A RANDOMISED CONTROLLED TRIAL OF HOME BASED OCCUPATIONAL THERAPY FOR STROKE PATIENTS

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A thesis submitted to the University of Glasgow for the Degree of MSc (Med. Sci.)

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November 1998

DECLARATION

I certify that all the work presented and the writing of this thesis is my own. Any assistance received is specified in the acknowledgements. This thesis does not include work forming part of a thesis for a degree in this or any other university.

November 1998

ACKNOWLEDGEMENTS

Many people have assisted me with this research and I would particularly like to thank all the patients at the Glasgow Royal Infirmary who agree to take part in the study and share their time and interest.

A research training fellowship awarded by the Chief Scientist Office, Scottish Office allowed me to complete a pilot study. **Chest, Heart and Stroke Scotland** funded the main research project and the Glasgow Royal Infirmary University NHS Trust provided funding for the independent assessor.

A grant from the Constance Owens Trust and the Hospitals Saving Association Charitable Trust, an award from the College of Occupational Therapy contributed to the funding of this MSc.

Thanks to the Academic Section of Geriatric Medicine for their academic, financial and secretarial support and especially to Dr Peter Langhorne for his expert supervision and endless encouragement.

This clinically based project would have been impossible without the support of the GRI/Lightburn stroke teams and occupational therapy colleagues at the Glasgow Royal Infirmary. A special thanks to Kirsten Forsyth and Karen Blackwood. Thanks also to Ann Allen who worked as the projects independent assessor for her conscientious and diligent contribution.

Finally, thanks must go to Alasdair my husband for his patient support and encouragement.

ABSTRACT

Discharge home would appear to be a critical stage in stroke rehabilitation with patients experiencing poor co-ordination of discharge planning, psychosocial problems and reduced quality of life. This study used a randomised controlled trial to evaluate the effectiveness of a short post-discharge home-based occupational therapy service on the recovery of stroke patients discharged home from hospital. The home based intervention programme was designed using focus group discussions to determine the views of patients and local therapists.

One hundred and thirty eight patients were randomly allocated to either a conventional out-patient follow-up or conventional services plus six weeks of home based occupational therapy intervention. All patients were assessed before discharge, at seven weeks and six months to measure functional ability, quality of life, and perception of outcome and experience of discharge. Information was also obtained on readmission rates, strain on carers and resources used to operate the home based service.

At seven weeks the intervention group showed significant ($p<0.05$) benefits in terms of improvement in self-care, extended activities of daily living, and satisfaction with their performance. The intervention group also reported improved subjective health experience on the emotion score of the COOP charts and in work/leisure on the London Handicap Scale. Patients receiving home-based occupational therapy were significantly less likely to deteriorate (death or increased disability) and were significantly more likely to continue therapy at home and to have received additional aids/equipment. No significant differences were observed in carer outcome between the two groups. By six months the treatment group were still reporting significant improvements in self-care and a trend towards treatment patients achieving higher functional scores was apparent but not statistically significant. No differences were observed in subjective health experience. However intervention patients were more satisfied with the preparations made for them to return home, with the stroke information they received and who to contact for further advise.

The study concluded that a brief occupational therapy service carried out in the patient's home immediately after discharge can provide a continuity of care between hospital and the community and improve the functional outcome and satisfaction of stroke patients. The effects of the intervention were diluted over time and did not appear to influence the subjective health experience of patients or carers.

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CHAPTER ONE

THE EFFECTS OF STROKE, RECOVERY AND REHABILITATION: A REVIEW OF THE LITERATURE

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Chapter One

1.1. STROKE DEFINITIONS

The World Health Organisation defines stroke as "rapidly developing 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 vascular origin" (1). This definition of stroke excludes transient ischaemic attacks (symptoms less than 24 hours), subdural haematoma and haemorrhage or infarction caused by infection or tumour (2). Stroke may also be called a cerebro-vascular accident (CVA) and can be classified into three main pathological categories:

1. Cerebral infarction: this occurs as a result of vascular occlusion. Occlusion is caused either by a thrombus forming in a cerebral artery or from a blood clot (embolism) from an artery or the heart that has become dislodged in a cerebral artery. Cerebral infarction accounts for about 85% of first-ever stroke (3).

2. Primary Intracerebral Haemorrhage: this occurs when blood leaks from vessels within the brain producing local brain tissue destruction and the displacement of brain structures. The main causes are hypertension but can be a result of anticoagulant therapy, trauma and arterial malformation. Primary intracerebral haemorrhage accounts for about 10% of first ever strokes (3).

3. Subarachnoid Haemorrhage: this occurs when there is a bleed into the subarachnoid space surrounding the brain. It is usually caused by the rupture of an aneurysm on one of the external arteries at the base of the brain. Subarachnoid haemorrhage accounts for 5% of first ever strokes (3).

The size and location of the infarct or haemorrhage determines the extent of neurological damage and degree of impairment. Large strokes may lead to loss of consciousness and death, or if the person survives permanent disability. Small lesions of the cerebral hemispheres are generally not life threatening and may not result in any permanent loss of function. However, even a small lesion in a critical area of the brain can lead to death or extensive impairment.

1.2. STROKE INCIDENCE

Stroke is the third most frequent cause of death (4) in developed countries after ischaemic heart disease and cancer and it presents a major healthcare problem in the UK population. The Oxfordshire Community Stroke Project (5) estimated that 2 in every 1000 people will experience a first ever stroke annually, that is approximately one person every five minutes. Within Scotland these figures are probably greater, with stroke resulting in the second highest death rate in people aged 15-64 years in Western Europe, second only to Portugal (6), a 30% higher mortality rate than in England and Wales (7). Although the age-specific incidence of stroke may be stable or declining (8), the number of strokes is expected to increase due to the increase in the elderly population (2). A NHS management report published in 1992 (9) predicts a 30% increase in the population over 75 years of age, resulting in a 25% increase in the incidence of stroke by the year 2022.

The incidence of stroke rises sharply with age in both men and women. After the age of 55 years the risk of having a stroke doubles with every decade (10). Men have a higher incidence of stroke than women do but this difference is more marked in middle age but reduces in old age (11).

1.3. STROKE RISK FACTORS

Stroke usually occurs in people with vascular risk factors, such as hypertension, diabetes mellitus, smoking or in people who have a history of vascular disorders such as myocardial infarction. Risk factors also include age, heart disease, high fibrinogen levels, obesity, heavy alcohol consumption, high concentrations of cholesterol and oral contraceptive use (2).

1.4. IMPAIRMENT, DISABILITY AND HANDICAP

The impact of stroke can be great and bring change to many aspects of individuals every day life. Statistics suggest that 33% of victims die after stroke, 45% of survivors achieve functional independence and 22% remain dependent on others for care (11).

The effects of stroke have been considered using the World Health Organisation (WHO) International Classification of Disease (ICD) (12-14) (Figure I). This divides the consequences of disease into four levels:

- **Pathology**: refers to the underlying pathology causing the stroke.
- **Impairments**: any loss or abnormality of psychological, physiological, or anatomical structure or function caused by stroke.
- **Disability**: any restriction or lack (resulting from an impairment) of ability to perform an activity within the range considered normal for a human being.
- **Handicap**: the disadvantage for a given individual, resulting from an impairment or a disability that limits or prevents the fulfilment of a role that is normal for that individual.

Figure I. THE INTERNATIONAL CLASSIFICATION OF DISEASE – AN EXAMPLE OF CLASSIFICATION

Stroke			
Pathology	Impairment	Disability	Handicap
Embolic occlusion of the middle cerebral artery from thrombus in the left atrium	Muscle weakness Loss of sensation Dysphasia	Reduced mobility Unable to dress Reduced verbal communication	Unable to work Financial problems Social isolation

It is recognised that several problems exist trying to apply the ICD definitions.

- A consensus of the meaning of impairment, disability and handicap has not been achieved and confusion exists about the use of these terms (15). The term "normality" is unclear and the concept of handicap is difficult to define and measure (13,16,17). There is also no inclusion of the concept of quality of life within the model. The ICD classification is currently under review (18) and proposals include changing the "disability" to "activity"

(negative circumstance are to be described as "activity limitation.") Similarly, "handicap" has been replaced by participation (negative circumstances are to be described as "participation restriction".) The new proposals for ICD-2 should be published in 1999 and attempt to describe the multi-dimensional aspects of health at the level of the body, person and society influenced by the environmental and personal context of the individual.

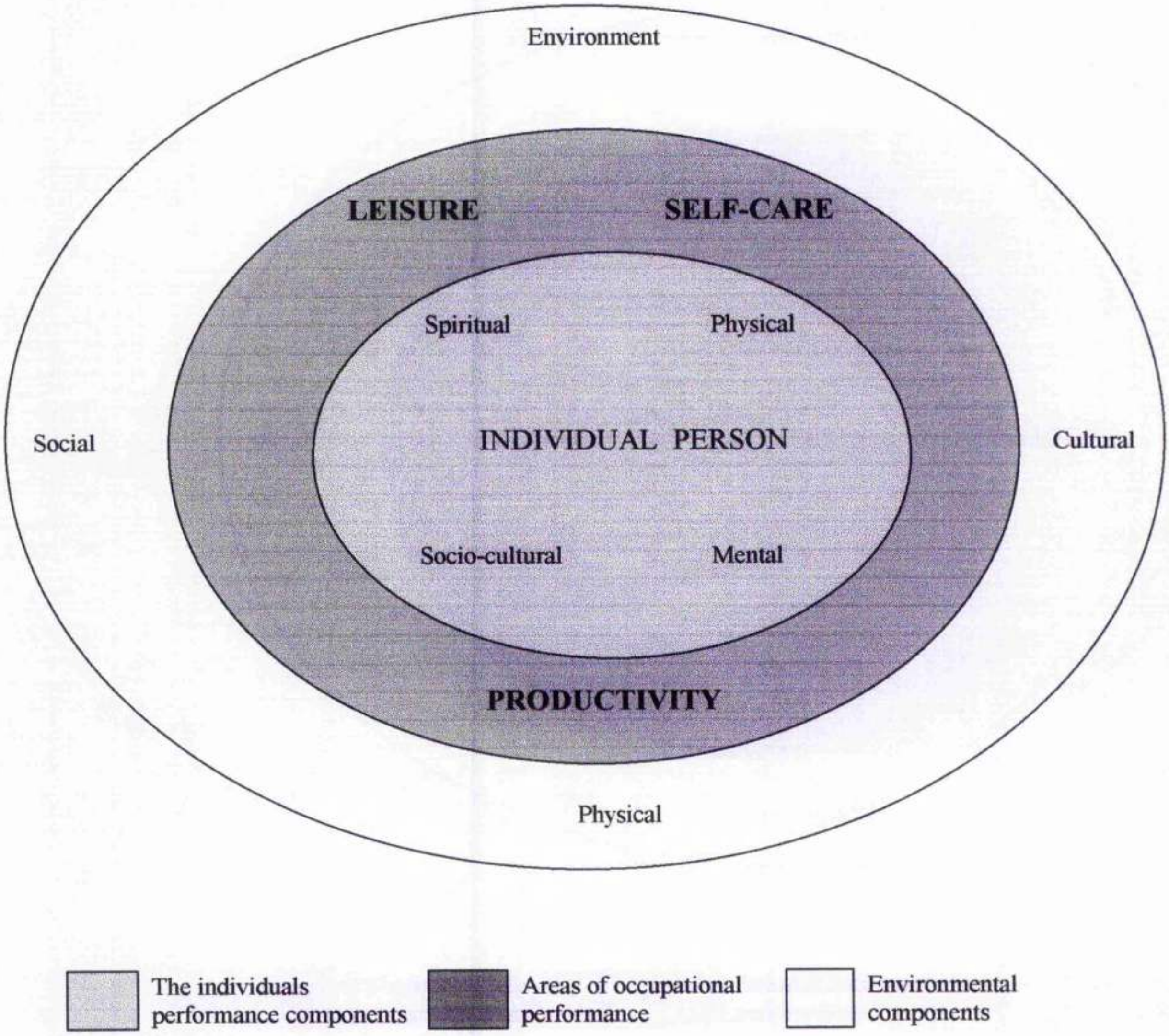
- This reductionist structure of the ICD may be useful in the acute treatment of stroke when diagnosis and medical intervention is required. However, such divisions may become less clearly defined and change according to the individuals personal circumstances as the person recovers and returns to his/her previous lifestyle and social roles (19). Wade suggests that as the focus of interest progresses from pathology to handicap attention should pass from the patient to the environment (13).

- Disabled activists would claim that the ICD model is oppressive as it shifts the focus for the reason for disability away from exploitive social/environmental organisations onto the disabled individual (16,17,20,21). Jongbloed proposes that rehabilitation professionals need to pay more attention to the interaction between the environment and individual factors and be less ready to accept individual explanations for problems that are essentially economic, social or political (22).

Due to the practical difficulties of applying the IDH model, the uncertainty of definitions and because of the opposition expressed by disabled people, the consequences of stroke for the purposes of this thesis will be described under the headings person, occupational performance and environment. This classification is based on the person-environment-occupation model (Figure II) proposed in the Canadian Guidelines for Occupational Practice (23,24) and adapted from the work of Reed and Sanderson (25). Human experience can be viewed as a complex interaction between the person, their occupations and roles and the environment in which they live, work and play. Stroke can influence these interactions and result in major changes in lifestyle.

Figure II

THE MODEL OF OCCUPATIONAL PERFORMANCE



From Occupational Therapy Guidelines for Client-centred Practice C.A.O.T. 1991 (24)

1.5. THE PERSON

The person can be defined as a unique being made up of mind, body and spirit who assumes a variety of simultaneous roles (24). Christiansen and Baum (26) describe the person as consisting of a personality (motivations, goals, experiences and belief systems) and performance components (cognitive, psychological, sensory, neuromotor, physiological, general health). Stroke may affect the "person" in the following ways.

Level of Consciousness: Stroke may cause a reduced level of consciousness, disordered patterns of breathing and circulatory failure. This may result in fatality and place the patient at greater risk of complications such as airway obstruction, pressure sores and infection. Some patients never regain consciousness and die as a consequence of the stroke. Fatality statistics suggest that between 12% - 19% of people die in the first month following a stroke (8). Case fatality is also influenced by age, stroke category, level of consciousness, size and site of lesion. Stroke survivors are at greater risk of dying than age-matched healthy individuals and it has been estimated that 15% of survivors die each subsequent year following a stroke (11).

Motor and Sensory Loss: Wade et al (27) suggest that between 50-80% of patients have some form of motor deficit after stroke. Motor deficits result in a loss of range of movement, co-ordination and muscular strength leading to muscle imbalance and ultimately loss of purposeful movement (28). Deficits might include hemiplegia, monoplegia, dysphagia, dysarthria, loss of bladder and bowel control. Motor deficits may also result in complications such as muscle flaccidity, spasticity, joint contracture, shoulder pain, deep vein thrombosis, loss of function (11) and falls (29). Stroke can cause epilepsy which is more common after subarachnoid haemorrhage (30).

25% of patients are reported to experience sensory deficits after stroke (27). These may include disturbances to any of the senses such as visual field loss (hemianopia), poor scanning or eye fixation, reduced auditory ability, proprioceptive loss, disorders of balance such as ataxia and loss of sensation such as numbness, parathesthia or increased sensitivity causing pain.

Cognitive and Perceptual Loss: 35% of stroke survivors are reported to experience cognitive problems (31). Cognitive problems may include language production and comprehension deficits (the aphasias), reading disorders (the dyslexias), writing disorders (the dysgraphias), recognition deficits which might include any of the senses (the agnosias), memory deficits, attentional and praxic deficits including uni-lateral neglect and problems with sequencing and planning (32,33). Problems may be further confounded by a lack of insight. Several studies have concluded that patients with attentional deficits particularly uni-lateral neglect are less likely to recover the ability to carryout everyday activities compared to patients without attentional deficits (34-37).

Psychological Problems: A high degree of distress has been found in people after stroke and about 25-30% of survivors are thought to experience depression (38-41), this may continue to affect patients long-term (38). An association has been made between depression and failure to resume activities after stroke (38,40,42). About 15% of patients are believed to have difficulties controlling the expression of emotion following stroke (43). Anderson et al (44) reported that out of 84 handicapped stroke survivors assessed at one year, 51% had psychiatric disorders including major depression, agoraphobia, anxiety disorders. Psychological problems may also include stress, lability, restlessness, fatigue, worry, listlessness, feelings of sadness and changes in personality (45).

Quality of Life: Quality of life is an important aspect of outcome after stroke and it remains a difficult concept to define and measure (8). It has been described as multi-dimensional, consisting of physical, functional, psychological and social health (46). Stroke appears to result in survivors having a poorer self image (41). Niemi et al (47) and Ahliso et al (48) suggest that many patients experience a decrease in quality of life despite making a good recovery in terms of discharge from hospital and everyday activities such as self-care. Reduced quality of life has also been attributed to loss of social status (49), social stigmatism (50,51) and a dysfunctional response to disability (52,53). Studies indicate that stroke has a major affect on relationships. Studies report deterioration in interpersonal relationships (42,44,52) and reduced sexual function (42,54).

1.6. OCCUPATIONAL PERFORMANCE

Occupational performance is defined by Reed and Sanderson (25) as activities carried out by the client in areas of self-care, productivity and leisure (*Figure II*). Occupational performance is dependent on the interaction of the person with their environment (24).

Estimates suggest that at one year after stroke about 80% of survivors are at home and 12% live in institutions (55). Despite the fact that only a small number of patients survive who are significantly dependent on others (56,57), these figures conceal considerable disability with many patients failing to return to their previous level of everyday activity (44,47,49,50,58). The effect of stroke on occupational performance would appear to be extensive.

Self-care: Self-care consists of activities which are done routinely to maintain health and well-being in the environment (24) and include such tasks as personal care (e.g. dressing, bathing, feeding, toiletting), functional mobility (e.g. stairs, in/out of a car) and community management (e.g. managing finances, using public transport, time management).

Many patients achieve independence in personal care (40,57) although bathing may remain a problem (5). Wade et al (59) suggest that approximately 66% of patients regain functional mobility within one year of stroke but these results may mask the real effects of stroke on lifestyle as many survivors walk slower and some never walk outside (8,60). Kettle and Chamberlain (61) in a cohort of 70 stroke survivors discharged home from a stroke unit reported that only 15% were able to walk more than 440 yards outside, only one subject could drive a car after their stroke and few of the patients could use public transport. No such problems were identified in a control group of age matched controls.

Dressing after stroke has been investigated by several researchers. Dressing is a complex self-care activity and requires motor, sensory, cognitive, perceptual skills and dressing problems would appear to be common after stroke (62,63). Studies by Williams (64) and Warren (65) have indicated that patients with perceptual problems are more likely to be dependent in dressing than those without. Walker and Lincoln (66) suggest that dressing is a global skill requiring a combination of abilities. In their study of dressing processes after stroke independence in dressing the lower half of the body was found to be significantly correlated with physical difficulties such as hemiplegia and balance and independence in dressing the upper half of the body was significantly associated with perceptual and cognitive abilities.

Problems in self-care after discharge appear to persist and studies have shown that patients may demonstrate self-care independence in hospital but become less independent after discharge (40,67-69). Deterioration's in self-care function was reported by Corr and Bayer (68) in a cohort study of 49 patients discharged from a stroke unit. They found that levels of dependency recorded at discharge tended to persist or worsen over the subsequent 7 to 12 months. This decline in function was particularly marked in activities related to grooming and feeding. Studies also suggest that many patients expend much of their energy trying to accomplish self-care and have little energy left for leisure and social activities (50,58,70).

Productivity: This consists of activities done to enable the person to provide support for self, family and society through the production of goods and services. Productivity includes paid/unpaid work and domestic activity (24).

Difficulties in carrying out in domestic activities such as meal preparation, laundry and shopping appear to persist after stroke and are related to the task involved and the presence of a carer at home (40,47,68). Anderson's cohort reported that all work related activities were effected by stroke, but lighter housework was less affected than others such as shopping, heavy housework and cooking.

Problems associated with in returning to work after stroke appear to be similar to domestic activities. Several studies have shown that work activity both voluntary and paid decreases after stroke (44,47,71). Belanger (71) in a survey of 129 patients found that only two were doing unpaid work and voluntary work at 6 months post stroke and out of the 15 people working before their stroke only one had returned to paid employment. Return to work would appear to be influenced by benefit provision, flexibility of working conditions and type of job (42,61,72).

Leisure: Leisure consists of the components of life, which are free from productivity and self-care activities (24). Leisure activity often decreases after stroke (39,40,47,49,50,52,61,68,71) with few patients returning to previous activities and or taking up new activities (58,73). Sjogren (50) reported a decrease in both outdoor and indoor leisure activities including activities that involved social interaction and entertainment. Drummond (58) in a survey of 150 stroke patients showed a decrease in the number and frequency of leisure activities. Passive activities such as watching the television and just sitting were the two most frequent leisure activities after stroke. Decreases in leisure participation have been contributed to psychosocial factors (stigma, depression, loss of confidence), physical limitations, environmental barriers (inaccessible public transport) and lack of information (39,58). Drummond suggests that stroke survivors are unable to modify or replace their lost activities and supports the view of Sjogren (50) and Viitanen et al (54) that marked changes in leisure reflect an unsuccessful coping with stroke.

1.7. ENVIRONMENTAL INFLUENCES

Environmental influences are defined as factors beyond the individual and can be viewed as the context within which the persons occupational performance takes place (23,24). Warlow et al (8) suggest that "environmental factors become extremely important in determining the effect of the stroke on a persons role in society and their handicap." Stroke can be seen to have reaching social implications, affecting not just the individual but the family and wider community.

The Physical Environment: The Stroke Association (74) suggest that extensive environmental barriers exist that reduce quality of life for stroke survivors with many experiencing a lack of access to information and statutory services, delays and bureaucracy and inadequate housing and environmental adaptations, with younger stroke people facing more restrictions. Belanger et al (71) investigated the social integration of disabled stroke survivors. They noted that environmental factors such as the proximity of friends and family, the presence of a carer at home, accessible facilities, and the ownership of a car were associated with patients returning to domestic and leisure activities and walking outside.

Psychosocial Environment: Stroke has been described as a "family illness" (75) and the presence of a carer is one environmental aspect believed to influence adaptation to stroke (76). The bulk of social support for stroke patients is provided by informal sources of care such as family and friends. In most cases the stroke patient lives with the principle carer who is usually a spouse, offspring or daughter-in-law who may also be responsible for others (39,77,78). Estimates report that 25% of stroke survivors living at home one year after their stroke are wholly dependent upon their immediate carer and an additional 30% require on-going support (77).

Emotional distress in carers is reported to be high (39,74,78-80) and some authors suggest that it is the psychological strain of caring for a stroke survivor that places the most burden on carers (44,77,79). Many carers feel unable to leave patients unattended for all or part of a day (62). Brocklehurst et al (77) noted that a deterioration in the chief carer health was common during first year of stroke and that many of the problems encountered by carers were related to the behaviour of patients and the need to provide constant supervision. Distress is felt to be particularly high in carers supporting stroke patients with dementia or with abnormal behaviour (44).

The presence of a carer appears to influence discharge planning (35). Friedman (81) reported that the availability of a carer was critical in preventing patients from being discharged to institutions. Patients without carers who returned home had milder initial strokes and were more able seven days after stroke compared to those with a carer who returned home.

Several studies have suggested that some carers may be over-protective towards patients and prevent them from maximising their potential (67,82). This may be influenced by poor communication/education and involvement of carers in rehabilitation programmes and a lack of co-ordinated and statutory support including respite care after discharge (62,67,79,80,83). Carers may need to give up employment in order to care for a relative, placing further financial strains on themselves and the stroke survivor.

The economic effect of stroke on survivors is believed to be great. The Stroke Association (74) reported that a loss of income was particularly marked in the younger stroke group with 40% saying they felt they were in a poverty trap. A recent report published by the Scottish Office (2) calculated that stroke in 1991 caused a gross productive loss of £49 million in Scotland. Loss of income reduces choice, health and quality of life (84-86).

Some authors propose that restrictions in occupational performance are caused by contemporary social organisation which take little account of people with impairments and exclude them from mainstream social activity (87). Restrictions are believed to be the result of social forces, cultural values and prejudices, which marginalise disabled people (17).

Evidence does suggest that stroke services are poorly targeted and discharge badly co-ordinated (61,74,88-90). An audit carried out by Ebrahim et al (88) found that of the 183 patients followed up six months after discharge, two-thirds had disabilities but less than half were receiving regular help of any kind. Community and rehabilitation provision was not related to disability and large numbers of the patients appeared to have slipped through the service provision net. A survey of 44 Glaswegian patients (90) carried out six months after discharge concluded that many of the stroke patients suffered higher levels of handicap than their disability indicated and this was contributed to difficulties accessing statutory services. Forster and Young (91), Tyson (92) and Kettle and Chamberlain (61) have suggested that present rehabilitation approaches with their emphasis on short-term physical recovery do little to prepare patients for a "career in disability" and might actually contribute to a poor return in social and psychological functioning. Young (93) believes that hospital based care has become the default service for stroke, providing terminal or palliative care and a refuge for patients that are socially disadvantaged (e.g. those living alone) but fails to address the long-term handicap and psychosocial needs of patients. Hospital staff he suggests have become entrapped by a short-term view which focuses on discharge from hospital as the end point of rehabilitation. A view supported by Warlow et al (8) who suggest that the traditional separation of care into acute medical, rehabilitation and continuing care is artificial and potentially harmful to patients and advocate an integrated, problem - and goal orientated approach to care.

1.8. RECOVERY

After stroke the majority of survivors will experience a period of recovery in neurological impairment and functional disability. Recovery appears to be most rapid in the first few weeks following stroke with most of the recovery occurring within three months. Most stroke survivors reach a recovery plateau at 6-9 months after stroke (36,94,95), although some studies do suggest limited recovery beyond this time (8,94,95).

Recovery may be a result of several factors. In the first few days after stroke, spontaneous neurological recovery occurs when neurones not permanently damaged by the stroke begin to function because of an improved blood supply, a resolution of cerebral oedema or reversible metabolic problem (8). Later improvements may be a result of neuroplasticity. Growing evidence suggests that the central nervous system is able to repair itself, a process called neuroplasticity. New cerebral areas are activated during this process of reorganisation, which can lead to the restoration of function (96-98). Stroke survivors are also able to minimise their limitations through compensating for impairment and adapting their environment to maximise independence (8,99).

