

**A RANDOMISED CONTROLLED TRIAL OF
OCCUPATIONAL THERAPY FOR STROKE PATIENTS
NOT ADMITTED TO HOSPITAL.**

by

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ABSTRACT

Not all stroke patients are admitted to hospital. The literature indicates that between 22% and 60% of stroke patients remain in the community, often with little or no rehabilitation.

Occupational therapy is commonly used in the treatment of stroke patients and aims to promote recovery through purposeful activity. Several small trials have suggested that this approach may be effective in reducing disability but none has examined the effect of occupational therapy on stroke patients not admitted to hospital. Therefore the aim of this study was to evaluate the effect of occupational therapy on the disability and handicap experienced by stroke patients who remain in the community. Patients were recruited to the study from a community stroke register. This register covered a geographical area of Nottingham and Southern Derbyshire; incorporating 73 general practitioner practices, covering 494,000 patients. Patients were included in the study if they fulfilled the WHO definition of stroke and had not been admitted to hospital. Patients were excluded if they lived in a nursing or residential home, could not speak or understand English prior to their stroke or had a previous history of dementia. At one month after stroke patients were assessed on a series of physical and cognitive assessments. Patients were then randomly allocated to a treatment group or a control group.

Patients allocated to the treatment group received visits from a research occupational therapist for up to five months. The main aim of treatment was independence in

personal and extended activities of daily living. Patients were also encouraged to participate in leisure activities.

Two hundred and forty patients were notified to the study and of these, 55 patients were excluded. Of the remaining 185 patients, 94 were randomly allocated to the treatment group and 91 to the control group. All baseline assessments and demographic data were well matched between the groups.

Twenty two patients could not be assessed at six months; 13 patients had died during follow up and nine withdrew from the study.

Significant differences were found between the groups at six months after stroke on the Barthel Index ($p=0.002$, 95% CI 0 to 1), Nottingham Extended Activities of Daily Living ($p=0.009$, 95% CI 1 to 4), Rivermead Gross Function ($p=0.004$, 95% CI 0 to 2), Caregiver Strain Index ($p=0.02$, 95% CI 0 to 2) and the London Handicap Scale ($p=0.03$, 95% CI 0.3 to 13.5). There were no significant differences between the groups on the Hospital Anxiety and Depression scale, General Health Questionnaire 28 for either the patient or the carer or on the Nottingham Leisure Questionnaire. This study demonstrated that occupational therapy significantly reduced the level of disability and handicap experienced by stroke patients who remained in the community and also significantly reduced the strain of the carer.

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CHAPTER ONE
INTRODUCTION

1.1 STROKE

The World Health Organisation (WHO) defines stroke as 'rapidly developed clinical signs of focal (or global) disturbance of cerebral function, lasting more than 24 hours or leading to death, with no apparent cause other than of vascular origin' (Aho et al, 1980).

Stroke has also been termed cerebro vascular accident (CVA), hemiplegia, apoplexy and brain attack. Transient Ischaemic Attack (TIA) is a 'mini stroke' with neurological symptoms lasting less than 24 hours. Figures from the Oxford Community Stroke Project suggest that 11.6% of TIA's progress to stroke over the first year, reducing thereafter to 5% (Dennis et al. 1990).

The incidence of stroke is reported as 2.4 per 1,000 of the general population (Oxford Community Stroke Project, 1983). This means that a general practitioner with an average list size of 2,000 patients will see approximately five patients with a new diagnosis of stroke per year. The incidence of stroke increases with age; indeed several community studies have demonstrated that the risk of stroke is 15 to 30 times higher at age 75 or over than for ages under 65 (Garraway et al, 1979; Oxford Community Project, 1983; Reunanen et al, 1986). It has however been reported that stroke is on the decline throughout the world (Garraway et al, 1979; Tanaka et al, 1981, and Ueda et al, 1981). Ebrahim (1990) suggests four possible reasons why this may be so: more vigorous treatment for high blood pressure; reduced exposure to risk factors associated with high blood pressure (reduced salt intake); reduced exposure to other risk factors for stroke (increased exercise, stopping smoking, leading a 'healthy lifestyle'); and the competing risk of ischaemic heart disease.

Stroke is the third most common cause of death in the United Kingdom and accounts for 10-12% of all deaths. An increase in stroke morbidity with age has been reported, with 88% of stroke deaths occurring in the over 65 year old age group. It is therefore not surprising that the British Government considered stroke to be a high priority area in their document 'The Health of the Nation' (Dept of Health, 1992). The main aim promoted in this document was to reduce the death rate from stroke in people aged 65 to 74 by at least 40% by the year 2000. All general practitioners received a related document (Royal College of General Practitioners, 1996) detailing key objectives for the prevention of stroke, as it was considered that general practitioners may be in a prime position to influence a number of lifestyle risk factors. Risk factors to be targeted included: diet, obesity, blood pressure, alcohol, physical inactivity and smoking. The impact of this possible intervention has yet to be evaluated.

Stroke patients occupy approximately 12% of a general physician's acute beds (Carstairs, 1976). The cost of stroke is therefore considerable and accounts for 4-5% of NHS expenditure in England and Wales and 4.3% of the NHS budget in Scotland. Wade and Hewer (1987) suggested that much of the cost of stroke relates to the physical disability which determines time in hospital more than the need for prolonged investigation or treatment. This suggestion is endorsed by Wolfe et al (1995) who stated in a recent study that the average cost of an acute stroke to the NHS in the United Kingdom varies from £2,650 to £4,450 per case depending on the district of residence of patients, with 93% of costs being for hospital inpatient care. Stroke also has a major cost implication for the stroke

patient themselves and their carers in terms of financial expenditure (adaptation to housing, specialised transport, private domestic support) and loss of income.

The aftermath of stroke can leave a patient with one or many impairments. The most commonly associated impairment after stroke is hemiplegia, where one side of the body has a marked weakness, and as a consequence, inhibits function.

This in turn leads to difficulties in carrying out every day tasks such as dressing, feeding and bathing. Occupational therapy is targeted at identifying and solving these everyday difficulties. However many other impairments lead to a reduction in activities of daily living (ADL) and may not always be visible to the untrained eye, such as: memory difficulties, speech and language difficulties, perceptual problems, mood disorders and motor problems.

Rehabilitation is commonly prescribed in the treatment of stroke and aims to reduce the impact of stroke on the patient and the carer. Ebrahim (1990) states that rehabilitation is concerned with 'reablement' - the restoration to former rights, and the resettlement into the community. Stroke rehabilitation involves the active participation of a multidisciplinary team: the patient, carer, occupational therapist, physiotherapist, speech and language therapist, psychologist, nurse and doctor. With the exception of nursing and medical care, the occupational therapist and physiotherapist are the most commonly found professional members on the multidisciplinary team. It is the involvement of the occupational therapist that is of interest in this study.

1.2 OCCUPATIONAL THERAPY

The Committee of Occupational Therapists for the European Communities (COTEC) (1989) defines occupational therapy as:

"the assessment and treatment of people using purposeful activity to prevent disability and develop independent function." The World Federation of Occupational Therapists (1989) also published a short, readily understood and easily remembered definition:

"Occupational therapy is the treatment of physical and psychiatric conditions through specific activities in order to help people reach their maximum level of function and independence in all aspects of daily life." An earlier definition by Turner (1981) states the more holistic approach, still favoured by many occupational therapists in the late nineties:

"Occupational therapy is the treatment of the whole person by his active participation in purposeful living." If we are to delve further into the past, we find a definition of occupational therapy offered in 1910 and still relevant today:

"the science of healing by occupation."

Occupation "is the dominant activity of human beings that includes serious, productive pursuits and playful and creative behaviours." (Kielhofner and Burke, 1980).

1.2.1 HISTORY

The roots of occupational therapy were established in the eighteenth century with the work of the French physician and psychiatrist Phillipe Pinel and the Englishman William Tuke who in founding an asylum, 'The Retreat at York' made

early attempts to rehabilitate the mentally ill (Hagedorn, 1997). By the twentieth century a group of professionals evolved the concept of occupation as a restorative agent and of the person as an active participant in promoting their own health.

The term 'occupational therapy' was coined by George Burton in 1914 and the first school of occupational therapy in Great Britain was founded in Bristol in 1930 (Mc Donald, 1964). The main impetus came to occupational therapy during the second world war with the first curative workshop set up at Shepherd's Bush Military Hospital by Sir Robert Jones, an eminent British surgeon of the day. He enthused about the value of occupational therapy and urged the War Office to set up other centres. Unfortunately at this time treatment activities were limited to the field of crafts, as the more realistic occupations were not possible because of trade prejudice (McDonald, 1964).

Occupational therapy treatment in the nineties continues to be innovative and has the added luxury of little restriction in the occupations to which it can apply.

However Reed and Sanderson (1983) list some basic concepts that do not belong to occupational therapy :

- occupational therapy should not be used as a means of keeping a person busy
- occupational therapy does not provide employment
- occupational therapy does not teach specific job skills
- occupational therapy should not be unplanned or a haphazard programme of activities.

Joice and Coia (1989) describe the core skills of the occupational therapist as :

- a. **The use of selected activity.** The chosen activity must be purposeful and meaningful to the individual.
- b. **Activity analysis.** Activities can be broken down into physical, cognitive, interpersonal, social, behavioural and emotional components; an understanding of these components is essential if the activity is to meet the demands of the individual.
- c. **Assessment and treatment of functional capabilities.** The therapist must have the ability to competently assess the functional capabilities of the individual and apply the appropriate treatment.

The occupational therapist therefore intends to promote recovery through purposeful activity and encourages the patient to practice activities of everyday life. These activities may include:

Personal care - e.g. washing, dressing, cleaning teeth, grooming.

Extended Activities of Daily Living - e.g. outdoor mobility, household tasks, leisure interests.

Vocational tasks - e.g. practice in a specific work related activity.

1.2.2 THEORY OF OCCUPATIONAL THERAPY

Since the early nineteen hundreds, occupational therapists have recognised the importance of having a strong theory of occupation to support their practice; unfortunately it has taken many years to address this issue. Several authors have

contributed to this theoretical base in the last thirty years, producing many models and approaches to be used in treatment.

One of the greatest difficulties for occupational therapists reading the literature is that the terminology is used and interpreted in different ways, leading to confusion.

" Differing definitions abound and it is clear within the profession we have not reached a consensus about how these terms are used " (Hagedorn, 1992).

Hagedorn, a recognised expert in this theoretical field, offers her own definition of a model :

"A model is a statement of an organised and synthesized body of knowledge which demonstrates relationships between elements within the model and between theory and practice, and co-ordinates the application of relevant approaches and techniques."

The main purpose of a model is to assist occupational therapists in making sound judgements concerning methods of evaluation and intervention. The model therefore brings certain ideas together and excludes others and also provides boundaries for the profession; it supplies a frame work of what to do, how to do it, and why to do it. It has been suggested that there is no ideal model of health for occupational therapy to follow (Reed and Sanderson, 1983), but that occupational therapists must select the best aspects which closely fit the beliefs and values of occupational therapy. As the profession has developed, therapists became increasingly dissatisfied with the exclusive use of health models, which focus on

'illness', and consequently started to develop specific models for occupational therapy, focusing on 'wellness'.

Two of the most commonly used models applied by occupational therapists in the United Kingdom are; the rehabilitation model and the model of adaption through occupation. Each will be considered in turn.

1.2.2.1 THE REHABILITATION MODEL

The rehabilitation model (McDonald, 1964) is still one of the most widely used models in occupational therapy, with the majority of British textbooks on physical disabilities (published before 1990) based upon it. The primary assumptions with this model suppose that:

- therapy should promote personal independence and restore function to its previous level or as far as physically possible.
- regaining function can be obtained by graded practice of the damaged ability.
- activity should be realistic.
- where disability persists this may be compensated for by teaching new skills, provision of aids and appliances or by obtaining help from another individual.

Due to its long association with the medical model, the rehabilitation model can focus on the lost function and lose sight of the wider issues surrounding illness. For example, the therapist may concentrate on the loss of function in the affected arm and leg and give little attention to the psychological impact of the patients altered body image. Another legacy from the medical model was that the therapist tended to be the controlling partner; prescribing, advising and providing resources.

Fortunately this is changing with the therapist now encouraging the patient to direct the rehabilitation process and to select and prioritise personal goals.

The main advantage of this model is that it is highly practical (maximising existing function and compensating for deficits) and is a well understood model which works well with a team approach. This model has stood the test of time better than most.

1.2.2.2 MODEL OF ADAPTION THROUGH OCCUPATION

Kathlyn Reed's model of adaption through occupation was developed in the early eighties (Reed, 1984) and like many other models, is still evolving. It is based on the premise that all individuals use a problem solving process in their recovery from illness. This model adheres to the processes of development, learning and adapting. Reed believes that the therapist can help the individual to adapt to illness through participation in occupations and that occupational performance can be influenced by the environment.

Reed defines occupation as that which engages a person's time, energy and attention and divides them into three categories; self-maintenance, productivity and leisure. Occupations, in turn, have three performance areas each requiring the use of abilities and skills: sensorimotor, cognitive and psychosocial.

The relationship between the therapist and patient is based on a joint partnership, however the patients own goals are used to direct the priorities of therapy. The ultimate goal of adaption through occupation is life-satisfaction, which should allow the individual to relate to the environment and to meet their needs balanced by performance in self-maintenance, productivity and leisure. The main advantages

of this model are that it is a flexible, practical, holistic, client centred, problem solving approach and is widely used in the rehabilitation of physical disability.

1.2.2.3 APPROACHES TO INTERVENTION

A model guides the therapist towards certain actions and provides the profession with its own, unique framework into which approaches can be slotted if and when required (Corr, 1997). In simple terms an approach is the interface between a chosen model and the therapists practice. It may belong to more than one profession and is the therapists chosen method of putting their model into practice. Hagedorn (1992) describes the way in which an occupational therapist may use an approach:

"An approach is used to describe a set of ideas and actions which provide the therapist with a particular focus which will lead to the selection of specific assessments, media, treatment techniques, or a style of relationship with the patient/client."

Occupational therapists, depending on the clinical field in which they work, may use one or a combination of approaches. Below is a list of some of the approaches available:

- Biomechanical approach
- Neurodevelopmental approach
- Functional approach
- Analytical approach
- Interactive approach
- Behavioural approach

- Cognitive approach

Occupational therapists working in stroke care will use the most appropriate approach to deal with a particular problem experienced by the patient. The two most frequently used approaches in stroke care are the neurodevelopmental approach and the functional approach.

Neurodevelopmental approach

The techniques associated with this approach were rooted in physiotherapy and have undergone some adaptation so that they may be applied to activity based occupational therapy. This approach is based on several primary assumptions:

1. Neurological development occurs in stages - these stages cannot be 'jumped' or missed. In order to regain function, the patient must be taken through a normal developmental sequence.
2. There is a strong link between sensory input and motor output.
3. Use of proprioception, positioning and reflexes can facilitate normal movement, posture and reactions. (Hagedorn, 1992).

The neurodevelopmental approach is an umbrella term which incorporates several sub approaches. These include: Bobath, Brunnstrom, Rood, Ayres and Carr and Shepherd; each having their own emphasis on the techniques used.

The neurodevelopmental sub approaches themselves are not always compatible with each other, as is illustrated in a quote from Trombly (1989);

"The Brunnstrom approach utilises primitive reflexes to elicit movement when the patient is otherwise unable to move, whereas the Bobath approach actively inhibits the appearance of these reflexes."

Functional approach

The functional approach aims to restore global functional independence regardless of the lack of specific ability or component skills. It therefore can justify the use of other skills, other parts of the body, aids and adaptations to compensate for lack of function and is often seen as a last resort when other approaches (e.g. neurodevelopmental) have reached a plateau or failed. This approach can be applied in different ways:

- teaching an alternative method which minimises the disability while encouraging function.
- use of specific devices to compensate for lack of function (e.g. one handed tin opener).
- use of another part of the body to perform the function of the disabled part.
- alteration of the environment.
- requesting other people to carry out tasks (e.g. homecare aid to wash and iron clothes).

In the ideal world the functional approach would only be implemented if the patient had reached a plateau or failed with the neurodevelopmental approach. However due to severe time constraints on therapy practice, the functional approach is often mixed with the neurodevelopmental approach. Therefore in clinical practice the occupational therapist will use one or both approaches to suit the patient's abilities and limited treatment time available.

1.2.3 OCCUPATIONAL THERAPY SETTINGS

Occupational therapists work in a variety of settings; hospitals (ward based), day hospitals, day centres, out-patient departments, social service departments and health centres.

Patients who are not admitted to hospital may be referred by their general practitioner for assessment and/or treatment, to any of the above occupational therapy services (with the exception of ward based therapy).

Day Hospital and Outpatient Services

Patients may be referred by their general practitioner to the day hospital or outpatient services if it is thought that they might benefit from further medical and/or therapy intervention. Patients can attend for up to five days a week but it is more usual to attend one or two days per week. Frequently in this setting occupational therapy provides practice in self care and domestic skills such as bathing, dressing and making a meal. Emphasis may also be placed on leisure pursuits such as craft and social activities.

In an evaluation study of therapy for stroke patients at home, Gladman et al (1991) reported that 17% of patients discharged from hospital returned to day hospital care and 20% returned to outpatient departments. In a recent community stroke survey (Noad et al, 1998) patients admitted to hospital were compared with those who remained at home. Of those not admitted to hospital, 46% per year were seen at outpatient departments and 9% attended a day hospital. This was in comparison with patients who had been admitted to hospital, of whom 71% were seen at outpatient departments and 23% attended a day hospital.

Occupational Therapy At Home

In some parts of the United Kingdom, new community occupational therapy posts are developing within primary care settings; for example in general practitioner surgeries or within health centres. These posts mainly come under the jurisdiction of the fundholding general practitioner, or more recently primary care groups, but in some cases these posts are funded by NHS hospital therapy managers. The efficacy of these new posts has not yet been scientifically evaluated.

In Nottingham and Southern Derbyshire the only occupational therapy service for stroke patients in their own home is by the social services occupational therapist (SSOT). These posts are funded by local health authorities.

This specialist group of occupational therapists are mainly concerned with clients who have permanent and substantial disability and aim to help clients live independently in the community. Social services occupational therapist's can provide equipment to help the client function more independently or can simply supply equipment to ease the burden on the carer, such as the provision of a hoist for bathing. Another remit of the SSOT is to give advice and facilitate structural changes within the disabled person's environment. This can range from outside ramps to enable wheelchair access to major adaptations such as building a ground floor toilet and bathroom. Social services occupational therapist's also provide advice on financial benefits when appropriate.

A recent report was commissioned by the Social Services Inspectorate (SSI) (1994) entitled "Occupational Therapy - The Community Contribution". This report surveyed 11 local authorities employing 293 SSOT's and examined the contribution of occupational therapy services in meeting the needs of people with disabilities. The report noted that 40% of referrals were made by clients and

carers and 22% of clients had a primary diagnosis of neurological origin. An average of 50 open cases were held per occupational therapist with the occupational therapist frequently acting as key worker, often by default as well as by design.

One of the main concerns of the SSI was with regard to staffing levels. Inspectors found a high level of part-time employment (47%) and an overall vacancy rate of 12%. Relatively inexperienced staff accounted for a high proportion of SSOT's; 13% had been qualified for less than a year and only 23% had held their present post for more than four years. The loss of staff was attributed to poor salary, lack of job satisfaction and very high overall workload.

The views of service users were also considered. Many stated that making first contact was difficult and that they had experienced an unsatisfactorily long wait for the initial assessment. Service users also expressed the view that where SSOT's were able to offer a broader role, giving time to their wider psycho-social needs and those of their carer, this was greatly appreciated.

This report provided a valuable insight into the difficulties of occupational therapists working in local authorities. It also confirmed that although the occupational therapist was a highly valued specialist, their individual case contribution was clearly very limited.

1.2.4 OCCUPATIONAL THERAPY AND RESEARCH .

Occupational therapy is a young profession to the world of research, with many occupational therapy training schools introducing research modules into the

curriculum in the mid 1990's. It was necessary to rectify this omission, as schools of occupational therapy at this time, moved from diploma to degree courses.

The British College of Occupational Therapists, also realising that the profession was falling behind in the scientific evaluation of occupational therapy practice, commissioned the Research and Development Committee to develop a Research Strategy to meet the research needs of newly qualified and practising occupational therapists (Eakin et al, 1997). Occupational therapists were reminded from the Code of Ethics and Professional Conduct (COT,1995) that they had:

" a duty to ensure that wherever possible their professional practice is based upon established research findings."

The Research Strategy also addressed how the College of Occupational Therapists could help and support occupational therapists involved in research at three levels:

- occupational therapists as research consumers
- occupational therapists as participants in research
- occupational therapists as proactive researchers.

One of the main recommendations of the strategy was to raise the profile of research within the profession, and to accomplish this the appointments of a Group Head for Research and a Research Information Officer were required. Another recommendation was that the Research and Development Committee became a Research Board, with the power to participate and vote at the meetings held by the Council of Occupational Therapists. All this was achieved in 1997.

This delayed action, in developing a research culture within the profession of occupational therapy, explains the dearth of evidence for practice in the therapy literature.

1.3 COMMUNITY STROKE REHABILITATION

Lincoln (1991) defines rehabilitation as “ the process of restoring an individual to the fullest level of function, a process which includes the promotion of physical, mental and social well-being and independence”.

Another definition by the World Health Organisation (1980) describes rehabilitation as:

"a problem-solving and educational process aimed at reducing the disability and handicap experienced by someone as a result of a disease, always within the limitations imposed both by available resources and by the underlying disease."

Wade (1992) interprets the WHO definition of rehabilitation as "acting upon pathology, impairment or disability to reduce handicap.....in essence it is the management of change." He then goes on to suggest that although the final goal is always to minimise handicap it is easier and most effective to concentrate on disability.

In the field of stroke rehabilitation, the reduction of disability poses a substantial challenge. The ultimate aim of stroke rehabilitation must surely be to return and maintain an individual in their own environment. In the ideal world this means being able to conduct all rehabilitation within the patient's home or immediate district or locality in which the patient lives; the delivery of this treatment is known as community rehabilitation. Several community rehabilitation studies have

investigated the effect of therapy for stroke patients admitted to hospital (see chapter 1.3.2 and 1.4), however the evaluation of therapy for stroke patients not admitted to hospital has yet to be investigated.

Before discussing the evidence available on community stroke rehabilitation, it is important to try to determine the number of patients remaining at home after stroke and define the reasons why this is so.

1.3.1 STROKE: HOME OR HOSPITAL?

Several authors (Bamford et al, 1988; Brocklehurst et al, 1978; Hewer, 1976; Wolfe et al, 1993) report approximately 40% to 78% of stroke patients are admitted to hospital. Attempts to report the incidence of stroke patients not admitted to hospital have proved to be very difficult. This is due to insufficient information, possibly as a result of undernotification by general practitioners. However Bamford and colleagues (1986) were successful in their identification of community stroke patients. In a prospective study of acute cerebrovascular disease encompassing a community of 105,000 people, Bamford et al collected data on 515 consecutive patients registered with the Oxford Community Stroke Project (OCSP). Referrals were primarily obtained from 50 collaborating general practitioners, though to ensure complete case ascertainment, a systematic search of hospital casualty and admission registers and death certificates was conducted. This study concluded that 42% of stroke patients with first ever stroke were not admitted to hospital. A comparison of stroke patients admitted to hospital and those living at home, demonstrated that having a severe stroke and living alone increased the odds of being admitted to hospital; points also endorsed by other

authors (Brocklehurst et al, 1978; Wade and Langton Hewer, 1985). In 42% of patients admitted to hospital there was no precipitating medical reason, and the provision of nursing or non-medical care was a contributory factor in 87% of cases. It is interesting to note that none of the general practitioners cited early access to rehabilitation as a reason for admission to hospital. Bamford and colleagues also commented that all stroke patients who were in a private or religious nursing home remained there after the stroke despite over half having had a severe stroke.

One of the main limitations of the OCSP was the recruitment of first stroke patients only. It is unfortunate that the authors did not also recruit patients with recurrent stroke in their study as this may have provided valuable additional data on stroke incidence and also further information on factors determining hospital admission. Another limitation of the study was that there was little information accumulated concerning disability.

A similar study by Wolfe et al (1993) also observed first stroke patients but provided a great deal of information on disability levels and use of services. Wolfe and colleagues found a higher rate of admission to hospital (78%) than has previously been reported elsewhere, with younger and incontinent patients more likely to be admitted. The overall level of rehabilitation rate was low, especially for stroke patients remaining in the community. Nineteen percent of stroke patients not admitted to hospital received physiotherapy, while only 4% received occupational therapy. Unfortunately the authors did not comment on who provided the occupational therapy service; this may have been provided by hospital out-patient departments, day hospitals or social service departments. However the work by Wolfe and colleagues further substantiates the claim that

community stroke services are haphazard, fragmented, and poorly tailored to patients' needs (Kings Fund Consensus, 1988).

The studies detailed above provide valuable information on the epidemiological aspects of stroke in the community, but we have to look to other studies to investigate the impact of community therapy on disability.

1.3.2 COMMUNITY STROKE REHABILITATION - WHAT EVIDENCE DO WE HAVE?

This section will consider the work of several authors who have made an important contribution to the evaluation of community stroke therapy services; encompassing the work of occupational therapists, physiotherapists, district nurses, social workers and speech and language therapists. The evaluation of community occupational therapy intervention per se, would also appropriately come under this heading, however it was considered more appropriate for it to be self contained and is reported at length in a later section of this chapter (Occupational therapy and community stroke rehabilitation - chapter 1.5).

A controlled trial in Bristol by Wade et al (1985a) investigated the value of a home-care service as a supplement to the services already available to stroke patients at home. Patients were randomly allocated to two groups depending on the district nursing service used by the 96 participating general practitioners. This study employed part time therapy staff (occupational therapist/ physiotherapist and speech and language therapist) who provided as much therapy to patients in

their own home as they thought necessary. A full time nurse acted as co-ordinator for both home and hospital patients. At six months after stroke there were no significant differences between the groups in terms of functional recovery, social activity or stress on relatives. Unfortunately there were several methodological difficulties with this project. The patients were not randomly allocated to the two groups; the group to which they were allocated was determined by the geographical coverage of the district nursing service. This may have resulted in notification bias. Wade and colleagues (1985a) commented that "the principle of randomisation at entry to the study was widely misunderstood and was unpopular with general practitioners." The study also employed part time therapy staff who may not have been in a position to offer the necessary optimal dosage of rehabilitation; a factor previously demonstrated to be important in functional outcome (Smith et al, 1981). The authors suggested that the service offered may not have been sufficiently different from that already available. Patients were also assessed on outcome measures by an 'unblinded' independent assessor; however observer bias seems unlikely as the authors found no significant differences between the two groups. It therefore appears that the resources available and the design of the study were inadequate to fully assess the effectiveness of this service provision.

In a later study Wade et al (1992) investigated a more focused area of rehabilitation and evaluated the effect of physiotherapy for stroke patients more than one year after the onset of stroke. This late intervention was not representative of current clinical practice and concluded that there was a significant but unsustained improvement in mobility.

Young and Forster (1991) also specifically investigated a physiotherapy component of stroke rehabilitation and compared the effectiveness of physiotherapy as delivered in a day hospital to physiotherapy delivered at home. All patients received an eight week course of therapy. Both groups demonstrated a significant improvement in functional abilities, however despite participating in fewer physiotherapy sessions, the patients receiving home physiotherapy were more capable of using a flight of stairs and had a higher social functioning score, as measured by the Frenchay Activities Index. (This index is scored from inactive (0) to active (30) and covers tasks such as cooking and going out.) The functional improvement shown at the eight week assessment was still upheld after a further four months, however despite a trend towards higher social functioning in the home treatment group, this did not reach statistical significance (Young and Forster, 1992). An interesting point from this study was that the patients in the home treatment group received virtually no occupational therapy (n=6), compared to the day hospital group (n=61). It has been suggested by Walker et al, (1996) that training in ADL activities in a hospital environment may be unrealistic and that success does not necessarily translate into a real life situation. Patients in the home treatment group were given practice in ADL tasks by the physiotherapist in their own domestic environment, which may have accounted for the small but significant difference between the groups on social functioning. It is possible that if the patients had received training in activities of daily living skills from an occupational therapist, who has specialised training in this area, the effect seen in the Frenchay Activities Index at eight weeks may have been upheld at six months.

Gladman et al, (1993a) conducted a similar study in Nottingham evaluating the effect of home care therapy (occupational therapy and physiotherapy) compared with a conventional hospital-based rehabilitation service. However despite being one of the largest trials of stroke rehabilitation reported in the United Kingdom, there were no overall significant differences between the groups in the effectiveness of the home care and hospital based services. In a more detailed analysis, Gladman and colleagues (1993a) illustrated that younger stroke patients appeared to do better with home therapy while some frail elderly patients benefited from day hospital attendance. These findings appear to conflict with the results described by Young and Forster (1992) but may be explained by the fact that patients in the Bradford study were younger and were less frail than patients in the Nottingham study.

The studies described above include many different aspects of community rehabilitation treatment and do not provide definitive answers to the individual research questions posed. The Stroke Collaborators Trialists Group (funded by Stroke Association) is currently including the information obtained from each study in a meta-analysis, with the aim of testing the null hypothesis; 'community stroke rehabilitation is ineffective.' The results from this meta-analysis will be easier to generalise than those from the individual trials because the number studied will be much larger and the peculiarities of any of the individual trials will become diluted.

It is not possible to quantify the direct effect of individual therapy intervention from the multi-professional community studies detailed above. However it is worthwhile noting that there have been other multi-professional randomised controlled trials,

based during in-hospital stay, which have indicated that significant differences between the groups may be attributed to occupational therapy provision.

1.4 OTHER MULTI-PROFESSIONAL STUDIES SUPPORTING THE BENEFITS OF OCCUPATIONAL THERAPY FOR STROKE PATIENTS

Garraway et al (1980) conducted one of the first randomised controlled trials comparing the management of elderly patients with acute stroke on a stroke unit and general medical wards. This study reported that patients from the stroke unit were discharged from hospital significantly earlier and had a significantly higher proportion of patients who were assessed as independent, than patients randomly allocated to the medical wards. Although a high proportion of patients in both groups were referred to physiotherapy, only 47% of patients on the medical wards received occupational therapy compared to 88% on the stroke unit. Patients on the stroke unit were also seen by the occupational therapist significantly earlier (mean = six days) than patients on the medical wards (mean = 21 days). Co-workers on this study (Smith et al, 1982) attributed the greater independence of stroke unit patients to the early referral to occupational therapy.

A similar study took place in Nottingham (Juby et al, 1996) randomising 176 patients to a stroke unit and 139 patients to general medical wards. This study concluded that patients randomly allocated to a stroke unit were significantly more independent in personal and extended activities of daily living than patients allocated to the general medical wards. Drummond et al (1996) analysed these results further and concluded that stroke unit rehabilitation seemed to improve

feeding, dressing and household activities more than in general medical settings, despite levels of mobility improving equally in both settings.

Despite a meta-analysis of 10 trials of stroke units (Langhorne et al, 1993) demonstrating that organised care for stroke was better than disorganised care, it is still unclear which aspects of stroke unit care influence outcome after stroke. However the results from the two studies detailed above may suggest that occupational therapy input could be an important factor.

1.5 OCCUPATIONAL THERAPY AND COMMUNITY STROKE REHABILITATION

The late eighties and early nineties witnessed an increased involvement in research activities by occupational therapists, mainly in the development of neurological outcome measures: Rivermead Perceptual Assessment Battery (Whiting et al, 1985), Stroke Drivers Screening Assessment (Nouri and Lincoln, 1994) and the Nottingham Stroke Dressing Assessment (Walker and Lincoln, 1991). Unfortunately due to the lack of research expertise within the profession at this time, many of these projects were led by psychologists and doctors. A report by the Royal College of Physicians (1992) highlighting the lack of research evidence, stated "there have been no reliable randomised controlled trials of occupational therapy treatment." This comment had been noted earlier by Lincoln (1991) who in a review of specialised techniques in rehabilitation commented "that although there is some indication that occupational therapy has beneficial effects, the main aspect of occupational therapy, that of giving practice in activities of daily living to improve functional performance, has not yet been

adequately evaluated." However by 1995, some evidence was beginning to emerge describing the benefits of specific occupational therapy intervention to stroke patients.

The following trials, all of which were randomised and controlled, evaluated the effect of occupational therapy treatment for stroke patients. All trials were conducted after discharge from hospital, at a time when there was very little sen/ice intervention; this allowed the researchers to investigate the specific effect of occupational therapy intervention.

1.5.1 TWO TRIALS OF LEISURE THERAPY

It is understood from previous literature that there is a decline in leisure activities after stroke (Sjogren and Fugl-Meyer, 1982; Feibel et al, 1982; Drummond 1990). Greveson and James (1991) suggest that there is little support or advice offered on leisure pursuits after stroke, while Sjogren and Fugyl-Meyer (1982) feel that this decline is due to the patients inability to cope with the impact of stroke.

Despite this healthy debate on why there should be a decline in leisure activities, other authors (Mancini, 1978; Allen and Beattie, 1984; Sneegas, 1986) suggest that satisfactory leisure is associated with life satisfaction; thus further reinforcing the importance of leisure pursuits in the aftermath of stroke.

One previous study of leisure rehabilitation conducted with stroke patients (Jongbloed and Morgan, 1991) found no significant difference between a treatment group and a control group. This study investigated 40 stroke patients discharged from hospital. The objective of the occupational therapy intervention was to assist the subjects in resuming former leisure activities, engage in new

activities, or both. Patients in both groups received five, one hour visits from the research therapist. Patients in the control group were not actively encouraged to participate in leisure pursuits but were asked questions about leisure activity involvement throughout their lifespan. Unfortunately this study contained methodological flaws. The control group were exposed to discussion about leisure, which may in itself encouraged the patients to resume leisure activities. It may therefore be that this 'discussion' intervention was neither an appropriate control group nor an appropriate comparison treatment group. It may also be that the size of the study was not sufficiently large to detect a significant difference between the groups.

Due to the limitations of the Jongbloed and Morgan study, Drummond and Walker (1995) conducted an evaluation of the effect of a leisure rehabilitation programme for a group of stroke patients discharged from hospital. As the authors were concerned that there may be a possibility of an attentional effect (thereby gaining a positive effect from someone merely visiting them), this randomised controlled trial used a three group design:

Group 1 the leisure rehabilitation treatment group, received active leisure treatment by a senior occupational therapist, who encouraged activities such as baking, drawing, gardening and craft work. Patients were seen for a minimum of 30 minutes a week for the first three months and a minimum of 30 minutes a fortnight thereafter.

Group 2 the conventional occupational therapy treatment group, were seen for the same duration and frequency as Group 1. Occupational therapy activities included transfers, washing and dressing and where appropriate, perceptual treatments.

Group 3 the control group, had no additional input from the research occupational therapist.

All patients were followed up at three months and six months after discharge from hospital by an independent assessor who was blind to patient group allocation.

Sixty five patients were entered into the study. A significant difference in level of the leisure scores was found for the leisure treatment group only; this group also had higher mobility scores and showed a trend for improvement in psychological well being. Unfortunately there was an imbalance between the groups with respect to patient age, with the leisure group having a slightly younger mean age. This did not appear to affect the overall results when analysis of co-variance was used to control the influence of age.

This study strongly indicated that leisure rehabilitation, as provided by an occupational therapist, was effective in increasing leisure participation after stroke and contradicted the previous findings of Jongbloed and Morgan (1991).

One of the main limitations of this leisure study was that the sample size was small and may not have detected small differences in the outcome measures used (such as mood). The authors were also unable to comment whether this treatment effect could have been achieved by someone who was not a qualified occupational therapist or indeed if the study could have been conducted in a less intensive manner. A multi-centre study is currently funded by the NHS Research and Development Programme, and aims to address some of the unanswered questions.

The trials of Jongbloed and Morgan (1991) and Drummond and Walker (1995) present conflicting results. It may simply be, that the different results reflect the amount of therapy offered in the two studies. However it is most likely that the

control group in the Jongbloed and Morgan study received ongoing leisure discussion which then influenced their leisure participation. (Both groups in the Jongbloed and Morgan study increased their leisure activity, whereas only the leisure group improved in the Drummond and Walker study.)

1.5.2 A TRIAL OF DRESSING PRACTICE

Occupational therapists traditionally give dressing practice to stroke patients during their stay in hospital, however this may only consist of one session where the patient is assessed and given advice. It is therefore not surprising that 54% of patients still need some assistance to dress at six months after stroke (Ebrahim and Nouri, 1987) and 36% still have difficulty at two years after the onset of stroke (Edmans and Lincoln, 1987).

Some investigations have previously been conducted into dressing after stroke (Bach et al, 1971; Warren, 1981; Tsai et al, 1983). Unfortunately these studies were primarily concerned with the associations between dressing difficulties and perceptual deficits and did not address the evaluation of actual dressing treatment.

