at second interview (SD)**	**Mean score at third interview (SD)**	**T-tests (p-values)**
Self-rated health	3.47 (0.992)	3.34 (1.126)	3.15 (1.063)	*First/second interview:* t=0.866 (p=0.390) *First/third interview:* t=1.760 (p=0.084) *Second/third interview:* t=1.067 (p=0.291)
Number of medications	2.32 (2.268)	2.51 (2.309)	2.55 (2.470)	*First/second interview:* t=-1.648 (p=0.105) *First/third interview:* t=-1.302 (p=0.198) *Second/third interview:* t= -0.237 (p=0.814)
Number of health problems	1.55 (1.232)	1.74 (1.112)	1.87 (1.387)	*First/second interview:* t=-1.748 (p=0.086) *First/third interview:* t=-2.019 (p=0.049) *Second/third interview:* t=-0.926 (p=0.359)

Note: Results highlighted in red denote significant results ($p<0.05$).

the control group there was no significant change in any of the physical health measures over the course of the study (table 13.4). For the carer group there was a decrease in self-rated health and increase in the number of medications and number of major health problems over the duration of the study (table 13.3). All these changes were in the same direction suggesting deterioration in carer health but this only reached significance for major health problems (paired t=-2.019, p=0.049, 95% CI:-0.640 - -0.002). There was no significant difference at the final interview point between the carers and comparison non-carer group for any of the physical health measures (table 13.5, page 165).

Table 13.4: Comparison of health measures for comparison non-carers at the first and final interviews

Health measure	**Mean score at first interview (SD)**	**Mean score at final interview (SD)**	**T-test (p value)**
Self-rated health	3.41 (1.368)	3.49 (1.227)	t=-0.663 (p=0.511)
Number of medications	2.20 (2.309)	2.20 (2.198)	t=0 (p=1.000)
Number of health problems	1.69 (1.557)	1.71 (1.541)	t=-1 (p=0.322)
CIS-R	7.47 (5.594)	7.45 (5.613)	t=0.444 (p=0.659)
PGC Morale scale	11.06 (4.46)	11.14 (4.267)	t=-0.340 (p=0.735)

Table 13.5: Comparison of carer health with matched comparison non-carers at final interview

Health measure	**Mean score for carer at final interview (SD)**	**Mean score for control at final interview (SD)**	**T-test (p value)**
Self-rated health	3.20 (1.069)	3.49 (1.227)	t=-1.254 (p=0.213)
Number of medications	2.52 (2.443)	2.20 (2.198)	t=0.676 (p=0.501)
Number of health problems	1.84 (1.267)	1.71 (1.541)	t=0.444 (p=0.658)
CIS-R	12.58 (9.208)	7.45 (5.613)	t=3.340 (p=0.001)
PGC Morale scale	10.02 (4.008)	11.14 (4.267)	t=-1.342 (p=0.183)

Note: Results highlighted in red denote significant results ($p<0.05$).

Table 13.6: Factors independently associated with physical health of carers 13 months post-stroke

	Predicted by:	**% variance:**	**Statistics:**
Self-rated health	PGC Morale score at final interview	21.9%	R^2= 0.219, F=13.461, p=0.001
	Deprivation score	7.4%	R^2= 0.074, F=5.291, p=0.026
	Amount of formal support provided immediately post-discharge	7.1%	R^2= 0.071, F=5.565, p=0.023
	Presence of other care commitments	6.3%	R^2= 0.063, F=4.129, p=0.048
Number of medications	Number of medications 6 weeks post-discharge	68%	R^2= 0.680, F=101.910, p<0.001
	Level of handicap at final interview time	3.8%	R^2= 0.038, F=6.353, p=0.015
	Quality of social support 6 weeks post discharge	3%	R^2= 0.030, F=5.547, p=0.023
	Amount of formal support provided in the 6 weeks post-discharge	2.8%	R^2= 0.028, F=5.574, p=0.023
	Quality of social support at the time of the final interview	2.7%	R^2= 0.027, F=5.916, p=0.019
Number of health problems	Number of health problems 6 weeks post-discharge	43.6%	R^2= 0.436, F=37.136, p<0.001
	CIS-R score at the final interview	7.9%	R^2= 0.079, F=7.688, p=0.008
	Number of drugs 6-weeks post-discharge	7.0%	R^2= 0.070, F=8.938, p=0.005
	Presence of other care commitments	6.5%	R^2= 0.065, F=7.066, p=0.011

Stepwise regression analysis was then performed entering independent variables into the model as listed in table 11.3, page 130. The results are recorded in table 13.6, page 165. Again the previously measured physical health status measures were major factors independently associated with both the number of drugs and number of major health problems. Morale measured at the final interview was a major indicator of self-reported health, which may represent the more subjective nature of self-rated health, or that a significant part of morale is physical health. The deprivation score was also a significant predictor of self-rated health. Other associated factors reflect carer workload and the support received to help them with that workload.

Table 13.7: Psychological health scores for carers and non-carers at final interview

	Mean score for carers (SD)	**Mean score for non-carers (SD)**	**Effect of being a carer**	**Effect of gender**	**Effect of place of recruitment**
PGC Morale Scale	10.02 (4.01) *Range 3-17*	11.14 (4.27) *Range 3-17*	t=-1.342 *(2-tailed sig. 0.183)*	t=-0.200 *(2-tailed sig. 0.842)*	t=0.684 *(2-tailed sig. 0.856)*
CIS-R score	12.58 (9.21) *Range 0-34*	7.45 (5.61) *Range 0-23*	t=3.340 *(2-tailed sig. 0.001)*	t=0.614 *(2-tailed sig. 0.541)*	t=-0.182 *(2-tailed sig. 0.175)*

Note: Results highlighted in red denote significant results (p<0.05).

13.6 Morale and psychological health

Carers' morale scores were not significantly different from the comparison non-carers scores at baseline but fell significantly between the pre-discharge and post-discharge interviews (t=2.856, p=0.006, CI: 0.454-2.602). This was a lasting effect as carers still had significantly lower morale scores over a year after stroke than prior to the stroke patient's discharge home (t=2.052, p=0.045, CI: 0.023-2.093). However, morale scores did not significantly change between the first post-discharge interview and final interview, 15 months after the stroke (table 13.8, page 167). The morale of the comparison non-carers did not change significantly over the same time period (table 13.4, page 164). At 15 months post-stroke there was no difference in morale according to which centre that carers were recruited from or gender of the carer (table 13.7).

At the time of the final interview, 15 months after the stroke, 38% of carers (20 carers) had significant psychological distress (CIS-R >12) and 19 of those carers (36%) had scores above the level where intervention should be considered (i.e. CIS-R >17). Amongst the control group, 8 (16%) of non-carers had significant psychological distress with four (8%) above treatment intervention levels.

Comparing the non-carers with carers, CIS-R scores for the carers were higher than those of the comparison non-carer group at baseline before the stroke patient was discharged home, and remained high throughout the duration of the study. There was still a significant difference in CIS-R scores between carers and non-carers over a year after the stroke (table 13.7, page 166 - mean score 12.59 vs. 7.45, t=3.340, p=0.001, CI: 2.082 - 8.180). This suggests that either our carer group was significantly different from the comparison group in respect of psychological health at baseline, or that the high psychological distress scores seen amongst our carer group reflects distress caused by stroke affecting someone close to the carer and/or anticipation of the care-giving role for that stroke patient. At 15 months post-stroke there was no difference in CIS-R according to which centre carers were recruited from or gender (table 13.7, page 166).

The distribution of psychological symptoms on the CIS-R is shown in figure 13.1, page 168. All symptoms had reduced by thirteen months post-stroke with the exceptions of poor concentration, irritability and worries about physical health which had markedly increased. Worries about their own physical health could be explained by carers worrying

Table 13.8: Comparisons of psychological health of carers throughout the study period

Health measure	**Mean score at first interview (SD)**	**Mean score at second interview (SD)**	**Mean score at third interview (SD)**	**T-tests (p-values)**
PGC Morale Scale	10.98 (3.805)	9.45 (4.547)	9.87 (4.025)	*First/second interview:* t=2.856 (p=0.006) *First/third interview:* t=2.052 (p=0.045) *Second/third interview:* t= -0.975 (p=0.334)
CIS-R score	11.21 (9.136)	13.15 (9.879)	12.87 (9.680)	*First/second interview:* t=-1.308 (p=0.197) *First/third interview:* t=-1.504 (p=0.139) *Second/third interview:* t=0.241 (p=0.811)

Note: Results highlighted in red denote significant results (p<0.05).

13.1: Change in psychological symptoms for carers over time

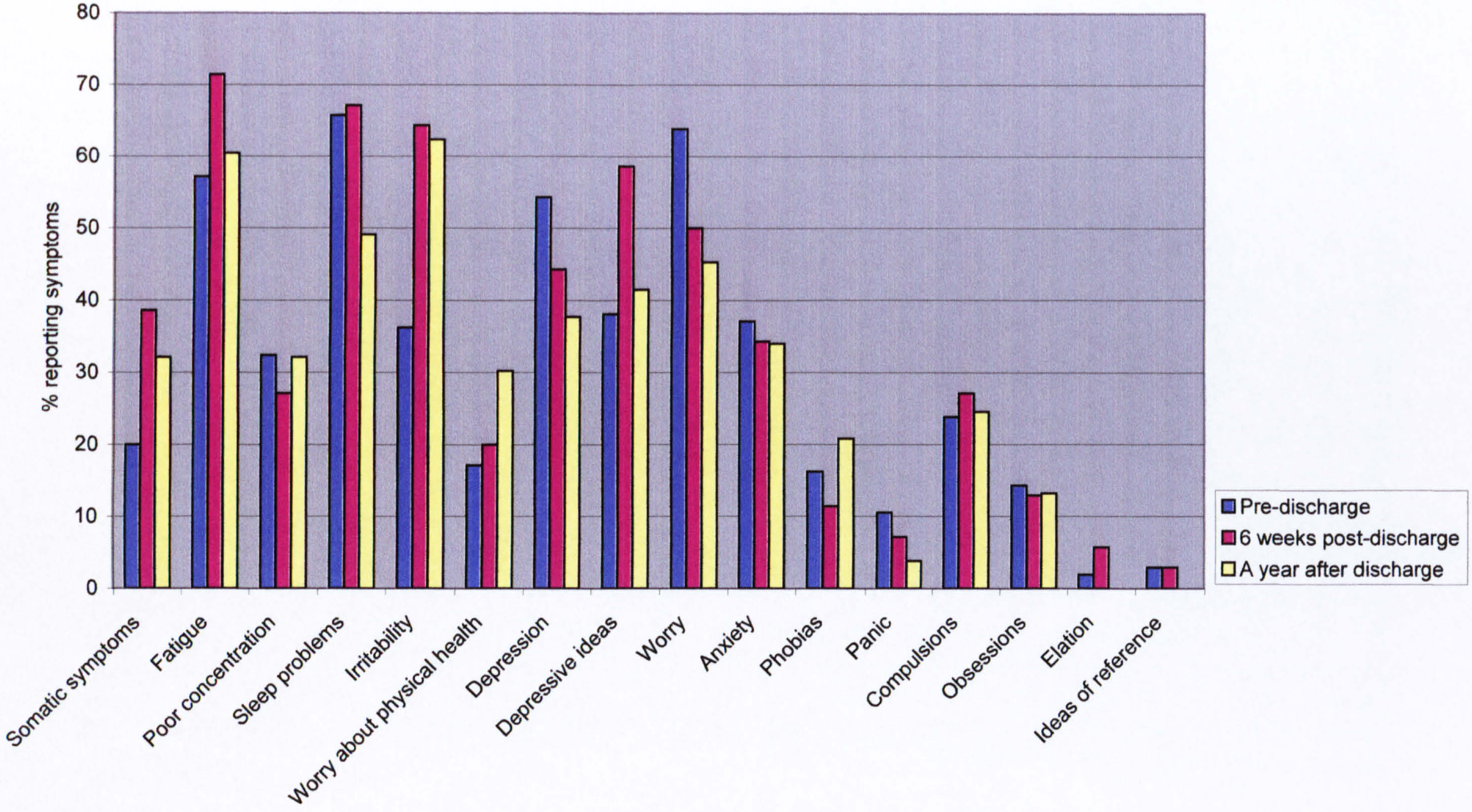


Figure 13.2: Comparison of psychological symptoms for carers and comparison non-carers at final interview

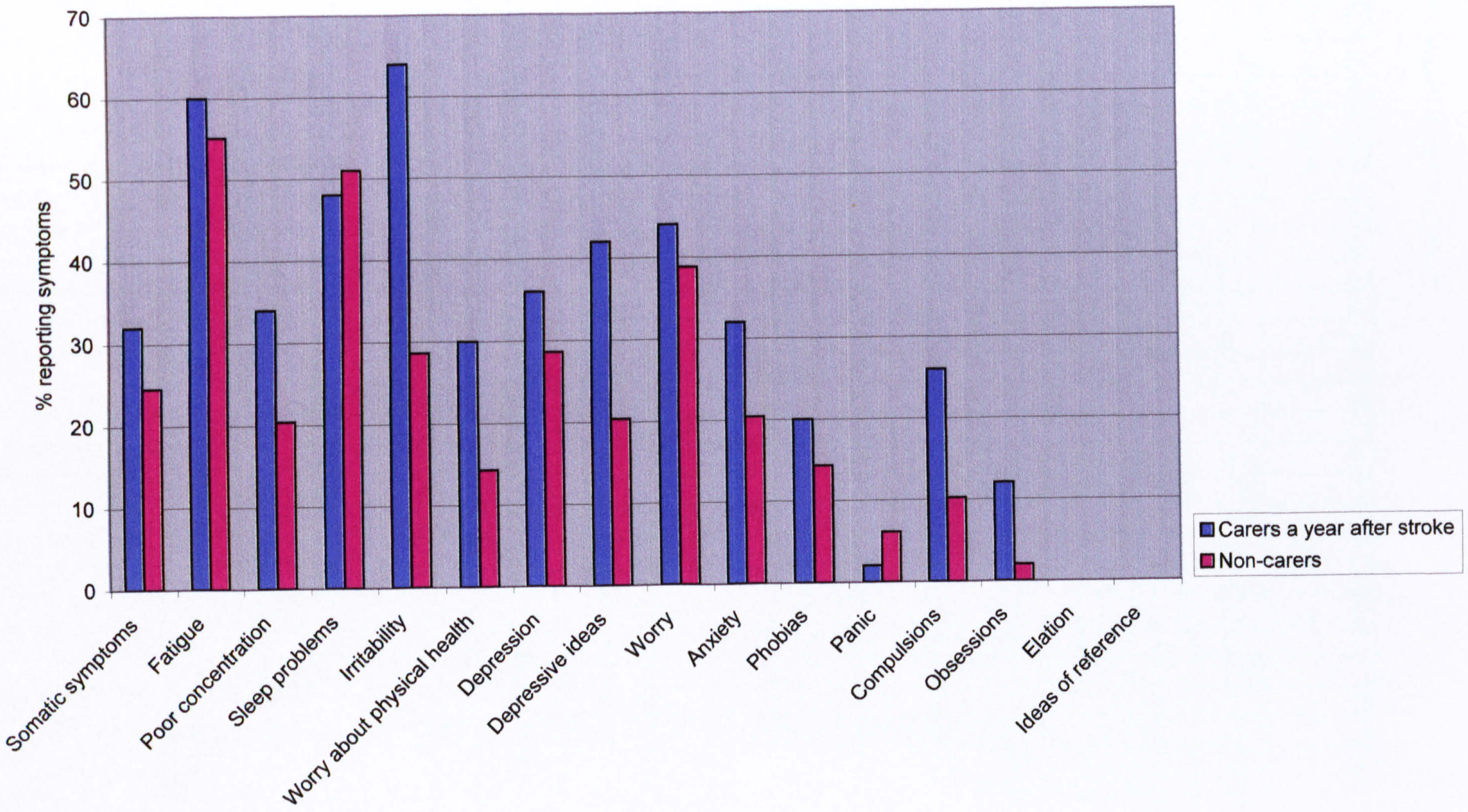


Table 13.9: Factors independently associated with psychological health of carers at the time of the final interview

	Predicted by:	**% variance:**	**Statistics:**
PGC Morale scale	PGC Morale score post-discharge	38.8%	R^2= 0.388, F=30.465, $p<0.001$
	Number of major health problems pre-discharge	10.3%	R^2= 0.103, F=9.463, p=0.003
	Activity restriction post-discharge	9.8%	R^2= 0.098, F=11.002, p=0.002
	PGC Morale score pre-discharge	5.9%	R^2= 0.059, F=7.580, p=0.008
	Number of drugs at final interview	3.9%	R^2= 0.039, F=5.474, p=0.024
	CIS-R score post-discharge	3.9%	R^2= 0.039, F=6.071, p=0.018
	Satisfaction with formal support at final interview	2.5%	R^2= 0.025, F=4.326, p=0.044
CIS-R	CIS-R score pre-discharge	39.9%	R^2= 0.399, F=32.598, $p<0.001$
	CIS-R score post-discharge	17.6%	R^2= 0.176, F=19.973, $p<0.001$
	Income	4.7%	R^2= 0.047, F=5.886, p=0.019
	Alcohol consumption post-discharge	4%	R^2= 0.040, F=5.467, p=0.024

about what would happen to the stroke patient they were looking after, if they fell ill. Compared to control non-carers, carers still had markedly elevated levels of all the psychological symptoms recorded with the exceptions of sleep problems and panic (figure 13.2, page 169).

Stepwise regression analysis using the parameters listed in table 11.3, page 130 was then performed. Findings are listed in table 13.9. As for physical health, the major factors predicting both the PGC morale score and CIS-R score at the time of the final interview, were the previous values on these measures. However, in the case of the PGC Morale scale, physical health measures also predicted a significant part of the variance (14.2% in total) as did restriction of usual activities i.e. those the carer used to do prior to the stroke.

	Availability of support index				**Quality of support index**			
	All carers	*Carers without controls*	*Carers with controls*	*Controls*	*All carers*	*Carers without controls*	*Carers with controls*	*Controls*
Range	0-6	0.6-1.83	0-6	0.17-5	1-6	2.8-5.67	1-6	1.67-7.33
Mean	1.38	1.23	1.38	1.32	5.10	4.21	5.15	5.35
Median	1.25	1.33	1.23	1.17	5.60	4.17	5.63	5.67
Standard deviation	0.92	0.62	0.62	0.93	1.20	1.43	1.18	1.08

Table 13.10: Social support at the final interview

13.7 Social support

Results of the social support questionnaire recorded during the final interview are recorded in table 13.10. For the comparison non-carers, there was no significant change in social support, either in terms of quantity or quality, between the time of their first and final interviews (t=0.301, p=0.765 and t=-0.680, p=0.500 respectively). There was also no significant difference in quantity or quality of social support at the time of the second interview between the carers with controls and those without (t=.0.236, p=0.816 and t=1.328, p=0.190 respectively).

Both paired sample t-test and Wilcoxon signed rank tests revealed a significant change in social support for the carers between early interviews and the long-term follow up interview – see table 13.11. This suggests perceived social support decreases steadily over time after stroke in both quantity (in other words, the carer has fewer informal supporters to call upon for help) and in quality (in other words, carers are less satisfied with the help they receive from those informal supporters). There was no significant correlation between either the quantity or quality of social support and the relationship score between the carer and stroke patient.

Table 13.11: Social support changes over time

		Wilcoxon signed ranks test		**Paired t-test**			
		z	*p*	*Mean scores*	*t*	*p*	*Confidence interval*
Quantity of support	t_1 vs. t_3	-2.789	0.005	1.63 vs. 1.05	3.08	0.003	0.11-0.54
	t_1 vs. t_2	-1.79	0.074	1.63 vs. 1.45	1.64	0.106	-
	t_2 vs t_3	-1.923	0.055	1.45 vs. 1.05	1.26	0.214	-
Quality of support	t_1 vs. t_3	-6.352	<0.001	5.75 vs. 5.00	3.36	0.001	0.21-0.82
	t_1 vs. t_2	-2.11	0.035	5.75 vs. 5.34	1.80	0.078	-
	t_2 vs t_3	-2.40	0.019	5.34 vs. 5.00	2.53	0.014	0.06-0.53

t_1 *- recorded at first interview*

t_2 *– recorded at second interview*

t_3 *- recorded at third interview*

Note: Results highlighted in red denote significant results (p<0.05).

Table 13.12: Relationship of carer and stroke patient at the time of the final interview

		Number of carers	Percent
How would you describe your relationship?	Excellent	34	64.2
	Good	11	20.8
	Indifferent	5	9.4
	Bad	3	5.7
Do you feel appreciated?	Very Much	31	58.5
	A bit	11	20.8
	Not sure	4	7.5
	Not really	2	3.8
	Definitely not	5	9.4
Do you argue?	Very infrequently	13	24.5
	Very occasionally	17	32.1
	From time to time	8	15.1
	Often	13	24.5
	All the time	2	3.8
How close is your relationship?	Very close	33	62.3
	Close	12	22.6
	In between	18	34.0
	Distant	5	9.4
	Very distant	0	0

13.8 Relationship quality

Most of the carers continued to consider that they had good relationships with the stroke patient. The results are recorded in table 13.12. The cumulative relationship scores had a range of 4 to 15; mean of 7.55 and standard deviation of 3.18. There was no significant change in the stroke patient's and carer's relationship for any of the individual elements of the relationship measured between the second and third interviews, though there was a significant reduction in the feeling that the carer was appreciated between the first and third interviews ($z=-2.001$, $p=0.045$).

Following the significant reduction in overall quality of the relationship between carer and stroke patient between the pre-discharge and early post-discharge interviews, there was no further significant change in the quality of this relationship between the early and late post-discharge interviews ($t=0.594$, $p=0.555$). Therefore, once the initial adjustment to the caring situation had been made, the quality of the relationship between the carer and stroke patient remained static.

13.9 Activity restriction

The mean activity restriction score was -2.57 (median -3.00; range-6 - +2; SD 2.08). This shows that carers still had a considerable degree of activity restriction a year after the stroke with almost half their usual activities being restricted. Looking at individual items, carers' activities were altered in all but six cases (11%) compared to activities prior to the stroke. However, twelve carers (23%) did not report a reduction in their activity levels overall which implies they had compensated for the reduction in some activities by increasing others.

This activity restriction level was significantly different (according to the paired t-test and Wilcoxon signed ranks test) from that measured six weeks after discharge, with carers having significantly less activity restriction at the time of the final interview (mean activity restriction scores -3.19 vs. -2.62, $t=-2.198$, $p=0.033$, 95% CI -1.1- -0.5, and $z=-2.182$, $p=0.029$ respectively). Reasons given for restriction of usual activities included the stroke (64%), other factors unrelated to the stroke (13%) and a combination of factors including stroke (11%). Since the level of disability of the stroke patients did not change significantly (see below) this probably represents an adjustment process.

Disability measure		**Symptoms**	**Number** *(%)*
Oxford Handicap Scale	*0*	No symptoms	1 *(1.9)*
	1	Minor symptoms which do not interfere with lifestyle	2 *(3.8)*
	2	*Minor handicap:* Symptoms that lead to some restriction in lifestyle but do not interfere with the patient's capacity to look after him or herself	12 *(22.6)*
	3	*Moderate handicap:* Symptoms that significantly restrict lifestyle and prevent totally independent existence	18 *(34.0)*
	4	*Moderately severe handicap:* symptoms that clearly prevent independent existence though not needing constant attention	12 *(22.6)*
	5	*Severe handicap:* totally dependent patient requiring constant attention day and night	8 *(15.1)*

Table 13.13: Level of disability of stroke patients at final interview

13.10 Level of disability

Carer reported levels of disability of the stroke patients are recorded in table 13.13. The mean Oxford handicap score was 3.17 (median=3.00; range 0 – 5; SD=1.17). Sadly, there was no significant difference in handicap scores between the two time points at which they were recorded (though the difference did approach significance – t=1.996; p=0.055).

Table 13.14: Formal support services involved at the time of the final interview

Service	**Number *(%)* in contact in the 6 weeks prior to the final interview.**	**Number *(%)* of these carers receiving the service at the post discharge interview**
General practitioner	41*(77.4)*	48 *(90.6)*
Community nurse	28*(52.8)*	37 *(69.8)*
Social services	14*(26.4)*	17 *(32.1)*
Physiotherapist	17 *(32.1)*	34 *(64.2)*
Occupational therapist	8 *(15.1)*	30 *(56.6)*
Home carers	20*(37.7)*	24 *(45.3)*
Counsellor	0	1 *(1.9)*
Voluntary support groups	10*(18.9)*	11 *(20.8)*
Day centre or day hospital	13*(24.5)*	17 *(32.1)*
Hospital outpatients	22*(41.5)*	24 *(45.3)*
Community psychiatric nurse	4*(7.5)*	3 *(5.7)*
Other services (not on the original list)		
- speech therapist	3 *(5.7)*	3 *(5.7)*
- specialist stroke support nurse	2 *(3.8)*	6 *(11.3)*
- in-patient care / respite	10*(18.9)*	1 *(1.9)*
- phlebotomy	4*(7.5)*	1 *(1.9)*
- chiropody	7*(13.2)*	0
- dentist	4*(7.5)*	1 *(1.9)*
- sitter	3 *(5.7)*	0
-Indian head massage	1 *(1.9)*	0
- ambulance	1 *(1.9)*	0
- dietician	1 *(1.9)*	0
- night nurse	1 *(1.9)*	0
- cleaner	2 *(3.8)*	2 *(3.8)*

Figures in red denote a reduction in percentage of carers receiving a service

Figures in green denote an increase in percentage of carers receiving a service

13.11 Quantity and cost of formal service provision:

All but two carers (3.8%) had some input from formal support services in the six weeks prior to the final interview (mean number of services involved =4.09; range 0-10 services; SD =2.30) – see table 13.14, page 174. There was a significant reduction in the number of services involved with the carers between the two interviews (mean number of services post-discharge = 5.45; mean number of services involved at final interview = 4.09, t=4.201, p<0.001, 95% CI: 0.71-2.01).

The amount of time formal support services spent with the carers and stroke patients varied considerably from no support to a maximum of 339 hours in the six weeks prior to the final interview (mean=41.17 hours; SD=64.73). There was no significant difference in the time formal support services spent with carers between the post-discharge interview and the final interview.

By the time of the final interview, secondary care services provided in the community in the immediate post-discharge phase had been withdrawn. In the majority of cases, the services being received at this point in time were being provided on a long-term basis and were constant. In the six weeks prior to the final interview, formal care cost a minimum of £62 and a maximum of £2687 (mean = £635.13; median =£427; SD=£660.12). This gives an estimated cost to health and social care services of maintaining a stroke patient long-term in the community with an informal carer, once a steady state of community formal support has been reached, of £5,504.46 per year using the mean value of cost of care, or £3,700.67 per year using the median value of cost of care for calculation purposes. Perhaps not surprisingly, as the cost of care was so closely related to the time formal services allocated to supporting the stroke patient and carer, there was no significant reduction or increase in the cost of care between the early discharge period and final interview (Z=-0.056, p=0.955).

13.11.2 Effects of place of recruitment and gender of the carer on service provision

By the time of the final interview, 15 months after the stroke, there were no associations between the place of recruitment and formal support in terms of the number of services (t=0.054, p=0.957), hours of formal support provision (U=277.0, p=0.188) or the cost of care (U=248.0, p=0.067). The effects of place of recruitment on individual service provision seen at the time of the post-discharge interview had disappeared.

At the time of the final follow up interview there was also no difference between male and female carers in terms of the number of services received (t=1.181, p=0.243), hours of formal service input (U= 247.0, p=0.600), or the cost of care (U=272.5, p=0.992). In addition, at individual service level, there was no differential between the services provided to male and female carers.

13.11.3 Examination of factors contributing to formal support services provision:

When the number of formal support services involved one year after stroke was entered into the stepwise regression model described on page 111 as the dependent variable, with independent variables recorded in table 12.11 (page 153), the level of handicap at one year post stroke was the only predictor of the number of services involved, accounting for 14.7% of the variance (R^2=0.144, F=8.268, p=0.006).

Using the same model but with the time allocated to the patient-carer dyad as the dependent variable instead of the number of services, five factors were independently associated with time allocated by formal support services (table 13.15, page 177) but again, the level of handicap was the most important predictor accounting for 28.2% of the variance (R^2 change=0.282, F change=18.862, p<0.001). In addition, the quality of social support and the quality of the relationship with the stroke patient at the time of the final interview, accounted for a further 15.1% of the variance in time allocated, suggesting that social factors are still important in determining the amount of formal support over a year after stroke.

Previous experience of caring for a disabled person was also an important factor determining the amount of formal support provided. Carers with previous experience in a professional capacity received a mean of 14.83 hours of formal help; carers with previous experience of informal care received a mean of 25.86 hours formal help; and carers with no previous experience received a mean of 52.25 hours formal help in the six weeks

Table 13.15: Factors independently associated with formal support for carers, cost of care and carer satisfaction with that support 13 months post-stroke

	Predicted by:	**% variance:**	**Statistics:**
Number of services involved	Oxford Handicap score at final interview	14.7%	$R^2= 0.147, F=8.268, p=0.006$
Hours of service provision in the preceding 6 weeks	Oxford Handicap score at the time of the final interview	28.2%	$R^2= 0.282, F=18.862, p<0.001$
	Social support quality 6 weeks post discharge	10.5%	$R^2= 0.105, F=8.061, p=0.007$
	Previous experience caring for a disabled person	9.2%	$R^2= 0.092, F=8.115, p=0.007$
	Income	4.7%	$R^2= 0.047, F=4.860, p=0.033$
	Quality of relationship with the stroke patient at the time of the final interview	4.6%	$R^2= 0.046, F=4.347, p=0.043$
Cost of care	Quantity of care at the early post-discharge interview	39.4%	$R^2= 0.394, F=31.262, p<0.001$
	Number of services at the early post-discharge interview	14.3%	$R^2= 0.143, F=14.527, p<0.001$
	Cost of care at the early post-discharge interview	10%	$R^2= 0.100, F=12.702, p=0.001$
	CIS-R score prior to discharge	3.3%	$R^2= 0.033, F=4.515, p=0.039$
Satisfaction with service provision	Quality of relationship score pre-discharge	17.2%	$R^2= 0.172, F=9.951, p=0.003$
	Patient's age	12.1%	$R^2= 0.121, F=8.066, p=0.007$
	CIS-R score at the time of the final interview	7.7%	$R^2= 0.077, F=5.633, p=0.022$
	Cost of care	5.6%	$R^2= 0.056, F=4.374, p=0.042$

before the final interview. This implies that previous experience is a factor taken into account when providing support. Finally income was a minor factor in determining number of hours of formal support. This is probably due to carers with higher income purchasing additional support.

Stepwise regression using the cost of care as the dependent variable revealed four factors independently associated with the cost of care over a year after stroke. The most important of these were the time input from formal support services, the number of services involved and the cost of care during the early post-discharge interval, which together predicted 63.7% of the variance (R^2 change=0.394, F change =31.262, $p<0.001$; R^2 change=0.143, F change=14.527, $p<0.001$; R^2 change=0.100, F change=12.702, p=0.001 respectively). The CIS-R score at the pre-discharge interview was also a minor, and interesting, indicator of cost of care (R^2 change=0.033, F change=4.515, p=0.039).

When considering factors associated with individual service provision, the only service for which any associations were found was the community nursing service. Community nurses were more likely to be involved the older the carer (χ^2=13.445, df=3, p=0.004) and the older the stroke patient (χ^2=12.516, df=3, p=0.006). Rather surprisingly community nurses were more likely to be involved if the carer did *not* have other care commitments (22% vs. 59%, χ^2=4.076, df=1, p=0.044) though this result only just achieves significance and may be spurious, given the number of comparisons made.

13.12 Satisfaction with formal service provision

Using the global satisfaction score as a measure of carer satisfaction, overall 15 carers (28.3%) were very satisfied with the community support services received; 24 carers (45.3%) were satisfied; 10 carers (18.9%) were neither satisfied nor dissatisfied; three carers (5.7%) were dissatisfied; and one carer (1.9%) was very dissatisfied. Analysis using the Wilcoxon signed ranks test showed that there was no significant difference between global satisfaction scores at the two time points at which they were measured.