Prognostic indicators have been developed by researchers in an attempt to identify characteristics that predict patient outcome. A literature review of this area is difficult due to a lack of consensus on patient sampling, the timing of initial assessments, choice of outcome measures and measurement criteria (8,100). Factors which appear to have an adverse effect on recovery include prior stroke (100-103), a reduced level of consciousness (103,104), urinary and bowel incontinence (57,100,103-105), visuo-spatial deficits (32,100,103,106), proprioceptive loss (107,108) and the severity of the initial stroke (99,100,103,109). There appears to be no relationship between gender (100,110) and functional outcome. Other prognostic indicators considered by researchers include severity of paralysis (100,103,111), motor deficits such as balance in a sitting position and use of arms (103,105), age (57,100,112,113), side of lesion (32,34,110,114,115), functional score on admission (100,103) and educational/socio-economic status (116). Consensus on their value remains unclear. Recovery should not be regarded as uni-dimensional phenomenon but most likely involves the interaction of various prognostic factors and environmental influences. Care should be taken when trying to predict the rate of recovery for an individual patient, as the rate and completeness of recovery will vary.

1.9. REHABILITATION

Rehabilitation has been described by the World Health Organisation (12) as a, "problem-solving, educational process, aimed at reducing disability and handicap experienced by someone as a result of disease, always within the limitations imposed both by available resources and by the underlying disease." (ICD, 1980). Rehabilitation is "a process aimed at minimising the functional affects of stroke, minimising the impact of stroke on the patient's and carer's life, and maximising autonomy" (8)

Traditionally stroke rehabilitation has been directed at treating impairment but increasingly there is an emphasis on disability and handicap issues (14,91,92,117,118). Rehabilitation may also be viewed in terms of competent performance, with the aim of restoring patients to their previous levels of function (119). Others such as MacWalter (120) have considered "physical, psychological and social adaptation" and the prevention of secondary complications of stroke to be important elements of rehabilitation.

Rehabilitation in Britain is carried out in many different clinical settings, by a variety of professionals. More commonly services are multi-disciplinary based with the majority of teams including medical, nursing, therapy and social work team members (120). Existing in-patient services cover a wide variety of models of acute/rehabilitative care (121). These include rehabilitation based on acute medical or geriatric units, or within designated specialist areas such as a rehabilitation or stroke units. Out-patient/community services are more diverse and may include primary care services, hospital out-patient services, community based hospital services, day hospitals and social services.

The effect of rehabilitation on recovery remains controversial. Despite the huge resources invested annually into stroke care, research within the field of stroke rehabilitation has been limited. Studies suggest that stroke patients account for 6.4% of bed days and 4.7% of the total NHS budget (122,123). Many stroke survivors are not admitted to hospital and the cost both financially and in terms of quality of life for the individual, carers and the community is unknown but thought to be high (2). Trials investigating the efficacy of rehabilitation interventions have had equivocal results (97,124-127) and randomised studies have failed to show long-term benefits (11,128,129). However there is some evidence from small randomised trials that therapy intervention may result in improved functional outcome for some stroke patients (126,130-137) and despite the lack of evidence, practitioners remain convinced that rehabilitation is beneficial (8,11,97,118). Difficulties arise when trying to compare studies because of methodological differences such as variations in outcome measurements, sample differences and lack of agreement on when to measure outcome (8,126).

Audits over the last few years (88,89) have identified that existing models of stroke care are often haphazard, fragmented and poorly tailored to patients needs. This along with evidence that early rehabilitation by well organised specialist services results in a more rapid recovery to independence and more rapid discharge from hospital (88,117,120,138,139) has resulted in many developments in stroke care (121) and the publishing of service guidelines and policies (2). One such area of development is the provision of community based rehabilitation services. Historically therapy treatment for stroke patients has focused on hospital care but this focus is now shifting to intervention within the home as strategies are developed to expand community care (140,141) and reduce in-patient stay. The contribution of community stroke rehabilitation will be examined in further depth with an emphasis on occupational therapy.

1.10. COMMUNITY BASED REHABILITATION SERVICES

Between 60% and 70% of survivors of first ever stroke are likely to live at home and about one-third of these will consider themselves dependent on others for help (5). Over the past twenty years, the long-term needs of stroke survivors have been increasingly recognised (93) and this has coincided with a growing interest in the value of caring for stroke patients at home with more effective community support (93,129,142,143,144).

Support for community intervention was voiced in the early 1980's. Brocklehurst et al (77) suggested that the social effects of stroke could be addressed by mobile community teams and Garraway (67) who proposed that the short-term functional benefits achieved by stroke units might be sustained through a longer period of follow-up. Andrews and Stewart (82) believed that the needs of carers could be more effectively addressed by home-orientated rehabilitation. The management of stroke rehabilitation was felt to continue beyond the acute phase in hospital and home care it was suggested might be cheaper (144-146).

More recently researchers such as Young, Forster and Gladman (147) and Evans et al (129) have added their support to the development of more organised community services for stroke patients. Young (93) advocates the expansion of complementary community services. This he believes might address the limitations of "short-termist" hospital based care and deal with the long-term handicap and psychosocial needs of patients, allowing "patients to reach their full potential". Evans et al (129) in a meta-analysis of multi-disciplinary versus medical care recommended that services needed to be continued at home or in a subacute area to optimise effectiveness of in-patient rehabilitation.

Home based intervention has been recommended for several reasons:

- The individuals home environment is a more realistic place to identify real problems and find relevant solutions for both the patients and carer (67,82,148-151).
- The practical problems of transporting patients to out-patient services could be minimised (152,153).

- More effective communication may occur with other services such as homehelp and the provision of home adaptations (148,149).

Several forms of home based intervention have been investigated and these include:

- Acute home based intervention: this form of intervention does not involve admission to hospital and both acute and rehabilitation needs are addressed at home.
- Early supported discharge: this involves the acute treatment of patients in hospital, early discharge e.g. two to three weeks after admission and a further rehabilitation at home.
- Home-based rehabilitation: involves the provision of further rehabilitation at home after acute treatment and initial rehabilitation in hospital.

Acute Home Based Intervention

Wade et al (154) carried out a non-randomised controlled trial to evaluate a home care service for acute stroke patients. Referral to the multi-disciplinary service was made via designated GP practices and a control group consisting of a further forty-seven GP practices who continued with normal practice. The trial demonstrated that patients treated at home had slightly higher rates of admission, longer lengths of hospital stay and showed no significant differences in emotional adjustment or functional abilities compared to the patients in hospital. Wade noted that staff were wary of using the new service, fearing that it was simply a cost cutting device and GP's allocated to the trial group did not keep more patients at home. The results may have reflected the difficulties gaining acceptance of a new service rather than the effectiveness of community treatment for acute stroke patients. Wade concluded that home based services may be of value in the management of stroke but that care should be taken before expanding services to reduce hospital use and further research was recommended.

Similar caution to acute home care intervention has been expressed by Lincoln (155). She suggests that current research of hospital based stroke care shows that co-ordinated multi-disciplinary care is better than disorganised care. Co-ordinated care she believes is lacking in the community due to fragmented management structures, a lack of specialist workers, poor resources and a focus on support rather than rehabilitation. Care should be taken before transferring hospital based care to the community and new services should be developed within the context of research evidence from randomised controlled trials.

Early Supported Discharge

A further development in the use of home rehabilitation stroke services has been the recent investigation of early supported discharge services.

Widen - Holmqvist et al (114) followed up eighty-one moderately disabled stroke patients who had been randomly allocated to either home rehabilitation or routine rehabilitation services. Home rehabilitation involved early discharge with continuity of therapy at home as an alternative to sustained rehabilitation in hospital. The three months results did not reveal a significant difference in functional outcome between the two services, however higher scores were observed in frequency of activities, independence in ADL, total motor capacity, manual dexterity and walking ability in the home rehabilitation group. Further results are expected but the researchers tentatively concluded that home rehabilitation for the majority of moderately disabled stroke patients during the first three months after acute stroke is more beneficial than routine rehabilitation in Sweden.

A study carried out by Rudd et al (156) set about to assess the clinical effectiveness of an early supported discharge policy for stroke patients using a community based rehabilitation team in South London. One year after randomisation they found no significant difference in clinical outcomes and concluded that early discharge with specialist care is feasible and as clinically effective as conventional care and acceptable to patients. Considerable reductions in the use of hospital beds were also achieved. Similar results were reported by Rodgers et al (150) in a an early supported discharge trial carried out in Newcastle-upon- Tyne. Patients in the early supported discharge service stayed in hospital for a significantly shorter length of time and reported improved self-care, domestic and leisure activity scores. No statistical differences were found in global health status or carer stress. The study concluded that an early supported discharge service following acute stroke with individualised rehabilitation in the community is feasible but a larger multi-centred trial is needed before such a service is widely adopted.

Home-based rehabilitation

Traditionally after acute admission and initial rehabilitation in hospital patients have continued rehabilitation as out-patients usually attending hospital therapy departments or day hospitals with social services and primary care services providing varying amounts of assessment and treatment. Several studies have compared these conventional interventions with community based stroke rehabilitation.

A family placement scheme for patients discharged from hospital was surveyed by Geddes, Chamberlain and Bonsall (157). Stroke patients stayed with trained volunteer carers before returning home and the scheme was designed to provide a period of intensive support at the time of discharge. The researchers suggested that the scheme produced sustained improvements in functional ability. The study was not randomised and the sample size was small but the results suggested that community rehabilitation should be investigated further.

In 1992, Young and Forster (135) carried out a randomised controlled trial in Bradford to compare day hospital (DH) and home physiotherapy (HPT) intervention for stroke patients. One hundred and twenty-four patients discharged to home and over the age of sixty were recruited and patients that had returned to their previous functional level or who lived outside the catchment area were excluded. Patients were stratified by their Barthel Index score and length of time since stroke and then randomly allocated to eight weeks of physiotherapy treatment either at the day hospital or at home. The six months study results showed that both treatment groups had significantly improved in functional abilities between discharge and six months. The improvements were significantly greater for patients treated at home and the home treated patients received less treatment. More than one third of the patients in both groups showed depression and a quarter of the carers were emotionally distressed. Young and Forster concluded that home physiotherapy seemed more effective and more resource efficient than day hospital and that new strategies needed to be developed to address the psychosocial needs of patients and carers.

A similar project was conducted by Gladman et al in Nottingham (149) (The Domino study). This study compared the functional ability and perceived health status of three hundred and twenty-seven stroke patients discharged from hospital and randomly allocated into three strata (elderly care, general medical and stroke unit) to receive home-based (domiciliary) or hospital-based care (day hospital and out-patient therapy). Patients discharged to institutional care, with a terminal illness, in hospital of less than seven days, or who had received rehabilitation before their stroke or had no significant disability were excluded. The home-based intervention consisted of physiotherapy and occupational therapy and lasted for six months. The six months results showed no overall difference in the effectiveness of home-based and hospital based services although younger stroke unit patients appeared to do better with home therapy regaining more household and leisure activities while some frail elderly patients benefited from hospital attendance. By one year (158) the benefits of the home therapy for the younger stroke unit patients had been lost because the out-patient group continued to improve and the advantage of day hospital was maintained with fewer frail elderly care patients dying or going into residential care.

The Bradford and Domino studies would initially appear to have conflicting results but these differences could have several explanations:

- Sample characteristics - the Domino study patients may have been more frail and were therefore more likely to benefit from day hospital than the Bradford patient as they were on average seven years older. The studies might be suggesting that home therapy is of most benefit to those who are not frail.
- Intervention differences - The amount of therapy provided was greater in the Bradford study as all patients received eight weeks of treatment whereas only 75% of the Domino elderly care stratum did.
- The results may reflect location differences in health policy and population characteristics. The Bradford physiotherapy service had more staff and was an established team compared to newly formed Domino team.

These differences were examined in an analysis of the two trials (147) which demonstrated little difference in efficacy between home and hospital-based care, but a small advantage of home therapy was found in improving function between hospital discharge and six months. The analysis did not support the Domino finding that day hospital significantly prevents death or institutionalisation for the frail elderly. On the basis of this analysis it was suggested that an effective home therapy programme service should aim to deliver 15-20 visits per patient. It was concluded that home therapy should be the choice of after care in urban settings in the UK. This conclusion was based on the cheaper cost of home therapy.

Forster and Young carried out a further randomised controlled trial to evaluate whether specialist nurse visits would enhance the social integration and perceived health of stroke patients or alleviate stress in carers (159). Two hundred and forty patients aged sixty or over were recruited, stratified by their functional ability, residency, social activity pre-stroke and then randomly allocated to a treatment or a control group. All the patients received the usual services and the treatment group received the additional nursing outreach service. This consisted of twelve months of follow-up with a minimum of six visits in the first six months by an experienced outreach nurse who provided support and a structured information programme. The study showed no significant differences in perceived health, social activities or stress among carers between the treatment and control groups. They suggested that the results may have been diluted by contacts between the groups at community gatherings e.g. stroke clubs and by patients experiencing other life events such as new physical illness or bereavement affecting their psychological state and social functioning. The sample size of the trial was also found to be too small, emphasising the need for multi-centred studies. Forster and Young concluded that no proved strategy exists to address the psychosocial difficulties of stroke patients and their families.

On-going support for patients after discharge has also been investigated by Dennis et al (160). This randomised trial evaluated the effectiveness of a Stroke Family Support Worker (SFSW). Results showed no significant differences in physical outcome between the SFSW intervention group and the control group. Patients in the treatment group were possibly more helpless, less well socially adjusted and more depressed, whereas carers in the treatment group were possibly less hassled and anxious. However both patients and carers in the treatment group expressed significantly greater satisfaction regarding receipt of information, having their needs listened to and knowing who to contact concerning stroke related difficulties.

Studies evaluating home-based rehabilitation would appear to be inconclusive although intervention using more active, behavioural approaches such as physiotherapy and occupational therapy (147) might be more effective that the "talking cures" such as counselling and education intervention (159-161). Several studies have been carried out to investigate more specifically the role of occupational therapy in home based rehabilitation and these will be examined in greater depth.

1.11. OCCUPATIONAL THERAPY

The development of community care including rehabilitation for stroke patients has become of increasing interest to the occupational therapy profession. This interest is reflected in the 1989 Commission of Inquiry Report carried out by Blom - Cooper (162) which suggested that; "on both humanitarian and economic grounds, the need to provide caring and rehabilitation services in the community rather than in institutions is becoming ever more pressing. .... The incentives for hospitals to maximise the use of their expensive facilities are likely to increase still further and to lead to even greater pressures on them to discharge patients who, not so long ago, would have expected to spend days or weeks undergoing rehabilitative diagnosis and therapy while still occupying a hospital bed..... Increasingly into the twenty-first century occupational therapy should be largely relocated in the community care services."

Occupational therapy developed as a profession from the beginning of the 20th century. It emerged from the 19th century philosophy of moral treatment for the mentally ill and the rehabilitation of war veterans from the two world wars (119). It has been defined as 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 (163). Occupational therapists have and continue to make an important contribution to the stroke multi-disciplinary rehabilitation team (8).

Theoretical Base

Occupational Therapy is based on the belief and theories that;

- All individuals have value (164) and are able to influence their own physical and mental health and their social and physical environment through purposeful activity (165). "occupational therapy acknowledges and practices within a humanistic view of the individual as a whole person. Individuals are viewed as integrated beings in which no area of function can be isolated as a separate entity, but viewed as part of the total make-up." CAOT 1991(24). Kielhofner (165,166) views individuals as "open systems" that interact with their environment through a cyclical process of input (information received from the environment), throughput (the internal response influenced by volition, habits and performance level of the individual), output (occupational performance which influences the environment) which results in further input.

- Reed and Sanderson (25) define occupation as "purposeful behaviour designed to achieve a desired goal." Occupation is fundamental to human existence because it maintains and provides for life-support systems and gives meaning to life (167). Christiansen suggests that occupation refers to engagement in activities, tasks and roles for the purpose of productive pursuit, maintaining oneself in the environment and for the purposes of relaxation, entertainment, creativity and celebration (26) and Turner (164) proposes that the absence or disruption of occupation is a threat to health. Occupation has been classified into three categories; self-maintenance, productivity (work) and leisure (play) (24,25,119,168).

  Occupation is viewed as a dynamic process which changes in form and complexity over time and in different places. It can be influenced, altered and changed by the individuals performance (personality, abilities and skills) and environment. Hagedorn (119) suggests that occupational therapy may involve the manipulation of the environment to enable individuals to regain, develop or retain occupational skills. Baum and Law (169) have described this process as occupational performance, "the point when the person, the environment and the person's occupation intersect to support the tasks, activities, and roles that define that person as an individual."

- Reed and Sanderson (25) suggest that occupational therapists are able to use directed, purposeful occupations to treat illness or disability and to "influence positively a person's state of well-being and thus the state of a person's health". Within the "open systems" theory this process is viewed as using therapeutic behaviours to intervene in dysfunctional cycles to restore normal functioning (165). Parker (161) supports this theory in a review of leisure in stroke rehabilitation. She suggests that psychological health, as well as physical function is susceptible to modification by behavioural means, with activity which directly bring about enjoyment being perhaps more effective in alleviating misery than the so-called talking cures. It is the experience of the "doing" process which is felt to bring results (164). Thus the " use of purposeful task engagement is the essential uniqueness of occupational therapy." CAOT 1991 (24).

Aims of Intervention

Within the field of rehabilitation occupational therapists aim, "to address function and use specific procedures and activities to; develop, maintain, improve and/or restore the performance of necessary functions, compensate for dysfunction, minimise or prevent debilitation and/or promote health and wellness." (170)

Within stroke rehabilitation occupational therapy involves maintaining a balance between promoting intrinsic recovery which aims to reduce impairments and maximising adaptive recovery which aims to accept limitations, find alternative strategies to function including adaptation of the environment (171,172). "Life goes on and for those who survive after stroke so does the need to engage in daily activities" Eakin 1991 (172). Occupational therapy intervention includes;

- Assessment (24,119,173). This might include assessing impairments, difficulties in occupational performance, environmental/social limitations and patients/carers opinions and needs. Assessment enables the occupational therapist to establish a baseline against which improvements can be measured (173) and assists with realistic goal setting. It requires an understanding of activity analysis in which the components required to perform an activity are identified (119,168) allowing the identification of dysfunction in occupation.

- Goal setting involves developing strategies for intervention (174). This stage will be influenced by the priorities of the patient and the approach of the individual occupational therapist. Various neuro-integrative approaches have been proposed including Rood (175), Brunnstrom (176), Bobath (177), Motor Relearning (178), Proprioceptive neuromuscular facilitation (179) and functional (173). The merits of the different approaches remain controversial and scientific evidence of effectiveness is lacking (172). In practice most therapists appear to adopt a pragmatic/eclectic approach, using methods which they have found to work (27). Eakin (172) warns against over focusing on motor performance approaches suggesting this might impose severe limitations on the goals and processes of occupational therapy, particularly in the area of activities of daily living training.

A client-centred approach to goal setting involves identifying problems that are important to the patient/client and strengths/resources that can be used to solve the problem. "Client-centred occupational therapy practice is an alliance formed between client and therapist to use their combined skills and strengths to work towards client goals related to occupational performance." (180)

- Therapeutic Intervention. This is determined by the intervention goals and may include:
  - Facilitating normal movement during activity (164,181).
  - Correcting or compensating for perceptual/ cognitive/sensory problems (33,164,173).
  - Preventing deformity e.g. positioning and splinting (164,173).
  - Facilitating maximum independence in self-care, productivity and leisure (3,66,161,164,172,173).
  - Support/ stroke education. Helping patients and carers to adjust to disability (8,164).
  - Minimising handicap - Provision of adaptive equipment, facilitating changes to the environment and providing information of community services (2,182).
  - Liaison with members of the multi-disciplinary team (8,132).

  Therapeutic intervention is influenced by the relationship between the occupational therapist and the patient (174). Mosey (184) suggests that "such a relationship is concerned with promoting growth and development, improving and maintaining function, and fostering a greater ability to cope with the stresses of life."

- Evaluation. This involves evaluating the success of the intervention and may result in setting new goals and further intervention.

A need for occupational therapy intervention for stroke patients after discharge has been highlighted by Ebrahim et al (88) in an audit of stroke services. This reported that many patients with severe disabilities had not received potentially useful aids and Greveson and James (39) suggested that more attention should be given to those activities that are not essential to life such as leisure as a means of improving quality of life.

1.12. DOMICILIARY OCCUPATIONAL THERAPY FOR STROKE PATIENTS - A SYSTEMATIC REVIEW

Several studies have been carried out to evaluate home-based occupational therapy services for stroke patients. In this section, I have examined these in greater depth using the method of systematic review and meta-analysis.

Systematic review involves the systematic and objective identification, collation and analysis of all the relevant information on a subject and can provide a means of obtaining more reliable conclusions about the effectiveness of healthcare interventions (185,186). This was carried out in order to obtain more reliable information about the effectiveness of such interventions and to assist sample size calculations for the research trial. (Chapter 3)

Primary Review Question

The primary review question can be summarised as: "Does routine home-based occupational therapy after discharge improve the outcome of stroke patients?"

The following definitions were used:

- Home-based occupational therapy - an occupational therapy intervention carried out in the patients home environment. Intervention should involve treatment of occupational performance problems (self-care, productivity, leisure) compared with no intervention.
- After discharge - the intervention should be carried out after discharge from hospital.
- Stroke patients - patients fulfilling the WHO clinical definition of stroke (1); including cerebral infarction, intracerebral haemorrhage and sub-arachnoid stroke.
- Outcome - death, deterioration in function (occupational performance), final extended activities of daily living score (187).

Selection Criteria

Selection criteria were chosen to help select reliable trials relevant to my research question. All the trials selected needed to show clear evidence of randomisation, recruited only stroke patients, used an intervention that represented conventional occupational therapy practice, followed-up the majority of patients and used a blinded assessment of outcomes.

Literature Search

The literature search was carried out using MEDLINE, CINAHL, the Occupational Therapy and Physiotherapy databases and supplemented with information from the Cochrane Library, references from articles and reviews and personal contacts with active researchers. The key words used during the search were cerebrovascular disorders, cerebral vascular accident, rehabilitation, occupational therapy, home occupational therapy. The searches plus exploded "terms" are described in Appendix A.

Attempts were made to carry out a comprehensive literature review but it was noted that electronic data bases such as Medline may not index all the relevant references or journals. Dickerson et al (188) suggest that if comprehensive systematic reviews of randomised clinical trials depended solely on Medline searches, 50% of available published trials would be omitted. This figure may be even higher for therapy trials that are less in number and published in unindexed journals. Even a skilled searcher may miss important material (189) and problems exist because different studies are categorised under different key words making the selection of suitable MeSH terms hazardous. The other disadvantage of only using electronic databases is that they only identify published trials, which are potentially biased towards a positive result (189).

Five potentially relevant studies identified through the literature search were assessed by two reviewers and met the criteria for inclusion in the review. Turton and Frasers study (181) was rejected because the occupational therapy intervention focused only on upper limb rehabilitation and occupational performance outcome was not measured. The following trials were identified and are summarised in Table 1.

Table One – HOME BASED OCCUPATIONAL THERAPY STROKE TRIALS

STUDY	STUDY DESIGN	SAMPLE	INTERVENTION	PRIMARY OUTCOME MEASURES	TRIAL CONCLUSIONS	ADDITIONAL COMMENTS
Cardiff **Occupational Therapy for stroke patients after hospital discharge.** Corr, S. Bayer, A. (190)	Randomised controlled trial	n = 110 from stroke units	Control Group Conventional treatment only Treatment Group Conventional plus 4 contacts over 24 weeks by an O.T.	Death/institutionalisation Barthel Index Nottingham EADL Geriatric Depression scale Pearlman's Quality of Life Blinded assessment at 1 year after stroke	No significant differences between treatment and control group in activities of daily living or mood. The treatment group received more equipment and had less re-admissions	Sample included 44% of patients who were discharged to institutional care Results included a description of withdrawals/dropouts
Nottingham 1995 **Leisure Rehabilitation after Stroke.** Drummond, A.E.R. Walker, M.F. (136,192)	Three group randomised controlled trial	n = 65 from a stroke unit	Control Group Conventional intervention Conventional O.T. Self-care/domestic intervention. 15 contacts over 6 months Leisure OT Leisure intervention. 15 contacts over 6 months	Death/institutionalisation Rivermead ADL (self-care) Nottingham EADL Nottingham Leisure Questionnaire. Rivermead Motor function scale Blinded assessment at 3 and 6 months after discharge to home.	Leisure rehabilitation does increase involvement in leisure activities after stroke	Improved performance in mobility and psychological well-being was also observed in the leisure group Results included a description of withdrawals/dropouts

OT = Occupational therapy

Table one continued: **STUDY**	**STUDY DESIGN**	**SAMPLE**	**INTERVENTION**	**PRIMARY OUTCOME MEASURES**	**TRIAL CONCLUSIONS**	**ADDITIONAL COMMENTS**
Nottingham 1996 **Evaluation of dressing practice for stroke patients after discharge from hospital.** Walker,M.F. Drummond, A.E.R. Lincoln N.B. (137)	A randomised crossover design study	n = 30 From general medical, elderly and stroke unit	3 months of dressing practice given by an occupational therapist Median of eight visits	Rivermead ADL (self-care) Nottingham Stroke Dressing Assessment, Nottingham Health Profile. Blinded assessment at 3 and 6 months after recruitment	Dressing practice given at home to stroke patients with residual problems in dressing leads to a sustained reduction in their problems	Patients recruited were living at home and still had dressing problems six months after discharge from hospital. All the patients completed the study - no dropouts
Vancouver **An investigation of Involvement in Leisure activities after a stroke.** Jongbloed, L. Morgan, D. (191)	Randomised controlled trial	n = 40 From a rehab. hospital. Up to 15 months after stroke	Control Group Counselling by OT Treatment Group Five one hour sessions of leisure intervention by an OT	Katz Adjustment Index Blinded assessment before intervention, 5 and 18 weeks after initial visit by OT	No significant differences in activity involvement between the control and treatment group.	The control group did discuss leisure activity with an OT. This may have contaminated the results. All the patients completed the study - no dropouts
Nottingham 1997 **A randomised controlled trial of enhanced occupational therapy for stroke patients.** **Logan,P.A. Ahern,J. Gladman,J.R.F. Lincoln,N.B. (193)**	Randomised controlled trial	n = 111 Discharged from hospital and referred to social services OT	Control Group Conventional social services OT intervention. 2 visits. Treatment Group Enhanced service by OT. 6 visits	Death and institutionalisation Barthel Index Nottingham EADL General Health Questionnaire Blinded assessment at 3 and 6 months after recruitment	Patients receiving the enhanced service had significantly better extended ADL scores at 3 months and more adaptive equipment. This benefit was not sustained	The conventional social service was mainly provision of equipment and the enhanced service included OT treatment. Results included a description of withdrawals/dropouts

- Cardiff - Corr and Bayer (190) conducted a randomised controlled trial of occupational therapy for stroke patients discharged from stroke units. One hundred and ten patients were recruited irrespective of discharge destination and randomly allocated to an intervention or control group. The intervention was additional to existing services and consisted of four contacts over twenty-four weeks by an occupational therapist following discharge and consisted of advice, ADL, provision of equipment. Standardised outcome measures were used at one year. Results showed no significance in baseline characteristics apart from gender with more women than men in the intervention group. 40% of the intervention group and 49% of the control group were in institutional care. There were no significant differences between the two groups in activities of daily living, mood and perceived quality of life however the intervention group had received significantly more adaptive equipment and re-admission to hospital was significantly smaller.