Walker et al (1996) conducted a trial of dressing practice by an occupational therapist for stroke patients at six months after discharge from hospital. Thirty patients were randomly allocated to two groups. Group 1 received three months of treatment followed by three months of non-intervention. Group 2 received the opposite sequence, resulting in a cross-over design study. During the treatment phase, patients were seen for a mean of seven treatment sessions. At three months and six months after entry into the study, all patients were assessed on a

series of outcome measures, which included the Nottingham Stroke Dressing Assessment (Walker and Lincoln, 1991). There was a significant change in dressing abilities for both groups during the treatment phases only. The cross over design also enabled the authors to investigate dressing abilities during the phase of non-intervention, who concluded that the treatment effect was not lost during this phase. (In a similar trial of late physiotherapy by Wade et al, (1992) there was no indication of carryover into the non-intervention phase.)

It is possible that in this dressing study some improvement may have been because patients had been independent on discharge from hospital but had 'lost' the skill through lack of practice. Despite the demonstration of an improvement in dressing and undressing abilities, the treatment effect did not generalise into other areas of activities of daily living; this may have been due to the small numbers in each group.

In attempting to evaluate the late contribution of dressing practice to a group of stroke patients, this study concluded that despite positive results, much more research was needed to describe and understand the methods and strategies used by occupational therapists in this field.

1.5.3 A TRIAL OF ENHANCED SOCIAL SERVICE OCCUPATIONAL THERAPY

Occupational therapists bridge the boundary of health and social care to achieve the aim of resettlement after discharge from hospital. The main role of the social services occupational therapist (SSOT) is to encourage independence in self care and to ensure that the patient's environment is safe and conducive to an independent lifestyle. A study (Clarke et al, 1995) documenting the services to

211 stroke patients in Nottingham by a social services occupational therapist, reported a median of two visits; one visit to assess the needs of the patient and one to deliver aids and adaptations. After this time the case was closed. Such a service is clearly limited, with no 'hands on' therapy provided. This survey prompted a trial of enhanced SSOT (Logan, 1997) for stroke patients discharged from hospital. One hundred and eleven patients were recruited to the study; 53 to the enhanced service and 58 to the routine service. At three months after entry to the study the enhanced group had received significantly more treatment sessions and had higher extended activities of daily living scores. By six months there was no significant difference between the extended activities of daily living scores of the two groups except in the mobility subscale, which was better in the group receiving the enhanced service. The carers of patients receiving the enhanced service were however significantly less distressed than carers of those receiving the routine service. It therefore seems that enhanced social services occupational therapy is of some value to stroke patients living in the community. However this trial did not conduct any baseline measures which are used to describe the study participants and to check the comparability between the groups of factors which may affect the response to treatment. A main limitation of this study was that the number of patients allocated to each group was small, as drop out rates were high, and consequently the power of the study may not have been large enough to detect a significant difference in extended activities of daily living at six months.

1.5.4 TWO STUDIES OF OCCUPATIONAL THERAPY INTERVENTION AFTER DISCHARGE FROM HOSPITAL

To investigate the need for the continuation of occupational therapy after discharge from hospital, Corr and Bayer (1992) surveyed the long term needs of stroke patients in the areas of extended activities of daily living and social functioning. The findings of this survey concluded that patients, even with minimal physical barriers to independence, often did not return to normal day-to-day life. As a result of this survey, Corr and Bayer (1995) conducted a randomised controlled trial of further intervention by an occupational therapist after discharge from two stroke units in South Glamorgan. One hundred and ten patients were recruited; 55 to the intervention group and the remainder to the control group. Occupational therapy treatment included teaching new skills, facilitating independence in activities of daily living, giving information and liaising with other agencies. This intervention was supplementary to the already existing follow up services, such as day hospital and community physiotherapy. Patients in the intervention group were reviewed at two, eight, 16 and 24 weeks following discharge. There were no significant differences between the groups at one year after stroke in terms of personal activities of daily living, extended activities of daily living, mood or quality of life. However the intervention group received significantly more equipment and the number of hospital re-admissions were significantly reduced. The authors suggested that the lack of significant differences between the groups may have been due to the use of insensitive measures (the Barthel Index and Nottingham Extended ADL were used) and proposed that a qualitative methodology may have been more appropriate. This justification seems unlikely as the outcome measures used in this study have

been shown to detect improvement in other occupational therapy studies (Drummond and Walker, 1995; Logan et al, 1997). A possible reason for the lack of treatment benefit may be due to the timing of the outcome assessment schedule. It may be that patients had significantly improved by the end of therapy intervention but had lost their skills by the one year assessment. The authors also state that occupational therapy treatment was carried out as needed, but give no indication of mean number of visits made to the intervention group. It is possible that the frequency of intervention was too low.

A similar randomised controlled study was carried out in Glasgow by Gilbertson et al (1998). This study investigated whether or not an occupational therapy outreach service, targeted at improving extended activities of daily living and facilitating a smooth transition from hospital to home, could improve functional outcome for stroke patients. This study differed from Corr and Bayer (1995) in that it included all stroke patients discharged from hospital, not just patients discharged from stroke units, and was designed to give all patients in the intervention group six weeks of intensive occupational therapy at home. This study also assessed the resource implications of setting up a post-discharge occupational therapy outreach service. Sixty-seven patients were randomly allocated to the treatment group and 71 patients to the control group. There were no significant differences between the groups at baseline for demographic data (the majority of patients were living in the most deprived areas of Glasgow) however there was a slight imbalance, in favour of the control group, in the level of personal activities of daily living ($p=0.07$), as measured on the Barthel Index. At seven weeks after discharge from hospital the intervention group showed

significant benefits over controls in terms of self care activities, extended activities of daily living and handicap. At six months after discharge from hospital the intervention group retained better outcomes than the control group for self care activities.

As stated earlier the aforementioned studies were conducted on patients who had been admitted to hospital and were then discharged back into the community. Despite these studies suggesting that occupational therapy is beneficial in reducing disability, there is little information available of the effect of occupational therapy intervention on those stroke patients who were never admitted to hospital.

Regardless of where stroke patients are treated (at home or in hospital) the main aim of occupational therapy is to reduce disability. It is also important to understand the impact of impairments and handicaps in the recovery process from stroke. This concept of impairment, disability and handicap is well illustrated in the International Classification of Impairments, Disabilities and Handicaps (ICIDH) (WHO, 1980).

1.6 DISABLEMENT: IMPAIRMENT, DISABILITY AND HANDICAP

One of the problems frequently experienced in rehabilitation is the lack of a common language. Each hospital, and indeed each therapist and doctor may have their own language to describe the consequence of stroke. It is therefore imperative to have a universally approved terminology to describe the various effects of stroke.

The International Classification of Impairments, Disabilities and Handicaps (ICIDH) was put forward by the World Health Organisation (WHO, 1980) as a useful conceptual framework to describe the consequence of disease. Although the components of this framework are often described as being on a continuum, it must not be assumed that each component always leads to the next. As with any model, the ICIDH has its limitations, for example it is too detailed for routine clinical use and it seems biased towards rheumatological disease. However the most important concept of this model is that any illness can be considered at each level: impairment, disability and handicap. Disablement is the umbrella term which covers all three dimensions. Each dimension will be considered in turn.

Impairment

Impairment is described in the ICIDH as '....any loss or abnormality of psychological, physiological, or anatomical structure or function.' Impairments are therefore the direct consequence of the underlying pathological cause of stroke, such as cerebral infarction or haemorrhage. Impairments due to stroke include for example; hemiplegia, loss of sensation, hemianopia, memory problems, perceptual difficulties, mood disorders and aphasia. Difficulties in each of these impairments may have a significant influence on the success of therapy intention and on ultimate functional independence. For example, if a patient has difficulty with their memory they may forget the strategies to dress independently that the occupational therapist had shown them during treatment. Physical therapies, such as physiotherapy or electromyographic (EMG) biofeedback, are directed at influencing this level (Wariow et al, 1996).

Disability

Wood (1988) defines disability as 'the loss or reduction of functional ability and activity consequent upon impairment. It is characterised by excesses and deficiencies of behaviour and other functions customarily expected of the body or its parts, and represents objectification of impairments in everyday life and activity.' Wade (1992) succinctly summarises disability as 'the personal nuisance caused by pathology.' For example, disabilities caused by stroke may include inability to walk, feed, dress and bathe. The remediation of these difficulties in activities of daily living are the focus of occupational therapy treatment. Occupational therapy is primarily directed at this level and occupational therapists aim to find strategies to overcome functional difficulties.

Handicap

The ICIDH definition for handicap is '....a disadvantage for a given individual, resulting from an impairment or a disability that limits or prevents the fulfilment of a role that is normal (depending on age, sex, and social and cultural factors) for that individual.' Wade (1992) succinctly sums up the ICIDH definition and describes handicap as 'the freedom the patient has lost due to the pathology.....it determines the real severity of an illness.' However as each individual's response to disability may be different, it cannot be assumed that patients with equal disability will obtain similar handicap levels. Handicap is more difficult to define than the other levels of the ICIDH but may have the greatest impact on the individual's day to day life. Examples of handicap caused by stroke may include loss of employment, loss of driving licence and social isolation. Many aspects of

treatment will impact on handicap but occupational therapy and social work are those most obviously aimed at influencing this level (Wariow et al, 1996).

The ICDH is most commonly used in health care settings dealing with disablement, such as rehabilitation units and nursing homes. In the domain of stroke, the ICDH allows us to speak a common language and is an indispensable classification that provides us with a framework to evaluate and improve the everyday life of stroke patients living with disablements.

1.7 WHY USE A RANDOMISED CONTROLLED TRIAL?

"The randomised controlled trial is a tool to be used, not a God to be worshipped." Keith Andrews (1991)

When conducting a scientific study, it is essential to address why a specific methodological design has been chosen. There is no such thing as the perfect method; each method has its own strengths and weaknesses. However the crucial component in any chosen method must be to apply scientific rigour. This is what the author attempted to do.

The use of the randomised controlled trial (RCT) in health care was put forward for consideration (Cochrane, 1972) following misgivings of the adequacy of introducing innovations in health care on the basis of observational evidence only. It is now generally accepted as the gold standard for evaluation studies.

"The aim of the well designed RCT is to eliminate the possibility of reaching an erroneous or ambiguous conclusion; in particular, attributing beneficial effects to a treatment which it does not possess" (Moffett, 1991). This is one of the main advantages for choosing such a design, indeed it provides mathematical proof in support or against a specified form of treatment. The purpose of random allocation is to distribute prognostic factors evenly between the groups under evaluation. In doing so, this allows the resulting differences to be attributed to the intervention under test.

As seen earlier, there have been a few RCT studies evaluating the effect of occupational therapy intervention. Other occupational therapy studies have involved the use of single case designs (Edmans and Lincoln, 1989 and 1991) and **observational** techniques (Walker and Lincoln, 1990). These designs may have been implemented to generate an hypothesis or may have been applied due to the limited availability of selected patients. The main restriction with single case designs and observational studies, is the difficulty of generalisation of results.

An important consideration when planning an RCT, is the availability of suitable patients. Because stroke is such a heterogeneous condition, the findings of small trials make it difficult to extrapolate the conclusions and produce guidelines for patients seen in clinical practice. In Nottingham we are fortunate in that we have hospital and community stroke registers which make it possible to identify large numbers of patients. This makes it possible to ensure that the sample size is large enough to detect a significant difference between the groups.

It would be foolish to suggest that the implementation of an RCT would always provide a definitive answer to the question posed; it may merely contribute to the existing body of evidence and often points the way for further investigation.

1.8 THE PRESENT INVESTIGATION

From this review of occupational therapy and community stroke rehabilitation it is possible to see many gaps in existing knowledge. While there is growing evidence to support the efficacy of occupational therapy in the treatment of community stroke patients, we are still unclear whether or not treatment by an occupational therapist will improve disability levels for stroke patients not admitted to hospital. It may be that occupational therapy intervention, which includes practice in self care tasks, extended activities of daily living and encouragement to participate in leisure activities, will lead to a reduction in disability and improve the psychological impact of stroke.

It was therefore decided to conduct a study of occupational therapy with the overall aims:

1. To assess the level of disability experienced by stroke patients not admitted to hospital.
2. To evaluate the effect of occupational therapy intervention for stroke patients not admitted to hospital.
3. To determine the role of the occupational therapist in the treatment of community stroke patients.

CHAPTER TWO
MEASUREMENT

2.1 INTRODUCTION

Measurement is an essential component of any scientific evaluation and a chosen measure must provide the information needed to answer the research question posed. This chapter describes the qualities favoured in a suitable measure, the variety of measures considered for the present study and the reasons why a specific measure was chosen.

The Reader's Digest Universal Dictionary defines measurement as "a basis for evaluation or comparison: the measure of an achievement". Wade (1992), an eminent commentator in the field, defines measurement as "the use of a standard to quantify an observation".

There are four levels of measurement: nominal, ordinal, interval and ratio.

Nominal scales represent the lowest level of measurement and consist of labelling of classes of objects or events. For example;

- side affected by stroke - left/right
- patient lives - alone/with spouse/with carer

The majority of measures used by rehabilitationalists in stroke care, are ordinal in nature (i.e. ranked by the degree of 'goodness'). An ordinal scale however does not permit the therapist to determine how far apart the points are on the scale. It simply allows the points to be ranked hierarchically. For example, one is unable to say that a score of 18 on an activities of daily living measure is twice as good as a score of nine.

Interval scales not only provide a rank ordering but also specify the distance between the two points. An example of an interval scale would be temperature. There are very few interval scales used in rehabilitation.

The highest level of measurement is the ratio scale. An example of a ratio scale would be age. Not only is it possible to calculate the mean age of a group of patients but it is also possible to say that a patient of 90 years old is twice as old as a patient aged 45 years old.

Clinically, therapists frequently refer to the measurement of a patient as an 'assessment'. Wade (1992) argues that the term 'assessment' is wrongly utilised when used synonymously with 'measurement'. He states that although both terms are closely intertwined, assessment involves the process of determining the meaning of measurement(s). He does however concede that "in practice it is difficult to draw any firm distinction between the two."

2.2 WHY MEASURE?

To ensure good clinical practice, measurement should be an essential component of stroke management. Unfortunately many rehabilitationalists do not do this routinely. We must therefore ask ourselves the question 'Why do we measure?'

There are many reasons for the use of measures and the following list is not exhaustive, however the main reasons for the use of measurements in this thesis are presented below.

1. **Diagnosis.** Measurements may be used to document whether or not a specific problem exists, such as the presence of speech or language problems, difficulty remembering instructions, or difficulty getting dressed.
2. **Quantification.** By quantifying the extent of the problem it is possible to establish the level of severity.
3. **Process.** During the rehabilitation process it is necessary to document the type and amount of therapy given as this provides valuable information when investigating the efficacy of a particular treatment.
4. **Finance.** To establish the patient's eligibility for allowances or to determine the payment of therapists.

2.3 CHOOSING A MEASURE

One of the most difficult challenges for the health care worker in stroke rehabilitation, is deciding which measure to use. Before making a choice it is necessary to review all available relevant measures, to assess their suitability in each particular circumstance. For example, the London Handicap Scale (Harwood et al, 1994) was designed specifically for use in epidemiological and randomised controlled studies and would be of little value to clinicians.

It is also advisable to use an existing measure, providing it meets several criteria:

1. Is it standardised?

In order to obtain accurate results, each assessment must be administered in a consistent way. The assessment must be precisely defined and comprehensive

instructions provided. Administration procedures should be strictly adhered to, so that it is performed in the same way by each assessor and on each occasion.

2. Is it valid?

The Collins dictionary definition of valid is 'sound; capable of being justified.' To obtain a sound assessment it must be:

- (a) Relevant i.e. does it measure what it was designed to measure?
- (b) Complete i.e. has it collected all the relevant information?
- (c) Accurate i.e. "the indication of proportion of times that an answer to a question will be correct" (Young, 1971)

Validity is a property that is greatly sought when devising or considering any measure used in stroke outcome. Wilkin et al(1993) notes that there are three main types of validity:

- **Construct validity.** A construct can be thought of as a 'mini-theory' to explain the relationships among various behaviours or attitudes. Many constructs have arisen from larger theories or clinical observations, before there were any ways of objectively measuring their effects (Streiner and Norman, 1989). For a measure to have construct validity, one must ask "does it agree with other variables, that in theory, it ought to agree with?"
- **Criterion validity.** For a measure to have criterion validity it must be tested against another measure which is accepted to be a 'gold standard'. In simple terms; does it agree with other existing measures?

- **Content validity.** This ensures that the measure has enough items and adequately covers the domain under investigation. Does it cover the right areas? One way of checking the content validity is to ensure that all the component items come from the same level of impairment, disability or handicap.

3. Is it reliable?

A reliable test must be sound and consistent, and must also have:

- (a) Inter-rater reliability i.e. do different assessors assessing the same subject obtain the same score?
- (b) Intra-rater reliability i.e. does the same assessor on different occasions obtain the same score?
- (c) Test-retest i.e. on retesting the same patient in a situation where nothing is expected to have changed, are the same scores obtained. (Partridge and Barnitt, 1986)

Wade(1992) suggests that the ideal stroke measure should not only be standardised, valid and reliable but also be:

- a. Clinically useful** - this enables realistic treatment goals to be set.
- b. Provide comprehensive data**
- c. Able to detect small changes** - this will allow the measure to be responsive enough to detect the effect of therapeutic interventions.
- d. Easy and quick to administer** - this is especially important if multiple measures are to be administered.
- e. Easily communicable.**

2.4 WHEN SHOULD A MEASURE BE USED?

In any randomised controlled trial, baseline and outcome measures are implemented at different time points. The purpose of assessments before intervention (baseline) and at the end of intervention (outcome) are described below.

Baseline assessments are used to check the comparability between the groups on factors which may affect the response to treatment. For example, if patients allocated to the treatment group had significantly more memory or perceptual problems than the patients allocated to the control group, this may mean that patients in the treatment group have more difficulty in achieving independence in extended activities of daily living. This potential problem of imbalance between the groups would therefore have a bearing on the interpretation of the subsequent outcome assessments.

Outcome assessments at six months (i.e. end of treatment phase) are used to assess factors likely to be affected by occupational therapy intervention. For example, if the main aim of occupational therapy is to reduce disability and handicap, it is therefore reasonable to postulate that occupational therapy treatment may influence activities of daily living (self care and extended) and level of handicap.

Outcome assessments at twelve months (i.e. six months after treatment phase has finished) are used to assess if there are any continuing benefits from the occupational therapy treatment phase.

The measurements used in this thesis were chosen using the aforementioned selection criteria. The remainder of this chapter will discuss the various measures considered and reasons will be given why specific measures were selected.

The administration of the chosen measures will be discussed in chapter three. A list of the chosen measures (baseline, six months and one year) is also detailed in chapter three.

2.5 ACTIVITIES OF DAILY LIVING.

'The ADL index is a tool to help; it does not give the absolute truth.' Derick T. Wade (1992).

Activities of daily living is a global term encompassing the day to day tasks individuals need to carry out in every day life (or at least every week), for example feeding, toileting, bathing and dressing. Problems encountered with activities of daily living after a stroke are common and often remain unresolved. For example, Ebrahim and Nouri (1987) studied 120 patients at six months after stroke, to establish the extent and type of help provided by relatives and friends. Assistance in dressing was given to 54% of patients. Edmans and Lincoln (1987)

investigated functional independence two years after the onset of stroke and found that 36% of stroke patients still required assistance with dressing.

An activity of daily living (ADL) scale is a measure of disability and has become the mainstay of disability measurement (Barer and Nouri, 1989).

There are many ADL scales available to the health care professional with variable assessment criteria and methods of scoring. However despite ADL being a central part of occupational therapy practice there has been very little contribution to this field by the profession itself (Eakin, 1989).

There are three main categories into which an ADL scale will fall:

1. Checklist. This type of scale acts as an aide memoir to ensure no aspect of disability is overlooked. These scales tend to describe disabilities but do not measure them. Some occupational therapists use ADL checklists in clinical practice to record difficulties, however as the present study of occupational therapy was to evaluate the effect of occupational therapy intervention, an ADL scale which measures specific daily activities was thought to be more suitable.

2. Summed Index. In these scales, patients are tested on several items (each being scored) and the individual scores are summed to give a total score. The Barthel Index (Mahoney and Barthel, 1965) is an example of this type of scale.

3. Hierarchical Scale. These scales are based on the premise that certain activities precede others. The inherent assumption is that 'a person who is less fully independent will have lost specific functions in a predictable sequence'

(Gresham et al, 1980). The Rivermead Activities of Daily Living Scale (Whiting and Lincoln, 1980) is an example of this category.

ADL indices should record the patients actual performance and not an expected performance; 'does the patient do it' and not 'do you think the patient can do it'. Wade (1992) states that if there is a discrepancy between observed performance and expected ability, this should not be interpreted as a failure of the index but an opportunity for rehabilitation.

It is usual for stroke patients admitted to hospital to be assessed in self care activities of daily living such as feeding, dressing and bathing. This area is known as personal activities of daily living (PADL). However as patients recruited to this trial of occupational therapy were already living in the community, it would be reasonable to assume that they may also be participating in extended activities of daily living (EADL), such as making a hot drink, doing the washing up, using public transport and using the telephone. It was therefore decided that two ADL scales were needed; one to cover the basic self care tasks and one to cover the more difficult extended tasks of daily life.

There are many ADL indices in use throughout the United Kingdom; Feinstein et al (1986) identified 43 published indices. Of the reviewed self care ADL measures four were considered.

- **The Nottingham 10 Point ADL Index** (Ebrahim et al, 1985) was developed for specific use with stroke patients. It was developed in response to the need for

a ranked scale of self care activities of daily living for use with elderly stroke patients. The purpose of a ranked scale is that the score obtained, may be translated into a certain level of activity. For example, if two patients have the same scores of four, they will then have the same level of activity; they will be able to drink from a cup, eat, wash their face and hands and transfer from the bed to the chair. This makes the meaning of the score easily communicable to other members of staff. The Nottingham 10 point scale is easy to use (Ebrahim et al, 1985). Unfortunately it requires observation and is therefore time consuming to complete. It also lacks evidence for reliability, has no published guidelines and is not used widely either for research purposes or in clinical practice.

- **The Rivermead Activities of Daily Living Scale** (Whiting et al, 1980) was developed for use in both research and clinical practice. It is a comprehensive scale containing three sections: self care, household 1 and household 2. It is a hierarchical scale, requiring actual observation of the activities. However if the patient scores three consecutive fails then the assessment is terminated, as it is unlikely that they would be able to complete the remaining activities. It was developed for specific use with stroke patients and is valid for younger (Whiting et al, 1980) and older stroke patients (Lincoln and Edmans, 1990) and has inter-rater and test-retest reliability (Whiting et al, 1980). It has also been demonstrated to be sensitive to change in an occupational therapy trial of dressing practice after stroke (Walker et al, 1996). However it was decided not to use this scale as it required observation of each item and therefore would be too time consuming for use in the present study.

- **The Northwick Park Index of Independence in ADL** (Benjamin, 1976) was developed to meet the needs of a large randomised controlled trial of therapy late after stroke. It includes many self care activities, and also incorporates household tasks. An example of activities included are dressing, use of taps, transfer off floor and indoor mobility. The validity (Sheikh et al, 1979) and reliability (Sheikh, 1986) of the Northwick Park Index have been established. However, as with the Rivermead Activities of Daily Living Scale, it is time consuming to complete as it requires actual observation of every item.
- **The Barthel Index** (Mahoney and Barthel, 1965) was the self care ADL measure of choice. The Barthel Index is reliable (Collin et al, 1988; Roy et al, 1988) and the predictive validity has been demonstrated for ability to live independently (DeJong and Branch, 1982), and vocational status 18 months after discharge from hospital (Goldberg et al, 1980). The Barthel has also been shown to be sensitive to clinical interventions both in hospital (Indredavik et al, 1991) and in the community (Young and Foster, 1992). It does, unlike some of the aforementioned indices, cover continence of both bladder and bowel. These are important activities in which to achieve independence, so that a complete resettlement into the community may be possible. However it may be argued that continence is an impairment and not a disability. One of the main advantages of the Barthel Index is the ease with which it is administered; it is a self report assessment and does not require actual observation of each activity. The main reason for selecting this index was not that the Barthel is 'better' than the other measures considered, but that it is the

most widely-used ADL index in rehabilitation studies of stroke (Wade and Collin, 1988).

It is possible that patients who are not admitted to hospital, may be independent in simple self care activities but have difficulty with extended activities of daily living, such as shopping or travelling on public transport. Two measures were considered.

- **The Frenchay Activities Index (FAI)** (Holbrook and Skilbeck, 1983) was developed to measure activities that were not essential to functional independence but which reflect a higher level of social independence. It is a comprehensive measure of extended activities and includes activities such as housework, shopping, hobbies, travelling and gainful employment. The FAI has been documented to be a valid, reliable and sensitive measure (Wade et al, 1985b; Schuling et al, 1993) and has been used in many studies of stroke. However in more recent trials, the FAI has been found to be unresponsive to therapeutic intervention; in a trial of mobility one year after stroke (Wade et al, 1992), a trial of specialist nurse support for stroke patients in the community (Forster and Young, 1996) and a trial of a stroke family care worker (Dennis et al, 1997). The Frenchay Activities Index requires patients to recall the frequency of participation of each activity in the last three months and the last six months which may prove difficult for stroke patients with cognitive difficulties, such as impaired memory. It was therefore considered unsuitable for use in the present trial.

- **The Nottingham Extended Activities of Daily Living** (Nouri and Lincoln, 1987) is a hierarchical scale and was developed for use with stroke patients living in the community. It is a simple index of 22 items covering four areas: Mobility, Kitchen, Domestic tasks and Leisure. Gladman et al (1993b) have also demonstrated that the kitchen and domestic sections can be combined to form a single household hierarchical scale. The validity (Gladman et al, 1993b; Lincoln and Gladman, 1992) and reliability (Nouri and Lincoln, 1987; Gompertz et al, 1993) of the Nottingham Extended Activities of Daily Living scale have been well established. This scale has been used in other trials evaluating the effect of occupational therapy intervention (Drummond and Walker, 1995; Logan et al, 1997; Corr and Bayer, 1995; Gilbertson et al, 1998) and has been found to be sensitive to the effects of therapeutic intervention (Drummond and Walker, 1995; Logan et al, 1997; Gilbertson et al, 1998). The Nottingham Extended Activities of Daily Living scale was therefore the measure of choice.

2.6 MOTOR FUNCTION

Physiotherapists are aware of the need to monitor the recovery of stroke patients, with many physiotherapy departments using assessments to record a patients' level of function (Sackley and Lincoln, 1990). Unfortunately despite the fact that many published standardised assessments have been developed, therapists are reluctant to use them, preferring often to develop their own.

In a recent review of standardised scales to document outcome in stroke rehabilitation, Lennon (1995), suggests the use of three motor scales; the Motor Club Assessment (MCA) (Ashburn, 1982); the Motor Assessment Scale (MAS)

(Carr et al, 1985) and the Rivermead Motor Assessment (RMA) (Lincoln and Leadbitter, 1979).

Two additional assessments are often used to monitor motor recovery after stroke: the Motricity Index (Demeurisse et al, 1980) and the Brunstrom Fugl-Meyer Assessment (Fugl-Meyer et al, 1975). However these assessments concentrate on impairment and pay little attention to functional motor tasks. For this reason they were not considered for use in the present trial.

The three assessments recommended by Lennon (1995), the MCA, MAS and the RMA, were therefore investigated for possible use in the present trial. Each will be considered in turn.

The Motor Club Assessment (Ashburn, 1982) was compiled by a consensus group of specialist physiotherapists and contains two sections. The first section covers motor ability and is concerned with movements of the arm and leg. The second section concentrates on the disability related aspects of mobility and incorporates activities such as walking, standing and transfers. The validity and reliability of this assessment have not been formally tested, but it is used in many physiotherapy departments in the United Kingdom.

The Motor Assessment Scale (MAS) (Carr et al, 1985) was developed for use in clinical practice and for research. It is a hierarchical scale designed to measure functional capabilities of patients with stroke and is the assessment of choice for physiotherapists using the Movement Science Approach (Ada and Canning, 1990). It comprises eight sections:

- supine to side lying

- supine to sitting over side of the bed
- balanced sitting
- sitting to standing
- walking
- upper-arm function
- hand movements
- advanced hand movements.

In addition to these eight motor items, the MAS includes one section measuring general tone (the inter-rater reliability for the tone subsection is poor). The MAS has been well studied, with evidence of good validity (Poole and Whitney, 1988; Loewen and Anderson, 1988), test-retest reliability (Carr et al, 1985) and inter-rater reliability (Carr et al, 1985; Poole and Whitney, 1988). However this assessment is time-consuming, taking 20-30 minutes to complete. For the purpose of the present study a shorter, less detailed assessment was required.

The Rivermead Motor Assessment (Lincoln and Leadbitter, 1979) has three sections: gross function, arm, leg and trunk and covers aspects of both functional disability and impairment. The assessment was designed to be used in clinical and research settings and has been demonstrated to be both valid and reliable (Lincoln and Leadbitter, 1979, Collen et al, 1990). As the present occupational therapy trial was not designed to influence impairment, the gross function section was the only section considered. Like the other sections, the gross function follows a hierarchical scale. This reduces the administration time, simplifies the interpretation of its scoring system and conserves the patient's energy. The scalability (i.e. that assessed items are in the appropriate order of difficulty) has

been further confirmed for the gross function section in both acute (Adams et al, 1997a) and nonacute stroke patients (Adams et al, 1997b). The gross function section has also been found to be reliable when administered verbally (Sackley and Lincoln, 1990) and may be used separately from the rest of the scale (Collen et al, 1990). It is quick to administer (taking approximately five minutes to complete), and was already familiar to the therapists employed in the trial. The RMA is recommended for use by the Association of Chartered Physiotherapists Interested in Neurology (ACPIN) (Lennon, 1995).

The main reason for using a motor assessment in this trial of occupational therapy was to describe the functional capabilities of the population studied and not to detect recovery of impairment of the arm or leg. Therefore a brief assessment which focused on gross motor functional abilities was sought. The Rivermead Motor Assessment (gross function section) was therefore the measure of choice.

2.7 LANGUAGE

It has been estimated that 37% of stroke survivors have a speech and language disorder (Bonita and Anderson, 1983). The Oxford Community Stroke Project reported an incidence of 20% (unpublished data, Wariow et al, 1996). Although there may be discrepancies in the reporting of speech and language difficulties, Enderby and Phillips (1986) suggest that the incidence and prevalence of speech and language problems are frequently underestimated.

speech and language therapists use long, linguistically complex and carefully validated aphasia tests which are not suitable for administration by other health care professionals. "Short tests are available: some are parts of tests screening for cognitive disturbance, some have not been validated and others are too insensitive to be useful" (Enderby et al, 1987). For these reasons the **Frenchay Aphasia Screening Test** (FAST) (Enderby et al, 1987) was developed. This test was not designed to differentiate between the different types of aphasia but to provide an indication of deficits in the four main areas of expression, understanding, reading and writing. Comprehension is tested by asking the patient to respond to questions based on two stimulus cards; one depicting a riverside scene and the other shape recognition. Expressive skills are evaluated by asking the patient to describe the same riverside scene and to name as many animals as they can remember in 60 seconds. The FAST has been found to be quick to administer (3-10 minutes), simple, reliable and valid (Enderby et al, 1987; O'Neill et al, 1990).

The Sheffield Screening Test for Acquired Language Disorders (SST) (Syder et al, 1993) is a similar assessment and can also be administered by professionals other than speech and language therapists. This screening test, which includes receptive and expressive language skills, enables health care professionals to detect the presence of high-level language disorders in adults. This gives the assessor a clear indication whether or not a speech and language referral is required. The Sheffield Screening Test for Acquired Language Disorders has been demonstrated to be valid and reliable (Syder et al, 1993).

As the FAST and the SST were both developed to enable health care professionals to detect the presence of language disorders in adults, it was difficult to decide which one to utilise as a baseline measure of language ability (both were valid and reliable). Al-Khawaja et al, (1996) compared the FAST with the SST. This study demonstrated that the two tests were simple, short and similar in their predictive value for the screening and diagnosis of aphasia. Al-Khawaja found the SST to have additional advantages, as it does not require any specific equipment or stimulus cards, and it was not affected by visual neglect. The SST also detects high level speech difficulties (Syder et al, 1993) which might be more likely to occur in a community sample. The SST was therefore the chosen measure.

2,8 PERCEPTION

"Perception involves active processing of the continuous torrent of sensations..... the perceptual functions include such activities as awareness, recognition, discrimination, patterning, and orientation." Lezak (1995).

Perceptual problems are common in both right and left hemiplegic stroke patients (Edmans and Lincoln, 1987). An example of a perceptual problem may be when a patient has the visual ability to recognise an object, yet is unable to appreciate it's spatial location (i.e. recognises a garment of clothing but is not sure how to put it on). Such deficits can adversely affect the patients' response to the rehabilitation process; consequently affecting their ability to perform activities of daily living (Andrews et al, 1980; Bernspang, 1987; Edmans and Lincoln, 1990).

Occupational therapists, in their daily work, attempt to diagnose and treat the perceptual problems experienced by stroke patients.

The Rivermead Perceptual Assessment Battery (RPAB) (Whiting et al, 1985) was specifically designed for use by occupational therapists and has been widely adopted as a standardised assessment instrument (Walker et al, In preparation). The RPAB consists of 16 subtests ranging in difficulty from simple matching of pictures to more complex three dimensional spatial tasks. The main disadvantage of this assessment is that it takes up to two hours to complete. A shortened version (Lincoln and Edmans, 1989) is available but was still considered to be too time consuming to administer as a baseline measure in this trial of occupational therapy.

The Star Cancellation Test is one of 15 subtests of the Behavioural Inattention Test (Wilson et al, 1987) and has been documented to be the most sensitive of the 15 subtests at detecting visuospatial neglect (Halligan et al, 1989). Stone et al (1991) included this test as one of six short tests and found that this 'pocket battery', validated against an occupational therapist's assessment of neglect on self care tasks, detected neglect in 90% of neglect patients. The Star Cancellation Test is an untimed test and comprises an apparent jumble of words, letters, and stars. Of the stars, some are large and some are small. It is the smaller of the stars that are the target stimuli. The examiner demonstrates by crossing out two of the small stars, leaving 54 to be crossed out by the patient. It is a simple test to administer and provides a degree of quantification of unilateral spatial neglect. However in the present trial we wished to implement a perceptual screening tool

that covered the wider assessment of perceptual organisation (not only spatial neglect).

The Rey-Osterrieth Complex Figure Test (Rey Figure) (Rey, 1959) was designed to investigate perceptual organisation. The patient is asked to copy the drawing of a complex figure which is made up of 18 components. It is standardised and has been found to be reliable (Carr and Lincoln, 1988). Administration and scoring procedures for this test are well described by Lezak (1995). Lincoln et al. (1998a) suggests that occupational therapists use the Rey Figure as a quick perceptual screening tool and noted that it was sensitive for use as a screening device (i.e. will detect all those who have a perceptual problem) but was unfortunately not specific (i.e. may identify some people as having a perceptual problem when they have not). The Rey Figure was administered as a baseline measure.

2.9 MEMORY

'You have to begin to lose your memory, if only in bits and pieces, to realise that memory is what makes our lives. Life without memory is no life at all.....Our memory is our coherence, our reason, our feeling, even our action. Without it we are nothing.....'

Luis Bunuel,

Impaired memory is common in patients who have suffered a stroke (Tinson and Lincoln, 1987; Stewart et al, 1996) and may have a significant influence on functional recovery after stroke. Various scales have been developed to measure memory specifically; these include the **Wechsler Memory Scale** (WMS) (Wechsler, 1945), the **Rey Auditory Verbal Learning Test** (AVLT) (Lezak, 1976) and the **Benton Visual Retention Test** (VRT) (Benton and Sivan, 1992) and the **Recognition Memory Test** (RMT) (Warrington, 1984). All the above scales were designed to assess various aspects of memory in depth, but a memory assessment was needed that was quick to administer and could be used in isolation.

The **Adult Memory and Information Processing Battery** [AMIPB] (Coughlan and Hollows, 1985) contains six tests; two verbal memory tests (one of which is a story recall), two visual memory tests and two information-processing tests. Unlike other memory assessments (e.g. the Wechsler Memory Scale) the AMIPB was developed on an English population and was therefore more relevant for patients

in the present trial. The AIMPB has proven validity and reliability (Coughlan and Hollows, 1985).

The reason for assessing memory in the present trial was to establish the impact of memory difficulties on the daily life of patients after stroke. It has been documented in previous studies that a story recall test is the strongest predictor of reported memory performance in daily life in elderly adults (Sunderland et al, 1983; Tinson and Lincoln, 1987). Lezak(1995) comments that "story recall is a more natural medium for testing memory than smaller speech units."

For the reasons described above the story recall section of the AIMPB was used in the present trial.