The mean satisfaction score on the satisfaction questionnaire was 26.25 (range 0- 69; SD=18.59). Individual scale items and responses are listed in table 13.16, page 179. Using the paired t-test and Wilcoxon signed ranks test there was no significant difference between satisfaction scores six weeks post-discharge and at the time of the final interview. There was also no association between the place the carer was recruited from and satisfaction with service provision (t=-0.623, p=0.536), nor was there any association

Question	**Number %**					
	Strongly agree	*Agree*	*Neither agree nor disagree*	*Disagree*	*Strongly disagree*	*Missing*
You are satisfied with the total amount of help provided to you (include in this help to allow you time to do what you want to do and time off)	20 (37.7)	15 (28.3)	3 (5.7)	8 (15.1)	7 (13.2)	0
You are confident that services provided to you would adapt if your situation were to change (for example if you were ill or had an accident and were unable to do what you do now for the person you care for)	21(39.6)	8 (15.1)	7 (13.2)	4 (7.5)	13 (24.5)	0
You are satisfied with information you have been given about help available from the community services for you (include health, social and voluntary services)	25 (47.2)	9 (17.0)	1(1.9)	7 (13.2)	11 (20.8)	0
Services and equipment provided to you are usually of good quality	45 (84.9)	3 (5.7)	1(1.9)	2 (3.8)	1(1.9)	1(1.9)
You are confident you would know whom to contact from the community services if you had a problem	30 (56.6)	7 (13.2)	2 (3.8)	3 (5.7)	11 (20.8)	0
You are satisfied with information you have been given about your role as a carer	20 (37.7)	6 (11.3)	1(1.9)	13 (24.5)	13 (24.5)	0
You have been given enough training for the tasks (such as lifting or bathing) you need to do for the person you look after	26 (49.1)	7 (13.2)	4 (7.5)	5 (9.4)	10 (18.9)	1(1.9)
You are satisfied with information you've been given about stroke	29 (54.7)	15 (28.3)	1(1.9)	4 (7.5)	4 (7.5)	0
You are satisfied with information you have been given about what to expect of someone who has had a stroke	18 (34.0)	6 (11.3)	3 (5.7)	11 (20.8)	15 (28.3)	0
You are confident you would know where to get information about any matter related to stroke or looking after someone who has had a stroke if you needed it	30 (56.6)	9 (17.0)	1(1.9)	4 (7.5)	9 (17.0)	0
You are satisfied with help you've received from the community services when you've had a problem	35 (66.0)	6 (11.3)	4 (7.5)	2 (3.8)	6 (11.3)	0
The professionals involved with your care seem as concerned about you as the person you look after	24 (45.3)	6 (11.3)	2 (3.8)	7 (13.2)	14 (26.4)	0
You feel your opinion is ignored in making decisions about the person you care for	8 (15.1)	1(1.9)	6 (11.3)	6 (11.3)	32 (60.4)	0
You are satisfied about information you have been given about financial help you might be entitled to (including benefits)	30 (56.6)	3 (5.7)	0	4 (7.5)	15 (28.3)	1(1.9)
Given the choice, there are tasks you do now as a carer that you would rather not do	4 (7.5)	5 (9.4)	1(1.9)	6 (11.3)	36 (67.9)	1(1.9)
Services involved with your care lack co-ordination or don't work together	12 (22.6)	6 (11.3)	9 (17.0)	3 (5.7)	23 (43.4)	0
You could have been consulted more about the person you look after	14 (26.4)	6 (11.3)	1(1.9)	5 (9.4)	27 (50.9)	0
As far as you can tell, the professionals involved with your care (doctors, nurses, social workers or any other professionals you see) seem to understand what being a carer is like	29 (54.7)	3 (5.7)	7 (13.2)	3 (5.7)	11 (20.8)	0
You would have liked more help applying for benefits and services	13 (24.5)	5 (9.4)	1(1.9)	3 (5.7)	30 (56.6)	1(1.9)
Essential changes to equipment, housing or services have been made too slowly	11 (20.8)	1(1.9)	2 (3.8)	4 (7.5)	34 (64.2)	1(1.9)
Services provided to you are at times of the day when it is convenient to have them	40 (75.5)	8 (15.1)	0	3 (5.7)	2 (3.8)	0
Information you have received has generally been accurate	44 (83.0)	4 (7.5)	4 (7.5)	0	1(1.9)	0

▨ *Marks negatively worded questions*

Figures in red indicate a predominantly dissatisfied or neutral (i.e. evenly spread between satisfied and dissatisfied) response

Table 13.16: Answers to the satisfaction with community service questionnaire more than a year after stroke

between gender of the carer and satisfaction with community support (t= 1.309, p=0.196).

13.12.1 Comparison of carers satisfied and not satisfied with formal care:

Again subjects were split between the group who expressed satisfaction for the formal care provided using the global satisfaction measure (i.e. responded that they were very satisfied or satisfied) and the group that did not. A year after the onset of caring responsibility, the effect of social support seemed to have worn off. At the time of the final interview, the only variables with a significant difference in means between those satisfied and dissatisfied with care were the age of the carer (mean age of those satisfied 67.82 years; mean age of those dissatisfied 59.57 years; t=2.271; p=0.027; CI: 0.956-15.542) and the number of medications the carer was taking (those satisfied were taking an average 2.95 medications as opposed to an average 1.43 mediations; t=2.034; p=0.047; CI: 0.020-3.020).

Age effects are well-recognized in the satisfaction literature with older individuals tending to be more satisfied with care. The lower average number of medications being taken in the group dissatisfied with care may be a spurious result. It only just reaches significance and, because of the large number of comparisons being made, might be a type I error. Alternatively if real, it may reflect the fact that people taking more medications have more contact with the health professions and might, through that, have their needs better met.

13.12.2 Examination of factors independently associated with satisfaction with community support:

Stepwise multiple linear regression using the satisfaction score as the dependent variable, and the independent variables listed in table 12.11 (page 153), yielded four factors independently associated with satisfaction scores together accounting for 42.6% of total variance in satisfaction scores (table 13.15, page 176). These factors were the quality of relationship score pre-discharge (R^2 change = 0.172, F change =9.951, p=0.003); the patient's age (R^2 change = 0.121, F change=8.066, p=0.007); the carer's CIS-R score at the time of the final interview (R^2 change = 0.077, F change =5.633, p=0.022); and cost of care (R^2 change = 0.056, F change =4.374, p=0.042).

The quality of the relationship between the stroke patient and carer prior to discharge home was the most important factor predicting satisfaction with formal support services, accounting for 17.2% of the variance. Good pre-existing relationship was strongly correlated with higher levels of satisfaction (r=0.425, p=0.002). The patient's age was also significantly correlated with the satisfaction score at the time of the final interview, with carers of older stroke patients having a higher degree of satisfaction, and thus lower satisfaction scores (r= -0.317, p=0.021). This suggests stroke patient age and social factors are the strongest predictors of satisfaction. However, the fact that the CIS-R predicted a small but significant proportion of the variance suggests mood also influences satisfaction.

The influence of the cost of care on satisfaction levels is interesting. Carers satisfied with care do have a higher mean cost of care (£668.88 for carers satisfied compared to £598.46 for carers dissatisfied with care). However, this difference does not reach significance. It may be that, as income had an influence on the amount of service provision, those with higher income were able to purchase, or were just more articulate in demanding, the care they wanted and hence were more satisfied with that care. Alternatively it may be that those receiving higher cost care have more contact with service providers and are more likely to have their needs addressed.

13.13 Summary of results from the third interview

Final follow up interviews were carried out with 53 carers and 49 comparison non-carers. The carers' interviews took place a mean time interval of 15.5 months after the initial stroke. Over the course of the study, smokers had cut down significantly on the amount they smoked but there was no change in alcohol consumption and, after the reported weight losses in the immediate aftermath of stroke, no further weight changes were recorded.

There was a tendency to worsening health over the study period as gauged by all three measures of physical health used, but this reached significance only for the number of reported health problems. The physical health of comparison non-carers remained steady. Again, previously measured physical health status was the major predictor of physical health as measured by the number of medications or health problems. The major indicator of self-rated health was morale, perhaps reflecting the more subjective nature of this measure.

The psychological health of carers as measured by the CIS-R remained significantly worse than that of the comparison non-carer group though there was no significant deterioration over the course of the study. Morale dropped dramatically between the carers' pre-discharge and early post-discharge interviews but remained static thereafter. As with physical health, the major predictors of both the CIS-R and morale scores were the scores on previous measurements of them, though self-rated physical health and restriction of usual activities was also independently associated with a significant part of the variance in morale.

Perceived social support decreased steadily over the course of the study, both in quantity and quality. This was accompanied by a significant reduction in the number of formal support services involved, but not time allocated, between the early and late post-discharge interviews. The cost of support in the community remained static. The level of handicap was the most important indicator of both the number of formal services provided and total hours of formal support provision. The number of hours of formal support provision was also associated with social factors (the quality of social support and quality of the relationship with the stroke patient), previous experience of care giving and income. Satisfaction with that support was determined by the age of the stroke patient, the pre-stroke quality of the relationship with the stroke patient, psychological distress and cost of care.

Chapter 14: Limitations of the study

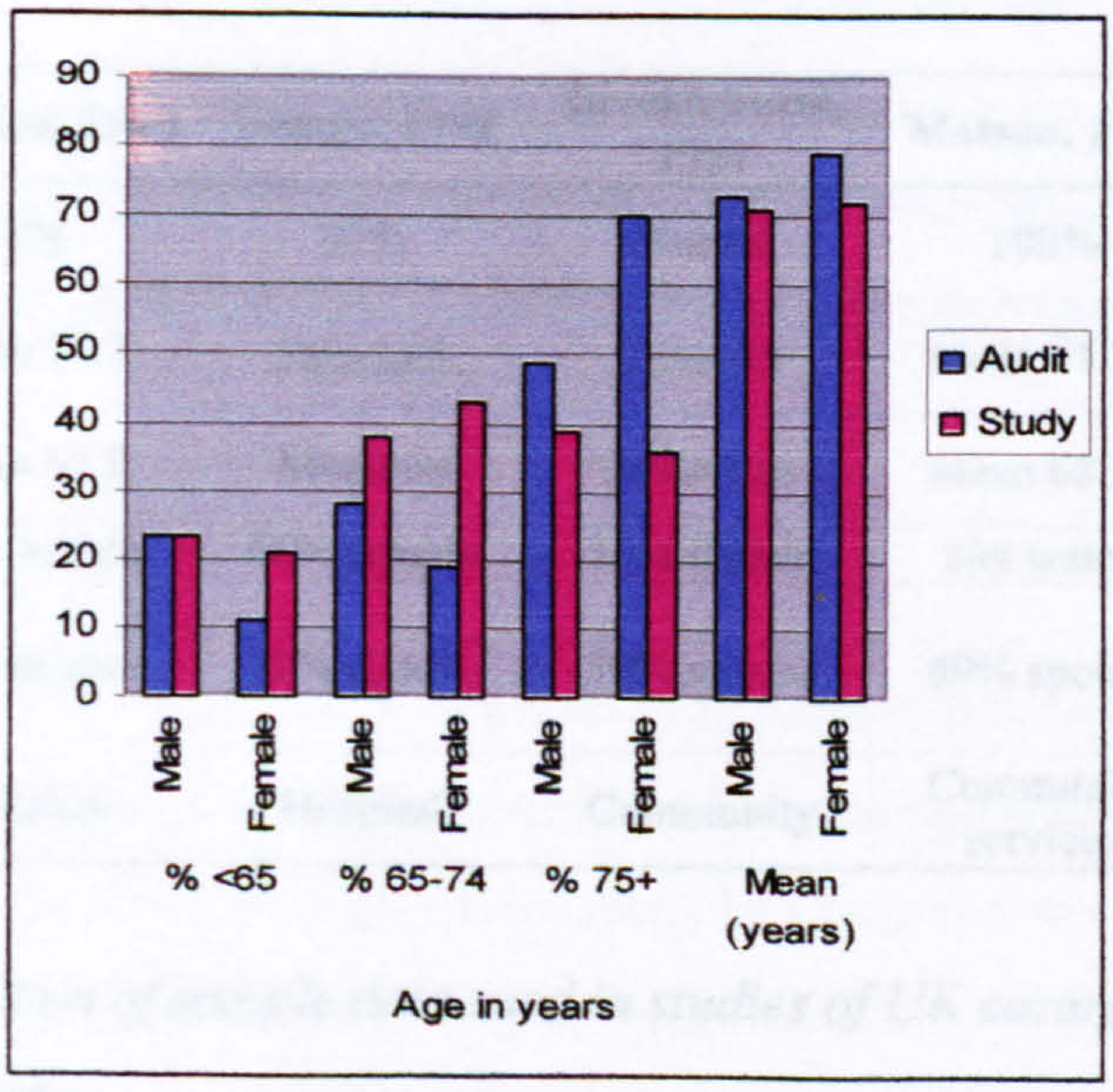
14.1 Was the sample population representative?

In this study, the carers were recruited via stroke patients. For the study to be generalisable to all carers of stroke patients in the community, the patients through whom the carers were recruited must be representative of all stroke patients living in the community with hands-on, day-to-day carers.

14.1.1 Comparison with National Stroke Audit data:

The National Sentinel Stroke Audit is an audit of stroke care in 235 hospitals in England, Wales and Northern Ireland (95% of those caring for patients after a stroke). Data collected in 2001/2002 (National Sentinel Stroke Audit, 2002), at the same time as recruitment started for this project, showed that 53% of stroke patients were male and 47% were female. The age distribution is shown in figure 14.1. Of those admitted to hospital 36% were admitted to a stroke unit at some point in their stay. Overall the average length of stay between admission and discharge or death was 34 days. Twenty-nine percent died in hospital – 12% within seven days of admission; 24% within 30 days.

Figure 14.1: Comparison of data from the National Sentinel Stroke Audit and this study



As can be seen from figure 14.1 (page 183), the study population of stroke patients was different in composition from those patients described in the National Sentinel Stroke Audit in several respects. First, 73% of stroke patients were male and 27% were female in the study population. Second, although the average age of stroke patient was similar in the National Stroke Audit and this study, more stroke patients in the 65-74 year age groups were accessed in this study compared to the National data and fewer in the over 75 age group, particularly few very elderly female stroke patients, who accounted for 70% of the population of women with stroke in the National stroke audit but only 36% of female stroke patients in this study.

A possible reason for this is that very elderly patients are more likely to be admitted from residential care and thus would be automatically excluded from this study. Elderly patients also tend to be admitted under the care of the elderly care teams. These teams often have substantial rehabilitation facilities of their own and may be less likely to refer on to the stroke team. The recruitment process for this study would miss such patients. Lastly, even if these patients were identified and they were going to return home, a much higher proportion of them are widows or widowers and live alone. Therefore they would be excluded from the study on the basis that they did not have an identifiable day-to-day informal carer.

	Hodgson, 1996	**Dennis, 1998**	**Brocklehurst, 1981**	**Matson, 1992**	**This study**
Co-resident carers?	78%	91%	Not all	100%	97%
Patient age (years)	Mean 73.7	56% ≥65	75%≥65	Mean 71.36	Mean 71.6
Carer age (years)	Mean 63.8	Mean 60	24%>70y.	Mean 68.36	Mean 66.8
Carer gender	68% female	66% female	75% female	Not stated	77% female
Carer relationship to stroke patient	66% spouse	79% spouse	59% spouse	89% spouse	92% spouse
Recruited from	Hospital	Hospital	Community	Community services	Hospital

Table 14.1: Comparison of sample data used in studies of UK carers of community residing stroke patients.

14.1.2 Comparison with other studies of carers done in the UK:

Perhaps a better comparison is with other studies of carers of stroke patients performed in the UK. Comparative data from UK studies which contained appropriate data in their published reports are presented in table 14.1, page 184. Only very basic demographic data about these samples could be accessed through the study reports, but it does seem from these figures that the sample recruited for this study was reasonably similar to samples from these other studies.

14.1.3 Comparison with National deprivation data:

Another indicator of the representativeness of this sample comes from the deprivation score data. National data show the average deprivation score for the whole of England and Wales is 21.70 (range 1.16 – 83. 77 with lower numbers indicating less deprivation; SD 15.39) (Department of the Environment, Trade and the Regions, 2000). Based on postcode data collected during interviewing (see pages 106 - 108), the mean deprivation score for this study sample was 19.18 (range 3.16-53.79, SD 11.55). Therefore the study sample had a very similar average deprivation level and deprivation range to the whole population of England and Wales.

However, the population recruited for this study was exclusively from a limited area in the South of England. Although the carers were from a mixed rural, inner city and suburban population that covered several hospital, health authority, primary care organization and social services areas, generalisability to other groups in society cannot be assumed. For example, the carers enrolled in this study were mostly homeowners with little ethnic mix.

14.1.4 Lack of ethnic mix

During the entire study period only five non-Caucasian patients were admitted to the study hospitals with a diagnosis of stroke and identified as possible study participants. Two were excluded as their carers could not speak English, two were included and one died. One of the carers included was of Indian origin (Sikh); the other was of Chinese ethnicity but born in the UK. Only three carers interviewed were born outside the UK.

Ethnicity may have an effect on care giving. For example, Grant J et al. (2004b) found that amongst a sample of 52 carers of stroke patients recruited from a stroke unit in Birmingham, Alabama, and interviewed one or two days prior to discharge of the stroke patient, and again five, nine and thirteen weeks post-discharge, Caucasian carers were nearly four times more likely to develop 'depressive behaviour' than African Americans. Therefore the findings of this study cannot be generalised to non-Caucasian carers.

14.2 Was the comparison non-carer group suitable?

There were problems obtaining a suitable comparison non-carer group. Initially the aim was to recruit non-carers through GPs covering the study catchment area, asking them to select individuals who were not currently carers and, in the GP's judgment, would be able to take on caring responsibilities if placed in that position. Unfortunately it became clear very quickly that not only were very few GPs recruiting comparison non-carers, which meant that it was difficult to obtain comparison non-carers from the same areas as all our carers, but also, from comments made by the recruiting GPs, that the comparison group being selected by GPs was highly skewed towards individuals they felt would make 'good' study subjects.

An alternative method of recruitment was required and a decision was made to recruit comparison non-carers through the carers themselves. Carers were asked to nominate a friend or relative within ten years of their own age and living within the study catchment area. This proved a much more successful method of recruitment but was the group of comparison non-carers we obtained a suitable comparison group?

First of all, was the comparison group well matched to the carers who nominated them? Table 14.2 (page 187) compares basic background data for the carer group with their matched controls and the carer group overall. Although the mean age of the non-carers and deprivation score of the non-carers were slightly less than those of the carers, these differences were not significant and overtly, it would seem that the comparison non-carers group was well-matched with both the carers who recruited them and the whole study population of carers.

Table 14.2: Comparison of comparison non-carers with their matched controls and the entire carer group

	Entire carer group	Carer group nominating controls	Comparison non-carer group
Centre recruited from	55% Southampton; 45% Christchurch	62% Southampton; 38% Christchurch	62% Southampton; 38% Christchurch
Gender	27% male; 73% female	28% male; 72% female	26% male; 74% female
Age	66.8 years	66.3 years	65.3 years
Deprivation score	19.2	19.6	17.8

However, during the course of the analysis it became apparent that those carers who nominated comparison non-carers were different in several respects from those who did not. Table 14.3 compares those carers who did nominate a comparison non-carer with those that did not. Carers who did nominate a comparison non-carer had significantly higher quality support networks and higher pre-discharge morale scores than those who did not. A similar finding was reported by Grant et al (2004a) in their study of stroke

Table 14.3: Comparison of carers who nominated comparison non-carers with those who did not and the entire study population of carers

	Entire carer group	Carer group nominating controls	Carer group who did not nominate controls
Centre recruited from	55% Southampton; 45% Christchurch	62% Southampton; 38% Christchurch	58% Southampton; 42% Christchurch
Gender	27% male; 73% female	28% male; 72% female	26% male; 74% female
Age	66.8 years	66.3 years	67.2 years
Deprivation score	19.2	19.6	18.8
Amount of social support	1.6	1.7	1.5
Social support quality	5.4	5.6	5.1*
Self-rated health	3.5	3.5	3.4
Number of medications	2.4	2.3	2.5
Number of health problems	1.7	1.5	1.8
Morale	9.9	11.2	8.8**
Psychological distress	12.0	11.2	12.8

* p=0.004 **p=0.005

Note: both p values are for the comparison of the carer group nominating controls and the carer group who did not nominate controls patients' carers a day or two before discharge of the stroke patient from a rehabilitation unit. Carers with impaired social functioning (and thus, for the purposes of this study, who would be less likely to recruit a comparison non-carer), had higher psychological distress scores as measured with the Center for Epidemiologic Studies Depression Score.

However, as, from the literature, one might expect that those who have less support in their caring activities will suffer more health and social consequences (King RB et al., 2001; King RB et al., 2002; Schulz R, Tompkins CA, & Rau MT, 1988; Tompkins CA, Schulz R, & Rau MT, 1988), as carers who did not nominate a non-carer were left out of the analysis when carers and non-carers were compared, the higher quality of social support amongst those nominating non-carers would only serve to lessen differences between carers and non-carers and make the comparison more conservative. Likewise, the higher morale scores of carers who nominated non-carers would serve to lessen differences between the carers and the non-carers, thus making any comparison between the groups more conservative. This increases the likely significance of any differences in morale or social support found between the carer and non-carer groups.

14.3 Limitations of the recruitment process

14.3.1 Finding stroke patients:

National Sentinel Stroke Audit figures collected in 2001/2002 (National Sentinel Stroke Audit, 2002), at the time recruitment started for this project, show that only 36% of stroke patients spent any time on a stroke unit. Three possible reasons for this are that there are not enough stroke unit beds so some stroke patients end up on acute medical wards instead; that some stroke patients are admitted via elderly care teams who have their own rehabilitation facilities and so there is no need to transfer them to a stroke unit; and, that patients who suffer mild strokes are usually only admitted to the "acute admissions" ward and then discharged home within a few days.

In both recruitment centres used for this study, stroke patients admitted under the care of other medical teams were assessed by stroke unit staff to make a decision about whether they would benefit from the facilities available on the stroke unit before admission to the unit. Around half of those assessed were refused transfer to the stroke unit and a proportion of those accepted never reached the stroke unit due to lack of space.

At one of the recruitment centres, access was available to the list of patients admitted with a diagnosis of stroke, or subsequently diagnosed with stroke, who were in-patients on other wards. Due to the stroke unit and acute admissions wards being in different hospitals at the other recruitment centre, there was no such access to patients on other wards. As admissions data supplied by the hospitals concerned were anonymised it is not possible to judge how many stroke patients, and thus their carers, were missed in this way or whether these stroke patients were in any way different from the population accessed during the course of this study. However, it is likely that our population of stroke patients consisted of those more severely affected by stroke who were likely to benefit from stroke unit assessment and rehabilitation, and excluded a proportion of the elderly patients managed by the elderly care teams instead and those with mild strokes discharged without intervention from the stroke team.

14.3.2 Delays in recruitment:

There is a marked difference between the 34 day average stay for stroke patients recorded in the 2001/2002 National Sentinel Stroke Audit (National Sentinel Stroke Audit, 2002) and the 20 week (140 day) average stay for the stroke patients associated with this study. This is largely accounted for by the way recruitment was performed.

Information about stroke admissions since the last visit to the unit was collected from each recruitment centre once a fortnight. Patients with mild strokes were often missed as they had been admitted and discharged within that time frame. Even if they were identified and still in-patients when information was collected, by the time the stroke unit had supplied the letter inviting the carer to participate and the carer had been contacted, agreed to participate and the first interview had been arranged, the stroke patient had often been discharged.

Therefore this study had a sample consisting of carers of stroke patients who had suffered more severe strokes, resulting in longer hospital stays. One would expect the carers of such patients to be a high risk group for psychological and physical health problems as the initial event (the stroke) is in most cases severe and traumatic for the carer; the carers endure a long spell of hospital visiting and discharge planning; and then most go on to look after stroke patients with significant disabilities. However, this bias towards carers of patients who have had more severe strokes should be taken into account when interpreting the findings and generalising them to other carers of stroke patients.

14.4 Limitations of the assessment procedure

14.4.1 Interviewing technique:

Apart from the initial interviews when the stroke patient was an in-patient, the stroke patient was allowed to be present when the carer was interviewed, if desired by the patient. This was because carers could not often obtain substitute care for the stroke patients when they were visited so it was often not possible to interview carers alone. In addition, preliminary piloting had shown that some stroke patients disliked their carers being interviewed alone because they felt as if their carers were 'talking about them behind their backs'. Other researchers in this field have encountered similar problems (personal communication S. Glasdam, 1999).

The effect of having the stroke patient present is not clear. In practice, once it had been stressed that it was the carer's viewpoint that was required, the stroke patients took a passive role and did not intervene. This is supported by the close correlation of many repeated measures between the pre-discharge interviews, when the stroke patients were not present, and the early post-discharge interviews, when the stroke patients were often present. However, it is possible that the presence of the stroke patient hampered open and frank expression of the carer - but in other cases this may have had the reverse effect.

14.4.2 Measures used:

Most of the measures used were easy to administer and well tolerated by the carers with the exception of the social support questionnaire which some found difficult to understand and answer. However, there were limitations to several of the measures used.

14.4.2.1 Measurement of amount and costs of formal support:

The measure of formal service input used was a self-report checklist. The accuracy of carer reports of service provision has not been established. The accuracy of self-reported service provision data amongst stroke patients has been examined and questioned. One study showed there are often discrepancies between the recollections of the service user and the records of the service provider (Luther A, Lincoln NB, & Grant F 1998) with service users underestimating the input they had received.

Therefore, wherever possible, attempts were made to verify service provision (for example, by checking district nurse notes) but this was often difficult as stroke patients and their carers receive a wide range of services. Corroborating encounters with such a large array of service providers from such a large number of different sources was impossible given the resource limitations. Moreover, many encounters were recorded in the stroke patient's records and not the carer's records. Permission had not been granted to access the stroke patients' records.

The costs of formal support were estimated by multiplying the number of hours of carer or stroke patient contact recorded on the formal services checklist for each service listed, by the unit costs for that service. However, carers were often not specific enough about the nature of the service provided, the service provider or the length of encounters for this to be anything more than a rough estimate of costs. Moreover, published unit costs were not available for all the services carers listed, so extrapolations of cost based on similar services provided by professionals with similar qualifications or training had to be made for these services.

14.4.2.2 Measurement of carer satisfaction with community care:

There is considerable debate about the meaning of satisfaction scores. Without a clear meaning of the score, it is difficult to interpret data. Many researchers now feel that measures of 'patient experience' are more robust and more useful in the context of measuring care provided (Coulter A., Fitzpatrick R., & Davis L-J., 2002). If the study were performed again now, it is likely that an experience questionnaire would be used in preference to a satisfaction questionnaire. However, the *Carer Satisfaction with Community Care Questionnaire* includes many elements of 'carer experience' and therefore is a useful gauge of process.

The *Carer Satisfaction with Community Care Questionnaire* was developed very recently. It has undergone initial validation testing but, at the time this study commenced, had not been widely used. Therefore, a single item global satisfaction question was used alongside the new satisfaction questionnaire to provide validity to results obtained using the new measure and also enable direct comparison with other carer studies.

14.4.2.3 Measurement of relationship quality and activity restriction:

The relationship quality scale used for this study and the activity restriction scale have limited validity and reliability data available. The results including these measures should be viewed with caution.

14.5 Failure to achieve the required sample size

Forty-nine carers and matched controls were required to complete all three interviews for this study to enable the major aim of the study, detection of expected differences in psychological distress based on CIS-R scores, to be met. This goal was achieved with 53 carers and 49 comparison non-carers finishing the study.

The secondary sample size calculation suggested 62 carers would need to complete the study, undertaking all three interviews, to have sufficient numbers to compare carers satisfied with care and those dissatisfied with care. In the end, only 53 carers completed all three interviews. It was disappointing not to achieve the sample size required within the recruitment time frame available and there are several possible reasons for this which relate to incorrect assumptions made at the planning stages of the project.

First there were problems prior to the stroke patient being discharged. With all the exclusion criteria employed, there was a severely limited pool of stroke patients whose carers would be eligible for the study. This meant that finding subjects was harder than expected and took considerably longer than expected.

Then there was a major error in the assumption that there would be a 30% drop out rate between identification of carers and discharge home. The drop out rate between the carer agreeing to take part and undertaking the first interview was 29% which was almost exactly the 30% drop out rate predicted. But there was a further 31% drop out rate between the first interview and second interview. In total 73 of the carers who agreed to participate dropped out before the second interview - almost half.

There were two reasons for this. In calculating that 116 carers would need to be identified, it had been assumed 10% of stroke patients would die before returning home (Wolfe CD et al., 2000) and 20% would not return home (Royal College of Physicians 1998). In fact, 13% of the stroke patients identified, and whose carers agreed to take part in the study, died before getting home and 27% admitted from home were subsequently admitted into residential care, amounting to a drop out rate of 40%. Due to the method of recruitment, the sample was biased towards those who had suffered more severe strokes and had higher levels of disability and therefore were more likely to die or end up in residential care. In addition, no allowance had been made for the 8% of carers who agreed to participate but could not take part as the stroke patient they were intending to care for was discharged before the initial interview could be arranged. Once carers had reached the first post-discharge interview, the drop out rate was 20% as predicted.

Prior to the project starting, it was expected that any short-fall in the percentage of stroke patients returning home could be made up by recruiting until the required sample size had returned home. In practice, this was not possible as the time lag between first interview and return home was often quite protracted (on average about five weeks) and also stroke patients recruited from one of the recruitment centres were usually discharged home via a period of rehabilitation and convalescence in a peripheral hospital where it was very difficult to track their progress. Recruitment was continued until 147 carers had been enrolled and over a hundred first (pre-discharge) interviews had been completed. Eventually time limitations prevented further recruitment.

Despite this shortfall, there were very few results which proved negative, but were on the borderline of significance and might have been positive if the study had more power (type II errors). However, had the study had more power, the trends in deterioration in physical health might have been more pronounced and could have achieved significance for more than one measure of physical health.

Table 14.4: Reasons for carers to be lost to follow up from the cohort

Loss to follow up between first and second interview		Loss to follow up between second and third interview	
6	Death of stroke patient	9	Death of the carer or stroke patient
23	Placement of the patient into residential care	7	Carer and/or stroke patient admitted to residential care
1	Carer had a stroke	4	Relocation of stroke patient and/or carer
1	Exclusion due to low AMTS	1	Withdrawal from the study

14.6 Losses to follow up

As discussed on page 45, in any cohort study, a number of exposed individuals will be lost to follow up by the end of the study. The reasons for loss are very important as, if the reason for loss to follow up is related both to the exposure and to the outcome (e.g. if carers who become depressed are more likely to move closer to their families and thus be lost from the study), a biased estimate of the association might result.

There was considerable loss to follow up in this study. Reasons for loss to follow up are listed in table 14.4. All those lost to follow up were accounted for. It is unlikely that death of a stroke patient or carer will bias estimate of association. Those lost to follow up between the first and second interview were lost before the carers became carers in the community. As carers in the community were the focus of this project, this is unlikely to have much effect on the findings.

The 12 carers lost to follow up for reasons highlighted in the table - admission to residential or nursing home, relocation and withdrawal from the study - could result in a biased estimate of association if, for example, the carers most depressed were most likely to drop out. However, when those carers who continued in the study and those carers who withdrew from the study were compared for all the health and social measures tested in this study, there were no significant differences between those continuing in the study and those who dropped out.

14.7 Effect of chance

The more tests performed on a set of data, the more likely the chance of rejecting the null hypothesis when it is true (a Type I error). In any study such as this, where multiple measures are being taken with a relatively small sample size, using a significance level of $p=0.05$, one in 20 associations will happen by chance. This problem is called the inflation of the alpha level. One strategy used to allow for this is to correct the alpha level when performing multiple tests, for example by using Bonferroni or Šidák corrections (Abdi H., 2007).

Making the alpha level more stringent (i.e. smaller) creates fewer errors, but may also make it harder to detect real effects. Extrapolating from this, for this study where multiple comparisons have been made, results of comparisons where significant associations have been found should be viewed with caution, particularly when p values are at the borderline of significance. An example of a possible type I error in this study is the apparent carer gender difference in occupational therapy provision early after the discharge of the stroke patient home.

After some discussion, it was decided not to apply a Bonferroni correction as this was an exploratory study which aimed to generate ideas for further research. Using a Bonferroni correction would make it more likely that real effects were missed. The robustness of findings with borderline p-values was explored further with reference to other literature instead. The major findings of this study had very low p-values, suggesting that they were robust and applying a Bonferroni correction would be unlikely to alter them.