Corr and Bayer suggested that influence of occupational therapy on disability and handicap may have been diluted by several factors. The small sample size. A high number of patients were severely disabled which may have limited their potential to respond to the occupational therapy imput. Many patients in institutional care were not encouraged towards independence. The problems of accessing community services especially the provision of adaptive equipment. A lack of sensitivity to change of the standardised outcome measures and qualitative methods may have been more appropriate. They concluded that a follow-up service by an occupational therapist benefits stroke patients by addressing any problems they have post discharge, ensuring they receive all necessary adaptive equipment and helping to maintain them at home.

- Vancouver - The use of leisure intervention has been investigated by Jongbloed and Morgan (191) who randomised forty patients into two groups. Group one received occupational therapy intervention related to leisure and group two was visited by an occupational therapist who discussed leisure but did not offer intervention. Patients were included if they had experienced a stroke within the past 15 months, had completed a rehabilitation programme and were not depressed or severely dysphasic. The results showed no significant differences between the two groups in activity involvement of satisfaction. Jongbloed and Morgan suggested that these findings may have resulted from inadequate intervention and the strong influence of environmental factors on leisure participation.

- Nottingham 1995 - Drummond and Walker (136) investigated the effectiveness of a leisure rehabilitation programme for stroke patients discharged from a stroke unit and living at home. A three-group pre-test - post-test study design was used. Patients were excluded from recruitment if they had severe comprehension difficulties, lived outside of the catchment area or were discharged to institutional care. Patients were randomly allocated to either leisure treatment, conventional occupational therapy treatment or no additional imput. The conventional therapy treatment consisted of self-care and domestic activities and where appropriate perceptual treatments. Intervention for the treatments groups lasted for six months with a mean of fifteen visits and the outcome assessments took place at three and six months. Sixty-five patients were randomised and a significant difference in age was found at the beginning of the study with leisure group having younger patients. The results showed that leisure scores were significantly higher in the leisure rehabilitation group, even when effect of the confounding variable of age was removed. The results of the Drummond and Walker study (192) also demonstrated that subjects receiving leisure rehabilitation performed significantly better in mobility and psychological well-being that the subjects in the other groups.

The Drummond and Walker results appear to contradict the findings of the Jongbloed and Morgan study. The different results might be due to differences in the amount of therapy offered. In the Jongbloed study only five one-hour visits were offered in comparison with the average of fifteen in the Drummond study. The control group in the Jongbloed may also have been contaminated by leisure discussion, resulting in patients in the control group participating more in leisure activities. Drummond suggests that the Jongbloed study might show that leisure counselling may an effective intervention strategy.

- Nottingham 1996 - Walker et al (137) carried out an evaluation of dressing practice for stroke patients using a crossover design. Thirty patients were randomised at discharge from hospital to receive no intervention for three months followed by three months of dressing practice intervention or the reverse. Stroke patients were eligible to enter the study if they had a dressing problem and lived at home. Patients who were blind, deaf, with dementia or who could not understand English before their stroke were excluded. The occupational therapy treatment took place in the patients home. Standardised assessments were used including the Nottingham Stroke Dressing Assessment and the self-care section of the Rivermead ADL.

The result of the study showed that both groups demonstrated statistically significant improvement in dressing skills during the treatment phase. Patients who received treatment in the first three months maintained their improvement. Walker concluded that dressing practice given at home to patients who have residual problems in dressing after acute stroke by an occupational therapist leads to a sustained reduction in their problems.

- Nottingham 1997 - The effect of social service occupational therapy was investigated further by Logan et al (193) in a randomised controlled study to compare the interventions of conventional social services occupational therapy with an enhanced occupational therapy service for stroke patients. One hundred and eleven stroke patients discharged home and referred to social service occupational therapist were randomly allocated to be a conventional or enhanced service. The conventional service prioritised patients for the assessment and provision of aids only whereas the enhanced service included additional sessions and activities of daily living treatment. There was no significant difference between the two groups demographically. Assessments compared the functional ability, perceived help, equipment needed and satisfaction with services. The results showed that those patients who received the enhanced service had significantly higher extended ADL at three months than those seen by the conventional service. This benefit remained significant in mobility at six months.

Analysis

In a systematic review, the data from individual studies can often be combined in a pooled analysis. This process, called meta-analysis, can be either based on data abstracted from published papers or on data obtained by asking the authors of published/ unpublished papers for the original single patient data (189). The latter is more accurate and comprehensive (194) but the time and resources were not available to carry out such a detailed analysis.

The data analysis reflected the primary aim of identifying whether home based occupational therapy would prevent functional deterioration and improve occupational performance and that the Nottingham EADL (187) had been selected to inform the power calculations for the proposed study. The following outcome data were therefore collected for analysis;

Dichotomous Outcomes: The number of patients who had died or deteriorated (institutionalised or withdrawn) by the end of the study follow-up.

Continuous Data: Median Nottingham EADL scores (on a score of 0-66) at three months and end of study follow-up.

The data were analysed on Review Manager software with assistance from Dr Peter Langhorne. The Nottingham 1995 trial (192) was treated as two studies, conventional OT v control (A) and leisure OT v control (L). Care was also taken to include only data from the first phase of the Nottingham 1996 trial (137) as a crossover design had been used.

Several limitations became evident when collecting/loading the data:

- Measurements had been carried out at different times during recovery - e.g. Cardiff had measured outcome at one year after stroke whereas Nottingham 1996 had completed assessments as three and six months after discharge. The majority of outcomes were therefore recorded at the end of follow-up. In addition, I also collected extended ADL data from three of the studies at three months as this shorter follow-up period was relevant to my own proposed study
- An incomplete data set - Studies such as the Vancouver and Nottingham 1996 had not collected data on extended ADL outcome. A complete data set was therefore not available for extended ADL outcomes.
- Although the majority of studies had used the Nottingham Extended ADL (187), they had reported median values rather than the means and standard deviations (SD) required for analysis. i.e. they had correctly treated extended ADL scores as ordinal measures and had used median and range statistics to describe central tendency and spread. Data presented in this way could not be analysed using conventional methods.

All the statistical analyses were based on the principle of examining the differences between treatment and control groups within each trial.

Dichotomous outcomes were calculated as odds ratios (OR's) with 95% confidence intervals (95% CI). In this analysis the chance (odds ratio) of an adverse outcome taking place in the treatment group as opposed to the control group is calculated together with an estimate of the range of results with which the estimated odds ratio is reasonably compatible (confidence interval).

Continuous data which were expressed as the median Nottingham Extended ADL scores had to be analysed as the average median difference i.e. the difference in median scores between the intervention and control groups within single trials was calculated and summed for all trials.

The summed result was weighed for trial size as follows:

$$\frac{\Sigma\,(d \times n)}{\Sigma\,(n)}$$

where Σ = sum total
d = median difference for individual trial
n = number of participants in each individual trial

Results

There was a non-significant reduction in the odds of death or deterioration by the end of follow-up (OR 0.57; 95% CI 0.33-0.98; $p<0.05$) among the treatment group, but no firm conclusion could be drawn due because of the wide confidence interval (Table 2).

Table Two: Systematic Review: Death or Deterioration by the End of Follow-up

Study	Treatment Group	Control group	Odds Ratio (Peto OR)	95% Confidence intervals
Cardiff	25/55	29/55	0.75	[0.36, 1.58]
Nottingham 1995 - A	1/21	3/23	0.38	[0.05, 2.87]
Nottingham 1995 - L	1/21	3/23	0.38	[0.05, 2.87]
Nottingham 1996	0/15	0/15	1.00	[0.00, 0.00]
Nottingham 1997	6/53	14/58	0.42	[0.16, 1.11]
Vancouver	0/20	0/20	1.00	[0.00, 0.00]
Total (95% CI) **Chi-square p =1.21**	**33/185**	**49/194**	**0.57**	**[0.33, 0.98]**

The pooled data showed a modest improvement of 9 points for the treatment group on the 66 point Nottingham EADL score at the three month follow up (Table 3). However the individual trial results ranged from -3 to +15.

Table Three: Systematic Review: Nottingham EADL Score (by three months)

Study	Treatment n	Treatment median score	Control n	Control median score	Median difference
Cardiff					
Nottingham 1995 - A	20	25	21	28	-3.00
Nottingham 1995 - L	21	35	21	28	+7.00
Nottingham 1996					
Nottingham 1997	43	24	43	9	+15
Vancouver					
Total	**84**		**85**		**+8.6**

Improvements in the Nottingham EADL scores were not so noticeable at the end of follow-up when the equivalent median difference in score showed an improvement of 2 points out of 66 and a range of individual trial results of -3 to +9.

Discussion

The effectiveness of home based occupational therapy for stroke patients remains uncertain. However this small systematic review does indicate a potential reduction in death/deterioration and improved function in those groups of patients that received home-based intervention. This improvement in outcome may not be sustained over time as improvement was more apparent at three months than at the end of follow-up.

These results should be treated with caution however as they are based on incomplete sets of data and small study sample sizes. The total median Nottingham EADL scores may have been distorted by a lack of data in two trials (191,137). The current trials are heterogeneous, examining different interventions in a variety of patient groups at various intervals after stroke and the definition of deterioration also differed between the trials. This highlights a need for further research and for researchers to use common trial protocols and outcome measures to facilitate more accurate systematic analyses.

A comparable systematic review of physiotherapy after stroke (195) noted that there is a potential bias in rehabilitation trials where the outcome assessor is aware of the treatment the patient has received. Bias, they suggest can also occur where patients are not all accounted for at the end of follow-up in an "intention-to-treat" analysis. All the trials reviewed demonstrated evidence of "blinded assessment" and accounted for all the patients who entered their trials. This would suggest that improvements in function and reduction in death/institutionalisation are a result of the intervention and not a consequence of patients dropping out of the trials.

This small review appears to support a role for home-based occupational therapy in stroke rehabilitation but indicates a need for further evidence. The review also provides useful information on which to base a future sample size calculation.

SUMMARY - KEY POINTS

- Stroke is a major cause of disability in Britain. It effects motor, sensory, cognitive and perceptual skills and has an influence on the psychological health and the occupational performance of individuals. It places a burden not only on the stroke survivor but on carers and wider society. Stroke survivors face additional environmental barriers such as poorly co-ordinated statutory services, a lack of support for informal carers, economic restrictions and badly designed architectural environments. All these cause further restrictions to the lifestyle of survivors and reduce quality of life.

- Current stroke care services face the challenge of meeting the on-going and psychosocial needs of stroke survivors and their carers. The efficacy of home-based intervention remains inconclusive but would appear to improve function.

- A review of home-based occupational therapy indicated a positive effect on patients short-term outcomes and appears to support the role of home-based intervention. However the review also highlighted the need for further evidence in the form of well designed randomised controlled trials.

CHAPTER TWO

A PILOT STUDY: ESTABLISHING A NEED FOR A HOME BASED OCCUPATIONAL THERAPY SERVICE

Chapter Two

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Chapter Two

Clinical observation and anecdotal evidence suggested that stroke patients at the Glasgow Royal Infirmary (GRI) were experiencing similar occupational performance problems and environmental barriers as described in the literature review. The potentially positive effect of home based occupational therapy indicated by the literature appeared to justify the setting up of a pilot study to investigate the need for a home based service for stroke patients discharged home from the GRI. The pilot study was carried out as part of a Chief Scientist Office (Scottish Office) research training fellowship and took place between the 4/10/95 and the 20/12/95.

2.1 AIMS OF THE PILOT STUDY

- To describe the experiences of stroke patients discharged home from hospital.
- To pilot the research design of a randomised controlled trial (RCT) of home based occupational therapy for stroke patients discharged home from hospital.

2.2 PRIMARY RESEARCH QUESTIONS

1. Do patient outcomes deteriorate after discharge?
2. What types of outcome are important to patients?
3. Is the proposed RCT of home based occupational therapy a valid and justifiable project?
4. Is the research design of the proposed RCT practical and appropriate?

2.3 PLAN OF PILOT INVESTIGATION

Research methods can be categorised into two approaches (189);

1. Observational in which the researcher observes a population or a group of patients. The researcher may only use data that is already available or may collect further data from interviews or datasets such as death certificates.

2. Experimental in which intervention is performed as a result of planning by the researcher. The researcher attempts to manipulate a variable (the independent variable) in order to assess the effect on another variable (the dependent variable).

During the pilot project an observational approach using qualitative and quantitative research methods was adopted:

- Qualitative methods examine the meanings of individuals' experiences and actions within the context of their social environments (196) and data is usually descriptive and based on language or pictures described by the investigator. This is analysed to generate theory, which explain social phenomena in its natural setting (197). Examples of observational qualitative methods include in-depth interviews, focus groups and diary keeping (198).

- Quantitative methods involve the systematic collection of facts from which a hypothesis can be tested and generalisations made (199). Quantitative methods acquire data that is numerical and can be statistically interpreted in order to support or reject the hypothesis. Examples of observational quantitative methods include surveys and cohort studies.

It has been suggested that not all the questions asked in medical research can be addressed by experimental quantitative methods (191,200). It was for this reason that an observational approach using both qualitative and quantitative methods was used to build a wider picture of both quantifiable answers as well as the meanings and experiences of the research participants. This could then be used to inform the aims and design of the main experimental study.

Several research methods were used during the pilot study and will be described as:

- The patients perspective - A quantitative observational cohort study
  Qualitative in-depth interviews and focus group

- The occupational therapy perspective - A qualitative professional focus group

2.4 THE PATIENTS PERSPECTIVE - AN OBSERVATIONAL COHORT STUDY

In an observational cohort study, a group of patients is observed over a particular period of time and any changes that occur during that time are recorded (189). This small pilot study used a longitudinal design in which patients were followed up for 6 weeks after discharge.

Recruitment

Over a period of six weeks, six patients out of the one hundred and two referred to the hospital occupational therapy service were recruited into the study. Patients suitable for the pilot study were identified through the GRI stroke register. The proposed criteria for the randomised controlled trial was used and eligible patients were those admitted with a clinically diagnosed acute stroke, who had received in-patient occupational therapy and lived within the GRI catchment area. Patients being discharged to institutional care and those considered inappropriate for further rehabilitation (e.g. those with terminal illness, gross cognitive/ communication disorders or a complete return to pre-stroke status) were excluded. Decisions regarding appropriateness were based on the view of the multi-disciplinary team managing the patient at the time of discharge. It was noted that sixty-six of the sampling population had no discharge date during the recruitment period and would have been considered if more time had been available (Table 4). Ethical permission was obtained from the GRI ethics committee. The signed consent forms and procedure were piloted as part of the cohort study.

Table Four: Pilot study: Recruitment of Patients from In-patient Occupational Therapy

Outcome at time of recruitment	Number of patients	%
Deceased	5	5%
Discharged to institutional care	8	8%
Not diagnosed with stroke	10	10%
Discharged out of catchment area	1	1%
Returned to pre-stroke functional level	2	2%
Home-based therapy inappropriate	3	3%
Refused consent to pilot study	1	1%
No discharge date at time of recruitment	66	65%
Recruited to study	6	6%
TOTAL	**102**	**100%**

Data Collection

Data were collected on baseline patient characteristics and included age, gender, deprivation (153), date of stroke, date of discharge home, carer details, severity of stroke - Modified Barthel Index (201) at 7-10 days post admission and dependency levels at discharge - Oxford Handicap Scale (202). Relevant problems influencing the assessment were noted. All the assessments were carried using four face to face, structured interviews:

- Measurement 1 - (baseline) - collected 2-3 days before discharge.
- Measurement 2 - at one week after discharge home.
- Measurement 3 - four/six weeks after discharge home
- Measurement 4 - independent assessor, 5-6 weeks after discharge at the stroke clinic.

The measurements consisted of standardised outcome measures selected for their reliability and validity and aimed to measure occupational performance (self-care, productivity, leisure activities) and quality of life. All the measurements were used in the main study and are described in greater depth in chapter three. The outcome measures used were:

- Self-care - Modified Barthel Index (201)
- Outdoor mobility / productivity / leisure - Nottingham Extended ADL Scale (187)
- Patients perception of occupational performance - Canadian Occupational Performance Measure (COPM) (203)
- Quality of life - Dartmouth COOP Charts (204)
- Readmission
- Patients were asked if they would cope at home and on services provided since discharge.

Patients were asked to answer all the questions based on their current functional status with the exception that while in hospital patients were asked to predict their function for those activities they had not attempted in hospital. The utility of the interview schedule was noted through assessor observation and patient feedback. A questionnaire was given to the hospital occupational therapist responsible for each patient. This consisted of questions on discharge arrangements and possible barriers to recovery. At the stroke clinic patients were asked to complete a short audit sheet consisting of questions about the occupational therapy service. Data was collected on mileage, workload and resources needed to set up an intervention service.

Analysis

Descriptive statistics were used because of the small sample size and included:

1. A description of the characteristics of the sample group.
2. The serial changes in outcome between measurement 1, 2, 3, 4 for each patient.
3. Inter-rater reliability between the research occupational therapist and independent assessor: a comparison of measurement 3 and 4.
4. Practicalities of patient recruitment and use of chosen outcome measures.

Results

The sample were male with a mean age of 70.83 (SD 8.4, range 58-82). Five lived with a spouse and one lived alone. The sample group had spent a mean of 34 days (SD 30.72, range 14-98) in hospital. At the time of recruitment, three demonstrated slight disability, one moderate disability and one moderately severe disability on the Oxford Handicap Scale. The patients lived in predominantly deprived areas. Measurement 4 was not completed for patient five as he did not attend the stroke clinic.

Discharge questions

Four of the six patients anticipated that they would manage well/okay once at home, one patient did not know and only one felt they would cope poorly. The majority of patients reported that they were coping once at home.

Modified Barthel Index

Patients described increases and decreases in function as measured by the Modified Barthel Index (BI). The median score showed small variations between measurements and the IQR was at its widest one week after discharge. The ceiling effect of the BI was noted. (Table 5)

Table Five: Pilot Study: Total Modified Barthel Scores

	Measurement 1	Measurement 2	Measurement 3	Measurement 4
Median Score	18	19	18	20
IQR	18 - 20	14 - 19	17 - 19	18 - 20
Range	11 - 20	12 - 20	14 - 20	18 - 20

Nottingham Extended Activities of Daily Living

Patients described a decline in Nottingham Extended ADL score immediately after discharge (Table Six) with the final assessment remaining lower than the anticipated score given before discharge. This decline after discharge was observed in all the three areas of the outcome measure - mobility, domestic and leisure activities. Some variation was observed between assessors at measurement 3 and 4.

Table Six: Pilot Study: Total Nottingham Extended Activities of Daily Living

	Measurement 1	Measurement 2	Measurement 3	Measurement 4
Patient 1	13	5	12	13
Patient 2	9	5	5	4
Patient 3	11	8	6	8
Patient 4	16	8	10	13
Patient 5	1	1	2	-
Patient 6	17	8	15	8
Median	12	6.5	8.3	8
IQR	9.5 - 15.25	5 - 8	5.25 - 11.5	8 - 13
Range	1 - 17	1 - 8	2 - 15	4 - 13

Canadian Occupational Performance Measure

The median change in performance score was observed to decrease one week after discharge but showed an increase before the clinic (Table seven). However patients reported to be satisfied with their occupational performance after discharge but this trend was not maintained at the pre-clinic measurement. Change in performance and satisfaction scores were obtained by subtracting the individual scores at measurement 2, 3, 4 from each individual's baseline score and calculating the median score for each measurement point. Inter observer variation was observed between measurement 3 and 4.

Table Seven: Pilot study: The Canadian Occupational Performance Measure

	One week after discharge	Before the stroke clinic	At the stroke clinic
COPM median performance score (IQR)	-0.32 (-0.54 - 0.05)	0.41 (-0.12 - 1.11)	0 (-0.1 - 1.12)
COPM median satisfaction score (IQR)	0.83 (0.33 - 1)	0.12 (0 - 0.89)	0.83 (0.71 - 2.06)

COOP Charts

The scores of the individual COOP charts varied and no clear trends were observed, demonstrating a variety of functional health experiences.

Community service provision

Patients reported a variety of experiences of service provision after discharge home. The service most commonly received by patients was homehelp. The services requested at discharge which had still not been received at the stroke clinic included GP, community occupational therapy, and speech and language therapy. By the time they attended the stroke clinic patients had received more pieces of adaptive equipment than requested but had received less adaptations to the home environment and wheelchairs than planned by the hospital occupational therapist.

Practicalities of the cohort study

- A minimum of two contacts per week were needed with hospital occupational therapist and recruitment was difficult from the busy medical wards and during staff leave. It was acknowledged that some patients might be missed. Hospital staff did not always identify patients with minor symptoms although during assessment these patients did describe functional problems. No other problems were identified with the study selection criteria.

- Patients understood the consent documentation and process and were positive about the layout, content and length of the measurement questionnaires. Each assessment took approximately forty-five minutes to complete. Several patients found the COPM scoring difficult. Patients with expressive dysphasia were able to complete the measurements and used visual prompt cards successfully. The hospital occupational therapy discharge form was too lengthy and the Barthel Score post-admission was not consistently taken. The stroke clinic service audit form was abandoned because it lacked sensitivity.

- Difficulties were noted in the inter-rater reliability of some of the cohort outcome measures. The Barthel Index appeared reliable and score variation was less than the 4/20 points described by Collin et al (205) as indicating 'real' change in function. Reliability was reduced on the Nottingham EADL and the COPM, as the scores of some patients indicated clinically significant differences between assessors (203,206). It was decided that structured, written measurement guidelines would be used in the RCT. The different assessment environments (e.g. hospital versus home) and the presentation of the assessor may have influenced patient response and resulted in variations between the assessors. It was felt that future assessments should be carried out by a single independent assessor in the patient's home.

2.5 THE PATIENTS PERSPECTIVE - INDEPTH INTERVIEWS AND FOCUS GROUP

In-depth patient interviews and a focus group were used to allow patients to describe their "stroke experiences" and provision of statutory services in their own terms.

The use of multiple methods in qualitative research is called triangulation in which evidence is obtained from a range of independent and different source (207). In-depth interviews involve longer and more extensive discussion and are useful for handling sensitive topics and exploring issues in greater depth (198). Focus groups are a form of group interview that uses communication between the group members to generate data. Focus groups are a quick and resource efficient way of gathering data from several people simultaneously (198,200) and it was hoped that the group dynamics might produce more creative and novel views than one to one interviews (200,207).

Patient Interviews

The first three patients (Appendix B) recruited into the cohort study were selected for interview, all needed to have intact verbal communication. There was no intention to select patients typical of a stroke population: they were individuals who were willing to share their unique experiences. The sample size was limited by time restrictions of the pilot project. Participants were all male and interviewed at home immediately after measurement two of the cohort. Carers were present and each thirty minute interview was recorded using a Dictaphone. Spontaneous discussion was encouraged during the interviews and I tried to remain neutral during the interview and confirmed my understanding by reflecting back information to the participants. The following topics were discussed using open-ended questions:

- Discharge - The best and worse things about coming out of hospital
- Stroke experience - A description of stroke experiences
- Recovery -Recovery since stroke, changes in lifestyle, additional support systems.

Analysis

The interviews were transcribed from tape and analysed using a coding strategy developed from the text. Each interview was analysed separately and the data were combined. Words and groups of words with similar themes were grouped into categories/sub-categories and recurrent themes were highlighted (207). A more detailed analysis can be found in Appendix B. The following categories/ themes were selected:

Inpatient care: Patients described criticisms and positive aspects about their in-patients. Practical aspects of care were important to patients, they wanted a comfortable hospital environment and for staff to be friendly, competent and informative. Traditional acute medical roles such as doctors and nurses were readily identified with staff controlling decision making. There was a lack of description of the purposes of rehabilitation and the focus on therapy and the role of therapist were less dominant.

Discharge: All the patients wanted to leave hospital. Home was viewed as a more realistic environment and difficulties about returning home were associated mainly with practical arrangements. This period of change appeared to generate a mixture of feelings with patients describing happiness, relief, uncertainty, humiliation and insecurity about abilities.

Stroke experience: All the patients used negative words and at times strongly emotive words to describe their stroke experience. Stroke was seen to effect all areas of life including physical, mental, emotional and relationship aspects.

Recovery: All the patients were able to identify improvements in function and suggested that recovery was progressive and would take time. None however felt they had returned to their previous health state and all described problems. The patients continued to experience problems as well as recovery once at home.

Patient Focus Group

Members of the focus group were volunteers recruited from a physiotherapy stroke exercise class. Class members needed to be mobile, have an interest in keeping fit and have a physical impairment due to stroke. The class was supervised by a physiotherapist, had no age or geographical restrictions and did not offer transport. Two female therapy researchers facilitated the group. One was known to some of the group as a research therapist and the other was in uniform, co-ordinated the exercise class and had recruited the group members. The focus group took place after an afternoon exercise session in a small room containing technical equipment. The participants sat close together on upright chairs and a static video camera was set up in the corner of the room. The researchers stayed within the semi-circle of the group and the discussion lasted approximately ninety minutes.

The group consisted of seven men who had met each other at least twice before the discussion, some had known each other for several years (Appendix C). All lived with a carer, were unemployed or retired and their age ranged from 30 to 70 years. One group member left during the discussion.

The group discussion was facilitated by a structured plan (Appendix C) and the researchers attempted to remain neutral, used probing and open ended questions and reflected back information to the group to check for correct interpretation. Group members were encouraged to interact and to achieve a group consensus at some points during the discussion.

Analysis

The video was transcribed and analysed using a coding strategy developed from the text and influenced by the topic subject areas. Both researchers analysed the data independently and then brought their coding strategies and interpretations together for confirmation or rejection. The final analysis was formed from the consensus between the two researchers. The themes that were highlighted in the patient focus group were also compared with the analysis of the one-to-one patient interviews.

A summary of the consensus categories and themes developed by the researchers are now described and a more in-depth analysis can be found in Appendix C.

Living with a stroke: It was agreed that stroke affected everybody differently but psychological difficulties after stroke appeared to be a common experience for the majority of group members. The word loss was used frequently by the group. Patients viewed their stroke as affecting many different inter-relating aspects of their lifestyle and they mainly described their experiences using negative terms. The group selected seven stroke experiences as having the most effect on life and placed them in the following order of importance: loss of confidence, not being able to do things the same, frustration, changes in personality, depression, physical change and fatigue.