2.10 ASSESSMENT OF MOOD

Mood is defined in the Reader's Digest Universal Dictionary as "a temporary state of mind or feeling, as evidenced by one's behaviour or the tendency of one's thoughts." Patients who have had a stroke have more mood disorders than their 'non-stroke' peer group (House et al, 1991; Burvill et al, 1995). In the first year after stroke, mood disorders have been estimated to affect 23% to 60% of patients (Young and Forster, 1991; Wade et al, 1987; Robinson et al, 1984; Ebrahim et al 1987; Burvill et al, 1995). Of the symptoms identified after stroke, depression and anxiety are particularly common. The estimates of numbers of individuals affected by depression vary, however several authors have reported approximately one third of stroke patients are depressed at any stage up to two years after their stroke (Robinson et al, 1984; Ebrahim et al, 1987; Wade et al, 1987).

Many commentators conclude that depression has serious implications for the successful recovery after stroke. Depression in stroke survivors has been associated with delayed resumption of premorbid social activities (Fiebel and Springer, 1982), lower levels of social activities (Wade et al, 1987), fewer social contacts (Astrom et al, 1993), and a decline in leisure activities (Drummond 1990). Community based stroke studies (House et al, 1991; Wade et al, 1987) have reported lower prevalence figures for depression after stroke than studies using samples of hospitalised patients. For example, House et al (1991) reported the frequency of depression in an Oxford community based study as approximately 20% at one month after stroke.

Depression is thought to be related to the extent of functional recovery after stroke (Ebrahim et al, 1987) and since occupational therapy aims to directly address this area, it was decided to measure the depression in this community sample. The aim was also to assess whether or not occupational therapy treatment had a significant impact on mood.

Ideally, the diagnosis of depression would be made by psychiatric interview (House, 1987), however this was felt to be impractical when screening large numbers of patients. For the purpose of this study a self-report questionnaire was more appropriate. Many measures have been developed to detect depressive symptoms, however few have been validated for use with physically disabled adults. We therefore only considered measures that had previously been used with stroke patients.

The **Beck Depression Inventory** (Beck et al, 1961) is a self report questionnaire consisting of 21 items (each item has four statements assigned values from zero to three) and has been used with stroke patients. Validity and reliability of the Beck Depression Inventory are all well proven in a wide variety of circumstances (Beck and Beamesderfer, 1974; Meites et al, 1980), however in stroke the validity has not yet been established. It has been criticised for being too difficult to understand (Wade et al, 1987) and some patients were unable to complete it (House et al, 1991).

The **Self-Rating Depression Inventory** (Zung, 1965) is a twenty item self-rating scale designed to provide a simple quantitative measurement of the subjective experience of depression. The twenty items are divided between positive and negative phrasing which is intended to detract patients from observing a trend in their responses. For example, 'I have trouble sleeping through the night' and 'I find it easy to do the things I used to.' Unfortunately the validity has been questioned (Wilkin et al, 1992) and in particular it's validity as a measure of depression in patients disabled by stroke has not yet been established.

The **Wakefield Depression Inventory** (WDI) (Snaith et al, 1971) was primarily designed for use with physically healthy young people but has been used in several studies of stroke (Lincoln et al, 1985; Drummond and Walker, 1995). This inventory consists of twelve statements to which the patient is required to assign one of four responses;

Yes, definitely

Yes, sometimes

No, not much

No, not at all

Examples of the statements in the WDI would include: 'I have lost interest in things' and 'I get off to sleep easily without sleeping tablets.' The maximum score which can be obtained by the WDI is 36.

The WDI only assesses depression and not other aspects of psychological distress, such as anxiety. The validity of the WDI to diagnose depression in the older physically disabled adult has yet to be demonstrated.

CHOSEN MEASURES:

The **General Health Questionnaire** (Goldberg, 1972) is a self-administered screening questionnaire suitable for use in community and non-psychiatric clinical settings. It is based on the principle that psychological distress depends on a critical number of key symptoms rather than any particular symptom. It is one of the most widely used measures of psychological distress in stroke (O'Rourke et al, 1998) and has been used extensively in studies of stroke rehabilitation (Lincoln et al, 1985; Juby et al, 1996; Young and Foster, 1992; Dennis et al, 1997). There are several available versions of the GHQ: 12, 28, 30 and 60.

The GHQ-28 was developed using factor analysis (Goldberg and Hillier, 1979) and has an advantage over the other versions in that it provides four scaled sub-scores:

1. somatic symptoms
2. anxiety and insomnia
3. social dysfunction

4. severe depression

These sub-scales are not independent of one another but can be used to detect the area in which problems are concentrated.

The GHQ -28 was chosen because it does not take long to administer (approximately ten minutes) and has proven validity when used with neurological patients (Bridges and Goldberg, 1986). The sensitivity of the GHQ has been demonstrated in studies of stroke rehabilitation (Juby et al, 1996; Dennis et al, 1997).

The **Hospital Anxiety and Depression scale** (HAD) (Zigmond and Snaith, 1983) was specifically designed to cover both depression and anxiety and was intended to be used as a screening tool and to chart progress over time. The HAD scale specifically excludes somatic symptoms such as dizziness and headaches which might be attributable to a physical condition. The scale consists of fourteen items; seven of which refer to anxiety and seven to depression. It is a brief assessment to administer taking approximately five minutes to complete.

The validity of the HAD scale has been established (Zigmond and Snaith, 1983; Aylard, 1987; Wilkinson and Barczak, 1988) and has been used in several stroke studies (Lincoln et al, 1997 and Dennis et al, 1997). In an evaluation study of a stroke family care worker (Dennis et al, 1997) the HAD scale has been demonstrated to be a sensitive measure.

The **Simple Mood Rating** (Lincoln et al, 1985) was chosen as a simple measure of patient mood. This measure was included, because an unknown percentage of stroke patients may have experienced difficulty with the more complex mood

assessments. For example, patients with mild comprehension difficulties would be unable to complete the General Health Questionnaire. However it should be noted that the Simple Mood Rating lacks reliability, validity and has unknown sensitivity.

The burden of stroke is carried not only by the patient, but also by the carer. As many as 79% of stroke patients live with a carer (Legh-Smith et al, 1986). Wade et al (1986) in a large community study of stroke, found 11-13% of carers had significant depression over the first two years after stroke. Carnwath and Johnson (1987) reported from a sample of stroke patients that 39% of spouses were depressed compared with 12% of age and sex matched controls. Depression experienced by the carer may have an adverse effect on the stroke patient, if they are rendered less able to provide optimal care (Evans et al, 1991). It was therefore considered important to measure the psychological impact of stroke on the carer.

The Caregiver Strain Index (Robinson, 1983) was specifically designed to assess the level of strain experienced by the carer of the patient. The use of this index is becoming increasingly popular in stroke studies (Wilkinson et al 1997; Lincoln et al, 1998b).

The Caregiver Strain Index contains thirteen items related to strain, including inconvenience, confinement, family adjustments, upsetting behaviour, the person seeming to be different, work adjustments, changes in personal plans, completing demands on time, emotional adjustments, the feeling of being completely overwhelmed, disturbed sleep, physical strain and financial strain.



The validity and reliability of the Caregiver Strain Index has been established (Robinson, 1983). It is very quick to complete, taking approximately five minutes.

The **GHQ 28** (as discussed previously) was also administered to the carer to screen for psychological distress.

2.11 LEISURE

Several studies have documented a reduction in leisure activities following stroke (Labi et al, 1980; Sjogren and Fugl-Meyer, 1982; Drummond 1990). Drummond (1994) noted that many of these studies used different definitions of 'leisure' and that some of the instruments used for assessing leisure were not appropriate for use in the United Kingdom.

The Frenchay Activities Index (Holbrook and Skilbeck, 1983) and the Nottingham Extended Activities of Daily Living Index (Nouri and Lincoln, 1987) contain several leisure activities but were insufficient to cover the whole domain of leisure.

The **Nottingham Leisure Questionnaire** (Drummond and Walker, 1994) was developed as a comprehensive measure of leisure activity for use with stroke patients in the United Kingdom. This questionnaire comprises 37 leisure pursuits, with an 'other' category to allow patients to list activities not included in the questionnaire. Examples of activities included are; walking, cooking for pleasure, shopping for pleasure, gardening and swimming.

The Nottingham Leisure Questionnaire has been demonstrated to be a sensitive measure (Drummond and Walker, 1995). The validity of this questionnaire has

been established (Drummond, 1991) and has excellent inter-rater and test re-test reliability (Drummond and Walker, 1994). It was therefore the measure of choice.

2.12 HANDICAP

Handicap can result from a pathology, an impairment or a disability and is dependent on the psychological coping mechanisms of the individual.

Prior to the early 1990's several scales have been used to measure handicap: the Frenchay Activities Index (Holbrook and Skilbeck, 1983), the Nottingham Extended ADL Index (Nouri and Lincoln, 1987), the Life Satisfaction Index (Neugarten et al, 1961), the Nottingham Health Profile (Hunt et al, 1980) and the Rankin Scale (Rankin, 1957). However many of the items included in these scales are more commonly recognised as disability items.

The London Handicap Scale (LHS) (Harwood et al, 1994) was devised to specifically measure items of handicap. Six different aspects of handicap are assessed: mobility, physical independence, occupation, social integration, orientation and economic self-sufficiency. The respondent chooses the level which most closely fits his or her situation (level one denotes no disadvantage and level six denotes extreme disadvantage), together this forms a description profile of the individual. This profile can then be converted into an overall severity score using a table of scale weights.

The LHS was designed for use as an epidemiological tool with which to compare populations or groups. It can be used with people of all ages, chronic disease and multiple pathologies and has specifically been validated for use with stroke

patients (Harwood and Ebrahim, 1995). It also has good reliability and is sensitive to change (Harwood and Ebrahim, 1995).

This chapter has described the reasons for the selection of the baseline and outcome measures used in the present trial; chapter three will now discuss the administration of the chosen measures.

CHAPTER THREE
METHODS

3.1 DESIGN

To enable detection of the benefits, if any, of occupational therapy intervention to stroke patients not admitted to hospital, a large randomised controlled trial was the design of choice. A flow chart summarising the design used in this study may be found in figure 3.1.

In summary patients were identified from a community stroke register, which covered a geographical area of Nottingham and Southern Derbyshire. If entry criteria were met the patient was visited in their own home at one month after the stroke.

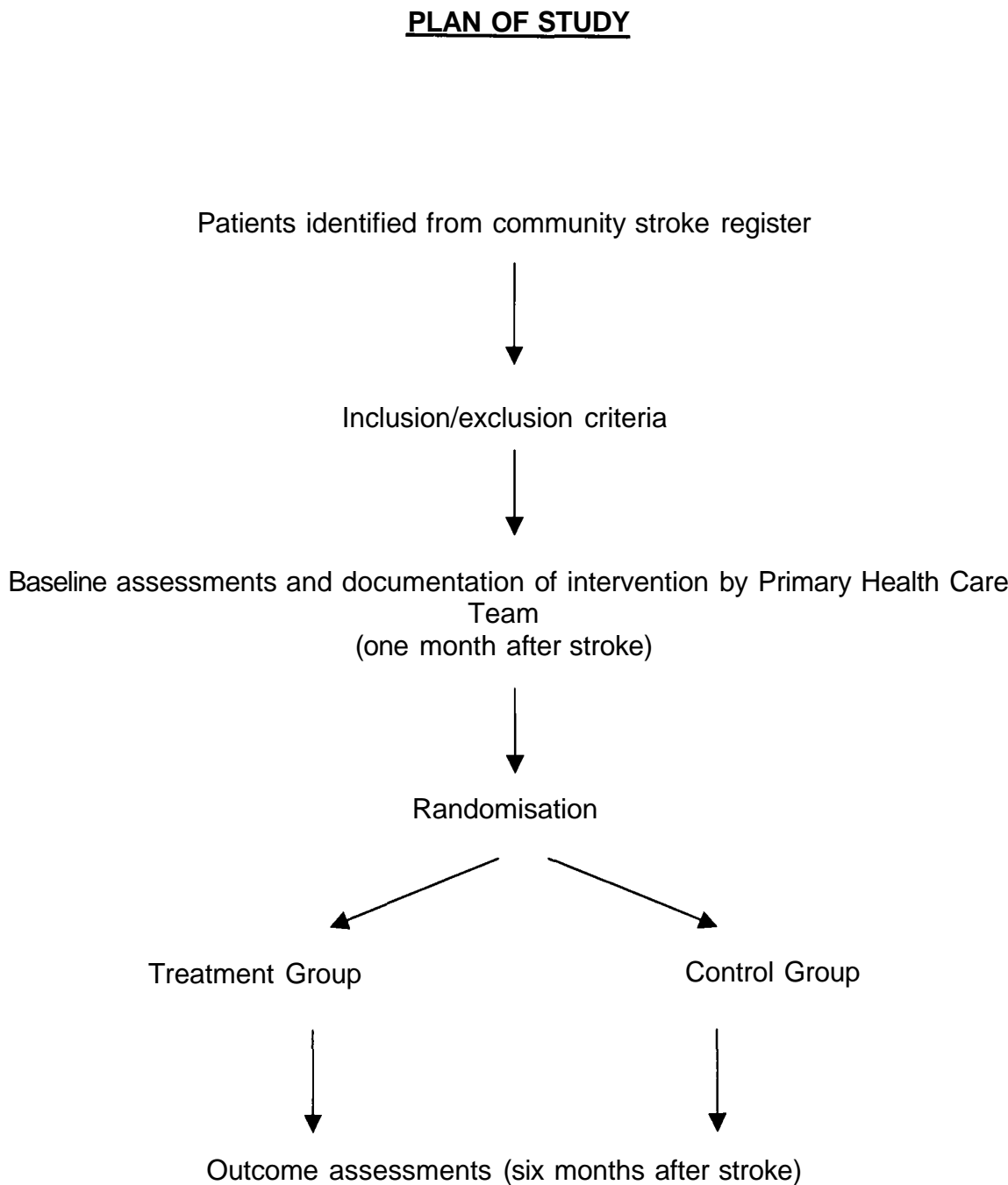
The implementation of a two group design (treatment group and control group) or a three group design with the additional group receiving placebo treatment, was considered. A two group design was chosen because the main aim of the study was to establish whether an overall occupational therapy treatment package was beneficial to stroke patients remaining in the community, as opposed to the effectiveness of any specific components. This pragmatic design is well recognised and has been implemented in earlier studies of rehabilitation (Gladman et al, 1993; Young and Forster, 1992). This approach described by Schwartz and Lellouche (1967) and Barer et al (1988), compares the effect of the total occupational therapy 'treatment package' operating under realistic conditions, with the control group receiving no additional treatment.

Baseline measures were administered to all patients at one month after stroke.

On completion of baseline assessments, subjects were randomly allocated to the treatment group or control group using a series of prepared sealed opaque envelopes. The envelopes contained slips of paper allocating the designated group, determined from random number tables. Two part time (0.5) senior

occupational therapists, administered the treatment to patients in the treatment group for a maximum of five months. Each therapist had their own caseload. The control group received no additional occupational therapy for the duration of the study. Patients were assessed on a series of outcome measures at six months after the stroke by an independent assessor who was blind to patient group allocation. Patients were also assessed on outcome measures at twelve months after the stroke, however these results are not presented in this thesis.

Figure 3.1



3.2 ETHICAL CONSIDERATIONS

Ethical approval was sought and granted from the Nottinghamshire Ethical Committee (Appendix 1) and also from the Southern Derbyshire Ethical Committee (Appendix 2), since some patients were recruited from Amber Valley and Erewash Districts in Southern Derbyshire. The content of the intervention proposed in the study was deemed to be of no health risk to the participants, and was therefore in keeping with guidelines from the Royal College of Physicians of London report entitled "Research Involving Patients" (1990).

All patients were given an information sheet, written in layman's terms, detailing the purpose and nature of the study (Appendix 3). This information also gave the reassurance that should they wish to withdraw from the study at any time, their future care would in no way be compromised.

Verbal consent was requested and all patients were asked to read and sign a consent form agreeing to take part in the study (Appendix 4).

All information obtained was coded with a subject number, to ensure confidentiality, and locked in a filing cabinet. When this information was transposed on to computer records, the coded subject numbers were used.

3.3 STROKE REGISTER

A hospital stroke register has been in operation in Nottingham since 1983, however this register only contained information about stroke patients who had been admitted to hospital, and contained no information about patients who remained in the community following stroke.

The Nottingham Community Stroke Register was established in 1994 as a two year project funded by the Stroke Association and Nottingham Health Authority. The aim of this new register was to identify all new cases of stroke who were not admitted to hospital. The register targeted a geographical area of Nottingham as outlined by the Nottinghamshire FHSA and included 72 general practitioner practices. An attempt was made to obtain a representative sample of general practices within Nottingham in terms of size of practice, age structure of patients, fundholding, computerisation, teaching and deprivation. Fifty two practices agreed to participate and the remaining twenty refused.

3.4 RECRUITMENT OF GENERAL PRACTITIONERS

A research general practitioner (GP) was responsible for the day to day running of the Nottingham Community Stroke Register. On identifying the 72 practices chosen for the sample, the GP wrote to all senior partners describing the purpose and main aims of the Community Stroke Register and invited them to take part. It was also explained that another aim of the register was to recruit patients for a trial of occupational therapy. This letter was followed a few days later by a telephone call, at which time a visit was offered by the research GP who would explain the studies in greater detail. Practices received up to five phone calls; if at that point consent had not been given, any further attempts were abandoned. Fifty two practices agreed to take part in the study with a total number of 157 partners and 334,220 patients.

In order to make notification as easy as possible, a prepared form was devised (Appendix 5) and circulated to all GP's who agreed to notify stroke patients.

General practitioners were asked to provide basic information comprising name and address of the patient, date of birth, date of stroke, a name of carer (if applicable) and name of patients own general practitioner.

General Practitioners were requested to notify the Nottingham Community Stroke Project (NCSP) based in the Division of Stroke Medicine at Nottingham City Hospital as soon as possible after making the diagnosis of stroke. All GP's were sent a copy of the WHO definition of stroke (Aho et al, 1980) which also included guidelines on transient ischaemic attack (TIA).

A newsletter was sent every few months to all 52 practices, containing information on the progress of the Nottingham Community Stroke Project and the Community Occupational Therapy Intervention Study, and requesting further support in the recruitment of patients.

To boost the rate of recruitment to the occupational therapy study, general practices were targeted in Amber Valley and Erewash districts in Southern Derbyshire. This area was chosen as it was known not to have any specialist stroke services, such as a stroke coordinator. A list of general practices for these districts was obtained from the Derbyshire FHSA. Thirty two practices were contacted and twenty one agreed to take part in the study. The same process used in the NCSP to recruit and inform practices, was implemented.

To encourage recruitment from other health care workers, the research occupational therapist gave informal talks to groups of community physiotherapists, district nurses, homecare aids and social services occupational therapists.

3.5 POWER OF THE STUDY

Projecting from previous records of patients admitted with a diagnosis of stroke to Nottingham's two main city hospitals and taking into consideration the size of the population targeted, it was estimated approximately 200 patients would be identified by the Nottingham Community Stroke Register in Nottingham each year. Of these 200 patients, approximately 150 would be suitable for recruitment to the present study.

Using power calculations (Altman, 1980) it was estimated 200 patients were required for the study; 100 patients randomly allocated to the treatment group and 100 patients randomly allocated to the control group. This was the number of patients required which would detect treatment effects of three points on the Nottingham Extended ADL scale, with a probability of 0.05 and a power of 80%. This is the effect seen in a previous trial of occupational therapy (Drummond and Walker, 1996) and a study of domiciliary therapy (Gladman et al, 1993).

3.6 SELECTION OF SUBJECTS

Patients who had suffered a recent stroke (less than one month duration) as defined by the WHO definition, and had not been admitted to hospital were eligible to take part in the study. It was estimated that approximately 200 cases of stroke would remain in the targeted community each year. The main source of referral for admission to the study was through the general practitioner, who was requested to notify the Nottingham Community Stroke Register as soon as possible after making the diagnosis of stroke. This method of recruiting patients for community based studies has been well documented to be problematic

(Tognoni et al, 1991; Jonker and Sumajow, 1992). However this was thought to be the most systematic approach possible, to recruit stroke patients not admitted to hospital.

Selection criteria are necessary to ensure that appropriate treatment is delivered to appropriate patients and that the sample is representative of those who might be given the treatment in clinical practice. The inclusion and exclusion criteria used in the present study are listed below:

Inclusion Criteria

- 1. Patients must fulfil the WHO definition of stroke.**
- 2. Not admitted to hospital.**

Exclusion Criteria

- 1. Reside in a nursing or residential home.** As staff in institutional care are subject to shifts and are not solely responsible for individual patients (unlike carers living with patients at home) it was thought to be impracticable to carry out structured therapy sessions. This group of patients also do not routinely receive hospital out-patient occupational therapy treatment.
- 2. Previous history of dementia.** Patients suffering from dementia would be unreliable in their answering of questions, thus making it difficult to assess the efficacy of occupational therapy intervention.
- 3. Could not speak or understand English prior to the stroke.** This major language barrier would be too restrictive in the provision of treatment and the ability to complete outcome assessments.
- 4. No consent given.**
- 5. Died before baseline assessments at one month after stroke.**

3.7 INITIAL CONTACT WITH PATIENT

Patients were contacted by letter from the research occupational therapist at one month after stroke. The letter (Appendix 6) stated that the patient's GP had notified the study of the recent stroke and was also aware that the therapist was to visit the patient in the near future. The letter briefly described the purpose of the occupational therapy study and permission was requested to visit patients in their own home.

On visiting the patient at home the study was described in greater detail. The research therapist explained the background of the study and why it was felt to be an important research question. An information letter (Appendix 3) was also given to all patients describing the study in layman's terms.

Due to the possibility of the patient being allocated to either the treatment or control group, both scenarios were described to the patient. For example, if the patient was allocated to the treatment group, this would mean that the research occupational therapist would visit on a regular basis for a period of five months and provide advice and guidance on self care activities such as washing, dressing and bathing. Help would also be provided for more complex activities of daily living such as making a meal, using public transport and shopping. A description of what would happen if the patient was allocated to the control group was also given. For example, if the patient was assigned to the control group there would be no additional occupational therapy treatment (other than routine clinical practice). The only additional input would be from an independent assessor who would visit at six and twelve months after the stroke to measure the patient's functional abilities. Patients were told that there was no evidence available to

support that occupational therapy treatment was effective for patients not admitted to hospital and that this was the main question under investigation.

The patient and carer were then given the opportunity to ask any questions concerning the purpose of the study or the content of treatment. If they agreed to participate in the study they were asked to sign a consent form (Appendix 4).

3.8 BASELINE ASSESSMENTS

Patients who gave written consent to take part in the study were assessed using measures of physical and cognitive function. Baseline assessments were carried out at one month after the onset of stroke. The reason for assessing patients at one month after stroke was that it was felt that this interval gave the GP sufficient time to enlist additional services should they be deemed appropriate. Also by this time the most rapid recovery from stroke had been made.

Baseline assessments were conducted in the patient's own home. Prior to the administration of assessments, patients were asked if they wore spectacles or a hearing aid, and if so, they were asked to wear them during the assessment period. This ensured that vision and hearing (as far as is possible) did not affect the patient's ability to carry out the assessments.

All assessments were conducted prior to opening the previously prepared envelope, which allocated patients to either the treatment group or the control group. This process had been described to the patient by the research therapist and was also contained in the patient information letter.

At six months after the stroke, all patients (both groups) were assessed on a series of outcome measures by an independent assessor who was 'blind' to patient group allocation. Again these assessments took place in the patient's own home. Similarly both groups were assessed at twelve months after stroke (results of the twelve month assessment are not reported in this thesis).

Each assessment is designed to measure the extent of loss of a particular function and where available, a standardised, valid and reliable assessment was used. All assessments were administered to all patients, however some patients were unable to complete all of them. For example a patient with a severe dysphasia would be unable to complete the Hospital Anxiety and Depression scale (Zigmond and Snaith, 1983) or the General Health Questionnaire (Goldberg, 1972). Listed below are the baseline and outcome measures used and the order in which they were administered.

BASELINE MEASURES

- Barthel Index
- Nottingham Extended Activities of Daily Living
- Rivermead Motor Assessment (gross function)
- Sheffield Screening Test for Acquired Language Disorders
- Rey Osterrieth Complex Figure Test (copy)
- Mood Rating Scale
- Hospital Anxiety and Depression Scale
- General Health questionnaire (GHQ-28)
- The Adult Memory and Information Processing Battery (AMIPB) - Story recall
- Caregiver Strain Index

SIX MONTH OUTCOME MEASURES

- Barthel Index
- Nottingham Extended Activities of Daily Living
- Rivermead Motor Assessment (gross function)
- Hospital Anxiety and Depression Scale
- General Health Questionnaire (GHQ-28) - to patient
- General Health Questionnaire (GHQ-28) - to carer
- The Nottingham Leisure Questionnaire
- The London Handicap Scale
- Caregiver Strain Index

TWELVE MONTH OUTCOME MEASURES

- Barthel Index
- Nottingham Extended Activities of Daily Living
- General Health Questionnaire (GHQ-28) - to patient
- General Health Questionnaire (GHQ-28) - to carer.

The reasons why different measures were used at baseline and six and twelve month outcome has been discussed in Chapter 2.4.

The administration of each assessment will now be considered in turn.

3.9 BARTHEL INDEX

The Barthel Index (Mahoney and Barthel, 1965) is a self care assessment covering ten areas, including continence of bowel and bladder, grooming, toileting,

feeding, transfers, mobility, dressing, stairs and bathing. For the purpose of this study the Collin et al (1988) version of the Barthel Index was used and provided a score between 0-20 (Appendix 7).

It is easy to use and is administered in just a few minutes. The patient was told that the Barthel Index was a very short assessment which would help the researcher determine their ability to carry out daily tasks such as washing and dressing. Each item in the index was read aloud to the patient and then the patient was asked to state which of the options available were applicable to them. One disadvantage of this measure is that it has ceiling and floor effects. To overcome the ceiling effects it was decided to use an additional measure; the Nottingham Extended Activities of Daily Living scale.

3.10 NOTTINGHAM EXTENDED ACTIVITIES OF DAILY LIVING

The patients were told that the Nottingham Extended Activities of Daily Living scale (EADL) (Nouri and Lincoln, 1987) would give more detailed information on how well they were able to carry out more complex every day tasks, such as outdoor mobility and shopping.

The Nottingham Extended ADL scale (Appendix 8) is a 22 item questionnaire used to assess stroke patients living in the community. This scale includes questions such as;

'Do you walk around outside?'

'Do you drive a car?'

'Do you do your own shopping?'

The 22 items cover four sections and include mobility (six items), kitchen (five items), domestic (five items) and leisure (six items) activities. All items in the assessment are more complex than basic self care activities and it was therefore chosen to complement the Barthel Index.

Each item is scored on the response to four options: No (0 points), With help (0 points), On my own with difficulty (1 point), On my own (1 point). An alternative scoring system is 0,1,2,3 respectively. A total score for each subsection can then be calculated. It is possible to add the kitchen section score with the domestic section score to form a household score (Gladman et al, 1993b). If the four subsections are totalled an overall score, with a maximum of 22 or 66 points (depending on the scoring system used), makes comparisons between groups possible.

3.11 RIVERMEAD MOTOR ASSESSMENT (gross function)

The Rivermead Motor Assessment (Appendix 9) consists of three sections; which include measures of disability (gross function) and impairment (arm, leg and trunk). The intervention proposed in this trial of occupational therapy was not primarily aimed at further functional recovery of the arm and leg; therefore it was decided to use the gross function section only. This section which incorporates 13 items, covers a range of functional abilities from sitting unsupported and independent transfers to climbing stairs and hopping.

Patients were told that the Rivermead Motor Assessment would inform the researcher how well they were able to move around. Patients were asked whether they could perform each of the 13 activities and the interviewer recorded

either a pass or a fail. This method of administration has been demonstrated to be reliable (Sackley and Lincoln, 1990). The score of 1 is given if the patient can do the activity according to the specific guidelines of the assessment and 0 if they can not do it . The assessment is stopped after three successive O's have been scored as the patient is very likely to be unsuccessful in the remaining tasks. The maximum possible score obtained is 13.

3.12 SHEFFIELD SCREENING TEST FOR ACQUIRED LANGUAGE DISORDERS

The Sheffield Screening Test for Acquired Language Disorders (Syder et al, 1993) (Appendix 10) was developed to enable health care professionals (other than speech and language therapists) to detect the presence of high-level language disorders in adults.

Patients were told that this assessment was a very quick language assessment, which would detect if they required a further assessment from a speech and language therapist. This assessment consists of two sections:

1. Receptive language skills

This section covers five areas of comprehension; verbal comprehension of single words, comprehension of sequential commands, comprehension of a complex command, recognition of differences in meaning between words and comprehension of narrative. The maximum possible score for this section is nine points.

2. Expressive language skills.

This section also covers five areas; word finding, abstract word finding, sequencing, definitions and verbal reasoning. The maximum possible score for this section is 11 points.

The authors provide age related cut-off scores for this test;

- age 59 and under 17
- age 60 to 69 16
- age 70 and over 15

If the patient scores less than the cut-off score relevant for their age group, the authors recommend referral to a speech and language therapist for a more detailed assessment.

3.13 REY-OSTERRIETH COMPLEX FIGURE TEST (copy)

The Rey-Osterrieth Complex Figure Test (Rey, 1959) is a quick and simple test which identifies patients with visual neglect and difficulty with visual spatial relations. It can also be used to assess visual memory, but was not used for that purpose in the present study. It is also known as Complex Figure Test and Rey Figure Test.

The patient was told that the assessment was designed to assess their vision.

The patient was asked to sit at a table; the paper containing the Rey Figure was placed in front of them. The patient was then asked to copy the figure "as best as they could."

The figure comprises a variety of horizontal, vertical and diagonal lines along with geometric shapes which are joined together to form a complex but inter-connected

figure. Eighteen components are scored separately and then added to form a total score (see Appendix 11). The maximum possible score for completion of the Rey Figure is 36 points. The maximum time permitted to complete the drawing was five minutes.

3.14 MOOD RATING SCALE

The Mood Rating Scale (Lincoln et al. 1985) (Appendix 12) is a very simple measure of patients' mood. This assessment was designed for the needs of stroke patients with speech difficulties in a randomised controlled trial of speech therapy. As the percentage of patients remaining in the community after a stroke who would have significant speech difficulties was unknown, it was decided to include this simple measure of mood in conjunction with other more complex and reliable measures, such as the Hospital Anxiety and Depression scale (Zigmond and Snaith, 1983) and the General Health Questionnaire (Goldberg, 1972). The patient was told this assessment was to find out "how they felt within themselves" at the present time.

Mood was assessed on six simple four-point rating scales:

Do you feel:

very angry	angry	calm	very calm
very happy	happy	sad	very sad
very secure	secure	afraid	very afraid
very anxious	anxious	relaxed	very relaxed
very depressed	depressed	cheerful	very cheerful
very contented	contented	frustrated	very frustrated

The above six questions were presented on cards for the patient to read. The interviewer read aloud each option so the patient could indicate which was applicable to them. For example, the patient was asked if they generally felt very anxious, anxious, relaxed or very relaxed. Patients responded by either stating their preferred option, pointing to the chosen word(s), or saying 'yes' when the alternatives were read by the examiner. The responses of the patient were scored 0,1,2 or 3 , with 0 being the most negative response and 3 the most positive response.

3.15 THE HOSPITAL ANXIETY AND DEPRESSION SCALE

The Hospital Anxiety and Depression (HAD) scale (Zigmond and Snaith, 1983) is a self assessment scale which was developed to detect depression and anxiety symptoms. It was devised as a screening tool to be used in a hospital medical outpatient setting and was designed to divide the assessment of mood into two aspects; anxiety and depression (see Appendix 13). There are 14 questions in total, seven related to symptoms of anxiety and seven related to depressive symptoms. Each question gives four options scored 0, 1, 2 or 3, with the higher score indicating the presence of a depressive or anxiety symptom. A total score is formulated for both anxiety and depression sections. The authors report cut off points as:

7 or less	= no significant symptoms
8-10	= borderline
11 or more	= significant symptom

The patient was told that this assessment was similar to the Mood Rating Scale but that it was intended to find out how they were feeling in more depth. The patient was handed the assessment form and asked to tick the box which contained the option most applicable to them at that time. If the patient had difficulty in using a pen, the examiner would tick the relevant box under the guidance of the patient.

3.16 GENERAL HEALTH QUESTIONNAIRE (GHQ-28)

The General Health Questionnaire (Goldberg, 1972) was developed to detect psychological distress and has been used in several stroke studies. The GHQ-28 is divided into four sub-sections, each section containing seven questions (see Appendix 14). As this questionnaire is self administered the patient was given the assessment form and a pen to circle their chosen response to all twenty eight questions. The patient was told that the questionnaire was designed to detect if they "were feeling low or distressed." As the final section covers severe depression all patients were told that it was necessary to include such questions as:

'Have you recently thought of the possibility that you might make away with yourself?' as some patients after stroke may have similar feelings.

Each question is scored zero to three, with zero denoting the least distressed. A score for each sub-section can be calculated and when all four sub-sections are added together a total score is obtained. A cut off score of 12 is promoted by the authors (Bridges and Goldberg, 1986) as most efficient at separating cases from non-cases.

3.17 THE ADULT MEMORY AND INFORMATION PROCESSING BATTERY (AMIPB) - STORY RECALL.

The Adult Memory and Information Processing Battery (Coughlan and Hollows, 1985) is an assessment of memory and information-processing ability. The battery was originally developed for use by clinical psychologists, but is now used by other health care professionals. Each test in the battery can be used in isolation.

There is evidence that the verbal memory test 'story recall' is the most closely related test to memory problems in everyday life (Tinson and Lincoln, 1987). Therefore this test was used (Appendix 15). The story recall is designed to assess immediate registration of verbal information and retention over time.

A short story is read to the patient, and is then asked to immediately recall it. Patients are allowed up to two minutes to recall the story and are allocated a score of 0, 1 or 2 depending on the accuracy of their recall. The story contains 28 ideas, therefore a maximum possible score is 56. After 23-30 minutes the patient was then asked to recall the same story; the same scoring system also applied.

3.18 THE NOTTINGHAM LEISURE QUESTIONNAIRE

The Nottingham Leisure Questionnaire (Drummond and Walker, 1994) was developed to collect information on the recreational habits of patients before and after stroke.

This questionnaire (Appendix 16) comprises 37 leisure pursuits and includes items such as watching television, gardening, indoor games, driving and do-it-yourself.

Patients were asked to identify, from the 37 items (each item read aloud by the interviewer) the leisure activities they had taken part in since their stroke. They were also asked how often they participated in them. Frequency of participation was measured on a five point rating scale:

'very regularly' = four points

'regularly' = three points

'occasionally' = two points

'infrequently' = one point

'never' = no points.

Since it was unrealistic to produce an exhaustive list of possible activities that the patient may have participated in, the interviewer asked if they had participated in any other activity, not included on the list. An example of this may be caravanning.

Two leisure scores were formulated from this questionnaire:

- Total Leisure Activity (TLA). This represents the number of activities the patient engaged in since the onset of stroke.
- Total Leisure Score (TQTL). This score represents the frequency in which patient's participated in their chosen leisure pursuits.

3.19 THE LONDON HANDICAP SCALE

The London Handicap Scale (Harwood et al, 1994) was developed to provide a profile of handicaps on six different dimensions, culminating in an overall handicap severity score. (Please see Appendix 17) These six dimensions are:

- mobility
- physical independence
- occupation
- social integration
- orientation
- economic self-sufficiency.

Each dimension has six levels, arranged in order of increasing disadvantage. The patient is told that the questionnaire is about the way their health affects their everyday life. They were asked to read each question, then choose the option which most closely described them by ticking the appropriate box. This information formed a descriptive profile on the patient which was then converted into an overall severity score using a table of scale weights.

3.20 CAREGIVER STRAIN INDEX

The support provided by informal carers often determines whether an older person will remain in the community or be institutionalised. The Caregiver Strain Index (Robinson, 1983) (see Appendix 18) was developed as a result of the shift from long-term care in institutions to community-based services. It was devised as a screening tool and for research purposes, to identify stressors on caregivers. It is a brief test comprising of 13 statements which cover physical and psychological

situations thought to act as stressors. The statements were read aloud to the carer and they were asked to reply if the statement applied to them. If the statement did apply it was scored as one, if it did not apply it was scored as zero. The scores ranged from 0-13. A high score denoted a high level of stress. Robinson (1983) reported that there were no significant differences between the CSI scores for men or women, relationship of the carer to the patient or the health of the carer. However the author does suggest that younger family members taking on the role of informal carer, have a higher CSI score.

3.21 PROCEDURE

All patients identified by the community stroke register were considered for inclusion in the study. If the criteria were met (please see Chapter 3.6 for details on inclusion and exclusion criteria) a letter was sent describing the purpose of the study and requesting consent to a visit by an occupational therapist.

Patients were assessed at one month after stroke in their own home by a senior occupational therapist. On arrival at the home of the patient a description of the study was given, and verbal and written consent were requested (please see Chapter 3.7 for more detail). A brief history of the illness was taken, with the therapist recording the following information:

- Confirmation of name, date of birth, address and telephone number
- Name of general practitioner
- Side affected by stroke
- Previous strokes: none / one / two / three or more
- Date(s) of previous stroke(s) where relevant

- Nature of residential accommodation e.g. house, flat, warden aided
- Lives: alone / with spouse / with carer
- Since onset of stroke contact with:
 - a physiotherapist
 - an occupational therapist
 - a speech and language therapist
 - other health care worker
- Services arranged by general practitioner in the last four weeks

In addition to demographic details, a series of baseline assessments were administered. The assessments were administered in a set order, and took approximately one to one and a half hours to complete.