14.8 Summary:

When interpreting the results of this study it is important to consider:

- *The carers:* Due to the method of recruitment used in this study, carers tended to look after younger stroke patients who were most likely to pass through stroke units, and those who had longer hospital stays and thus were more affected by their strokes. Due to the geographical locations of the stroke units used for recruitment purposes, all but two of the carers recruited were Caucasian. Care should be taken when applying any results to other groups of carers.
- *The non-carer group:* The carers nominating comparison non-carers had higher morale and higher quality support networks than those not nominating comparison non-carers. This would serve to lessen any differences in health and social measures between the carer and comparison groups.
- *The measures used:* Most measures used were pre-validated. Caution should be exercised in interpreting results obtained using the two measures not pre-validated (activity restriction and relationship quality). Further caution should be exercised in interpreting the data on number and cost of formal support services involved in the community as it was obtained by carer report and it is not clear how reliable that is.
- *Losses to follow up and failure to reach the required sample size:* There was considerable loss to follow up among the carers recruited to our cohort. However, all carers lost to follow up were accounted for and comparisons of those lost to follow up and those remaining in the study suggest that this did not prejudice any outcomes, except by reducing the power of the study. The sample size required to compare carer with non-carer psychological health was reached. However, due to the shortfall of carers completing all three interviews, the required sample size to compare carers satisfied with community care with those dissatisfied with that care was not reached. Therefore, it is possible that some of the real differences between those carers satisfied and those not satisfied with formal support services were not detected due to insufficient power of the study (i.e. type II errors).
- *Effect of chance:* Multiple comparisons were made in the analysis of the data from this study. This makes the chance of a type I error, detecting a difference when there

is none, more likely. This is particularly relevant when considering findings where the p levels are at the borderline of significance.

Chapter 15: Discussion of results

This study aimed to investigate the health and social effects of caring on informal carers of stroke patients in the community at different points in time after the stroke; investigate the relationship between health and social factors and satisfaction with care; and, investigate the relationship between satisfaction with care and level of service input. The piloting for the project took place in 2001 and the main study was conducted over a three year period from 2001 to 2004 with all interviews completed by July 2004.

15.1 Physical health effects of caring

15.1.1 Weight change:

Over half the carers reported they had lost weight since the patient's stroke at the time of the first interview when the stroke patient was still in hospital. Three times more female than male carers reported weight loss. Weight then stabilised when the stroke patient returned home and many had regained weight by the final follow up interview.

At the time of the first interview, carers reporting weight loss had a mean score of 14.26 on the CIS-R compared to 9.04 for carers not reporting weight loss, and a mean score of 8.75 on the PGC Morale scale compared with a score of 11.32 for carers not reporting weight loss. Perceived weight change since the stroke accounted for 11% of the variance in CIS-R and 13.3% of the variance in PGC Morale score seen prior to discharge and also 9.6% of the variance in self-rated health seen at the first post-discharge interview.

Although this was a secondary, rather than an a priori finding, it is interesting and could potentially be useful in a clinical setting. There are several plausible explanations for it. The most likely is that the acute stress of the stroke led to carer weight loss. In support of this, Freedman and Daly (1997) found for carers of elderly patients, that weight change was significantly associated with higher scores on standardised measures of burden and stress and with poorer self-rated health and more psychotropic medication use. They suggested that weight change could be a valid indicator of stress among carers.

An alternative explanation might be that carers alone at home because their spouse was in hospital, might not have been motivated to prepare food as they usually would and therefore ate less. In addition, the time and effort spent visiting the stroke patient in hospital might result in less food consumption and more exercise than the carers were used to and lead to weight loss. However, this could not explain the associations of weight loss with differences in morale or CIS-R score seen in this study. Finally, as this was weight loss gauged on carer report, it might not be real. Perception of weight loss might just be an indicator of stress.

15.1.2 Alcohol consumption:

There was a significant increase in alcohol consumption between the pre-discharge interview and the first post-discharge interview. Five carers (7% - two men and three women) were drinking well in excess of recommended limits at the six week follow up interview. The average amount of alcohol consumption remained the same a year later. Alcohol consumption at the first post-discharge interview was a risk factor for psychological distress over a year after the stroke, accounting for 4% of the variance in CIS-R scores at the time of the final interview.

Alcohol consumption is not something commonly measured in the caring literature and only one other study could be found which noted a link between caring activities and alcohol consumption. In a sample of carers of demented elderly people, Gallant and Connell (1998) found that caring negatively influenced health behaviours including alcohol consumption and that these changes were directly related to depressive symptoms and objective carer burden.

Again there might be several explanations for the change in alcohol consumption in this study. It could have been due to the stress of the caring situation, or that carers did not like to drink alone when the stroke patient was in hospital, or even that carers did not have time to visit the places where they usually consumed alcohol while the stroke patient was in hospital and they were visiting regularly.

15.1.3 Smoking:

There was a significant reduction in the number of cigarettes smoked by carers who smoked between the pre-discharge and final interviews. This could have been because they were smoking more due to the acute stress of the stroke at the time of the first interview and, as the stress abated they smoked less or, alternatively, they could have cut down on their smoking due to efforts to pursue a healthier lifestyle to keep themselves healthy and/or prevent further stroke.

In this study, the amount smoked was a major predictor of self-rated health early after discharge, accounting for 10.6% of the variance. Self-rated health is a subjective measure and there are two possible explanations for this finding. First, it is well known that smoking has a multitude of health effects. Smokers might really have had poorer health due to the fact they smoked. Second, health education about stroke stresses the effects of smoking. This might have brought those effects home to the smokers and made them feel less healthy as a result. Third, self-rated health is subjective and could be influenced by mood. Heavy smoking is associated with depression amongst other groups (Cassidy K. et al., 2004) so this could, in turn, affect self-rated health.

The second explanation is more likely because if those smokers who were smoking more in the study actually had poorer health than the non-smokers and those smoking less cigarettes, one might expect that fact to be reflected in both the number of medications listed and the number of health problems listed. No such associations were seen. In addition, the number of cigarettes smoked actually decreased during the duration of the study. There was no corresponding reduction in stress levels as measured on the CIS-R or PGC Morale scale suggesting that alleviation of stress was not the cause of the reduction. No parallels could be found in the carer literature.

15.1.4 Physical health measures:

For the purposes of this study, three physical health measures were used alongside each other. These were self-rated health, the number of medications and the number of health problems. It was found that all three were closely correlated with each other (self-rated health and number of medications - r=-0.408, p<0.001; self-rated health and number of health problems - r=-0.410, p<0.001; number of health problems and number of drugs - r=0.609, p<0.001).

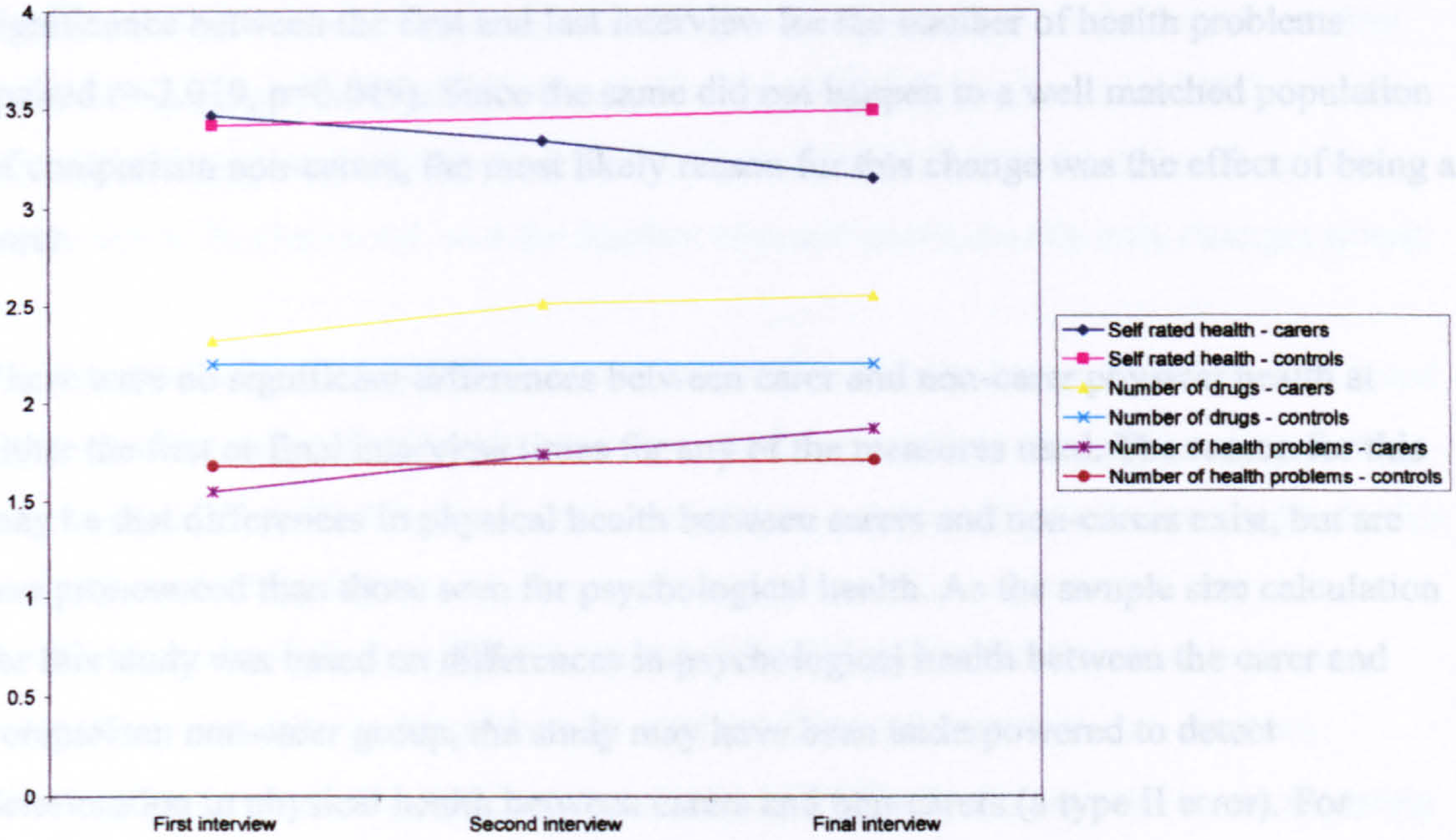
The number of medications and the number of health problems were associated in very similar ways with similar amounts of variance in outcomes at each of the time points suggesting they were measuring the same entity. Self-rated health seemed to be more subjective as it was associated with both physical health and mood. This is supported by its strong correlation with results on the PGC Morale scale, a general wellbeing scale (r=0.405, p=0.001).

This is also supported by an analysis of data from the Whitehall II study, in which data from 20 London civil service departments were collected, and the French Gazel cohort study, in which data were collected from France's national gas and electricity company (Singh-Manoux A., et al., 2006). Self-rated health data were available on 6889 men and 3403 women from the Whitehall II study and 13 008 men and 4688 women from the Gazel study. Stepwise multiple regression showed that 34.7% of the variance in self-rated health in the Whitehall II study was predicted by five factors: physical symptom score, sickness absence, longstanding illness, minor psychiatric morbidity, and number of recurring health problems. Four measures explained 41.4% of the variance in self-rated health in the Gazel study. These were physical tiredness, the number of health problems in the past year, physical mobility, and the number of prescription drugs used. Therefore, measures of both mental and physical health contribute to the self-rated health construct.

15.1.4 Health changes found with the physical health measures used in this study:

As discussed in Chapter 2 (pages 17-21), the effects of informal care giving on physical health are not entirely clear. In postal surveys (Henwood M, 1998; Princess Royal Trust for Carers, 2004) carers report high level of physical illness which they attribute to caring but these are self-selected populations and the physical illnesses attributed to the caring experience might have happened anyway.

Figure 15.1: Chart to illustrate changes in physical health for carers and controls over the duration of the study



No other studies were identified comparing the physical health of carers of stroke patients with a non-carer comparison group. In the general carer literature, whether self-rated health, number of medications, use of health services or the number of health problems is used as the measure of physical health, studies comparing carers with matched non-carers have mixed results. In some studies carers have similar health to a control comparison group (George LK & Gwyther LP; Baumgarten M et al., 1992; Kiecolt-Glaser JK et al., 1991; Cattanach L & Tebes JK 1991); while in others their health appears worse (Haley WE et al., 1987; Pruchno RA & Potashnik SL, 1989). Meta-analysis findings support a negative effect of caring on physical health but the effect is smaller than for psychological health (Vitaliano, Zhang & Scanlan, 2003; Pinquart & Sorensen, 2003b).

The results of this study are in keeping with these findings. For all three of the health measures used there was a trend towards deterioration in health through the duration of the study (figure 15.1). These deteriorations reached significance for both the number of medications and the number of health problems reported between the pre-discharge and early post-discharge interviews (paired t = -2.112, p=0.038 and paired t = -2.075, p=0.042 respectively) and, despite the small sample size by the end of the study, reached significance between the first and last interview for the number of health problems (paired t=-2.019, p=0.049). Since the same did not happen to a well matched population of comparison non-carers, the most likely reason for this change was the effect of being a carer.

There were no significant differences between carer and non-carer physical health at either the first or final interview times for any of the measures used. The reason for this may be that differences in physical health between carers and non-carers exist, but are less pronounced than those seen for psychological health. As the sample size calculation for this study was based on differences in psychological health between the carer and comparison non-carer group, the study may have been underpowered to detect deterioration in physical health between carers and non-carers (a type II error). For example, the average number of medications for carers at the time of the final interview was 2.5, and for non-carers, 2.2, giving an effect size of 0.3. The standard deviation of that measure was roughly 2.3. This would mean that 271 carers and comparison non-carers would be needed to demonstrate a significant difference between the two groups if that difference was real. We only had 53.

15.1.5 Factors independently associated with physical health:

At the time of the first interview, before the stroke patient was discharged home, the age of the carer was the only predictor of physical health for all three measures, accounting for 4.2% of the variance in self-rated health, 14.8% of the variance in the number of medications and 8.7% of the variance in the number of health problems. The older the carer, the worse was their physical health. The effect of age on health is obvious and commonly seen in the literature (Svedberg P. et al, 2005; Zahran H.S. et al., 2005).

The factors independently associated with all three health measures at the time of the second and third interviews are listed in table 15.1, page 204. Six weeks after discharge of the stroke patient home, the major predictor for all three physical health scores was physical health prior to the stroke patient's discharge. This effect was most marked for the number of health problems (where previous health was the only predictor) and the number of medications. This is not surprising as there was only a relatively short time between the pre-discharge and first post-discharge interviews (a mean of 12.3 weeks). Most chronic physical conditions are unlikely to disappear, new conditions may take some time to be diagnosed, and the number of medications usually only changes slowly.

The effect of previous health scores on self-rated health was less pronounced. Self-rated health is more subjective than the other two measures and can change from day to day. One might expect other factors to influence the way carers view their own health. In this study those factors were:

- Gender - male carers had significantly worse self-rated health than female carers
- Smoking - smokers had significantly worse self-rated health than non-smokers
- Perceived weight loss before hospital discharge of the stroke patient - carers reporting weight loss had significantly worse self-rated health, *and*

Independently associated factors	**% variance**								
	1st interview			**2nd interview**			**3rd interview**		
	Self-rated health	*Drugs*	*Health problems*	*Self-rated health*	*Drugs*	*Health problems*	*Self-rated health*	*Drugs*	*Health problems*
Age	4.2	14.8	8.7	-	-	-	-	-	-
Gender	-	-	-	6.1	-	-	-	-	-
Deprivation	-	-	-		-	-	7.4	-	-
Smoking	-	-	-	10.6	-	-	-	-	-
Weight loss of the carer immediately after the stroke	-	-	-	9.6	-	-	-	-	-
Previous physical health scores	-	-	-	20.1	83	63.4	-	68	50.6
Work load and help available	-	-	-	11.2	1.3	-	13.4	12.3	6.5
Mood/morale	-	-	-	-	-	-	21.9	-	7.9

Table 15.1: Summary of factors independently associated with variance in physical health measures

- Workload - level of handicap of the stroke patient (3% of variance); perceived quality of formal support to help the carer look after the stroke patient (4.9% of variance); and perceived quality of informal support (3.3% of variance)

At the time of the final interview, scores on the previous physical health measures were still the best predictors for the number of medications and number of health problems. However, by that time, over a year after the stroke, other factors were also playing a part. Measures associated with workload (level of handicap, quality of informal support, other care commitments and formal support provision) had an influence on all three health measures. Psychological health was associated with physical health as measured by both the number of health problems and self-rated health. These effects were most marked for self-rated health, again reflecting its more subjective nature and the ease with which it can change.

Associations with physical health are not widely reported in the stroke carers' literature. However, the finding of an association of physical health and mood amongst carers of stroke patients is one that has been reported before (Hodgson SP, Wood VA, & Langton-Hewer R, 1996; King RB et al., 2001; Schulz R, Tompkins CA, & Rau MT, 1988; Tompkins CA, Schulz R, & Rau MT, 1988; Carnwath TCM & Johnson DAW, 1987). Mood as a association of physical health is also a finding commonly replicated in studies looking at factors predicting self-rated health in the community using general populations (Finnegan L, Marion L & Cox C, 2005; Molarius A & Janson S, 2002).

15.2 Psychological health effects of caring

15.2.1 The interpretation of morale in this study:

Morale was measured for this study using the Philadelphia Geriatric Centre Morale Scale. Morale is a measure of general well-being and strongly correlated with other life satisfaction and adjustment measures (Lohman N., 1977). In other studies, morale has been found to be associated with continued mobility and feeling well, having an adequate income, not spending too much time alone, being able to expect care when ill and having a locally integrated or wider community focussed support network (Weinger GC, Davies,

& Shahtahmasebi S, 1995). From this morale appears to be associated with life satisfaction, adjustment, physical health and informal social support. In other words, it is a synthesis of health and social well-being.

Using data from this study, the PGC Morale scale scores were strongly correlated with CIS-R scores ($r=-0.730$, $p<0.001$), self-rated physical health scores ($r=0.405$, $p=0.001$) and quality of social support ($r=0.511$, $p<0.001$). Thus morale appears to be a complex measure, spanning the gap between the more objectives measures of physical and psychological health, and social well-being, and not a pure measure of psychological health.

15.2.2 Health changes found with the CIS-R and PGC Morale Scale:

<u>15.2.2.1: Differences due to place of recruitment and gender:</u>

There was no effect of recruitment centre on either CIS-R scores or PGC Morale scores at any of the interview time points. At the time of the first interview, prior to the discharge home of the stroke patient, male carers had significantly lower levels of psychological distress and higher morale than female carers (mean 8.18 vs. 13.40, $t=-2.571$, $p=0.018$ and mean 9.33 vs. 11.54, $t=2.335$, $p=0.021$ respectively). Although this difference between male and female carers was not replicated at the early or late post-discharge interviews, it is unlikely to be a type I error as it was found using two independent measures of psychological health.

Gender differences have been explored in the stroke care giver literature. Despite gender stereotypes which suggest women carers would perform better and cope better with a care giver role, two studies were identified in which male carers had significantly better psychological health than female carers (van den Heuvel ETP et al., 2001; Dennis M et al., 1998) as in this study, and three studies in which the gender of the carer was reported as having no effect (Stein PN et al., 1992; Hodgson SP et al., 1996; Tiegs TJ et al., 2006).

These mixed results could be due to the timing of the assessments. The gender differences seen in this study were limited to the acute phase after stroke when the stroke patient was still in hospital. By the time the stroke patient had been home six weeks the gender differences seen pre-discharge had disappeared. This is in keeping with findings by Zarit et al. (1986). They concluded that if gender differences in carer distress exist initially, they may disappear over time.

The stroke carer literature is mixed in its support for this theory. In the study by Dennis et al. (1998), there was a very early measure of psychological health taken less than thirty days after the stroke in which male carers reported less distress than female carers. Tomkins et al. (1988) also detected an effect of gender very early after stroke. One of the studies in which there was a lack of effect of gender either did not state the time period after stroke when the measures were recorded (Stein PN et al, 1992) and another did not have an early measure of these variables (Hodgson SP et al., 1996). On the other hand, van den Heuvel et al. (2001) noted gender differences in psychological health amongst care givers three and a half years post stroke and Tiegs et al. (2006) found no relationship between carer gender and poor quality of life one month after the stroke.

15.2.2.2: Differences in CIS-R and PGC Morale scores at different times after stroke:

At the time of the first interview, 37% of carers had significant psychological distress (i.e. a CIS-R score >12) and 24% of carers had CIS-R scores in the range which would suggest they might require treatment for their distress (i.e. CIS-R score >17). Between the pre-discharge and early post-discharge interviews there was a significant reduction in psychological health as measured with the CIS-R (paired t = 3.765, p<0.001 - figure 15.2, page 206) with marked increases in fatigue, irritability and depressive ideas. At that time, 54% of carers (40 carers) had CIS-R scores of more than 12, and 24% (18 carers) scores greater than 17.

There was no further change in CIS-R between the six-week post-discharge interviews and final interviews (figure 15.2, page 206) but the distribution of symptoms did change. Smith LN et al. (2004) examined the component symptoms of psychological distress at a year after stroke and found that carers were more anxious than depressed. In this study

Figure 15.2: Chart to illustrate CIS-R scores of carers and comparison non-carers through the time period of the study

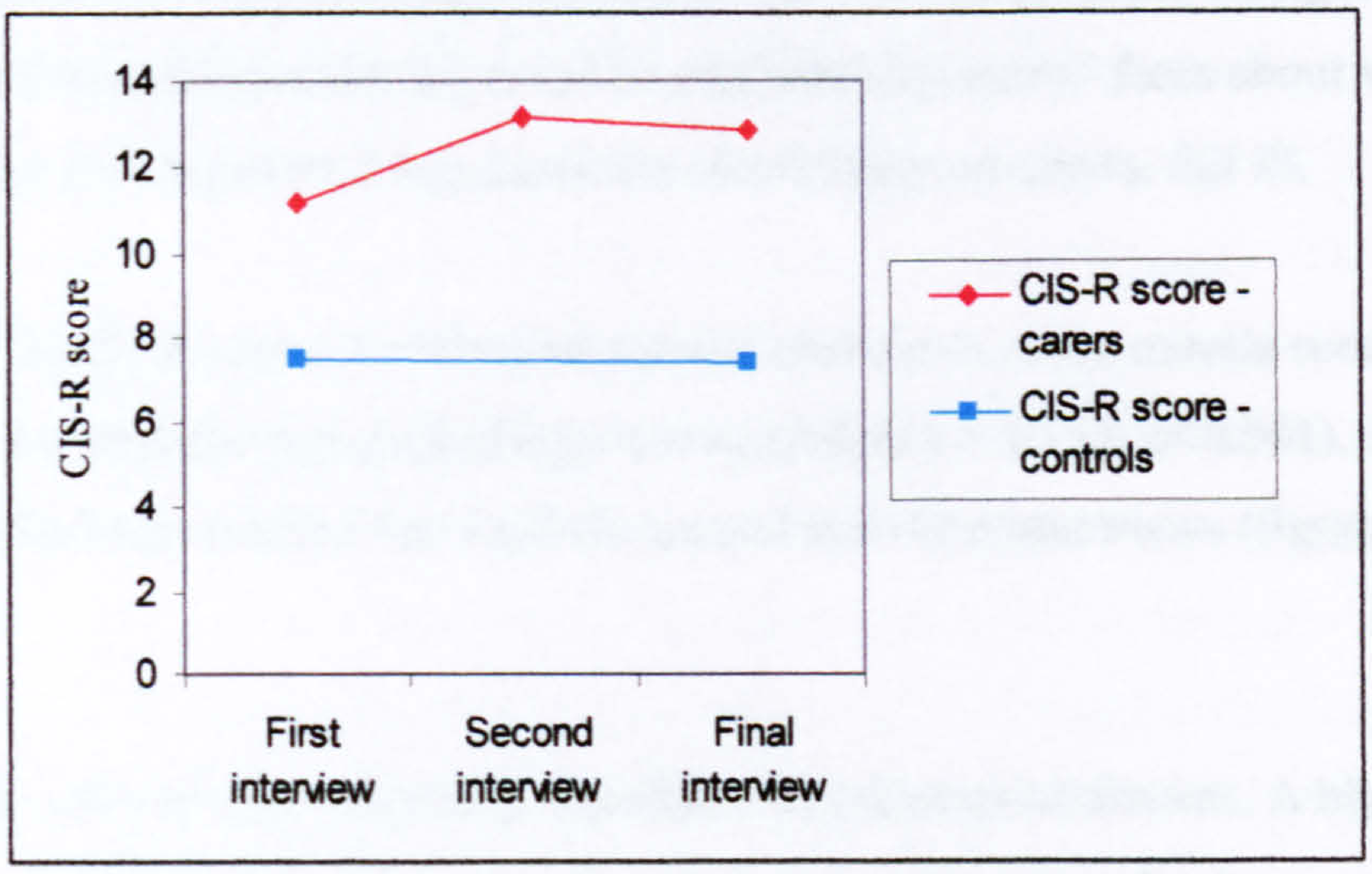
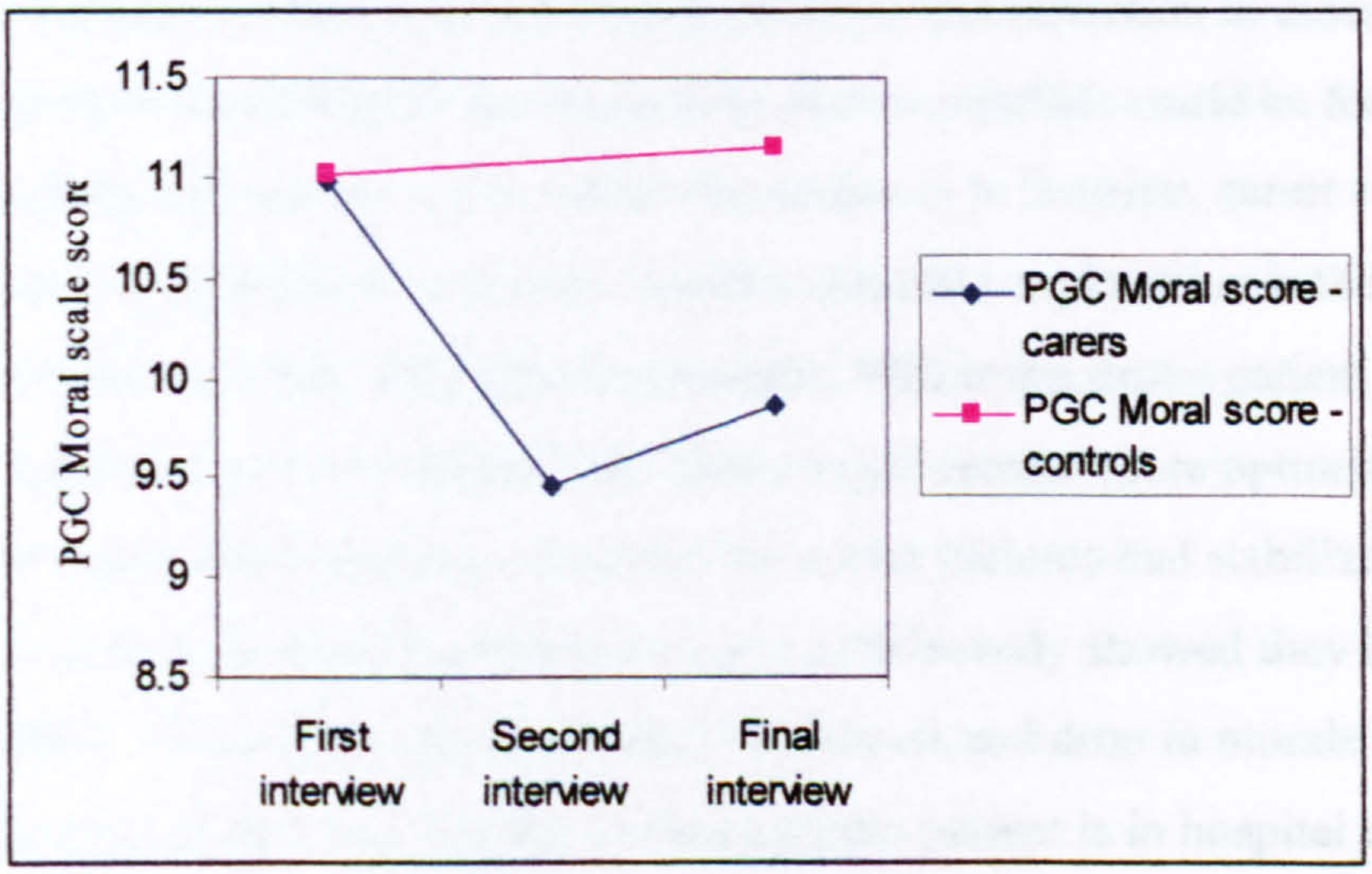


Figure 15.3: Chart to illustrate PGC Morale scores of carers and comparison non-carers through the time period of the study



however, symptoms described by the carers a year after stroke were very varied. There was a reduction in all symptoms of depression and anxiety between the second and third interviews with the exceptions of poor concentration, irritability and worries about physical health which all markedly increased. The reasons for these changes are not clear but worries about physical health could be explained by carers' fears about what would happen to the stroke patients they cared for should they, as carers, fall ill.

As for the CIS-R, between the first and second interviews, carer morale scores dropped significantly compared to pre-discharge scores (paired $t = 3.765$, $p<0.001$). There was then no further deterioration between the second and third interviews (figure 15.3, page 208).

In this study 37% of carers reported significant psychological distress. A high incidence of anxiety and depression amongst carers of stroke patients has also been noted by many other investigators. Most studies estimate the level of depression amongst people caring for stroke survivors to be in the region of 40% (Carnwath TCM & Johnson DAW, 1987; Coughlan AK & Humphrey M, 1982; Draper BM, 1992; MacKay A & Nias BC, 1979; Stein PN et al., 1992; Williams AM, 1993) which is in keeping with our findings.

Reasons for the marked increase in psychological distress and reduction in morale between the first and second interviews are unclear and no parallels could be found in the literature. A possible explanation is that whilst the patient is in hospital, carers receive support from staff which helps their morale. Another possible explanation is that the bulk of recovery after stroke occurs in the first few months. Whilst the stroke patient is still improving and receiving active treatment, the carers might remain more optimistic about outcome. By six weeks after discharge, many of the stroke patients had stabilized and the Oxford Handicap Scores collected during the course of this study showed they improved very little thereafter. This increase in psychological distress and drop in morale could represent a realisation of that fact. Finally, whilst a stroke patient is in hospital the care giver may assist ward staff, but is not the person taking responsibility for care. Once the stroke patient is home, the realities of long-term hands-on caring become more apparent and this, in turn may cause psychological distress and drop in morale.

15.2.2.3: Differences between carers and non-carers:

At the time of the first interview, 16% of non-carers reported significant psychological distress (i.e. a CIS-R score >12), with 15% having scores in the range which would suggest that they require treatment for their distress (i.e. a CIS-R score >17). Even at the time of the first interview, before the stroke patient was discharged home, carers had a significantly higher level of psychological distress compared to non-carers (figure 15.2, page 208 - mean 11.16 vs. 7.52, t=2.405, p=0.018) and population norms (15% of a normal population vs. 37% of the study population with CIS-R scores of >12). This difference remained and a year after stroke, carers still had significantly higher levels of psychological distress than non-carers (mean score 12.59 vs. 7.45, t=3.340, p=0.001). There were no significant differences between the morale scores of carers and non-carers (figure 15.3, page 208).

At the time of the first interview, symptoms more common amongst carers than non-carers ranged from depressive symptoms including fatigue, poor concentration, irritability, depression and depressive ideas, to anxiety symptoms including worry, anxiety and obsessions and compulsions. Although many carers complained of sleep problems, this complaint was equally common amongst the non-carers. The picture was very similar a year later.