Living with a stroke was coded using the following sub-categories:

a) Emotional Experiences: Emotional difficulties were discussed frequently, these included loss of confidence, depression, low mood, feelings of annoyance, lack of motivation, personality change and disinhibition. Emotional difficulties were linked with a changed in interactions with others and social isolation.

b) Physical / cognitive experiences: Many of the group members described physical and cognitive changes. These included loss of fitness, power (strength), abilities, speech, eyesight, hearing, fine movements, sensation, physical shaking, slower reactions, not able to think/ understand, reduced orientation, brain damage, loss of energy.

b) Occupational Performance Experiences: Changes in occupational performance were described in general terms and included work, specific lost abilities included squash, playing the piano, driving, dexterity, work, money difficulties and playing sports. The group summarised these activities into "not being able to do things the same."

d) Recovery experiences: The group described two recovery themes. Permanency of brain damage versus improvement of problems through recovery of function and adaptation to disability.

Group members had mixed views about the future. Some believed their choices were influenced by external forces such as disability policy, lobbying by disabled rights campaigners, local government resources, the lottery fund and stroke research. Other group members described internal influences on future choices such as self-determination. The two youngest group members were more negative about the future.

Support after discharge: The formal support systems in the community described by the group appeared to be scant and inaccessible. Formal support systems included bathroom adaptations by social services, the GRI stroke clinic, GP support, the physiotherapy exercise class, Welfare Rights Officer, Chest, Heart and Stroke (CHSS) Groups. Difficulties accessing services were described including feelings of abandonment, having to fight for support, ineffective social work/DHSS involvement and restrictions due to communication problems. The voluntary services and informal systems of support seemed to be more effective at meeting the groups needs. Group members were more positive about the support provided by the voluntary organisation CHSS and the idea of a stroke co-ordinator/ advocate was suggested. Some group members felt you needed to get on and do things yourself and that informal support was mainly provided by the family.

2.6 DISCUSSION OF THE PATIENTS PERSPECTIVE - COHORT STUDY, INTERVIEWS AND FOCUS GROUP

These small pilot projects support the view that discharge is a critical stage in rehabilitation (67,68,74,88,90). As in the studies of Drummond (58), Kettle and Chamberlain (61) Greveson and James (39) all the participants in the cohort study despite having slight/moderate disability reported functional difficulties after discharge particularly in extended activities of daily living. Many of the patients did not receive services and adaptations recommended at discharge. Psychosocial difficulties and reduced quality of life after stroke were reported in the COPM, qualitative interviews and focus group and supported the Stroke Association (74) view that patients often felt inadequately prepared to return to the community. The pilot indicates that functional and emotional problems are important to patients and that new methods of service provision are needed to address these issues. The follow-up of patients from hospital into the community would seem justifiable and might help to solve problems experienced by patients particularly at discharge.

In the qualitative projects the men recently discharged described a hospital environment in which they were "looked after" by staff whereas the members of the focus group who had been at home for longer, described situations where they were able to make decisions about their own lives. It may be more appropriate to rehabilitate stroke survivors once medically stable within the familiar environment of their own homes where they have more control of decision-making. Jongbloed and Crichton agree that an equal partnership between client and therapist is more easily achieved in the clients home rather than in a hospital setting (22). The patient pilot studies were too small to draw reliable conclusions and the sample groups were not very representative of the GRI stroke population. However they did describe the function and the views of some men living in the east of Glasgow, six of whom had been recently discharged from hospital and seven who had experienced a stroke within the last seven years. The sample was all male and it was felt that the lack of female representation influenced the NEADL, a concern described by its authors (187). Sampling could have been improved by setting up a quantitative trial with a larger and more representative sample from the stroke population or by using theoretical sampling (208) in a more vigorous qualitative study.

As with all qualitative methods the researchers and research environment were an integral part of the research process. I was aware of my lack of research experience, which may have influenced the discussions. I am female, non-disabled, younger than the male participants and was introduced as a therapist and representative of the trust. All these factors may have influenced the responses of the participants and previous studies have noted that recipients of health care are often reluctant to criticise (198). The focus group took place within a busy teaching hospital and consisted of established relationships and this may have influenced responses with some group members feeling inhibited. The overall qualitative analysis was strengthened by data from the cohort study and current stroke literature. The credibility could have been further improved by presenting the analysis to the patients for confirmation.

It was noted that the in-depth interviews and the qualitative analysis were labour intensive. The qualitative pilot data was informative but the methods were felt to be time consuming and not possible for to include within the structure of a randomised controlled trial. As a mixed qualitative and quantitative approach for the main study was felt to be advantageous, the qualitative part of the project was handed over to a colleague.

2.7 THE OCCUPATIONAL THERAPY PERSPECTIVE - A FOCUS GROUP

The final piece of pilot work consisted of an occupational therapy focus group. The purpose of the group was to inform the planning of a home based occupational therapy intervention that integrated with local occupational therapy services, was consistent with normal occupational therapy practice and attempted to meet the needs of stroke survivors.

All the qualified occupational therapists involved in treating stroke patients at the Glasgow Royal Infirmary Trust were invited to attend a focus group. Four volunteered and the remaining two were on annual leave. All had worked in the Trust for over a year, knew each other and consisted of head, senior and junior grades. The group moderator was myself - a senior occupational therapist experienced in stroke rehabilitation and known to all the group members. As moderator I tried not to offer opinions but used probing questions to expand the discussion. The group discussion lasted sixty minutes and was held in a quiet treatment area. The group members sat in semi-circle around a table, the discussion was recorded using a static video camera. The group started late and one member had to leave before the end of the discussion.

Group objectives

1. To define a post-discharge home based occupational therapy service for stroke patients.
2. To discuss the practical implications of providing the service.
3. To discuss the integration of the proposed service with existing occupational therapy services.

Group discussion

Group members were aware of the group objectives, encouraged to be as open and confidentiality was emphasised. The proposed research service was presented as aiming to enhance the present service not compete against it. The discussion followed a structured plan. This was based on the group objectives and can be found in Appendix D.

Analysis

The analysis was carried out using the same methods as the patient interviews and focus group. A summary of the analysis was circulated to all the group members and confirmation of trustworthiness was sought. The aim of analysis was to produce descriptive information that could be used to plan and give direction to the proposed research service. A more detailed analysis can be found in Appendix D and a summary containing the categories and sub-categories are described below:

Beliefs

Throughout the discussion reference was made to beliefs. These will be described first as they appeared to influence the groups views on the proposed home based service. Beliefs was sub-categorised into:

a) The effects of stroke - Stroke was presented as a negative health experience which brought lifestyle changes such as shock, reduced confidence, outdoor mobility and social activities.

b) Discharge - The hospital environment was described as "protective," a "cacooned environment," which "shielded" patients from the difficulties of managing at home, created "learned helplessness", restricted patients from achieving independence and resulted in some stroke patients denying long term lifestyle changes in their desire to return home. Discharge was viewed as an isolating and a difficult time of change, with patients needing to "come to terms" with difficulties and requiring time to adjust to home. One group member suggested that hospital based intervention might not be adequate to prevent difficulties at home.

c) Occupational therapy - Occupational therapists were described as autonomous professionals and case managers. Patients were felt to have the ability to change their lives and the therapeutic relationship was viewed as a positive means of helping patients progress. Two group members felt that handing back control to the patient was a goal of rehabilitation, included "facilitating" and "collaboration". This process was felt to be difficult to achieve in the hospital environment due to its medical emphasis. Multiple factors were felt to influence the success of rehabilitation - patient motivation, the therapist/patient relationship, the presence of carers, service resources, environment and the extend the patient took responsibility for their own lives. Intervention was viewed as a holistic process involving carers and environmental adaptation as well as physical treatment. It was not viewed as structured and prescriptive but "adaptable" and "flexible" and dependent on the needs of the patient

Setting up the service:

The group supported the need for an additional service to treat stroke patients at home and assist with community integration, this was not felt to be met by present services. Present out-patient services were felt to be limited in their ability to deal with community issues, lacked client-centredness and their sparseness was felt to cause functional deterioration, created isolation and prevented patients from reaching their full potential. It was anticipated that a home based service would be more flexible than current social services occupational therapy services which were described as "disintegrated" and "prescriptive."

Aims of the new research service:

a) Bridge between hospital and home - supporting patients through discharge, a continuation at home of the goals identified in hospital and a link with community services.

b) To provide a realistic service that is relevant to patients needs - The home was viewed as a more realistic environment to treat stroke patients, achieve a client-centredness approach and facilitate integration back into the community.

c) To provide treatment as well as equipment provision - the new service should do more than provide equipment, it should involve assessment and treatment.

Service operation

- Who should provide the service? - hospital occupational therapist and occupational therapy assistants.
- Where should the intervention occur? - the home and the community e.g. visiting the shops, going for a walk, doing a leisure activity.
- When should the intervention happen? - No consensus was reached on when to start the service. Suggestions ranged from starting on day of discharge to avoid crisis, to a week after discharge to allow patients' time to adjust to life at home. All agreed that the service needed to be slowly withdrawn, possibly once the community services or day hospital services were established or when the plans from the in-patient homevisit had been carried out. The time scale varied from two to six months.
- How should the intervention be carried out? Using flexible, graded, individualised structured programmes to continue hospital intervention and establish new goals. Links between the hospital and home based service could be maintained through joint home programmes, handover of patients' notes and joint therapy/homevisit sessions.

- What should the intervention consist of? - Assessment, motor relearning, maintaining activities of daily living, upper limb programmes, vocational advice, activities outside of the house, leisure activities, using community resources, joint work with community staff, provision of education/information, patients/carers support, environmental change.

Potential limitations

These included resource limitations such as staffing, the time consuming nature of community intervention and the lack of specialist rehabilitation facilities. It was suggested that the day hospital with its access to the multi-disciplinary team might be more appropriate for some patients. Role conflict with other professionals such as the liaison health visitors and the bureaucracy of community services were discussed. These limitations were not presented as insurmountable and the group did offer some solutions such as increasing staffing levels and decreasing in-patients caseload, using relevant, realistic local community resources and building links with the day hospital.

Discussion

This focus group represented the views of therapists working with stroke patients at the Glasgow Royal Infirmary Trust and not the views of occupational therapists in general. The limitations in representation were not felt to be significant, as the purpose of the group was to determine local views on service delivery in order to plan the home based occupational therapy research intervention. Transferability and credibility could have been strengthened by running a variety of focus groups to challenge or support the interpretations (e.g. including community occupational therapists, other professionals, patients, carers) or by using triangulation to confirm the emerging theories (e.g. interviews with therapists, a national postal questionnaire).

The group appeared to function in an open atmosphere with all the group members contributing to the group discussion. The senior staff did initiate more discussion. This might suggest a hierarchy within the group and a higher representation of junior staff may have evoked different discussion. The group was representative of the local service which promotes stroke rehabilitation as a speciality and has a high proportion of senior occupational therapy staff.

The group suggested that discharge was a significant time of adjustment and the belief that stroke patients adjust psychologically by progressing through denial to acceptance has support from some theorists (209,210). However Oliver (17) and Finkelstein (211) warn against making assumptions suggesting that a great deal of variability exists in individuals reactions to negative life events. The views expressed by the focus group may reflect current professional/cultural beliefs and not those experienced by patients (17,21).

A client-centred approach in which "control was given back to the patient" was mentioned at several points during the discussion. The interest in this approach reflects a growth in the belief of client-centred practice within occupational therapy and represents current debate within the profession (24,212-214). The group supported the idea of client-centred care but this appeared to conflict with the discussion on service provision which was therapist controlled. This apparent conflict of views may reflect the difficulties of implementing client-centred practice within a medically dominated health care system (22,212,214) in which some theorists propose that patients are "looked after" by staff who make decisions for them (17,22,215).

The intervention described is similar to that described in recent home based occupational therapy studies (136,137,190,193) and the ideas expressed about the uniqueness and complexity of the individual, the therapeutic relationship and the process of occupational therapy are supported by current occupational therapy theories and models of practice (24,76,119,165).

The focus group appears to support the view (93,129,147) that stroke patients would benefit from community rehabilitation services and that home is a realistic environment to address the on-going psychosocial needs of patients. Views about the integration of the research service with existing community and out-patient services were unclear and this apparent confusion may reflect the lack of co-ordination of present service provision documented in the literature and the division between acute and community services created by current political policy (140-143).

Several influencing factors should be considered when reviewing the analysis. The presence of myself as researcher may have encouraged compliant or conflict avoiding responses from the group and my direct involvement in planning the research service will have influenced the interpretation of the data. I tried to remain aware of my biased position, minimised my contributions and used my informed position to understand the discussion. A lack of neutrality was unavoidable and is often adopted in action research when the researcher and the participants collaborate in cyclical process of investigating a problem, determining the solution and reviewing the change (200). I circulated the analysis to the group to confirm interpretation and establish some trustworthiness and a second focus group could have been held after the intervention stage of the proposed research study to evaluate changes in the service delivery and complete the action research cycle. Involving a second person to audit and confirm the data interpretation could have strengthened dependability of the analysis.

The findings of this single focus group can only be applied to the Glasgow Royal Infirmary Occupational Therapy Service. However, interesting ideas about developing a home based service for stroke patients were expressed and the underlying beliefs of the occupational therapists were explored. The occupational therapists identified a need for the proposed service and the aims and many of the service operation proposals developed in the focus group were used to set up the research service.

2.8 SUMMARY OF THE PILOT STUDY - KEY POINTS

- This small pilot study supports the view that patients discharged home from the GRI continue to experience problems in function and in accessing community services. The cohort study described problems in activities of daily living and the patient interviews and focus group highlighted psychological difficulties.

- The occupational therapy focus group supported the need for a home based stroke service and advocated the home environment as an appropriate environment in which to continue rehabilitation. The group suggested aims and characteristics of a home based service.

- The cohort study demonstrated that the proposed design of a randomised controlled trial of home based occupational therapy was feasible and practicable and recommended that clear structured guidelines would improve the reliability of the proposed outcome measures.

- This small pilot project indicated a need at the Glasgow Royal Infirmary to investigate the effect of a home-based Occupational Therapy Service on supporting stroke patients through discharge and addressing their occupational performance and psychological problems once at home.

CHAPTER THREE

HOME BASED OCCUPATIONAL THERAPY FOR STROKE PATIENTS DISCHARGED HOME FROM HOSPITAL - A RANDOMISED TRIAL

Chapter Three
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Chapter Three

3.1. INTRODUCTION

Evidence from the literature review and pilot work was felt to justify the setting up of a research project to evaluate a home-based occupational therapy service for stroke patients at the GRI. The current occupational therapy service at the GRI lacked an outpatient service for stroke patients, providing an opportunity to pilot a new community based intervention. It was hoped that this study would contribute to the growing body of stroke rehabilitation research and provide further evidence to assist decision-making by occupational therapists and therapy service purchasers. A research proposal was submitted to Chest, Heart and Stroke, Scotland and funds were awarded to carry out a two year study. Additional financial support was also provided from the Glasgow Royal Infirmary University NHS Trust.

3.2. HYPOTHESIS

The hypothesis was that a post-discharge home based occupational therapy service would be more effective than present occupational therapy practice in improving outcome of stroke patients discharged home from the Glasgow Royal Infirmary University NHS Trust. (GRI)

The study set out to address the following questions:

1. Does the intervention of a short post-discharge home based occupational therapy service improve the outcome for stroke patients discharged from hospital?
2. Which outcomes (if any) are most affected by the intervention?
3. Which patients (if any) benefit from the intervention?
4. What are the resource implications of setting up a post-discharge home based occupational therapy outreach service.

3.3. PLAN OF INVESTIGATION

An experimental quantitative approach was used and a randomised controlled trial (RCT) design was selected for the study. Randomised controlled trials are used to study the effects of healthcare interventions and aim to provide evidence in support of or against a form of treatment compared to no treatment or another form of treatment (216). This is achieved by comparing two (or more) groups of patients: in one (the treatment group) the intervention under investigation is used and is compared with no treatment or with another package of treatment which is the same except for the factor which is being studied (the control group) (217).

Selection of patients

This pragmatic study was designed to reflect current occupational therapy practice at the GRI and patients were recruited from all the occupational therapy in-patient stroke service settings. This included eight general medical wards and two care of the elderly wards at the Glasgow Royal Infirmary Site and one elderly stroke rehabilitation unit and one elderly general rehabilitation ward at the neighbouring rehabilitation hospital. Recruitment was carried out by myself (LG) and a research assistant (AA). Potential patients were identified through daily liaison with ward and therapy staff and patients were selected for the study using the following criteria:

Inclusion Criteria:

a) Patients with a clinical diagnosis of stroke as defined by the WHO (1). This was confirmed using CT scan results and when these were not available verbal confirmation from the patients doctor.

b) Patients receiving in-patient occupational therapy at the time of discharge. The GRI stroke service offers a blanket referral system and most patients in the hospital with occupational performance problems are known to the occupational therapy service. It would be this group of patients that would be targeted for a routine home based intervention if such a service was in operation.

c) Patients living within the GRI catchment area. This was selected to reflect the limitations of a normal service and represent a feasible journey time for home visits.

Exclusion Criteria:

a) Patients who did not consent to participate in the trial.

b) Patients discharged to institutional care. Patients discharged to residential or nursing home care were felt to be have different needs and require a different form of intervention compared to those discharged to a home environment.

c) Patients for who further rehabilitation were considered inappropriate. Decisions regarding appropriateness reflected the view of the multi-disciplinary stroke team managing their care at the time of discharge. This included patients with terminal illness, patients with multiple disability where stroke impairment was a minor concern, patients who had returned to their previous functional abilities and those discharged home to be nursed by relatives.

d) Patients who were unable to complete the assessments due to gross communication or cognitive disability. Attempts were made to be as inclusive as possible and patients were accepted if they were able to make consistent yes/no responses.

e) During the first eight months of the study, patients were not included if they were taking part in a randomised trial to investigate the use of electrical stimulation at the wrist in upper limb impairment after stroke. This was done to reduce the possibility of the two studies influencing one another and minimise the burden of assessment for patients.

A record was kept of all the eligible patients referred to occupational therapy including the number and reason for not recruiting individual patients to the study.

Informed consent

Once suitable patients were identified for the study they were approached on the ward and the study was discussed with them with the aid of an information sheet (Appendix E). Care was taken to explain the aims of the study, the follow-up procedure, the use of a treatment and control group, rights to withdraw and confidentiality. Carers were involved when appropriate. Patients were asked to give written consent to enter the study (Appendix F) and this was obtained in the presence of a witness.

The ethical issue of using a control group and with-holding home based occupational therapy intervention was considered. The use of a control group was felt to be just because it is not known if home based occupational therapy would be effective or who would derive most benefit. Therefore treatment needed to be allocated on a random basis. It was also made clear during the consent procedure that all patients would continue to receive conventional out patient services. The GRI currently has no home based occupational therapy services for stroke patients and therefore the study was not withdrawing an established service but providing a new pilot service to some patients. The GRI research ethical committee gave ethical committee approval.

Baseline Information

After informed consent the following patient information was collected in the week before discharge (Appendix G) from medical notes, hospital staff and the patient themselves.

Personal Information - Date of birth, marital status, presence of carer at home, gender, postcode. The postcode was used to identify a deprivation score - (DEPCAT score), a method of scoring deprivation developed by Carstairs and Morris (86). The DEPCAT scores were created by combining four variables, the proportions of the population in households without access to a car, in overcrowd households, with the head of household in social class IV of V and in households with unemployed men. Each Scottish postcode is linked with a DEPCAT score between 1 (affluent) and 7 (deprived) and represents the levels of deprivation in that geographical area, not the individuals social class.

Admission details - Date of stroke, date of admission, date of discharge.

Pre-stroke functional status - history of previous strokes, pre-stroke mobility (able to walk 200 metres outside, able to walk indoors, unable to walk without help), level of statutory support e.g. homehelp, meals on wheels, District Nurse support, employment status and pre-stroke Oxford Handicap score (202). The Oxford handicap scale was modified from the Rankin Score (101) and consists of a 5-point rating scale of overall level of independence. The scale ranges between 0 (no symptoms) to 5 (severe handicap).

Characteristics at study entry - this included site of lesion, presence of hemiparesis, hemisensory loss, visual/spatial inattention, hemianopia, dysphasia, cognitive impairment, anxiety, depression.

Baseline measurements were also taken before discharge. These included the Modified Barthel Index (201), the Canadian Occupational Performance Measure (203), the Euroquol (218) and questions on discharge expectations. The selection and content of these outcome measures will be discussed in detail under outcome measures.

Stratified Randomisation

The purpose of randomisation is to distribute evenly between the treatment and control groups any factor likely to affect the outcome. This allows eventual differences between the two groups to be attributed to the intervention under test rather than the imbalance of prognostic factors (219). It was decided to use a stratified randomisation process (207) in which gender and day hospital were represented evenly in both the control and treatment group. The influence of gender on the Nottingham Extended ADL Scale has been highlighted by the scales authors (187) and the male patients in the pilot study did appear to be reporting low levels of extended ADL activity as many did not normally carry out domestic tasks. At the day hospital patients receive out patient occupational therapy and this intervention was felt could have an influence on functional recovery.

Therefore at discharge patients were categorised as male/female and day hospital input/ no day hospital intervention. Then randomly allocated to either:

1. Conventional out-patient follow-up (control group) or
2. Conventional out-patient follow-up plus a 6 week home based occupational therapy intervention (treatment group)

A telephone randomisation system was used in which contact was made with a central office. Patients were then randomised by an independent person using serially numbered, opaque, sealed envelopes which had been prepared in advance using a computer generated (Minitab) randomisation schedule based on - 4 and 6 block random number series. The trial staff were not aware of the block sizes.

Control of bias

Andrews recommends that when carrying out a RCT: (216)

- The person carrying out the assessments should be blinded (unaware of) to which group is treatment or control
- The patient should be unaware if they are in the treatment or control group
- The person treating the patient should be unaware of which group the patient is in.

Bias within the study was therefore controlled in the following ways:

- An independent research assistant (AA) who was based on a different site to myself (LG) administered the assessments. AA was not involved or informed of the group allocation of patients. Equivalence in the assessment schedules was achieved by using standardised interview instructions at the seven weeks assessment and the six months postal questionnaire reduced the assessor bias entirely.

- During the consent procedure, patients were informed that they might be allocated to either the treatment or the control group but care was taken to present the treatment in a neutral way so as not to prejudice attitudes against the control treatment. Patients were also reassured that they would receive all the other conventional services after discharge.

- It was not feasible for myself as research occupational therapist to remain unaware of the group allocation of each patient because I was providing the intervention and I was involved in recruitment due to the geographical limitations of recruiting across two hospital sites. However all baseline assessments were carried out before randomisation.

Sample size

Trials must be carefully designed to ensure that they have sufficient power to detect a meaningful difference between the treatment and control group (189) i.e. there must be a sufficient number of people in each group to lower the probability of random error (216). Insufficient numbers may result in a type I error in which there appears to be a difference between the control of treatment groups when there is not. Or a type II error in which the results of the trial suggest there is no difference between the two groups when a difference exists.

Power calculations were based on 2 analyses:

1. Nottingham EADL scores
2. Odds of a poor outcome

1. Using the Nottingham EADL the sample size for the study was calculated using the formula: $d = \delta/\sigma$ (220)

$$d = \delta/\sigma$$

$$d = 9/18$$

$$d = 0.5$$

d = standardised difference

δ = effect size (9 points on the 66 point Nottingham EADL score)

σ = standard deviation (18 points)

The standardised difference of 0.5 was then applied to a sample size table (220). Using a 80% power it was calculated that a minimum of one hundred and twenty eight patients (sixty-four in each group) would be required to detect a nine point change on the sixty-six point version of the Nottingham EADL (187) assuming a standard deviation of eighteen points and a two sided significance level of 5%.

These calculations were based on the pilot study of patients discharged from the GRI. This indicated: an apparent drop (i.e. discrepancy between anticipated and actual level of function) in Nottingham EADL of fifteen points after discharge home. The standard deviation of Nottingham EADL scores of the patients discharged home in the pilot study was 12-18 points on the 66 point version of the scale. The systematic review reported an improvement of nine points for the treatment group on the 66 point version of the Nottingham EADL score by three months. (Chapter 1: 36)

2. Odds of a poor outcome - use of the Nottingham EADL as an outcome could not accommodate missing data due to patients death or severe illness. A second calculation was therefore based on the odds (chance) of a patient having a poor outcome (deterioration in Modified Barthel Index or death) during the study. A sample size of one hundred and twenty patients would be sufficient to detect (at 5% significance with 80% power) an odds ratio of death or deterioration of 0.4 in the treatment versus control group. This is compatible with the systematic review of previous home based occupational therapy trials (Chapter 1: 36).

Intervention

After randomisation patients allocated to the treatment group were visited by a senior one occupational therapist for a maximum of six weeks. Frequency of the intervention was at the discretion of the therapist but patients were visited on average ten times and contact was progressively reduced - five visits week 1-2, three visits week 3-4, two visits week 5-6.

The intervention was based on the service proposals discussed in the occupational therapy pilot focus group and descriptions from the trials conducted by Drummond and Walker (136,137), Corr and Bayer (190) Logan et al (193). It consisted of:

a) An assessment of the patient, the environment, carers needs and follow-up of discharge arrangements.

b) The identification of occupational performance problems (self-care, domestic, work and leisure activities) as perceived by the patient.

c) Liaison with other agencies and the use of community resources e.g. housing, dial-a-bus, community physiotherapists, district nurses, community occupational therapists, local sport facilities and stroke clubs. The handover to the GRI multi-disciplinary stroke clinic of any outstanding needs at the eight weeks clinic appointment.

d) The treatment of occupational performance problems using individualised patient goal setting and written therapy programmes. Patients were encouraged to continue with their therapy programme between visits. Examples of treatment include:

- General advice on management, positioning, normal movement, perceptual/ visual/ sensory deficits and anxiety, functional use of the upper limb.
- Discussion/practising/modifying self-care activities e.g. dressing, bath transfers, feeding.
- Discussion/practising/modifying domestic activities e.g. laundry, ironing, snack making.
- Discussion/practising/modifying community mobility e.g. using external steps, car/ bus transfers, negotiating kerbs/gradients/crowds/escalators, advice on driving.
- Discussion, practising, modifying leisure activities e.g. swimming, shopping, bowls, golf
- Discussion, practising, modifying work and voluntary activities.
- Provision or referral for equipment or environmental adaptations including wheelchairs.
- Provision of information and support for the patient and carer.

Intervention was based on the Occupational Performance Model of Practice (24) as described in chapter one and an eclectic approach was taken to treatment using physical/rehabilitative, environmental, psycho-emotional and neuro-integrative theories (119) as appropriate to solve individual occupational performance problems.

Control Group

These patients had access to conventional services (community occupational therapy, homehelp etc.) but did not receive the novel home based occupational therapy outreach intervention. The control group was followed-up by the occupational therapy service at eight weeks at the GRI multi-disciplinary stroke clinic and patients were referred to the relevant agencies in the normal way.