On completion of the baseline assessments the therapist opened a prepared, sealed, opaque envelope which contained a slip of paper designating the patient to the treatment group or the control group. If the patient was allocated to the treatment group they were visited by the occupational therapist for up to five months. All visits and the length of time spent on each visit were documented. Patients allocated to the control group received no further contact with the research occupational therapist.

At six and twelve months after the stroke all patients participating in the study were assessed by an independent assessor who was unaware of the patients group allocation. Patients were then thanked for participating and finally discharged from the study.

3.22 OUTCOME ASSESSMENTS

Approximately two weeks before the outcome assessment was due, patients were sent a letter by an independent assessor requesting a visit, with a date and time suggested. If this was not suitable, the patient was invited to telephone the department to arrange another time at their convenience. As five months may have elapsed since the patient was last seen, as in the case of the control group, the independent assessor checked with the general practitioner that all patients were still alive, before sending the letter.

Outcome assessments were carried out at six and twelve months after stroke in the patient's own home. The same independent assessor carried out the six and twelve month assessments. Visits were made as close to the exact date as possible. The role of the independent assessor was to assess without bias, the abilities of the patient. Therefore the 'blindness' of the assessor was crucial to the integrity of the study. Several steps, as recommended by Siemonsma and Walker (1997) were taken to ensure 'blindness':

- The independent assessor was accommodated in a separate office from the treatment team
- When the treatment team were not in the department, telephone calls were taken by the departmental secretary, thereby avoiding any contact with the independent assessor
- Lists of patient's names and addresses were housed separately from case notes
- The treatment team were not allowed to discuss patients in the presence of the independent assessor

- The independent assessor introduced herself to the patient as the independent assessor, not as her own professional background. No health care professional uniform was worn, in order to discourage the patient from asking 'treatment type' questions. For example, if the independent assessor was a physiotherapist the patient might have asked specific questions about exercises to help their hemiparetic arm
- The independent assessor documented the timing and date of the home visit appointment (an in-house security measure) in a separate departmental book
- Patients in the treatment group were asked by the treating therapist, if possible, not to mention the occupational therapists name when the independent assessor visited
- The independent assessor provided the treatment team with a list of appointment dates and times, to prevent visiting at the same time.

To identify the number of times unblinding occurred, the independent assessor monitored her blindness during the visit. This was done by documenting if she thought she had been unblinded to the patient's group allocation. If she had not been unblinded, she was asked to document by 'best guessing' whether the patient was in the treatment group or the control group. The reasons for unblinding, for example unblinding by other people, by the environment or by the patient, were not recorded.

Over the course of the trial, three independent assessors (a nurse, a physiotherapist and a psychologist) were employed. Independent assessors often do not remain for a long time in such posts, due to the repetitive nature of the job.

Independent assessors may take on such a job as a stepping stone to a more active role in a research project.

3.23 CONTENT OF TREATMENT

As a result of collaboration with the therapist, patient, family and information obtained from the baseline assessments, a treatment programme was devised for each patient.

Initially patients were offered leaflets from the Stroke Association giving basic information on stroke, its nature and its effects. If more detailed information was required this was provided. Health promotion information was also discussed including smoking, diet, exercise and the importance of taking aspirin, if prescribed.

Emphasis of occupational therapy treatment ^{XX} was on independence in personal self-care and extended activities of daily living. Self care, included activities such as washing, dressing, stair mobility and bathing. Extended activities of daily living encompassed a higher level of activity such as outdoor mobility, making a meal, driving a car and household chores. Patients were encouraged to maximise their functional level of independence.

In order to do this the therapist may have:

- **Taught the correct method of achieving a goal.** If the patient was unable to dress independently, the therapist may have taught certain dressing techniques. For example, crossing the affected leg over the other to allow the affected foot to clear the floor, enabling socks, pants and trousers to be put on with ease.

- **Suggested an alternative way of achieving the goal.** If the patient was unable to pull up and fasten their trousers the therapist may have suggested adapting the trousers with elastic, using a D ring, or using velcro. If this was unsuccessful the therapist may then have suggested the use of jogging trousers.
- **Provided equipment.** Bathing and feeding aids were frequently used pieces of equipment. A bath board and bath seat may be used singly or in tandem to divide bathing into safe and easy stages. If a larger piece of equipment was prescribed, such as a stair rail or shower installation, the therapist would request a visit from the social services occupational therapist. The budget for such adaptations is held within the social services department. Nursing equipment can be requested by the therapist from Homeloans and wheelchairs from the Disablement Services Centre.
- **Provided specific information.** For example, if the patient was keen to go shopping but felt their spouse was unable to cope with the demands of pushing a wheelchair around a shopping area, information would be provided on how to obtain an electric wheelchair from Shopmobility in the town centre. The information was given at a level appropriate to the background of the patient. For example, if the patient was a retired doctor or rehabilitationalist, their specific written information requirements would be on a different level to that of the lay public. In this case perhaps specific medical journal articles would be appropriate.
- **Given encouragement by setting small achievable goals.** Returning to taking the bus into town to shop would be a good example of this and is best tackled in a stepwise fashion:

1. short walks outside
2. gradually build up distance and stamina
3. practice getting on and off stationary buses at the local park and ride
4. accompany patient into town on the bus
5. finally the patient is able to embark on the journey on their own.

- **Set therapy goals from session to session.**

If the therapist had established that the patient was safe to carry out a set activity, she may have asked the patient to achieve this task several times before the next therapy session. For example, if the therapist had practised getting the patient in and out of the bath (including a wet bath), she may ask the patient to have two more baths prior to her next visit.

- **Referred to another agency** e.g. physiotherapist, speech and language therapist, social services occupational therapist, continence nurse. This may be necessary if problems were highlighted that were outwith the scope of occupational therapy treatment. For example, if the patient was having continence problems, this was referred on to the continence nurse for a full assessment.

- **Helped the patient to accept and come to terms with their disability.**

Despite appropriate help and advice from the therapist and other professional disciplines some problems remained unsolved. This may be due to there being no solution to the problem or it may be that the patient made an informed choice not to follow advice.

Patients were also actively encouraged to participate in leisure pursuits.

Wherever possible, patients were encouraged to continue previous interests and

appropriate advice and practical help was given. For example, if the patient was a keen gardener but now felt unsteady when kneeling down to weed the flower beds then specific gardening equipment to ease this difficulty was suggested.

Assistance was given on where to obtain this piece of equipment and the cost of purchasing it. If it was no longer possible to continue with previous activities, alternative options were considered.

The frequency of treatment visits was discussed and agreed between the therapist, the patient and where appropriate, the carer. This depended mainly on the complexity of the problems identified. For example, if a treatment aim involved the use of public transport, this may take several sessions to build up stamina and confidence. Whereas if the patient required adapted cutlery to cut up their meal, this could be achieved with much less intention.

Similarly, duration of visits depended upon the individual treatment aim. Where possible every effort was made to provide the required time and attention needed successfully to achieve the task.

The main constraint on treatment content was financial. For example, there would be little point of referral to wheelchair services for an electric wheelchair if the patient did not have the financial ability to buy and maintain such a piece of equipment. (At the time of the study electric wheelchairs were not issued by the Health Service or Local Authority). Similarly it would not be advantageous to encourage a patient to go on a much needed holiday if they were already experiencing financial problems.

Two part-time senior occupational therapists were responsible for the treatment of the stroke patients in the study. As it was important for them to communicate with each other on a regular basis, they shared an office where they would discuss the progress of patients, on a weekly basis. If problems were encountered during the treatment phase, each therapist tried to provide advice on how to tackle the problem. Where appropriate, treatment was provided by the other therapist during periods of illness or annual leave. After each visit the therapist recorded the length of the visit, the content of the session and the need for any referrals to other agencies.

3.24 PILOT STUDY

In order to assess the feasibility of conducting a large randomised controlled trial of occupational therapy, an initial pilot stage was conducted. The purpose of this phase was to trial the process of identifying, assessing and managing stroke patients not admitted to hospital. The methodology remained unaltered after the pilot phase.

During the six month pilot phase, patients were identified from the Nottingham Community Stroke Register. During this time, it became apparent that there was an adequate referral rate from which larger numbers could be identified. All patients were successfully randomised to either the treatment group or the control group, and all gave written consent. The pilot study was conducted by a senior occupational therapist experienced in stroke care and research methods. The assessments used did not appear to cause any distress to the patients and were

of appropriate content and length. The baseline and outcome assessments were felt to be comprehensive.

Patients were successfully managed by the treating therapist who assessed, prescribed and carried out appropriate occupational therapy treatment.

Since the patients in the pilot phase were to be included in the main study, no analysis was carried out on this subgroup of patients.

3.25 ANALYSIS

Data were analysed using the SPSS-X (1988) Statistical Package for the Social Sciences. Demographic data were analysed using chi-square tests for categorical data (e.g. sex of patient) and t tests for interval or ratio data (e.g. age). All baseline and outcome assessments were ordinal in nature (i.e. ranked by the degree of 'goodness') and were analysed using non-parametric statistics, such as Mann-Whitney 'U' Tests and Spearmans Rank Correlation Coefficients. The 95% confidence intervals were analysed using Minitab (1996). Alpha was set at $p=0.05$.

During the analyses many multiple comparisons were made and it should be noted that this may have caused statistically significant results to have occurred by chance. Where multiple testing has been used, the main aim was to generate hypotheses for future studies.

The results chapter begins with presentations of general practitioner notifications and patient demographic characteristics. An analysis of each baseline and

outcome assessment is then presented. The content of treatment sessions are also described.

CHAPTER FOUR

RESULTS

4. 1. NOTIFICATION BY GENERAL PRACTITIONERS

Seventy three general practitioner practices agreed to notify the study of all new incident cases of stroke in the community. The participating practices comprised 254 general practitioner partners (mean 3.4, s.d. 2.11, range 1 -11) and covered a population of 494,000 patients (mean 6766, s.d. 4197, range 1750 - 22000). The practices represented a range within Nottinghamshire and Southern Derbyshire, in terms of size of practice, age structure of patients, fundholding, computerisation, teaching and deprivation. The number of notifications for each practice ranged from a minimum of zero to a maximum of 16 (mean 2.66, s.d 3.4). Twenty one practices (29%) made no notifications. Two hundred and forty notifications were made over a 48 month period from February 1994 to March 1998. Four of the notifications were made by the community physiotherapist; permission to include these patients in the trial was sought from the relevant general practitioner.

To detect if larger or smaller practices notified more patients to the trial a Spearmans Rank Correlation Coefficient was carried out. There was no significant correlation between the number of general practitioner partners in a practice and the number of referrals made to the study ($r_s = 0.11$, $p= 0.33$).

4.2 SAMPLE STUDIED

Fifty five patients were excluded from participation in the trial before randomisation. Reasons for exclusion can be seen in table 4.1.

Table 4.1

REASONS FOR EXCLUSION FROM THE STUDY

Address in Nursing Home/ Residential Home	28
Died before initial assessment	11
Refused to participate in the study	9
Previous history of dementia	2
Not a stroke	2
Prolonged illness	2
Unable to speak or understand English	1
<hr/>	
TOTAL	55

Of the 28 patients in institutional care (Nursing Home = 22, Residential Home = 6) 10 were men and 18 were women. The mean age of patients was 81.6 years (s.d. 6.5, range 71-95). Eleven patients had a left hemiplegia, 15 had a right hemiplegia and two had speech problems only.

Of the 11 patients who died before assessment at one month, three were men and eight were women. Five patients lived alone, five lived with a spouse and one

lived with a carer. Five patients had a left hemiplegia, four had a right hemiplegia and two patients had a bilateral stroke.

Of the nine patients who refused to take part in the study five were men and four were women. Five patients had a left hemiplegia and four had a right hemiplegia. Three patients lived alone and six lived with a spouse.

Table 4.2 illustrates a comparison of patients included with patients excluded from the study. There were no significant differences between the two groups for sex or side of stroke, but there was a significant difference between the groups for age. Patients who were excluded from the trial were older.

Table 4.2

COMPARISON OF INCLUDED PATIENTS
AND EXCLUDED PATIENTS

MEASURE		Included n = 185	Excluded n = 55	COMPARISON
AGE	Mean	74.3	77.8	t = -2.62 p = 0.009
	s.d.	8.3	9.0	
	Min - Max	45-95	46-95	
SEX	Male	94	22	$\chi^2 = 1.98$ p = 0.15
	Female	91	33	
SIDE	Left	85	22	$\chi^2 = 2.78$ p = 0.59
	Right	80	29	
	Other	20	4	

One hundred and eighty five patients were therefore entered into the study. Ninety four patients were allocated to the treatment group and 91 were allocated to the control group.

The demographic characteristics of the sample studied can be seen in Table 4.3. The mean age of patients recruited to the study was 74 years (s.d. 8.37, range 45-95). There was an approximately equal number of men and women and an equal number of left and right sided strokes. One third of patients lived alone. For the majority of patients (n=110), the main carer living with the stroke patient was a spouse.

Of the stroke patients recruited to the study, 70% had no previous history of stroke, while 5% had experienced three or more strokes.

To detect if there was an imbalance between the groups for demographic characteristics, a comparison analysis was carried out. Parametric t tests were implemented to analyse interval data, while chi-square tests were used for categorical data. Table 4.4 illustrates no significant differences between the treatment group and the control group for age, sex, side of stroke, whether they lived alone or with a carer, history of previous stroke or intervention by the primary health care team.

Most patients (n=143,77%) had not been referred to any community services by their primary health care team. Twenty six (13%) patients had been referred for rehabilitation. Of the ten patients referred to an occupational therapy service, five were made by a single general practitioner. There were no referrals by the primary health care team to a continence service, day centre, stroke club or hospital rehabilitation out patient department. Five patients (3%) were referred by the primary health care team to two community services, while two patients (1%) were referred to a combination of three community services.

Table 4.3.

DEMOGRAPHIC
BASELINE CHARACTERISTICS

n=185

MEASURE		n	%
SEX	Male	94	51
	Female	91	49
SIDE	Left	85	46
	Right	90	43
	Other	20	11
LIVES	Alone	61	33
	With spouse	110	59
	With carer	14	8
PREVIOUS HISTORY OF STROKE	None	129	70
	One	36	20
	Two	10	5
	Three or more	10	5
PRIMARY HEALTH CARE TEAM INTERVENTION	None	143	77
	Occupational Therapy	10	5
	Physiotherapy	14	8
	Speech and Language	2	1
	Nursing	6	3
	Day Hospital	6	3
	Homecare Aid	12	6
	Meals on wheels	1	0.5

Table 4.4

DEMOGRAPHIC BASELINE CHARACTERISTICS

COMPARISON OF
TREATMENT GROUP AND CONTROL GROUP

MEASURE		treatment n=94	Control n=91	COMPARISON
AGE	Mean SD Min - Max	73.6 8.1 53-95	75.1 8.6 45-92	t=-1.24 p=Q.21
SEX	Male Female	52 42	42 49	$\chi^2=1.55$ p=0.21
SIDE	Left Right Other	45 39 10	40 41 10	$r^2=0.29$ p=0.86
LIVES	Alone With spouse With carer	28 58 8	33 52 6	$\chi^2=0.97$ p=0.61
PREVIOUS HISTORY OF STROKE	None One Two Three or more	67 18 4 5	62 18 6 5	$\chi^2=0.54$ p=0.90
PRIMARY HEALTH CARE TEAM INTERVENTION	None Occupational Therapy Physiotherapy Speech and Language Nursing Day Hospital Homecare Aid Meals on wheels Combination of two Combination of three	70 6 9 0 4 3 6 0 2 1	73 4 5 2 2 3 6 1 3 1	$\chi^2=0.87$ p=0.35

4.3 BASELINE ASSESSMENTS

4.3.1 BARTHEL INDEX

Table 4.5 illustrates the median, minimum and maximum value and the lower and upper inter-quartile range for the total Barthel Index score. A Mann-Whitney U test confirmed that there was no significant difference between the groups.

Table 4.5

COMPARISON OF GROUPS ON THE BARTHEL INDEX

MEASURE		Treatment	Control	COMPARISON Mann-Whitney U Test
BARTHEL INDEX	Median	18	18	U = 4145 p = 0.71
	Min - Max	3-20	2-20	
	IQR	15-20	15-20	

Table 4.6 illustrates the distribution of the Barthel scores for each group at baseline. The majority of patients (55%) obtained scores of 18 or more and were able to achieve most personal activities of daily living. However, 38 (20%) patients (19 allocated to the treatment group and 19 to the control group) obtained scores of less than 15, indicating moderate to severe disability in personal activities of daily living.

Figure 4.1 illustrates the distribution of the Barthel score for each group.

Table 4.6

DISTRIBUTION OF BARTHEL SCORES FOR EACH GROUP AT
BASELINE

Barthel Score	Treatment Group	Control Group
18-20	50(53%)	51(56%)
15-17	25(27%)	21(23%)
<15	19(20%)	19(21%)

Figure 4.1

Distribution of Barthel scores for treatment group and control group

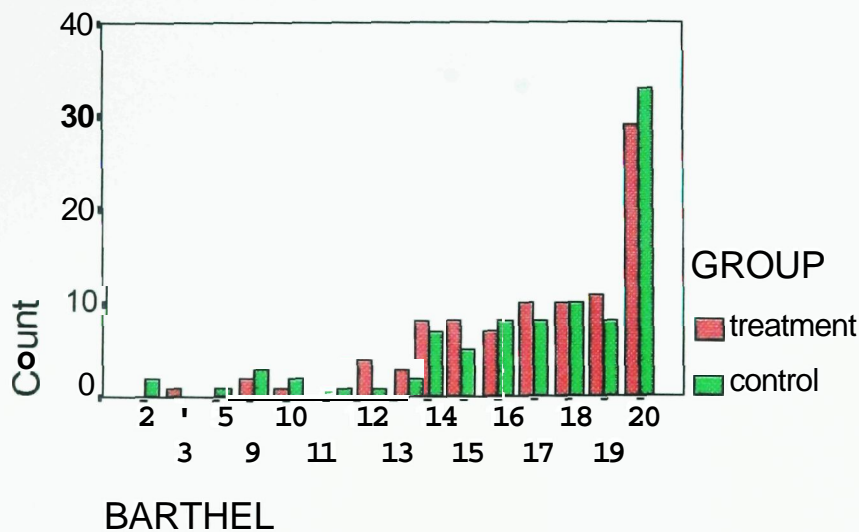


Table 4.7 illustrates the frequency of patients dependent on each item of the Barthel Index. The two most difficult tasks were stair mobility and bathing.

Table 4.7

FREQUENCY OF PATIENTS DEPENDENT ON EACH ITEM OF
THE BARTHEL INDEX

ITEM	n=	%
Bowels	10	5
Bladder	34	18
Grooming	28	15
Toilet	24	13
Feeding	63	34
Transfer	22	12
Mobility	27	15
Dressing	61	33
Stairs	93	50
Bathing	95	51

4.3.2 NOTTINGHAM EXTENDED ACTIVITIES OF DAILY LIVING SCALE

Table 4.8 illustrates the median, minimum and maximum value and the lower and upper inter-quartile range for the total score of the Extended Activities of Daily Living scale. Scores are also presented for mobility, kitchen, domestic and leisure sections of the scale. Comparisons are made between the groups using a Mann-Whitney U Test.

To obtain a more sensitive analysis of the Nottingham Extended Activities of Daily Living scale the scoring system: 0 "no" = dependent, 1 "with help" = Requires help, 2 "on my own with difficulty" = independent but with difficulty and 3 "on my own" = independent was used. This scoring system has been used in other occupational therapy studies (Gilbertson et al, 1998; Drummond and Walker, 1996). However the validity and reliability studies of this scale were based on a scoring system of 0 = dependent and 1= independent. The baseline scores and comparisons between the groups are therefore also presented (see Table 4.9) in their original scoring system.

Table 4.8

COMPARISON OF GROUPS ON THE NOTTINGHAM EXTENDED ACTIVITIES
OF DAILY LIVING SCALE (Scoring 0.1.2.3)

EXTENDED ACTIVITIES OF DAILY LIVING SCALE		Treatment	Control	COMPARISON Mann-Whitney U Test
Total Score	Median Min - Max IQR	29 0-57 16-43	32 0-66 13-48	U = 4003 p = 0.45
Mobility	Median Min - Max IQR	7 0- 18 2- 15	7 0- 18 3-15	U = 3974 p = 0.40
Kitchen	Median Min - Max IQR	11 0- 15 6- 15	13 0-15 4- 15	U = 3965 p = 0.37
Domestic	Median Min - Max IQR	3 0- 15 1 -7	3 0- 15 1-9	U = 4083 p = 0.59
Leisure	Median Min - Max IQR	6 0- 18 4-9	7 0- 18 3- 12	U = 3929 p = 0.33

Mann-Whitney U Tests confirmed there were no significant differences between the groups.

Table 4.9

COMPARISON OF THE GROUPS ON THE NOTTINGHAM EXTENDED
ACTIVITIES OF DAILY LIVING SCALE (Scoring 0.0.1.1)

EXTENDED ACTIVITIES OF DAILY LIVING SCALE		Treatment	Control	COMPARISON Mann-Whitney U Test
Total Score	Median Min - Max IQR	10 0- 19 4-15	11 0-22 3- 16	U = 3969 p = 0.54
Mobility	Median Min - Max IQR	2 0-6 0-5	2 0-6 0-5	U = 4002 p = 0.60
Kitchen	Median Min - Max IQR	4 0-5 2-5	5 0-5 1 -5	U = 4049 p = 0.59
Domestic	Median Min - Max IQR	1 0-5 0-2	1 0-5 0-3	U = 4166 p = 0.75
Leisure	Median Min - Max IQR	2 0-6 1 -3	2 0-6 1 -4	U = 3982 p = 0.40

Mann-Whitney U Tests confirmed that there were no significant differences between the groups. Figure 4.2 illustrates the distribution of EADL scores for each group.

Figure 4.2

Distribution of EADL scores for treatment group and control group

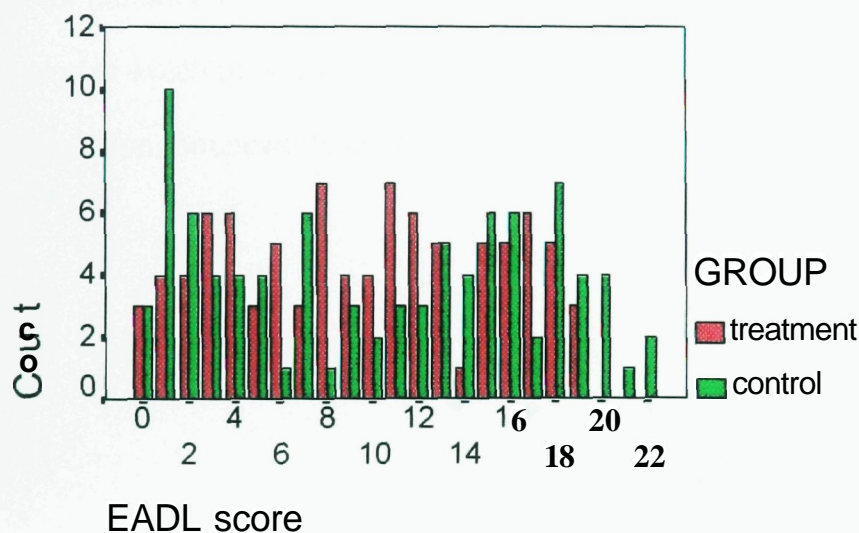


Table 4.10 illustrates the frequency of patients dependent on each individual item of the Extended Activities of Daily Living scale.

Scores for kitchen activities were generally high at initial assessment, indicating that tasks such as feeding oneself, making a hot drink and carrying drinks from one room to the other were easier to achieve than items from the mobility, domestic or leisure sections. However scores for domestic activities indicated that tasks such as managing money, washing clothes, housework and shopping were more difficult for patients to achieve.

The EADL items in which most patients were dependent were: driving a car, managing the garden, housework, shopping, writing letters and going out socially.

Table 4.10

<u>FREQUENCY OF</u>		
<u>PATIENTS DEPENDENT ON EACH ITEM OF THE EXTENDED</u>		
<u>ACTIVITIES OF DAILY LIVING SCALE</u>		
ITEM	n =	%
<u>Mobility</u>		
Walk around outside	81	44
Climb stairs	92	50
Get in / out of a car	100	54
Walk over uneven ground	89	48
Cross roads	109	59
Travel on public transport	141	76
<u>Kitchen</u>		
Feed oneself	52	28
Make a hot drink	46	25
Carry drinks from room to room	63	34
Washing up	72	39
Make a hot snack	82	44
<u>Domestic</u>		
Manage money	76	41
Wash small items of clothes	131	71
Housework	151	82
Shopping	151	82
Full clothes wash	140	76
<u>Leisure</u>		
Read newspaper / book	35	19
Use telephone	41	22
Write letters	142	77
Go out socially	142	77
Manage garden	148	80
Drive a car	155	84

The EADL scale was the main outcome measure used in the study, and as it had no published cut off points to indicate a 'good' or 'poor' score, it was decided to split the groups into high scores and low scores using the median score (for the group as a whole) as the cut off point. Patients with scores of 30 or less were categorised into a low scoring group. The remainder were categorised into a high scoring group.

Ninety five patients were categorised into the low scoring group and 90 patients were categorised into the high scoring group. Table 4.11 illustrates the number of patients categorised into each group..

Table 4.11

n=185	Treatment Group	Control Group
Low score	52	43
High score	42	48

4.3.3 RIVERMEAD MOTOR ASSESSMENT - GROSS FUNCTION SECTION

Table 4.12 illustrates the median, minimum and maximum value and the lower and upper inter-quartile range for each group for the Gross Function section of the Rivermead Motor Assessment. A Mann-Whitney U Test showed no significant difference between the groups.

Scores of less than six, from a possible score of 13, indicated that 24(13%) patients were unable to walk without assistance. Scores of 10 or more indicated that 60 (32%) patients could walk independently outside for 40 metres.

Figure 4.3 illustrates the distribution of the Gross Function total score for each group.

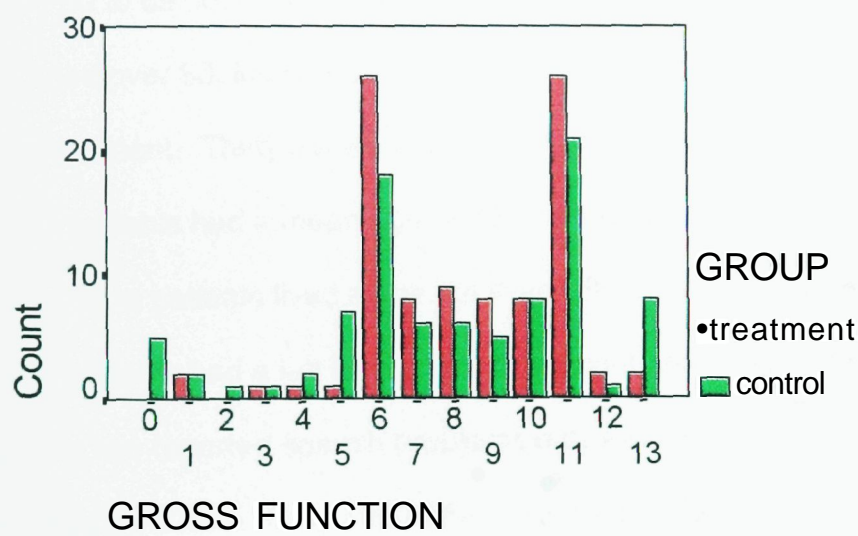
Table 4.12

COMPARISON OF GROUPS ON THE RIVERMEAD MOTOR ASSESSMENT - GROSS FUNCTION SECTION

RIVERMEAD MOTOR ASSESSMENT		Treatment	Control	COMPARISON Mann-Whitney U Test
GROSS FUNCTION SECTION	Median Min - Max IQR	8 1-13 6-11	8 0- 13 6-11	U = 4032 p = 0.49

Figure 4.3

Distribution of Gross Function total score
for the treatment group and the control group.



4.3.4 SHEFFIELD SCREENING TEST FOR ACQUIRED LANGUAGE DISORDERS

Table 4.13 illustrates the median, minimum and maximum value and lower and upper inter-quartile range for the total score on the Sheffield Screening Test for Acquired Language Disorders. No significant differences were found between the groups.

A cut off score of less than **19** for patients aged 59 or younger, less than **18** for patients aged 60 to 69, less than **17** for patients aged 70 to 79 and less than **15** for patients aged over 80, indicated the need for a more detailed speech and language assessment. Thirty seven patients (20%) obtained scores below the cut off. These 37 patients had a mean age of 72 years (s.d. 8.9, range 45-91) and **19** were men. Nine patients lived alone, 24 lived with a spouse and four lived with a carer. Nine patients had a left hemiplegia, 24 a right hemiplegia, one had a bilateral stroke, two reported speech problems only and one reported no residual difficulties following stroke. Only one patient had been referred to the speech and language therapist by the primary health care team.

Figure 4.4 illustrates the distribution of the Sheffield Screening Test for each group.

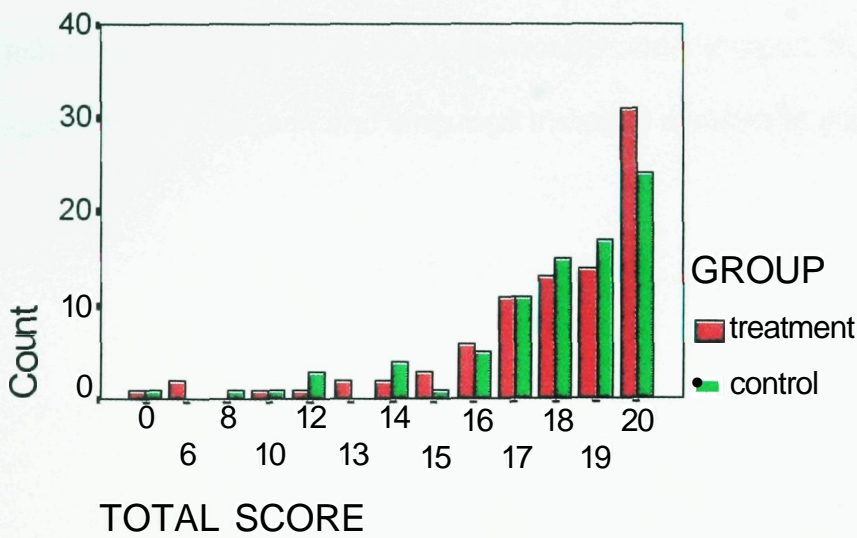
Table 4.13

**COMPARISON OF GROUPS ON THE SHEFFIELD SCREENING TEST FOR
ACQUIRED LANGUAGE DISORDERS**

		Treatment	Control	COMPARISON Mann-Whitney U Test
SHEFFIELD SCREENING TEST	Median	19	18	
	Min - Max	0-20	0-20	U = 3478
	IQR	17-20	17-20	p = 0.67

Figure 4.4

**Distribution of the Sheffield Screening Test total score for the treatment
group and the control group.**



4.3.5 THE REY-OSTERRIETH COMPLEX FIGURE TEST- COPY

Table 4.14 illustrates the median, minimum and maximum value and lower and upper inter-quartile range for the Rey-Osterrieth Complex Figure Test.

A cut off score of less than 29, as recommended by Lincoln et al (1998), indicated that 79 (43%) patients had significant visuospatial problems.

The 79 patients had a mean age of 75 years (s.d. 7.9, range 57 - 92) and 33 were men. Forty patients lived with a spouse, eight with a carer and 31 lived alone.

Thirty six patients had a left hemiplegia, 33 a right hemiplegia, three had bilateral weakness, four had speech difficulties with no limb impairment and three reported no residual difficulties as a result of their stroke. For 53 patients it was their first stroke, while 15 had had one previous stroke, six had had two previous strokes and five had three or more previous strokes.

Of the 79 patients with visuospatial difficulties, two had been referred by the primary health care team to a social services occupational therapist, four to a physiotherapist, one to a speech and language therapist and two to a Day Hospital.

Table 4.14

COMPARISON OF GROUPS ON REY FIGURE COPY

		Treatment	Control	COMPARISON Mann-Whitney U Test
REY FIGURE COPY	Median	28	28	U = 2765 p = 0.76
	Min - Max	1.5-36	0-36	
	IQR	20-32	18-34	

There was no significant difference between the groups when analysed by a Mann-Whitney U test.

4.3.6 ADULT MEMORY INFORMATION PROCESSING BATTERY (AMIPB)

STORY RECALL

The median score, minimum and maximum value and upper and lower inter-quartile range of the AMIPB Story Recall can be found in Table 4.15. Using cut off scores recommended in the published manual (Coughlan and Hollows, 1985) and adjusting for age, 42 (23%) patients were categorised as having significant memory problems. Of the 42 patients with significant memory problems, the mean age was 76 years (s.d 9.1, 45-92) and 26 were women. Twenty patients lived alone, 17 lived with a spouse and five lived with a carer. Fourteen patients had a left hemiplegia, 21 a right hemiplegia, two bilateral weakness and five had speech difficulties but no limb involvement.

Table 4.15

COMPARISON OF GROUPS ON AMIPB STORY RECALL

AMIPB		Treatment	Control	COMPARISON Mann-Whitney U Test
STORY RECALL	Median	8	7.5	
	Min - Max	0 - 38	0 - 34	U = 2412
	IQR	1 - 14	1 - 15	p = 0.78

No significant difference was found between the groups on the AMIPB Story Recall.

4.3.7 CAREGIVER STRAIN INDEX

Table 4.16 illustrates the median, minimum and maximum value and lower and upper inter-quartile range for the Caregiver Strain Index.

Table 4.17 illustrates the frequency of carers experiencing difficulty with individual items of the Caregiver Strain Index. The restriction on the carers free time and the upset caused by observing that the patient had changed so much from their former self, were the two items that caused most strain to carers. For 39% of the carers, they described themselves as feeling completely overwhelmed.

A cut off score of seven or more indicated significant carer strain (Robinson, 1983). Of the 120 carers assessed, 30(25%) were categorised as experiencing significant strain. The 30 carers with significant strain were responsible for patients who had a mean age of 74 years (s.d. 8, range 61-95). Of the carers, 21 were a spouse, five were a family carer (e.g sister or daughter) and four were

carers who did not live with the patient but provided care each day. Thirteen patients had a previous history of stroke.

Table 4.16

COMPARISON BETWEEN THE GROUPS ON
THE CAREGIVER STRAIN INDEX

		Treatment	Control	COMPARISON Mann-Whitney U Test
CAREGIVER STRAIN INDEX	Median Min - Max IQR	4 0- 12 1 -7	4 0-11 1 -7	U = 1697 <u>p = 0.63</u>

There was no significant difference found between the groups on the Caregiver Strain Index.

Table 4.17

**Frequency of carers experiencing difficulty with individual items of the
Caregiver Strain Index.**

ITEM	n=	%
Sleep is disturbed	47	39
It is inconvenient	53	44
It is a physical strain	49	41
It is confining	56	47
Family changes	36	30
Changes in personal plans	30	25
Other demands on time	28	23
Emotional adjustments	26	22
Upsetting behaviour	27	22
Patient has changed	54	45
Work adjustments	11	9
Financial strain	18	15
Feel completely overwhelmed	47	39

4.3.8 GENERAL HEALTH QUESTIONNAIRE 28

Median scores, minimum and maximum values and lower and upper inter-quartile ranges are displayed in Table 4.18 for the total score and the four sub-scales of the General Health Questionnaire 28. A Mann-Whitney U Test found no significant difference between the groups.

The usual way of scoring the GHQ, when it is to be used for case identification, is the 'GHQ method' of 0-0-1-1 (Goldberg and Williams, 1991). Therefore the scores were transformed from the Likert scoring (0-1 -2-3) for this purpose. Using this method and the threshold score of 12 or more recommended by Bridges and Goldberg (1986), 44 patients (24%) were identified as suffering from significant psychological distress.

The 44 cases identified had a mean age of 72 years (s.d 6.6, range 53-88) and 25 were women. Thirteen patients lived alone, 25 lived with a spouse and six lived with a carer. Fourteen patients had a left hemiplegia, 25 a right hemiplegia, one had a bilateral stroke, three had speech difficulties with no limb impairment and one patient reported no residual difficulties following stroke.