Roughly 40% of carers have significant psychological distress as recorded in this study and many others (Carnwath TCM & Johnson DAW, 1987; Coughlan AK & Humphrey M, 1982; Draper BM, 1992; MacKay A & Nias BC, 1979; Stein PN et al., 1992; Williams AM, 1993). The background level of depression in this age group is 8-15% (Beekman AT et al., 1995; Copeland JR et al., 1999; Livingstone G, Manela M, & Katona C, 1997; Osborn DP et al., 2002). However, most of the carer studies fail to distinguish between clinical (major) depression and sub-clinical mood disturbance creating uncertainty in what has actually been measured. General population studies of

Table 15.2: Summary of factors independently associated with variance in psychological health measures

Independently associated factors	**% variance**					
	1st interview		**2nd interview**		**3rd interview**	
	PGC Morale scale	*CIS-R*	*PGC Morale scale*	*CIS-R*	*PGC Morale scale*	*CIS-R*
Weight loss of the carer immediately after the stroke	13.3	11	-	-	-	-
Quality of social support	5.1	8.5	17.1	17.8	-	-
Previous low mood/morale	-	-	36.4	28	48.6	57.5
Poor physical health	-	-	9.2	-	14.2	-
Restriction of usual activities	-	-	-	-	9.8	-
Satisfaction with formal support	-	-	-	-	2.5	-
Income	-	-	-	-	-	4.7
Alcohol consumption	-	-	-	-	-	4

the same age group, show that 20-30% screen positive for mood disturbance (Beekman AT et al., 1995; Cooper JE et al., 1977; Livingston G et al., 2000; Osborn DP et al., 2002). In this study, 16% of the non-carers had significant psychological distress (i.e. a CIS-R score >12) suggesting that carers are two and a half times more likely to suffer significant psychological distress than non-carers.

The differences in CIS-R score findings between the carers and non-carers seen in this study at both comparison time points suggest that either the carer group enrolled in this study was significantly different from the comparison group in respect of psychological health at baseline, or that the high psychological distress scores seen amongst this carer group reflect distress caused by the stroke and/or their new care giving role and that this is an early effect, occurring within a few days or weeks of the initial stroke event, and before our first interview point. This effect persists for in excess of a year (figure 15.3, page 208).

15.2.3 Factors independently associated with psychological health:

There were only two factors independently associated with both CIS-R and morale scores at the time of the first, pre-discharge interview. Perceived weight loss since the time of the stroke accounted for 11% of the variance in CIS-R scores and 13.3% of the variance in PGC Morale scores. The amount of perceived weight loss was significantly correlated with both scores, with those carers who felt that they had lost weight having lower morale. Perceived weight loss since stroke is not commonly measured in the stroke carer literature but is a very simple measure. Freedman and Daly (1997) found for carers of elderly patients, that weight change was significantly associated with higher scores on standardized measures of burden and stress and with poorer self-rated health and more psychotropic medication use and this would support those finings.

When assessing carers, stroke unit staff are concerned not only about the carer's well-being, but also about suitability of that carer for the care tasks which will need to be performed once the stroke patient goes home. Carers are not patients of the unit and so it could be considered an intrusion of privacy if staff ask directly in more than very general terms about their health. It is even more difficult to ask about carers' psychological health because of the social taboos surrounding that topic. On the other side, carers might be reluctant to give the 'wrong' response (i.e. that their physical or psychological health is not good) for fear of being considered unsuitable to be carers and thus jeopardising the stroke patients' chances of going home. Asking carers if they think that they have lost any weight since the patient's stroke is a relatively simple question to ask, which is unlikely to cause offence or illicit an inaccurate response. Given its strong association with psychological distress of carers, perhaps carers should be asked if they think they have lost weight as a matter of routine in the early post-stroke phase in order to flag up carer psychological distress.

The quality of support the carer expected to receive from friends and relatives accounted for a further 8.5% of the variance in CIS-R scores and 5.1% of the variance in PGC morale scores. Both measures were correlated with the carers' quality of social support scores. Those that had a lower quality support network had higher psychological distress levels and lower morale. Quality of social support in various guises is a common factor associated with psychological distress amongst carers of stroke patients (Grant et al., 2000; van den Heuvel ETP et al., 2001; King et al., 2002; Tompkins CA et al., 1998).

Factors independently associated with morale in the period soon after the stroke patient came home, and a year after stroke, are summarised in table 15.2, page 211. The effect of quality of informal support had worn off by the time of the final interview. No similar effects could be found in the carer literature. A possible reason for this is that, with time, carers re-establish a routine and adjust to their new lifestyles. They are therefore less dependent on friends and relatives for either moral support or physical care giving duties. Physical health is an indicator of morale. This probably relates to the nature of the construct, as morale is related to physical health and social well-being as well as psychological health (see pages 59-60).

Over a year after the stroke, morale was also related to carer activity restriction and a very minor part of the variance was accounted for by carers' assessment of quality of formal support as measured by satisfaction with services. Two other studies have found associations between psychological distress and lifestyle impact (Nieboer A, et al., 1998; Singh M & Cameron J, 2005). This study suggested that carers adjust to their role and by a year after stroke have resumed some of their usual activities (see below). Activity restriction may predict morale as those who still have severely restricted activities after that time may have failed to adjust to their new role, possibly due to a lack of coping mechanisms, or a lack of support, or lack of other resources, and therefore may have been unable to resume enough aspects of their usual lives to maintain morale.

At the time of the final interview, the CIS-R score was also independently associated with income and alcohol consumption. At least one other study has found a link between income and depression among carers of stroke patients (Schulz R et al., 1988). This is also in keeping with a substantial body of literature which links income with the general well-being of adults (George L., 1988). Again, this link was not present when the carers were interviewed less than 10 weeks (mean 6.7 weeks) after stroke. It appeared first between six and nine months after stroke. Alcohol consumption is not commonly measured in the carer literature and no other studies reporting this link could be found. However, in general community populations, high alcohol consumption is related to depression (Sareen J et al., 2004).

15.3 Social effects of caring

15.3.1 Restriction of usual activities:

This study showed that carers experienced significant restriction in their usual activities as a result of the stroke. This was defined as the restriction of the six activities out of all they did regularly prior to the stroke that they would miss the most. By the time of the second interview, when carers were performing hands-on caring duties, their usual activities had been severely curtailed so that, on average, carers did less than half of the activities they would normally being doing on a regular basis. The stroke was given in most cases as the major reason why activities had changed.

There was still significant activity restriction a year after stroke but less so than early after stroke (mean activity restriction scores -3.19 vs. -2.62, t=-2.198, p=0.033). Other explanations, apart from the stroke, for a change in activities were more commonly cited at the final interview. This suggests carers initially stop doing their usual activities to care for the stroke patient. With time they adapt to their situation and can return to some activities, though overall activity levels remain reduced.

In this study, activity restriction was strongly correlated with morale (r=0.534, p<0.001 or Spearman's rho = 0.531, p < 0.001) and less strongly correlated with CIS-R scores (r=-0.347, p=0.012 or Spearman's rho = 0.328, p = 0.018). The more the carer's activities were curtailed, the lower the morale and the higher the CIS-R score. Activity restriction was a significant indicator of morale over a year after the stroke, accounting for 9.8% of the variance of this measure, but was not associated with CIS-R scores. There are parallels for this in the literature as Nieboer et al. (1998) and Williamson, Shaffer and Schulz (1998) independently found links between activity restriction and depressive symptoms in different groups of carers.

Finally, activity restriction was responsible for 8.4% of the variance in satisfaction with formal care as measured six weeks after the stroke patient was discharged home. This could be explained by the fact that those carers who find their activities are curtailed the most may be dissatisfied that the formal care providers are unable to provide enough support to enable them to do at least some of the activities they are missing. There were no parallels for this found in the care giving literature.

15.3.2 Relationship between the carer and stroke patient:

At the time of the first interview, most carers felt that they had a good relationship with the stroke patient. However there was a significant deterioration in the relationship between the pre-discharge interview and the six-week post-discharge interview (mean 6.81 vs. 7.85, $t= -3.502$; $p=0.001$), and then the relationship remained stable thereafter. The aspects of the relationship carers felt had deteriorated following discharge of the stroke patient home were the overall quality of their relationship with the stroke patient ($z=-2.828$; $p=0.005$); the stroke patient's appreciation of their efforts ($z=-2.108$; $p=0.035$); and the closeness of their relationship ($z=-3.157$; $p=002$).

There are at least two possible explanations for the change in quality of the relationship seen in this study. Firstly, the relationship might have deteriorated due to the stress of the caring situation and/or changes in the stroke patient due to the stroke. Alternatively the carers may have reported better relationships with the stroke patients whilst the stroke patients were in hospital, either due to absence making them feel closer to the stroke patient, or a wish not to speak ill of someone in hospital.

Several studies (Motenko AK 1989; Williamson GM, Shaffer DR, & Schulz R 1998) in the caring literature make links between relationship quality and outcome in terms of depressive symptoms. One study has shown a similar change in relationship quality between six weeks post stroke and six months post stroke (Schulz R, Tompkins CA, & Rau MT 1988). These time points are roughly equivalent to the time points of the measures used in this study but the authors do not make it clear in the published paper describing the study whether the stroke patients were still in hospital at the time of the six week post-stroke interviews. The authors explained the changes by attributing them to increased contact between the carers and stroke patients due to the disability caused by the stroke.

A small pilot study by Enterlante and Kern (1995) may explain this further. They interviewed ten wives of male stroke patients in a rehabilitation hospital and again two weeks after their spouse's discharge from hospital using the Buxbaum Marital Role Questionnaire. They found that, rather surprisingly, the wives' social activities did not decrease after the patients' return home after the stroke. However, the wives' responsibilities increased significantly, their satisfaction with household responsibilities reduced significantly, and they were significantly less happy with their marriages.

The quality of the relationship between the stroke patient and the carer may be noticed incidentally by staff on stroke units planning discharge, but is not something that is routinely asked about. However, the quality of this relationship measured at the time of the first post-stroke interview, before the stroke patient is discharged home, is the largest single predictor of satisfaction with formal services provision, accounting for 17.2% of the variance in this measure more than a year after the stroke. Perhaps, it should be part of the routine enquiry. The quality of the relationship at the time of the final interview is also a minor indicator of number of hours of service provision at that time, accounting for 4.6% of the variance in that measure. The implications of these findings will be discussed further on page 240-241.

15.3.3 Informal support:

15.3.3.1 Amount and quality of social support:

Carers in this study had very variable amounts of informal support ranging from none to extensive networks of family and friends. The perceived quality of support was also very variable with some carers having large networks of supporters but feeling socially isolated, and others having virtually no informal support but being content to support themselves. There was a significant reduction in both reported quantity (in terms of numbers of supporters) and quality of social support between the pre-discharge interview and the final interview (figure 15.4).

At the time of the first interview in this study, carers were assessing their level of support before they had tested their supporters once the stroke patient was home. How they perceived the quality of support might have been altered by the realities of support in the interim between the two interviews. However, the quantity and quality of support continued to decrease right up until the time of the final interview suggesting that, even if a false perception of support that would be available was the cause of the apparent decrease in informal support levels between discharge and the six week follow up interview, there was a further decrease in the amount of support after that time which could not be accounted for in this way, and was probably due to a genuine reduction in informal support over time.

There are parallels for this in the literature. A similar picture was found by Schulz et al (1988). In that study, respondents reported significant decreases over the time period

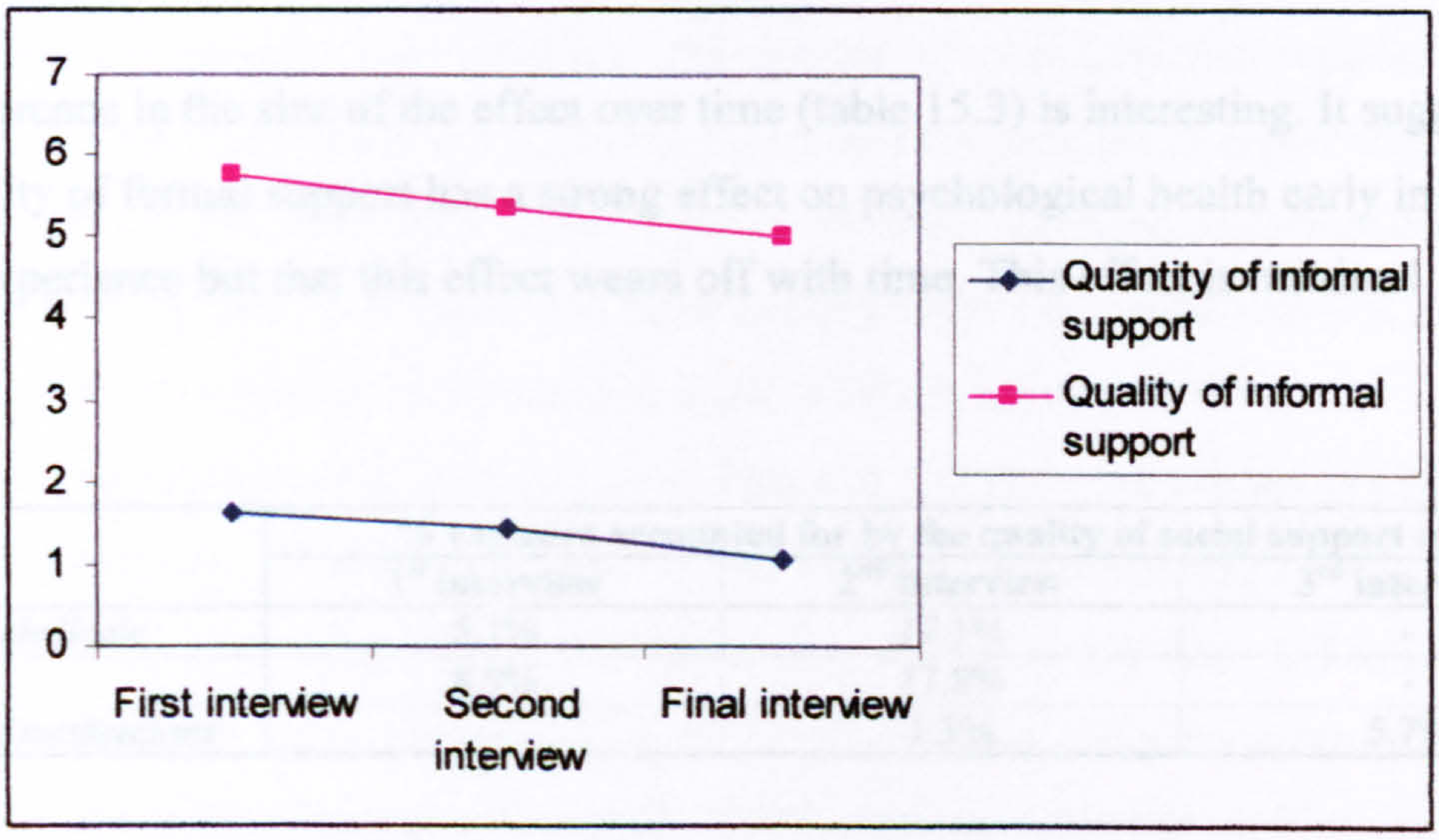


Figure 15.4: Chart to illustrate perceived changes in informal social support for carers over the duration of the study

from six weeks post stroke to six months post-stroke in the perceived availability of support and quality of support. Interestingly they also monitored the number of contacts with the support network. These increased over that time period.

15.3.3.2 Interactions between informal social support and other health measures:

It has long been held (Thoits PA 1982) that social support interacts significantly with life events (or strains) to produce an impact on physical or psychological well-being. The combination of low support and one or more life events significantly increases symptoms of physical or psychological distress. This was upheld by this study for quality (in terms of how helpful the carer perceives the support to be) but not quantity of support (in terms of number of supporters identified).

In this study the quality of social support was a factor independently associated with the CIS-R and PGC Morale scale scores, and the numbers of medications that carers were taking (table 15.1, page 204). Quality of social support was strongly correlated with both measures of psychological health used. The higher the quality of social support reported, the higher the Morale and lower the CIS-R score, and hence level of psychological distress ($r=0.366$, $p=0.002$ and $r=-0.416$, $p<0.001$ respectively).

The difference in the size of the effect over time (table 15.3) is interesting. It suggests that quality of formal support has a strong effect on psychological health early in the care giving experience but that this effect wears off with time. This effect is maximal

	% variance accounted for by the quality of social support score		
	1st interview	**2nd interview**	**3rd interview**
PGC Morale Scale	5.1%	17.1%	-
CIS-R	8.5%	17.8%	-
Number of medications	-	1.3%	5.7%

Table 15.3: Variance in health measures independently associated with quality of social support

soon after discharge when the hands-on care giving experience is new to the care giver. The effect on health measured through the number of medications is delayed. The quality of social support accounts for a very small percentage of the variance in number of medications early after discharge but a larger proportion at the time of the final interview. Medications are prescribed for psychological as well as physical health problems. No other measures of physical health are associated with quality of social support, so this may just represent the time lag between having a psychological health problem and receiving treatment for it, but it warrants further investigation.

15.4 Formal support provision

As in other surveys of carers in the community (Henwood M 1998; Warner L & Wexler S 1998), in this study the community worker most likely to have contact with the stroke patients and their carers was their GP. Multiple services were involved with most carer-patient pairs. The number of services involved decreased with time but not the time allocated for support of the patient and carer. This is probably because the amount of respite care increased markedly between the two time points. Respite care is the single biggest contributor to time in terms of hours of support.

Cost of care was strongly associated with the number of hours of formal support provision. In this study, it did not significantly change between the first post-discharge interview and the final interview. By the time of the final interview, acute rehabilitation services had completed their input, and most stroke patient-carer pairs had reached a steady state with long-term care packages in place where needed. In the six weeks prior to the final interview, formal care cost a minimum of £62 and a maximum of £2687. This gives an estimated cost to health and social care services of maintaining a stroke patient, with an informal carer, long-term in the community, once a steady state of formal health and social care input has been reached, of £5,504.46 per year using the mean value of cost of care for calculation purposes, or £3,700.67 per year using the median value of cost of care for calculation purposes.

15.4.1 Effects of patient and carer characteristics on individual service provision:

The presence of dysphasia increased the number of services involved. As might be expected there was a highly significant association between speech therapy input and dysphasia. The levels of handicap of the dysphasic patients were similar to the group without dysphasia, so this was probably accounted for by the additional speech therapy support these patients received.

Early on, only the provision of occupational therapy was related to any patient or carer characteristics. Occupational therapy was provided almost twice as often to patients with male carers as to patients with female carers. The reasons for this are unclear as disability levels were similar between the two groups of patients. This could be a type I error but a similar gender difference for district nurse support was found during the piloting of this project (Simon C, 2003). It has been established that there are gender differences in other areas of healthcare (Raine R et al., 2002; Raine R, Hutchings A, & Black N, 2003) and differential community support according to the gender of the carer warrants further investigation.

Later on (at the time of the final interview), these differences had disappeared. Then, the only association was the provision of community nursing services which was strongly related to the age of the couple - both patient and carer.

15.4.1 Effect of place of recruitment:

There was no significant difference in the overall quantity or cost of formal support provision between the two recruitment centres used at either time point. However, there were differences in individual service provision early after the discharge of the stroke patient. At that time point, there were differences in home care provision, day hospital or day centre care provision, and outpatient follow up rates.

When entered into a stepwise regression model, the place of recruitment was a factor which predicted around 11% of the variance in number of services provided early after stroke. This effect had gone over a year after stroke. This might be due to differences in

Table 15.4: Summary of factors independently associated with formal support provision

Predictors	**% variance in service provision**					
	2nd interview			**3rd interview**		
	Number	*Time*	*Cost*	*Number*	*Time*	*Cost*
Income	-	-	-	-	4.7	-
Other care commitments	-	9.8	13.1	-	-	-
Previous experience of caring	-	-	-	-	9.2	-
Place of recruitment	10.8	-	-	-	-	-
Health of the carer prior to discharge	8.6	-	-	-	-	3.3
Functional handicap	13	26.5	28.4	14.7	28.2	-
Social factors	-	6.8	4.8	-	15.1	-
Previous measures of formal support provision	-	-	-	-	-	63.7

pre-discharge planning or differences in the availability of specific services in the two locations. The fact this effect disappeared in this study by the time of the final follow up interview, suggests the former explanation is correct, however differences in the distribution of numbers in receipt of individual services suggests the latter. For example there is no stroke unit day hospital in Southampton, so it is hardly surprising that very few carers benefited from day hospital services in this area.

In reality the explanation probably lies somewhere between the two possible reasons. Real differences in service availability exist but these tend only to be in relation to services directly connected to secondary care. Once the effect of provision of these services is removed, usually when the stroke patient has been discharged from secondary care follow up, the level and type of service provision in the two recruitment areas becomes broadly similar.

15.4.1 Other factors independently associated with formal service provision:

15.4.1.1 Functional handicap:

In this study, the number of services involved, time allocated by formal support services to carers and stroke patients, and cost of care were all strongly correlated with the level of handicap of the stroke patient as assessed by the carer. When entered into a stepwise regression model, the level of handicap was the most powerful predictor of all three measures of formal support provision early after discharge. It remained the most powerful predictor of number and hours of formal support services 11 months later (table 15.4, page 221). This is in keeping with other research looking at the services provided after stroke (Legh-Smith J, Wade DT, & Langton-Hewer R 1986).

Related to this, it is interesting that, in this study, a year after stroke, previous caring experience was associated with the amount of formal community support received, with previous experience of caring predicting less support from the community services in terms of time. There are two plausible reasons for this. It might be that carers who have been in the caring situation before are more self-sufficient and thus require less ongoing help. Alternatively, it might be because many of those with previous caring experience had gained that experience in a professional capacity and therefore were able to do tasks which otherwise would require input from formal support services.

15.4.1.1 Impact of social factors on formal support provision:

At both post-discharge interview points, social factors also contributed to the variance in provision of formal community support. Early after discharge the number of informal supporters was important. If fewer informal supporters had been identified, the carer was likely to receive more hours of formal support. The presence of other caring responsibilities was also an important factor, with carers with multiple caring responsibilities, either for other disabled people or children, receiving more support. Later on, the quality of support was more important, with the quality of the relationship between the carer and stroke patient at that time accounting for 4.6% of the variance in number of formal services involved and the quality of social support provided in the immediate post-discharge period accounting for 10.5% of the variance in time allocated to each carer-patient dyad.

This is a unique finding and no parallels could be found in the carer or stroke literature. It probably reflects an assumption early on that, if there is a large informal social network supporting the carer, fewer formal support services will be required. The change in emphasis from quantity to quality of support over time may mirror adaptation of the services provided to the situation as it unfolds. One very helpful supporter is probably more important and useful to a carer than a host of inept ones.

15.4.1.1 Effect of carer health on formal support provision:

At the early post-discharge interview, self-rated health was the only physical or psychological health measure which had an impact on formal support provision. Self-rated health prior to discharge accounted for 8.9% of the variance in number of services provided. Carers who rated their own health as poor received more services.

There are two possible reasons for this. When planning the discharge of a stroke patient, generally the only information available about the carer's health is that provided by the carer, or in other words, the carer's self-rated health. If this is taken into account when planning the discharge, one would expect it to have an influence on service provision as was demonstrated in this study. Alternatively, as service input for the patient-carer dyad was recorded, and not service provision for the stroke patient alone, carers who consider their health to be poor might be receiving more services for themselves. This explanation is less likely as carer self-rated health deteriorated over the course of the study. If the second scenario were true, the impact of self-related health on service provision would be expected to increase with time. However, the influence of self-rated health on service provision had disappeared by the time of the final interview. Again, no parallels could be found in the carer literature.

Before the stroke patient was discharged home, over a third of carers had CIS-R scores in excess of 12, indicating significant psychological distress. However, this was not reflected in the amount of formal support provision for those carers six weeks after discharge, even though carer distress became significantly worse around the time of discharge. This may be because carer distress is not being detected before discharge and thus is not a factor considered when planning discharge, or it may be that care is only directed towards the stroke patient. The former explanation is more likely as self-rated health was a factor associated with number of services. However, the only determinant for self-rated health prior to discharge was the carer's age. This suggests that carer distress is not detected and so cannot be taken into account. Further research is needed into ways to detect carers with high levels of distress and identify interventions to support them.

In this study, cost of care over a year after stroke was influenced by the CIS-R score of the carer pre-discharge which predicted 3.3% of the variance in cost. The reason for this was clear when individual service provision was examined. Carers with high CIS-R scores were more likely to have home care involvement (χ^2=4.668, df=1, p=0.031) and more likely to have respite care (χ^2=7.302, df=2, p=0.026). Both of these were large contributors to hours of support provision and therefore cost.

15.5 Satisfaction with formal support provision

The 63.5% of carers of stroke patients satisfied with community services six weeks post-discharge is a figure typical of satisfaction surveys of mixed groups of carers (Henwood M, 1998; Warner L & Wexler S, 1998) and other studies of carers of stroke patients (Hodgson SP et al., 1997; Visser-Meily JMA et al., 2005), but low when compared to general population surveys of satisfaction with community services, in which typically around 90% express satisfaction with services (Khayat K & Salter B, 2001; Williams SJ & Calnan M, 1991).

This figure rose to 73.6% satisfied at the time of the final interview. The reasons for this are not clear but a possible explanation is that those who were struggling due to disability or illness of the carer or stroke patient, were less satisfied than those who were not. In many cases these carers would be lost from follow up due to the death of either the carer or stroke patient, or to failure of care at home resulting in the stroke patient being placed into residential care. However, satisfaction scores post-discharge of the group of carers who were followed up to the end of the study and the group of carers who dropped out between the second and third interviews were no different suggesting that this explanation is incorrect.

15.5.1 Effect of measure of satisfaction used:

Two measures of satisfaction were used for the purposes of this study. These were a single item global satisfaction question and the Carer satisfaction with community support questionnaire developed for this study. The two measures were highly correlated ($r=0.800, p<0.001$; Spearman's $rho=0.819, p<0.001$). Further validation analysis of the new satisfaction questionnaire is presented in Appendix 1.

	Question	**% dissatisfied**	
		2nd interview	**3rd interview**
1.	You are satisfied with the total amount of help provided to you (include in this help to allow you time to do what you want to do and time off)	23%	28%
2.	You are confident that services provided to you would adapt if your situation were to change (for example if you were ill or had an accident and were unable to do what you do now for the person you care for).	40%	32%
3.	You are satisfied with information you have been given about help available from the community services for you.(include health, social and voluntary services)	42%	34%
5.	You are confident you would know whom to contact from the community services if you had a problem	26%	27%
6.	You are satisfied with information you have been given about your role as a carer	57%	49%
7.	You have been given enough training for the tasks (such as lifting or bathing) you need to do for the person you look after.	34%	28%
9.	You are satisfied with information you have been given about what to expect of someone who has had a stroke	46%	49%
10.	You are confident you would know where to get information about any matter related to stroke or looking after someone who has had a stroke if you needed it.	16%	25%
12.	The professionals involved with your care seem as concerned about you as the person you look after	39%	40%
14.	You are satisfied about information you have been given about financial help you might be entitled to (including benefits).	35%	36%
16.	Services involved with your care lack co-ordination or don't work together	33%	34%
17.	You could have been consulted more about the person you look after	38%	38%
18.	As far as you can tell, the professionals involved with your care (doctors, nurses, social workers or any other professionals you see) seem to understand what being a carer is like.	26%	27%
19.	You would have liked more help applying for benefits and services	46%	34%

Table 15.5: Dissatisfaction with aspects of community service provision

15.5.2 Satisfaction with different aspects of formal community support:

Information about aspects of community support that carers were satisfied or dissatisfied with came from the individual items of the Carer satisfaction with community support questionnaire. This study shows that generally carers feel that their opinions are listened to, but perhaps they could have been consulted more. They are satisfied with the information they have received about stroke. They also feel that the quality of services received is good and they are very happy with the help received when they have had problems, particularly help received in crisis situations. The questions generating most dissatisfaction are presented in table 15.5, page 225.

Studies of community support following stroke suggest that, not only are support services insufficient, but that there is also a lack of awareness of community services which causes carers problems (Anderson R ,1988; Geddes JML & Chamberlain MA, 1994; Greveson G, 1991; Hanger HC & Mulley GP, 1993; Pound P, 1993; Silliman RA et al., 1987; Wolfe CDA et al., 1993; Woodhouse L & Muller DJ, 1987). Since these studies were published, considerable reforms to community care provision have taken place, but nevertheless these were both areas of dissatisfaction still commonly voiced by carers taking part in our study.

Information given to stroke patients and their carers is beneficial (Mant J et al., 1998). In the field of patient satisfaction, provision of information is strongly related to patient satisfaction as is encouraging and empathic behaviour (Williams S, Weinman J, & Dale J, 1998). In one study, topics poorly covered by information routinely provided for stroke patients were stroke disease and the effects of stroke, available services, and legal and financial matters (O'Mahoney PG et al., 1997). Another study found carers often discovered potentially beneficial services by chance (Greveson G, 1991). This study suggests such information is still lacking despite an increased emphasis on supporting carers in the community, and this may contribute to the relatively low levels of carer satisfaction seen consistently in the carer literature.

15.5.3 Factors associated with satisfaction with formal community support:

Correlations of factors with both the single item global satisfaction question responses and the satisfaction score using the new questionnaire are presented in table 15.6. From this it can be seen that poor satisfaction, as measured in this study, was associated with lower mood and poorer quality of social support. In addition, high levels of dissatisfaction on the new satisfaction questionnaire were correlated with increased level of handicap and restriction of the carer's usual activities.

A common factor in many satisfaction surveys is that very few individuals express dissatisfaction or are critical of their care (Abramowitz S, Cole AA, & Berry E, 1987; Hopton JL, Howie JGR, & Porter MD, 1993). As a result there is a tendency for satisfaction scores to respond poorly to change with researchers resorting to comparison of positive with more or less positive results. A way around this problem is the adoption of the "discrepancy model"(Carr-Hill RA, 1992; Fox JG & Storms DM, 1981;Williams B, 1994). This shifts the focus to concentrating on areas of expressed dissatisfaction.

Table 15.6: Correlations with satisfaction scores

	Correlations (Pearson's r)	
	Global satisfaction question	**New satisfaction questionnaire**
Self-rated health	N/S	N/S
Number of medications	N/S	N/S
Number of health problems	N/S	N/S
Morale	0.272**	0.266**
CIS-R	0.314**	0.316**
Quantity of informal support	N/S	N/S
Quality of informal support	0.289*	0.362**
Number of formal services involved	N/S	N/S
Time allocated by formal services	N/S	N/S
Activity restriction	N/S	0.291*
Functional handicap	N/S	0.300**

** p<0.01 * p<0.05 N/S = not significant

Note: All correlations listed are calculated using data from the first post-discharge interview.

For this reason, the data describing factors associated with satisfaction were further explored in two ways. First carers were split into a group expressing satisfaction with formal support provision with the single item global satisfaction question (i.e. those giving satisfied or very satisfied responses), and a group who did not express satisfaction (i.e. those giving neither satisfied nor dissatisfied, dissatisfied or very dissatisfied responses). Using data from the first post-discharge interview, 47 carers were found to be satisfied and 27 dissatisfied with the support received. The mean satisfaction score for the satisfied group was 17 (range 1-43) and the mean satisfaction score for the dissatisfied group was 47 (range 15-73).

Comparing the two groups, at the six-week post-discharge interview, there were three significant differences between them. Carers dissatisfied with formal care provision had significantly lower CIS-R scores than the carers who were satisfied. This could either mean that carers with lower mood are more likely to report poor satisfaction, or that dissatisfaction with formal support causes low mood.

There were also significant differences in quality of informal support between the two groups, with carers in the dissatisfied group having a poorer quality social support network and a poorer relationship with the stroke patient before the patient was discharged home. This implies poor carer support through a poorer relationship with the stroke patient, or a poorer wider social network, results in lower satisfaction with the formal support services provided.

Stepwise linear regression using the satisfaction score as the dependent variable and the variables listed in table 12.11 (page 153) as the independent variables yielded two factors together accounting for a total of 19.2% of the variance in satisfaction scores. These factors were the quality of informal social support post-discharge (10.8%) and the level of restriction of usual activities (8.4%). This implies that satisfaction levels early in the care experience are influenced by social factors and not by quantity of care.

Eleven months later when these analyses were repeated using data collected at the final interview, the findings were quite different. When carers were split into a group satisfied and a group dissatisfied with formal support provision, there were just two differences between the groups. The average age of the carers in the satisfied group was 67.8 years as opposed to 57.6 years in the dissatisfied group. In addition, carers in the dissatisfied group were taking significantly less medications than those in the satisfied group, however this may be a spurious result as it only just reaches significance, and thus may be a type I error, or may just reflect the older average age of the people in that group.

Stepwise regression analysis yielded four factors independently associated with satisfaction scores together accounting for 42.6% of total variance in the satisfaction score. These factors were the quality of carer-patient relationship score pre-discharge (17.2%), the patient's age (12.1%), the carer's CIS-R score at the time of the final interview (7.7%), and the cost of care (5.6%).