OUTCOME MEASURES

Measurements took place before discharge, at seven weeks (at the end of intervention) and at six months after randomisation. Warlow et al (8) suggest that six important factors should be considered when selecting an outcome measure after stroke:

- Validity. The scale should measure the aspect of outcome that it claims to measure. Validity includes criterion validity (the measure is related to an accepted gold standard), construct validity (the measure is compared to an existing measure of similar aspects of outcome), content /face validity (expert agreement that the measure is reasonable). Validity is often difficult to demonstrate.

- Reliability. This concerns reproducibility of a measurement between observers (inter-observer reliability) and over time (intra-observer or test-retest reliability).

- Relevance. The scale should measure aspects of outcome that are relevant to the patient/carer as well as the researcher. The outcome should be appropriate for the stroke population.

- Practicality. The complexity and length of assessment and method of administration should be considered. e.g. it might be more appropriate with a large sample group using a telephone questionnaire to select simple, short measures.

- Sensitivity. The scale should be able to distinguish patient groups with different outcomes or detect important changes within a particular patient.

- Communicability. The measure should be understandable to other health professionals and patients.

These guidelines were used to select the outcome measures for the study. Outcome measures were also selected if they had been used in previous stroke studies and or were being used in current research projects. It was hoped that this would allow the sharing of data with other centres such as the TOTAL project (Trial of occupational therapy and leisure) at Nottingham University (221) and contribute to future systematic reviews.

Five categories of outcome were selected for the trial (Figure III). These were:

1. Experience of discharge and maintenance at home
2. Occupational Performance (disability) - this was sub-categorised into self-care (personal activities of daily living) and productivity/leisure (extended activities of daily living)
3. Subjective Health Experience (quality of life/handicap)
4. Carer outcome - emotional status.
5. Service provision

Figure III: Summary of the trial data collection

Categories of outcome measurement	Outcome measure	A1/ A2	A3	B1	B2	C1
Characteristics		*			*	
Discharge experience and maintenance at home	Patient Discharge Questions	*		*		
	Re-admission/institutionalisation			*		*
	Discharge plan		*	*		
	Services received after discharge			*		
Occupational Performance	Modified Barthel Index	*		*		*
	Nottingham Extended ADL			*		*
	COPM	*		*		
Subjective Health Experience	COOP charts			*		
	Euroquol	*		*		*
	London Handicap Scale			*		*
Carer outcome	General Health Questionnaire				*	
Service Provision	Satisfaction with Service					*
	Expenses incurred			*		*

Key

A1/A2: Patient interview completed before discharge and the characteristics taken from clinical notes and the clinical team
A3: Questionnaire completed before discharge by hospital occupational therapist
B1: Patient interview completed at home - 7 weeks after discharge by an independent assessor.
B2: Postal questionnaire completed at home, 7 weeks after discharge by carer
C1: Postal questionnaire completed at home, 6 months after discharge by patient

COPM = Canadian Occupational Performance Measure
OT = Occupational Therapist

Experience of Discharge and Maintenance at Home

Three areas of outcome were selected to measure discharge experience and maintenance of once at home;

- Patient discharge questions
- Re-admission to hospital/institutionalisation
- The provision of equipment, adaptations and services

The discharge questions were included in the seven weeks assessment and re-admission and residency information was collected at seven weeks and six months.

Patient Discharge Questions: (Appendix H) Despite a growing interest in this field of patient care there appears to be a lack of standardised measures to examine the experience of discharge. Several recent studies have used qualitative interviews (222) or postal non-standardised questionnaires (223,224). I used short, structured questions in order to gain descriptive data about patient opinion on discharge expectation and discharge outcome. These were based on questions used by Styborn et al (225) to measure quality assurance on an elderly rehabilitation ward and Pound et al (226) questionnaire on patients satisfaction with stroke services.

Re-admission/Institutionalisation - patients were asked if they had been re-admitted to hospital and for how many days. Data was also collected on residency and death at 7 weeks and 6 months. This data was confirmed using SMR1 and patients hospital records.

Provision of equipment, adaptations and services- before leaving hospital the hospital occupational therapist completed a discharge plan for each patient (Appendix I). Patients were asked at the seven week assessment if the adaptations and equipment requested at discharge had been provided and about the frequency of statutory services since discharge e.g. homehelp, social work, community physiotherapy, primary care staff.

Occupational Performance

The earlier stages of hospital rehabilitation often focus on self-care activities whereas productivity and leisure activities tend to be addressed in greater depth within the community. It was therefore decided to measure self-care activities and productivity/leisure separately. The outcomes selected needed to be simple to use, easy to complete and the six month outcomes validated for postal use. Three outcome measures were selected:

- The Modified Barthel Index (BI) (201)
- The Nottingham Extended Activities of Daily Living Scale (Nottingham EADL) (187)
- The Canadian Occupational Performance Measure (COPM) (203),

These were included in the seven weeks and six months assessments apart from the COPM which was recorded at baseline and reassessed at seven weeks.

Self-care (Activities of Daily Living - ADL) - The Modified Barthel Index

Self-care consists of activities or tasks, which are done routinely to maintain the person's health and well-being in their environment (24). Wade (13) refers to self-care as activities of daily living (ADL) and uses the definition "basic, physical functions which underlie normal living." He suggests that ADL cover a single construct, which include excretion, mobility, cleanliness, feeding and dressing. The majority of ADL scoring systems measure the need for help/dependency on others, rather than the positive abilities of the individual.

The BI was selected to measure self-care/ADL because it has been recommended as the outcome of choice (13,227), is reported to be easily understood by different professionals (228), is simple and quick to use and has been used in other home based stroke studies (135,149,154,159,160,190,227). The Index is an ordinal scale, which consists of ten weighted self-care activities (Appendix J). Each item is rated in terms of whether the patient is able to perform the task or needs help/or is totally dependent on others. The original BI totalled one hundred points but this was simplified by Collin et al (205) giving a total score ranging from zero (dependent on all items) to twenty (independent). Collin et al (205) recommend that a change in four points on the twenty point scale is highly likely to reflect a genuine change in ADL status.

The BI was originally developed for use with neuro-muscular and musculoskeletal disorders but has also been used extensively in stroke rehabilitation research (229). Evidence exists to support the validity of the BI (57,227,229-231) and reliability (13,205,232). Wade and Collin (229) comment on its clinical utility, reporting that it is easy to use and can be used on the telephone (233,234) or by post (206,235).

The Barthel Index does have several weaknesses. Several modified versions of the BI exist which has lead to some confusion. In this study the Collins (205) version was selected as recommended by Wade (13). The index does have a marked ceiling and floor effect (13,236). This means that it is limited in its ability to detect change in very dependent or very able patients. De Haan et al (237) also commented that the BI emphasises the mobility aspect of daily living rather that upper limb function. To compensate for this shortcoming an extended ADL measure was selected for the study to complement the BI and to monitor change in more independent patients. The BI is insensitive to small differences and for these reasons it may not be the outcome of choice to evaluate an individual treatment programme but due to its utility it would appear to be an appropriate outcome measure to assess the disability levels of patient populations. Eakin (228) comments that the Index was designed for institutional use and may not be suitable for the community, however the scale has been used in previous stroke community studies and this factor was not felt to be significant. It was noted that the index is an ordinal scale with the weighting of the score based on judgmental, subjective decisions (228,238) and care was taken not to use the BI as an interval scale.

Several other self-care ADL outcome measures were reviewed but rejected for this study. These included:

- The Nottingham 10 point Activities of Daily Living scale (239). This hierarchical scale was designed specifically for stroke patients in hospital and evidence exists to support its reliability and ease of use (239). However it contains an extended activity of daily living task (making a cup of tea) which was felt to confuse the defined outcome categories and there are no published guidelines on how to score the performance.
- The Community Dependency Index (240). This scale is based on the BI but has been validated for use in the community. Although of interest, this assessment has not been used in previous stroke research, making collaboration with other projects more difficult.

- Kenny Self-care Evaluation (241). This score comprises of seventeen ADL categories including some unusual items such as bladder programme and dressing feet. This scale lacks evidence of reliability and had not been widely used (13,228).
- Katz scale (242). This scale consists of six ADL items and does not include walking. The scale was developed in the United States to provide an objective guide to the course of chronic illness (228). As mobility was felt to be an important component of ADL and due to the lack of evidence of the scales reliability (13) this scale was rejected.

Several combined personal and extended ADL outcome measures were reviewed including the Rivermead ADL Index (243), Northwick Park Index of Independence (244) and Functional Independence Measure (245) but these were felt be too long and the content too complex for use in this study. The self-care section of the Rivermead ADL Index was the only measure to have been used in previous British home based stroke trials (137,192).

Productivity/Leisure (Extended Activities of Daily Living - EADL) The Nottingham Extended Activities of Daily Living

Productivity and leisure activities have often been grouped together in outcome tools measuring extended activities of daily living (EADL) also known as instrumental activities of daily living (IADL) (246). Definitions of extended ADL vary but generally include cooking, shopping, housework, work and social/leisure activities (13,246).

The Nottingham Extended Activities of Daily Living (NEADL) was selected as the extended ADL score for the study (Appendix K) because it was easy to administer, could be used by post and has been used in previous home based occupational therapy stroke studies (190,192,193).

This ranked assessment scale consists of twenty-two activities grouped into four categories; mobility, in the kitchen, domestic tasks and leisure activities. The NEADL measures activity levels rather than capabilities and patients are asked if they are doing the activity and not if they are able to do the activity. The questions in each category were originally scored on the twenty-two point scale as either zero for with help or no, or one for on my own, or on my own with difficulty. The recommended sixty - six point scale (13) was used with the above responses. Lincoln and Gladman (247) found that the measure was sufficiently robust for the totalled scores to indicate overall independence between groups of patients and that the kitchen and domestic categories could be combined together when scoring. Evidence exists to support validity (247,248) and reliability (187) including postal use. Gompertz et al (206) in a study to evaluate reliability of stroke outcome measures recommended that a change in independence of two or three ADL activities represented a potential change on the Nottingham EADL twenty-two point scale. They discovered significant variations in test and retest scores and suggested that further refinements of the Nottingham EADL should be made. An influence of gender on the scale has been noted (187).

The Frenchay Activities Index (249,250) was reviewed but was rejected because it appeared to have weaker evidence of reliability than the Nottingham EADL (46,246), was reliant on the patient remembering their previous abilities and was not validated for postal use.

The Canadian Occupational Performance Measure - COPM

This was selected because it allowed patients to identify their own occupational performance problems at discharge. The COPM reflects the philosophy of the Model of Occupational Performance (24) and is based on the belief that the individual is a fundamental part of the therapeutic process (251). It was developed by the Canadian Association of Occupational Therapy (203) and is an individualised measure of patient self-perception in occupational performance. Using a semi- structured interview approach patients are asked to identify problems in self-care, productivity and leisure. If the patient selects more than five problems they are asked to choose the five most pressing difficulties. The patient is then asked to rate each problem using two, ten-point scales (Appendix L):

1. Performance (a self-evaluation of his/her current performance in the problem area)
2. Satisfaction (a self-evaluation of his/her satisfaction with that current performance)

A total performance score is then obtained by adding the individual performance scores for each problem and dividing by the number of problems identified. This method is repeated to obtain a total satisfaction score. At reassessment the process is repeated by using the same problems identified at the initial assessment and obtaining a new total performance and total satisfaction score. Change in performance and satisfaction is calculated by subtracting the initial total performance score from the reassessment total performance score. This method is repeated to obtain a total satisfaction score. Law et al (203) recommend that changes of 2 or more points on the COPM are important clinically. Administration of the COPM has been standardised through the use of a manual detailing methods of administration and scoring (203) and training video. The COPM by design is not norm referenced because occupational performance has been conceptualised as being individually determined.

Evidence exists to support test-retest reliability (203), content validity (252) and responsiveness to change (203,252) but the authors acknowledge that further work on reliability and validity is required (203). Trials on clinical utility of the measure suggest that some patients with cognitive/communication impairments or those unwilling to assume responsibility for change find it difficult to identify problems and priorities (252-254).

The authors suggest that carers may serve as proxies' (252). The COPM can be time-consuming and difficult to administer but despite these limitations it was felt to be useful for identifying patient priorities in occupational performance at discharge. Patients were encouraged to consider/anticipate problems they might face at home. The concerns of using the COPM across an in-patient to community setting were noted (253). This was not felt to be a major problem because one of the purposes of using the COPM was to monitor discharge experiences and evaluate if problems voiced by patients before discharge were addressed by the home based service.

Subjective Health Experience

Albrecht (255) comments that "clearly health involves something more than is captured in objective measures of morbidity, mortality and activity limitations." It was for this reason that subjective health experience was included within the battery of measures. Subjective health experience or "state of health" or quality of life of an individual remains a difficult concept to define and measure (13,46). Handicap has also been linked to the idea of quality of life (13,256). Wade suggests that quality of life refers to "a patient's reaction to the discrepancy between actual and expected achievements arising as a consequence of illness." Subjective health assessments ask people to report on their own health, illnesses and functional status. De Haan et al (46) recommends that a multi-dimensional approach should be used to assess quality of life, which should include an assessment of physical, functional, psychological and social health dimensions.

The subjective health status measures chosen for the study therefore needed to be multi-dimensional, concise, easy for patients to understand and to complement the other project outcome measurements.

Three subjective health measurements were selected:

- The Dartmouth COOP Charts (204)
- The Euroquol (218,257)
- The London Handicap Scale - LHS (256)

The Dartmouth COOP charts (Appendix M) These were developed to produce a brief, generic profile for use in General practice settings. Pictorial charts measure nine dimensions (physical condition, emotional condition, daily work, social activities, pain, change in condition, overall condition, social support and quality of life). Respondents are asked to rate themselves using the visual prompt of the charts according to how they have felt over the past four weeks. Each chart item is rated one to five points on an ordinal scale with higher scores indicating more problems. The scores are not combined to produce a total.

Evidence exists to support test-retest reliability inter-rater reliability, sensitivity to change and construct validity (204,258,259,260). Studies carried out to investigate the clinical utility reported that the COOP charts were acceptable to staff and patients (204,258,259) take about 3-5 minutes to administer, are easy to use and produce important clinical data (204).

More lengthy assessments such as the Medical Outcomes Study (MOS 36) (262), Nottingham Health Profile (NHP) (261) have been recommended for being more precise and detailed than the COOP charts (46,262). The NHP consists of thirty-eight questions covering sleep, pain, emotion, energy, social isolation and mobility and the MOS is a thirty-six item self-reporting questionnaire covering eight health states - physical ability, social activity, limitations in role activities because of physical or mental health, pain, mental health, vitality and general health perceptions. Although of value, these measures were felt to be too long and complex to administer as part of the battery of outcome measures for this study. The COOP charts were therefore selected for their multi-dimensional content, ease of use, evidence of reliability measuring outcome in community settings. The COOP charts were only used in the seven weeks assessment in order to simplify and reduce the length of the six months postal questionnaire.

The Euroquol (218) (Appendix N) This was developed as a single index, generic instrument for describing and valuing health states, with the aim of creating a compatible set of common core quality of life items that could be used in economic evaluations of health care. It was intended to complement other quality of life measures and facilitate the collection of a common data set for international reference purposes. It was designed as a simple, self-completed questionnaire and can be used by post. The five dimensions each with three levels of the scale include mobility, self-care, usual activities, pain/discomfort, anxiety/depression and a visual analogue scale on which patients rate their own health between zero to one hundred. Patients are asked if their general health today is better, much the same or worse than their general level of health over the last 12 months. Some evidence exists to support test-rest reliability (46) and validity (218,257). This Euroquol was included to assist economic analyses.

The London Handicap scale (Appendix O) this outcome tool was developed to measure disadvantage in mobility, physical independence, occupation, orientation, social integration and economic self-sufficiency. It is based on the WHO definition of handicap (12). The scale consists of a questionnaire with six questions representing the six domains noted above. Each question has a six point hierarchical scale of disadvantage in a self-completion format. The scores for each domain are given in a matrix and can be combined into an overall handicap score ranging from one (no handicap) to zero (maximum handicap) using a simple formula.

Evidence exists to support validity and reliability and the scale correlates with other outcome measures such as the Nottingham Extended ADL and Barthel Index (256). The LHS was found to be easy to administer by post (256) and was selected for its utility and to complement the COOP charts by providing additional information on disadvantages in mobility, self-care, orientation and economic self-sufficiency.

The Reintegration to Normal Living Index (263) (RNLI) was considered as an alternative to the LHS. This was rejected because the LHS was felt to be more comprehensive, easier to complete and a further battery of visual analogue scales was felt to be burdensome to patients.

The General Health Questionnaire (264), Hospital Anxiety and Depression Scale (265) and the Wakefield Self-assessment Depression Inventory (266) were considered but rejected because they were felt to measure misery/depression. This aspect of outcome was not selected for this study and psychological/emotional outcome was already being recorded in the COOP charts and Euroquol.

Carers outcome

The effect of the home based intervention on carers emotional state was investigated using a postal questionnaire consisting of carers characteristics such as gender, age and relationship to patient and the General Health Questionnaire-12 (264)(Appendix P).

The GHQ-12 was designed to detect non-psychotic psychiatric disorders in people in community and medical settings using a self-report questionnaire. The assessment consists of twelve questions which ask if the respondent has experienced a particular symptom or behaviour recently using a four-point scale; "less than usual", "no more than usual", rather more than usual" and "much more than usual". The responses are scored from zero to three, giving a total score of thirty-six with the higher scores indicating a greater probability of clinical disorder. It was selected because it provided a measure of psychological distress, was quick and easy to use in a postal questionnaire and had evidence of reliability and validity (267). The questionnaire was given to the carer at the seven week assessment by the assessor and respondents could return it by post if they wished. The carers strain index (268) was considered as a possible outcome measure. The scale was rejected because it was designed for hospital settings and was felt to lack validity and sensitivity to change.

Service Provision

Patient satisfaction with services: This was recorded in the six month postal questionnaire. Patients were asked to agree or disagree to twelve satisfaction statements which included satisfaction with recovery, amount of therapy they had received, preparation for home, adequate information, provision of equipment/support and a place of contact (Appendix Q). These statements were the same as used by Pound et al (226) and Dennis et al (160) in similar evaluations of stroke services.

Resources: The following information was collected to describe the resources and activity of the home based occupational therapy stroke service.

- The number, frequency and length of treatment sessions for each patient.
- Use of therapy time e.g. the amount of time spent travelling, liaison with other staff etc.
- The provision of adaptations and specialist equipment since discharge e.g. grab rails, bathing equipment.
- Service costs e.g. staff, travel expenses, equipment costs.

3.5 DATA ANALYSIS

The initial analysis was carried out by myself using SPSS software and the main analysis was subsequently carried out at the Robertson Institute of Bio-statistics at the University of Glasgow. The analysis was carried out on an intention-to-treat basis, meaning that all the patients entered into the study were included in the analysis and remained in their designated group irrespective of whether they received the treatment or not and all the patient in the study were followed up (189). A record was kept of the number of patients who completed the outcome assessments and the number that withdrew with the reason for withdrawal if known e.g. deceased, lost to follow-up, refusal to complete assessment.

The baseline measurements and group characteristics were compared to see if the groups were the same at the beginning of treatment. This comparison is important as it demonstrates that any differences between the two groups observed at the end of intervention are more likely due to the treatment and not pre-existing variables.

All the outcome data was treated as nominal or ordinal and non-parametric statistical tests were used to explore the relationship between the treatment and control group after the intervention using a conventional significance level of $p<0.05$. The analysis consisted of three approaches:

1. The comparison of the treatment and control group at seven weeks and six months. The Nottingham EADL was selected as the primary outcome measure as it measured both occupational performance and reflected changes in community based activities of daily living. Several pre-specified patient subgroups were examined based on age, gender, dependence, attendance at day hospital and presence of carer.

2. Odds ratio (95% CI) was used to analyse the odds of a good or poor outcome (death or deterioration in activities of daily living).

3. An analysis of change within the groups over time. This was carried out by comparing the differences between the groups in basclinc and at seven weeks and baseline and at six months using the Modified Barthel Index and the COPM.

Finally descriptive data was used to record the activity and resources used to operate the home based occupational therapy service.

CHAPTER FOUR

RESULTS OF THE RANDOMISED TRIAL

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Chapter Four

4.1 RECRUITMENT

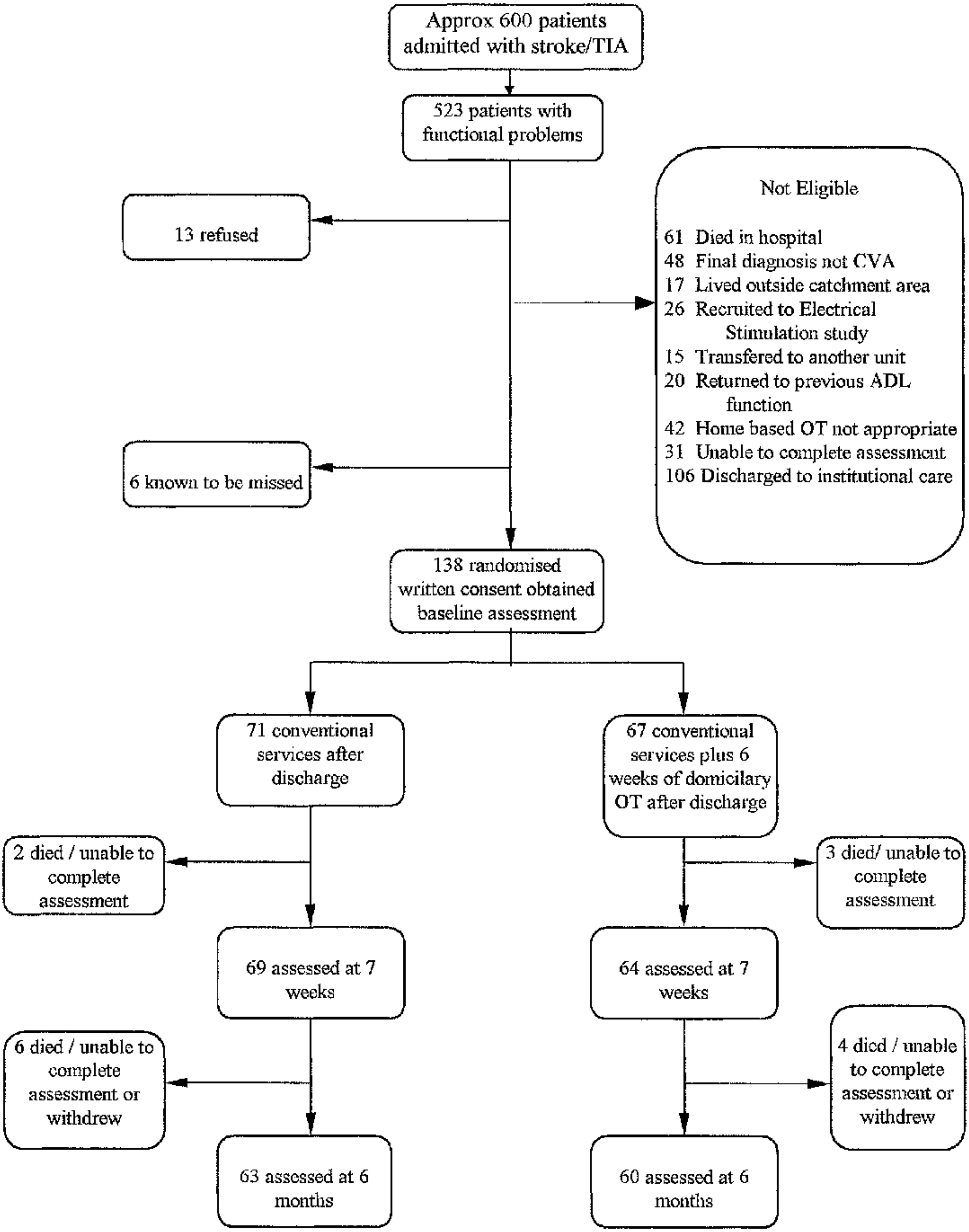
A profile of the study can be seen in figure IV. The study identified 523 potential recruits for the project. Of this number, 366 patients were not eligible, 13 refused consent and 6 were identified as missed. Of the patients rejected; 61 died in hospital, 48 were incorrectly diagnosed as stroke, 17 lived outside the hospital catchment area, 15 were transferred to another hospital, 20 returned to their previous level of function, 106 were discharged to institutional care. A further 42 patients were inappropriate for home based occupational therapy due to terminal / mental illness and medical complications, 31 were unable to complete the assessment and 26 were taking part in a RCT of electrical stimulation (ES). The ES group consisted of 15 women and 11 men, with an average age of 50 years with a median discharge Rankin score of 1 (minor symptoms).

138 patients were recruited to the study, 71 were allocated to the control group to receive conventional services and 67 were allocated to the treatment group to receive conventional services plus a 6 week home-based occupational therapy service.

69 control and 64 treatment patients took part in the 7 weeks assessment. Although two of the treatment patients were incorrectly diagnosed and had brain tumours, they were analysed in their original group; i.e. in an intention-to treat analysis. 1 control and 2 treatment patients had died by 7 weeks and 1 control and 1 treatment patient were medically unstable and not well enough to interview.

63 control and 60 treatment patients completed the 6 months postal questionnaire. 4 control patients and 6 treatment patients had died and 4 control patients and 1 treatment patient did not return their 6 months questionnaire.

Figure IV: A FLOW CHART TO ILLUSTRATE THE TRIAL PROFILE



4.2 BASELINE ANALYSIS

To avoid the potential for bias, all the baseline information and measurements were carried out before randomisation. Baseline demographic data can be found in Table 8. There were no significant demographic differences between the control and treatment group in age, gender, deprivation, presence of carer at home, previous handicap prior to stroke and previous stroke. The average age was 69 years with the majority of patients living in the most deprived geographical areas.

The treatment group tended to have spent a longer time in hospital and had lower modified Barthel scores at discharge compared to the control group, however these differences were not statistically significant. Similar numbers of patients from each group attended the day hospital after discharge and the Euroquol health state scores of the two groups were similar. Significantly more treatment patients had a hemianopia ($p = 0.03$) than the control group but no other differences were found in impairments at baseline. See Table 9 for results.

The majority of patients in both groups believed they would cope at home, however 30% were unsure or concerned about their ability to carry out normal everyday activities. The numbers of patients that completed the COPM can be seen in figure V. Of the 71 control group patients; 61 completed the assessment, 7 were unable to complete and 3 patients did not identify any occupational performance problems. Of the 67 treatment group; 55 completed the assessment, 6 were unable to complete the COPM and 6 patients did not identify any problems and. At baseline the treatment group scores reported slightly lower COPM performance scores, significantly lower COPM satisfaction scores ($p = 0.005$) and identified slightly more problems on the COPM. See Table 10 for results.