Table 4.18

COMPARISON BETWEEN THE GROUPS ON THE GENERAL HEALTH
QUESTIONNAIRE 28

GHQ 28		Treatment	Control	Comparison Mann-Whitney U Test
TOTAL SCORE	Median Min-Max IQR	26 9-57 18-35	27 9-53 19-32	U = 3494 p = 0.71
SOMATIC SYMPTOMS	Median Min-Max IQR	8 0- 19 5- 10	8 0-17 5-11	U = 3555 p = 0.86
ANXIETY AND INSOMNIA	Median Min-Max IQR	7 0-31 3-11	7 0-21 4- 10	U = 3454 p = 0.62
SOCIAL DYSFUNCTION	Median Min-Max IQR	9 4- 17 8- 13	9 7- 17 8- 12	U = 3121 p = 0.12
SEVERE DEPRESSION	Median Min-Max IQR	0 0- 15 0-3	0 0- 12 0-5	U = 3605 p = 0.98

4.3.9 HOSPITAL ANXIETY AND DEPRESSION SCALE

Table 4.19 illustrates the scores for the treatment and control groups for the Hospital Anxiety and Depression scale. Scores are presented for both the anxiety section and the depression section. Mann-Whitney U Tests found no significant differences between the groups for either the anxiety or the depression sections. Scores of greater than seven in each section indicated that 72 (39%) patients were significantly anxious and 48 (26%) were significantly depressed.

Of the 72 patients who were significantly anxious, 24 lived alone, 41 lived with a spouse and seven lived with a carer. The mean age was 73 years (s.d 8.5, range 53 - 92) and 45 were women. Thirty one patients had a left hemiplegia, 34 a right hemiplegia, one bilateral stroke, five had speech difficulties only and one patient reported no residual difficulties.

Of the 48 pateints who were significantly depressed, 11 lived alone, 29 lived with a spouse and eight lived with a carer. The mean age was 72 years (s.d. 7.7, range 53-88) and 24 were women. Twenty two patients had a left hemiplegia, 22 had a right hemiplegia, one had a bilateral stroke and three had speech difficulties only.

Table 4.19

COMPARISON BETWEEN THE GROUPS ON THE HOSPITAL ANXIETY AND DEPRESSION SCALE

HOSPITAL ANXIETY AND DEPRESSION SCALE		Treatment	Control	COMPARISON Mann-Whitney U Test
HAD Anxiety	Median	7	7	U = 3859 p = 0.86
	Min - Max	0-20	0-18	
	IQR	4-11	4-9	
HAD Depression	Median	6	5	U = 3407 p = 0.53
	Min - Max	0- 15	0- 13	
	IQR	3-8	3-7	

4.3.10 MOOD RATING SCALE

Table 4.20 illustrates the median scores, minimum and maximum values and the lower and upper inter-quartile ranges for the Mood Rating Scale. A Mann-Whitney U Test confirmed that there was a significant difference between the groups, in favour of the control group.

To investigate which sections of the simple mood ratings were significantly different between the groups chi-square tests were carried out (see Table 4.21). This indicated that patients allocated to the treatment group felt significantly more frustrated than patients allocated to the control group.

Table 4.20

COMPARISON BETWEEN THE GROUPS ON MOOD RATING SCALE

		Treatment	Control	COMPARISON Mann-Whitney U Test
MOOD RATING SCALE	Median Min - Max IQR	9 4 - 15 7 - 11	8 1 - 13 6 - 10	U=3018 p = 0.01

Table 4.21

COMPARISON BETWEEN THE GROUPS ON INDIVIDUAL ITEMS OF THE MOOD RATING SCALE

MOOD RATING SCALE	Chi-square value	df	Significance p=
very angry - very calm	4.79	3	0.18
very happy - very sad	6.35	3	0.09
very secure - very afraid	2.95	3	0.39
very anxious - very relaxed	5.06	2	0.07
very depressed - very cheerful	6.58	3	0.08
very contented - very frustrated	8.38	3	0.03

4.3.11 SUMMARY OF BASELINE ASSESSMENTS

The baseline assessments confirmed that a substantial proportion of stroke patients not admitted to hospital have significant physical and cognitive deficits. With the exception of the Mood Rating Scale, the physical and cognitive baseline assessments were well matched between the two groups.

4.4 RESULTS AT SIX MONTHS AFTER STROKE.

4.4.1 SAMPLE STUDIED

Of the 185 patients entered into the study, 22 patients could not be assessed at six months. Thirteen patients died before assessment (treatment group n=6, control group n=7) and nine withdrew from the study (treatment group n=4, control group n=5).

The 13 patients who died before the six month outcome assessment were aged 79.9 years (s.d. 6.9, range 70-92) and seven were women. Four patients lived alone, eight with a spouse and one lived with a carer. Four patients had a left hemiplegia, six had a right hemiplegia, one had a bilateral stroke and two patients had reported speech problems only. Eight patients had no previous history of stroke and five patients had a history of one previous stroke.

Of the nine patients who withdrew from the study, seven lived with a spouse and two lived alone. There were four women and five men and none had had a previous stroke. The mean age of the patients who withdrew was 75 years (s.d. 12.6, range 46-91). Four patients had suffered a left hemiplegia and five patients a right hemiplegia.

As the number of withdrawals from the study was small and evenly distributed between the groups, the analysis was conducted on the completed assessments only and not on an intention to treat basis. Eighty four patients in the treatment group and 79 in the control group were compared on outcome measures at six months after stroke. A comparison of patients in the treatment group and control group on demographic characteristics can be found in Table 4. 22. There was a significant difference between the groups for sex, with the treatment group having significantly more men and the control group having significantly more women.

Table 4.22

DEMOGRAPHIC CHARACTERISTICS
OF STROKE PATIENTS ASSESSED AT SIX MONTH
ASSESSMENT

Comparison of treatment group and control group

MEASURE		Treatment n=84	Control n=79	COMPARISON
AGE	Mean SD Min - Max	73.2 7.7 53-92	74.7 7.9 55-92	$t=-1.15$ $p=0.25$
SEX	Male Female	49 35	33 46	$\chi^2= 4.40$ $p=0.03$
SIDE	Left Right Other	42 33 9	36 36 7	$\chi^2=2.77$ $p=0.59$
LIVES	Alone With spouse With carer	22 54 8	32 42 5	$\chi^2=4.12$ $p=0.38$
PREVIOUS HISTORY OF STROKE	None One Two Three or more	62 15 3 4	52 17 5 5	$\chi^2=0.54$ $p=0.90$

4.4.2 OUTCOME ASSESSMENTS

Outcome assessments will be presented individually. Comparisons between the groups were made using a Mann-Whitney U test, available from the SPSSX statistical package. Alpha was set at $p = 0.05$. The 95% Confidence Intervals were calculated using Minitab.

4.4.2.1 BARTHEL INDEX AT SIX MONTHS

Table 4.23 illustrates the median, minimum and maximum values and inter - quartile ranges for the Barthel Index at six months after stroke. A highly significant difference was found between the groups, in favour of the treatment group, using a Mann-Whitney U test.

Table 4.24 illustrates the distribution of the Barthel total scores for each group at six months. Figure 4.5 illustrates the same information in graphical form.

Table 4.25 illustrates a comparison between the groups on individual items of the Barthel Index. Statistically significant differences were found between the groups, in favour of the treatment group, for climbing stairs and bathing.

The results of the Barthel Index at six months suggested that occupational therapy inter/ention significantly improved function in personal activities of daily living.

Table 4.23

COMPARISON BETWEEN THE GROUPS ON THE BARTHEL INDEX
AT SIX MONTHS

MEASURE		Treatment	Control	COMPARISON Mann-Whitney U Test
BARTHEL INDEX	Median Min - Max IQR	1 20 4-20 18-20	18 6-20 16-20	U = 2444 p = 0.002 95% CI = 0 to 1

Table 4.24

DISTRIBUTION OF BARTHEL SCORES FOR EACH GROUP AT SIX MONTHS

Barthel Score	Treatment Group	Control Group
18-20	65 (77%)	45 (57%)
15-17	14 (17%)	23 (29%)
<15	5 (6%)	11 (14%)

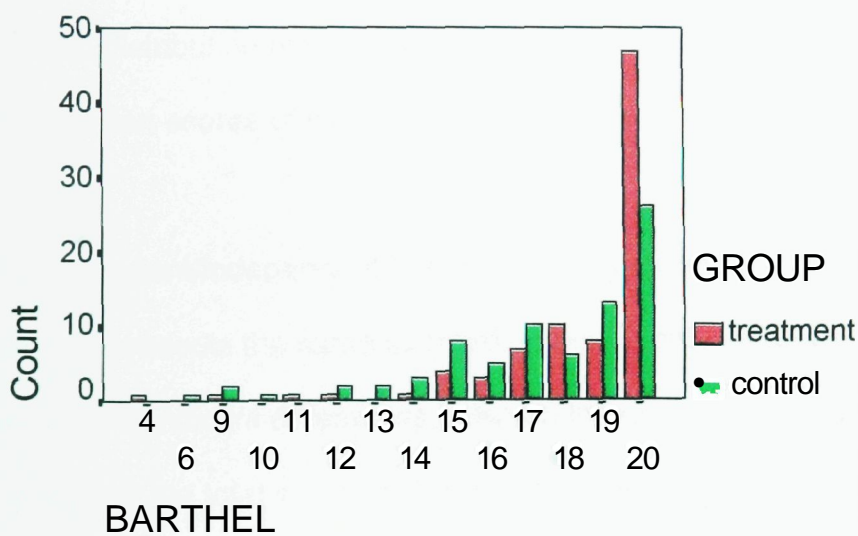
Table 4.25

COMPARISON BETWEEN THE GROUPS ON INDIVIDUAL ITEMS OF THE BARTHEL INDEX

Barthel Item	Treatment Group % Independent	Control Group % Independent	Chi-square value	df	Significance p=
Bowels	96	95	0.22	1	0.63
Bladder	81	77	0.38	1 2	0.82
Grooming	92	83	2.49	1	0.11
Toilet use	93	89	0.94	2	0.62
Feeding	87	82	1.97	2	0.37
Transfer	96	89	3.65	2	0.16
Mobility	96	90	4.07	3	0.25
Dressing	81	72	3.60	2	0.16
Stairs	79	56	9.77	2	0.007
Bathing	70	54	4.34	1	0.03

Figure 4.5

DISTRIBUTION OF BARTHEL SCORES AT SIX MONTHS



**4.4.2.2 NOTTINGHAM EXTENDED ACTIVITIES OF DAILY LIVING SCALE
AT SIX MONTHS.**

Table 4.26 illustrates the median, minimum and maximum score and the inter-quartile ranges for the Nottingham EADL scale at six months after stroke. Details of the mobility, kitchen, domestic and leisure scores are also presented.

Significant differences were found between the groups, in favour of the treatment group, for the total score and all four sections. Figure 4.6 illustrates the median score and inter-quartile range of the EADL total score in graphical form. Figure 4.7 illustrates the distribution of the EADL total score for both groups. Figure 4.8 illustrates the median scores of individual sections for each group on the Nottingham EADL.

Applying the dependent/independent (0,0,1,1) scoring system for the Nottingham EADL Table 4.27 presents the same information on the data as found in Table 4.26. There were significant differences between the groups, in favour of the treatment group, for the total score, mobility, kitchen and domestic sections of the Nottingham EADL. There was not a significant difference between the groups on the leisure section of the Nottingham EADL using this scoring system.

Table 4.28 illustrates a comparison between the groups on individual items of the Nottingham EADL. Eight individual items were significantly different between the groups: four in the mobility section, three in the kitchen section and one in the leisure section.

Table 4.26

COMPARISON BETWEEN THE GROUPS ON THE NOTTINGHAM
EADL AT SIX MONTHS (scoring 0.1.2.3)

EXTENDED ACTIVITIES OF DAILY LIVING INDEX		Treatment	Control	COMPARISON Mann-Whitney U Test
Total Score	Median Min - Max IQR	46 2-66 33-55	33 3-66 19-50	U = 2402 p = 0.002 95% CI = 3- 14
Mobility	Median Min - Max IQR	14 0 - 18 6-16	9 0-18 3-15	U = 2475 p = 0.004 95% CI = -.001 to 5
Kitchen	Median Min - Max IQR	15 1-15 12-15	13 0-15 6-15	U = 2490 p = 0.002 95% CI = 0 to 2
Domestic	Median Min - Max IQR	9 0-15 5-12	6 0-15 3 - 11	U = 2521 p = 0.007 95% CI = 0 to 4
Leisure	Median Min - Max IQR	9 0-18 6-14	8 0-18 6-12	U = 2717 p = 0.04 95% CI = 0 to 3

Table 4.27

COMPARISON BETWEEN THE GROUPS ON THE NOTTINGHAM

EADL AT SIX MONTHS (scoring 0.0.1.1)

EXTENDED ACTIVITIES OF DAILY LIVING INDEX		Treatment	Control	COMPARISON Mann-Whitney U Test
Total Score	Median Min - Max IQR	16 1 -22 11 - 19	12 0-22 6-17	U = 2533 p = 0.009 95%CI = 1 to 4
Mobility	Median Min - Max IQR	5 0-6 2-6	3 0-6 1 -5	U = 2566 p = 0.01 95% CI = 0 - 2
Kitchen	Median Min - Max IQR	5 0-5 4-5	5 0-5 2-5	U = 2672 p = 0.01 95% CI = -.0003 to .0001
Domestic	Median Min - Max IQR	3 0-5 1-4	2 0-5 1 -4	U =2651 p = 0.02 95% CI = 0 to 1
Leisure	Median Min - Max IQR	3 0-6 2-5	3 0-6 2-4	U = 2830 p = 0.09 95% CI = .0001 to .999

Figure 4.6

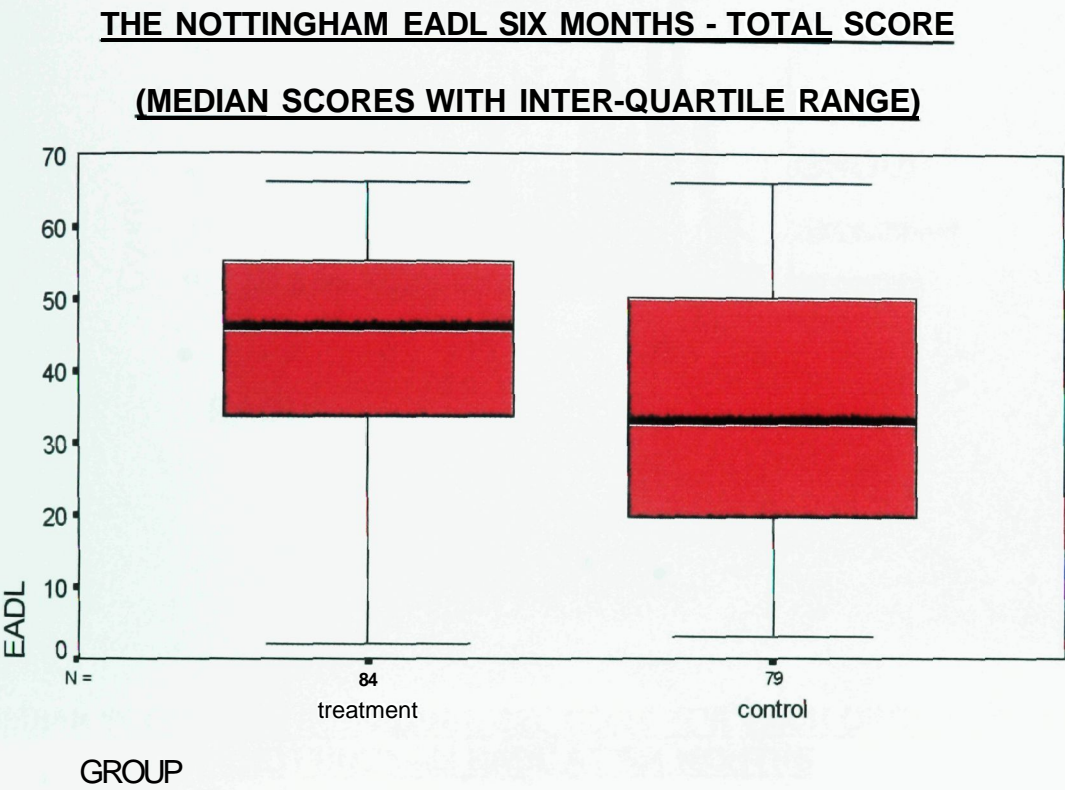


Figure 4.6 shows a box-and-whisker plot. The box indicates the lower and upper quartiles and the central line is the median. The points at the end of the 'whiskers' indicate the extreme values.

Figure 4.7

Distribution of EADL total scores for the treatment group and the control group at six months.

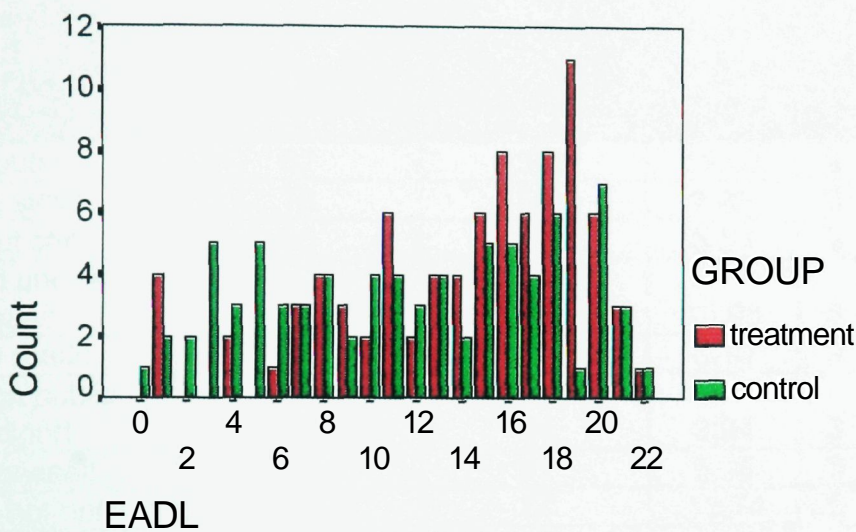


Figure 4.8

MEDIAN SCORES ON INDIVIDUAL SECTIONS FOR EACH GROUP ON THE NOTTINGHAM EADL AT SIX MONTHS

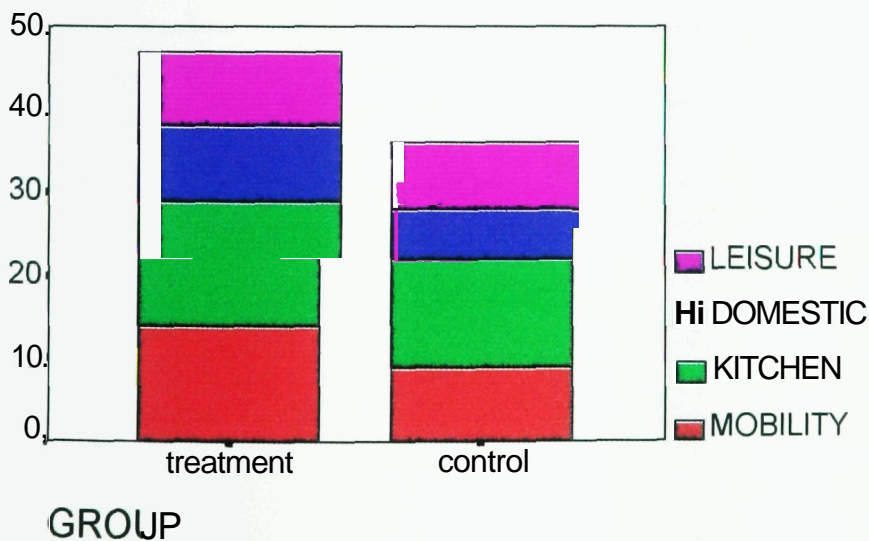


Table 4.28

**COMPARISON BETWEEN THE GROUPS ON INDIVIDUAL ITEMS
OF THE EADL SCALE**

EADL Item	Treatment Group % Independent	Control Group % Independent	Chi- square value	df	Significance p=
walk outside	82	58	13.53	3	0.003
climb stairs	73	56	9.83	3	0.02
in/out car	65	61	3.53	3	0.31
walk on uneven ground	73	44	15.96	3	0.001
cross roads	65	49	8.10	3	0.04
travel on public transport	40	34	3.94	3	0.26
feed oneself	94	91	5.15	3	0.16
make a hot drink	90	77	10.74	3	0.01
carry drinks from room to room	84	70	8.68	3	0.03
wash up	81	67	6.36	3	0.09
make a hot snack	81	62	10.81	3	0.01
manage own money	82	72	4.31	3	0.22
wash small items of clothing	46	30	5.62	3	0.13
housework	50	39	5.06	3	0.16
shopping	44	32	5.92	3	0.11
full clothes wash	40	32	1.66	3	0.64
read newspaper/book	86	89	3.35	3	0.34
use telephone	88	90	0.31	3	0.95
write letters	52	34	7.90	3	0.04
go out socially	46	38	3.37	3	0.33
manage garden	36	25	4.37	3	0.22
drive a car	20	16	0.38	1	0.53

As at baseline (Table 4.11) the treatment and control groups were split into high scoring and low scoring groups using the median EADL score at baseline. Table 4.29 illustrates the numbers of patients categorised into each group. Using a chi-square analysis this demonstrated that at six months after stroke there was a significant difference between the proportion of patients in each group. There were significantly more patients from the treatment group in the high scoring EADL group at six months after stroke.

Chi-square value = 7.83, df = 1, p = 0.005

Table 4.29

n=163	Treatment Group	Control Group
Low score	18	33
High score	66	46

In summary, the results of the Nottingham EADL reported that there were highly significant differences between the groups (in favour of the treatment group) at the six month assessment.

4.4.2.3 RIVERMEAD MOTOR ASSESSMENT - GROSS FUNCTION SECTION AT SIX MONTHS

The median, minimum and maximum scores and the lower and upper inter-quartile ranges for the gross function section of the Rivermead Motor Assessment, for both groups at six months, can be found in Table 4.30. Figure 4.9 illustrates this information in graphical form. Significant differences were found between the groups, in favour of the treatment group. Figure 4.10 illustrates the distribution of the Gross Function scores for each group.

Table 4.31 illustrates a comparison between the groups on individual items of the Gross Function section of the Rivermead Motor Assessment. A significant difference was found between the groups on five consecutive items: climbing stairs (with banister), walk 10 metres without an aid, walk five metres pick up a bean bag and return, walk outside for 40 metres and climb four steps (no banister).

Table 4.30

COMPARISON BETWEEN THE GROUPS ON THE RIVERMEAD MOTOR ASSESSMENT - GROSS FUNCTION SECTION AT SIX MONTHS

RIVERMEAD MOTOR ASSESSMENT		Treatment	Control	COMPARISON Mann-Whitney U Test
GROSS FUNCTION SECTION	Median	10	10	U = 2480
	Min - Max	1 -13	0 -3	p = 0.004
	IQR	9-13	6-11	CI = 0-2

Figure 4.9

GROSS FUNCTION SCORES AT SIX MONTHS
(median scores with interquartile range)

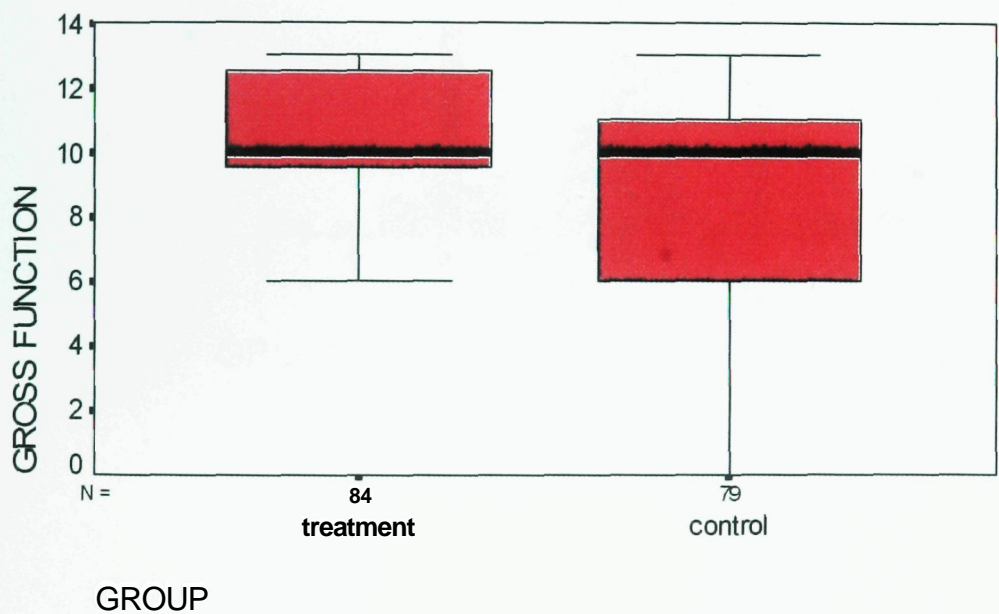


Figure 4.10

Distribution of Gross Function total score for both groups at six months

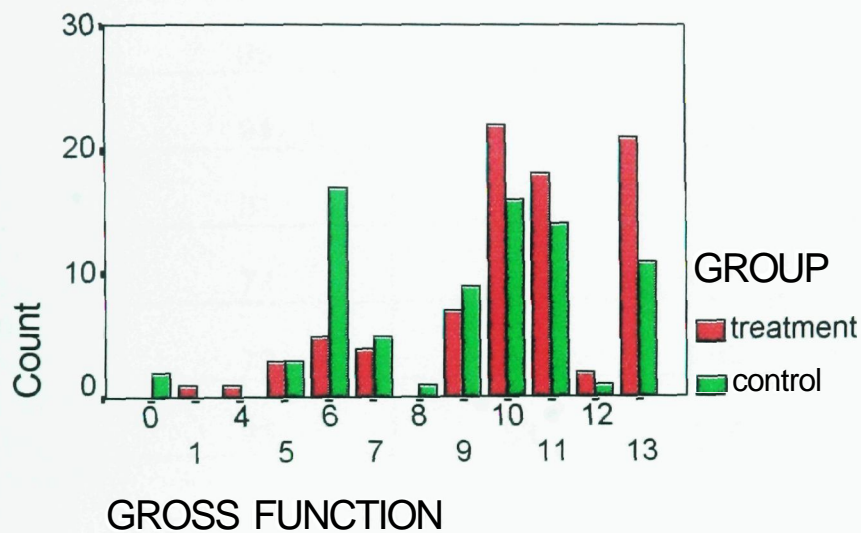


Table 4.31

**COMPARISON BETWEEN THE GROUPS ON INDIVIDUAL ITEMS
OF GROSS FUNCTION**

Gross Function Item	Treatment Group % Independent	Control Group % Independent	Chi-square value	df	Significance p=
sit unsupported	96	90	3.25	1	0.07
lying to sitting	94	90	0.48	1	0.48
sit to stand	95	96	0.004	1	0.94
Transfer towards unaffected side	99	96	1.13	1	0.28
Transfer towards affected side	96	94	0.20	1	0.64
walk 10 metres (with aid]	94	91	0.48	1	0.48
climb stairs (with banister)	81	67	4.11	1	0.04
walk 10 metres (without aid)	74	58	4.45	1	0.03
walk 5 metres pick up bean bag	79	54	9.85	1	0.001
walk 40 metres outside	75	53	8.64	1	0.003
climb 4 steps (no banister)	46	33	4.80	1	0.02
run 10 metres	19	13	1.31	1	0.25
hop on affected leg	25	14	3.31	1	0.06

The results of the Gross Function section of the Rivermead Motor Assessment at six months suggested that occupational therapy intervention significantly improved motor performance.

4.4.2.4 CAREGIVER STRAIN INDEX AT SIX MONTHS

The median, minimum and maximum scores and the lower and upper inter-quartile ranges for the Caregiver Strain Index, for both groups at six months can be found in Table 4.32. Significant differences were found between the groups, in favour of the treatment group.

Table 4.33 illustrates a comparison between the groups on individual items of the Caregiver Strain Index. Significant differences were found between the groups in favour of the treatment group on four items: disturbed sleep, physical strain, family changes and other demands on time.

Table 4.32

COMPARISON BETWEEN THE GROUPS ON THE CAREGIVER STRAIN INDEX
AT SIX MONTHS

		Treatment	Control	COMPARISON Mann-Whitney U Test
CAREGIVER STRAIN INDEX	Median	1	3	U = 853.5 p=0.02 95% CI = 0 to 2
	Min - Max	0-10	0-10	
	IQR	0 - 4	1-6	

Table 4.33

**COMPARISON BETWEEN THE GROUPS ON INDIVIDUAL ITEMS
OF THE CAREGIVER STRAIN INDEX**

Caregiver Strain Item	Treatment Group % "No "	Control Group % "No "	Chi-square value	df	Significance p=
Sleep is disturbed	81	60	5.34	1	0.02
It is inconvenient	76	80	0.004	1	0.94
It is a physical strain	91	82	4.00	1	0.04
It is confining	69	57	1.61	1	0.20
There have been family changes	86	70	6.34	1	0.01
There have been changes in personal plans	64	50	2.15	1	0.14
There have been other demands on my time	95	72	8.26	1	0.004
There have been emotional adjustments	88	80	1.78	1	0.18
Some behaviour is upsetting	74	62	1.83	1	0.17
It is upsetting to find „... has changed so much	69	60	1.16	1	0.28
There have been work adjustments	88	90	0.09	1	0.75
It is a financial strain	84	82	0.18	1	0.66
Feel completely overwhelmed	79	82	0.003	1	0.95

This result suggests that the carers of the patients in the intervention group were significantly less strained at six months after the stroke than carers in the control group.

4.4.2.5 GENERAL HEALTH QUESTIONNAIRE 28 AT SIX MONTHS

The median, minimum and maximum scores and the lower and upper inter-quartile ranges are presented for the total score of the General Health Questionnaire 28 in Table 4.34. Scores are presented for both the patient and the carer at six months. Mann-Whitney U Tests showed no significant differences between the groups for either the patient or the carer.

Table 4.35 illustrates the individual sections of the GHQ 28 for the patient and the carer. There was a significant difference between the groups in one section (somatic symptoms) for the patient GHQ 28. There were no significant differences between the groups for all other sections of the GHQ 28, either for the patient or the carer.

Table 4.34

COMPARISON BETWEEN THE GROUPS ON THE GHQ 28 TOTAL SCORE AT
SIX MONTHS

GENERAL HEALTH QUESTIONNAIRE		Treatment	Control	COMPARISON Mann-Whitney U Test
GHQ 28 Patient	Median	20	23	U = 2889
	Min - Max	7-54	8-63	p = 0.29
	IQR	14-30	15-35	95% CI = -6 to 2
GHQ 28 Carer	Median	18	18	U = 1050
	Min - Max	8-63	3-49	p = 0.75
	IQR	11 - 24	13-27	95% CI = -4 to 3

Table 4.35

COMPARISON BETWEEN THE GROUPS ON THE INDIVIDUAL SECTIONS OF

GHQ 28

GHQ 28 Individual section		Treatment Group	Control Group	Comparison Mann-Whitney U Test
Patient -Somatic symptoms	Median Min - Max IQR	5 0-16 3-8	6 0- 17 4- 10	U = 2617 p = 0.04
Patient -Anxiety and insomnia	Median Min - Max IQR	5 0- 16 2-8	4 0-20 2- 10	U = 3183 p = 0.96
Patient - Social dysfunction	Median Min - Max IQR	8 3- 16 7-11	9 5-20 8-12	U = 2667 p = 0.06
Patient - Severe depression	Median Min - Max IQR	1 0-12 0-5	1 0- 18 0-4	U = 3164 p = 0.91
Carer - Somatic symptoms	Median Min - Max IQR	4 1 -18 2-7	5 0-18 2-7	U = 1033 p = 0.65
Carer - Anxiety and insomnia	Median Min - Max IQR	6 0-17 2-9	6 0-20 4-11	U = 972 p = 0.36
Carer - Social dysfunction	Median Min - Max IQR	7 4- 17 7-8	7 1 -12 6-8	U = 1059 p = 0.79
Carer - Severe depression	Median Min - Max IQR	0 0-13 0-2	0 0-7 0-2	U = 1072 p = 0.86

These results suggest that occupational therapy intervention had no significant effect on the mood of the patient or the carer.

4.4.2.6 HOSPITAL ANXIETY AND DEPRESSION SCALE AT SIX MONTHS

Table 4.36 illustrates the median, minimum and maximum scores and the lower and upper inter-quartile range for the Hospital Anxiety and Depression scale scores at six months. Scores are presented for both the anxiety section and the depression section. There were no significant differences between the groups at six months for either the anxiety score or the depression score.

Table 4.36

COMPARISON BETWEEN THE GROUPS FOR THE HOSPITAL ANXIETY AND DEPRESSION SCALE AT SIX MONTHS

HOSPITAL ANXIETY AND DEPRESSION SCALE		Treatment	Control	COMPARISON Mann-Whitney U Test
HAD Anxiety	Median	5	6	U = 3024.5
	Min-Max	0-19	0-15	p = 0.55
	IQR	2-9	2-9	95% CI = 1 to -2
HAD Depression	Median	5	6	U = 2702.5
	Min-Max	0-14	0-16	p = 0.08
	IQR	2-7	3-9	95% CI = -.001 to -2

4.4.2.7 THE NOTTINGHAM LEISURE QUESTIONNAIRE

Table 4.37 illustrates the median, minimum and maximum scores and the lower and upper inter-quartile ranges for the total leisure score (TQTL) and the total leisure activity score (TLA) for both groups at six months after stroke.

The Mann-Whitney U Test confirmed that there were no significant differences between the groups for either the total leisure score or the total leisure activity score.

Table 4.37

COMPARISON BETWEEN THE GROUPS ON THE NOTTINGHAM LEISURE QUESTIONNAIRE AT SIX MONTHS

NOTTINGHAM LEISURE QUESTIONNAIRE		Treatment	Control	COMPARISON Mann-Whitney U Test
Total leisure score	Median	38	31	U = 2855.5
	Min - Max	0-75	11-68	p = 0.19
	IQR	L 27-48	23-43	95% CI = -1 to 8
Total leisure activity score	Median	13	11	U = 2885.0
	Min - Max	0-28	4-23	p = 0.18
	IQR	9- 17	8-16	95% CI = -1 to 3

These results suggest that the occupational therapy intervention under investigation did not significantly influence the number of leisure activities that patients participated in or the frequency in which they engaged in them.

Table 4.38 illustrates a comparison between the groups on individual items of the Nottingham Leisure Questionnaire. Two items were significantly different (in favour of the treatment group) between the groups: looking after pets and holidays.

Table 4.38

**COMPARISON BETWEEN THE GROUPS ON INDIVIDUAL ITEMS
OF THE NOTTINGHAM LEISURE QUESTIONNAIRE**

Nottingham Leisure Questionnaire Item	Chi-square value	df	significance D =
Watching TV	5.01	4	0.28
Listening to radio	0.48	4	0.97
Visiting family/friends	3.58	4	0.46
Reading books	0.36	4	0.98
Singing	2.98	4	0.55
Gardening	6.63	4	0.15
Swimming	1.20	3	0.75
Daydreaming	2.83	4	0.58
Crafts	7.51	4	0.11
Attending sporting events	7.38	4	0.11
Attending classes	3.34	3	0.34
Collecting things	5.91	4	0.20
Shopping for pleasure	8.62	4	0.07
Cooking for pleasure	2.83	4	0.72
Reading newspapers/magazines	2.40	4	0.66
Just sitting	0.63	4	0.95
Walking	5.26	4	0.26
Volunteer work	0.01	3	0.99
Indoor games	0.48	4	0.97
Bicycling	2.94	2	0.22
Dancing	5.28	4	0.25
Looking after/exercising pets	7.67	3	0.05
Eating out	4.92	4	0.29
Going to pubs	0.53	4	0.97
Going to plays/cinema/museums	1.89	3	0.59
Photography	2.75	4	0.63
Exercise/fitness	3.76	4	0.43
Activities at clubs/centres	2.73	4	0.60
Going to parties	5.77	3	0.12
Entertaining at home	8.45	4	0.07
Church activities	2.49	4	0.64
Relaxation	5.67	4	0.22
Fishing	1.74	4	0.78
Driving	0.77	3	0.85
Do-It-Yourself	2.33	4	0.67
Sporting activities	1.88	4	0.75
Holidays	9.8	4	0.04

4.4.2.8 THE LONDON HANDICAP SCALE AT SIX MONTHS

Table 4.39 illustrates the median, minimum and maximum scores and lower and upper inter-quartile ranges for the treatment and control groups on the London Handicap Scale at six months after stroke. A significant difference between the groups, in favour of the treatment group, was found.

Table 4.40 illustrates the median, mode, minimum and maximum scores and lower and upper inter-quartile ranges for each domain of the London Handicap Scale. Mann-Whitney U tests indicated that there were statistically significant differences between the groups for three of the six domains: mobility, physical independence, and work and leisure.

Table 4.39

A COMPARISON BETWEEN THE GROUPS ON THE LONDON HANDICAP SCALE (TOTAL SCORE) AT SIX MONTHS

		Treatment Group	Control Group	COMPARISON Mann-Whitney U Test
THE LONDON HANDICAP SCALE	Median	76.1	65.2	U = 2671.5
	Min - Max	26.8-100	17.7-100	p = 0.03
	IQR	60.8-88.6	47.9-86.9	95% CI = 0.3 to 13.5

The results from this analysis indicated that at six months after stroke the intervention group were significantly less handicapped than the control group.