15.5.4 Discussion of satisfaction findings:

Therefore it would appear that, early on, pre-existing social factors, particularly the quality of the carer's relationship with the stroke patient, and the quality of support received by the carer from friends and relatives immediately after the stroke and until the stroke patient has returned home, determine how satisfied a carer is with the outside support provided by the formal support services. Restriction of the carer's activities is independently associated with satisfaction, and carers who are dissatisfied are more likely to have low mood as measured on the CIS-R.

Later on, the quality of the original relationship between the carer and patient is still extremely important and older patient-carers dyads are more likely to be satisfied than their younger counterparts. Again, carer mood is an important factor. The cost of care also has an influence.

The association of social factors and satisfaction is perhaps logical. Expectations of the care that should be received have a fundamental role in peoples' satisfaction (Sitzia J &

Wood N, 1997). Therefore different levels of satisfaction do not necessarily imply different levels of quality but may reflect different perspectives on similar levels of quality (Bond S & Thomas LH, 1992). This is supported by research evidence. For example, Larsen and Rootman (1976) showed that the more a doctor's performance meets a patient's expectations the more satisfied the patient will be. Likewise, Abramowitz et al (1987) showed that patients with "lower expectations" tend to be more satisfied.

There is also evidence that expectations change with knowledge and experience. Bond and Thomas (1992) noted that increasing the quality of care raises expectations. Therefore, paradoxically, ultimately a higher quality of care may be associated with lower levels of satisfaction. A problem with all this research is that the expectations of patients are difficult to define and even more difficult to measure objectively (Stimpson G & Webb B, 1975).

Extrapolating from this, if a carer has good informal support then it enables the carer to get on with necessary tasks without requiring formal support services as back up. Whether those services meet the carer's needs is therefore less important, carer expectations are lower, and that might result in higher satisfaction scores.

It is also possible to construct a link between activity restriction and satisfaction along the same lines. It was noticeable whilst doing the interviews how varied "usual activities" were. Some carers had highly social and active lives, while others' lives revolved around the home. For those who usually stayed at home, maintenance of usual activities would be fairly easy with minimal formal service input. For those whose lives were dominated pre-stroke by activities outside the home, their expectations would be different. It would be more difficult for the formal services to support them to pursue these activities and therefore the activities would be more severely restricted, which might result in lower satisfaction with support services.

There has also been some concern that satisfaction levels reflect the characteristics of the people interviewed and not the care provided (Lunnen KM & Ogles BM, 1997; Aspinal F. et al., 2003). In other words a depressed carer might be expected to be less satisfied with the care provided than a happy one. For this reason there is some debate about the meaning of satisfaction scores as outcome measures in healthcare settings.

An association between age and satisfaction is commonly found in the satisfaction literature across the breadth of healthcare provision. There is evidence that older people are more satisfied with healthcare services than younger people not only in the UK, where it can be argued that older people's expectations are different as they remember pre-NHS days (Salvage AV, Jones DA, & Vetter NJ, 1988, Fakhoury et al., 1997; Lecouturier et al., 1999), but also in other countries throughout the world (Houts PS et al., 1986; Zahr LK, William SG, & El-Hadad A, 1991). The results of this study are entirely in keeping with this literature.

Associations between mood and satisfaction are also common in the satisfaction literature (Fung et al., 2005; Chesterman J, Bauld L, & Judge K, 2001). This study would support the hypothesis that low mood predicts satisfaction. However many satisfaction studies have not demonstrated this (Singh M & Cameron J, 2005; Visser-Meily JMA et al., 2005). One of the problems with all the satisfaction literature is the lack of a common point at which the cut off between 'satisfied' carers and 'dissatisfied' carers is placed. None of the studies quoted define that cut off. In addition, very few use validated measures of satisfaction (Sitzia J, 1999).

Chapter 16: Conclusions

16.1 Relationship of study findings to the original study aims:

16.1.1 What are the health and social effects of caring for a stroke patient?

This study demonstrated many different effects of care giving on the health and social functioning of carers of stroke patients and showed that these varied with time. Changes are summarized in figure 16.1, page 233.

Time 1 - pre-discharge:

- *Psychological health:* Would-be carers already had significant psychological distress compared to comparison non-carers. This was more apparent among female than male carers. The two indicators identified for the amount of distress were the quality of the carer's informal support network and the carer's perceived weight loss since the stroke. Carers with poorer quality social networks had more distress as did patients who perceived they had lost weight.
- *Physical health:* Physical health of carers at this time was no different to that of non-carers and was predicted by the carer's age.

Time 2 - Six weeks after discharge:

- *Lifestyle:* Alcohol consumption had increased.
- *Psychological health:* Psychological health of the carer had become significantly worse. Factors independently associated with carer distress at this time point were poorer quality of informal support, lower carer mood prior to the discharge home of the stroke patient, and poorer physical health of the carer. The gender difference in psychological health seen before the stroke patient was discharged home was no longer present.
- *Physical health:* Physical health of the carer had also become significantly worse. Poorer self-rated physical health of carers was independently associated with poorer physical health of the carer before the stroke patient was discharged, gender (female carers reported poorer physical health than male carers) and smoking habits of the carer (carers who smoked more reported worse health), perceived carer weight-loss

igure 16.1: Summary of health and social changes through the duration of the study

immediately after the stroke, greater level of handicap of the stroke patient, poorer perceived quality of informal social support and poorer quality of support from formal services.

- *Social well-being:* Social functioning was affected, with carers' usual activities restricted by more than half and a significant deterioration in the relationship between the carers and the stroke patients they cared for.

Time 3 - A year after discharge:

- *Lifestyle:* Carer smoking had significantly decreased since the time of the stroke.
- *Psychological health:* There was no further deterioration in psychological health but distress levels remained significantly higher amongst the carers than the non-carers. Predictors of psychological distress were previous distress, lower income and higher alcohol consumption. Morale was independently associated with previous distress, poorer physical health, greater activity restriction and lower satisfaction with formal support services.
- *Physical health:* Physical health continued to deteriorate with a significant increase in ongoing health problems between the first and third interviews. This trend was not seen amongst non-carers. Factors independently associated with poor physical health were previous poor health, poor psychological health, increased level of handicap of the stroke patient, presence of other care commitments, poorer quality of social support and less formal support.
- *Levels of stroke handicap:* Sadly the levels of handicap reported for the stroke patients did not significantly decrease over the course of the study.
- *Social well-being:* Although quality and quantity of social support decreased steadily from pre-discharge levels, there was no further deterioration in the relationship between the stroke patient and carer after the initial adjustment period after discharge home. There was some recovery in the number of usual activities the carer was able to do which probably indicates an adjustment process.

16.1.2 What is the relationship between health and social factors and satisfaction with formal service provision?

In this study, about 64% of informal co-habitant carers of stroke patients who had suffered their first stroke were satisfied with the community support they had received in the first six weeks after the stroke patient was home. This figure rose to roughly 74% satisfied after a year caring. This figure is low for client satisfaction surveys within healthcare settings implying that there is room to improve quality and/or quantity of carer support. Poor satisfaction was associated with low mood and poor quality of social support. In addition, high levels of dissatisfaction on the new satisfaction questionnaire were correlated with an increased level of handicap of the stroke patient and greater restriction of the carer's usual activities.

In the early period after the stroke patient was discharged, carers satisfied with community care had lower levels of psychological distress. They also had better social support with a better relationship with the stroke patient and higher quality support from the wider social network. Indicators of satisfaction were a higher quality of informal social care and lack of lifestyle restriction.

A year after discharge home, the carers satisfied with care were older than those dissatisfied with care, and taking fewer medications. Satisfaction scores were predicted by the original quality of relationship between the stroke patient and carer, carer age, the psychological health of the carer and the cost of the formal care provided to the stroke patient and carer.

16.1.3 What is the relationship between satisfaction and level of service provision?

In this study, the number of services involved, time allocated by the formal support services to carers and stroke patients, and the cost of care were all strongly linked with the level of handicap of the stroke patient as assessed by the carer both after discharge and later, when the carer had become established. As might be expected, the more handicapped the stroke patient, the more formal support was provided.

Early after discharge formal community support of the carer was also related to the self rated health of the carer, number of informal supporters identified by the carer and presence of other care commitments. Carers reporting poorer health received more formal support, as did carers who had other care commitments, and those who had fewer informal supporters that they could identify to call upon.

This changed with time and later on, the quality rather than quantity of informal social support became a more important factor. A year after discharge, previous experience of being a carer resulted in carers receiving less formal support. Early differences in service provision between recruitment centres had gone. The only link between satisfaction and level of service provision was through the cost of care which accounted for 5.6% of the variance in satisfaction scores. Carers able to afford additional care had in many cases purchased formal care service support and thus were able to tailor support better to their wants and needs.

16.2 Summary of unique findings from this study:

- 40% of carers of stroke patients, compared with 15% of matched non-carers, have significant psychological distress. This distress starts very early on, and before the stroke patient the carer intends to look after even returns home. The level of psychological distress remains constant for at least a year afterwards.
- Physical health also suffers with significant deterioration in carer physical health over the first year of caring for a stroke patient at home. Although this study was not powered to detect differences in physical health between carers and non-carers, similar deterioration in non-carer health was not seen over the same time period.
- Quality of social support has a strong association with carer psychological distress early in the carer experience. Perceived quality and quantity of informal social support diminish with time after the stroke. Carers with poorer social support whilst the stroke patient is in hospital, and in the first six weeks after discharge, have more psychological distress.
- Perceived weight loss is associated with carer distress whilst the stroke patient is still in hospital.

- Provision of formal services to carers of stroke patients in the community is determined by level of handicap of the stroke patient. Early on, within six weeks of discharge, number of informal supporters, carers' other care commitments, and carers' self-perceived health, determine the amount of care provided. Later on, amount of formal support provision reflects the quality of the social support network and relationship between the carer and stroke patient, previous experience of care giving and, to a minor extent, income.
- Between 64% and 74% of carers were satisfied with the community support provided when the stroke patient returned home, depending on when satisfaction was measured. Satisfaction with formal support services was not related to the amount of formal support provided nor its cost. It was related to carer age, with older carers reporting more satisfaction, and carer mood so that carers with higher CIS-R scores reported less satisfaction. In addition, social factors determined satisfaction. Again quality of social support was important, both within the home through the carer's relationship with the stroke patient, and through the wider social network. The degree to which the carer's usual activities were prevented also impacted on satisfaction with services provided.

16.3 Model construction

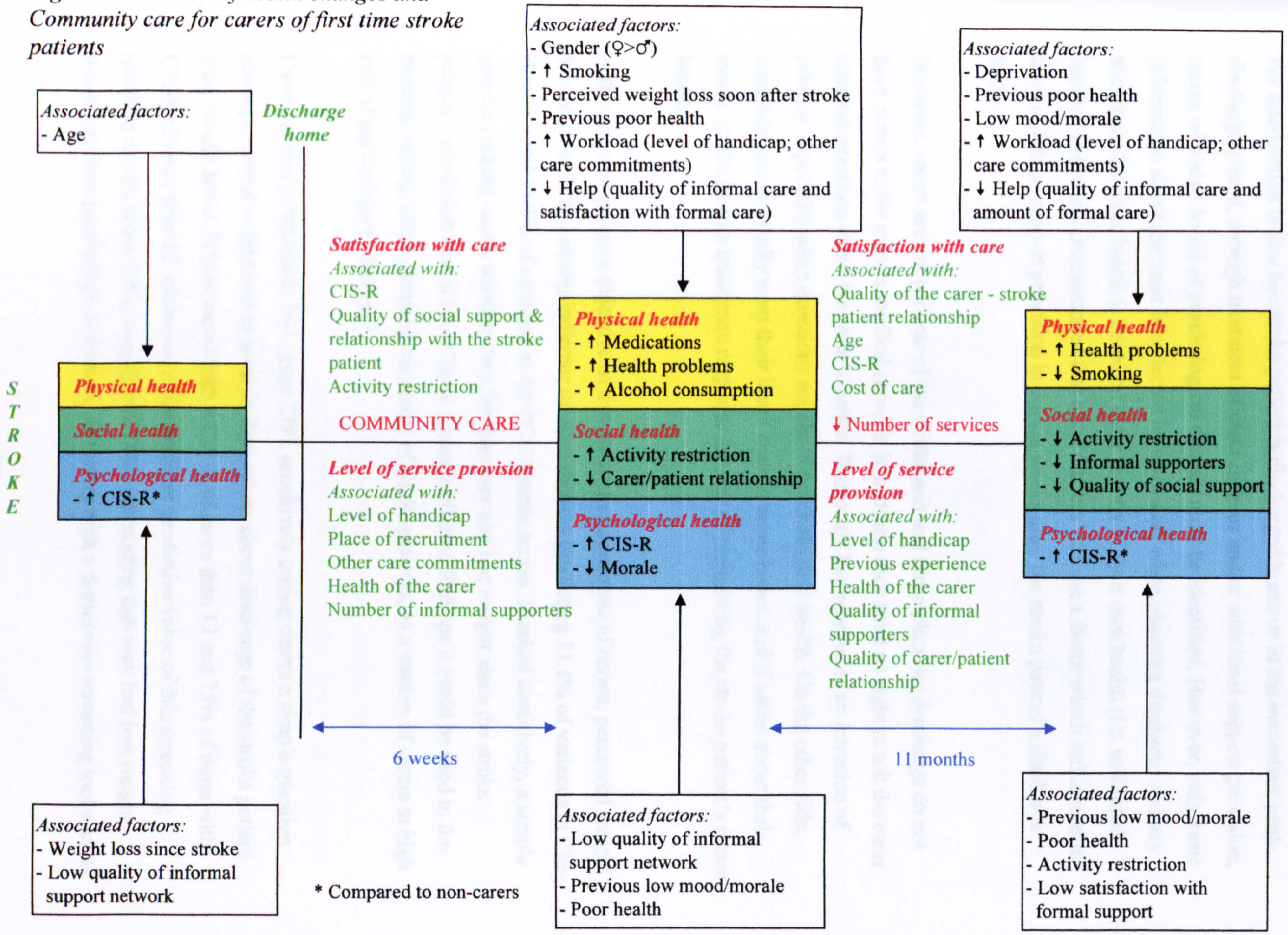
From the findings of this study, and the theoretical stress-coping model described in Chapter 2 (pages 10-11), a model of health changes and community care for carers of first time stroke patients can be constructed (figure 16.2, page 238).

16.4 Implications for practice

16.4.1 Whilst the stroke patient is on the stroke unit:

Health scores early after stroke, when the stroke patient is still in hospital, are important predictors of health later on. Even at this point 37% of carers have a high level of psychological distress, two and a half times the percentage of non-carers. Nearly a quarter have distress levels which are above the level which suggests they require treatment and women are more at risk than men. Distress levels further increase in the six weeks after the stroke patient returns home and before stabilising at a level much higher than similar non-carers. Alcohol consumption also increases after discharge.

Figure 16.2: Model of health changes and Community care for carers of first time stroke patients



For intervention before the stroke patient is discharged home or in the immediate post-discharge period, through treatment of carer distress and/or additional support provision, carers with high levels of psychological distress must be identified. However, only basic information about the carer is collected by ward staff when planning discharge and any allowance for carer health is based on carer reports of their own health (i.e. self-rated health). This study demonstrated that carer distress was not a factor which influenced the level of formal support provision in the six weeks after the stroke patient's discharge home.

However, carers are not patients of the stroke unit and those planning discharge do not have access to the carer's medical records. In addition they have no right to ask the carer detailed questions about the carer's health. This could be regarded as an intrusion of privacy, especially when questions are about psychological health. On the other side, would-be carers usually want their loved ones to come home, and if asked about their mood, might give an inaccurate response for fear of prejudicing the stroke patient's return home.

Although not a primary objective of this study, in this sample of carers, perceived weight loss of carers was a strong indicator of carer distress predicting 11.1% of variance in CIS-R scores and 13.3% of variance in the PGC Morale scores. If asked sensitively, a simple question asking carers whether they felt that they had lost weight since the stroke patient's admission would be unlikely to cause offence. Perhaps it could be used in the hospital setting, when planning discharge of stroke patients, as a marker of carers at high risk of psychological distress?

From the study data (table 16.1, page 239), sensitively asking carers a simple question about perceived weight loss as soon as discussions about discharge of the stroke patient start, would detect 71% of carers with a CIS-R of more than 12 and 75% of those with CIS-R of more than 17. However, as the positive predictive value of this screening question is only about 50%, roughly half those responding that they had lost weight would not have psychological distress, so testing with a depression screening tool such as

Table 16.1: Sensitivity, specificity and positive predictive value of carers reports of weight loss since stroke

		Number with CIS-R score >12 (>17)		
		+ve	-ve	
Number with perceived weight loss since stroke	+ve	28 (19)	30 (39)	**Positive predictive value** CIS-R > 12 = 48% CIS-R > 17 = 33%
	-ve	11 (6)	36 (41)	**Negative predictive value** CIS-R > 12 = 77% CIS-R > 17 = 87%
		Sensitivity CIS-R >12 = 72% CIS-R >17 = 76%	**Specificity** CIS-R > 12 = 55% CIS-R > 17 = 51%	

the Hospital Anxiety and Depression Scale would then be essential. This could be done by referring carers to their GPs for further assessment and intervention where necessary. For those with confirmed psychological distress, this should be taken into account when planning the discharge of the stroke patient, and should be a factor taken into consideration when arranging formal support when the patient goes home.

Another interesting secondary finding was that services provided in the community when the stroke patient first returned home were determined not only by the level of handicap of the stroke patient, but also by the number of informal supporters identified by the carer, the carer's other care commitments, and the carer's self-perceived health. This probably reflects the factors considered when discharge planning. However, later on, amount of formal support provision reflected the quality of the social support network and quality of the pre-discharge relationship between the carer and stroke patient, previous experience of care giving and, to a minor extent, income. This suggests that an adaptation of the formal support services supplied occurs after discharge. Perhaps these factors, as well as carer mood should be considered when discharge planning.

16.4.2 When the stroke patient returns home:

Within six weeks of the stroke patient returning home, this study showed that there was a marked deterioration in carer distress and morale. In addition, this study showed that physical health deteriorated. Carers are therefore an at-risk group for physical and mental health problems. Particular risk factors for poor health are:

- Poorer quality of the relationship between the carer and stroke patient
- Poorer quality and quantity of the social network
- More severe restriction of usual activities
- Higher levels of handicap of the stroke patient

Screening carers in the community, in the early phase after discharge of the stroke patient home, might identify a population of carers at high risk who warrant additional support and/or monitoring. This could be done by any key worker involved with the stroke patient and carer.

16.4.3 Improving formal support services in the community:

Just under 64% of the informal carers of stroke patients who had suffered their first stroke and were involved with this study were satisfied with the community support they received in the first six weeks the stroke patient was home. This figure rose to just under 74% satisfied after a year caring. This figure is low for client satisfaction surveys within healthcare settings, implying that there is room to improve the quality and/or quantity of carer support.

Carers' satisfaction with community support services was largely dependent on age, mood and social factors such as availability of good informal support. These same factors also tended to predict health. This implies that improving community support services should not be aimed at increasing the numbers of services or the hours of support they provide but should be targeted at improving social networks and enabling carers to have time to do their usual activities.

However this study also highlighted aspects of formal care which could be improved. These were:

- Improvements in training of carers and health professionals, and better information provision for carers, particularly about the carer's role and rights, and what they should expect from the stroke patient

- Including carers as part of the care team by asking them for their views and considering their perspective, *and*
- Reassuring carers by ensuring they have contact points in case of difficulty and know what is available should they require it.

16.5 Implications for research

Further research questions highlighted by the findings of this project, can be divided into those important in secondary care environments, and those of relevance to primary care.

16.5.1 Further research in secondary care:

This project shows that carer distress starts very early in the carer's career, before the stroke patient is discharged from hospital. In the secondary care setting, further research is needed into identification and support of carers in distress:

- Is the finding of perceived weight loss as an indicator of poor psychological health reproducible? If so, is asking about weight loss after stroke an effective way of screening for carer distress? Who should follow these carers up and how?
- Which carers need intervention?
- Does intervention for distressed carers at this early stage prevent later problems with their own health and/or improve the well-being of stroke patients after discharge? In particular, does intervention at this early stage prevent later breakdown of the care giving situation which results in the stroke patient being placed into residential care?
- What interventions are effective, feasible and acceptable to carers?
- Does consideration of the quality of the social support network and relationship between the carer and stroke patient and the carer's previous experience of care giving when discharge planning, result in better support of the carer once the stroke patient returns home? If so, does that impact on satisfaction with community support and/or carer and/or stroke patient well-being?

16.5.2 Further research in primary care:

Once the stroke patient is home, the primary care and social services teams take on the bulk of formal support activities. Long questionnaires are not feasible in this situation. Research is needed to develop a quick instrument which could be used by primary care or social services personnel to screen carers for carers at risk of poor health outcomes when placed in a new care giving situation. This tool would need to encompass the psychological distress and physical health of the carer, the level of handicap of the stroke patient, the quality and quantity of the social network, including the carer's relationship with the stroke patient, and the level of lifestyle restriction of the carer.

Possible elements of this screening tool include the NICE two-question screen for depression currently used within the quality and outcomes framework to identify high risk individuals with depression (*'During the last month, have you often been bothered by feeling down, depressed or hopeless?'* and *'During the last month, have you often been bothered by having little interest or pleasure in doing things?'* - NICE, 2004) and the Oxford Handicap Scale (Bamford J et al., 1988), which is an easy to administer tool designed for use with stroke patients, and which performed well when used with carers as an indirect measure of stroke patient handicap in this study.

Once 'at risk' carers are identified, work is needed to establish how best to support them. Interventions should focus on improving social networks and enabling carers to have time to do their usual activities. Work is needed to establish the components of these interventions. Then work is needed to establish whether intervention among groups of carers at high risk of developing adverse health outcomes, makes any difference to outcome.

Finally, further research is needed to develop strategies to improve the quality and/or quantity of formal community support. These should particularly focus on methods of information provision, ways of co-ordinating services, improving communication between carers and community care professionals, and tailoring services better to the needs of carers and stroke patients so that carers can be confident formal services will support them when required.

Appendix 1: Carer Satisfaction with Community Care Questionnaire

*	Denotes statements derived wholly or in part from the subthemes identified in phase 1 of the development process
∇	Denotes statements derived wholly or in part from the caregiver literature – particularly the National Carer's Code (Carers National Association, 1999)

We are interested to know how satisfied you are with overall care you have received - where overall means care from ALL the people I have just listed. Please tell me how strongly you agree or disagree with these statements:

		Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree
1.* ∇	You are satisfied with the total amount of help provided to you (include in this help to allow you time to do what you want to do and time off)	0	1	2	3	4
2.*	You are confident that services provided to you would adapt if your situation were to change (for example if you were ill or had an accident and were unable to do what you do now for the person you care for).	0	1	2	3	4
3.*	You are satisfied with information you have been given about help available from the community services for you.(include health, social and voluntary services)	0	1	2	3	4
4.*	Services and equipment provided to you are usually of good quality	0	1	2	3	4
5.*	You are confident you would know whom to contact from the community services if you had a problem	0	1	2	3	4
6.*	You are satisfied with information you have been given about your role as a carer	0	1	2	3	4
7.* ∇	You have been given enough training for the tasks (such as lifting or bathing) you need to do for the person you look after.	0	1	2	3	4
8.*	You are satisfied with information you've been given about stroke.	0	1	2	3	4
9.*	You are satisfied with information you have been given about what to expect of someone who has had a stroke	0	1	2	3	4
10.*	You are confident you would know where to get information about any matter related to stroke or looking after someone who has had a stroke if you needed it.	0	1	2	3	4
11.* ∇	You are satisfied with help you've received from the community services when you've had a problem	0	1	2	3	4
12.* ∇	The professionals involved with your care seem as concerned about you as the person you look after	0	1	2	3	4

		Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree
13.*	You feel your opinion is ignored in making decisions about the person you care for	4	3	2	1	0
14.*	You are satisfied about information you have been given about financial help you might be entitled to (including benefits).	0	1	2	3	4
15. ∇	Given the choice, there are tasks you do now as a carer that you would rather not do	4	3	2	1	0
16.* ∇	Services involved with your care lack co-ordination or don't work together	4	3	2	1	0
17.*	You could have been consulted more about the person you look after	4	3	2	1	0
18.*	As far as you can tell, the professionals involved with your care (doctors, nurses, social workers or any other professionals you see) seem to understand what being a carer is like.	0	1	2	3	4
19.*	You would have liked more help applying for benefits and services	4	3	2	1	0
20.* ∇	Essential changes to equipment, housing or services have been made too slowly	4	3	2	1	0
21.*	Services provided to you are at times of the day when it is convenient to have them	0	1	2	3	4
22.*	Information you have received has generally been accurate	0	1	2	3	4

A1.1 Further validation of the new questionnaire

As this is a new scale, data collected in this study was analysed for further validity and reliability analysis (see pages 49 - 52 for discussion of the meaning of these terms). Results with comparative figures from the piloting data are summarized in table A1.1

Using data from the six weeks post discharge interviews, correlation between the global satisfaction question response and the new satisfaction questionnaire scores was strongly positive (Pearson's R=0.800, $p<0.001$; Spearman's rho=0.819, $p<0.001$), indicating the two measures are related to each other. One would expect this to be the case if the new scale was measuring the same concept. The similarities between the findings of associations with the global satisfaction question and the new scale also add weight to the criterion validity.

Table A1.1: Comparative reliability and validity data for the new questionnaire.

Validity/reliability measure		**Spearman's rho**		**Pearson's R**		**Cronbach's alpha**	
		This study	*Pilot*	*This study*	*Pilot*	*This study*	*Pilot*
Test-retest reliability		0.729*	0.885*	0.716*	0.880*		
Comparison with a single item global satisfaction measure	*1st interview*	0.809*	0.797*	0.800*	0.796*		
	2nd interview	0.646*		0.662*			
Cronbach's alpha	*1st interview*					0.892	0.859
	2nd interview					0.889	

* p<0.001

Using a paired t-test, difference in means on satisfaction scores measured at the two time points was not significant ($t_{\text{difference in means}}=1.161$, p=0.251, 95% CI: -1.69-6.33), suggesting satisfaction levels were stable. Therefore data from the six weeks post discharge interviews and year post stroke interviews were used to obtain further test-retest reliability statistics.

The average time between these interviews was 10.8 months (range 6.1-17.3 months, SD 2.4 months). There was a high level of correlation between the satisfaction scores using the new measure at six weeks post discharge and the time of the final interview (Pearson's R=0.716, p<0.001; Spearman's rho=0.729, p<0.001) indicating a high level of test-retest reliability. Correlation of individual statements revealed just four statements with poor correlation between the two interview times (table A1.2). This might represent true changes between those times but could reflect poor wording of the statements. Amendments were made to the statements for the next version of the scale. Cronbach's alpha for the scale was 0.89 indicating a high level of internal reliability.

Factor analysis is a statistical way of identifying whether groups of items are related to each other. Varimax rotation is used to ensure maximal separation of the factors. A loading value of 0.5 or greater was used to indicate an item loaded strongly. A factor is considered important and worthy of inclusion within the scale if its Eigen value (a

Table A1.2: Poorly correlating statements and amendments for later versions.

Original statement	***Spearman's rho (test-retest reliability)***	***New statement***
Services and equipment provided to you are usually of good quality	0.211	Any equipment provided to you is of high quality *and* Any services provided to you are of good quality
You are satisfied with help you've received from the community services when you've had a problem	0.231	When you've had a problem, the response you've received from the community services has been adequate
Services provided to you are at times of the day when it is convenient to have them	0.153	
Information you have received has generally been accurate	0.270	Any information you have received has been accurate overall

measure of its power to explain variation between subjects) exceeds a certain value. There is debate about what that value should be but for this study a value of 1.1 was used (Jollife IT & Morgan BJT 1992).

Factor analysis using principal components analysis with varimax rotation on questionnaire responses with missing values substituted with mean response for that carer revealed six factors (table A1.3). Three questions (numbers 1, 7 and 17) did not load onto any factors. Factors identified were labelled information and empathy for the carer; flexibility of support; quality of support; help with caring tasks; confidence in knowing where to go; convenience. A repeat factor analysis using the second set of data revealed that these factors were stable.

Appendix 1: Carer Satisfaction with Community Care Questionnaire

Table A1.3: Questionnaire items, responses and factor loading values.

Question	% who agreed (*% who strongly agreed*)	% who disagreed (% *who strongly disagreed*)	Factor loading
Factor 1: Information and empathy for the carer (α = 0.829)			
You are satisfied with information you have been given about help available from the community services for you.(include health, social and voluntary services)	42 (*39*)	31 (*24*)	.56
You are satisfied with information you have been given about your role as a carer	25 (*20*)	42 (*38*)	.54
You are satisfied with information you've been given about stroke.	54 (*43*)	17 (*14*)	.63
You are satisfied with information you have been given about what to expect of someone who has had a stroke	36 (*29*)	34 (*15*)	.51
The professionals involved with your care seem as concerned about you as the person you look after	42 (*37*)	29 (*24*)	.84
You feel your opinion is ignored in making decisions about the person you care for	16 (*11*)	50 (*49*)	.50
As far as you can tell, the professionals involved with your care (doctors, nurses, social workers or any other professionals you see) seem to understand what being a carer is like.	45 (*29*)	34 (*15*)	.60
Factor 2: Flexibility of support (α = 0.769)			
You are confident that services provided to you would adapt if your situation were to change (for example if you were ill or had an accident and were unable to do what you do now for the person you care for).	38 (*20*)	30 (*21*)	.76
Services involved with your care lack co-ordination or don't work together	24 (*13*)	42 (*39*)	.62
Essential changes to equipment, housing or services have been made too slowly	24 (*23*)	48 (*41*)	.82
Factor 3: Quality of support (α = 0.710)			
Services and equipment provided to you are usually of good quality	69 (*63*)	2 (*1*)	.88
You are satisfied with help you've received from the community services when you've had a problem	51 (*49*)	12 (*8*)	.62
Information you have received has generally been accurate	71 (*60*)	3 (*3*)	.60
Factor 4: Help with caring tasks (α = 0.695)			
You are satisfied about information you have been given about financial help you might be entitled to (including benefits).	46 (*36*)	26 (*16*)	.62
Given the choice, there are tasks you do now as a carer that you would rather not do	19 (*14*)	52 (*47*)	.54
You would have liked more help applying for benefits and services	34 (*30*)	38 (*32*)	.77
Factor 5: Confidence in knowing where to go (α = 0.632)			
You are confident you would know whom to contact from the community services if you had a problem	55 (*49*)	19 (*19*)	.85
You are confident you would know where to get information about any matter related to stroke or looking after someone who has had a stroke if you needed it.	62 (*53*)	12 (*10*)	.71
Factor 6: Convenience (α = 0.874)			
Services provided to you are at times of the day when it is convenient to have them	66 (*58*)	5 (*2*)	.87

▨ *Marks negatively worded questions*

Appendix 2: Enrolment questionnaire

Words / items in red were removed for the comparison non-carers' enrolment questionnaire

Informal Carers of stroke patients study

CARERS ENROLMENT QUESTIONNAIRE

Please could you answer these questions. They will give us background information about you we can then use later in our study. Please write in CAPITAL LETTERS.

Date completed: ……/ ……/ ……………..

1) CONTACT DETAILS

- What is your name? …………………………………………………..
- Male ☐ Female ☐
- Address: ……………………………………………….
  ……………………………………………….
  ……………………………………………….
  ……………………………………………….
- Post code: ……………………
- Telephone number: ………………………..
- Daytime telephone number (if different): ………………………..
- Who is your GP? …………………………..
- Which surgery is he/she based at? ……………………………………………
- What is the stroke patient's name? ………………………………
- What is the stroke patient's date of birth? ……../ ……./ 19……..
- On what date did the stroke patient have his/her stroke? ……../ ……./ …..……..
- Who is their GP? ……………………………
- Which surgery is he/she based at?…………………………………………

2) ABOUT YOU

- What is your date of birth? ……./……/19……
- What is your relationship to the stroke patient (please tick correct response)

Spouse ☐
Child ☐
Parent ☐
Other ☐

please state ……………………

- Do you intend to look after the stroke patient if s/he becomes fit enough to go home after this stroke? Yes ☐ No ☐

- *Are you employed? (please tick correct response)*

1 Full Time ☐
2 Part time ☐
3 Unemployed ☐
4 Retired ☐

What sort of work does /did that involve?