Table 8: RCT: BASELINE - DEMOGRAPHIC CHARACTERISTICS

	Control Group **n = 71**	**Treatment Group** **n = 67**	**Comparison of groups**
Age **Mean (median, range, SD)**	69 (71, 31-89, 12)	69 (71, 28-89, 12)	NS T-test p = 0.75
Gender			
Male	32 (45%)	30 (45%)	NS Chi-square p = 0.97
Female	39 (55%)	37 (55%)	
Attended the Day Hospital			
Yes	21 (30%)	15 (22%)	NS Chi-square p = 0.34
No	50 (70%)	52 (78%)	
Deprivation Score - DEPCAT **Median (IQR)**	7 (5 - 7)	7 (5 - 7)	NS Mann-Whitney p = 0.57
Presence of carer at home			
No	24 (34%)	31 (46%)	NS Chi-square p = 0.13
Yes	47 (66%)	36 (54%)	
Previous CVA			
No	58 (81%)	49 (73%)	NS Chi-square p = 0.23
Yes	13 (19%)	18 (27%)	
Previous handicap prior to stroke - Modified Rankin **Median (IQR)**	0 (0 - 2)	0 (0 -1)	NS Mann-Whitney p = 0.83

Table 9: RCT: BASELINE - PATIENT CHARACTERISTICS

	Control Group n = 71	Treatment Group n = 67	Comparison of groups
Time from stroke to discharge home **Median (IQR)**	23 (13 - 66)	33 (17- 64)	NS Mann Whitney p = 0.23
Day hospital after discharge			
No	50 (70%)	52 (78%)	NS Chi-square p = 0.34
Yes	21 (29%)	15 (22%)	
Baseline Total Modified Barthel Score **Median (IQR)**	18 (16-19)	17 (15-18)	NS Mann-Whitney p = 0.07
Baseline Euroquol - Health state **Median (IQR)**	50 (50 - 65)	60 (50 - 75)	NS Mann-Whitney p = 0.26
Side of lesion			
Right	38 (53%)	34 (51%)	NS Chi-square p = 0.85
Left	31 (43%)	30 (45%)	
Other	2 (3%)	3 (4%)	
Hemiparesis			
Yes	60 (84%)	60 (90%)	NS Chi-square p = 0.38
No	11 (16%)	7 (10%)	
Hemi-sensory Loss			
Yes	15 (21%)	19 (28%)	NS Chi-square p = 0.32
No	56 (78%)	48 (72%)	
Visual Inattention			
Yes	16 (22%)	13 (19%)	NS Chi-square p = 0.65
No	55 (77%)	54 (81%)	
Hemianopia			
Yes	7 (10%)	16 (24%)	Significant Chi-square p = 0.03
No	64 (90%)	51 (76%)	

Table 9 continued..

	Control Group n = 71	**Treatment Group** n = 67	**Comparison of groups**
Dysphasia			
Yes	16 (22%)	22 (33%)	NS
No	55 (77%)	45 (67%)	Chi-square
			p = 0.17
Brain-stem / cerebellar			
Yes	4 (6%)	9 (13%)	NS
No	67 (94%)	58 (87%)	Chi-square
			p = 0.12
Cognitive Impairments			
Yes	19 (27%)	12 (18%)	NS
No	52 (53%)	55 (82%)	Chi-square
			p = 0.21
Anxiety			
Yes	17 (24%)	13 (19%)	NS
No	54 (76%)	54 (81%)	Chi-square
			p = 0.52
Depression			
Yes	5 (7%)	5 (7%)	NS
No	66 (92%)	62 (93%)	Chi-square
			p = 0.92

Figure V – COMPLETION OF THE COPM

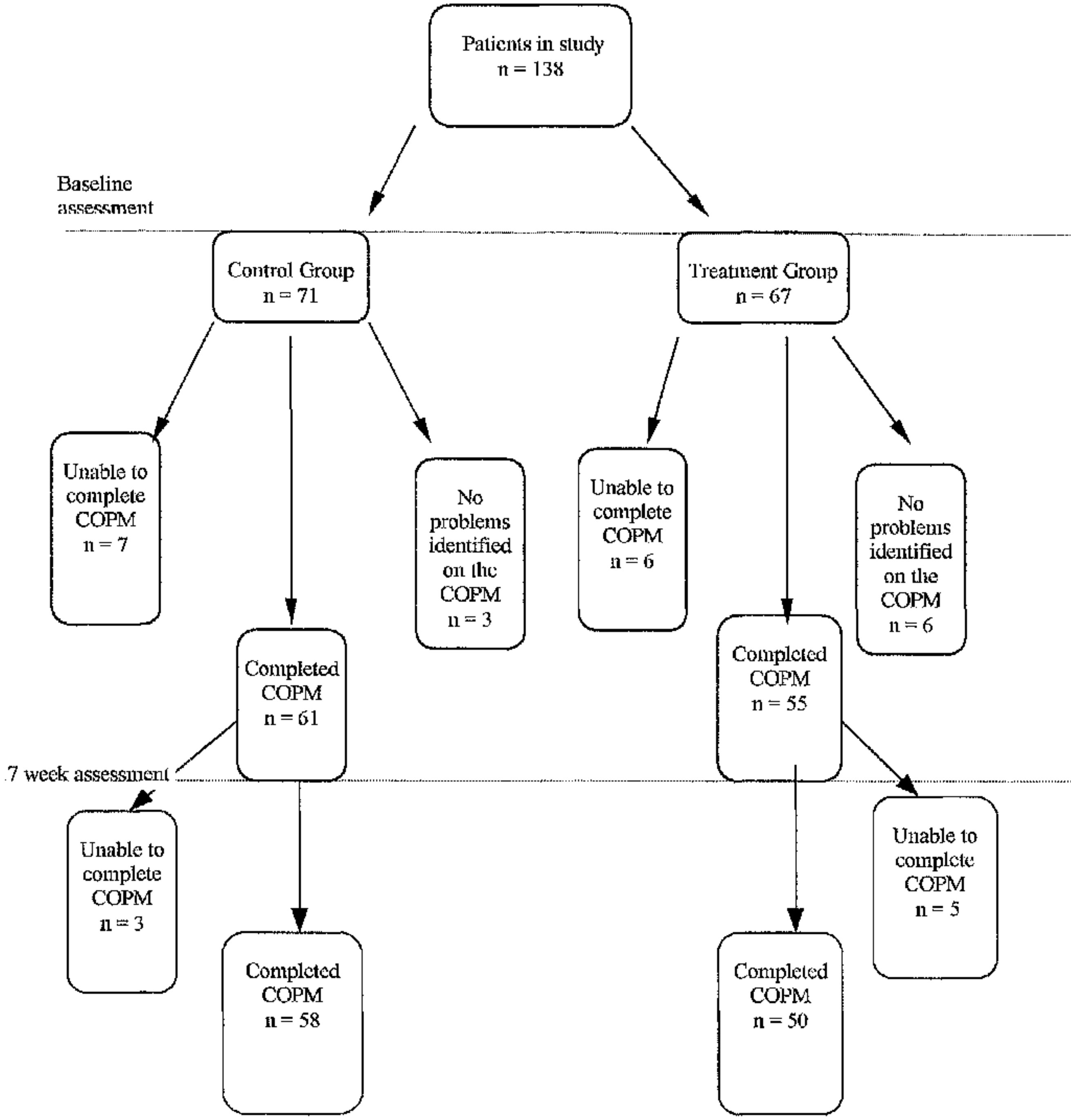


Table 10: RCT: BASELINE - PATIENT EXPECTATIONS AT DISCHARGE

PATIENT DISCHARGE QUESTIONS	Control Group n = 71	Treatment Group n = 67	Comparison of groups
"I think I will be able to cope at home"			
Strongly disagree	0 (0%)	0 (0%)	
Disagree	5 (7%)	5 (7%)	NS
Agree	47 (66%)	42 (63%)	Chi-square
Strongly agree	19 (27%)	20 (30%)	p = 0.90
"How do you think you will be able to carry out normal every day activities"			
Well	17 (24%)	13 (19%)	NS
Okay	36 (50%)	31 (46%)	Chi-square
Poorly	5 (7%)	6 (9%)	p = 0.70
Don't know	13 (18%)	17 (25%)	
COPM AT BASELINE Median (IQR)	**Control Group n = 61**	**Treatment Group n = 55**	**Comparison of groups**
Baseline COPM performance score	5 (3 - 5.66)	3.5 (2.75 - 5)	NS Mann-Whitney p = 0.08
Baseline COPM satisfaction score	5 (3 - 6.1)	3.4 (2.9 - 5)	Significant Mann-Whitney p = 0.005
COPM - THE NUMBER OF PROBLEMS IDENTIFIED Median (IQR)	**Control Group n = 64**	**Treatment Group n = 61**	**Comparison of groups**
Problems in personal care	62 1 (0-1)	70 1 (0-2)	NS Mann Whitney p = 0.37
Problems in domestic activities	36 0 (0-1)	42 0 (0-1)	NS Mann Whitney p = 0.31
Problems in work activities	6 0 (0-0)	4 0 (0-0)	NS Mann Whitney p = 0.77
Problems in leisure activities	68 1 (0-2)	66 1 (1-1)	NS Mann Whitney p = 0.38
Other problems e.g. impairments	10 0 (0-0)	20 0 (0-0)	NS Mann Whitney p = 0.20
Total Number of Problems	182 3 (2-4)	202 3 (2-5)	NS Mann Whitney p = 0.09

4.3 EXPERIENCE OF DISCHARGE AND MAINTENANCE AT HOME

At 7 weeks there was no difference in the place of residence and readmission rates of the two groups with the majority of patients remaining in their own homes since discharge home. 7 (10%) of the control group and 5 (7%) of the treatment group were in hospital and 1 treatment patient had been admitted to a nursing home. The number of re-admissions and length of stay (0 – 37 days) was also similar for both groups. Patients receiving home-based occupational therapy were significantly more likely to maintain or improve in activities of daily living ($p = 0.02$). The majority of patients in both groups strongly agreed or agreed that they were coping at home and able to carry out normal everyday activities better or as they expected. A smaller number of patients expressed concerns about their ability to carry out normal activities. Results can be seen in Table 11.

There was a significant reduction in the odds of the combined outcome of death or deterioration by 7 weeks (OR 0.44 and 95% Confidence Interval of 0.22 – 0.89; $p<0.01$) among the treatment group.

A summary of the services received can be found in Table 12. 219 items of adaptive equipment were recommended by hospital occupational therapists before discharge. The majority of patients received this equipment and no significant difference was found in provision of recommended equipment to the two groups. However patients in the treatment group received significantly more pieces of additional equipment by 7 weeks ($p = 0.02$)

65 environmental adaptations were recommended by hospital occupational therapists before discharge and treatment group patients were significantly more likely to receive these adaptations ($p = 0.01$). Patients in the treatment group were also significantly more likely to report that they continued to practice therapy at home ($p = 0.02$).

Patients in the treatment group received more post discharge Speech and Language Therapy ($p = 0.03$), no other significant differences were found in the allocation of out-patient/community services received by the two groups after discharge. The majority of patients receiving other services reported only one or two contacts apart from the homehelp service which visited 40% of the patients at least once a week.

Similar results were observed at 6 months. There was no difference in the place of residence and readmission rates of the two groups with the majority of patients remaining in their own homes between discharge and 6 months. 3 (4%) of the control group and 4 (5%) of the treatment group were in hospital and 1 treatment patient and 1 control patient had been admitted to institutional care. 31% of the control group and 34% of the treatment group had been readmitted to hospital and the average length of stay (SD) for those admitted was 9 days (26) for the control group and 11 days (27) for the treatment group. More treatment group were maintained or improved in activities of daily living ($p = 0.06$) by 6 months. Results can be seen in Table 13.

There was a non-significant reduction ($p>0.1$) in the odds of death or deterioration by 6 months (OR 0.64 and 95% Confidence Interval of 0.32 – 1.26) among the treatment group.

Table 11: 7 WEEK RESULTS – EXPERIENCE OF DISCHARGE AND MAINTENANCE AT HOME

	Control Group n = 71	Treatment Group n = 67	Comparison of Groups
Place of residence			
Home	63 (89%)	59 (88%)	NS Chi-square p = 0.64
Hospital	7 (10%)	5 (7%)	
Institutional care	0	1 (2%)	
Dead	1 (1%)	2 (3%)	
Readmission			
Yes	10 (14%)	11 (16%)	NS Chi-square p = 0.70
No	61 (85%)	56 (84%)	
Number of re-admissions			
0	61 (85%)	56 (84%)	NS Chi-square p = 0.93
1	9 (13%)	10 (15%)	
2	0	0	
3	1 (2%)	1 (2%)	
Length of readmission stay			
Median (Mean, IQR, S.D.)	0 (3, 0 - 0, 9)	0 (2, 0 - 0, 7)	NS Mann Whitney p = 0.76
Min - Max no. of days	0 - 37	0 - 37	
Global outcome Death and Deterioration in Barthel index			
Better	25 (35%)	38 (57%)	Significant Chi-square p = 0.03
The same	16 (24%)	13 (19%)	
Worse/died	30 (42%)	16 (24%)	
Coping at home	n = 68	n = 63	
Strongly agree	19 (28%)	14 (22%)	NS Chi-square p = 0.59
Agree	40 (60%)	43 (69%)	
Disagree	8 (12%)	4 (6%)	
Strongly disagree	1 (2%)	1 (2%)	
Normal everyday activities	n = 68	n = 63	
Better than expected	23 (34%)	20 (32%)	NS Chi-square p = 0.46
As expected	25 (37%)	30 (48%)	
Worse than expected	18 (27%)	12 (19%)	
Much worse than expected	3 (4%)	1 (2%)	

Table 12: RCT: SERVICES RECEIVED AT 7 WEEKS AFTER DISCHARGE

	Control Group	Treatment Group	Comparison of Groups (Chi-square)
Continuing with therapy			
Not at all	36(52%)	19 (31%)	Significant p = 0.02
Less than once a week	0	3 (5%)	
Once a week	3 (4%)	1 (2%)	
More than once a week	8 (12%)	5 (8%)	
Everyday	22 (32%)	34 (55%)	
Equipment recommended at discharge and received by 7 weeks			
Not received	12 (12%)	12 (10%)	NS p = 0.69
Received	89 (88%)	106 (90%)	
Environmental adaptations recommended at discharge and received by 7 weeks			
Not received	20 (59%)	9 (29%)	Significant p = 0.01
Received	14 (41%)	22 (71%)	
Number of patients who had received extra equipment not recommended at discharge by 7 weeks			
Not received	58 (84%)	43 (67%)	Significant p = 0.02
Received	11 (16%)	21 (33%)	
Number of patients who had received extra environmental adaptations not recommended at discharge by 7 weeks			
Not received	68 (98%)	62 (97%)	NS p = 0.51
Received	1 (2%)	2 (3%)	

Table 12 continued

Services received by 7 weeks	Control Group n = 69	Treatment Group n = 64	Comparison of groups (Chi – square)
Hospital OT service			
No contact	39 (56%)	33 (51%)	NS
Contacted once/twice	29 (42%)	29 (45%)	p = 0.72
Contacted weekly	0	1 (2%)	
Contacted twice weekly	1 (2%)	1 (2%)	
Contacted > twice weekly/daily	0	0	
District Nurse			
No contact	42 (60%)	40 (62%)	NS
Contacted once/twice	18 (26%)	17 (27%)	p = 0.92
Contacted weekly	6 (9%)	4 (6%)	
Contacted twice weekly	1 (2%0	2 (3%)	
Contacted > twice weekly/daily	2 (3%0	1 (2%)	
General Practice			
No contact	29 (42%)	27 (42%)	NS
Contacted once/twice	38 (55%)	35 (55%)	p = 0.99
Contacted weekly	2 (3%)	2 (3%)	
Contacted twice weekly	0	0	
Contacted > twice weekly/daily	0	0	
Social Services OT Service			
No contact	50 (72%)	47 (73%)	NS
Contacted once/twice	18 (26%)	16 (25%)	p = 0.99
Contacted weekly	1 (2%)	1 (2%)	
Contacted twice weekly	0	0	
Contacted > twice weekly/daily	0	0	
Physiotherapy			
No contact	56 (81%)	49 (76%)	NS
Contacted once/twice	5 (7%)	6 (9%)	p = 0.29
Contacted weekly	3 (4%)	7 (11%)	
Contacted twice weekly	2 (3%)	2 (3%)	
Contacted > twice weekly/daily	3 (4%)	0	
Speech and Language Therapy			
No contact	66 (95%)	56 (87%)	Significant
Contacted once/twice	0	6 (9%)	p = 0.03
Contacted weekly	2 (3%)	0	
Contacted twice weekly	1 (2%)	2 (3%)	
Contacted > twice weekly/daily	0	0	

Table 12 continued…

Services received by 7 weeks	Control Group n = 69	Treatment Group n = 64	Comparison of groups (Chi-square)
Health Visitor			
No contact	57 (82%)	53 (83%)	NS
Contacted once/twice	11 (16%)	10 (16%)	p = 0.99
Contacted weekly	1 (2%)	1 (2%)	
Contacted twice weekly	0	0	
Contacted > twice weekly/daily	0	0	
Homehelp services			
No contact	42 (60%)	36 (56%)	NS
Contacted once/twice	0	1 (2%)	p = 0.46
Contacted weekly	2 (3%)	3 (5%)	
Contacted twice weekly	10 (14%)	5 (8%)	
Contacted > twice weekly/daily	15 (22%)	19 (30%)	
Social Worker			
No contact	54 (78%)	51 (80%)	NS
Contacted once/twice	14 (20%)	13 (20%)	p = 0.63
Contacted weekly	1 (2%)	0	
Contacted twice weekly	0	0	
Contacted > twice weekly/daily	0	0	
Meals on Wheels			
No contact	64 (92%)	57 (89%)	NS
Contacted once/twice	0	1 (2%	p = 0.42
Contacted weekly	0	1 (2%)	
Contacted twice weekly	3 (4%)	1 (2%)	
Contacted > twice weekly/daily	2(3%)	4 (6%)	
Stroke Clinic			
No contact	60 (86%)	55 (86%)	NS
Contacted once/twice	9 (13%)	9 (14%)	p = 0.86
Contacted weekly	0	0	
Contacted twice weekly	0	0	
Contacted > twice weekly/daily	0	0	

Table 13: 6 MONTH RESULTS: MAINTENANCE AT HOME

	Control Group n = 71	Treatment Group n = 67	Comparison of Groups
Place of residence			
Home	61 (86%)	57 (85%)	NS Chi-square p = 0.89
Hospital	3 (4%)	3 (5%)	
Institutional care	1 (1%)	1 (1%)	
Dead	5 (7%)	6 (9%)	
Not known	1 (1%)	0	
Readmission			
Yes	22 (31%)	23 (34%)	NS Chi-square p = 0.67
No	49 (69%)	44 (66%)	
Number of re-admissions			
0	48 (68%)	44 (66%)	NS Chi-square p = 0.81
1	18 (25%)	17 (25%)	
2	4 (6%)	3 (4%)	
3	1 (1%)	2 (3%)	
4	0	1 (1%)	
Length of readmission stay			
Median (Mean, IQR, S.D.)	0 (9, 0 - 6, 26)	0 (11, 0 - 8, 27)	NS Mann Whitney p = 0.69
Min - Max no. of days	0 - 176	0 - 132	
Global Outcome Death and Deterioration in Barthel Index	n = 67	n = 66	
Improved	15(22%)	27 (41%)	NS Chi-square p = 0.06
Same	11(16%)	6(9%)	
Worse/died	41 (61%)	33 (50%)	

4.4. OCCUPATIONAL PERFORMANCE

At 7 weeks, 70 control patients and 65 treatment patients had completed the Modified Barthel Index. The treatment group had higher modified Barthel scores (p = 0.06) and statistically greater changes in the modified Barthel Index score over time (p = 0.0007) with a median change in score (IQR) in Barthel Index of 1 (0-2) compared to the control groups median score (IQR) of 0 (-3-1). See Table 14.

69 of the control patients and 64 treatment patients had completed the Nottingham Extended ADL at 7 weeks. Significantly better scores were also observed on the Nottingham Extended ADL (p = 0.05) with the treatment group reporting a median (IQR) score of 27 (20-43) compared to the control groups median (IQR) score of 23 (12-33). The three sections of the Nottingham Extended ADL were analysed independently and the treatment group demonstrated a significantly better domestic score (p = 0.04), plus non-significant improvements in the mobility and leisure scores. See Table 14.

58 of the control patients and 50 of the treatment patients completed the COPM at 7 weeks. The COPM performance (p = 0.002) and COPM satisfaction (p = 0.01) scores were significantly higher in the treatment group. The treatment group reported significantly greater changes in occupational performance (p=0.0006) and satisfaction scores (p=0.0001) on the COPM between discharge and 7 weeks. Significantly more of the treatment group reported improvements in their occupational performance (p=0.006) and satisfaction (p=0.00005) COPM scores by seven weeks. See Table 14.

63 control patients and 60 treatment patients were assessed on the Modified Barthel Index and Nottingham Extended ADL at 6 months. A median Modified Barthel score of 17 was recorded in both groups (p = 0.39). However statistically significant maintenance/improvements in the modified Barthel Index score between baseline and 6 months (p = 0.05) were reported by the treatment group with a median (IQR) change of score of 0 (-2-2) compared to the control groups median change in score of -1(-3-0). Changes in Barthel between 7 weeks and 6 months were the same for both groups with a median score of -1 and similar IQR's. See Table 15.

The treatment group reported better scores were on the Nottingham Extended ADL ($p = 0.39$) at 6 months with a median (IQR) score of 29 (16-38) compared to the control groups score of 23 (14-38). The three sections of the Nottingham Extended ADL were analysed independently and the treatment group demonstrated non-significant improvements on the mobility, domestic and leisure scores. Both groups reported deterioration in their median scores between 7 weeks and 6 months and this was greater in the treatment group. See Table 15.

An initial inspection of the median modified Barthel and Nottingham Extended ADL values in tables 9, 14, 15 might suggest that errors have been made in the analyses as the arithmetic difference between baseline and final outcome does not always correspond to the calculated value in the tables. This is because the size of groups changed over time and non parametric analysis using median rather than mean values was used as the key summary statistic.

Table 14:RCT: 7 WEEK RESULTS – OCCUPATIONAL PERFORMANCE

	Control Group	Treatment Group	Comparison of Groups
MODIFIED BARTHEL INDEX	n = 70	n = 65	Mann Whitney
Total 7 week score	17 (14 - 19)	18 (16 - 20)	NS p = 0.06
Change between baseline - 7 weeks	0 (-3 - 1)	1 (0 - 2)	Significant p = 0.0007
Median (IQR)			
TOTAL NOTTINGHAM EADL	n = 69	n = 64	Mann Whitney
Total score	23 (12 - 33)	27 (20 - 43)	Significant p = 0.05
Mobility Score	6 (2 - 10)	7 (4 - 12)	NS p = 0.08
Domestic Score	11 (4 - 20)	15 (9 - 23)	Significant p = 0.04
Leisure Score	6 (3 - 9)	7 (4 - 9)	NS p = 0.33
Median (IQR)			
COPM	n = 58	n = 50	Mann Whitney
7 week performance score	3.5 (2 - 5.4)	5.35 (3.66 - 7.1)	Significant p = 0.002
7 week satisfaction score	4 (1.75 - 6)	5.42 (3.5 - 7)	p = 0.01
Performance Score (change between baseline and 7 weeks)	0 (-2.5 -1)	1 (0 - 2.8)	p = 0.0006
Satisfaction score (change between baseline and 7 weeks)	-0.4 (-2 - 1)	1.63 (0 - 3)	p = 0.0001
Median (IQR)			
COPM	n = 58	n=50	Chi-square
Improvements in performance score			
Score deteriorated or stayed the same (score < 0)	34 (58%)	16 (30%)	Significant p = 0.0057
Score improved (score > 0)	24 (41%)	34 (68%)	
Improvements in satisfaction score			
Score deteriorated or stayed the same (score < 0)	40 (68%)	15 (30%)	Significant p = 0.00005
Score improved (score > 0)	18 (31%)	35 (70%)	

Table 15: RCT: 6 MONTHS RESULTS – OCCUPATIONAL PERFORMANCE

	Control Group n = 63	Treatment Group n = 60	Comparison of Groups
MODIFIED BARTHEL INDEX			Mann Whitney
Total 6 month score	17 (13 - 18)	17 (15 - 19)	NS p = 0.39
Change between baseline - 6 months	-1 (-3 - 0)	0 (-2 - 2)	Significant p = 0.05
Change between 7 weeks - 6 months	-1 (-2 - 0)	-1 (-2.5 - 0)	NS p = 0.85
Median (IQR)			
TOTAL NOTTINGHAM EADL			Mann Whitney
Total score	23 (14 - 38)	29 (16 - 38)	NS p = 0.39
Mobility Score	6 (3 - 11)	8 (4- 12)	NS p = 0.38
Domestic Score	12 (5 - 19)	14 (6 - 21)	NS p = 0.40
Leisure Score	6 (3 - 9)	7 (3 - 10)	NS p = 0.98
Change between 7 weeks and 6 months	-1 (-7 - 6)	-2.5 (-9.5 - 4)	NS p = 0.16
Median (IQR)			

4.5. SUBJECTIVE HEALTH EXPERIENCE

At 7 weeks, 69 of the control patients and 64 of the treatment patients completed the COOP charts, Euroquol and London Handicap Scale. The treatment group reported significantly better scores on the emotional conditions section of the COOP charts ($p = 0.02$) and the occupation (work/leisure) section of the London Handicap Scale ($p = 0.04$). No other significant differences between the treatment and control groups were recorded on the COOP charts, Euroquol or London Handicap Scale. Both groups reported mid range scores on the global questions e.g. quality of life (COOP charts), current health state score (Euroquol) and poor physical condition, social activities levels (COOP charts) and economic self-sufficiency (LHS). See tables 16 and 17.

At 6 months, 62 control patients and 60 treatment patients completed the Euroquol and London Handicap Scale. The treatment group reported a non-significant higher current health state median score (IQR) of 55 (45-65) compared to the control groups median score of 50 (35-60). More of the treatment group reported that their general health had either improved or got worse compared to the control group who reported that their health had stayed the same. Both groups reported similar scores on the London Handicap Scale with a total median score (IQR) of 0.45 (0.29-0.64) for the control group and 0.41 (0.38-0.53) for the treatment group. See tables 18 and 19.