Table 4.40

**A COMPARISON BETWEEN THE GROUPS ON EACH DOMAIN OF THE
LONDON HANDICAP SCALE**

LHS domain		Treatment Group	Control Group	Mann-Whitney U Test
Mobility	Median	2	2	U = 2722 p = 0.04
	Mode	1	2	
	Min - Max	1 -5	1 -5	
	IQR	1 -3	2 -4	
Physical independence	Median	1	2	U = 2717 p = 0.03
	Mode	1	1	
	Min - Max	1 -5	1 -6	
	IQR	1 -3	1 -4	
Work and Leisure	Median	3	3	U = 2721 p = 0.04
	Mode	1	3	
	Min - Max	1 -6	1 -6	
	IQR	1 -4	2 -5	
Social integration	Median	2	2	U = 3052 p = 0.34
	Mode	1	1	
	Min - Max	1 -5	1 -5	
	IQR	1 -2	1 -2	
Orientation	Median	1	2	U = 2902 p = 0.12
	Mode	1	1	
	Min - Max	1 -3	1 -5	
	IQR	1 -2	1 -2	
Economic Self-sufficiency	Median	2	2	U = 2965 p = 0.22
	Mode	1	2	
	Min - Max	1 -5	1 -5	
	IQR	1 -3	1 -3	

4.4.2.9 SUMMARY OF OUTCOME ASSESSMENTS

Significant differences were found in favour of the treatment group at six months after the stroke in the Barthel Index, the Nottingham EADL, RMA Gross Function, Caregiver Strain Index and the London Handicap Scale. No significant differences were found between the groups on the Nottingham Leisure Questionnaire, the HAD scale or the GHQ 28 for either the patient or the carer.

4.5 BLINDNESS OF THE INDEPENDENT ASSESSOR

The independent assessor monitored her 'blindness' on 108 occasions.

(Blindness was not monitored on all patients since it was introduced after the study had commenced.) Unblinding was recorded by the assessor on 13 occasions, one of which was incorrect. The assessor guessed the group allocation correctly on 62 (57%) occasions. On 26 occasions the independent assessor guessed correctly that the patient was allocated to the treatment group and on 36 occasions she guessed correctly that the patient was allocated to the control group. See Table 4.41.

To detect the level of agreement between the independent assessor's guess and the correct group allocation, Cohen's Kappa coefficient (1960) was applied. The kappa coefficient was calculated at $k = 0.15$. Using Landis and Koch's (1977) guidelines to interpret values between 0 and 1, the strength of agreement between the assessors guess and the correct group allocation was judged to be poor. To investigate if the guess rate of the independent assessor was significantly better than chance, the kappa value (0.15) was divided by the standard error (0.09) to give a normalised statistic.

This value was then compared with a standardised normal distribution.

$$\frac{0.15}{0.09} = 1.66 \qquad p = 0.09$$

This revealed that the guess of the independent assessor was not significantly better than chance.

Table 4.41

AGREEMENT BETWEEN INDEPENDENT ASSESSOR'S GUESS AND
CORRECT GROUP ALLOCATION

n=108	TREATMENT GROUP	CONTROL GROUP
GUESS TREATMENT GROUP	26	16
GUESS CONTROL GROUP	30	36

4.6 MULTIPLE LINEAR REGRESSION ANALYSIS

In order to detect which factors identified at baseline were associated with level of EADL at six months after the stroke, a controlled stepwise multiple regression analysis was implemented. This technique was considered appropriate for relating a dependent variable (outcome) to both categorical and continuous independent variables (predictors). The dependent variable was EADL at six months. It was also considered more appropriate to predecide the order of steps in the model, as opposed to the computer programme deciding the order. By doing this the researcher was able to use her clinical judgement on the application of the model. Step one indicated the initial severity of disability, step two included the possible predictor variables and step three included the group allocation of the patients recruited to the trial.

The variables entered into the equation, quoting adjusted R square value at each step , were as follows:

Step one: initial EADL (adjusted R square =0.56, $p<0.0001$).

Step two: sex, memory recall, speech total, Rey figure, age (adjusted R square = 0.61). This step significantly increased the value of R, $p=0.005$.

Step three: group allocation (adjusted R square = 0.66). Finally this third step significantly increased the value of R, $p=0.0001$.

This analysis revealed that when all variables were added to the model, it accounted for 66% of the variance of the EADL score at six months. Four factors were positively associated with independence in EADL at six months after the stroke: initial EADL ($p<0.0001$), memory recall ($p=0.005$), speech total ($p=0.03$) and group allocation ($p=0.0001$). Sex ,age and perceptual difficulties as

measured on the Rey Figure, were not significantly associated with independence in EADL at six months.

To investigate the normality of the data, a histogram, a scatterplot and a normal p-p plot were conducted on the regression standardised residuals. No unusual phenomena were observed.

4.7 VISITS BY THE RESEARCH OCCUPATIONAL THERAPIST

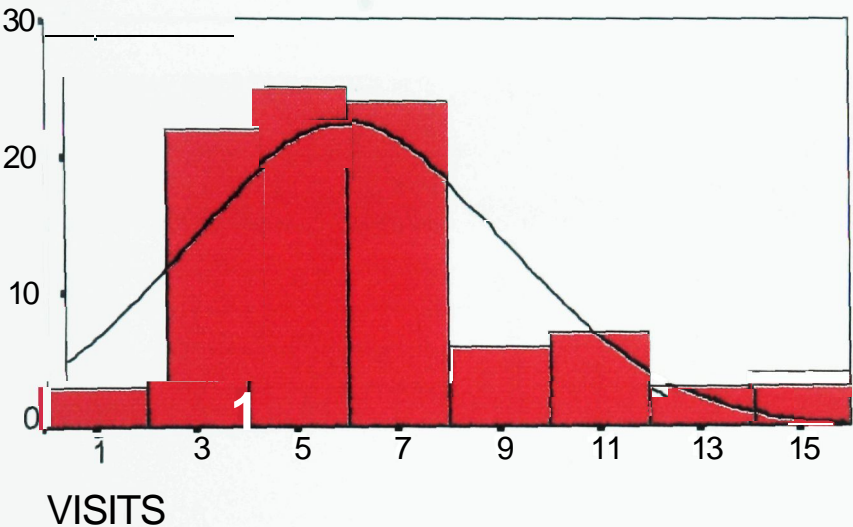
Figure 4.11 illustrates a histogram (displaying a normal curve) of the number of visits received in the treatment group. This demonstrates that the number of visits were not normally distributed. Non-parametric statistics were therefore used.

The median number of visits received was five (range 1-15, IQR 3 -7).

The median length of each visit was 52 minutes (range 24 - 90, IQR 44 - 60).

Figure 4.11

NUMBER OF VISITS MADE BY THE OCCUPATIONAL THERAPIST



4.8 TREATMENT SESSIONS

Each visit made by the occupational therapist was categorised into the type or types of treatment administered during that session. Treatment sessions were categorised into five domains: self care, extended activities of daily living, leisure activities, upper limb activities and relaxation. Table 4.42 illustrates the median, minimum and maximum value and inter-quartile range of each treatment domain. The most frequent type of treatment session delivered during the study period was leisure.

Table 4.42

TREATMENT SESSIONS - TYPE AND FREQUENCY

Type of session	Total Number of sessions	Median	Min -Max	IQR
Self care	149	1	0-12	0 - 3
EADL	242	2.5	0-9	0 - 4
Leisure	283	3	0 -8	2 - 4
Upper limb	151	0	0-10	0 - 3
Relaxation	51	0	0 - 4	0 - 1

The relation between each of the treatment domains and their associated outcome measure at six months, were investigated using Spearman Rank Correlation Coefficients. Unfortunately there was no specific outcome measure to investigate the effect of the upper limb treatment domain. Table 4.43 illustrates these correlations.

Table 4.43

RELATION BETWEEN TREATMENT DOMAINS AND ASSOCIATED OUTCOME
MEASURES AT SIX MONTHS

Treatment domain	Associated outcome measure	r_s	p
Self-care	Barthel Index	-.49	<0.0001
EADL	Nottingham EADL	0.13	0.21
Leisure	Nottingham Leisure Questionnaire	0.02	0.84
Relaxation	Hospital Anxiety and Depression scale (anxiety section)	0.33	0.002

These analyses suggested that there was a significant correlation between the frequency of self-care sessions and the independence in personal ADL. There was also a significant correlation between the frequency of relaxation sessions and the anxiety section of the Hospital Anxiety and Depression scale. There were no significant correlations between the number of EADL sessions and the Nottingham EADL or between the number of leisure sessions and the Nottingham Leisure Questionnaire.

To detect if the level of disability at baseline assessment was correlated with the number of treatment sessions, (i.e. perhaps more dependent patients received more treatment sessions) Spearman Rank Correlation Coefficients were used. Table 4.44 illustrates these correlations. The baseline assessments did not contain measures of leisure or upper limb function.

Table 4.44

**RELATION BETWEEN TREATMENT DOMAINS AND ASSOCIATED
MEASURES AT BASELINE**

Treatment domain	Associated outcome measure	r_s	p
Self-care	Barthel Index	-.59	<0.0001
EADL	Nottingham EADL	-.15	0.13
Relaxation	Hospital Anxiety and Depression scale (anxiety section)	0.20	0.05

These results suggested that there was a significant correlation between the number of self care sessions and independence in personal care, as measured at one month after stroke. There was also a significant correlation between the number of relaxation sessions and the anxiety section of the Hospital Anxiety and Depression scale. There were no significant correlations between the number of EADL sessions and the Nottingham EADL.

4.9 REFERRALS MADE TO OTHER HEALTHCARE AGENCIES

During the trial a total of 137 referrals (Median 1, range 0 - 8, IQR 0 - 2) were made by the two research occupational therapists to other healthcare agencies. These referrals were made on behalf of the patients allocated to the treatment group. There were no referrals made on behalf of patients in the control group. Table 4.45 lists the number of referrals made to each agency. The largest number of referrals were made to the social services occupational therapist (n= 43).

Of the 43 patients referred to the social services occupational therapist, the mean age was 73 years (s.d. 6.5, range 57-86) and 16 were men and 27 were women. Fourteen patients lived alone, 22 lived with a spouse and 7 lived with a carer. Twenty three patients had a left hemiplegia, 17 had a right hemiplegia, three had a bilateral stroke and two patients had speech difficulties only. Patients referred to the SSOT had a median baseline Barthel score of 16 (range 9 - 20, IQR 14 - 18). The median baseline EADL score was 18 (range 4 - 57, IQR 12-30) and the median baseline Gross Function score was six (range 1 - 11, IQR 6 - 8).

Of the 19 patients referred to a stroke club the mean age was 76 years (s.d. 5.8, range 62 - 86) and seven were men and 12 were women. Five patients lived alone, 12 lived with a spouse and two lived with a carer. Ten patients had a left hemiplegia, seven had a right hemiplegia, one had a bilateral stroke and one had speech difficulties. Patients referred to a stroke club had a median baseline Barthel score of 16 (range 9 - 20, IQR 14 - 18) and a median baseline EADL score of 24 (range 4 - 57, IQR 12 -37).

Of the 14 patients referred to community physiotherapy, four were men and 10 were women. The mean age was 76 years (s.d. 5.8, range 66 - 86) and six patients had a left hemiplegia and eight had a right hemiplegia. Seven patients lived alone, six lived with a spouse and one lived with a carer. The median baseline Gross Function score was six (range 5 - 11, IQR 6 - 9). The median baseline Barthel score was 15 (range 12 - 20, IQR 14 - 17) and the median EADL score was 23 (range 4 - 57, IQR 12 -29).

The 14 patients referred for Homecare Aid comprised three men and 11 women. Nine patients lived alone, four lived with a spouse and one lived with a carer. Six patients had a left hemiplegia, seven had a right hemiplegia and one patient had

speech difficulties only. The mean age of patients referred for Homecare Aid was 76 years (s.d. 9.5, range 57 - 95). The median baseline Barthel score was 15 (range 12-20, IQR 14-17) and the median baseline EADL score was 21 (range 3-30, IQR 11 -27).

Of the eight patients referred to the speech and language therapist four were men and four were women. The mean age was 72 years (s.d. 9.7, range 53 - 87).

Three patients lived alone and five lived with a spouse. Two patients had a left hemiplegia, three had a right hemiplegia and three had speech problems only.

The median baseline Sheffield Screening Test score was 18 (range 0 - 20, IQR 6 • 19). Two patients referred to the speech and language therapist had scores of less than 15.

Table 4.45

REFERRALS MADE TO OTHER HEALTHCARE AGENCIES

(n= 137)

HEALTHCARE AGENCY	NUMBER OF REFERRALS MADE THROUGHOUT THE DURATION OF THE STUDY
Social Services Occupational Therapist	43
Stroke Club	19
Community Physiotherapist	14
Homecare Aid	14
Continence Nurse	10
Driving Centre	10
Homeloans	9
Speech and Language Therapist	8
Outpatient Occupational Therapist	4
ALAC (Wheelchair centre)	2
Optician	3
District Nurse	1

4.10 AIDS TO DAILY LIVING ISSUED TO PATIENTS

One hundred and forty three (Median 0, range 0 - 9, IQR 0 - 3) aids to daily living were issued to patients in the treatment group during the study period.

Table 4.46 illustrates the type and number of aids issued to patients. The most frequently issued aids were the bathboard and bathseat.

Of the 26 patients issued a bathboard during the study, 15 were still dependent and 11 were independent at six months after the stroke. Of the 23 patients issued

a bathseat, ¹⁰ were independent at six months. All three patients issued with dressing aids were independent in dressing at six months. Sixteen patients were issued with stair rails, and at six months after stroke, 12 were independent when climbing stairs. Eighteen patients were issued with 20 feeding aids; of these patients ¹¹ were independent in feeding at six months. Of the 15 patients supplied with adapted grip (n=16) to their cutlery, 12 were independent in feeding at six months after the stroke.

Table 4.46

TYPE AND FREQUENCY OF AIDS TO DAILY LIVING ISSUED

(n = 143)

TYPE OF AID ISSUED	n =
Bathboard	26
Bathseat	23
Feeding aid	20
Dycem mat	18
Grab handle / stair rail	16
Adapted handle (e.g. fork)	16
Kitchen aid	13
Chair raiser	4
Dressing aid	3
Ramp	2
Shower seat	1
Adjustable table	1

4.11 SPECIFIC INFORMATION GIVEN TO PATIENTS

One hundred and forty nine (Median 1, range 0 - 6, IQR 1 - 2) specific pieces of information were given to stroke patients and their carers during the study period.

Table 4.47 illustrates the type and frequency of information given. The most frequent piece of information given to stroke patients and their carers was a selection of Stroke Association information leaflets.

Of those 23 patients given attendance allowance information, all applied and all 23 received the allowance. The research therapist had to attend one tribunal on behalf of a patient to ensure that the allowance was rightfully awarded.

Of the 22 patients who received dial-a -ride information, only five patients made use of this service. Of the 15 patients who received information on the Piper solo personal alarm, five patients obtained one through their local social services department. Seven patients, of the 12 who received information on driving, had returned to driving by six months after their stroke. Four of the five carers who received information on respite care, used this service. The two patients who received holiday information from the research therapist went on holiday to a hotel which catered for special needs and of the two patients who received information on bereavement counselling only one used this service.

Table 4.47

TYPE AND FREQUENCY OF INFORMATION GIVEN TO PATIENTS
AND CARERS (n= 149)

INFORMATION	n =
Selection of relevant Stroke Association leaflets	68
Attendance allowance	23
Dial - a - ride	22
Piper solo (personal alarm)	15
Driving information	12
Respite care	5
Holiday	2
Bereavement counselling	2

CHAPTER FIVE

DISCUSSION

5.1 INTRODUCTION

The discussion has been divided into six sections: summary of overall findings, limitations of methods used, link between theory and practice, discussion of results, practical implications of results and suggestions for future research.

5.2 SUMMARY OF OVERALL FINDINGS

Between February 1994 and March 1998, 240 stroke patients managed in the community were identified. Fifty five patients were excluded. Of the remaining 185 patients, 94 were randomly allocated to the treatment group and 91 to the control group.

Baseline characteristics (demographic, physical and cognitive assessments) were well matched between the treatment and control groups. These data revealed that stroke patients remaining in the community at one month after stroke had significant physical and cognitive difficulties and that the primary health care team had little involvement in the coordination of further services.

The number of visits received in the treatment group ranged from one to 15 with a median of five visits. The content of treatment sessions were categorised into five domains: self care, extended activities of daily living, leisure activities, upper limb activities and relaxation. The most frequent type of treatment session delivered during the study was leisure.

At six months after stroke significant differences were found in favour of the treatment group in the Barthel Index, the Nottingham EADL, Rivermead Motor Assessment Gross Function section , Caregiver Strain Index and the London Handicap Scale. No significant differences were found between the groups on the

Hospital Anxiety and Depression scale, General Health Questionnaire 28 for the patient or the carer or the Nottingham Leisure Questionnaire.

5.3 LIMITATIONS OF METHODS USED

5.3.1 SIZE OF SAMPLE

The present trial of occupational therapy is one of the largest published in the therapy literature and has produced evidence to support that treatment by an occupational therapist can reduce disability and handicap in stroke patients not admitted to hospital. However we found that the occupational therapy treatment administered during the study had no significant impact on the mood of the patient or the carer. This may be because the effect was too small to be identified in this sample size. A current trial in Nottingham investigating the effect of occupational therapy on the mood of stroke patients discharged from hospital, estimated that 450 patients were required to detect a clinically significant difference in the mood of the patient, as measured by the General Health Questionnaire. Therefore larger studies or the findings of meta-analysis will be required to confirm or refute whether or not physical or behavioural approaches are helpful in reducing post-stroke depressive symptoms.

5.3.2 SAMPLE OF PATIENTS

Patient selection methods were discussed in chapter three. However, our sample was not complete since it depended on general practitioner notification. Twenty one practices (29%) made no notifications throughout the four year project. This

suggested that many stroke patients were missed. Previous literature indicates that a general practitioner with an average list size of 2,000 patients would expect to see five new cases of stroke per year (Oxford Community Stroke Project, 1983); of whom up to four may be admitted to hospital. Anecdotal evidence would suggest that when dealing with the one patient per year not admitted to hospital the general practitioner simply forgot about the present trial.

In the absence of a complete sample it is not possible to state whether certain groups of patients were missed. We are therefore unable to clarify if notified patients were more or less disabled than those not notified to the study. The Barthel Index would suggest that there was a wide spread of disability scores in our sample and were similar to that seen in another study of community stroke patients (Wolfe et al, 1993). However the studies of Bamford et al, 1986 and Wade and Hower, 1987 reported slightly more patients with severe disability (these studies included patients in institutional care). With respect to the age range of the patients notified, we were aware that the 55 patients who were excluded before randomisation, were significantly older than those admitted to the trial. This was largely due to the considerable number of excluded patients who were in nursing or residential care.

The problems of recruiting patients from general practitioners have been previously discussed by several authors (Peto et al, 1993, Tognoni et al, 1991 and Jonker and Sumajow, 1992). This literature suggested that the low level of study recruitment was not specific to our study. Indeed, it has been shown to be true of infectious disease notification (Voss, 1992) and the recording of chronic diseases (Coulter et al. 1989).

Awareness of possible recruitment difficulties enabled us to ensure that the duration of the study period was of adequate length to obtain our desired sample size.

5.3.3 SCOPE OF DATA COLLECTION

A considerable amount of information was collected during baseline and outcome assessment periods and it is possible that relevant information was missed.

Baseline information adequately described the sample and no obvious omissions were observed. However during analysis of the content of occupational therapy treatment it became apparent that a suitable measure to detect the effectiveness of treatment, with regard to arm function, had been omitted. In light of recent evidence (Parry et al, In press; Sunderland et al 1992; Turton and Fraser, 1990) suggesting that therapy for the upper limb has a desirable effect on the less severely impaired arm, it may be that the occupational therapy intervention under investigation had a positive effect on arm function.

To the best of the author's knowledge all other areas were included, hence the sizeable battery of physical and cognitive assessments.

5.3.4 MEASURES USED

The measures used in the present trial were selected after reviewing several relevant scales and careful consideration of the literature. The strengths and weaknesses of each measure used have already been described in chapters two and three. Occupational therapy aims to influence activities of daily living and it

could be argued that the ADL outcome measures in the present trial (i.e. Nottingham Extended Activities of Daily Living scale and the Barthel) were not sensitive enough to detect beneficial therapy intervention. For example if a patient was identified at baseline as having difficulty with bathing the therapist might prescribe the use of bathing aids, such as a bath board and bath seat. Provision of this equipment may have been issued not only to promote personal hygiene but may have been provided primarily for the safety of both the patient and the carer. Despite providing this equipment, instructing on its use and supervising regular practice, the patient may still be dependent on the assistance of their carer at the end of the intervention period; however the treatment goal set by the therapist was nonetheless achieved. It is therefore possible that some positive benefits of therapy intervention were not captured. The Barthel Index is known to have both ceiling and floor effects. To overcome the ceiling effects the Nottingham Extended Activities of Daily Living scale was used. In the community setting it is likely for many patients that treatment will be aimed at achieving independence in both personal and extended activities of daily living. It may therefore be possible to amalgamate the Barthel Index and the Nottingham ADL scale to form a unidimensional outcome scale.

5.3.5 TIMING OF INTERVENTION

There is some evidence from the literature (Garraway et al, 1981) that earlier access to rehabilitation promotes earlier levels of independence. It may therefore be that if the research therapist had seen patients at an earlier stage (i.e. before one month) their recovery may have been greater or would have occurred earlier.

However the fact that patients made a significantly better recovery than the patients allocated to the control group would suggest that the timing of therapy was appropriate. The rationale for making initial contact with patients at one month, was based on the premise that the intervening time interval would allow for possible intervention to be organised by the primary health care team and the rapid initial recovery from the stroke to have taken place.

It may also be argued that the duration of patient/therapist contact was too long, taking place over a five month period. However the median number of visits during this period was five, permitting little scope for patients or carers to become dependent on the visits made by the therapist. This frequency of visits would also be a practical possibility within the provision of a clinical service.

The outcome assessments took place at six months after stroke, at a time when all contact with the research therapist had ended. We therefore do not know if patients would have continued to improve with a longer duration of treatment or greater intensity of therapy input.

5.3.6 EXPERIENCE OF THERAPIST

During the study two senior 1 occupational therapists provided treatment for all 94 patients allocated to the treatment group. It could be argued that these therapists had a specific interest in this area and may have been more experienced in the treatment of stroke patients than colleagues recruited to a comparable service. Bearing in mind this possible bias in service provision, it was decided to recruit a clinician who was an experienced senior 1 therapist and had specialised in the care of stroke patients along with a 'time served' senior 2 occupational therapist,

with some but not extensive experience of stroke care. (The more junior therapist was upgraded to a senior 1 therapist, due to the level of responsibility the work required). This combination was thought to be the most representative of current clinical practice and therefore the most appropriate to evaluate the provision of an occupational therapy service.

The present study was not designed to investigate the differences in practice or outcome between the two therapists, however there may have been some merit in doing so. Patients treated by the more experienced therapist obtained higher scores in personal and extended activities of daily living. The less experienced therapist made fewer visits to patients, supplied more aids and referred more patients to other health care services than the more experienced therapist.

Caution must be used when making any inferences from this information as patients were randomly allocated to the treatment group or the control group but were not randomly allocated to the more experienced therapist or the less experienced therapist. This may have caused some bias in the sample of patients treated by each therapist. For example, all patients identified from Southern Derbyshire were seen by one therapist; the therapist lived in this area and it was more practical for her to visit this group of patients than her colleague. It may be that the patients recruited from this location were different (younger/older, more/less disabled, access to more/fewer community services) from the patients in Nottinghamshire. As the present study was a pragmatic trial and designed to investigate a service operating under realistic conditions, the delegation of work load and location was thought to represent what would ordinarily happen in routine clinical practice.

5.3.7 STATISTICS

When a large number of comparisons are conducted on one set of data it is possible that statistically significant results may occur by chance. In this study, because of the breadth of data collected, many such procedures were used. This is particularly pertinent when interpreting the results of more detailed exploration of the data, for example the individual comparison of each item on the Nottingham Extended Activities of Daily Living scale. However the rationale for exploring the data in this way was not to obtain a definitive answer to the question posed but to generate hypotheses for future studies.

5.4 LINK BETWEEN THEORY AND PRACTICE

The theory of occupational therapy has been described in chapter one and the content of treatment used in the present trial has been described in chapter three. The principles of both the rehabilitation model and the model of adaption through occupation were implemented during the treatment phase of the study. The treating occupational therapists however did not consciously state or document at the beginning of each session which model of practice they were to adopt or indeed which approach they were about to implement. The implementation of models or approaches appeared to occur instinctively.

The theory of occupational therapy is reinforced during under-graduate training, but little is known about its application after graduation day. At a National Occupational Therapy Conference, Kelly (1998) presented results from a small study which concluded that five or six years after graduation, occupational therapists stated that they were not using models of practice. The only occasions

when models were implemented, were when the therapists were supervising students or talking to other professionals. The work of Kelly would appear to support the findings of the present trial and endorses anecdotal information from clinical therapists (Walker et al, In preparation).

5.5 DISCUSSION OF RESULTS

This section will cover four areas; patient notification, disability at one month after stroke, comparisons between the treatment group and the control group at six months and the content of occupational therapy treatment.

5.5.1 PATIENT NOTIFICATION

Notification to the present study was much lower than would be expected from a community sample of stroke patients. From the 494,000 patients targeted in the study it was expected that 250 stroke patients would remain in the community each year. Only one quarter (n=60) of expected notifications were obtained each year. The reasons why this may have occurred have been discussed in chapter 5.3.2.

There was a very low level of rehabilitation intervention before the one month baseline assessment. This suggested that patients were either judged not to require rehabilitation, or that such services were not available, or both. Of the ten referrals made to an occupational therapy service, five were made by a single general practitioner. This general practitioner was atypical because he was married to the lead occupational therapy researcher! Of his five referrals to an

occupational therapy ten/ice three patients were randomly allocated to the control group and two to the treatment group.

When interpreting the results of the primary health care team intervention, one must bear in mind that the study relied on the self reporting of patients and carers and that this may not have been reliable (Luther et al, 1998).

5.5.2 DISABILITY AT ONE MONTH AFTER STROKE

The results of baseline assessments demonstrated that patients not admitted to hospital following stroke had considerable cognitive and physical difficulties. Each aspect of disability measured at baseline will be discussed in turn.

Most patients were functioning at a high level of self care activity, however 20% of patients obtained Barthel scores of less than 15 which indicated moderate to severe disability. This is in contrast to the studies of Bamford et al, 1986 and Wade and Hower 1987, who reported that 23% and 26% respectively of stroke patients managed in the community were classified as severely disabled.

However the studies by Bamford and Wade and Hower included patients who were living in nursing and residential homes, who were perhaps older and more severely disabled.

Many patients had difficulties with the more complex extended activities of daily living, such as kitchen and domestic tasks, outdoor mobility and shopping.

Domestic tasks were the most difficult for patients to achieve independently. In a recent study Lincoln et al (1998b) examined the individual items of the Nottingham Extended Activities of Daily Living, before and after stroke, in a group

of stroke patients not admitted to hospital and found that patients' difficulties occurred mostly in advanced mobility. The frequency of problems encountered may have varied between the two studies because Lincoln and colleagues included patients in nursing and residential homes, who may have experienced more limited mobility and did not carry out any domestic tasks. Nonetheless these findings indicated that patients were greatly restricted in the variety of activities in which they participated. The primary aim of occupational therapy was to restore patients to their highest level of functioning in activities of everyday life, it was therefore an appropriate intervention to evaluate in this group of patients.

The Rivermead Motor Assessment Gross Function section demonstrated that the majority of patients (68%) were unable to walk outdoors without help. This restriction on outdoor mobility would severely limit access to many pleasurable pursuits such as shopping, going to the pub, going to the bingo or visiting the hairdresser. The distribution of Gross Function scores at one month can be found in Figure 4.3. This figure demonstrated that the Gross Function scale was not normally distributed or an interval scale; some steps were large and some little, and was perhaps not sensitive at certain points of the scale. For example the step between a score of six and a score of seven was very large indicating that it was more difficult to progress from walking indoors ten metres with an aid to climbing stairs with the aid of a bannister. It appeared to be easier to move from a score of seven (climbing stairs) to a score of eight (walk ten metres without an aid).

Twenty percent of patients obtained scores below the cut off for the Sheffield Test for Acquired Language Disorders, indicating the need to refer to a speech and

language therapist for a more detailed assessment. This figure is comparable to that found by the Oxford Community Stroke Project (Unpublished data, Wariow et al, 1996) in a similar population. Communication with visitors, carers, social contacts or outside agencies would therefore be a challenge for this group of patients. An awareness of speech difficulties may have reduced the patients' level of confidence and prevented them from getting out and about, if otherwise physically able.

Using the recommended cut off by Lincoln et al (1998a), the Rey-Osterrieth Complex Figure Test-copy, identified 43% of patients as having significant visuospatial problems. In comparison, the Oxfordshire Community Stroke Project (OCPS) (Unpublished data, Wariow et al, 1996) reported only 12% of patients with visuospatial problems. The OCSP used unstructured and non-standardised testing of visuospatial dysfunction including bilateral simultaneous stimulation (wagging fingers), clock drawing and simple figure copying. Nonetheless it would still appear that 43% of patients identified with visuospatial difficulties is a considerable number of patients in a sample of this size. However as Lincoln and colleagues (1998a) have highlighted, the Rey Figure is a very useful screening tool and is sensitive (i.e. will detect all those who have a perceptual problem) but does lack specificity (i.e. may identify some patients as having a perceptual problem when they have not). It is therefore most likely that several patients have been identified in the present study as having a problem when in reality they may have none.

Verbal memory problems occurred in 23% of patients. As cognitive impairment has not been formally assessed in detail in previous surveys of community stroke patients it is difficult to comment on the incidence of this problem in this population. However a study by Lincoln and Tinson (1989) followed a series of stroke patients admitted to hospital under 80 years of age and found that 49% of patients had significant memory failure at one month after stroke. Stewart et al (1996) studied a sample of patients late after stroke (12 to 36 months post cerebrovascular accident) who had reported they had experienced memory impairment following stroke, and found that 50% were impaired on one or more of the memory measures used. It may be that stroke patients not admitted to hospital suffered less impairment and therefore experienced fewer memory difficulties.

One quarter of the carers reported that they were experiencing significant strain at one month after stroke. Although the physical demands of looking after a stroke patient can be very high, Brocklehurst et al (1981) reported that it was the patient's psychological and resulting behavioural problems which cause most distress to carers. It would appear from our sample that restriction of free time and observed changes in the patient caused most strain. Lincoln et al (1998b) studied a sample of community stroke patients (including patients in nursing and residential homes) and found 15% of carers at one month after stroke had significant strain. In a study by Wilkinson et al (1997) significant strain, also measured by the Caregiver Strain Index, was reported in 20% of carers of stroke patients four to five years after stroke. At this later stage after stroke the three areas which caused the most stress to carers were observed changes in the

patient, upsetting behaviour and changes in personal plans. It would therefore appear that carer strain is common after stroke and is a long term problem.

Clinical depression has been found to be associated with impaired recovery from stroke (Morris et al, 1992, Ebrahim et al, 1987). There is also some evidence to suggest that mood disorders may add to the handicap caused by the physical effects of stroke, by disrupting the rehabilitation process (Adams and Hurwitz, 1963, Robinson et al 1984). The frequency of depression at one month after stroke in the present study was reported as 26% on the Hospital Anxiety and Depression scale and psychological distress was reported as 24% as measured on the GHQ 28. These findings are comparable to the Oxfordshire Community Stroke Project (House et al, 1991) who reported significant depression in 20% of stroke patients remaining in the community (as measured on the Present State Examination (Cooper et al, 1977) and the Beck Depression Inventory (Beck et al, 1961) and those of the Perth Community Stroke Study (Burvill et al, 1995) who reported a prevalence of 23% at one month after stroke (as measured on the Present State Examination (Cooper et al, 1977). In a recent study Lincoln et al (In press) compared a group of stroke patients who had not been admitted to hospital with a group of stroke patients who had been admitted to hospital but were at home by one month after stroke, and found that there was no significant difference between the two groups for mood, as measured by the Hospital Anxiety and Depression scale.

The Mood Rating Scale (Lincoln et al, 1985) was used in conjunction with the GHQ 28 (Goldberg, 1972) and the Hospital Anxiety and Depression scale

(Zigmond and Snaith, 1983) as a simple measure of mood. This was the only baseline assessment that was found to be significantly different between the treatment and control groups, with patients allocated to the treatment group feeling significantly more frustrated than patients allocated to the control group. This isolated significant difference between the groups may be due to chance or explained by noting that the Mood Rating Scale lacks reliability and validity.

5.5.3 COMPARISONS BETWEEN THE TREATMENT GROUP AND THE CONTROL GROUP AT SIX MONTHS

Significant differences were found between the groups, in favour of the treatment group, on the Barthel Index, Nottingham EADL, Rivermead Motor Assessment Gross Function, Caregiver Strain Index and the London Handicap Scale.

The main aim of occupational therapy intervention in this study was to increase stroke patients' participation in everyday activities and we can conclude from our results that this approach was beneficial in reducing disabilities for this group of patients. For personal activities of daily living, the treatment group achieved significantly higher scores for climbing stairs and bathing. It is important to note that bathing aids and stair rails were the aids most frequently requested from the social services occupational therapist. While social services occupational therapists assess for the need of such aids, deliver and instruct on their safe usage, they do not provide regular practice until the patient, and if relevant the carer, are confident to use them without the presence of a healthcare professional. The research therapist encouraged regular practice in the use of

such aids, until she was of the opinion that they could be used safely and independently.

For the more complex extended activities of daily living (total score of the Nottingham Extended Activities of Daily Living scale and all four sections; mobility, kitchen, domestic and leisure) there were significant differences between the groups when using the 0,1,2,3 scoring system. However when implementing the 0,0,1,1 scoring system the leisure section showed no significant difference between the groups. This suggests that the latter scoring system may be less sensitive to change over a period of intervention. However the 0,0,1,1 scoring system had been developed to confirm that the assessment comprised four unidimensional Guttman-scaled subscales. The benefits highlighted in the Nottingham EADL are an important finding since EADL performance has been associated with lower levels of institutionalisation, and less dependence upon social and health resources (Gladman et al, 1993b). The size of the treatment effect (3 EADL points) is larger than that seen in a positive trial of a stroke unit (Juby et al, 1996) (2 EADL points), and so is likely to be considered of genuine clinical importance. To illustrate this, for a patient scoring at the median of the control group to reach the median of the treatment group, he or she would have to have gained independence in housework, walking over uneven ground and in crossing roads. This result adds to the evidence of smaller trials which have demonstrated that occupational therapy was beneficial to community stroke patients (Drummond and Walker, 1995; Walker et al, 1996; Logan et al, 1997; Gilbertson et al, 1998).

The median scores for the Rivermead Motor Assessment Gross Function for the treatment group and the control group were the same at six months, however the inter-quartile ranges were quite different (see figure 4.10). Significant differences were found between the groups, all in favour of the treatment group, on five of the 13 items. These items; climb stairs (with bannister), walk 10 metres (without aid), walk five metres pick up bean bag, walk outside 40 metres, climb stairs (without bannister) further support the findings of the individual comparisons on the Barthel Index and the mobility section of the Nottingham EADL, which found similar items with significant differences between the groups.

Four items of the Caregiver Strain Index demonstrated significant differences between the groups; disturbed sleep, physical strain, family changes and other demands on time. It may be that the research therapist helped ease the physical strain for the carer; for example by teaching the patient and carer how to safely enter and exit the bath without physical assistance*. It may also be that the therapist encouraged the carer to prioritise their time; for example by no longer cleaning their sons house* or shopping for their daughter while she was at work*. (* are specific examples from the intervention group).

There was a significant difference between the groups on the London Handicap Scale. When comparisons were made between individual items this revealed that it was the mobility, physical independence and work and leisure sections that were significantly different between the groups. This would suggest that occupational therapy has a beneficial effect in reducing the level of handicap experienced by stroke and that the London Handicap Scale is measuring similar domains as the Barthel Index, Nottingham EADL and the Rivermead Motor Assessment Gross

Function section, thereby adding further weight to the main findings. This finding supports those of Gilbertson et al (1998) who also identified a significant difference between two groups on the London Handicap Scale in an experimental trial of community occupational therapy.

The results obtained from the HAD scale and the GHQ 28 were comparable; the HAD identifying 26% of patients who were depressed and the GHQ 28 identifying 24% of patients who were suffering from psychological distress.

There were no significant differences between the groups for the mood of the patient or the carer as measured on the HAD and/or GHQ 28. This may be due to the possibility, as suggested earlier, that the effect was too small to be identified in this sample size. Or it may be due to the fact that no specific therapeutic strategies to affect mood were used. However the mood of stroke patients would appear to be stubbornly resistant to change (Lincoln et al, 1985; Logan et al, 1997; Young and Forster 1992; Forster and Young, 1996) and as yet, no known strategy can be recommended to address this problem.