Occupation ____________________

- Are you married? (please tick the box which applies best)

1 Single ☐
2 Married ☐
3 Divorced ☐
4 Separated ☐
5 Widowed ☐

If single, separated or divorced:

Are you living with someone as though you are married?
1 No ☐
2 Yes ☐

- Were you born in the UK?

1 Yes ☐
2 No ☐

- Have your finances been sufficient for Yes ☐ No ☐

your needs until now?

- What is your approximate monthly income as a family?

less than ☐ £1000	£1000 ☐ -£2000	more than ☐ £2000

- What was the highest educational qualification you achieved?

1 None ☐
2 O-level (or equivalent) ☐
3 A-level (or equivalent) ☐
4 Diploma ☐
5 Degree ☐

- What type of housing do you live in?

1 Flat ☐
2 Bungalow ☐
3 House ☐
4 Other ☐

- Do you have a warden? Yes ☐ No ☐

- Do you own your own home or are you a tenant?

1 owner, occupier ☐
2 rented, local authority or housing association ☐
3 rented, private ☐
4 institution, including hostel ☐
5 no fixed abode ☐

- Do you have any children? Yes ☐ No ☐

If yes, How many are living with you at home?

1 None ☐
2 One or more ☐

Number of children living at home _____

- Do you currently care regularly for any children under 16 years of age? Yes ☐ No ☐

- Have you ever cared for a person with a disability before?

  1 Yes ☐
  2 No ☐

  If yes, was that professionally or caring informally for another friend or relative?

  …………………………………………………………

- Do you currently care for any other disabled or elderly adults?

  1 Yes ☐
  2 No ☐

Appendix 3: The CIS-R

<u>ABOUT YOUR MOOD :</u>

- Have you ever been to your doctor (or any other practitioner) for an emotional reason or problem?

    1 Yes ☐
    2 no ---------------→ GO ON TO NEXT SECTION

➢ Were you referred to a psychiatrist?

1 No ☐
2 GP treatment ☐
3 Out patient psychiatric treatment ☐
4 In patient treatment in a psychiatric unit ☐
5 Counselling by a non-medical psychotherapist ☐
6 Alternative practitioners ☐

➢ Were you given tablets for this? What sort of tablets were they?

1 No ☐
2 not known ☐
3 benzodiazepines ☐
4 antidepressants ☐
5 neuroleptics ☐

SOMATIC SYMPTOMS:

Have you had any sort of ache or pain recently, for example headache or indigestion?
Have you been troubled by any sort of bodily discomfort recently?

- Is this pain/discomfort brought on or made worse by feeling low, anxious or stressed?

  No --------→ GO ON TO NEXT SECTION
  Yes or don't know --------→ CONTINUE THIS SECTION

- On how many days have you noticed this pain/discomfort during the past week?

  None --------→ GO ON TO NEXT SECTION
  0 <= 3 days ☐
  1 >= 4 days ☐

- Has the pain/discomfort lasted more than 3 hours on any day during the past week?

  0 less than 3 hours ☐
  1 more than 3 hours ☐

- Has the pain / discomfort been unpleasant in the past week?

  0 not at all ☐
  1 a little unpleasant ☐
  2 unpleasant ☐

- Has the pain / discomfort bothered you when you were doing something interesting in the past week?

  0 no, pain does not bother subject ☐
  1 yes, pain troublesome on one or more occasion ☐
  2 has not done anything interesting ☐

FATIGUE:

Have you noticed you have been getting tired recently?
Have you felt you have been lacking in energy?

- On how many days have you felt tired /lacking in energy during the past seven days?

  0 <= 3 days ☐
  1 >= 4 days ☐

- Have you felt tired or lacking in energy for more than 3 hours on any day in the past week?

  0 less than 3 hours ☐
  1 more than 3 hours ☐

- Have you felt so tired/lacking in energy that you've had to push yourself to get things done in the past week?

  0 No ☐
  1 yes, on one or more occasions ☐

- Have you felt tired/lacking in energy when doing things that you enjoy doing during the past week?

  0 no, not tired during enjoyable activities ☐
  1 yes, tired during enjoyable activity ☐

- What is your explanation for feeling tired/lacking in energy?

  1 not known ☐
  2 problems with sleep ☐
  3 medication ☐
  4 physical ☐
  5 working too hard ☐
  6 stress or other psychological reason ☐
  7 other - specify .... ☐

CONCENTRATION AND FORGETFULNESS:

Recently, have you been able to concentrate on what you are doing or does your mind tend to wander?
Have you found that you have been forgetting things?

- On how many days have you noticed problems with your concentration or memory during the past week?

  0 <= 3 days ☐
  1 >= 4 days ☐

- Can you concentrate on a TV programme, read a newspaper article or talk to someone without your mind wandering?

  0 Yes ☐
  1 no, cannot concentrate on one or more ☐

- Have your forgotten anything important in the past 7 days?

  0 No ☐
  1 yes, has forgotten something important ☐

- Have you given up doing anything because you couldn't concentrate?

  0 No ☐
  1 Yes ☐

SLEEP PROBLEMS

Have you been having problems with your sleep in the past week?
Has sleeping more than usual been a problem recently?

- How many hours sleep did you lose / gain on the worst night you have had in the past week?
  I want you to include sleep lost at the beginning, middle and end of the night.

0 < 15 minutes : go to next section, SLEEP = 0 ☐
1 < 1 hour ☐
2 1-3 hours ☐
3 > 3 hours ☐

In calculating the time lost from sleep, allow 15 minutes for the subject to return to sleep if woken.

- On how many nights in the past week have you had any problems with your sleep?

0 <= 3 days ☐
1 >= 4 days ☐

- *If applicable*: On how many nights in the past week did you lose/gain more than 3 hours sleep?

0 1-3 nights ☐
1 >= 4 nights ☐

- Do you wake more than half an hour earlier than you need to and can't get back to sleep?

0 No ☐
1 yes, but I can get back to sleep quickly ☐
yes and I can't get back to sleep ☐

What are your sleep difficulties caused by?

1 noises (babies crying, busy roads etc.) ☐
2 shift work ☐
3 pain (which is not considered psychogenic) ☐
4 pain (which is considered psychogenic) ☐
5 worries or reasons not known ☐
6 to go to the toilet ☐

IRRITABILITY:

Many people become irritable or short tempered at times, though they might nost show it.
Have you been irritable or short tempered with those around you recently (for instance the person you care for)?
Do you ever get short tempered or angry over things which seem trivial when you look back at them?
What sort of things have made you irritable/ short tempered in the past week?

- On how many days have you felt irritable/short tempered during the past week?

0	<=3 days	☐
1	>=4 days	☐

- Have you felt irritable / short tempered for more than one hour on any day in the past week?

0	less than 1 hour	☐
1	more than 1 hour	☐

- Have you felt so irritable / short tempered that you have wanted to shout at someone in the past 7 days? (Even if you haven't actually shouted)

0	No	☐
1	Yes	☐

- Have you had any arguments, rows or quarrels or lost your temper with anyone in the past 7 days? Was this justified?

0	No	☐
1	yes, but subject feels it was justified	☐
2	yes	☐

WORRY ABOUT PHYSICAL HEALTH

If physically ill: Do you worry about your physical health?

If well: Many people get concerned about their physical health.
Do you worry at all about YOUR physical health?

Do you find yourself worrying that you might have a serious illness like cancer, heart disease or AIDS?

- On how many days during the past week have you found yourself worrying about your physical health?

  0 <= 3 days
  1 >= 4 days

- Have you been worrying too much in view of your actual physical health?

  0 No ☐
  1 yes, worrying too much ☐

- How unpleasant has this worrying been in the past week?

  0 not at all ☐
  1 a little unpleasant ☐
  2 unpleasant ☐

- Have you been able to take your mind off your health worries, for instance by doing something?

  0 Yes ☐
  1 no, couldn't distract themselves one or more times ☐

DEPRESSION

Almost everyone becomes low in mood or depressed at times.
Have you had spells of feeling low in mood, sad or miserable recently?
Have you been able to enjoy things as much as you usually do?
What sort of things have you been getting low about?

- On how many days have you felt low spirited, miserable, depressed or unable to enjoy things in the past 7 days?

0	on 2 or 3 days	☐
1	on 4 or more days	☐

- In the past week have you been able to enjoy things as much as usual?

0	yes, able to enjoy things	☐
1	no, less enjoyment than usual	☐
2	no enjoyment in anything	☐

- Have you felt low spirited for more than 3 hours on any day in the past week?

0	less than 3 hours	☐
1	3 hours or more	☐

- In the past week, when something nice happened or when you were in company, did this lift your mood?

0	Yes	☐
1	no, on one or more occasion	☐

- Which of these most affects your mood?

1	members of your family	☐
2	relationships with friends or work colleagues	☐
3	Housing	☐
4	Money	☐
5	Your own physical health	☐
6	Your own mental health	☐
7	Work or absence of work	☐
8	Legal difficulties	☐
9	Political issues	☐

DEPRESSIVE IDEAS:

- Some people find their mood affects their interest in sex. Has there been any change in your interest in sex recently?

0	Not applicable	☐
0	No change	☐
1	Increase	☐
1	Decrease	☐

- In the past 7 days have you felt guilty or have you blamed yourself when things have gone wrong even if it hasn't been your fault?

0	never or only if it is your fault	☐
1	sometimes	☐
2	often	☐

- During the past week have you been feeling you are not as good as other people? For instance that you are inferior or second rate?

0	as good as anyone else	☐
1	not as good as others	☐
2	often	☐

- Have you felt hopeless at all during the past 7 days for instance about your future?

0	No	☐
1	Yes	☐

- *If any score on this section:* In the past week, have you been feeling that life is not worth living?

0	No ------------------------→ GO ON TO NEXT SECTION	
1	Sometimes	☐
1	always	☐

- *If scored 1 in the last question:* Have you thought of killing yourself in the past week?

0	Has thought about it in the past	☐
1	No	☐
2	Has thought about it in the past week	☐

WORRY

Do you find yourself worrying more than you need to?
Have you had any worries at all recently?
What sort of things were you worried about?

- On how many of the past 7 days have you been worrying about things?

0	<= 3 days	☐
1	>= 4 days	☐

- How unpleasant has your worrying been in the past week?

0	not at all	☐
1	a little unpleasant	☐
2	unpleasant	☐

- Have you worried for more than 3 hours on any day in the past week?

0	less than 3 hours	☐
1	3 hours or more	☐

- Have you been worrying too much in view of your circumstances?

0	No	☐
1	yes, worrying too much	☐

- What is the thing you most worry about?

1	members of the family	☐
2	relationships with friends or work colleagues	☐
3	housing	☐
4	money	☐
5	your own physical health	☐
6	your own mental health	☐
7	work or absence of work	☐
8	legal difficulties	☐
9	political issues	☐

ANXIETY:

Have you been anxious or nervous recently?
Do you find that your muscles feel tense or you can't relax?
Is you anxiety or tension only brought on by something specific?

Yes ----------------→ *score under phobias*
No ----------------→ CONTINUE

- On how many of the past 7 days have you been nervous or anxious?

0 <= 3 days ☐
1 >= 4 days ☐

- How unpleasant has your worrying been in the past week?

0 not at all ☐
1 a little unpleasant ☐
2 unpleasant ☐

- In the past week, when you've been nervous or tense have you had ANY of the following symptoms?

☐...... heart racing or pounding
☐...... feeling dizzy
☐...... butterflies in your stomach
☐...... hands sweating or shaking
☐...... difficulty getting breath
☐...... dry mouth

0 No ☐
1 Yes ☐

Have you felt nervous or anxious or tense for more than 3 hours on any day in the past week?

0 No ☐
1 yes, more than 3 hours. ☐

PHOBIAS:

Some people get nervous or uncomfortable about specific things or situations even if there is no real danger, for instance:

- Speaking or eating in front of strangers
- The sight of blood
- Crowded shops
- Spiders
- Heights
- Being far from home

Are you anxious or nervous about any specific things or situations?

- Which of these makes you most nervous or anxious?

1 travelling alone by bus or train; being far from home, enclosed spaces, being in crowds or being alone
2 eating, speaking in front of strangers, being watched or stared at, any social situation
3 the sight of blood
4 insects, spiders or animals, heights or any specific single cause
5 none of these

- How many times in the past 7 days have you felt nervous or anxious about a specific thing?

None ---------------------→ GO ON TO NEXT BULLETED QUESTION
0 <= 3 days ☐
1 >= 4 days ☐

Did you have any of the following symptoms at those times?

☐...... heart racing / pounding
☐...... feeling dizzy
☐...... butterflies in stomach
☐...... hands sweating / shaking
☐...... difficulty in getting your breath
☐...... dry mouth

0 no ☐
1 yes ☐

- In the past week, have you avoided a situation or thing because of your fear?

0 No ☐
1 Yes ☐

If yes, how many times have you avoided a situation or thing in the past 7 days?

1 <= 3 days ☐
2 >= 4 days ☐

PANIC

ONLY ASK QUESTIONS IF THE SUBJECT HAS SCORED ON ANXIETY OR PHOBIAS

Does your anxiety or tension ever get so bad that you panic?
In other words, you feel you might collapse, lose control, go crazy or even die unless you do something about it?

- How often has this happened in the past week?

0	not at all	☐
1	once	☐
2	more than once	☐

- How unpleasant have these feelings of panic been in the past week?

0	a little uncomfortable	☐
1	unpleasant	☐
2	unbearable, very unpleasant	☐

- Did this panic or the worst of these panics last for longer than 10 minutes?

0	less than 10 minutes	☐
1	more than 10 minutes	☐

- Are you relatively free of anxiety between these panics?

☐...... Yes
☐...... No

- *If phobia:* Is the panic always brought on by that situation or thing?

☐...... Yes
☐...... No

COMPULSIONS:

Do you feel that you keep on doing things over and over again even though you've already done them?
For instance, turning off taps, locking doors or windows, washing yourself etc.
What do you tend to repeat?

- What is the greatest number of times you have repeated things you have already done (and do not need doing again) in the past week?

0 1-2 times ☐
1 3 or more times ☐

- On how many days in the past week have you repeated things in this way?

0 <= 3 days ☐
1 >= 4 days ☐

- have your tried to stop yourself repeating things in the past 7 days?

0 No ☐
1 Yes ☐

- Has repeating things made you upset or annoyed with yourself in the past week?

0 not at all ☐
1 upset or annoyed ☐

OBSESSIONS

Do you ever have unpleasant thoughts or ideas that you would prefer not to think about but they still keep coming into your mind?
I mean the same thought or idea over and over again rather than worrying around a subject.
What are these thoughts? *Don't press people to answer*

- On how many days in the past 7 days have you had these distressing thoughts?

  0 <= 3 days ☐
  1 >= 4 days ☐

- Have you tried to stop yourself thinking these thoughts in the past 7 days?

  0 No ☐
  1 yes, tried to stop thoughts ☐

- Have you become upset or annoyed with yourself when you have had these thoughts in the past week?

  0 not upset at all ☐
  1 upset or annoyed ☐

- What is the longest time you have spent thinking these thoughts in the past week?

  0 < 15 minutes ☐
  1 >= 15 minutes ☐

ELATION:

Do you ever feel very cheerful, more cheerful than usual or on top of the world for no apparent reason?
Do you get periods when you are full of energy and have exciting ideas?

- On how many days have you felt like this in the past week?

0	<= 3 days	☐
1	>= 4 days	☐

- Has this feeling been pleasant or unpleasant in the past week?

0	Pleasant	☐
1	Unpleasant	☐

- Has your mind been so active that you couldn't stop your thoughts racing when you have been cheerful or full of energy?

0	can stop racing thoughts	☐
1	cannot stop thoughts racing	☐

- When you were feeling full of energy in the past week, did you think you were better than other people or had special skills?

0	felt the same as other people	☐
1	felt better than other people	☐

- Have you been needing less sleep?

  Yes – code in sleep section
  No

IDEAS OF REFERENCE:

Do you ever get the feeling that strangers are taking special notice of you when you are in public?

- Has this been upsetting or has it made you angry, worried or nervous over the past week?

  0 not at all ----------------→ GO ON TO NEXT SECTION ☐
  1 upset, anxious, angry, nervous or worried in the last week ☐

- On how many days in the past 7 days have you had this feeling?

  0 <= 3 days ☐
  1 >= 4 days ☐

- When you are in public do you sometimes feel that people are saying things about you or laughing at you?

  0 people only look at or take notice of the subject ☐
  1 feels they also say things about and/or laugh at the subject ☐

  If so, are these people really talking about you, or is it just a feeling you have?

  0 just a feeling ☐
  1 belief in ideas of reference ☐

- Do you tend to feel nervous in public? Yes ☐ No ☐
- Have you avoided public places or meetings recently? Yes ☐ No ☐

If either of the answers to the last 2 questions is yes then return to phobias section if social phobia not already elicited.

ONSET:

If any section has scored >=2: You have told me of some psychological symptoms you have had over the past week.

Give example

Which of these do you find the worst?
When did this symptom start?

Starting date ....../ ....

Number of weeks duration: ....

21) IMPAIRMENT:

In the past week, have these symptoms actually stopped you from getting on with the tasks and activities you usually do or would like to do?

If answers no: Has it made it more difficult even though you have got everything done?

0	not impaired	☐
1	more difficult but gets everything done	☐
2	it has stopped one activity	☐
3	it has stopped more than 1 activity	☐

Appendix 4: The Philadelphia Geriatric Center Morale Scale

I am now going to ask you some questions about how you feel at the moment about your life. Some questions might sound similar to ones which we will ask you later but don't worry about that:

• Do little things bother you more this year than last?	Yes	0	No	1
• Do you sometimes worry so much that you can't sleep?	Yes	0	No	1
• Are you afraid of a lot of things?	Yes	0	No	1
• Do you get angry more than you used to?	Yes	0	No	1
• Do you take things hard (take things to heart)?	Yes	0	No	1
• Do you get upset easily?	Yes	0	No	1
• Are things getting worse or better now?	Better	1	Worse	0
• Do you have as much energy as you had last year?	Yes	1	No	0
• Do you feel as you get older you are less useful?	Yes	0	No	1
• Are things better or worse than you thought they would be?	Better	1	Worse	0
• Are you as happy now as you were when you were younger?	Yes	1	No	0
• Do you sometimes feel life is not worth living?	Yes	0	No	1
• Do you have a lot to be sad about?	Yes	0	No	1
• Is life hard work much of the time?	Yes	0	No	1
• How satisfied are you with your life today?	Satisfied	1	Not satisfied	0
• How much do you feel lonely?	A lot	0	Not much	1
• Do you see enough of your friends and relatives?	Yes	1	No	0

Appendix 5: The physical health questionnaire

ABOUT YOUR HEALTH :

- Over the last six weeks, how would you describe your health?

Extremely good	Quite good	Average	Not good	Very bad

- Have you had any problems with your physical health recently?

Yes ☐ No ☐

Have you been to hospital recently?

Yes ☐ No ☐

If yes, what was that for? ……………………………………………………

Are you taking any medicines yourself?

Yes ☐ No ☐

If yes, how many different drugs? ……….. drugs

Do you have any longstanding illness, disability or infirmity (anything that has troubled you over a long period of time)? Yes ☐ No ☐

If yes, does this illness restrict your activities in any way?

Yes ☐ No ☐

Current health problems ______________________

- Do you have or have you ever had any of these conditions, I'll read them out:

☐……. Heart, lung or chest disease?
☐……. Kidney, stomach or liver trouble?
☐……. Skin disease, arthritis or problems with movement or joints?
☐……. Diabetes, epilepsy, TB or jaundice?

Appendix 6: The social support questionnaire

For each question firstly list all the people you know (excluding yourself) who you can count on for help or support. Give the person's initials and their relationship to you e.g brother, friend etc.. (max. 9 people)

Then tell me how satisfied you are with the overall support you have on a scale of 1-6 where six is the most satisfied you could be and 1 is the least satisfied.

If you have no support for a question then still rate the level of satisfaction you feel.

Whom can you really count on to be dependable when you need help?
1. 2. 3. 4. 5. 6. 7. 8. 9.

Very Satisfied Very dissatisfied
6 5 4 3 2 1

Whom can you really count on to help you feel more relaxed when you are under pressure or tense?
1. 2. 3. 4. 5. 6. 7. 8. 9.

Very Satisfied Very dissatisfied
6 5 4 3 2 1

Who accepts you totally, including both your best and worst points?
1. 2. 3. 4. 5. 6. 7. 8. 9.

Very Satisfied Very dissatisfied
6 5 4 3 2 1

Whom can you really count on to care about you, regardless of what is happening to you?
1. 2. 3. 4. 5. 6. 7. 8. 9.

Very Satisfied Very dissatisfied
6 5 4 3 2 1

Whom can you really count on to help you feel better when you are feeling generally down in the dumps?
1. 2. 3. 4. 5. 6. 7. 8. 9.

Very Satisfied Very dissatisfied
6 5 4 3 2 1

Whom can you count on to console you when you are very upset?
1. 2. 3. 4. 5. 6. 7. 8. 9.

Very Satisfied Very dissatisfied
6 5 4 3 2 1

Appendix 7: Activity restriction questionnaire

Part 1: Distributed with the enrolment questionnaire

<u>ABOUT YOUR LIFESTYLE BEFORE THE STROKE:</u>
We would like to know what you have been used to doing at home so that we can see if those activities change after you start caring for a stroke patient. Before the stroke, what activities did you pass your time doing?

Please look at each item in the list below and tick those activities you did more than once a week. Then mark those that you would miss the most in order 1 to 6 - 1 being the activity you would miss the most etc.

Activity	**Tick activities which you did once a week or more before the stroke.**	**Mark the 6 activities out of the ones you have ticked that you would miss the most.** **1=would miss most.** **2=next most missed etc.**
Paid work		
Shopping for food		
Shopping (pleasure)		
Housework		
Gardening (indoor)		
Gardening (outdoor)		
DIY		
Walking		
Riding a bicycle		
Keep fit		
Dancing		
Other physical exercise What? …………………		
Listening to the radio		
Watching television		
Reading books		
Reading magazines or the newspaper		
Doing crosswords or puzzles		
Going to adult education classes		
Going to a club or society		
Chatting on the telephone socially		
Visiting friends and relatives		
Having visitors to your home		
Visiting restaurants or pubs		
Doing things for other people		
Attending church		
Voluntary work		
Playing games e.g. Cards		

Appendix 7: Activity restriction questionnaire

Activity	**Tick activities which you did once a week or more before the stroke.**	**Mark the 6 activities out of the ones you have ticked that you would miss the most.** **1=would miss most.** **2=next most missed etc.**
Going to the theatre or cinema		
Sewing/embroidery		
Other activities What?		

Thank you for completing this questionnaire. Our researcher will collect it from you when she comes to see you for the first interview.

Part 2: Completed during the second and third interviews by the interviewer.

Your Activities since the stroke?

Last time we met you gave me a list of activities that you did frequently before the stroke and that were important for you. I am now going to ask you about those activities again. I will remind you what those activities were and then ask you some questions about each.

The activities you chose as the 6 you enjoyed most of the activities you did frequently were:
1)
2)
3)
4)
5)
6)

Activities→	1	2	3	4	5	6
During the last 4 weeks, how much time have you spent on activity X? 0=none; 1=very occasionally; 2=almost every week; 3=almost every day	0 1 2 3	0 1 2 3	0 1 2 3	0 1 2 3	0 1 2 3	0 1 2 3
Since the stroke, have you spent more (M), the same(S) or less (L) time on this activity?	M S L	M S L	M S L	M S L	M S L	M S L
If there was a change in time, why was that? 0=no change; 1=due to stroke; 2=due to changes in your own health; 3=other reason	0 1 2 3	0 1 2 3	0 1 2 3	0 1 2 3	0 1 2 3	0 1 2 3

Appendix 8: Letters, information sheets and consent forms

Page(s)

Letter of invitation to take part in the study:

Information sheet:

Consent form:

University
of Southampton

Department of Primary Medical Care
University of Southampton
Aldermoor Health Centre
Aldermoor Close
Southampton
SO16 5ST

Date

Dear Carer's name,

We **need** your help please.

When they get home most people who have had a stroke have someone who keeps an eye on them or "carer". Often that person is their husband or wife but occasionally a daughter or son, friend or neighbour. The carer may help around the home, help look after the stroke patient or even just provide moral support. What the carer does depends on the needs of the stroke patient and circumstances of the carer.

I am a researcher in the Department of Primary Medical Care at Southampton University. I am doing a project in association with the stroke unit in Southampton /Christchurch investigating how carers of stroke patients are affected by their experience and what help and support they get from the community services.

I would like to invite you to take part. I enclose an information sheet about the project and an initial questionnaire for you to fill in. If filling in the questionnaire is a problem I am happy to come and do it with you.

If you would like to take part please ring and leave me a message on Telephone number (answerphone after 9 rings). Otherwise I will contact you by telephone in the next few weeks and ask you if you would like to take part.

Thank you for your help
Yours sincerely

Dr. Chantal Simon

INFORMAL CARERS OF STROKE PATIENTS STUDY

Dear ....

Thank you very much for taking part in this study.

I am now looking for a group of people who do NOT acre for anyone with a disability so that I can compare their health with the help of our group of carers. This will tell us if your health is affected by being a carer.

If you have a friend or relative who lives nearby in the Southampton or Bournemouth area and is of similar age (give or take ten years) to you but does NOT care for anyone with a disability, I would be grateful if you would pass this letter and the attached FREEPOST envelope on to them.

Yours sincerely

Dr. Chantal Simon

PLEASE TEAR OFF...

My name is Chantal Simon. I am doing some research investigating how informal carers of stroke patients are affected by their role. I hope to be able to improve the support they get as a result of this project.

Please can you help me? I need a group of people who do NOT care for anyone with a disability for comparison purposes. This will allow me to find out how much the carers' health is affected by their caring duties compared with people of similar age who are not carers.

Taking part involves two interviews spaced about a year apart and each lasting three quarters of an hour to an hour. These can be done at your convenience in your own home. The interviews ask mainly about your own health. They are completely confidential and no information will be passed on to anyone else.

If you would be prepared to take part, please fill in your name and address and a contact telephone number on the attached sheet and return it to me. I will then send you some more information and arrange to come and see you.

Thank you for your help

Dr. Chantal Simon

What is your name? ………………………………………………………

Are you? Male ☐ Female ☐

Address: ………………………………………………………

………………………………………………………

………………………………………………………

………………………………………………………

Postcode: ………………………………..

Telephone number: ………………………………..

Daytime telephone number (if different): ……………………………………..

If you are willing to take part please return this form in the FREEPOST envelope provided or post to:

Dr. Chantal Simon
Aldermoor Health Centre
Southampton
FREEPOST
SO16 5WB

NO STAMP IS NEEDED

If you would like more information please contact me on ……………………………..

INFORMAL CARERS OF STROKE PATIENTS STUDY

CARERS INFORMATION SHEET

Introduction:

Please can you help us? We know many carers of disabled people in the community are placed under a lot of stress. The primary care team (the GP and practice team, the community nursing services and the social services) is often the first port of call if a carer needs help. It is important that carers receive the help they need, when they need it, to make sure that care in the community is a success.

We want to study the health of carers of stroke patients in the community and assess their satisfaction with services they are receiving from their primary care teams.

As someone who intends to look after a friend or relative who has just had a stroke, we would like to invite you to take part in our project and tell us your views.

What will I have to do if I take part?

The study will last 1 year and will involve 100 carers throughout the South of England. If you agree to take part, you will be asked a few initial questions either at the hospital or at home, then interviewed by one of our researchers at 6-8 weeks after the person you will care for has gone home, and again one year after the stroke. The follow up interviews will take place either at your home, or your GP's surgery.

The initial questions will be about your lifestyle before the stroke happened, and your health at the time of the interview. The interviews at home will ask again about your health and lifestyle to see how they have changed. They will also look at the limitations the person you care for has, how you feel about your role as their carer and whether the primary care team is meeting your needs. You will be asked a series of questions on each occasion and your answers will be noted down for our records.

How much of my time would I need to give up to take part in the study?

About an hour is needed for each interview. The interviews will be conducted by a researcher by appointment and at your convenience.

What are the benefits of taking part?

The research will not help you directly, but it should help other people in the future. Information received by us from you will help us discover what the primary care team should do for carers and make them team aware of the needs carers have at different stages after they start caring. The primary care team can then use that information to guide their practice.

Do I have to take part?

No. You can make a free choice whether you wish to take part. Before you agree, you need to feel sure that the project is worthwhile. If you would prefer not to take part you do not have to give a reason, although giving a reason might help the research. If you refuse to take part, your doctor will not be upset and the way you are treated will not be altered. If you decide to take part but later change your mind, you can withdraw from the project at any time. Please tell us, but again you do not have to say why. You will not be put under any pressure to continue.

Do I have to decide at once?

If you are not sure what to decide, take time to think. You may want to talk to other people before you decide. The only time limiting factor is that, to take part in the study, we need to know you want to take part before the stroke patient you will care for goes home.

Will any answers I give be confidential?

Yes. The information you give us will be totally confidential. None of your answers will be released to any of the people caring for either yourself or the person who has had a stroke, not even your GP or other Professionals involved in your care.

If, during the course of the interview, we discover that you, or the person you care for, are at serious risk of harm, we will discuss the matter with you and inform your GP with your consent. Even if this happens, your answers to our questionnaire will stay confidential.

Although we need to keep your personal details to be able to contact you for follow up visits, the rest of the information you give us will be identified by a code number which only we will have access to. There is no chance that any information you give us will affect your care or the care of the person who has had a stroke.

Who should I contact if I need more information?

Contact me (Dr. Simon) via the Department of Primary Care of the University of Southampton. If I am not here, leave a message so that I can call you back on my return.

INFORMAL CARERS OF STROKE PATIENTS STUDY

COMPARISON GROUP INFORMATION SHEET

Introduction:

Please can you help us? We know many carers of disabled people in the community are placed under a lot of stress. The primary care team (the GP and practice team, the community nursing services and the social services) is often the first port of call if a carer needs help. It is important that carers receive the help they need, when they need it, to make sure that care in the community is a success.

We are studying the health of carers of stroke patients in the community and assess their satisfaction with services they are receiving from their primary care teams.

We need a group of people who are NOT carers to act as a comparison group. We would like to invite you to take part in our project in this comparison group.

What will I have to do if I take part?

The study will last 1 year and there will be about 50 carers in the comparison group spread throughout the South of England. If you agree to take part, you will be asked to complete a brief questionnaire, and then interviewed by one of our researchers. There will be a follow up interview about a year afterwards. All interviews will be done at your convenience will take place either at your home or any other mutually convenient place.

You will be asked a series of questions on each occasion and your answers will be noted down for our records. The interviewer will ask you mainly about your own health and lifestyle.

How much of my time would I need to give up to take part in the study?

About an hour is needed for each interview. The interviews will be conducted by a researcher by appointment and at your convenience.

What are the benefits of taking part?

The research will probably not help you directly, but it should help other people in the future. Information received by us from you will help us discover the effects of looking after someone who has had a stroke. It will enable us to make the primary care team aware of the problems carers have. They can then use that information to guide their practice.

Do I have to take part?

No. You can make a free choice whether you wish to take part. Before you agree, you need to feel sure that the project is worthwhile. If you would prefer not to take part you do not have to give a reason, although giving a reason might help the research. If you refuse to take part, your doctor will not be upset and the way you are treated will not be altered. If you decide to take part but later change your mind, you can withdraw from the project at any time. Please tell us, but again you do not have to say why. You will not be put under any pressure to continue.

Do I have to decide at once?

If you are not sure what to decide, take time to think. You may want to talk to other people before you decide. The only time limiting factor is that, to take part in the study, we need to know you want to take part before the stroke patient you will care for goes home.

Will any answers I give be confidential?

Yes. The information you give us will be totally confidential. None of your answers will be released to anyone else.

If, during the course of the interview, we discover that you are at serious risk of harm, we will discuss the matter with you and inform your GP with your consent. Even if this happens, your answers to our questionnaire will stay confidential.

Although we need to keep your personal details to be able to contact you for follow up visits, the rest of the information you give us will be identified by a code number which only we will have access to. There is no chance that any information you give us will affect your care or the care of the person who has had a stroke.

Who should I contact if I need more information?

Contact me (Dr. Simon) via the Department of Primary Care of the University of Southampton. If I am not here, leave a message so that I can call you back on my return.