Table 16: RCT: 7 WEEK RESULTS – SUBJECTIVE HEALTH EXPERIENCE

	Control Group n = 69	Treatment Group n = 64	Comparison of groups
COOP CHARTS			Mann Whitney
Physical condition	5 (5 - 5)	5 (4 - 5)	NS p = 0.19
Emotional condition	3 (2 - 4)	2 (2 - 4)	Significant p = 0.02
Daily work	3 (2 - 5)	3 (3 - 4)	NS p = 0.52
Social activities	4 (2 - 4)	4 (2 - 4)	NS p = 0.93
Pain	3 (1 - 4)	3 (1 - 4)	NS p = 0.38
Change in condition	2 (1 - 3)	2 (1 - 3)	NS p = 0.31
Overall condition	3 (3 - 4)	3 (3 - 4)	NS p = 0.74
Social Support	1 (1 - 2)	1 (1 - 2)	NS p = 0.62
Quality of life	3 (2 - 3)	3 (2 - 3)	NS p = 0.35
Median (IQR)			
EUROQUOL-			
Comparison of general health over past 12 months			
Better	7 (10%)	7 (11%)	NS
Much the same	18 (26%)	18 (28%)	Chi- square
Worse	44 (64%)	39 (61%)	p = 0.94
Current Health State Score	50 (40 - 60)	50 (40 - 60)	NS Mann Whitney p = 0.66
Median (IQR)			

Table 17: **RCT: 7 WEEKS RESULTS – THE LONDON HANDICAP SCALE**

Disadvantage at 7 weeks	**Control n = 69 Treat n = 64**	**None**	**Slight**	**Moderate**	**Considerable**	**Severe**	**Extreme**	**Comparison of groups using Mann Whitney U test**
Mobility	**Control Treatment**	7 (10%) 9 (14%)	10 (14%) 11 (17%)	33 (48%) 28 (44%)	16 (23%) 16 (25%)	2 (3%) 0	1 (1%) 0	NS p = 0.39
Physical Independence	**Control Treatment**	10 (14%) 9 (14%)	8 (12%) 11 (17%)	17 (25%) 17 (26%)	20 (29%) 23 (36%)	12 (17%) 2 (3%)	2 (3%) 2 (3%)	NS p = 0.21
Occupation	**Control Treatment**	1 (1%) 4 (6%)	9 (13%) 9 (14%)	14 (20%) 22 (34%)	18 (26%) 11 (17%)	19 (27%) 15 (23%)	8 (12%) 3 (5%)	**Significant p = 0.04**
Social Integration	**Control Treatment**	13 (19%) 20 (31%)	23 (33%) 24 (37%)	20 (29%) 8 (12%)	11 (16%) 11 (17%)	2 (3%) 1 (2%)	0 0	NS p = 0.08
Orientation	**Control Treatment**	24 (35%) 26 (41%)	19 (27%) 14 (22%)	23 (33%) 20 (31%)	2 (3%) 3 (5%)	1 (1%) 1 (2%)	0 0	NS p = 0.75
Economic self-sufficiency	**Control Treatment**	6 (9%) 5 (8%)	5 (7%) 4 (6%)	10 (14%) 10 (16%)	47 (68%) 45 (70%)	1 (1%) 0	0 0	NS p = 0.98

Total London Handicap Score at 7 weeks	**Median (Mean, IQR, S.D.)**	**Comparison of groups using Mann Whitney U test**
Control	0.43 (0.45, 0.33 - 0.55, 0.21)	NS p = 0.24
Treat	0.46 (0.49, 0.36 - 0.61, 0.21)	

Table 18: EUROQUOL - 6 MONTHS RESULTS – SUBJECTIVE HEALTH EXPERIENCE

	Control Group	Treatment Group	Comparison of groups
EUROQUOL-	n = 62	n = 60	
Comparison of general health over past 12 months	8 (13%)	11(18%)	NS
Better	30 (49%)	21 (35%)	Chi- square
Much the same	24 (38%)	28 (46%)	p = 0.31
Worse			
	n = 55	n = 57	NS
Current Health State Score	50 (35 - 60)	55 (45 - 65)	Mann Whitney p = 0.23
Median (IQR)			

Table 19: RCT: 6 MONTHS RESULTS – THE LONDON HANDICAP SCALE

Disadvantage at 6 months	Control n = 62 Treat n = 60	None	Slight	Moderate	Considerable	Severe	Extreme	Comparison of groups using chi-squared
Mobility	**Control**	7 (11%)	6 (10%)	27 (43%)	17 (27%)	4 (6%)	1 (2%)	NS
	Treatment	8 (13%)	10 (17%)	26 (43%)	12 (20%)	3 (5%)	1 (2%)	p = 0.84
Physical Independence	**Control**	8 (13%)	12 (19%)	16 (26%)	13 (21%)	8 (13%)	5 (8%)	NS
	Treatment	3 (5%)	8 (13%)	19 (32%)	19 (32%)	7 (12%)	4 (7%)	p = 0.46
Occupation	**Control**	8 (13%)	7 (11%)	9 (14%)	9 (14%)	18 (29%)	11(18%)7	NS
	Treatment	3 (5%)	4 (7%)	15 (25%)	16 (27%)	15(25%)	(12%)	p = 0.17
Social Integration	**Control**	14 (22%)	17 (27%)	17 (27%)	11 (18%)	2 (3%)	1 (2%)	NS
	Treatment	10 (17%)	22 (37%)	14 (23%)	14 (23%)	0	0	p = 0.42
Orientation	**Control**	18 (29%)	19 (30%)	23 (37%)	1 (2%)	1 (2%)	0	NS
	Treatment	20 (33%)	15 (25%)	23 (38%)	2 (3%)	0	0	p = 0.76
Economic self-sufficiency	**Control**	8 (13%)	18 (29%)	11 (18%)	21 (34%)	4 (6%)	0	NS
	Treatment	4 (7%)	11 (18%)	8 (13%)	32 (53%)	5 (8%)	0	p = 0.21

Total London Handicap Score at 6 months	Median (Mean, IQR, S.D.)	Comparison of groups using Mann Whitney U test
Control	0.45 (0.48, 0.29 - 0.64, 0.22)	NS p = 0.57
Treat	0.41 (0.45, 0.38 - 0.53, 0.16)	

4.6. CARERS OUTCOME

At 7 weeks, 77% of the carers returned their questionnaire, 49 in the control group and 49 in the treatment group. There were more partners in the control group and more siblings in the treatment group. Results can be seen in Table 20.

Carers in the control group scored slightly worse scores on the GHQ (12) with the control group reporting a median (IQR) score of 15 (11-21) and the treatment group reporting a median (IQR) score of 13 (11-17), the difference between the two groups was not statistically significant.

Table 20: RCT: 7 WEEK RESULTS – CARERS EXPERIENCE

	Control Group n = 58	**Treatment Group n = 49**	**Comparison of Groups**
Carers identity			
Partner	28 (48%)	16 (32%)	NS Chi-square p = 0.37
Son/dau/in-law	14 (24%)	17 (34%)	
Other relative	11 (15%)	8 (16%)	
Neighbour/friend	1 (2%)	3 (6%)	
Paid carer	4 (7%)	4 (8%)	
Other	0	1 (2%)	
Carers - GHQ (12) **Median (IQR)**	15 (11-21)	13 (11-17)	NS Mann Whitney p = 0.14

4.7. SUB-GROUP ANALYSIS

A pre-specified analysis was carried out of age, gender, attendance at day hospital, presence of carer at home and dependency level at baseline using the 7 weeks data. Errors in interpretation because of the small and unbalanced sub-groups sample sizes were a concern and because of this the results were not explored in detail. There was a trend in all the sub group analyses for the treatment group to report improved median scores on the Modified Barthel Index, COPM and Nottingham Extended ADL apart from control patients under 65 years who scored higher median scores on the Nottingham EADL.

The following analysis were significant ($p<0.05$):

- 47 treatment patients over or equal to sixty-five years reported significant improvements in the Modified Barthel Index ($p = 0.03$), COPM performance ($p = 0.0003$) and satisfaction ($p = 0.0001$) scores, Nottingham EADL ($p = 0.006$) compared to 52 control patients of the same age.
- Both men ($p = 0.02$) and women ($p = 0.01$) treatment group patients reported significant changes in the Modified Barthel Index between baseline and 7 weeks and women reported significant COPM performance (0.0003) and satisfaction scores ($p = 0.0004$).
- 48 treatment patients mildly disabled (scoring 15 -19 on the Modified Barthel Index) at baseline reported significant improvements in the Modified Barthel Index ($p = 0.03$), COPM performance ($p = 0.0003$) and satisfaction ($p = 0.0002$) scores and Nottingham Extended ADL ($p = 0.04$) compared to 53 control patients. This analysis was interpreted with care because of the small number of patients in the severely/moderately disabled and independent sub groups.
- Non-day hospital treatment patients reported significant improvement in changes on the modified Barthel Index ($p = 0.0009$) and COPM performance score ($p = 0.003$) and both day hospital ($p = 0.03$) and non-day hospital ($p = 0.002$) treatment patients reported significantly higher COPM satisfaction scores.
- Treatment patients with and without carers at home reported significantly higher COPM scores and treatment patients without carers described significantly higher scores on the Modified Barthel Index ($p = 0.03$) and Nottingham Extended ADL ($p = 0.03$).

4.8 HOME BASED OCCUPATIONAL THERAPY SERVICE PROVISION

Patient Satisfaction with Services

65% of the patients responded to the satisfaction questions. The majority of patients in both groups expressed satisfaction with services however more treatment group patients were satisfied than control patients apart from satisfaction with recovery. Patients in the treatment group were significantly more likely to report satisfaction with preparations for home at discharge ($p = 0.03$), the quantity of information received about rehabilitation and recovery ($p = 0.04$) and having a person to contact about problems related to their stroke ($p = 0.05$). See table 21.

Activity

Activity levels are recorded in table 22. My activity levels over the eighteen months intervention period of the study indicated that 37% of my time was spent in research activity and 60% was spent in clinical based activity. (20% of my time was spent in direct, face to face contact with patients, 14% in indirect patient contact e.g. case recording, liaison with other agencies/carers, preparation, 7% in travel, 11% in other clinical activity e.g. education, supervision of staff, administration and meetings and 11% on public holidays/leave). The calculations on service provision were therefore based on a 0.6 W.T.E. senior one occupational therapy post. Based on this, a 1.0 W.T.E. senior one occupational therapist would spend 34% of their time in direct patient contact, 24% of time in indirect patient contact, 12% in travelling and 19% of their time in other clinical activities.

Treatment sessions

67 of the treatment patients were treated over the 18 months intervention period. Each patient received an average of 10 sessions over 6 weeks; each session lasted on average 53 minutes and 17 minutes was spent in travel.

Based on the above data, approximately 80 patients could be treated annually by a 1.0 W.T.E senior one occupational therapist. The treatment sessions involved (See Figure VII)

- Assessment and initial goal setting - involving the assessment of occupational performance problems, environment and impairments, the setting of agreed goals and structured, written therapy programmes when appropriate e.g. upper limb training.

- The majority of time was spent addressing occupational performance problems. The Canadian occupational performance model was used to classify occupational performance interventions into self-care, domestic, work and leisure categories. These interventions were further divided into goal setting and activity. Goal setting involved the identification and selection of the most important occupational performance problems, breaking the problems into smaller achievable goals and establishing a plan of action. Patients could also decide if they needed the assistance of the occupational therapist or carers to achieve their goals. Activity were those interventions which directly involved occupational performance activity with the patient e.g. went out to the shops, practised the ironing, dressing etc. One treatment session might have involved a mixture of the interventions e.g. self-care goal setting, domestic activity and information giving. No attempt was made to measure intensity or quality of each type of intervention.

- The intervention also involved giving information, adaptive equipment, and advice to carers and liaison with other professionals.

Equipment provided

The equipment was provided from the hospital store and included cutlery, kitchen equipment, trolleys, dressing aids, toilet equipment, bathing equipment, writing equipment, relaxation tapes, equipment to assist with visual impairment. A total of £2'009.00 of adaptive equipment was issued to patients and I collected and returned £593.00 of adaptive equipment to the hospital store. Therefore a total of £1'416.00 was spent on equipment.

Direct Service costs

£26'000.00 per annum would be needed to set up a similar home based occupational therapy service for stroke patients. This includes salary, employers, equipment and travel costs. Please see Table 23.

Table 21: SATISFACTION WITH SERVICES AT SIX MONTHS

		Control	**Treat**	**Comparison of groups using Chi-square**
I am happy with the amount of recovery I have made	Agree Disagree	29 (67%) 14 (33%)	26 (60%) 17 (39%)	NS p = 0.50
I am satisfied with the amount of treatment the therapists have given me	Agree Disagree	32 (76%) 10 (24%)	37 (88%) 5 (12%)	NS p = 0.15
I was given all the information I needed about the allowances or services I might need	Agree Disagree	25 (60%) 16 (39%)	32 (73%) 12 (27%)	NS p = 0.25
Things were well prepared for my return home	Agree Disagree	30 (73%) 11 (27%)	39 (91%) 4 (9%)	Significant p = 0.03
I get all the support I need from services such as meals-on - wheels, home helps	Agree Disagree	22 (63%) 13 (37%)	24 (63%) 14 (37%)	NS p = 0.97
I am satisfied with the out-patient services provided by the hospital	Agree Disagree	30 (75%) 10 (25%)	39 (91%) 4 (9%)	NS p = 0.06
I am satisfied with the practical help I have received since I left hospital	Agree Disagree	27 (69%) 13 (31%)	34 (83%) 7 (17%)	NS p = 0.11
I have received enough information about recovery and rehabilitation	Agree Disagree	31 (74%) 11 (26%)	39 (91%) 4 (9%)	Significant p = 0.04
Somebody has really listened and understood my needs and problems since I left hospital	Agree Disagree	27 (67%) 13 (33%)	33 (77%) 10 (23%)	NS p =0.35
I have not felt neglected since I left hospital	Agree Disagree	30 (73%) 11 (27%)	37 (88%) 5 (12%)	NS p = 0.08
I have received enough special equipment	Agree Disagree	27 (65%) 14 (34%)	30 (73%) 11 (27%)	NS p = 0.47
I know who to contact if I have problems related to my stroke	Agree Disagree	28 (69%) 13 (30%)	38 (86%) 6 (14%)	Significant p = 0.05

Figure VI: RCT: Number of occurences of intervention strategies during the project

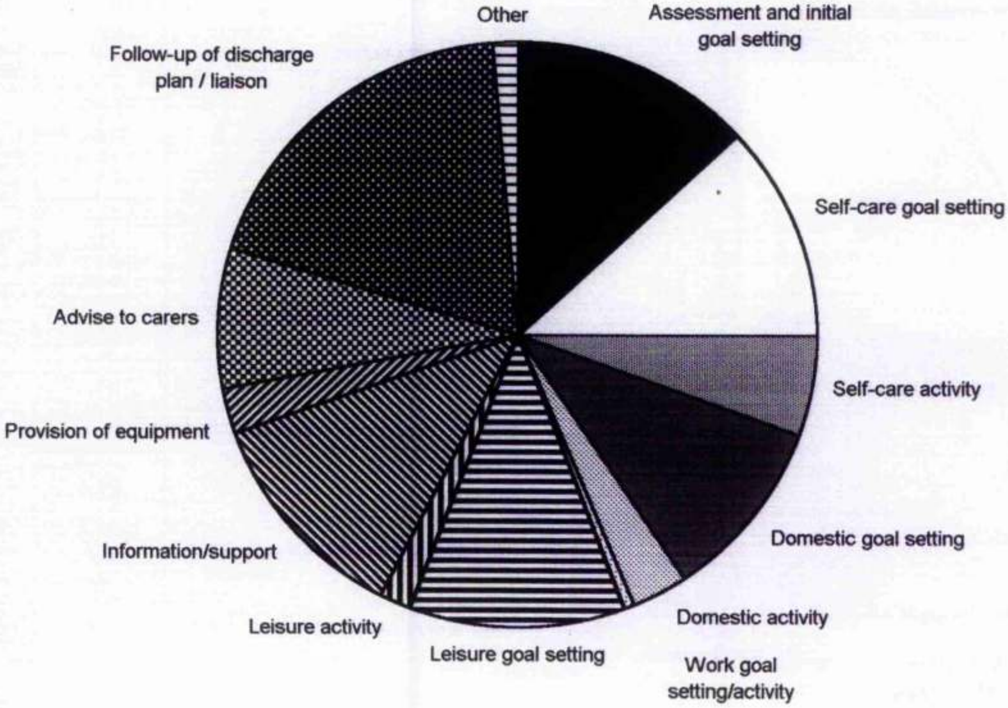


Table 22: OCCUPATIONAL THERAPY ACTIVITY LEVELS DURING THE STUDY INTERVENTION (OVER 18 MONTHS)

	Units (1/4 hour)	Time (hours)	% of study time	% time for a 1.0 W.T.E
Direct patient contact	2261	565.25	20%	34%
Indirect patient contact **case recording** **preparation** **communication - pt related**	1634	408.5	14%	24%
Travel - treatment sessions	789	197.25	7%	12%
Non-pt communication **staff meetings** **supervision** **general liaison**	452.5	113.12	4%	7%
General administration **admin** **development of service**	481.5	120.25	4%	7%
Clinical education **student supervision** **teaching** **courses**	346	86.5	3%	5%
Research	4049	1012.25	37%	N/A
Time-off **A/L / Bank holidays** **sickness**	1280	320	11%	11%
TOTAL	11293	2823.25	100%	100%

Key

W.T.E. - Whole time equivalent

Table 23: SERVICE COSTS OF THE HOME BASED OCCUPATIONAL THERAPY SERVICE

	0.6 W.T.E. senior one occupational therapist (point 03) - project costs over 18 months	1.0 W.T.E. senior one occupational therapist (point 03) – predicted cost per annum
Salary	£18'396.00	£20'440.00
Employers costs (12%)	£2'206.84	£2'452.80
Equipment	£1'416.00	£1'600.00
Travel expenses 3115.6 miles x 0.31p (Average of 4.5 miles per session)	£965.84	£1'140.80
Total	£22'984.68	£25'633.60

N.B. Salary estimated on January 1998 pay awardv

CHAPTER FIVE

DISCUSSION

Chapter Five

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Chapter Five

5.1. STUDY DESIGN

This research project aimed to investigate the effect of a six weeks post-discharge home based occupational therapy service on the outcome of stroke patients discharged home from the Glasgow Royal Infirmary. The project used a randomised controlled trial (RCT) study design in which a control group of stroke patients receiving conventional out-patient services was compared with a treatment group of stroke patients receiving conventional out-patient services plus brief, intensive home based occupational therapy. This design was felt to be appropriate because it is an accepted way to compare the effectiveness of different interventions and allows researchers to draw conclusions on whether changes in outcome are due to the intervention being investigated and not due to the influence of other variables (269,270).

For a RCT to detect effects of intervention on outcome, the group under comparison should be identical except for the experimental intervention i.e. other influencing variables should be equally distributed between both groups (271). In this study the variables gender, attendance at day hospital, age, deprivation, presence of carer at home, previous handicap, provision of services after discharge and impairment characteristics such as side of lesion and hemiparesis were distributed evenly across the control and treatment groups. Levels of disability were not evenly distributed, with the treatment group having slightly longer hospital admissions, lower modified Barthel Index scores, a higher incidence of hemianopia, plus significantly lower levels of satisfaction and more occupational performance problems on the COPM at baseline. A more even distribution of disability levels could have been ensured by stratifying randomisation using dependency levels (modified Barthel scores). This method was not selected because I was obliged to stratify randomisation by co-intervention (day hospital attendance) and a potential confounder of outcome measurement (gender) and did not wish to add additional strata. Despite lower baseline modified Barthel scores the treatment group still demonstrated significant changes in occupational performance when compared with the control group at seven weeks.

Blinded assessment is an important characteristic of RCT's, as it reduces the influence of assessment bias (219). A blinded assessor administered the outcome measurements and blinding was achieved by using standardised instructions and separating the assessor from the randomisation process and the delivery of the intervention. Independent randomisation was maintained throughout recruitment and carried out by a secretary not involved in the study, based in a different office. Other researchers (216,217,219) have noted the difficulties of maintaining blinded assessment and at times during the interviews some patients described experiences which allowed the assessor to make inferences about their group allocation. The use of postal questionnaires at seven weeks would have reduced this bias but this method may have reduced the number of responses and excluded the use of outcome measurements such as the COPM. Alternatively an independent, external research company could have carried out the interviews if funding had been available.

The study could be criticised for not having a "true placebo" in which control group patients received similar levels of attention from the occupational therapy services. Significant differences between the two groups might have been due to non-specific aspects (e.g. attention) of the intervention and not the occupational therapy intervention itself. The use of a placebo intervention for the control group was considered but several difficulties existed:

- It would have been difficult to justify the legitimacy of an intensive non-specific, non-therapy intervention to patients.

- A placebo intervention may have acted as an intervention in itself and contaminated the results. Attention/involvement with patients may be an important part of therapy and an integral part of the patient - therapist relationship. A similar problem was identified by the Vancouver study (191) which concluded that the results of a comparison of occupational therapy leisure intervention with an alternative "placebo" of leisure discussion were contaminated by the placebo acting as a form of intervention.

- A study comparing one aspect of occupational therapy intervention with another e.g. vocational training compared with domestic training, leisure therapy could have been used. Patients in all the groups would have received similar amounts of therapy contact and a greater inference could then have been made about the effects of different forms of interventions. The design would have involved randomising patients to several groups and a much large sample size would have been needed to ensure that the study had enough statistical power to detect a meaningful difference between the groups. This approach was felt to be reductionist as it required the intervention to be compartmentalised into pre-determined packages of care, it appeared to conflict with the client-centred approach (272) based on patient goals proposed by the study.

- A crossover design is sometimes used to reduce the motivational influence of an intervention (219). In this design, patients are randomly allocated to a treatment or control group and half way through the groups are switched over, by the end of the study all the patients will have received similar amounts of the intervention. A crossover design could not be used because the study was investigating the carry-over effect of the intervention beyond the treatment phase at 6 months and required a constant control group.

- A study comparing conventional services with a treatment service did mean that the control group received attention from other professionals/occupational therapy at the day hospital and stroke clinic. The study appeared to be answering a more relevant pragmatic clinical question; does the introduction of a new service make a difference to patients when compared to an existing service, even if it is having a non-specific "placebo" effect?

Internal validity was further supported by using an intention to treat analysis in which all the patients who entered the study were included in the analysis and every effort was made to follow-up non-responders. Of the one- hundred and thirty eight recruited, one- hundred and thirty three patients completed the seven weeks assessment. One of the controls and two of the treatment group had died by this point and one control and one treatment patient were too unwell to complete the assessment. One- hundred and twenty three patients completed the six months assessment and ten more patients had withdrawn due to death, illness or non- response. Care was taken to follow-up the postal questionnaires and the independent assessor did assist some patients who were unable to complete it on their own. Drop out from the study was therefore small and balanced between the two groups and did not affect the overall results. Using an intention to treat analysis meant that three treatment patients who had their diagnosis changed from stroke to carcinoma and one treatment and one control patient who were discharged to nursing home care after randomisation were included in the analysis. This may have influenced the final results but was felt to reflect a normal stroke home based occupational therapy service in which a small number of patients who did not meet the service referral criteria might be referred.

The one hundred and thirty three patients assessed at seven weeks did meet the required one-hundred and twenty eight patients recommended by the power calculation. However the six months assessment was slightly under powered. Small sample sizes can lead to Type II errors in which differences between the groups are not detected and the null hypothesis is incorrectly accepted. The under-powered six months assessments may have influenced the results and differences between the groups may have been missed. Despite this study being one of the largest studies undertaken to date, this highlights a need for occupational therapy research studies with greater statistical power.

The study sample represented a population of patients admitted to hospital with a diagnosis of stroke without gross communication or perceptual problems. All had experienced changes in their occupational performance as a result of their stroke and had been discharged to their own homes from general medical and stroke rehabilitation wards.

Current unpublished data from the Glasgow Royal Infirmary suggests that approximately six hundred patients with a disability sufficient to warrant an admission of three or more days are admitted over eighteen months. This trial identified five hundred and twenty five patients over this period and was therefore felt to be representative of the population of stroke patients admitted to the Trust each year who continue to experience occupational performance problems. The shortfall of seventy- five patients may have been a result of not identifying all the patients who had died or returned to full function as many of these patients would not have been referred to the occupational therapy service.

Sixty-nine percent of patients identified for the trial were not eligible for home based occupational therapy. A third of these patients were discharged to institutional care, and the remaining patients had died, were finally not diagnosed with a stroke, lived outside the catchment area, were discharged to another hospital or returned to full function. A total of one hundred and thirty eight patients were randomised and this represents 58% (138/237) of patients with residual disability who returned to a (local) private address. The numbers of patients not eligible for on-going rehabilitation at home was similar to previous published studies who excluded between fifty five percent and seventy two percent of potential recruits (149,156,159). The quantity of patients requiring home based intervention was therefore small but significant and similar to other studies and would suggest that a comparable service targeted at patients requiring home based follow-up could be set up without a huge shift in rehabilitation resources.

Twenty-six eligible patients were recruited to an electrical stimulation study during the first nine months of the study and this may have reduced the numbers of younger, less dependent patients with upper limb impairments. This was not felt to influence the overall study outcome because the number of patients lost was small and patients with similar demographic and impairment characteristics were represented within the study sample.

Forty-two patients were excluded from the study because home based intervention was not felt to be appropriate. The majority of these patients had a terminal or psychiatric illness or had other medical complications. The specific needs of these patients differ from the group investigated by the study and home based occupational therapy interventions using palliative care or mental health approaches should be evaluated for these patients.

Thirty-one patients with gross cognitive or communication problems were excluded as they were unable to complete the lengthy and potentially stressful assessments, consent from this group of patients was difficult to obtain. Some of these patients may have been treated by a home based occupational therapy service however the loss of this small number of patients was not felt to affect the validity of the study. Further research could be carried out to investigate the specific needs and appropriate assessment of this group of patients.

Based on this information approximately a third of stroke patients (130/400) patients (includes patients in ES study and with gross communication and perceptual problems) admitted to the Glasgow Royal Infirmary would be eligible for home based occupational therapy per year.

The small sample size, single site and the use of only one occupational therapist does compromise the application of the results to the wider stroke population. The environment of the study or the personality of the therapist providing the treatment may have influenced the results. These factors could only be overcome by setting up a larger multi-centred study involving several therapists of different grades. Alternatively a systematic review could be carried out of the current occupational therapy trials to gain a wider perspective on the effects of home based interventions.