There were no significant differences between the groups on the Nottingham Leisure Questionnaire. This was a surprising finding when it was noted that the most frequently addressed treatment domain during the study period was leisure activity. There is the possibility that this could be a spurious finding since frequency alone did not take into account the length or intensity of that specific session (e.g. did the therapist discuss a leisure activity for ten minutes or did she provide the materials and participate in an art session lasting ninety minutes?).

The lack of effect on leisure activity did not support earlier work by Drummond and

Walker (1995) who found that leisure treatment by an occupational therapist significantly increased the number of leisure activities that a stroke patient participated in and also significantly increased the frequency in which they participated in their chosen activity. Perhaps the leisure therapy provided in the present trial was too diluted and it may be that in order to significantly change leisure participation, treatment needs to be administered by a specialist leisure therapist.

5.5.4 TREATMENT BY THE OCCUPATIONAL THERAPIST

The research occupational therapist provided a median of five sessions, of approximately one hours duration, over the five month period. This indicated that the actual amount of occupational therapy delivered over the study period was fairly minimal. Earlier studies of occupational therapy showing a positive effect of treatment involved a slightly higher range of treatment sessions; ten visits (Gilbertson et al, 1998), eight visits (Walker et al, 1996), six visits (Logan et al, 1997). It could be that the aforementioned studies involved patients who had been admitted to hospital and had experienced more disability. Or it could also be that it was the content of treatment in the present study that was important and not just the frequency of visits.

The description of the content of occupational therapy treatment implemented during the study (Chapter 3.23) would suggest that the treatment delivered may not just be specific to stroke but could also be successfully applied to other neurological conditions, for example multiple sclerosis. Indeed it may also be relevant to other non neurological conditions such as the wide range of conditions

affecting the elderly in the community, for example rheumatoid arthritis, osteoarthritis and general mobility problems.

The research occupational therapists knew the outcome measures that were to be administered at the end of the five month period of intervention and this may have biased the emphasis on the content of treatment they provided. Standardised outcome measures are not used routinely in clinical practice but there may be a case for occupational therapy services to use ADL scales to inform decision making ~~when setting goals with the patient and the carer.~~ This process helps identify problems, so that treatment can be specifically targeted at these areas.

5.6 PRACTICAL IMPLICATIONS OF RESULTS

This study has shown that a considerable number of stroke patients remaining at home have significant rehabilitation needs and that these are amenable to treatment by an occupational therapist with measurable benefits. However in practical terms does this mean that all stroke patients not admitted to hospital should be referred to occupational therapy? In this study a pragmatic approach was used with the aim of testing whether the treatment under investigation had any use in practice. In a pragmatic trial treatment must be delivered in an optimal way, so that the results are relevant to clinical practice. This is what we set out to achieve and hopefully succeeded. Therefore the positive results of the trial would suggest that this service should be offered to stroke patients not admitted to hospital. However it may be that certain subgroups of patients benefited most from the occupational therapy intervention. The multiple linear regression analysis carried out to establish which factors were associated with a good outcome in

extended activities of daily living, indicated that the initial severity of the stroke, memory difficulties and speech and language problems were significantly associated with good outcome. Age, sex and perceptual difficulties were not significantly associated with outcome. However these variables can only be called predictors of outcome when they are tested on a new set of data, independent of the set of data from which the variable was identified (Gladman, 1995). Therefore these results require replication on another data set in order to accurately identify subgroups of patients who would benefit most from occupational therapy intervention.

However, if such a service were to be established what would the cost be to the general practitioner? In a hypothetical context, if a practice of three general practitioners, covering a population of 6,000 patients were to 'buy' such a service it was estimated that it would cost approximately £1400 per year. (N.B. this is a very rough figure.) This figure is based on four patients not being admitted to hospital multiplied by five sessions of occupational therapy multiplied by £70 (the current cost of an occupational therapy session is approximately £50-70).

Unfortunately this is not the total cost of such a service as we have not taken into account the cost of referring patients to other health services, such as community physiotherapy or to the social services occupational therapist. The economic costs were not specifically documented in this study and should be subject to further inquiry.

5.7 SUGGESTIONS FOR FUTURE RESEARCH

5.7.1 STAFFING

The treatment in the present trial often incorporated repetitive activities, such as practising going up and down stairs, dressing, preparing vegetables and getting in and out of the bath. There is evidence by Parry et al (In press) that certain stroke rehabilitation programmes involving repetitive practice can be carried out effectively by a trained and closely supervised physiotherapy assistant. It may therefore be that similar levels of functional improvement in community stroke patients, as found in the present study, can be achieved by a supervised occupational therapy assistant. Other benefits of assistant intervention may include a reduction in cost and wider coverage of an occupational therapy service. There is therefore a need to investigate the role of the occupational therapy assistant in the provision of stroke rehabilitation in the community.

5.7.2 OPENING THE 'BLACK BOX' OF OCCUPATIONAL THERAPY

TREATMENT

In the present study we have attempted to describe the content of the treatment administered by the research occupational therapists. However we were unable to say exactly what it was about the treatment that significantly improved the patients functional performance on personal and extended activities of daily living. Clinicians would argue that it is nearly impossible to say exactly what treatment is given to certain patients, since treatment is given in accordance with an overall approach and not as a specific prescription. It therefore seems that in order to understand the dynamics of occupational therapy treatment there is a need for a

systematic classification of the treatment techniques used and a greater understanding of patient/ therapist relationships. This may be achieved by using observational methodology. Black (1996) who supports the need for observational studies in health care, comments that observational methods can be implemented when experimental methods are inappropriate, impossible or inadequate. By implementing a different methodology known as a 'single case design' an individual patient can be studied in depth. A specific treatment strategy is alternately given and withdrawn, with the patient acting as their own control. The main disadvantage of this design is that the results are not easily generalisable to other patients, however it does generate a hypothesis that can be further evaluated in a large randomised controlled trial. This methodology has already been successfully implemented in occupational therapy by Edmans and Lincoln (1989, 1991). The single case design may therefore be helpful in working out which therapeutic techniques work and which do not.

5.7.3 GENERALISABILITY OF THE RESULTS

Are the patients included in the present trial representative of patients not admitted to hospital? As stated earlier, the sample was not complete as one had to rely on notification from general practitioners. However there is no reason to believe that the results would have greatly altered if a full case ascertainment had been achieved. It is therefore reasonable to propose that an occupational therapy service for this group of patients should be offered. However if such services were to be established, they should initially be evaluated to replicate these findings. Similarly, it is important to establish if the results in this study can be

achieved by different occupational therapists in different locations. For example
can these results be achieved in a rural setting? (t may be that the impact of this
service would be greater elsewhere in the United Kingdom as stroke awareness in
Nottingham is already high. A large multi-centre randomised controlled trial would
provide definitive answers to many of the unresolved questions posed. It is also
recommended that further work is required to examine the durability of these
benefits and their economic implications.

REFERENCES

Adams GF, Hurwitz LJ. (1963) Mental barriers to recovery from strokes. The Lancet; 2 :533-537.

Adams SA, Ashburn A, Pickering RM, Taylor D. (1997a) The scalability of the Rivermead Motor Assessment in acute stroke patients. Clinical Rehabilitation; 11: 42-51.

Adams SA, Pickering RM, Ashburn A, Lincoln NB. (1997b) The scalability of the Rivermead Motor Assessment in non-acute stroke patients. Clinical Rehabilitation; 11:52-59.

Ada L, Canning C. (1990) Physiotherapy: foundations for practice. Key issues in neurological physiotherapy. Butterworth Heinemann.

Aho K, Harmsen P, Hatano S, Marquardsen J, Smirnov VE, Strasser T. (1980) Cerebrovascular disease in the community. Bulletin of the World Health Organisation; 58:113-130.

Al-Khawaja I, Wade DT, Collin OF. (1996) Bedside screening for aphasia: a comparison of two methods. Journal of Neurology; 243: 201-204.

Allen LR, Beattie RJ. (1984) The role of leisure as an indicator of overall satisfaction with community life. Journal of Leisure Research; 2 : 99-109.

Altman DG. (1980) Statistics and ethics in medical research. Part Three: How large a sample? British Medical Journal; 281: 1336-1338.

Andrews K, Brocklehurst JC, Richards B, Laycock PJ. (1980) The prognostic value of picture drawings by stroke patients. Rheumatology Rehabilitation; 19: 180-188.

Ashburn A. (1982) Assessment of motor function in stroke patients. Physiotherapy; 68: 109-113.

Astrom M, Adolfsson R, Asplund K. (1993) Major depression in stroke patients: A three year longitudinal study. *Stroke*; 24: 976-982.

Aylard PR. (1987) A validation study of three anxiety and depression self assessment scales. *Journal of Psychosomatic Research*; 31: 261-268.

Bach P, Tracy HW, Huston J. (1971) The use of self-portrait method in the evaluation of hemiplegic patients. *Southern Medical Journal*; 64(12): 1475-1480.

Bamford J, Sandercock P, Warlow C, Gray M. (1986) Why are patients with acute stroke admitted to hospital? *British Medical Journal*; 292: 1369-1372.

Bamford J, Sandercock P, Dennis M, Warlow C, Jones L, McPherson K, Vessey M, Fowler G, Molyneux A, Hughes T, Burn J, Wade D. (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. *Journal of Neurology*; 5: 1373-1380.

Barer DH, Ebrahim SB, Mitchell JRA. (1988) The pragmatic approach to stroke trial design: Stroke Register, Pilot Trial, Assessment of neurological and functional outcome. *Neuroepidemiology*; 7: 1-12.

Barer D, Nouri F. (1989) Measurement of activities of daily living. *Clinical Rehabilitation*; 3: 179-187.

Beck AT, Ward CM, Mendelson M, Mock J, Erbaugh J. (1961) An inventory for measuring depression. *Archives of General Psychiatry*; 4: 561-571.

Beck AT, Beamesderfer A. (1974) Assessment of depression: the depression inventory. *Psychological Measurements in Psychopharmacology. Modern Problems in Pharmacopsychiatry; Volume 7. Karger, Basel.*

Benjamin J. (1976) The Northwick Park ADL Index. *British Journal of Occupational Therapy*; 301-306.

Benton A, Sivan A. (1992) Benton Visual Retention Test. 5th Edition. Psychological Corporation.

Bernspang B. (1987) Consequences of stroke. Doctoral thesis. University of Umea, Sweden.

Black N. (1996) Why we need observational studies to evaluate the effectiveness of health care. British Medical Journal; 312: 1215-1218.

Bonita R, Anderson A. (1983) Speech and language disorders after stroke: an epidemiological study. New Zealand Speech Language Therapy Journal; 38: 2-9.

Bridges KW, Goldberg DP. (1986) The validation of the GHQ-28 and the use of the M.M.S.E. in neurological in-patients. British Journal of Psychiatry; 148: 548-553. Check in library

Brocklehurst JC, Andrews K, Morris P, Richards BR, Laycock PL. (1978) Why admit stroke patients to hospital? Age and Ageing; 7: 100

Brocklehurst JC, Morris P, Andrews K, Richards B, Laycock P. (1981) Social effects of stroke. Soc Sci Med; 15: 35-39.

Bunhill PW, Johnson GA, Jamrozik KD, Anderson CS, Stewart-Wynne EG, Chakera TMH. (1995) Prevalence of depression after stroke: the Perth community stroke study. British Journal of Psychiatry; 166: 320-327.

Carnwath TOM, Johnson DAW. (1987) Psychiatric morbidity among spouses of patients with stroke. British Medical Journal; 294: 409-411.

Carr EK, Lincoln NB. (1988) Inter-rater reliability of the Rey figure copying test. British Journal of Clinical Psychology; 27: 267-268.

Carr JH, Shepherd RB, Nordholm L, Lynne D. (1985) Investigation of a new motor assessment scale for stroke patients. Physical therapy; 65: 175-180.

Carstairs V. (1976) Stroke: resource consumption and cost to the community. Stroke. Churchill Livingstone, London.

Clarke PA, Collins H, Gladman JRF. (1995) Community occupational therapy for stroke patients at home. Clinical Rehabilitation; 9: 91-96.

Cochrane AL. (1972) Effectiveness and Efficiency. London, Nuffield Provincial Hospitals Trust.

College of Occupational Therapists, London. (1995) Code of Ethics and Professional Conduct.

Collen FM, Wade DT, Bradshaw CM. (1990) Mobility after stroke: reliability of measures of impairment and disability. Int Disabil Studies; 12: 6-9.

Collin C, Wade DT, Davis S, Home V. (1988) The Barthel ADL Index: a reliability study. International Disability Studies; 10: 61-63. III
1

Committee of Occupational Therapists for the European Communities (COTEC). (1989) British Journal of Occupational Therapy; May OT News supplement: 10/05.

Cooper J, Nixon SA, Mann A. (1977) Reliability of the PSE (9th edition) used in a population study. Psychological Medicine; 7: 505-516.

Corr S, Bayer A. (1992) Poor functional status of stroke patients after hospital discharge: scope for intervention? British Journal of Occupational Therapy; 55: 383-85.

Corr S, Bayer A. (1995) Occupational therapy for stroke patients after hospital discharge - a randomised controlled trial. Clinical Rehabilitation; 9: 291-296.

Corr S. (1997) Approaches to occupational therapy intervention. Welsh School of occupational therapy - student notes. Unpublished.

Coughlan AK, Hollows SE. (1985) Adult Memory and Information Processing Battery. AK Coughlan, St James University Hospital, Beckett Street, Leeds LS9 7TF. {ack
modicum

Coulter A, Brown S, Daniels A. (1989) Computer-held chronic disease registers in general practice: a validation study. Journal of Epidemiology and Community Health; 43: 25-82.

DeJong G, Branch LG. (1982) Predicting stroke patient's ability to live independently. Stroke; 13: 648-55.

Demeurisse G, Demol O, Robaye E. (1980) Motor evaluation in vascular hemiplegia. *European Neurology*; 19: 382-389.

Dennis MS, Bamford JM, Sandercock PAG, Warlow CP. (1990) Prognosis of transient ischaemic attacks in the Oxfordshire Community Stroke Project. *Stroke*; 21:848-853.

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* ;314: 1071-1076

Department of Health (1992) *The Health of the Nation: a strategy for health in England*. London, HMSO.

Drummond A. (1990) Leisure activity after stroke. *Int Disabil Studies*; 12(4): 157-160.

Drummond AER. (1994) *Leisure rehabilitation after stroke*. Doctoral thesis. University of Nottingham.

Drummond AER, Walker MF. (1994) The Nottingham Leisure Questionnaire for Stroke Patients. *British Journal of Occupational Therapy*; 57(11): 414-418. } JLL

Drummond AER, Walker MF. (1995) A randomized controlled trial of leisure rehabilitation after stroke. *Clinical Rehabilitation*; 9: 283-290.

Drummond AER, Miller N, Colquhoun M, Logan PC. (1996) The effects of a stroke unit on activities of daily living. *Clinical Rehabilitation*;10: 12-22.

Drummond A, Walker MF. (1996) Generalisation of the Effects of Leisure Rehabilitation for Stroke Patients. *British Journal of Occupational Therapy*; 59(7): 330- 334.

Eakin P. (1989) Assessments of Activities of Daily Living: A Critical Review. *British Journal of Occupational Therapy*; 52(1): 11-15.

Eakin P, Ballinger C, Nicol M, Walker MF, Alsop A, Ilott I. (1997) College of Occupational Therapists - research and development strategy. *British Journal of Occupational Therapy*; 60(11): 484-486.

- Ebrahim S, Nouri F, Barer D. (1985) Measuring disability after a stroke. *Journal of Epidemiology and Community Health*; 39: 86-89.
- Ebrahim S, Nouri F. (1987) Caring for stroke patients at home. *Int Rehabil Med*; 8: 171-173.
- Ebrahim S, Barer D, Nouri F. (1987) Affective illness after stroke. *British Journal of Psychiatry*; 151: 52-56.
- Ebrahim S. (1990) *Clinical epidemiology of stroke*. Oxford University Press.
- Edmans JA, Lincoln NB. (1987) The frequency of perceptual deficits after stroke. *Journal of Clinical Rehabilitation*; 1: 273-281.
- Edmans JA, Lincoln NB. (1989) Treatment of visual perceptual deficits after stroke: four single case studies. *Int Disabil Studies*; 11: 25-33.
- Edmans JA, Lincoln NB. (1990) The relation between perceptual deficits after stroke and independence in activities of daily living. *British Journal of Occupational Therapy*; 53(4): 139-142.
- Edmans JA, Lincoln NB. (1991) Treatment of Visual Perceptual Deficits after Stroke: Single Case Studies on Four Patients with Right Hemiplegia. *British Journal of Occupational Therapy*; 54(4): 139-144.
- Enderby P, Phillips R. (1986) Speech and language handicap: towards knowing the size of the problem. *Br J Dis Comm*; 21: 151-165.
- Enderby PM, Wood VA, Wade DT, Langton Hewer R. (1987) The Frenchay Aphasia Screening Test: a short, simple test for aphasia appropriate for non-specialists. *Int Rehabil Med*; 8(4): 166-170.
- Evans RL, Bishop DS, Haselkorn JK. (1991) Factors predicting satisfactory home care after stroke. *Arch Phys Med Rehabil*; 72: 144-147.
- Feinstein AR, Josephy BR, Wells CK. (1986) Scientific and clinical problems in indexes of functional disability. *Annals of Internal Medicine*; 105: 413-420.

Fiebel JH, Springer CJ. (1982) Depression and failure to resume social activities after stroke. Archives of Physical Medicine and Rehabilitation; 63: 276-278.

Forster A, Young J. (1996) Specialist nurse support for patients with stroke in the community: a randomised controlled trial. British Medical Journal; 312: 1642-1646.

Fugl-Meyer AR, Jaasko L, Leyman I, Olsson S, Steglind S. (1975) The post-stroke hemiplegic patient. 1. A method for evaluation of physical performance. Scandinavian Journal of Rehabilitation Medicine; 7: 13-31.

Garraway WM, Whisnant JP, Furlan AJ. (1979) The declining incidence of stroke. New England Journal of Medicine; 300: 449-452.

Garraway WM, Akhtar AJ, Prescott RJ, Hockey L. (1980) Management of acute stroke in the elderly: preliminary results of a controlled trial. British Medical Journal; 280: 1040-1043.

Garraway WM, Akhtar AJ, Smith DL, Smith ME. (1981) The triage of stroke rehabilitation. Journal of Epidemiology and Community Health; 35: 39-44.

Gilbertson L, Langhorne P, Walker A, Allen A. (1998) A randomised controlled trial of home-based occupational therapy for stroke patients: results at 7 weeks. 7th European Stroke Conference abstract. Cerebrovascular Diseases; 8(4): 84.

Gladman JRF, Lomas S, Lincoln NB. (1991) Provision of physiotherapy and occupational therapy in outpatient departments and day hospitals for stroke patients in Nottingham. Int Disabil Studies; 13: 38-41.

Gladman JRF, Lincoln NB, Barer DH. (1993a) A randomised controlled trial of domiciliary and hospital-based rehabilitation for stroke patients after discharge from hospital. Journal of Neurology, Neurosurgery and Psychiatry; 56 : 960-966.

Gladman JRF, Lincoln NB, Adams SA. (1993b) Use of the Extended ADL Scale with Stroke Patients. Age and Ageing; 22: 419-424. *Chisah*

Gladman JRF. (1995) Predicting outcome in stroke patients. Clinical Geriatrics; 3: 25-32.

Goldberg D. (1972) The detection of psychiatric illness by questionnaire. London: Oxford University Press.

} Books

Goldberg DP, Hillier VE. (1979) A scaled version of the General Health Questionnaire. Psychological Medicine; 9: 139-145.

Goldberg RT, Bemad M, Granger CV. (1980) Vocational status: prediction by Barthel Index and PULSES profile. Arch Phys Med Rehabil; 61: 580-583.

Gompertz P, Pound P, Ebrahim S. (1993) The reliability of stroke outcome measures. Clinical Rehabilitation; 7: 290-296.

Gresham GE, Phillips TF, Labi MLC. (1980) ADL status in stroke: relative merits of three standard indexes. Archives of Physical Medicine and Rehabilitation; 61: 355-358.

Greveson G, James O. (1991) Improving long-term outcome after stroke - the views of patients and carers. Health Trends; 23 : 161-162.

Hagedorn R. (1992) Occupational therapy: foundations for practice. Churchill Livingstone.

Hagedorn R. (1997) Occupational therapy: foundations for practice. (2nd edition) Churchill Livingstone.

Halligan PW, Marshall JC, Wade DT. (1989) Visuospatial neglect: underlying factors and test sensitivity. Lancet; 2: 908-910.

Harwood R, Gompertz P, Ebrahim S. (1994) Handicap one year after stroke: validity of a new scale. J Neurology; 57: 825-829

} J. Neurology

Harwood R, Ebrahim S. (1995) Manual of the London Handicap Scale. Department of Health Care of the Elderly, University of Nottingham, UK. J

} J. VSP
Checklist

Hewer RL. (1976) Stroke: proceedings of the ninth Pfizer international symposium Edinburgh: Churchill Livingstone. Stroke Rehabilitation

Holbrook M, Skilbeck CE. (1983) An activities index for use with stroke patients. *Age and Ageing*; 12: 166-170.

House A, Dennis M, Mogridge L, Wariow C, Hawton K, Jones L. (1991) Mood disorders in the year after first stroke. *British Journal of Psychiatry*; 158: 83-92.

Hunt SM, McKenna SP, McEwan J. (1980) A quantitative approach to perceived health status: a validation study. *Journal of Epidemiology and Community Health*; 34:281-286.

Indredavik B, Bakke F, Solberg R, Rokseth R, Haaheim LL, Holme I. (1991) Benefit of a Stroke Unit: A Randomized Controlled Trial. *Stroke*; 22(8): 1026-1032.

Joice A, Coia D. (1989) A discussion on the skills of the occupational therapist working in a multidisciplinary team. *British Journal of Occupational Therapy*; 52(12): 466-468.

Jongbloed L, Morgan D. (1991) An Investigation of Involvement in Leisure Activities After a Stroke. *The American Journal of Occupational Therapy*; 45(5): 420-427.

Jonker PL, Sumajow C. (1992) Randomised clinical trials in general practice (letter). *British Medical Journal*; 304: 508.

Juby LC, Lincoln NB, Berman P. (1996) The Effect of a Stroke Rehabilitation Unit on Functional and Psychological Outcome: A Randomised Controlled Trial. *Cerebrovascular Diseases*; 6: 106-110.

Kelly G. (1998) Models. *British Journal of Occupational Therapy*; 61(8): 375.

Kielhofner G, Burke JP. (1980) A model of human occupation, part 1. Conceptual framework and content. *American Journal of Occupational Therapy*; 34(9): 572-581.

Kings Fund Forum Consensus Conference. (1988) Treatment of stroke. *British Medical Journal*; 297: 126-128.

Klaber Moffett JA. (1991) Symposium on methodology: Randomized controlled trials. *Clinical Rehabilitation*; 5: 1-4.

Labi MLC, Phillips TF, Gresham GE. (1980) Psychosocial disability in physically restored long term stroke survivors. Archives of Physical Medicine and Rehabilitation; 61: 561-565.

Landis JR, Koch GG. (1977) The measurement of observer agreement for categorical data. Biometrics; 33: 159-74.

Langhorne P, Williams BO, Gilchrist W, Howie K. (1993) Do stroke units save lives? Lancet; 342: 395-397.

Legh-Smith J, Wade D, Langton-Hewer R. (1986) Services for stroke patients one year after stroke. Journal of Epidemiol Community Health; 40: 161-165.

Lennon S. (1995) Using standardised scales to document outcome in stroke rehabilitation. Physiotherapy; 81(4): 200-202.

Lezak MD. (1976) Neuropsychological Assessment. New York. Oxford University Press.

Lezak MD. (1995) Neuropsychological Assessment. Third edition. Oxford University Press.

Lincoln NB, Leadbitter D. (1979) Assessment of Motor Function in Stroke Patients. Physiotherapy; 65(2): 48-51.

Lincoln NB, Jones AC, Mulley GP. (1985) Psychological effects of speech therapy. Journal of Psychosomatic Research; 29(5): 467-474. }

Lincoln NB, Edmans JA. (1989) A shortened version of the Rivermead Perceptual Assessment Battery. Clinical Rehabilitation; 3: 199-204. j Uiburg

Lincoln NB, Tinson DJ. (1989) The relation between subjective and objective memory impairment after stroke. British Journal of Clinical Psychology; 28: 61-65.

Lincoln NB, Edmans JA. (1990) A re-validation of the Rivermead ADL Scale for elderly patients with stroke. Age and ageing; 19: 19-24.

Lincoln NB. (1991) Specialized techniques in rehabilitation. *Reviews in Clinical Gerontology*; 1: 171-184.

Lincoln NB, Gladman JRF. (1992) The Extended Activities of Daily Living scale: a further validation. *Disability and Rehabilitation*; 14(1): 41-43.

Lincoln NB. (1994) Only hospitals can provide the required skills. *British Medical Journal*; 309: 1357-1358.

Lincoln NB, Flannaghan T, Sutcliffe L, Rother L. (1997) Evaluation of cognitive behavioural treatment for depression after stroke: a pilot study. *Clinical Rehabilitation*; 11: 114-122.

Lincoln NB, Drummond AER, Edmans JA, Yeo D, Willis D. (1998a) The Rey Figure copy as a screening instrument for perceptual deficits after stroke. *British Journal of Occupational Therapy*; 61(1): 33-35.

Lincoln NB, Gladman JRF, Berman P, Luther A, Challen K. (1998b) Rehabilitation needs of community stroke patients. *Disability and Rehabilitation*; 20(12): 457-463.

Lincoln NB, Gladman JRF, Berman P, Noad R, Challen K. A comparison of long term rehabilitation needs of community and hospital stroke patients. *Disability and Rehabilitation* (In press).

Loewen S, Anderson BA. (1988) Reliability of the modified motor assessment scale and the Barthel Index. *Physical Therapy*; 68(7): 1077-1081.

Logan PA, Ahern J, Gladman JRF, Lincoln NB. (1997) A randomized controlled trial of enhanced Social Service occupational therapy for stroke patients. *Clinical Rehabilitation*; 11: 107-113.

Luther A, Lincoln NB, Grant F. (1998) Reliability of stroke patients' reports on rehabilitation services received. *Clinical Rehabilitation*; 12: 238-244.

Mahoney FI, Barthel DW. (1965) Functional Evaluation: The Barthel Index. *Maryland State Medical Journal*; 14: 61-65

Mancini JA. (1978) Leisure satisfaction and psychological well being in old age; effects of age on outcome. Journal of the American Geriatric Society; 26(12): 550-552.

McDonald EM. (1964) Occupational therapy in rehabilitation, 2nd edn. Bailliere Tindall, London.

Meites K, Lovallo W, Pishkin V. (1980) A comparison of four scales for anxiety depression, and neuroticism. Journal of Clinical Psychology; 36(2): 427-432.

Minitab Users Guide (1996) Minitab Inc: USA

Moffett JAK. (1991) Randomized controlled trials. Clinical Rehabilitation; 5: 1-4.

Morris PLP, Raphael B, Robinson RG. (1992) Clinical depression is associated with impaired recovery from stroke. The Medical Journal of Australia; 157: 239-242.

Neugarten BL, Havighurst RJ, Tobin SS. (1961) The measurement of life satisfaction. Journal of Gerontology; 16: 134-143.

Noad R, Lincoln N, Challen K. (1998) Community and hospital stroke patients: long-term rehabilitation. British Journal of Therapy and Rehabilitation; 5(11): 578-581.

Nouri FM, Lincoln NB. (1987) An extended activities of daily living scale for stroke patients. Clinical Rehabilitation; 1: 301-305. *Library*

Nouri FM, Lincoln NB. (1994) The Stroke Drivers Screening Assessment. Nottingham Rehab, Nottingham. *Library*

O'Neill PA, Cheadle B, Wyatt R, McGuffog J, Fullerton KJ. (1990) The value of the Frenchay Aphasia Screening Test for aphasia: better than the clinician? Clinical Rehabilitation; 4: 123-128.

O'Rourke S, MacHale S, Signorini D, Dennis M. (1998) Detecting Psychiatric Morbidity After Stroke. Stroke; 29: 980-985.

Oxford Community Stroke Project (1983) Incidence of stroke in Oxfordshire: first year's experience of a community stroke register. British Medical Journal; 287: 713-717.

Parry RH, Lincoln NB, Vass CD. Effect of severity of arm impairment on response to additional physiotherapy early after stroke. Clinical Rehabilitation. In Press (accepted Oct 1998)

Partridge C, Barnitt R. (1986) Research guidelines: a handbook for therapists. Heinmann Medical Books: London.

Peto V, Copulter A, Bond A. (1993) Factors Affecting General Practitioners' Recruitment of Patients into a Prospective Study. Family Practice; 10(2): 207-211.

Poole, JL, Whitney SL. (1988) Motor assessment scale for stroke patients: concurrent validity and interrater reliability. Arch Phys Med Rehabil; 69: 195-197.

Rankin J. (1957) Cerebral vascular accidents in patients over the age of 60. 2. Prognosis. Scottish Medical Journal; 2: 200-215.

Reed KL, Sanderson SR. (1983) Concepts of occupational therapy. Williams & Wilkins, Baltimore.

Reed KL. (1984) Models of practice in occupational therapy. Williams & Wilkins, Baltimore.

Reunanen A, Aho K, Aromaa A, Knekt P. (1986) Incidence of stroke in a Finnish prospective population survey. Stroke; 17: 675-681.

Rey A. (1959) Le teste de copie de figure complexe. Paris: Editions Centre de Psychologie Appliquee.

Robinson BC. (1983) Validation of a Caregiver Strain Index. Journal of Gerontology; 38(3): 344-348.

Robinson RG, Starr LB, Price TR. (1984) A two year longitudinal study of mood disorders following stroke: prevalence and duration at six months follow-up. British Journal of Psychiatry; 144: 256-262.

Roy CW, Tognneri J, Hay E, Pentland B. (1988) An inter-rater reliability study of the Barthel Index. *International Journal of Rehabilitation Research*; 11:67-70.

Royal College of General Practitioners (1996) The Health of the Nation - What You Can Do About It. An Information Pack from General Practitioners to General Practitioners. Department of Health, London, HMSO.

Royal College of Physicians of London. (1990) Research involving patients.

Royal College of Physicians Report. (1992) Effective Health Care. Stroke Rehabilitation.

Sackley CM, Lincoln NB. (1990) The verbal administration of the gross function scale of the Rivermead Motor Assessment. *Clinical Rehabilitation*; 4: 301-303. J Libby

Schuling J, De Haan R, Limburg M, Groenier KH. (1993) The Frenchay Activities Index: Assessment of functional status in stroke patients. *Stroke*; 24(8): 1173-1177.

Schwartz D, Leilouche J. (1967) Explanatory and pragmatic attitudes in therapeutic trials. *Journal Chronic Dis*; 20: 637-648.

Sheikh K, Smith DS, Meade TW, Goldenberg E, Brennan PJ, Kinsella G. (1979) Repeatability and validity of modified Activities of Daily Living (ADL) index in studies of chronic disability. *Int Rehabil Med*; 1: 51-58.

Sheikh K. (1986) Disability Scales: Assessment of Reliability. *Arch Phys Med Rehabil*; 67: 245-249.

✓ Siemonsma PC, Walker MF. (1997) Practical guidelines for independent assessment in randomised controlled trials (RCT's) of rehabilitation. *Clinical Rehabilitation*; 11: 273-279. 1997 the formulation

Sjogren K, Fugl-Meyer AR. (1982) Adjustment to life after stroke with special reference to sexual intercourse and leisure. *Journal of Psychosomatic Research*; 26(4): 409-417.

Smith DS, Goldenberg E, Ashburn A, Kinsella G, Sheikh K, Brennan PJ, Meade TW, Zutshi DW, Perry JD, Reeback JS. (1981) Remedial therapy after stroke: a randomised controlled trial. *British Medical Journal*; 282: 517-520.

Smith ME, Garraway WM, Smith DL, Akhtar AJ. (1982) Therapy impact on functional outcome in a controlled trial of stroke rehabilitation. *Arch Phys Med Rehabil*; 63: 21-24.

Snaith RP, Ahmed SN, Mehta S, Hamilton M. (1971) Assessment of the severity of primary depressive illness; Wakefield self-assessment depression inventory. *Psychological Medicine*; 1: 143-149.

Sneegas JJ. (1986) Components of life satisfaction in middle and later life adults: perceived social competence, leisure participation and leisure satisfaction. *Journal of Leisure Research*; 4: 248-258.

Social Services Inspectorate. Department of Health. (1994) Occupational therapy - the community contribution.

SPSSX Users Guide (1988) 3rd Edition. McGraw Hill: New York.

Stewart FM, Sunderiand A, Sluman SM. (1996) The nature and prevalence of memory disorder late after stroke. *British Journal of Clinical Psychology*; 35: 369-379.

Stone SP, Wilson B, Wroot A, Halligan PW, Lange LS, Marshall JC, Greenwood RJ. (1991) The assessment of visuo-spatial neglect after acute stroke. *Journal of Neurology, Neurosurgery and Psychiatry*; 54: 345-350.

Streiner DL, Norman GR. (1989) Health measurement scales: a practical guide to their development and use. Oxford University Press.

Sunderland A, Harris JE, Baddeley AD. (1983) Do laboratory tests predict everyday memory? A neuropsychological study. *Journal of Verbal Learning and Verbal Behaviour*; 22: 341-357.

Sunderland A, Watts K, Baddeley AD, Harris JE. (1986) Subjective memory assessment and test performance in elderly adults. *Journal of Gerontology*; 41(3): 376-384.

Sunderland A, Tinson DJ, Bradley EL, Hewer DF, Wade DT. (1992) Enhanced physical therapy improves recovery of arm function after stroke. A randomised controlled trial. Journal of Neurology, Neurosurgery and Psychiatry; 55: 530-535.

Syder D, Body R, Parker M, Boddy M. (1993) Sheffield Screening Test for Acquired Language Disorders. NFER - Nelson. *J. Wray*

Tanaka H, Ueda Y, Date C. (1981) Incidence of stroke in Shibata, Japan: 1976 - 1978. Stroke; 12:460-466.

Tinson DJ, Lincoln NB. (1987) Subjective memory impairment after stroke. International Disability Studies; 9: 6-9. *J. ILL*

Tognoni G, Alli C, Bettelli G, Colombo F, Corso R, Marchioli R, Zussino A. (1991) Randomised clinical trials in general practice: lessons from a failure. British Medical Journal; 303: 969-971.

Trombley CA. (1989) Occupational therapy for physical dysfunction. (3rd edition) Williams and Wilkins, Baltimore.

Tsai LJ, Howe TH, Lien IN. (1983) Visuospatial deficits in stroke patients and their relationship to dressing performance. Journal of the Formosan Medical Association; 82: 353-359.

Turner A. (1981) Occupational therapy and physical dysfunction. Principles, skills and practice. First edition. Churchill Livingstone, Edinburgh.

Turton A, Fraser C. (1990) The Use of Home Therapy Programmes for Improving Recovery of the Upper Limb following Stroke. British Journal of Occupational Therapy; 53(11): 457-462.

Ueda K, Omae T, Hirota Y. (1981) Decreasing trend in incidence and mortality from stroke in Hisayama Residents, Japan. Stroke; 12: 154-160.

Voss S. (1992) How much do doctors know about the notification of infectious diseases? British Medical Journal; 304: 755.

Wade DT, Hewer RL. (1985) Hospital admission for acute stroke: who, for how long, and to what effect? *Journal of Epidemiology and Community Health*; 39: 347-352.

Wade DT, Hewer RL, Skilbeck CE, Sainton D, Burns-Cox C. (1985a) Controlled trial of a home-care service for acute stroke patients. *Lancet*; 1: 323-326.

Wade DT, Legh-Smith J, Hewer RL. (1985b) Social activities after stroke: measurement and natural history using the Frenchay Activities Index. *International Rehabilitation Med*; 7: 176-181.

Wade DT, Wood VA, Hewer RL. (1985) Recovery after stroke - the first three months. *Journal of Neurology, Neurosurgery and Psychiatry*; 48: 7-13.

Wade DT, Langon Hewer R. (1986) Management of Stroke: Home or Hospital? *June Hospital Update*.

Wade DT, Legh-Smith J, Hewer RL. (1986) Effects of living with and looking after survivors of a stroke. *British Medical Journal*; 293: 418-420

Wade DT, Hewer RL. (1987) Functional abilities after stroke: measurement, natural history and prognosis. *Journal of Neurology*; 50: 177-182.

Wade DT, Legh Smith J, Hewer RL. (1987) Depressed mood after stroke: a community study of its frequency. *British Journal of Psychiatry*; 151: 200-205.

Wade DT, Collin C. (1988) The Barthel ADL Index: a standard measure of physical disability? *Int Disabil Studies*; 10: 64-67.

Wade DT. (1992) Measurement in neurological rehabilitation. Oxford Medical Publications.

Wade DT, Collen FM, Robb GF, Wariow CP. (1992) Physiotherapy intervention late after stroke and mobility. *British Medical Journal*; 304: 609-613.