INFORMAL CARERS OF STROKE PATIENTS STUDY

Carer's Consent Form

Please could you complete the following questions:	*Please cross out as necessary*
Have you read the Carer Information Sheet?	Yes / No
Have you had an opportunity to ask questions and discuss this study?	Yes / No
Have you received satisfactory answers to all your questions?	Yes / No
Have you received enough information about the study?	Yes / No

To whom have you spoken?..

Do you understand that you are free to withdraw from the study:

- At any time? Yes
  /No
- Without having to give a reason for withdrawing? Yes
  /No
- And without affecting your future medical care? Yes /No

Do you consent to a researcher having access to your GP records to gain information on your past medical history and the help your GP thinks you are getting?	Yes / No
Do you agree to take part in this study?	Yes / No

Signed... Date.......................................

(Name in block letters) ....

Signed (Researchers):.. Date ....

Project co-ordinator: Dr. Chantal Simon

Project Supervisor: Professor Tony Kendrick

INFORMAL CARERS OF STROKE PATIENTS STUDY

Control's Consent Form

Please could you complete the following questions:	*Please cross out as necessary*
Have you read the Information Sheet?	Yes / No
Have you had an opportunity to ask questions and discuss this study?	Yes / No
Have you received satisfactory answers to all your questions?	Yes / No
Have you received enough information about the study?	Yes / No

To whom have you spoken?..

Do you understand that you are free to withdraw from the study:

- At any time? Yes
  /No
- Without having to give a reason for withdrawing? Yes
  /No
- 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) ....

Signed (Researchers):.. Date ....

Project co-ordinator: Dr. Chantal Simon

Project Supervisor: Professor Tony Kendrick

Reference List

A:

Abdi H 2007, "The Bonferroni and Šidák corrections for multiple comparisons". In: *Encyclopedia of Measurement and Statistics.* Ed: Neil Salkind. Thousand Oaks (CA): Sage

Abramowitz S, Cole AA, & Berry E 1987, "Analysing patient satisfaction: a multianalytic approach", *Quality Review Bulletin,* vol. 13, pp. 122-130.

Altman DG, Schulz KF, Moher D, Egger M, Davidoff F, Elbourne D, Gotzsche, Lang T, & CONSORT Group (Consolidated standards of reporting trials) 2001, "The revised CONSORT statement for reporting randomised trials: explanation and elaboration.", *Ann Intern Med,* vol. 134, no. 8, pp. 663-694.

Anderson CS, Linto J, & Stewart-Wynne EG 1995, "A population-based assessment of the impact and burden of caregiving for long-term stroke survivors", *Stroke,* vol. 26, no. 5, pp. 843-849.

Anderson R 1988, "The contribution of informal care to the management of stroke", *Int.Disabil.Studies,* vol. 10, no. 107, p. 111.

Aspinal F, Addington-Hall JM, Hughes R, & Higginson IJ 2003, Using satisfaction to measure the quality of palliative care: a review of the literature. *J.Adv.Nurs.* vol. 42, no. 4, pp. 324-9.

B:

Bakas T & Burgener SC 2002, "Predictors of emotional distress, general health, and caregiving outcomes in family caregivers of stroke survivors", *Top Stroke Rehab,* vol. 9, no. 1, pp. 34-45.

Baker R 1991, "The reliability and criterion validity of patients' satisfaction with their general practice", *Family Practice,* vol. 8, pp. 171-177.

Balcombe NR, Ferry PG, & Saweirs WM 2001, "Nutritional status and well being. Is there a relationship between body mass index and the well-being of older people? ", *Current Medical Research and Opinion,* vol. 17, no. 1, pp. 1-7.

Bamford J, Dennis M, Sandercock P, Burn J, & Warlow C 1990, "The frequency, causes and timing of death within 30 days of a first stroke: the Oxfordshire Community Stroke Project.", *J.Neurol.Neurosurg.Psychiatry*, vol. 53, pp. 824-829.

Bamford J, Sandercock P, Dennis M, Warlow C, Jones L, McPherson K, Vessey M, Fowler G, Molyneux A, Hughes T 1988, "A prospective study of acute cerebrovascular disease in the community: the Oxfordshire Community Stroke Project 1981-86. 1. Methodology, demography and incident cases of first-ever stroke.", *J.Neurol.Neurosurg.Psychiatry*, vol. 51, no. 11, pp. 1373-1380.

Bamford J, Sandercock P, Warlow C, & Slattery J 1989, "Interobserver agreement for the assessment of handicap in stroke patients.", *Stroke*, vol. 20, p. 828.

Banks P 1998, *The Carers Compass. Directions for improving support to carers.* King's Fund, London.

Bauld L, Chesterman J, Davies B, Judge K, & Mangalore R 2000, *Caring for Older People: An assessment of community care in the 1990s* Ashgate, London.

Baumgarten M, Battista RN, Infante-Rivard C, Hanley JA, Becker R, & Gauthier S 1992, "The phychological and physical health of family members caring for an elderly person with dementia", *J Clin Epidemiol*, vol. 45, no. 1, pp. 61-70.

Beauchamp T 2003, "Methods and principles in biomedical ethics", *J Med Ethics*, vol. 29, pp. 269-274.

Beauchamp T & Childress J 2001, *Principles of Biomedical Ethics*, 5th edition edn, Oxford University Press, Oxford.

Beech R, Rudd AG, Tilling K, & Wolfe CD 1999, "Economic consequences of early inpatient discharge to community-based rehabilitation for stroke in an inner-London teaching hospital", *Stroke*, vol. 30, no. 4, pp. 729-735.

Beekman AT, Deeg DJ, van Tilberg T, Smit JH, Hooijer C, & Van Tilberg W 1995, "Major and minor depression in later life: a study of prevalence and risk factors.", *J Affect Disord*, vol. 36, no. 1-2, pp. 65-75.

Ben Sira Z 1976, "The function of the professional's affective behaviour in client satisfaction: a revised approach to social interaction theory.", *J.Health and Soc.Behaviour*, vol. 17, pp. 3-11.

Reference List

Bethoux F, Calmels P, Gautheron V, & Minaire P 1996, "Quality of life of the spouses of stroke patients: a preliminary study", *Int J Rehabil Res,* vol. 19, no. 4, pp. 291-299.

Blake H & Lincoln NB 2000, "Factors associated with strain in co-resident spouses of patients following stroke.", *Clinical Rehabilitation,* vol. 14, no. 3, pp. 307-314.

Blake H, Lincoln NB, & Clarke DD 2003, "Caregiver strain in spouses of stroke patients", *Clinical Rehabilitation,* vol. 17, no. 3, pp. 312-317.

Bland JM & Altman DG 1994a, "Statistics notes: Regression towards the mean", *British Medical Journal,* vol. 308, p. 1499

Bland JM & Altman DG 1994b, "One and two sided tests of significance", *British Medical Journal,* vol. 309, p. 248.

Blessed G, Tomkinson BE, & Roth M 1968, "The association between quantitative measures of dementia and senile change in the central grey matter of elderly subjects", *Br J Psychiatry,* vol. 114, pp. 797-811.

Bond S & Thomas LH 1992, "Measuring patients' satisfaction with nursing care", *Journal of Advanced Nursing,* vol. 17, pp. 52-63.

Bonita R 1992, "Epidemiology of stroke", *Lancet,* vol. 339, pp. 342-344.

Bookwala J & Schulz R 2000, "A Comparison of Primary Stressors, Secondary Stressors, and Depressive Symptoms Between Elderly Caregiving Husbands and Wives: The Caregiver Health Effects Study", *Psychol Aging,* vol. 15, no. 4, pp. 607-616.

Boseley S 2003, "Fifth of GPs want to quit", *The Guardian* 3.1.2003.

Bowling A 1997, *Measuring Health: A review of quality of life measurement scales,* 2nd edition edn, Open University Press, Buckingham.

Bowling A 2001, *Measuring Disease: a review of disease specific quality of life measurement scales,* 2nd edition edn, Open University Press, Buckingham.

Brocklehurst JC, Morris P, Andrews K, Richards B, & Laycock P 1981, "Social Effects of Stroke.", *Soc Sci Med,* vol. 15A, pp. 35-39.

Bruce DG & Paterson A 2000, "Barriers to community support for the dementia carer: a qualitative study", *Int.J.Geriatr.Psychiatry,* vol. 15, pp. 451-457.

Brugha TS, Bebbington PE, Jenkins R, Meltzer H, Taub NA, Janas M, & Vernon J 1999, "Cross validation of a general population survey diagnostic interview: A comparison of CIS-R with SCAN ICD-10 diagnostic categories.", *Psychological Medicine*, vol. 29, no. 5, pp. 1029-1042.

Bugge C, Alexander H, & Hagen S 1999, "Stroke patients' informal caregivers. Patient, caregiver, and service factors that affect caregiver strain.", *Stroke*, vol. 30, no. 8, pp. 1517-1523.

Burnand B, Kernan WN, & Feinstein AR 1990, "Indexes and boundaries for "quantitative significance" in statistical decisions", *J Clin Epidemiol*, vol. 43, no. 12, pp. 1273-1284.

Butler P 2001, "Surgeries shut as GPs protest over workload", *The Guardian* no. 1.5.2001.

C:

Campbell A, Converse P, & Rogers WL 1976, *The quality of American life: perceptions, evaluations and satisfactions* Russell Sage, New York.

Campbell MJ, Julious SA, & Altman DG 1995, "Estimating sample sizes for binary, ordered categorical, and continuous outcomes in two group comparisons", *British Medical Journal*, vol. 311, pp. 1145-1148.

Carers UK 2004, *Carers Online* Carers UK, Available at Website: http://www.carersonline.org.uk Accessed 4.2.2004.

Carers' National Association 1995, *Working with primary care for carers* Carers' National Association.

Carers' National Association 1998, *The New Carers' Code.*

Carlsson GE, Moller A, & Blomstrand C 2003, "Consequences of mild stroke in persons <75 years - A 1-year follow-up", *Cerebrovascular Diseases*, vol. 16, no. 4, pp. 383-388.

Carnwath TCM & Johnson DAW 1987, "Psychiatric Morbidity among spouses of patients with stroke.", *British Medical Journal*, vol. 294, pp. 409-411.

Carr-Hill RA 1992, "The measurement of patient satisfaction", *J.Pub.Health Med.*, vol. 14, pp. 236-249.

Cartwright A 1964, *Human relations and hospital care* Routledge and Keegan Paul, London.

Cattanach L & Tebes JK 1991, "The nature of elder impairment and its impact on family caregivers' health and psychosocial functioning", *Gerontologist*, vol. 31, pp. 246-255.

Celani MG, Cantisani TA, Righetti E, Spizzichino L, & Ricci S 2002, "Different measures for assessing stroke outcome: an analysis from the International Stroke Trial in Italy", *Stroke*, vol. 33, no. 1, pp. 218-223.

Chiu L, Shyu WC, & Chen TR 1997, "A cost-effectiveness analysis of home care and community-based nursing homes for stroke patients and their families", *Journal of Advanced Nursing*, vol. 26, no. 5, pp. 872-878.

Churchill R 1999, *Manual of the Revised Clinical Interview Schedule* Institue of Psychiatry, London.

Cohen J 1960, "A coefficient of agreement for nominal scales", *Educational and Psychological Measurement*, vol. 20, no. 1, pp. 37-46.

Cohen S & Wills TA 1987, "Stress, social support and the buffering hypothesis", *Psychological Bulletin*, vol. 98, pp. 310-357.

Cooper JE, Copeland JR, Brown GW, Harris T, & Gourlay AJ 1977, "Further studies on interviewer training and inter-rater reliability of the Present State Examination (PSE)", *Psychol Med*, vol. 7, no. 3, pp. 517-523.

Copeland JR, Chen R, Dewey ME, McCracken CF, Gilmore C, Larkin B, & Wilson KC 1999, "Community-based case-control study of depression in older people. Cases and sub-cases from the MRC-ALPHA Study", *Br J Psychiatry*, vol. 175, pp. 340-347.

Coughlan AK & Humphrey M 1982, "Presenile stroke: long term outcome for the patients and their families", *Rheumatol.and Rehab.*, vol. 21, pp. 115-122.

Coulter A, Fitzpatrick R, Davis L-J 2002, *Patient and public perspectives on health care performance* Commission for Health Improvement

Curtice L, Petch A, Hallam A, & Knapp M 2001, *Over the threshold?An exploration of intensive domiciliary support for older people* The Scottish Executive Central Research Unit.

Curtis L, Netten A 2005, *Unit costs of health and social care* Personal Social Services Research Unit (PSSRU), University of Kent

D:

Daniels LR 2003, "Assessment of social support among veterans with military-related post-traumatic stress disorder: A study of the social support questionnaire", *Dissertation Abstracts International*, vol. 63, no. 11-A, p. 4092.

Dennis M, O'Rourke S, Lewis S, Sharpe M, & Warlow C 1998, "A quantative study of the emotional outcome of people caring for stroke survivors", *Stroke*, vol. 29, no. 9, pp. 1867-1872.

Dennis M, O'Rourke S, Slattery J, Staniforth T, & Warlow C 1997, "Evaluation of a stroke family care worker: results of a randomised controlled trial.", *British Medical Journal*, vol. 314, no. 7087, pp. 1071-1076.

Department of Health 1990, *NHS and Community Care Act.*

Department of Health 1996, *Carers (Recognition and Services) Act 1995: Policy Guidance* HMSO, London.

Department of Health 1998, *Modernising Health and Social Services: National Priorities Guidance 1999/2000 - 2001/2002* HMSO.

Department of Health 1999, *National service framework for mental health* Department of Health, http://www.doh.gov.uk/nsf/mentalhealth.htm.

Department of Health 2001, *National service framework for older people* Department of Health, http://www.doh.gov.uk/nsf/olderpeoplemaindoc.htm.

Department of Health 2003a, *Confidentiality: NHS Code of practice* Department of Health, london. Available at website: http://www.dh.gov.uk/assetRoot/04/06/92/56/04069256.pdf, Accessed 13/2/2004.

Department of Health 2003b, *Research Governance Framework*, 2nd edition - 2nd draft edn, http:www.doh.gov.uk.

Department of Health 2003c, *The GMS Contract* Available at website: http://www.doh.gov.uk/gmscontract Accessed 3.2.2004.

Department of the Environment, Transport and the Regions 2000, *Indices of Deprivation 2000.* Obtained by e-mail from: indices_deprivation2000@detr.gov.uk

Donabedian A 1980, *The definitiion of quality and approaches to its assessment* Health Administration Press, Ann Arbor, Michigan.

Donnelly M, Power M, Russell M, & Fullerton K 2004, "Randomized controlled trial of an early discharge rehabilitation service: the Belfast Community Stroke Trial", *Stroke*, vol. 35, no. 1, pp. 127-133.

Doran T, Drever F, & Whitehead M 2003, "Health of young and elderly informal carers: analysis of UK census data", *British Medical Journal*, vol. 327, p. 1388.

Draper BM 1992, "A comparison of caregivers for elderly stroke and dementia victims.", *JAGS*, vol. 40, pp. 896-901.

Dura JR, Haywood-Niler E, & Kiecolt-Glaser JK 1990, "Spousal caregivers of persons with Alzheimer's and Parkinson's disease dementia: a preliminary comparison", *Gerontologist*, vol. 30, no. 3, pp. 332-336.

E:

Ebrahim S & Nouri F 1987, "Caring for stroke patients at home.", *Int.Rehabil.Med.*, vol. 8, pp. 171-173.

Edwards M, Feightner J, & Goldsmith CH 1995, "Inter-rater reliability of assessments administered by individuals with and without a background in health care", *Occupational Therapy Journal of Research*, vol. 15, no. 2, pp. 103-110.

Elmstahl S, Malmberg B, & Annerstedt L 1996, "Caregiver's burden of patients 3 years after stroke assessed by a novel caregiver burden scale", *Arch Phys Med Rehabil*, vol. 77, no. 2, pp. 177-182.

Enterlante TM, Kern JM 1995, "Wives' reported role changes following a husband's stroke: a pilot study", *Rehabilitation Nurs.* vol 20, no. 3, pp. 155-160.

Evans RL, Noonan WC, Bishop DS, & Hendricks RD 1989, "Caregiver assessment of personal adjustment after stroke in a Veterans Administration Medical Center outpatient cohort", *Stroke*, vol. 20, no. 4, pp. 483-487.

F:

Farmer MM & Ferraro KF 1997, "Distress and perceived health: mechanisms of health decline", *J Health Soc Behav*, vol. 39, pp. 298-311.

Farrell C, Robinson J, & Fletcher P 1999, *A new era for community care? What people want from health, housing and social care services.* King's Fund, London.

Ferraro KF, Farmer MM, & Wybraniec JA 1997, "Health trajectories: long-term dynamics among black and white adults", *J Health Soc Behav*, vol. 38, no. 1, pp. 38-54.

Fitzgerald G 1989, "Effects of caregiving on caregiver spouses of stroke victims.", *Axone*, vol. 10, no. 4, pp. 85-88.

Fitzpatrick R 1984, "Satisfaction with health care," in *The Experience of Illness*, Fitzpatrick R, ed., pp. 154-175.

Fitzpatrick R 1990, "Measurement of patient satisfaction," in *Measuring the outcomes of medical care*, Hopkins D & Costain D, eds., Royal College of Physicians and Kings Fund Centre, London, pp. 19-26.

Forster A, Smith J, Young J, Knapp P, House A, & Wright J 2001, "Information provision for stroke patients and their caregivers.", *Cochrane Database Systematic Review*, vol. 3.

Forster A & Young J 1996, "Specialist nurse support for patients with stroke in the community: a randomised controlled trial", *British Medical Journal*, vol. 312, no. 7047, pp. 1642-1646.

Fox JG & Storms DM 1981, "A different approach to sociodemographic predictors of satisfaction with health care", *Soc Sci Med*, vol. 15A, pp. 557-564.

Fredman L & Daly MP 1997, "Weight change: An indicator of caregiver stress", *J.Aging and Health*, vol. 9, no. 1, pp. 43-69.

Frieman JA, Chalmers TC, Smith H Jr, & Kuebler RR 1978, "The importance of beta, the type II error and sample size in the design and interpretation of the randomised control trial: survey of 71 "negative" trials.", *NEJM*, vol. 299, pp. 690-694.

Fritz CL, Farver TB, Kass PH, & Hart LA 1997, "Correlation among three psychological scales used in research of caregivers for patients with Alzheimer's disease.", *Psychol Rep*, vol. 80, no. 1, pp. 67-80.

G:

Gallant MP & Connell CM 1998, "The stress process among dementia spouse caregivers: Are caregivers at risk for negative health behavior change?", *Research on Aging*, vol. 20, no. 3, pp. 267-297.

Ganster CD & Victor B 1988, "The impact of social support on mental and physical health", *Br J Med Psychol*, vol. 61, pp. 17-36.

Garraway WM, Walton MS, Akhtar AJ, & Prescott RJ 1981, "The use of health and social services in the management of stroke in the community: resaults from a controlled trial", *Age Ageing*, vol. 10, pp. 95-104.

Geddes JML & Chamberlain MA 1994, "Improving social outcome after stroke: an evaluation of a volunteer stroke scheme", *Clinical Rehabilitation*, vol. 8, no. 116, p. 126.

Geliebter A & Aversa A 2003, "Emotional eating in overweight, normal weight, and underweight individuals", *Eating behaviour*, vol. 3, no. 4, pp.341-347.

George L 1981, "Subjective well-being: Conceptual and methodological issues", In: C. Eisdorfer (Ed.), *Annual review of gerontology and geriatrics* (*Vol. 2*, pp. 345–382).

George LK & Gwyther LP 1986, "Caregiver well-being: A multidimensional examination of family caregivers of demented adults", *Gerontologist*, vol. 26, no. 253, p. 259.

Gilhooly MLM 1984, "The impact of caregiving on caregivers: factors associated with the psychological wellbeing of people supporting a dementing relative in the community", *Br J Med Psychol*, vol. 57, pp. 35-44.

Gillon R 2003, "Ethics needs principles-four can encompass the rest-and respect for autonomy should be "first among equals"", *J Med Ethics*, vol. 29, pp. 307-312.

Goldberg DP, Cooper B, Eastwood MR, Kedward HB, & Shepherd M 1970, "A standardized psychiatric interview for use in community surveys", *Br J Prev Soc Med*, vol. 7, no. 3, pp. 517-523.

Goodman CC & Pynoos J 1990, "A model telephone information and support program for caregivers of Alzheimer's patients.", *Gerontologist*, vol. 30, no. 3, pp. 399-404.

Grant JS, Bartolucci AA, Elliot TR, & Giger JN 2000, "Sociodemographic, physical, and psychosocial characteristics of depressed and non-depressed family caregivers of stroke survivors", *Brain Inj*, vol. 14, no. 12, pp. 1089-1100.

Grant JS, Elliot TR, Weaver M, Bartolucci AA, & Giger JN 2002, "Telephone intervention with family caregivers of stroke survivors after rehabilitation.", *Stroke*, vol. 33, no. 8, pp. 2060-2065.

Greveson G 1991, "Improving long-term outcome after stroke - the views of patients and carers.", *Health Trends*, vol. 23, pp. 161-162.

Greveson G, Gray CS, French JM, & James OFW 1991, "Long-term outcome for patients and carers following hospital admission for stroke", *Age Ageing*, vol. 20, pp. 337-344.

Griffiths R 1985, *Community Care*.

Guadagnoli E & Velicer WF 1988, "Relation of sample size to the stability of component patterns.", *Pschological Bulletin*, vol. 103, no. 2, pp. 265-275.

H:

Hagan HC, Moriarty DG, Zack MM, Scherr PA, & Brackbill R 1994, "Measuring health-related quality of life for public health surveillance", *Public Health Rep*, vol. 109, pp. 665-672.

Haley WE, Levine EG, Brown SL, Berry JW, & Hughes GH 1987, "Psychological, socila and health consequences of caring for a relative with senile dementia", *JAGS*, vol. 35, no. 5, pp. 405-411.

Hall JA & Dornan MC 1990, "Patient sociodemographic characteristics as predictors of satisfaction with medical care: a meta-analysis", *Soc Sci Med*, vol. 30, pp. 811-818.

Han B & Haley WE 1999, "Family caregiving for patients with stroke: review and analysis", *Stroke*, vol. 30, pp. 1478-1485.

Hanger HC & Mulley GP 1993, "Questions people ask about stroke", *Stroke*, vol. 24, no. 4, pp. 536-538.

Hanson EJ, Tetley J, & Clarke A 1999, "A multimedia intervention to support family caregivers", *Gerontologist*, vol. 39, no. 6, pp. 736-741.

Harris LE, Swindle RW, & Mungai SM 1999, "Measuring patient satisfaction for quality improvement.", *Med Care*, vol. 37, no. 1207, p. 1213.

Hatano S 1976, "Experience from a multicentre stroke register: a preliminary report.", *Bull WHO*, vol. 54, pp. 541-553.

Hebert R, Bravo G, & Preville M 2000, "Reliability, validity and reference values of the Zarit Burden Interview for assessing informal caregivers of community-dwelling older persons with dementia", *Canadian Journal on Aging*, vol. 19, no. 4, pp. 494-507.

Hennekens CH & Buring JE 1987, *Epidemiology in medicine*, First edition edn, Little, Brown and Company, Boston / Toronto.

Henwood M 1998, *Ignored and Invisible? Carers experience of the NHS* Carers National Association.

Hiidenovi H, Laippala P, & Nojonen K 2001, "Development of a patient-orientated instrument to measure service quality in outpatient departments", *Journal of Advanced Nursing*, vol. 34, no. 5, pp. 696-705.

Hirst M 2005, "Carer distress: a prospective population based study". *Soc. Sci. Med.*, vol. 61, no. 3, pp. 697-708

HM Government 1999a, *A National Strategy for Carers.* The Stationary Office, London.

HM Government 1999b, *With Respect to Old Age:Long Term Care - Rights and Responsibilities. A Report by The Royal Commission on Long Term Care* The Stationary Office, London.

HM Government 2000a, *National service framework for coronary heart disease.*

HM Government 2000b, *The NHS Plan.*

Hodgson SP, Wood VA, & Langton-Hewer R 1996, "Identification of stroke carers 'at risk': a preliminary study of the predictors of carers' psychological well-being at one year post stroke.", *Clinical Rehabilitation*, vol. 10, pp. 337-346.

Hodkinson HM 1972, "Evaluation of a mental test score for assessment of mental impairment in the elderly", *Age Ageing*, vol. 1, pp. 233-238.

Hooker K, Monahan DJ, Bowman SR, Frazier LD, & Shifren K 1998, "Personality counts for a lot: Predictors of mental and physical health of spouse caregivers in two disease groups", *J.Gerontology Psych.Sci.*, vol. 53B, no. 2, p. P73-P85.

Hopton JL, Howie JGR, & Porter MD 1993, "The need for another look at the patient in General Practice satisfaction surveys", *J.Family Practice*, vol. 10, pp. 82-87.

Hotopf M, Sharp D, & Lewis G 1998, "What's in a name?: A comparison of four psychiatric assessments", *Social Psychiatry & Psychiatric Epidemiology*, vol. 33, no. 1, pp. 27-31.

Houts PS, Yasko JM, Benham Kahn S, & Schelzel G 1986, "Unmet psychological, social and economic needs of persons with cancer in Pennsylvania", *Cancer*, vol. 58, pp. 2355-2361.

Hunt SM & McKenna SP 1992, "A British adaptation of the General Well-Being Index: a new tool for clinical research", *Br J Med Econ*, vol. 2, pp. 49-60.

I:

Idler EL & Benyamini Y 1997, "Self-rated health and mortality: a review of twenty-seven community studies", *J.Health and Soc.Behaviour*, vol. 38, no. 1, pp. 21-37.

Idler EL & Kasl S 1995, "Self-ratings of health: do they also predict change in functional ability?", *J Gerontol B Psychol Sci Soc Sci*, vol. 50B, p. S344-S353.

Intercollegiate stroke working party 2002, *Concise report of the National Sentinel Stroke Audit 2001/2* Royal College of Physicians, London.

Isaacs B, Neville Y, & Rushford I 1976, "The stricken: the social consequences of stroke", *Age Ageing*, vol. 5, pp. 188-192.

J:

Jenkins R, Bebbington P, Brugha T, Farrell M, Gill B, Lewis G, Meltzer H, & Petticrew M 2003a, "The national psychiatric morbidity surveys of Great Britain-strategy and methods", *International Review of Psychiatry*, vol. 15, no. 1-2, pp. 5-13.

Jenkins R, Lewis G, Bebbington P, Brugha T, Farrell M, Gill B, & Meltzer H 2003b, "The national psychiatric morbidity surveys of Great Britain-initial findings from the Household Survey", *International Review of Psychiatry*, vol. 15, no. 1-2, pp. 29-42.

Jenkins R, Lewis G, Bebbington P, Brugha T, Farrell M, Gill B, & Melzer H 1997, "The National Psychiatric Morbidity Surveys of Great Britain - initial findings from the Household Survey", *Psychological Medicine*, vol. 27, no. 4, pp. 775-789.

Jitapunkul S, Pillay I, & Ebrahim S 1991, "The abbreviated mental test", *Age Ageing*, vol. 20, pp. 332-336.

Jollife IT & Morgan BJT 1992, "Principal component analysis and exploratory factor analysis.", *Statistical Methods in Medical Research*, vol. 1, pp. 69-95.

Jones AL, Charlesworth JF, & Hendra TJ 2000, "Patient mood and carer strain during stroke rehabilitation in the community following early hospital discharge.", *Disabil Rehabil*, vol. 22, no. 11, pp. 490-494.

Jones DA & Vetter NJ 1985, "Formal and informal support received by carers of elderly dependants", *British Medical Journal*, vol. 291, pp. 643-645.

Jorgensen HS, Nakayama H, Raaschou HO, & Olsen TS 1999, "Stroke. Neurologic and functional recovery the Copenhagen Stroke Study", *Phys Med Rehabil Clin N Am*, vol. 10, no. 4, pp. 887-906.

Jorgensen HS, Nakayama H, Raaschou HO, Vive-Larsen J, Stoier M, & Olsen TS 1995, "Outcome and time course of recovery in stroke. Part II: Time course of recovery. The Copenhagen Stroke Study", *Arch Phys Med Rehabil*, vol. 76, no. 5, pp. 406-412.

K:

Kelly-Hayes M 1990, "Time interval, survival and destination: three crucial variables in stroke outcome research", *Stroke*, vol. 21, no. Supplement II, p. II-24-II-26.

Kendell RE 1968, "The reliability of the "Present State Examination"", *Social Psychiatry*, vol. 3, no. 3, pp. 123-129.

Kerr SM & Smith LN 2001, "Stroke: an exploration of the experience of informal caregiving.", *Clinical Rehabilitation*, vol. 15, no. 4, pp. 428-436.

Khayat K & Salter B 2001, "Patient satisfaction surveys as a market research tool for general practices", *British Journal of General Practice*, vol. 44, pp. 215-219.

Kiecolt-Glaser JK, Dura JR, Speicher CE, Trask OJ, & Glaser R 1991, "Spousal caregivers of dementia victims: longitudinal changes in immunity and health", *Psychosomatic Medicine*, vol. 53, pp. 345-362.

King RB, Carlson CE, Shade-Zeldow Y, Bares KK, Roth EJ, & Heinemann AW 2001, "Transition to home care after stroke: depression, physical health, and adaptive processes in support persons", *Res Nurs Health*, vol. 24, no. 4, pp. 307-323.

King RB, Shade-Zeldow Y, Carlson CE, Feldman JL, & Philip M 2002, "Adaptation to stroke: a longitudinal study of depressive symptoms, physical health, and coping process.", *Top Stroke Rehab*, vol. 9, no. 1, pp. 46-66.

Kinney JM, Stephens MAP, Franks MM, & Norris VK 1995, "Stresses and satisfactions of family caregivers to older stroke patients", *J.Applied Gerontology*, vol. 14, no. 1, pp. 3-21.

Kinsella GJ & Duffy FD 1979, "Psychosocial readjustment in the spousess of stroke patients", *Scandinavian J.Rehab.Med.*, vol. 11, pp. 129-132.

Kotila M, Numminen H, Waltimo O, & Kaste M 1998, "Depression after stroke: results of the FINNSTROKE Study", *Stroke*, vol. 29, no. 2, pp. 368-372.

Kozma A & Stones MJ 1987, "Social desirability in measures of subjective well-being: a systematic evaluation", *J.Gerontology*, vol. 42, pp. 56-59.

Kuder GF & Richardson MW 1937, "The theory of the estimation of test reliability", *Psychometrika*, vol. 2, pp. 151-160.

Kumar R 1996, *Research methodology* Sage, London.

L:

Larsen DE & Rootman I 1976, "Physician role performance and patient satisfaction", *Soc Sci Med*, vol. 10, no. 1, pp. 29-32.

Lau J, Schmid CH, & Chalmers TC 1995, "Cumulative meta-analysis of clinical trials builds evidence for exemplary medical care.", *J Clin Epidemiol*, vol. 48, no. 1, pp. 45-57.

Lawton MP 1972, "The dimensions of morale," in *Research Planning and Action for the Elderly*, Kent D, Kastenbaum R, & Sherwood S, eds., Behavioural Publications, New York.

Lawton MP 1975, "The Philadelphia Geriatric Center Morale Scale: a revision", *J.Gerontology*, vol. 30, pp. 85-89.

Lazarus RS & Folkman S 1984, *Stress, appraisal and coping* Springer.

Legh-Smith J, Wade DT, & Langton-Hewer R 1986, "Services for stroke patients one year after stroke", *J Epidemiol Comm Health*, vol. 40, pp. 161-165.

Lehman AF, Rachuba LT, & Postrado LT 1995, "Demographic influences on quality of life among persons with chronic mental illness", *Evaluation and Programme Planning*, vol. 18, pp. 155-164.

LeVois M, Nguyen TD, & Attkisson CC 1981, "Artifact in client satisfaction assessment: experience in community mental health settings", *Evaluation and Programme Planning*, vol. 4, pp. 139-150.

Lewick P. & Hill T. 2005, *Statistics: Methods and Applications,* 1st Edition, Statsoft Inc., ISBN: 1884233597

Lewis G 1994, "Assessing psychiatric disorder with a human interviewer or a computer", *J Epidemiol Community Health*, vol. 48, pp. 207-210.

Lewis G, Pelosi AJ, Araya R, & Dunn G 1992, "Measuring psychiatric disorder in the community: a standardized assessment for use by lay interviewers", *Psychological Medicine*, vol. 22, no. 2, pp. 465-486.

Ley P 1972, "Complaints made by hospital staff and patients: a review of the literature", *Bulletin of British Psychologists*, vol. 25, pp. 115-120.

Lincoln NB, Francis VM, Lilley SA, Sharma JC, & Summerfield M 2003, "Evaluation of a stroke family support organiser: a randomized controlled trial", *Stroke*, vol. 34, no. 1, pp. 116-121.

Linder-Pelz S 2001, "Toward a theory of patient satisfaction", *Soc Sci Med*, vol. 16, pp. 577-582.

Lindenthal JJ, Myers JK, & Pepper MP 1972, "Smoking, psychological status and stress", *Soc Sci Med*, vol. 6, no. 5, pp. 583-591.

Little A, Hemsley D, Bergmann K, Volans J, & Levy R 1987, "Comparison of the sensitivity of three instruments for the detection of cognitive decline in the elderly living at home", *Br J Psychiatry*, vol. 150, pp. 808-814.

Little P, Everitt H, Williamson I, Warner G, Moore M, Gould C, Ferrier K, & Payne S 2001, "Preferences of patients for patient centred approach to consultation in primary care: observational study", *British Medical Journal*, vol. 322, p. 468.

Livingston G, Watkin V, Milne B, Manela MV, & Katona C 2000, "Who becomes depressed? The Islington community study of older people.", *J Affect Disord*, vol. 58, no. 2, pp. 125-133.

Livingstone G, Manela M, & Katona C 1997, "Cost of community care for older people", *Br J Psychiatry*, vol. 171, pp. 56-59.

Lofland J & Lofland LH 1984, *Analyzing social settings.* Wadsworth Publishing Company, Inc., Belmont, CA.

Loo R 1983, "Caveat on sample size in factor analysis.", *Perceptual and Motor Skills*, vol. 56, no. 2, pp. 371-374.

Lunnen KM & Ogles BM 1997, "Satisfaction ratings: meaningful or meaningless?", *Behav Healthcare Tomorrow*, vol. 6, no. 4, pp. 49-51.

Luther A, Lincoln NB, & Grant F 1998, "Reliability of stroke patients' reports on rehabilitation services received", *Clinical Rehabilitation*, vol. 12, pp. 238-244.

M:

MacKay A & Nias BC 1979, "Strokes in the young and middle aged: consequences to the family and society", *J.Roy.Coll.Phys.Lond.*, vol. 13, no. 2, pp. 111-112.

Macnamara SE, Gummow LJ, Goka R, & Gregg CH 1990, "Caregiver strain: Need for late poststroke intervention", *Rehabilitation Psychology*, vol. 35, no. 2, pp. 71-78.

Mahoney FI & Barthel DW 1965, "Functional evaluation: The Barthel Index", *Maryland State Medical Journal*, vol. 14, pp. 61-65.

Mant J, Carter J, Wade DT, & Winner S 1998, "The impact of an information pack on patients with stroke and their carers: a randomized controlled trial", *Clinical Rehabilitation*, vol. 12, pp. 465-476.

Mant J, Carter J, Wade DT, & Winner S 2000, "Family support for stroke: a randomised controlled trial.", *Lancet*, vol. 356, no. 9232, pp. 808-813.

Matson N 1995, "Coping in context. Strategic and tactical coping in carers of stroke survivors and carers of older, confused people", *J.Comm.and Appl.Soc.Psych.*, vol. 5, pp. 89-104.

Matsuda O 1999, "Reliability and validity of the Subjective Burden Scale in family caregivers of elderly relatives with dementia.", *International Psychogeriatrics*, vol. 11, no. 2, pp. 159-170.

Mayo NE, Wood-Dauphinee S, Cote R, Gayton D, Carlton J, Buttery J, & Tamblyn R 2000, "There's no place like home : an evaluation of early supported discharge for stroke", *Stroke*, vol. 31, no. 5, pp. 1016-1023.

McClenahan R & Weinman J 1998, "Determinants of carer distress in non-acute stroke", *Int J Language and Communication Disorders*, vol. 33, no. Supplement, pp. 138-143.

McCormick IA, Siegert RJ, & Walkey FH 1987, "Dimensions of social support: A factorial confirmation", *American Journal of Community Psychology*, vol. 15, no. 1, pp. 73-77.

McIver S 1991, *Obtaining the views of outpatients* Kings Fund, London.

McKinley RK, Manku-Scott T, Hastings AM, French DP, & Baker R 1997, "Reliability and validity of a new measure of patient satisfaction with out of hours primary medical care in the United Kingdom", *British Medical Journal*, vol. 314, p. 193.

McLean J, Roper-Hall A, Mayer P, & Main A 1991, "Service needs of stroke survivors and their informal carers: a pilot study.", *Journal of Advanced Nursing*, vol. 16, pp. 559-564.

Medical Research Council 2000, *Good Research Practice* Medical Research Council, London.

Meltzer H & Jenkins R 1994, "The National Survey of Psychiatric Morbidity in Great Britain", *International Review of Psychiatry*, vol. 6, no. 4, pp. 349-356.

Meredith P, Emberton M, & Wood C 1995, "New directions in information for patients", *British Medical Journal*, vol. 311, pp. 4-5.

Microsoft 2003, "Excel," in *Office XP*, Microsoft Corporation, USA.

Mirowsky J & Ross CE 1992, "Age and depression", *J Health and Social Behaior*, vol. 33, pp. 187-205.

Moher D, Dulberg CS, & Wells GA 1994, "Statistical power, sample size, and their reporting in randomized controlled trials", *JAMA*, vol. 272, no. 2, pp. 122-124.

Moorey S 1988, "The psychological impact of cancer," in *Oncology for nurses and health care professionals*, Tiffany R & Webb P, eds., Harper and Row, London.

Morris JN & Sherwood S 1975, "A retesting and modification of the Philadelphia Geriatric Center Morale Scale", *J.Gerontology*, vol. 30, pp. 77-84.

Morris RG, Morris LW, & Britton PG 1988, "Factors affecting the emotional wellbeing of the caregivers of dementia sufferers.", *Br J Psychiatry*, vol. 153, pp. 147-156.

Motenko AK 1989, "The frustrations, gratifications, and well-being of dementia caregivers.", *Gerontologist*, vol. 29, no. 2, pp. 166-172.

MRC Health Services and Public Health Research Board 2000, *A framework for development and evaluation of RCTs for complex interventions to improve health* MRC, London.

Murray J, Ashworth R, Forster A, & Young J 2003, "Developing a primary care-based stroke service: a review of the qualitative literature.", *British Journal of General Practice*, vol. 53, no. 487, pp. 137-142.

N:

Naish J & Benaim R 1995, *Putting carers onto the agenda in general practice* University of London, London.

Napoleoni L 1994, *Carer reaction and satisfaction after stroke* Southampton University.

National Statistics 2004, *National Statistics full geographic search.* Accessed: January /February 2004. Available at Website: http://neighbourhood.statistics.gov.uk/default.asp?nsid=false&CE=True&SE=True

NICE (National Institute for Clinical Excellence) 2004, *Depression: Management of depression in primary and secondary care.* Available at website: http://www.nice.org.uk

Nieboer A 1996, *Life events and well-being* ICS.

Nieboer A, Schulz R, Matthews KA, Scheier MF, Ormel J, & Lindenberg SM 1998, "Spousal caregivers' activity restriction and depression: A model for changes over time.", *Soc Sci Med*, vol. 47, no. 9, pp. 1361-1371.

Novak M & Guest C 1989, "Application of a multidimensional caregiver burden inventory", *Gerontologist*, vol. 29, no. 6, pp. 798-803.

O:

O'Mahoney PG, Rodgers H, Thomson RG, Dobson R, & James OFW 1997, "Satisfaction with information and advice received by stroke patients.", *Clinical Rehabilitation*, vol. 11, pp. 68-72.

Office for National Statistics 2000, *Expectation of life at selected ages by gender, 1911 to 2021 (selected years).*, Social Trends Dataset ST30704 edn, http://www.statistics.gov.uk/statbase/xsdataset.asp?vlnk=665.

On-line medical dictionary 2004, http://www.cancerweb.ncl.ac.uk/omd.

Osborn DP, Fletcher AE, Smeeth L, Stirling S, Bulpitt CJ, Breeze E, Ng ES, Nunes M, Jones D, & Tulloch A 2003, "Factors associated with depression in a representative sample of 14 217 people aged 75 and over in the United Kingdom: results from the MRC trial of assessment and management of older people in the community", *Int J Geriatr Psychiatry*, vol. 18, no. 7, pp. 623-630.

Osborn DP, Fletcher AE, Smeeth L, Stirling S, Nunes M, Breeze E, Siu-Woon Ng E, Bulpitt CJ, Jones D, Tulloch A, & Siu-Woon E 2002, "Geriatric Depression Scale Scores in a representative sample of 14 545 people aged 75 and over in the United Kingdom: results from the MRC Trial of Assessment and Management of Older People in the Community.", *Int J Geriatr Psychiatry*, vol. 17, no. 4, pp. 375-382.

Oxford Paperback Dictionary 1983, 2nd Edition, Oxford University Press.

P:

Parker G 1992, "Counting care: numbers and types of informal carers," in *Carers:Research and Practice*, Twigg J, ed., HMSO, London, p. 6.

Patton MQ 1987, *How to use qualitative methods in evaluation* Sage Publications, London.

Pearlin LI 1990, "Caregiving and the stress process: an overview of concepts and their measures.", *Gerontologist*, vol. 30, pp. 583-594.

Peckham S & Wilson A 2001, *Evaluation of a carer's protocol in primary care.* RCGP, London.

Pinquart M & Sorensen S 2003a, "Associations of stressors and uplifts of caregiving with caregiver burden and depressive mood: a meta-analysis", *J Gerontol B Psychol Sci Soc Sci*, vol. 58, no. 2, p. P112-P128.

Pinquart M & Sorensen S 2003b, "Differences between caregivers and noncaregivers in psychological health and physical health: a meta-analysis.", *Psychol Aging*, vol. 18, no. 2, pp. 250-267.

Pope C, Ziebland S, & Mays N 1999, "Analysing qualitative data," in *Qualitative Research in Health*, 2 edn, Pope C, ed., BMJ Publishing Group.

Poulschock SW & Deimling GT 1984, "Families caring for elders in residence: Issues in the measurement of burden", *J Gerontol*, vol. 39, no. 2, pp. 230-239.

Pound P 1993, "Development and results of a questionnaire to measure carer satisfaction after CVA.", *J Epidemiol Comm Health*, vol. 47, pp. 500-505.

Pound P, Gompertz P, & Ebrahim S 1993, "Development and results of a questionnaire to measure carer satisfaction after stroke", *J Epidemiol Comm Health*, vol. 47, no. 6, pp. 500-505.

Pound P, Tilling K, Rudd AG, & Wolfe CD 1999, "Does patient satisfaction reflect differences in care received after stroke?", *Stroke*, vol. 30, no. 1, pp. 49-55.

Princess Royal Trust for Carers 2004, *Carers Health Survey*. Accessed in pdf format in February 2006 from website: www.carers.org

Pruchno RA & Potashnik SL 1989, "Caregiving spouses: physical and mental health in perspective", *JAGS*, vol. 37, pp. 697-705.

Punch KF 1998, *Introduction to social research: quantitative and qualitative approaches.* Sage, London.

Purk JK & Richardson RA 1994, "Older adult stroke patients and their spousal caregivers", *Families in Society*, vol. 75, no. 10, pp. 608-615.

Q:

Qureshi KN & Hodkinson HM 1974, "Evaluation of a 10 question mental test in the institutionalized elderly", *Age Ageing*, vol. 3, pp. 152-157.

R:

Raine R, Goldfrad C, Rowan K, & Black N 2002, "Influence of patient gender on admission to intensive care", *J Epidemiol Comm Health*, vol. 56, no. 6, pp. 418-423.

Raine R, Hutchings A, & Black N 2003, "Is publicly funded health care really distributed according to need? The example of cardiac rehabilitation in the UK", *Health Policy*, vol. 63, no. 1, pp. 63-72.

Raphael W 1967, "Do we know what patients think?", *Int J Nurs Stud.*, vol. 4, pp. 209-223.

Reese DR, Gross AM, Smalley DL, & Messer SC 1994, "Caregivers of Alzheimer's disease and stroke patients: Immunological and psychological considerations", *Gerontologist*, vol. 34, no. 4, pp. 534-540.

Robinson BC 1983, "Validation of a Caregiver Strain Index", *J Gerontol*, vol. 38, no. 3, pp. 344-348.

Robinson L, Francis J, James P, Tindle N, Greenwell K, Rodgers H 2005, " Caring for carers of people with stroke: developing a complex intervention following the Medical Research Council Framework", *Clinical Rehabilitation*, vol. 19, no. 5, pp. 560-571.

Rodgers B & Mann SA 1986, "The reliability and validity of PSE assessments by lay interviewers: a national population survey", *16*, vol. 3, pp. 689-700.

Rodgers H, Bond S, & Curless R 2001, "Inadequacies in the provision of information to stroke patients and their families.", *Age Ageing*, vol. 30, pp. 129-133.

Rodgers H, Soutter J, Kaiser W, Pearson P, Dobson R, Skilbeck C, & Bond J 1997, "Early supported hospital discharge following acute stroke: Pilot study results", *Clinical Rehabilitation*, vol. 11, no. 4, pp. 280-287.

Ross S & Morris RG 1988, "Psychological adjustment of the spouses of aphasic stroke patients", *Int J Rehab Res*, vol. 11, no. 4, pp. 383-386.

Rowlands O & Parker G 1998, *Informal carers: An independent study carried out by the Office for National Statistics on behalf of the Depoartment of Health as part of the 1995 General household survey* Office for National Statistics.

Royal College of Physicians 1998, *National Sentinel Audit for Stroke.* Royal College of Physicians, http://www.rcplondon.ac.uk/college/ceeu/ceeu_stroke_audit.htm.

Royal College of Physicians 2000, *National Stroke Guidelines* Royal College of Physicians, www.rcplondon.ac.uk/pubs/books/stroke/ceeu_stroke_service05.htm.

Royal Commission on the National Health Service 1979, *Access to Primary Care*, Research Paper No. 6 edn, HMSO, London.

Rudd AG, Wolfe CD, Tilling K, & Beech R 1997, "Randomised controlled trial to evaluate early discharge scheme for patients with stroke.", *British Medical Journal*, vol. 316, no. 7129, pp. 1039-1044.

S:

Salvage AV, Jones DA, & Vetter NJ 1988, "Awareness of and satisfaction with community services in a random selection of the over 75s", *Health Trends*, vol. 20, pp. 88-92.

Sarason BR, Shearin EN, Pierce GR, Gregory R, & Sarason IG 1987, "Interrelations of social support measures: Theoretical and practical implications", *Journal of Personality & Social Psychology*, vol. 52, no. 4, pp. 813-832.

Sarason IG, Levine HM, Basham RB, & Sarason BR 1983, "Assessing social support: The Social Support Questionnaire", *Journal of Personality & Social Psychology*, vol. 44, no. 1, pp. 127-139.

Sarason IG, Sarason BR, & Shearin EN 1986, "Social support as an individual difference variable: Its stability, origins, and relational aspects", *Journal of Personality & Social Psychology*, vol. 50, no. 4, pp. 845-855.

Sarason IG, Sarason BR, & Shearin EN 1987, "A brief measure of social suport: practical and theoretical implications", *J Soc Personal Relations*, vol. 4, pp. 497-510.

Schneider NG & Houston JP 1970, "Smoking and anxiety", *Psychological Report,* vol. 26, no. 3, pp. 941-942.

Scholte op Reimer WJM, de Haan RJ, Rijnders PT, Limburg M, & van den Bos GAM 1998, "The burden of caregiving in partners of long-term stroke survivors", *Stroke*, vol. 29, pp. 1605-1611.

Schulz R & Beach SR 1999, "Caregiving as a risk factor for mortality: the Caregiver Health Effects Study.", *JAMA*, vol. 282, no. 23, pp. 2215-2219.

Schulz R & Quittner AL 1998, "Caregiving for children and adults with chronic conditions: introduction to the special issue.", *Health Psych.*, vol. 17, pp. 107-111.

Schulz R, Tompkins CA, & Rau MT 1988, "A longitudinal study of the psychosocial impact of stroke on primary support persons", *Psychology and Aging*, vol. 3, no. 2, pp. 131-141.

Secretary of State for Health 1989, *Caring for People: community care in the next decade and beyond.* Department of Health, London.

Secretary of State for Health 1998, *Our Healthier Nation: A contract for health.* The Stationary Office, London.

Segal ME, Gillard M, & Schall RR 1996, "Telephone and in-person proxy agreement between stroke patients and caregivers for the functional independence measure.", *Am J Phys Med Rehabil*, vol. 75, no. 3, pp. 208-212.

Segal ME & Schall RR 1996, "Life satisfaction and caregiving stress for individuals with stroke and their primary caregivers", *Rehabilitation Psychology*, vol. 41, no. 4, pp. 303-320.

Siegel S & Castellan NJ 1988, *Nonparametric statistics for the behavioural sciences*, 2nd edition edn, McGraw-Hill, New York.

Silliman RA, Earp JL, Fletcher RH, & Wagner EH 1987, "Stroke: the perspective of family caregivers", *J.Applied Gerontology*, vol. 6, no. 4, pp. 363-371.

Silliman RA, Fletcher RH, Earp JL, & Wagner EH 1986, "Families of elderly stroke patients: Effects of home care", *JAGS*, vol. 34, pp. 643-648.

Simon C 2003, *A questionnaire to measure satisfaction of carers of stroke patients in the community with the community support services: Development and initial piloting* Southampton University, MSc in Research in Health: Thesis.

Simon C & Kendrick T 2001, "Informal carers - the role of general practitioners and district nurses", *British Journal of General Practice*, vol. 51, pp. 655-657.

Simon C & Kumar S 2002, "Stroke patients' carers' views of formal community support", *B J Community Nursing*, vol. 7, no. 3, pp. 158-163.

Simon C, Kumar S, & Kendrick T 2002, "Who cares for the carers? The district nurse perspective.", *Family Practice*, vol. 19, no. 1, pp. 29-35.

Simon C, Little P, Birtwistle J, & Kendrick T 2003, "A questionnaire to measure satisfaction with community services for informal carers of stroke patients: construction and initial piloting.", *Health and Social Care in the Community*, vol. 11, no. 2, pp. 129-137.

Sitzia J 1999, "How valid and reliable are patient satisfaction data? An analysis of 195 studies.", *Int.J.Qual.Health Care*, vol. 11, no. 4, pp. 319-328.

Sitzia J & Wood N 1997, "Patient satisfaction: a review of issues and concepts", *Soc Sci Med*, vol. 45, no. 12, pp. 1829-1843.

Skilbeck C, Wade D, Langton-Hewer R, & Wood VA 1983, "Recovery after stroke", *J Neurol Neurosurg Psychiatry*, vol. 46, pp. 5-8.

Smith LN, Lawrence M, Kerr SM, Langhorne P, Lees KR 2004, "Informal carers' experience of caring for stroke survivors", *J. Adv. Nurs.*, vol. 46, no. 3, pp. 235-244.

.**Spackman A** 1991, *The health of informal carers* Institute for Health Policy Studies, Southampton.

Spencer K, Tompkins CA, & Schulz R 1997, "Assessment of depression in patients with brain pathology: the case of stroke", *Pschological Bulletin*, vol. 122, pp. 132-152.

SPSS Inc. 2003, *SPSS v.11.5* SPSS Inc., Chicago, Illinois.

Stein PN, Gordon WA, Hibbard MR, & Sliwinski MJ 1992, "An examination of depression in the spouses of stroke patients.", *Rehabilitation Psychology*, vol. 37, no. 2, pp. 121-130.

Steptoe A, Wardle J, Pollard TM, Canaan L, & Davies GJ 1996, "Stress, social support and health-related behavior: a study of smoking, alcohol consumption and physical exercise", *J Psychosom Res*, vol. 41, no. 2, pp.171-180.

Stewart M 1984, "What is a successful doctor-patient interview? A study of interactions and outcomes", *Soc Sci Med*, vol. 19, pp. 167-175.

Stimpson G & Webb B 1975, *Going to see the doctor: the consultation process in general practice* Routledge and Keegan Paul, London.

Stoller EP & Puglieski KL 1989, "Other roles of caregivers: competing responsibilities or supportive resources", *J.Gerontology Soc.Sci.*, vol. 44, p. S231-S238.

Stroke Unit Trialists' Collaboration 1997, "Collaborative systematic review of the randomised trials of organised inpatient (stroke unit) care after stroke", *British Medical Journal*, vol. 314, no. 7088, pp. 1151-159.

Stroke Unit Trialists' Collaboration 2002, "Organised inpatient (stroke unit) care for stroke", *Cochrane Database Syst Rev* no. 1, p. CD000197.

Stuckey JC, Neundorfer MM, & Smyth KA 1996, "Burden and well-being: the same coin or related currency", *Gerontologist*, vol. 36, no. 5, pp. 686-693.

Stull DE, Kosloski K, & Kercher K 1994, "Caregiver burden and generic well-being: opposite sides of the same coin?", *Gerontologist*, vol. 34, no. 1, pp. 88-94.

Sturt E, Bebbington P, Hurry J, & Tennant C 1981, "The Present State Examination used by interviewers from a survey agency: report from the MRC Camberwell Community Survey", *Psychol Med*, vol. 11, no. 1, pp. 185-192.

Swinscow TDV 2002, *Statistics at Square One*, Paperback edn, BMJ Books, London.

T:

Tagliacozzo DL 1965, "The nurse from the patient's point of view," in *Social interaction and patient care*, Skipper Jr.JK & Leonard RC, eds., Lipincott, Philadelphia, PA, pp. 219-228.

Tardy CH 1985, "Social support measurement", *American Journal of Community Psychology*, vol. 13, no. 2, pp. 187-202.

Teng J, Mayo NE, Latimer E, Hanley J, Wood-Dauphinee S, Cote R, & Scott S 2003, "Costs and caregiver consequences of early supported discharge for stroke patients.", *Stroke*, vol. 34, no. 2, pp. 528-536.

The EuroQol Group 1990, "EuroQol-a new facility for the measurement of health-related quality of life.", *Health Policy*, vol. 16, no. 3, pp. 199-208.

The Stroke Association 2000, *Stroke - Questions and answers.* The Stroke Association.

Thoits PA 1982, "Conceptual, methodological and theoretical problems in studying social support as a buffer against life stress", *J Health and Social Behavior*, vol. 23, pp. 145-159.

Thommessen B, Wyller TB, Bautz-Holter E, & Laake K 2001, "Acute phase predictors of subsequent psychosocial burden in carers of elderly stroke patients.", *Cerebrovasc.Dis*, vol. 11, no. 3, pp. 201-206.

Thompson C & Briggs M 2000, "Support for carers of people with Alzheimer's type dementia", *Cochrane Database Syst Rev.*, vol. 2, no. CD000454.

Thompson E & Doll W 1982, "The burden of families coping with the mentally ill: An invisible crisis", *Family Relations*, vol. 31, no. 379, p. 388.

Thompson P & Blessed G 1987, "Correlation between the 37-item Mental Test Score and Abbreviated 10-item Mental Test Score by psychogeriatric day patients", *Br J Psychiatry*, vol. 151, pp. 206-209.

Thompson SC, Sobolew-Shubin A, Graham MA, & Janigian AS 1989, "Psychosocial adjustment following a stroke", *Soc Sci Med*, vol. 28, no. 3, pp. 239-247.

Thornton M & Travis SS 2003, "Analysis of the reliability of the modified caregiver strain index", *J Gerontol B Psychol Sci Soc Sci*, vol. 58, no. 2, p. S127-S132.

Tiegs TJ, Heesacker M, Ketterson TU, Pekich DG, Rittman MR, Rosenbek JC, Stidham BS, Gonzalez-Rothi LJ 2006, "Coping by stroke caregivers: sex similarities and differences.", *Top. Stroke Rehabil.*, vol. 13, no. 1, pp. 52-62.

Toedter LJ, Schall RR, Reese CA, Hyland D, Berk SN, & Dunn D 1995, "Psychological measures: reliability in the assessment of stroke patients", *Phys Med Rehabil Clin N Am*, vol. 76, pp. 719-725.

Tompkins CA, Schulz R, & Rau MT 1988, "Post-stroke depression in primary support persons: predicting those at risk", *J.of Consulting and Clin.Psychol.*, vol. 56, no. 4, pp. 502-508.

Twigg J & Atkin K 1994, *Carers Perceived: policy and practice in informal care* Open University Press.

V:

van den Heuvel ET, Witte LP, Stewart RE, Schure LM, Sanderman R, & Meyboom-de Jong B 2002, "Long-term effects of a group support program and an individual support program for informal caregivers of stroke patients: which caregivers benefit the most?", *Patient Education and Counseling*, vol. 47, no. 4, pp. 291-299.

van den Heuvel ET, Witte LP, Schure LM, Sanderman R, & Meyboom-de Jong B 2001, " Risk factors for burn-out in caregivers of stroke patients, and possibilities for intervention.", *Clin. Rehabil.*, vol. 15, no. 6, pp. 669-677.

van Heugten CM, Visser-Meily A, Post M, Lindeman E 2006, "Care for carers of stroke patients: evidence-based clinical practice guidelines", *J. Rehabil. Medicine*, vol. 38, no. 3, pp. 153-8.

van Swieten JC, Koudstaal PJ, Visser MC, Schouten HJ, & van Gijn J 1988, "Interobserver agreement for the assessment of handicap in stroke patients", *Stroke*, vol. 19, pp. 604-607.

Vardon VM & Blessed G 1986, "Confusion ratings and abbreviated mental test performance: a comparison", *Age Ageing*, vol. 15, pp. 139-144.

Visser-Meily A, Post M, Schepers V, Lindeman E 2005, "Spouses' quality of life 1 year after stroke: prediction at the start of clinical rehabilitation", *Cerebrovasc. Dis.*, vol. 20, no. 6, pp. 443-8

Visser-Meily JM, Post MW, Schepers VP, Ketelaar M, van Heugten CM, Lindeman E 2005, "Spouses' satisfaction with caregiver support in stroke rehabilitation", *Scandinavian J. Caring Sci.*, vol. 19, no. 4, pp. 310-16.

Vitaliano PP, Russo J, Young HM, Becker J, & Maiuro RD 1991, "The screen for caregiver burden", *Gerontologist*, vol. 31, no. 1, pp. 76-83.

Vitaliano PP, Young HM, & Russo J 1991, "Burden: a review of measures used among caregivers of individuals with dementia.", *Gerontologist*, vol. 31, no. 1, pp. 67-75.

Vitaliano PP, Zhang J, & Scanlan JM 2003, "Is caregiving hazardous to one's physical health? A meta-analysis", *Psychol Bull*, vol. 129, no. 6, pp. 946-972.

W:

Wade DT 1987, "Functional abilities after stroke: measurement, natural history and prognosis.", *J.Neurol.Neurosurg.Psychiatry*, vol. 50, pp. 177-182.

Wade DT 1992, "Single-item measures," in *Measurement in neurological rehabilitation*, Wade DT, ed., Oxford Medical Publications, Oxford, pp. 274-279.

Wade DT & de Jong BA 2000, "Recent advances in rehabilitation", *British Medical Journal*, vol. 320, pp. 1385-1388.

Wade DT, Legh-Smith J, & Langton-Hewer R 1986, "Effects of living with and looking after survivors of a stroke.", *British Medical Journal*, vol. 293, pp. 418-420.

Ware JE 1992, *SF-36 Health Survey - manual and interpretation guide.* Nimrod Press, Boston.

Ware JE, Snyder MK, Wright R, & Davies A 1983, "Defining and measuring patient satisfaction with medical care", *Evaluation and Programme Planning*, vol. 6, pp. 247-263.

Warner L & Wexler S 1998, *Eight hours a day and taken for granted* Princess Royal Trust for Carers.

Warner N 1995, *Better tomorrows: Report of a national study of carers and the community care changes* Carers' National Association, London.

Weinger GC, Davies, & Shahtahmasebi S 1995, "Morale in old age: refining the model", *Int.J.Geriatr.Psychiatry*, vol. 10, no. 11, pp. 933-943.

Wilcox VL, Kasl S, & Idler EL 1996, "Self-rated health and physical disability in elderly survivors of a major medical event", *J Gerontol B Psychol Sci Soc Sci*, vol. 51B, p. S96-S104.

Williams AM 1993, "Caregivers of persons with stroke: their physical and emotional wellbeing", *Quality of Life Research*, vol. 2, pp. 213-220.

Williams B 1994, "Patient satisfaction: a valid concept?", *Soc Sci Med*, vol. 38, pp. 509-516.

Williams S, Weinman J, & Dale J 1998, "Doctor-patient communication and patient satisfaction - a review", *Family Practice*, vol. 15, no. 5, pp. 480-492.

Williams SJ & Calnan M 1991, "Convergence and divergence: assessing criteria of consumer satisfaction across general practice, dental and hospital care settings", *Soc Sci Med*, vol. 33, pp. 707-716.

Williamson GM, Shaffer DR, & Schulz R 1998, "Activity restriction and prior relationship history as contributors to mental health outcomes among middle-aged and older spousal caregivers", *Health Psych.*, vol. 17, no. 2, pp. 152-162.

Wilson A, Parker H, Wynn A, Jagger CJ, Spiers N, Jones J, & Parker G 1999, "Randomised controlled trial of effectiveness of Leicester hospital at home scheme compared with hospital care", *British Medical Journal*, vol. 319, no. 7224, pp. 1542-1546.

Wilson A, Parker H, Wynn A, & Spiers N 2003, "Performance of hospital-at-home after a randomised controlled trial.", *J Health Serv Res Policy*, vol. 8, no. 3, pp. 160-164.

Wing JK, Nixon JM, Mann SA, & Leff JP 1977, "Reliability of the PSE (ninth edition) used in a population study", *Psychological Medicine*, vol. 7, no. 3, pp. 505-516.

Wolfe CD, Giroud M, KolominskyRabas P, Dundas R, Lemesle M, Heuschmann P, & Rudd A 2000, "Variations in stroke incidence and survival in 3 areas of Europe", *Stroke*, vol. 31, no. 9, pp. 2074-2079.

Wolfe CD, Taub NA, Woodrow EJ, & Burney PGJ 1996, "Assessment of scales of disability and handicap for stroke patients ", *Stroke*, vol. 22, pp. 1242-1244.

Wolfe CDA, Taub NA, Woodrow J, Richardson E, Warburton FG, & Burney PGJ 1993, "Patterns of acute stroke care in three districts of Southern England", *J Epidemiol Comm Health*, vol. 47, pp. 144-148.

Woodhouse L & Muller DJ 1987, "Caring for the carers: support levels for families of dysphasic adults", *JRSH*, vol. 2, no. 49, p. 50.

Woodward M 1992, "Formulas for sample-size, power and minimum detectable relative risk in medical studies", *Statistician*, vol. 41, pp. 185-196.

Woollan G 1997, *The Carers Handbook* Hampshire County Council Social Services.

Wyller TB, Thommessen B, Sodring KM, Sveen U, Pettersen AM, Bautz-Holter E, & Laake K 2003, "Emotional well-being of close relatives to stroke survivors.", *Clinical Rehabilitation*, vol. 17, no. 4, pp. 410-417.

Y:

Yates ME, Tennstedt S, & Chang B-H 1999, "Contributors to and mediators of psychological wellbeing for informal caregivers", *J.Gerontology Psych.Sci.*, vol. 54B, pp. 12-22.

Young JB & Forster A 1992, "The Bradford community stroke trial: results at six months.", *British Medical Journal*, vol. 304, pp. 1085-1088.

Z:

Zahr LK, William SG, & El-Hadad A 1991, "Patient satisfaction with nursing care in Alexandria, Egypt", *Int J Nurs Stud.*, vol. 28, pp. 337-342.

Zarit S, Reever K, & Bach-Petersen J 1980, "Relatives of the impaired elderly: Correlates of feelings of burden", *Gerontologist*, vol. 20, pp. 649-655.

Zarit, SH, Todd, PA, & Zarit, JM 1986. "Subjective burden of husbands and wives as caregivers", *Gerontologist*, vol. 26, pp. 260-266

Zorowitz RD 1999, "Returning to life. Stroke survivor community and Internet resources", *Phys Med Rehabil Clin N Am*, vol. 10, no. 4, pp. 967-985.