Walker MF, Lincoln NB. (1990) Reacquisition of dressing skills after stroke. *International Disability Studies*; 12: 41-43.

Walker MF, Lincoln NB. (1991) Factors influencing dressing performance after stroke. *Journal of Neurology, Neurosurgery and Psychiatry*; 54(8): 699-701.

Walker MF, Drummond AER, Lincoln NB. (1996) Evaluation of dressing practice for stroke patients after discharge from hospital: a crossover design study. *Clinical Rehabilitation*; 10: 23-31.

Walker MF, Sackley CM, Gatt J, Drummond A. (In preparation) A survey of occupational therapy approaches in the treatment of stroke.

Warlow CP, Dennis MS, van Gijn J, Hankey GJ, Sandercock PAG, Bamford JM, Wardlaw J. (1996) *Stroke : A practical guide to management*. Blackwell Science.

Warren M. (1981) Relation of constructional apraxia and body scheme disorders to dressing performance in adult CVA. *American Journal of Occupational Therapy*; 35: 431-437.

Warrington EK. (1984) *Recognition Memory Test*. Windsor: NFER - NELSON.

Wechsler D. (1945) A standardised memory scale for clinical use. *Journal of Psychology*; 19: 87-95.

Whiting S, Lincoln NB. (1980) An ADL Assessment for stroke patients. *Occupational Therapy*; February: 44-46.

Whiting S, Lincoln NB, Bhavani G, Cockburn J. (1985) *The Rivermead Perceptual Assessment Battery*. Windsor : NFER-Nelson.

Wilkin D, Hallam L, Doggett MA. (1993) *Measures of Need and Outcome for Primary Health Care*. Oxford University Press, Oxford.

Wilkinson MJB, Barczak P. (1988) Psychiatric screening in general practice: comparison of the General Health Questionnaire and the Hospital Anxiety and Depression scale. *Journal of the Royal College of General Practitioners*; 38: 311-313.

Wilkinson PR, Wolfe CDA, Warburton FG, Rudd AG, Howard RS, Ross-Russell W, Beech RR. (1997) A long-term follow-up of stroke patients. *Stroke*; 28: 507-512.

Wilson B, Cockburn J, Halligan P. (1987) The Behavioural Inattention Test. Fareham, Hampshire: Thames Valley Test Company.

Wolfe CDA, Taub NA, Woodrow J, Richardson E, Warburton FG, Burney PGJ. (1993) Patterns of acute stroke care in three districts of southern England. *Journal of Epidemiology and Community Health*; 47: 144-148.

Wolfe CDA, Beech R, Ratcliffe M, Rudd AG. (1995) Stroke care in Europe. Can we learn lessons from the different ways stroke is managed in different countries? *J Roy Soc Health*; June: 143-147.

Wolfe C, Rudd T, Beech R. (1996) Stroke Services and Research. The Stroke Association.

Wolfe CDA, Taub NA, Bryan S, Beech R, Warburton F, Warburton P, Burney GJ (1995) Variations in the incidence, management and outcome of stroke in residents under the age of 75 in two health districts of southern England. *Journal of Public Health Medicine*; 17(4): 411-418.

Wood PHN. (1988) The epidemiology of disablement. In: *Rehabilitation of the physically disabled adult*. London: Crook Helm.

World Federation of Occupational Therapy (WFOT). (1989) *British Journal of Occupational Therapy*; May OT News supplement: 10/05.

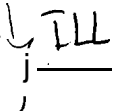
World Health Organisation. (1980) *The International Classification of Impairments, Disabilities, and Handicaps*. World Health Organisation, Geneva.

Young DW. (1971) Assessment of questions and questionnaires. *Methods of Information in Medicine*; 10: 222.

Young JB (1994) Is stroke better managed in the community? Community care allows patients to reach their full potential. *British Medical Journal*; 309: 1356-1357.

Young JB, Forster A. (1991) The Bradford community stroke trial: eight week results. *Clinical Rehabilitation*; 5: 283-292.

Young JB, Forster A. (1992) The Bradford community stroke trial: results at six months. British Medical Journal; 304: 1085-1092.

Zigmond AS, Snaith RP. (1983) The Hospital Anxiety and Depression Scale. Acta Psychiatrica; 67: 361-370. 

Zung WWK. (1965) A self-rating depression scale. Archives of General Psychiatry; 12:63-70.

APPENDIX 1

NOTTINGHAMSHIRE ETHICAL APPROVAL



NHS TRUST

Hucknall Road

Nottingham

NG5 1PB

Telephone

0602 691169

Medical Administration Dept.

Ext 45678

Fax No 0602-627788 46788

Our Ref EC94/50

Your Ref

Please ask for Dr.D.A.Curnock

21 March 1994

Mrs. M.F. Walker,
Research Occupational Therapist,
Dept. Stroke Medicine,

City Hospital

Dear Mrs. Walker,

Pilot Evaluation of occupational therapy for stroke patients in the community

Thank you for your letter of 14th March enclosing the full protocol and for **informing** the committee how you will identify and approach patients. The patient information letter is now satisfactory. The committee therefore has no further objection to this study and approval is granted.

Yours sincerely,

D A CURNOCK

Chairman

City Hospital Ethics Committee

APPENDIX 2

SOUTHERN DERBYSHIRE ETHICAL APPROVAL

SOUTHERN DERBYSHIRE ETHICS COMMITTEE

Chairman - Dr A Mellersh

Secretary - Mrs JS Michael

Tel: Derby (0332) 254616 (Direct Line)

Department of Medical Administration

Derbyshire Royal Infirmary

London Road

DE1 2QY

Our Ref: JSM/JB

Your Ref:

17 March 1995

Ms M Walker
Research Occupational Therapist
Stroke Research Unit
Nottingham City Hospital
Hucknall Road
Nottingham NG5 1PB

Dear Ms Walker,

SOUTHERN DERBYSHIRE ETHICS COMMITTEE
Evaluation of Occupational Therapy for Stroke Patients in the
Community - ** SPEC Ref: 95/02/20/Ext/NC &&

Thank you for submitting the above protocol for consideration by the Southern Derbyshire Ethics Committee. In accordance with our usual custom, I have consulted with one other member of the Southern Derbyshire Ethics Committee and am now able to approve the trial by Chairman's action.

We have just one concern relating to the Information Sheet and Consent Form for Patients in that it is accepted that occupational therapy for this type of patient is unproven; that there is no "current best" alternative therapeutic approach; and thus the logical first step is to compare occupational therapy with no intervention. Unfortunately, however, we feel that this will probably mean that some patients will feel disappointed that they are getting "nothing" by way of therapy. We feel, therefore that the Information Sheet should point out (in lay terms) that this is a trial of an unproven therapy, that patients have a 50:50 chance of being assigned to therapy or no therapy; and that the assignment will be made on a random basis. I would be pleased if you would let me have a copy of a revised Information Sheet for our file.

I shall inform the Committee of this at our next meeting and we look forward to learning the outcome of your study in due course.

**** It is important please that, in any future correspondence on this trial, you quote the SDEC reference number as shown in the heading ****

Yours sincerely,



A Mellersh

Chairman

Southern Derbyshire Ethics Committee

cc: Dr D Jenner, Research Manager

APPENDIX 3

PATIENT INFORMATION SHEET

OCCUPATIONAL THERAPY FOR STROKE PATIENTS NOT ADMITTED TO HOSPITAL

(INFORMATION LETTER)

NAME.....

This study is designed to find out ~~whether~~ occupational therapy can be helpful when treating stroke patients who are not admitted to hospital. As we are uncertain if therapy is beneficial to stroke patients not admitted to hospital we are allocating patients to one of two groups. Group 1 will receive additional input from an occupational therapist and group 2 will receive standard care. You will be allocated to a group on a random basis, therefore there is a 50:50 chance as to which group you are allocated.

You will be asked to carry out some assessments throughout the study in order to monitor any changes. You will be involved in the study for approximately twelve months.

If appropriate, treatment will involve practising tasks which have become difficult since your stroke, treatment ~~will~~ be given in your own home. The timing of the appointments will be arranged with you at your convenience. Treatment will last up to **five** months.

~~If~~ at any time you decide that you do not want to continue to take part in the study, you are free to withdraw.

Please feel free to discuss this sheet with others.

If you would like to discuss anything further or you need to alter the times of your appointments, please contact:

Marion Walker
Research Occupational Therapist
Stroke Research Unit
Nottingham City Hospital
Hucknall Road, Nottingham
NG5 1PB.

Telephone: (0115) 9691169 Ext. 47156

APPENDIX 4

PATIENT CONSENT FORM

**OCCUPATIONAL THERAPY FOR STROKE PATIENTS NOT ADMITTED TO
HOSPITAL**

(CONSENT FORM)

NAME.....

I understand that I am to take part in a study which is to investigate the rehabilitation needs of stroke patients who are not admitted to hospital.

I also understand that I will be assigned to either a five month period of treatment or a five month period of assessment.

Treatment will involve practising everyday tasks which have become difficult since my stroke.

I am aware that I am not obliged to take part and that I am free to withdraw from the research at any stage without affecting the care that I receive.

Details of the study have been fully explained to me by Mrs Marion Walker or Ms Tracey Whiteley and I agree to participate.

Patient

Signed.....

Date.....

Research Occupational Therapist

Signed.....

Date.....

APPENDIX 5

STUDY NOTIFICATION FORM

NOTTINGHAM COMMUNITY STROKE PROJECT
(Occupational Therapy Trial)

Registration form for Stroke Patients

Please include first and recurrent events.

Title: Mr / Mrs / Miss / Ms (delete as appropriate)

Name: _____
(first name) (family name)

Address: _____ Phone: _____

Date of Birth: __/__/____ Date of this Stroke: __/__/____

Today's date: _____

Initial assessment: TLA / minor stroke / major or disabling
(delete as appropriate)

Residential status (if known):

alone / alone in warden aided flat / alone in sheltered / with others
part 3 / private nursing home
(delete as appropriate)

Carer's name (if known and if relevant): _____

Carer's phone number: _____

Patient's own G.P: _____

Practice: _____

Any special advice or comments about contacting patient:

Please return to: **Marion Walker**

Nottingham Community Stroke Project, Stroke Research Unit, City Hospital
Hucknall Road, Nottingham. NG5 1PB.

Any queries:

Phone 9 691 169 ext 47156

APPENDIX 6

LETTER SENT TO PATIENT AT ONE MONTH

stroke Research Unit
Nottingham City Hospital
Hucknall Road,
Nottingham, NG5 1PB.

Telephone: 0115 9691169
Ext 47156.

Dear.....

I am one of a group of therapists working at Nottingham City Hospital who are investigating the contribution of rehabilitation therapy to the recovery process after stroke. I am particularly interested in people who have suffered a stroke and have not been admitted to hospital. We have been informed by your GP that you have recently suffered a stroke and have been managed at home since.

If you were to agree I would like to visit you at home onto ask some questions concerning your recovery since your stroke. For example I would like to know how you are managing to get around both indoors and outdoors and if you are able to carry out daily household tasks. If this is agreeable to you there is no need to confirm this appointment. However if you do not feel able to help me with this matter or you do not wish me to visit, please contact me or leave a message at the above address or telephone number. I hope that you will feel able to help us with this very important area of research.

Yours sincerely ,

Mrs Marion Walker
Research Occupational Therapist.

APPENDIX 7

BARTHEL INDEX

BARTHEL SCORE

Please Use Key

BOWELS	0 = Incontinent 1 = Occasional accident 2 = Continent	<input type="checkbox"/>
BLADDER	0 = Incontinent/catheterised 1 = Occasional accident (max 1 per day) 2 = Continent (for over 7 days)	<input type="checkbox"/>
GROOMING	0 = Needs help 1 = Independent, face/hair/teeth/shaving	<input type="checkbox"/>
TOILET USE	0 = Dependent 1 = Needs some help but can do something 2 = Independent (on & off, dressing/wiping)	<input type="checkbox"/>
FEEDING	0 = Unable 1 = Needs help, cutting, spreading butter 2 = Independent	<input type="checkbox"/>
TRANSFER	0 = Unable 1 = Major help (1-2 people, physical) 2 = Walks with help of 1 person (verbal/physical) 3 = Independent	<input type="checkbox"/>
MOBILITY	0 = Immobile 1 = Wheelchair independent including comers 2 = Walks with help of 1 person (verbal/physical) Independent (but may use any aid, e.g. stick)	<input type="checkbox"/>
DRESSING	0 = Dependent 1 = Needs help but can do about half unaided 2 = Independent	<input type="checkbox"/>
STAIRS	0 = Unable 1 = Needs help (verbal and physical/carrying aid) 2 = Independent up and down	<input type="checkbox"/>
BATHING	0 = Dependent 1 = Independent	
TOTAL		<input type="checkbox"/>

COMPLETED BY

APPENDIX 8

NOTTINGHAM EXTENDED ACTIVITIES OF DAILY LIVING SCALE

NAME OF PATIENT:

FORM FILLED EN BY PATIENT?

Yes

No

IF NO, PLEASE STATE YOUR NAME AND RELATIONSHIP TO THE PATIENT.

PLEASE TICK ONE BOX ONLY FOR EACH AND EVERY QUESTION ON THIS PAGE.

For these questions please record only WHAT YOU HAVE ACTUALLY DONE IN THE LAST WEEK OR SO (not what you think you could do, ought to do or would like to do).

	No	With help	On my own with difficulty	On my own
(a) Do you walk around outside?	B		B	
(b) Do you climb stairs?				
(c) Do you get in and out of the car?				
(d) Do you walk over uneven ground?	D	D	.	
(e) Do you cross roads?				
(f) Do you travel on public transport?				
(g) Do you managed to feed yourself?				
(h) Do you manage to make yourself a hot drink?			D	
(i) Do you take hot drinks from one room to another?				
(j) Do you do the washing up?				
(k) Do you make yourself a hot snack?				
(l) Do you manage your own money when you are out?				
(m) Do you wash small items of clothing?				
(n) Do you do your own housework?				
(o) Do you do your own shopping?				
(p) Do you do a full clothes wash?				
(q) Do you read newspapers or books?				
(r) Do you use the telephone?			D	
(s) Do you write letters?	D		.	
(t) Do you go out socially?	D			
(u) Do you manage your own garden?				
(v) Do you drive a car?				

APPENDIX 9

RIVERMEAD MOTOR ASSESSMENT (GROSS FUNCTION)

RIVERMEAD MOTOR ASSESSMENT
Date:

Score 1 or 0

No	GROSS FUNCTION		
1	Sit, feet unsupported (10 secs)		
2	Lying to sitting on side of bed		
3	Sit to stand, in 15 secs for 15 secs		
4	Transfer from chair to chair towards unaffected side		
5	Transfer from chair to chair towards affect side		
6	Walk 10 metres independently with an aid		
7	Climb stairs, may use banister		
8	Walk 10 metres without an aid		
9	Walk 5 metres, pick up bean bag from the floor and return		
10	Walk outside 40 metres (aid if needed)		
11	Walk up and down 4 steps (no banister or wall support)		
12	Run 10 metres (4 secs)		
13	Hop on affected leg 5 times on the spot		
	Total		

APPENDIX 10

**SHEFFIELD SCREENING TEST FOR ACQUIRED LANGUAGE
DISORDERS**

Sheffield Screening Test for Acquired Language Disorders

Diana Syder, Richard Body, Mark Parker, Margaret Boddy

Score Sheet

Client's Name.....

Date of birth.....

Tester's Name.....

Date of test.....

Full instructions for administration and scoring are contained in the Manual

Receptive Skills (Section 2)

1. Verbal Comprehension of Single Words

Score

I'm going to ask you to point to some of the things in the room.

door_____light_____chair_____ceiling_____corner_____

☐

2. Comprehension of Sequential Command

- a) Point to the window and then the door
b) Before pointing to the ceiling, touch the chair

☐
☐

3. Comprehension of a Complex Command

Tap the chair twice with a clenched fist, whilst looking at the ceiling

☐

4. Recognition of Differences in Meaning Between Words

I'm going to read you a list of words and I want you to tell me which is the odd one out:

- a) chicken, duck, apple, turkey
b) run, drink, walk, sprint
c) small, large, massive, huge

☐
☐
☐

5. Comprehension of a Narrative

- a) I'm going to read you a short paragraph and then ask you a question about it.
John went to the shop to buy a pen. When he got there he found that he had forgotten his wallet, so he came home and made himself a cup of tea.

What should he have taken with him?

☐

- b) I'm going to read you another paragraph
Mrs Smith visited several shops. She bought a newspaper, a cauliflower a stamp and some sausages.

What was the second shop she visited?

☐

Receptive Skills: Total Score ☐

Sheffield Screening Test for Acquired Language Disorder

Expressive Skills (Section 3)

6.

Word Finding

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

Score one mark if three names are given correctly

7.

Abstract Word Finding

Tell me another word that means the same as:

a) beautiful;

b) angry;

c) ridiculous.
- ☐
☐
☐

8.

Sequencing

Describe how you would make a cup of tea.
- ☐
- A correct answer contains two or more appropriate stages in the right order

9.

Definitions

Describe what the following words mean:

a) home;

b) search;

c) ambitious.
- ☐
☐
☐

10.

Verbal Reasoning

I'd like you to tell me:

a) why you would use an umbrella;

b) why people go on holiday;

c) what would you do if you were locked out of the house.
- ☐
☐
☐

Expressive Skills: Total Score ☐

Receptive and Expressive Skills: Total Score ☐

Receptive Skills: Total Score ☐

APPENDIX 11

REY FIGURE

Rev - Osterreitfa Scoring

Scoring - Consider each of the eighteen **units** separately. Appraise the accuracy of each unit and relative position within the whole of the design. For each unit score as follows:

Correct	placed properly	2 points
	placed poorly	1 point
Distorted or incomplete	placed properly	1 point
	placed poorly	1/2 point
Absent or not recognisable		0 points
Maximum		36 points

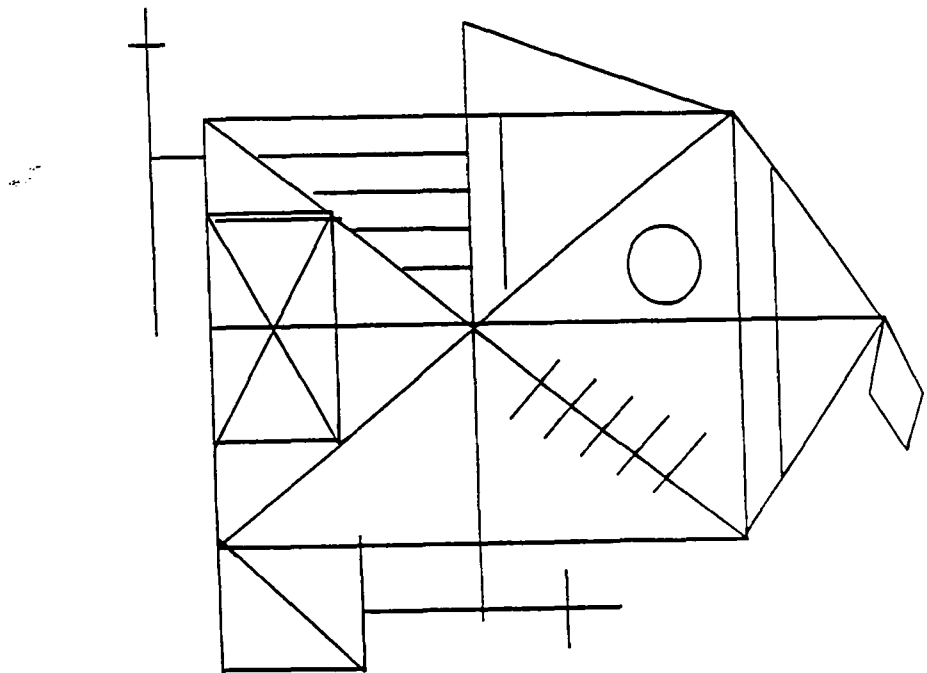
The scoring is fairly strict because the drawing is initially copied. Specific points to note are:

1. Cross must extend above rectangle and approximately down to 4
2. Must be more rectangular than square
4. & 5. Must be **approximately** correct. If their intersection with diagonal (3) is out **very** much. 1 point is given for the one that is most incorrect
6. Must be a **rectangle** and touch the diagonals
8. & 12. Lines need to be parallel and spacing approximately equal
10. & 15. Both to the left of the centre of the triangles
11. Placement of dots should be face-like
12. More square than rectangular

SCORING SYSTEM FOR REY-OSTERRIETH COMPLEX FIGURE TEST

Unit

1. Cross upper left corner, outside of rectangle
2. Large rectangle
3. Diagonal cross
4. Horizontal midline of 2
5. Vertical midline
6. Small rectangle, within 2 to the **left**
7. Small segment above 6
8. Four parallel lines within 2, upper left
9. Triangle above 2 upper right
10. Small vertical line within 2, below 9
11. Circle **with** three dots within 2
12. Five parallel lines within 2, crossing 3, lower right
13. Sides of triangle attached to 2 on right
14. Diamond attached to 13
15. Vertical line within triangle 13, parallel to right vertical of 2
16. Horizontal line within 13, parallel to right vertical of 2
17. ' Cross attached to low center
18. Square attached to 2, lower left



APPENDIX 12
MOOD RATING SCALE

MOOD RATING

STUDY NO:

1.	VERY ANGRY	ANGRY	CALM	VERY CALM
2.	VERY HAPPY	HAPPY	SAD	VERY SAD
3.	VERY SECURE	SECURE	AFRAID	VERY AFRAID
4.	VERY ANXIOUS	ANXIOUS	RELAX	VERY RELAX
5.	VERY DEPRESS	DEPRESS	CHEER	VERY CHEER
6.	VERY CONTENT	CONTENT	FRUST	VERY FRUST

APPENDIX 13

HOSPITAL ANXIETY AND DEPRESSION SCALE

Doctors are aware that emotions play an **important** part in most illnesses. If your doctor knows about these feelings he will be able to help you more.

This questionnaire is designed to help your doctor to know how you feel. Read each item and place a firm tick in the box oppositive to the reply which comes closest to how you have been feeling in the past week.

Don't take too long over your replies: your immediate reaction to each item will probably be more accurate than a long thought out response.

Tick **only** one box in each section

I feel **tense or 'wound up':**

Most of the time.....

A lot of the time.....

Time to time, occasionally...

Not at all.....

I **still enjoy the things I used to enjoy:**

Definitely as **much**

Not quite so much

Only a little

Hardly at all.....

I get a **sort of frightened feeling as if something awful is about to happen:**

Very definitely and quite badly

Yes, but not too badly.....

A little, but it doesn't worry me

Not at all.....

I can **laugh** and **see the funny side of things:**

As much as I always could

Not quite so much now

Definitely not so much now

Not at all.....

Worrying thoughts go through my mind:

A great deal of the tune

A lot of the time.....

From time to time, not too often

Only occasionally.....

I feel cheerful:

Not at all.....

Not often.....

Sometimes.....

Most of the tune

I can **sit** at ease **and feel relaxed:**

Definitely.....

Usually.....

Not often.....

Not at all.....

I **fecl** as if I am slowed down:

Nearly all the time.....

Very often.....

Sometimes.....

Not at all.....

I **get a sort of frightened feeling** like **'butterflies' in the stomach:**

Not at all

Occasionally.....

Quite often.....

Very often.....

I **have lost interest** in my appearance:

Definitely.....

I don't take so much care as I should

I may not take quite as much care

I take just as much care as ever.

I feel restless as if I have to be on **the** move:

Very much indeed.....

Quite a lot.....

Not very much.....

Not at all.....

I **look forward with enjoyment to things:**

As much as I ever did.....

Rather less than I used to.....

Definitely less than I used to

Hardly at all.....

I get sudden feelings of panic:

Very often indeed.....

Quite often.....

Not very often.....

Not at all.....

I can **enjoy** a **good book** or radio or **TV programme:**

Often.....

Sometimes.....

Not often.....

Very seldom.....

APPENDIX 14

GENERAL HEALTH QUESTIONNAIRE (28)

GENERAL HEALTH QUESTIONNAIRE

Please read this carefully:

We should like to know if you have had any medical complaints , and how your health has been in **general**. over the past few weeks. Please answer ALL the questions on the following pages simply by underlining the answer which you think most nearly applies to you. Remember that we want to know about present and recent complaints, not those that you had in the past.

It is important that you try to answer ALL the questions.

Thank you very much for your **co-operation**.

HAVE YOU RECENTLY:

A1 -	been feeling perfectly well and in good health?	Better than	Same as usual	Worse than usual	Much worse than usual
A2 -	been feeling in need of a good tonic	Not at all	No more than usual	Rather more than usual	Much more than usual
A3 -	been feeling run down and out of sorts?	Not at all	No more than usual	Rather more than usual	Much more than usual
A4 -	felt that you are ill?	Not at all	No more than usual	Rather more than usual	Much more than usual
A5 -	been getting any pains in your head	Not at all	No more than usual	Rather more than usual	Much more than usual
A6 -	been getting a feeling of tightness in your head	Not at all	No more than usual	Rather more than usual	Much more than usual
A7 -	been having hot or cold spells?	Not at all	No more than usual	Rather more than usual	Much more than usual
<hr/>					
B1 -	lost much sleep over worry?	Not at all	No more as usual	Rather more than usual	Much worse than usual
B2 -	had difficulty in staying asleep-once you are off?	Not at all	No more than usual	Rather more than usual	Much more than usual
B3 -	felt constantiy under strain?	Not at all	No more than usual	Rather more than usual	Much more than usual
B4 -	been getting edgy and bad-tempered?	Not at all	No more than usual	Rather more than usual	Much more than usual
B5 -	been getting scared or panicky for no good reason?	Not at ail	No more than usual	Rather more than usual	Much more than usual
B6 •	found everything getting on top of you?	Not at all	No more than usual	Rather more than usual	Much more than usual
B7 -	been feeling nervous and strung-up all the time?	Not at all	No more than usual	Rather more than usual	Much more than usual

HAVE YOU RECENTLY:

C1 -	been managing to keep yourself busy and occupied?	More so than usual	Same as usual	Rather less than usual	Much less than usual
C2 -	been taking longer over the things you do?	Quicker than usual	Same as usual	Longer than usual	Much longer
C3 -	felt on the whole you were doing things well?	Better than usual	About the same	Less well than usual	Much less well
C4 -	been satisfied with the way you've carried out your task?	More satisfied	About same as usual	Less satisfied than usual	Much less satisfied
C5 -	felt that you are playing a useful part in things?	More so than usual	Same as usual	Less useful than usual	Much less useful
C5 -	felt capable of making decisions about things?	More so than usual	Same as usual	Less so than usual	Much less capable
C7 -	been able to enjoy your normal day-to-day activities?	More so than usual	Same as usual	Less so than usual	Much less than usual

D1 -	been thinking of yourself as a worthless person?	Not at all	No more as usual	Rather more than usual	Much worse than usual
D2 -	felt that life is entirely hopeless?	Not at all	No more than usual	Rather more than usual	Much more than usual
D3 -	felt that life isn't worth living?	Not at all	No more than usual	Rather more than usual	Much more than usual
D4 -	thought of the possibility that you might make away with yourself?	Definitely not	I don't think so	Has crossed my mind	Definitely
D5 -	found at times you could not do anything because your nerves' were too bad?	Not at all	No more than usual	Rather more than usual	Much more than usual
D6 -	found yourself wishing you were dead and away from it all?	Not at all	No more than usual	Rather more than usual	Much more than usual
D7 -	found that the idea of taking your own life kept coming into your mind?	Definitely not	I don't think so	Has crossed my mind	Definitely

A

B

C

D

TOTAL

Have you had more than one stroke? YES / NO

APPENDIX 15

ADULT MEMORY INFORMATION PROCESSING BATTERY

- STORY RECALL

STORY RECALL

1 2 3 4

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

5 6

curtain / when she heard a noise / coming from the kitchen I. She

7 8 9

rushed to investiage / and found a boy / climbing out of the window /

10 11 12

with her handbag /. She threw a vase at him / but it missed / and he

13 .14 15

ran off laughing/. She chased after him, / past the shops / and

16 17 18

into the park / but he got away / by squeezing through some

19 10 21

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

22* 23 24

she described / the thief as quite tall / and neatly dressed / . He

25 26 27 28

had a scar / on his face / but she could not remember / the colour of

his hair / .

*** Ideas which receive partial score if implied in the subject's recall but not explicitly stated (see scoring guidelines).**

APPENDIX 16

NOTTINGHAM LEISURE QUESTIONNAIRE

LEISURE ACTIVITIES

VR=VERY REGULARLY R=REGULARLY O=OCCASIONALLY I=INFREQUENTLY N=NEVER

VERY REGULARLY These are activities carried out **EVERY DAY** regardless of the amount of time involved, e.g. Watching T.V. for 10 minutes or 5 hours every day is scored as VR.

REGULARLY These are activities carried out **WEEKLY** but not daily, e.g. Going to the pub once a week, going for a walk 5 times a week.

INFREQUENTLY These are activities which are carried out **MONTHLY/TWICE MONTHLY**, e.g. Visiting family, reading a book.

NEVER These are activities never/no longer carried out.

Please indicate which activities you participated in before your stroke.

L	Watching T.V.	VR	R	O	I	N
2.	Listening to radio/music	VR	R	O	I	N
3.	Visiting family/friends	VR	R	O	I	N
4.	Reading Books	VR	R	O	I	N
5.	Singing	VR	R	O	I	N
6.	Gardening	VR	R	O	I	N
7.	Swimming	VR	R	O	I	N
8.	Daydreaming	VR	R	O	I	N
9.	Crafts e.g. knitting/sewing	VR	R	O	I	N
10.	Attending sports events	VR	R	O	I	N
11.	Attending classes	VR	R	O	I	N
12.	Collecting things	VR	R	O	I	N
13.	Shopping for pleasure	VR	R	O	I	N
14.	Cooking for pleasure	VR	R	O	I	N
15.	Reading newspapers/magazines	VR	R	O	I	N
16.	Just sitting	VR	R	O	I	N
17.	Walking	VR	R	O	I	N
18.	Volunteer Work	VR	R	O	I	N
19.	Indoor games/cards/bingo/dominos	VR	R	O	I	N
20.	Bicycling	VR	R	O	I	N
21.	Dancing	VR	R	O	I	N

22.	Looking after/exercising pets	VR R O I N
23.	Eating Out	VR R O I N
24.	Going out to pubs	VR R O I N
25.	Going to plays/museums/cinema	VR R O I N
26.	Photography	VR R O I N
27.	Exercise/fitness	VR R O I N
28.	Activities at clubs/centres	VR R O I N
29.	Going to parties	VR R O I N
30.	Entertaining at home	VR R O I N
31.	Church activities	VR R O I N
32.	Meditation/relaxation	VR R O I N
33.	Fishing	VR R O I N
34.	Driving	VR R O I N
35.	D.I.Y.	VR R O I N
36.	Sporting activities e.g. tennis/golf/bowling	VR R O I N
37.	Holidays	
	How often did you go on holiday?	
	more than 3 times a year	
	2 times a year	
	once a year	
	once every 2 years	
	never	
38.	Other activities	VR R O I N

APPENDIX 17

LONDON HANDICAP SCALE

YOUR HEALTH AND YOUR LIFE

Today's date

Number

--	--	--	--

This questionnaire asks you six questions about your everyday life. The answers will tell us about the way your health affects your life.

Please answer each question. Tick the box next to the sentence which describes you best. Think about things you have done over the last week. Compare what you do with what someone like you who is in good health can do.

Getting around

Think about how you get from one place to another, using any help, aids or means of transport that you normally have available.

Q: Does your health stop you from getting around?

Please
tick one
box only

✓

Not at all: You go everywhere you want to, no matter how far away.

☐

Very slightly: You go most places you want, but not all.

☐

Quite a lot: You get out of the house, but not far away from it.

☐

Very much: You don't go outside, but you can move **around** from room to room indoors.

☐

Almost You are confined to a single room, but can move around
Completely: in it.

☐

Completely: You are confined to a bed or a chair. You cannot move around at all. There is no-one to move you.

☐

Looking after Yourself

Think about things like housework, shopping, looking after money, cooking, laundry, getting **dressed**, washing, shaving and using the **toilet**.

Q: Does your health stop you looking after yourself? Please

tick one
box only

☒

Not at all: You can do everything yourself.

☐

Very slightly: Now and again you need a little help.

☐

Quite a lot: You need help with some tasks (such as heavy housework or shopping), but no more than once a day.

☐

Very much: You can do some things but you need help more than once a day. You can be left alone safely for a few hours.

☐

Almost: You need help to be available all the time.

☐

Completely: You cannot be left alone safely.

Completely: You need help with everything. You need constant attention, day and night

☐

Work and Leisure

Think about things like work (paid or not), housework, gardening, **sports**, hobbies, going out with friends, travelling, reading, looking after children, watching television and going on holiday.

Q: Does your health limit your work or leisure activities?

Please
tick one
box only

☒

Not at all: You can do everything you want to.

☐

Very slightly: You can do almost all the things you want to do.

☐

Quite a lot: You find something to do almost all the time, but **cannot** do some things for as long as you would like.

☐

Very much: You are unable to do a lot of things, but can find something to do most of the time.

☐

Almost: You are unable to do most things, but can find something to do most of the time.

☐

Completely: You sit all day doing nothing. You cannot keep yourself busy or take part in any activities.

☐

Getting on with People

Think about family, friends and the people you might meet during a normal day.

Q: Does your health stop you getting on with people? Please

tick one
box only

☒

Not at all: You get on well with people, see everyone you want to see, and meet new people.

☐

Very slightly: You get on well with people, but your social life is slightly limited.

☐

Quite a lot: You are find with people you know ell, but you feel uncomfortable with strangers

☐

Very much: You are fine with people you know well but you have few friends and little contact with neighbours. Dealing with strangers is very hard.

☐

Almost Completely: Apart from the person who looks after you, you see no-one. You have no friends and no visitors.

☐

Completely: You don't get on with anyone, not even people who look after you.

☐

Awareness of your surroundings

Think about taking in and understanding the world about you, and find your way around in it.

Q: Does your health stop you understanding the world around you?

Please
tick one
box only

☒

Not at all: You fiilly understand the world arovmd you. You see, hear, speak and think clearly, and your memory is good.

☐

Very slightly: You have problems with hearing, speaking, seeing or your memory, but these do not stop you doing most things.

☐

Quite a lot: You have problems with hearing, speaking, seeing or your memory which make life difficult a lot of the time. But you do understand what is going on.

☐

Very much: You have great difficulty understanding what is going on.

☐

Almost You are unable to tell where you are or what day it is.

Completely: You **cannot** look after yourself at all.

☐

Completely: You are unconscious, completely unaware of anything going on around you

☐

Affording the things you need

Think about whether health problems have led to any **extra expenses**, or have caused you to earn less than you would if you were healthy.

Q: Are you able to afford the things you need?

Please
tick one
box only

☒

Yes, easily; You can afford everything you need. You have easily enough money to buy modern labour-saving devices, and anything you may need because of ill-health.

☐

Fairly easily; You have just about enough money. It is fairly easy to cope with expenses caused by ill-health.

☐

Just about; You are less well off than other people like you; however, with sacrifices you can get by without help.

☐

Not really; You only have enough money to meet your basic needs. You are dependent on state benefits for any extra expenses you have because of ill health.

☐

No; You are dependent on state benefits, or money from other people or charities. You cannot afford things you need.

☐

Absolutely not; You have no money at all and no state benefits. You are totally dependent on charity for your most basic needs.

☐

Please check that you have answered all six questions.

Remember, we only need to know which description is nearest to your situation.

THANK YOU.

APPENDIX 18

CAREGIVER STRAIN INDEX

CARER STRAIN INDEX

I am going to read a list of situations. They may relate to your experience in looking after _____

Would you **tell** me if any of these apply to you? (GIVE EXAMPLES)

	YES	NO
Sleep is disturbed (e.g. because _____ needs help to go to the toilet.		
It is inconvenient (e.g. because helping takes so much time).		
It is a physical strain (e.g. because of lifting in and out of bed).		
It is confining (e.g. helping restricts my free time)		
There have been family changes (e.g. because helping has disrupted routine there has been no privacy)		
There have been changes in personal plans (e.g. could not go on holiday)		
There have been other demands on my time (e.g. from other family members.		
There have been emotional adjustments (e.g. because of severe arguments)		
Some behaviour is upsetting (e.g. because of incontinence. _____ has trouble remembering things)		
It is upsetting to _____ find _____ has changed so much from his/her former self (e.g. he/she is a different person than he/she used to be)		
There has been work adjustments (e.g. having to take time off)		
It is a financial strain		
Feeling completely overwhelmed (e.g. because of worry about _____ concerns about how you will manage.		

TOTAL (Yes =1. No-0)

PUBLICATIONS

Walker MF, Gladman JRF, Lincoln NB, Siemonsma P, Whiteley T. (1999)
Occupational therapy for stroke patients not admitted to hospital: a randomised controlled trial. The Lancet; 345: 278-280.

Walker MF, Whiteley T. Content of occupational therapy treatment for stroke patients not admitted to hospital in a randomised controlled trial.
Submitted to British Journal of Occupational Therapy November 1999.