5.2 EXPERIENCE OF DISCHARGE AND MAINTENANCE AT HOME

The first aspect of outcome to be investigated was the experience of discharge and maintenance of patients at home. No difference was observed in re-admission rates of the two groups between discharge and seven weeks however the home based occupational therapy intervention was significantly more likely to maintain or improve activities of daily living over this period. In terms of numbers needed to treat (NNT) for every six patients treated by home based occupational therapy, one patient was maintained or improved in functional ability in the first seven weeks after discharge. This trend was still evident at six months but for every nine patients treated, one was maintained or improved in their functional ability due to the home based occupational therapy service (Appendix P). These results were supported by a significant reduction in the odds of death or deterioration at seven weeks which was still evident but not significant by six months. The Cardiff (190) and Nottingham -1997 studies (193) reported trends in maintaining patients in their own homes at home. The Nottingham - 1997 study reported a non-significant trend at six months of patients receiving home based occupational therapy avoiding moves into nursing homes. In the Cardiff study patients receiving a home based intervention were significantly less likely to be re-admitted to hospital by one year after discharge. Home based occupational therapy may well have an effect on maintaining patients. A larger study could examine the relationship between home based occupational therapy intervention and institutionalisation including resource implications and effect on patient well-being.

Before discharge the majority of patients believed they could cope at home, although a minority of patients (30%) were unsure or concerned about carrying out normal activities. The treatment group was significantly more dissatisfied than controls with their performance in self-care, domestic, work and leisure activities. Once at home the majority of patients believed they were coping and able to carry out normal everyday activities, although 31% of controls and 21% of treatment patients described their function as worse or much worse than they expected. This suggests that patients continue to have on-going concerns about their ability to function in the first few months after discharge but the simple discharge questions were not felt to be sensitive enough to identify the differences in outcome identified by the Nottingham EADL and COPM. Further research could be carried out to develop measurements sensitive to patients concerns about returning home. Qualitative methods using in-depth patient interviews could also be considered (273) to explore patients experiences of discharge.

Discharge experiences were described in the satisfaction questionnaire completed at the end of the six months assessment. Of the patients living at home at six months (75% of sample), 65% completed the satisfaction section in the postal questionnaire. The treatment group was significantly more satisfied with preparations for home, the quantity of information received about rehabilitation and recovery and having a person to contact about problems related to their stroke. This was further supported by data collected on the provision of adaptive equipment and environmental adaptations. The majority of patients in both groups received recommended equipment as this was provided through a stock of short-term loan equipment based at the hospital. However the treatment patients were significantly more likely to receive the recommended environmental adaptations and additional equipment. This suggests that a home based occupational therapy services is able to act as a bridge between hospital and home by facilitating the provision of recommended environmental adaptations, identifying additional needs for adaptive equipment and providing a continuity of approach. Similar observations were made in the Cardiff study (190) in which patients who received home based occupational therapy service were issued with significantly more adaptive equipment. The Nottingham 1997 study (193) reported that patients receiving a home based intervention experienced a more prompt and intensive service and were more likely to receive equipment and appliances, this was felt to lead to greater functional independence. It was also interesting that significantly more patients in the treatment group reported that they continued with therapy on their own once at home. This response may have been due to a reporting bias (in which patients in the treatment group felt that they were obliged to give a positive response to the question) or might also be a result of the client-centred, goal orientated approach used within the home based treatment. This type of approach may provide patients with the ability to problem solve independently and research could be carried out to investigate the structure and processes of effective rehabilitation. A co-ordinated, targeted home based occupational therapy stroke service started immediately after discharge would appear to lead to more timely environmental adaptations, appropriate provision of equipment and continuity of support which may contribute to the improved occupational performance of stroke patients.

The home based occupational therapy service did place additional referral or activity pressures on other services immediately after discharge, although the treatment group received significantly more Speech and Language Therapy. The sample of patients using this service was small and could be attributed to more patients in the treatment group having dysphasia at baseline. The equal distribution of services across the two groups also supports the view that differences in outcome were a result of the home based occupational therapy intervention. Occupational therapists do not work in isolation or have the skills to meet the diverse needs of stroke patients. A co-ordinated approach involving a multi-disciplinary team has been advocated by several authors (88,93,117,149,155) and the contribution and role of occupational therapy within such teams could be investigated further.

5.3 OCCUPATIONAL PERFORMANCE

The Modified Barthel Index, Nottingham EADL and the COPM analyses suggest that an intense, six week home based occupational therapy service provided immediately after discharge is able to address and solve some of the functional problems identified by previous studies and increase patients satisfaction with their occupational performance.

These results support the Nottingham 1995 (136) and Nottingham 1997 (193) trials of home based occupational therapy. Both trials had smaller sample sizes but reported significantly improved mobility and leisure scores with leisure rehabilitation (136) and significantly higher extended ADL scores (193).

The differences in median Modified Barthel and Total Nottingham ADL score between the treatment group and control group were small and it is difficult to know in real terms what these small differences really made to patients. Few rehabilitation studies have been able to demonstrate huge improvements in patient outcome and the results are influenced by confounding factors such as:

- Weakness in the outcome measurements such as, validity of content (e.g. did the measures encompass all the areas of occupational performance important to patients), lack of sensitivity to change (ceiling threshold of the Modified Barthel Index).
- Hetorogenity of the stroke population. Individuals differ in impairment, dependency, pre-morbid and social circumstances.
- Potential improvements as a result of therapy may be limited by social inequalities e.g. prejudice towards disabled people.

The control group may have been disadvantaged in the Modified Barthel Index analysis because this group was less dependent at baseline, with higher scores and therefore had less of a potential to report change. However the number of patients achieving 20 out of 20 points on the Modified Barthel at baseline was similar in both groups (treatment n = 7, control n = 9) and therefore the threshold affect of the Modified Barthel was not felt to be important.

The effect of the intervention on patient outcome did appear to be diluted over time and it was observed that the treatment group deteriorated in occupational performance between seven weeks and six months despite continuing to report higher median scores than the control group. Six weeks of home based occupational therapy intervention may not be long enough to make an impact on the long- term outcome of patients. The intensity and duration of intervention in other studies did appear to influence how long occupational performance improvements were sustained. In the Nottingham 1995 (136) study, treatment lasted for six months and intervention patients were recording significant improvements at six months. Occupational therapy intervention in the Nottingham 1997 (193) trial was less intense and shorter in duration and significant results were more apparent at three months. Further research could be carried out to investigate the effect of intensity and treatment duration of home based occupational therapy on the long-term occupational performance of stroke patients.

The home based service appeared to make a bigger impact on improving self-care and domestic activity and less on leisure activities. Participation in leisure activities involves more social integration and the use of community resources than self-care and domestic activities (58,191). Leisure activities may be restricted by factors outside the control of occupational therapy such as environment and financial restrictions e.g. access to public transport/buildings and affordable leisure pursuits. The duration of the six weeks service may not have been long enough to address these problems and many of these issues can only be addressed by wider changes in social policy. McColl (272) suggests that community based occupational therapy is influenced by three factors;

1) The environment which consists of the physical, social, political, economic, institutional and cultural environment.

2) Developmental factors which refer to the extent to which previous environments have provided support and challenges that lead to adaptation and development.

3) The personal which consists of the physical, psychological-emotional, cognitive-perceptual and sociocultural factors.

The client-centred approach used in the study appeared to influence personal factors but may have been less effective in addressing wider developmental and environmental resulting in restricted social and leisure activities. Examples include occupational performance problems due to economic deprivation, environmental barriers such as living in a third floor tenement flat or the social stigma of disability.

The Canadian Occupational Performance Measure demonstrated significant differences between the control and treatment group perception and satisfaction in their occupational performance. This outcome measure was interesting to use because it consisted of problems selected by the patients themselves and not those pre-determined by the researchers. Due to the semi-structured, discursive format of the COPM, ten control patients and eleven treatment patients were unable to complete the outcome measure, mainly due to communication or comprehension difficulties. Three of the control group and six of the treatment group were unable to identify any problems on the COPM. Non-compliance was therefore balanced between the two groups and despite the reduced sample size, the COPM demonstrated significant improvements for the treatment group in performance and satisfaction. It may have been beneficial to use the COPM in the six months assessment, however the COPM is not validated for use by post and resources were not available to complete the six months assessment using face to face interviews. Further qualitative work exploring this subject would provide information on the influence of these occupational performance improvements on the lives of individual patients.

5.4 SUBJECTIVE HEALTH EXPERIENCE

At seven weeks the treatment group were significantly less likely to report emotional problems such as feelings of unhappiness, anxiety, depression or irritability on the COOP charts and reported significantly better scores in occupations such as work, housework, gardening, sports, hobbies leisure activities on the London Handicap Scale. The two groups reported no other major differences in overall subjective health experience. Both groups reported mid range score on the global questions on quality of life, current health status and both groups reported poor physical conditions, levels of social activities and economic self-sufficiency. Similar results were observed on the London Handicap scale and Euroquol at six months although the treatment group reported slightly higher current health state scores on the Euroquol compared to the control group.

These results could be a due to a lack of sensitivity of the outcome measures or because an intense, brief home based occupational therapy service is able to address problems in occupational performance but unable to address the long-term misery and psycho-social problems of stroke survivors. The patients in this study did live in areas of high socio-economic deprivation and this may have influenced subjective health outcome (84). Young and Forster (135) suggest that physical recovery is not necessarily linked with quality of life or social activity after stroke and on-going psychosocial problems were reported in the Cardiff (190) and Nottingham - 1997 (193) home based occupational therapy trials. The Nottingham - 1995 study (192) did report that occupational therapy intervention using leisure therapy significantly improved psychological well-being for patients. Further research is required to identify the strategies that will address the long-term psycho-social affects of stroke.

5.5 CARERS OUTCOME

Carer stress after stroke is reported to be high (74,78-80) and both groups of carers in this study reported mid range scores on the GHQ, indicating some mood disturbance. The improvements in the treatment group's occupational performance and functional independence did not appear to have influenced the psychological outcomes of their carers. Wade et al (78) suggest that the effects of stroke on carers may be complex and that many factors affect the long-term psychological outcome of carers.

The results may have been compromised by the smaller sample size of carers who returned the postal questionnaire or the carers sample characteristics. A higher percentage of the control group carers were partners of patients and this might explain why the carers in the this group had slightly worse scores as these carers may have been more distressed because they were living with, as well as caring for their relative.

This study did not directly target the needs of carers but did involve them when appropriate in treatment. A more innovative community stroke team approach including professionals who specialise in carer support may meet the needs of carers more effectively. This view is supported by Anderson et al (44) who identifies a need to evaluate a comprehensive community based, multi-disciplinary stroke service which includes the carers experience of the patients illness and provides carer support and information.

5.6. SUB-GROUP ANALYSIS

Sub-group analyses were carried out using the seven weeks data to investigate which patients might benefit from the intervention. In order to reduce bias, the sub-groups (age, gender, dependency levels, and attendance at day hospital and presence of carer at home) were selected before the data analysis. Sample sizes were small for all these sub-groups so any interpretation of the results must bear in mind the high risk of random error (274).

Improved scores were reported in all the other treatment sub-groups apart for men under 65 who recorded lower Nottingham EADL median scores. Significant improvements on the Modified Barthel Index, COPM, Nottingham EADL and change in ADL were observed in the treatment group patients who were mildly disabled, living alone and aged over 64 years. It may be that these patients are at a greater risk of experiencing functional deterioration and therefore have the most to gain from an intervention targeted at improving their occupational performance.

5.7. HOME BASED OCCUPATIONAL THERAPY PROVISION

An explicit description of the content of the occupational therapy intervention was felt to be important in order to facilitate replication of the intervention in other locations. Collecting this information was difficult and it was accepted that the method of counting the number of times an intervention strategy occurred was crude and inaccurate as it gave no indication of the intensity of the strategy. Each treatment session was different, influenced by the patient's own goals and often several strategies were used at the same time. It was useful to use the standardised definitions of the Model of Occupational Performance to divide the intervention strategies into groups (23). Observation methods could have been used to record the intervention but this methodology is time consuming and was beyond the remit of this study. Further research could be carried out to improve methods of describing intervention, to achieve a consensus on a taxonomy of terms and to identify key components of the intervention.

Service planners setting up a similar service would need to consider travel costs/time. This would vary depending on the size of the service catchment area. Sufficient time should be allocated to allow a home based occupational therapist to travel and carry out clinical and indirect patient activities as well as direct patient contact.

Historically occupational therapy in the community has tended to focus on assessment and the provision of equipment (182). In this study a substantial amount of direct patient time was spent addressing occupational performance issues and involved actively practising occupational performance goals as well as assessment and the provision of equipment. This would suggest that treatment as well as assessment and information provision influences stroke patient outcome and further consideration should be given to the role of treatment after discharge.

CHAPTER SIX

CONCLUSION

Chapter Six

Conclusion

This study aimed to address some of the lifestyle difficulties faced by many stroke survivors when they arrive home after hospital admission. Many of these problems were described by stroke patients and health care workers during the pilot work for the project and identified in the current literature. A six weeks home based occupational therapy intervention programme was designed with consultation of patients and local therapists using focus groups and with reference to previous home based studies and the intervention was evaluated using a randomised controlled trial.

Several methods were used to maintain a rigorous, pragmatic evaluation of this new service including independent randomisation/ assessment and the use of an intention-to-treat analysis. Attempts were made to achieve "blinded assessment" but it was acknowledged that this was difficult to achieve and this may have influenced the study outcome, particularly at seven weeks.

Results from this study suggest that home based occupational therapy can improve the occupational performance outcome of stroke patients and that the intervention was also associated with a reduced risk of functional deterioration after discharge home. Patients who received home based occupational therapy were more satisfied with their occupational performance and received the adaptations and equipment that they required. The effect of the intervention was less marked at six months, however the overall reduction in the odds of deterioration was still apparent. A longer period of intervention may have maintained the initial effects of the intervention.

Home based occupational therapy did not appear to influence the "misery" after stroke and no differences were found in the subjective health experience of patients and carers between the two groups.

This study has several implications for current stroke rehabilitation practice. Consideration should be given to providing on-going occupational therapy for stroke patients after discharge home from hospital. Such a service could be client-centred, based on patient goals and focused on the assessment and treatment of self-care, domestic, work and leisure activities. It would aim to provide a bridge between hospital and home and have easy access to equipment and adaptations. Finally it should be responsive to patients needs, be able to provide intensive intervention, integrate patients into local community resources and terminate once all the patients goals have been addressed.

Further research could be carried out to:

- To investigate the provision of a home based occupational therapy intervention at an earlier stage of patient rehabilitation and the effect on the length of hospital stay.
- To investigate the influence of environmental settings on the effects of a stroke home based occupational therapy intervention e.g. rural versus city environments or deprived versus affluent areas.
- To investigate the outcome of stroke patients referred from General Practitioners who receive home based occupational therapy (patients not admitted to hospital).
- To investigate the effect of the length and intensity of home based occupational therapy on the outcome of stroke patients.
- To investigate the importance of staff skill mix in the provision of home based intervention, particularly the role of occupational therapy assistants.
- To develop reliable and valid outcome tools to measure the occupational performance of stroke patients with gross cognitive or perceptual problems.
- To develop reliable and valid outcome tools to measure discharge experience.
- To identify strategies to improve the long-term functional and psychosocial outcomes of stroke patients.
- To identify strategies that can improve the outcomes of carers of stroke patients.

It is hoped that this research will add information to the on-going debate on community stroke services and provide further evidence to support the contribution that occupational therapy can make to the rehabilitation and recovery of stroke survivors.

APPENDICES

APPENDICES

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Appendix A

A SYSTEMATIC REVIEW LITERATURE SEARCH

Search one

Using MEDLINE 1981 to May 1997

Set Number	Term searched or set combined
1	Cerebrovascular Disorders/rehabilitation (all documents)
2	Occupational therapy (all documents)
3	1 and 2
4	Limit 3 to English Language

Search two

Using CINAHL 1982 to 1997

Set Number	Term searched or set combined
1	Cerebral vascular accident/rehabilitation (all documents)
2	Occupational Therapy (all documents)
3	1 and 2
4	Home Occupational Therapy
5	1 and 4

Search three

Physiotherapy Index (1986-96) and Occupational Therapy Index (1996-97)

Key word = stroke

Appendix B

PILOT PROJECT: PATIENT INTERVIEWS

A Description of Participants

All the participants were male and were recruited from GRI acute medical wards. They lived at home with able wives and were experiencing functional difficulties since their stroke. The patient names are pseudonyms:

- James - 82 years old, length of hospital stay 24 days. He lived in a ground-floor flat, was previously active and worked as an upholsterer until he retired in his 70's.
- Gordon - 76 years old, length of hospital stay 34 days. He lived in a one-story house, was independent in self-care, enjoyed driving his car and getting out. He had experienced his second stroke and he also had an lower limb amputation.
- Robert - 72 year old, length of hospital stay 14 days. He lived in a one story house, previously enjoyed long walks but had been less active for several years. His family lived locally and were supportive.

Analysis of Patient Interviews

Inpatient care: Criticisms about in-patients experience varied and included a chaotic admission, outdated equipment, the distress of seeing others in pain, unsafe patient handling, unrealistic staff, confusion about medication, the hospital being an unrealistic environment. All three patients made positive comments about feeling confident in the friendly staff, nice food, good ward facilities, good relationships with other patients and informative books on stroke. Therapists were identified by their forenames and in contrast the term doctor and nurse were used by all the patients. The purpose of rehabilitation was not discussed and therapy sessions were described in several ways - as a test and a means of identifying problems. James viewed his discharge as being in the control of therapy and medical staff.

Discharge: All the patients wanted to leave hospital. "Getting back to familiar surroundings", was important to James and Gordon. Problems with discharge varied and were related to poor discharge arrangements, feelings of insecurity about abilities and humiliation.

Stroke experience: All the patients used negative words to describe their stroke experience. These included changes in mobility and balance, arm and leg weakness, problems with memory, unclear speech, feeling initially sick and unwell, high blood pressure, reduced vision, use of medication and tiredness. Gordon felt he had to make a "colossal effort" to do anything. All the patients described their stroke in functional terms, these included help to get to the bathroom, "not doing kitchen activities" and "not doing anything." All the patients described strong negative feelings. James felt humiliated and described feelings of isolation, of being a victim and feeling responsible for his stroke. Gordon described his stroke as a "colossal blow" and was worried about the effect it was having on his wife. Robert viewed his stroke as an unexpected and described fear for the future.

All the patients' comments were supported by their wives. James' wife felt there had been a change in her husband but that "it was getting back to normal." Gordon's wife described tearfully that she felt his "mild stroke was bad enough." Robert's wife was concerned about his mobility and felt that she had to make changes in her own routine to assist her husband.

Recovery: All the patients were able to identify improvements in function, believed that recovery was progressive and would take time. Gordon discussed limitations and was satisfied with the recovery of his walking and speech despite believing he might not achieve full function. He did feel that his expectations of domestic ability had not been reached and that his recovery was slower than anticipated due to fatigue and a lack of confidence. Robert contributed his lack of recovery to his wife, "I've not actually done anything, She'll not want me to do anything."

Appendix C
PILOT PROJECT: PATIENT FOCUS GROUP

Description of Participants (The names used are pseudonyms)

- Brian - stroke one year ago - problems manipulating objects in his left hand.
- Stan -stroke following cardiac surgery two years ago - has ataxia and dysarthria. -lives with his wife and young daughter - plans to retrain at University.
- Bob - sub-arachnoid haemorrhage seven years ago.
- Graham - a stroke a year ago - moderate left sided weakness and mild dysphasia.
- Bill -a sub-arachnoid haemorrhage 18 months ago - can walk short distances - has severe dysphasia and some cognitive difficulties.
- Steve walks short distances only - has a dense hemiplegia - stroke 2 years ago.
- Trevor - several strokes - is moderately disabled with some cognitive problems and expressive dysphasia.

Discussion Plan of Patient Focus Group

Introduction : The video camera and topic for discussion was introduced, confidentiality was assured. Participants were encouraged to be as open and forthright as they wished.

Brainstorm: Participants were asked to shout out any word that they felt described their stroke experience. Every word was written onto a flipchart by a researcher .

Card Exercise: Group members were asked to select their prime experience and these words were written onto cards by the researcher. The participants were then asked to place the cards in order of importance.

General discussion : The group was asked to describe the support services they had received since returning home. Finally group members were asked what they thought about their futures.

Analysis of patient focus group

The consensus categories developed were: - Living with a stroke. - Support after discharge

Living with a stroke

The word loss was used frequently by the group and it was agreed that stroke did not affect everybody in the same way. The group selected seven stroke experiences as having the most effect on life and placed them in the following order of importance: loss of confidence, not being able to do things the same, frustration, changes in personality, depression, physical change and fatigue.

Living with a stroke was coded using the following sub-categories:

a) Emotional Experiences: Emotional difficulties were discussed frequently. Steve described a "loss of spirit inside..... and then loss of confidence. You can't seem to do anything." Loss of confidence was selected as having the biggest effect on life after stroke. Depression, low mood were mentioned by the majority of the group members and emotional difficulties such as feelings of annoyance, lack of motivation and personality change were linked with social isolation. Stan suggested that "you become selfish. Your own needs come first. You become stubborn." Three group members felt that their personalities had changed since their stroke. Disinhibition was described by Stan as "what ever you have inside you, you must have held it back before but can't now," and Bob believed he was "quite outgoing at one point but not now."

b) Physical / cognitive experiences: Many of the group members described physical and cognitive changes. These included loss of fitness, power (strength), abilities, speech, eyesight, hearing, fine movements, sensation, physical shaking, slower reactions, not able to think/ understand, reduced orientation, brain damage. Four group members commented on loss of energy. Bob made a link between physical and emotional problems "Surely its all the physical problems that are causing you to be like this in the first place. Loosing your confidence, being frustrated and all the rest of it.... if you didn't have the physical problems you'd be okay." The group placed physical difficulties in the middle of a scale of "biggest effect on life."

c) Occupational Performance Experiences: Changes in occupational performance were described in general terms, specific lost abilities included squash, playing the piano, driving, dexterity, work, money difficulties and playing sports. Bob placed inability to work as one of the "biggest effects on life." The group summarised these activities into "not being able to do things the same." This was felt to have the second biggest effect on living with a stroke.

d) Recovery experiences: Recovery was described in negative and positive terms and included the permanency of brain damage, recovery of function and adaptation to disability. "Part of your brain is dead. Then through time some of it comes back? Not it all" (Brian). Stan had noticed that physical limitations had been a problem but he optimised what he could do and forgot about the things he could not do. He went on to say "I was told that you use about 10% of your brain and some of my brain has been dead. So you can use the other part of it."

Group members had mixed views about the future. Some believed their choices were influenced by external forces such as disability policy, lobbying by disabled rights campaigners, resources of local government, the lottery fund and the need for more stroke research. Other group members described internal influences on future choices. Brian believed that "you've got to make the most of it" and Stan was planning to go to University and eventually start up a new business "a stroke isn't the end, you don't just wait till you're dead." The two youngest group members Bob and Trevor were more negative about the future. Trevor just lived for each day and neither had any aspirations for the future.

Support after discharge

Formal support systems included bathroom adaptations by social services, the GRI stroke clinic, GP support, the physiotherapy exercise class, Welfare Rights Officer, Chest, Heart and Stroke (CHSS) Groups. Three group members felt they had received no support from formal organisations, with Stan suggesting that "they seem to drop you when you leave hospital". Stan described a fight for support and he experienced ineffective social work and DHSS support. Trevor felt that dysphasia had made it difficult for him to ask for support and Graham believed that many people dropped out of the statutory support system. Group members were more positive about the support provided by the voluntary organisation CHSS. Stan who recommended that "someone in authority who can tell you what to do" would be useful suggested the idea of a stroke co-ordinator/ advocate. Graham suggested that this type of service should be voluntary.

Family mainly provided informal support. Bill believed that you have to get on and do things yourself and an example of this was provided by Graham who provided his own banister rails at home. Stan described how initially he relied on his wife "to do most of the fighting for me because I wasn't capable myself."

Appendix D

PILOT PROJECT: OCCUPATIONAL THERAPY FOCUS GROUP

Discussion structure

The discussion was structured in the following way:

A brain storm. Group members were asked, "In an ideal world without resource constraints, what sort of follow-up service for stroke patients what you provide?" All ideas, however bizarre were written on a large sheet of paper.

The group was then asked:

Can you identify barriers that might limit a home based occupational therapy service for stroke patients? Are there solutions to overcoming the identified barriers? How could the new service be integrated into existing services?

Analysis of Occupational Therapy Focus Group

The categories and sub-categories developed were:

Beliefs

Throughout the discussion beliefs about the effects of stroke, discharge and occupational therapy were described and appeared to influence the views of the group on the proposed home based service. Beliefs was sub-categorised into:

a) The effects of stroke - Stroke was described by all the group members in negative terms, bringing "radical" change to patients lives, affecting the whole family, shock, denial, acceptance, reduced confidence and outdoor/social activity.

b) Discharge - Several group members believed that the hospital environment restricted patients from achieving independence and close staff supervision caused "learned helplessness" and loss of patient control. The hospital was viewed as a "protective" "cacooned environment," which "shielded" patients from the difficulties of managing at home. This was felt to result in some patients denying problems, with some wanting to get home so much but unable to accept the long-term lifestyle changes after stroke. Long admissions were perceived by one as detrimental because patients were away too long from home. Discharge was seen as an isolating and a difficult time of change for patients. Three groups members agreed that patients went through a period of adjustment and "coming to terms" with difficulties once at home.

c) Occupational therapy - The group described the therapeutic relationship as being beneficial to patients and the need for the service was not questioned. All the group members described occupational therapists as being autonomous professionals who made decisions and controlled intervention, a role termed as "case management" by the Head OT which she believed was a "fundamental and a core skill of occupational therapy." Two group members felt that handing back control to the patient was a goal of rehabilitation which included "facilitating" and "collaboration". This process was felt to be difficult to achieve in the hospital environment due to its medical emphasis.

Multiple factors were felt to influence therapy and some patients were felt to be "complexed." One group member suggested that physical recovery was not necessarily linked with a patients ability to manage at home. The group mentioned patient motivation, therapist/patient relationship, the presence of carer, service resources, environment and the extend the patient took responsibility for their own lives as influences on the success of rehabilitation.

Intervention was viewed as a holistic process which involved more that physical treatment. One group member suggested that occupational therapists should be involved "at every level, including resources within the environment." Intervention was not viewed as structured and prescriptive but "adaptable" and "flexible" and dependent on the needs of the patient

Setting up the service:

Limitations of the present service were discussed. Three group members felt that a lack of follow-up caused patients to regress in function, created isolation and prevented them from reaching their full potential. Present out-patient services were seen as limited in their ability to deal with community issues and lacked client-centredness. Both the head and day hospital occupational therapist agreed that day hospital intervention in particular was "specific", "organised around medical issues" and "limited because it doesn't give the real picture of home." The head OT anticipated that a home based service would offer a more flexible system than current social services occupational therapy services which she believed were "disintegrated" and "prescriptive" and did not offer treatment to stroke survivors.

Aims of the new research service:

a) Bridge between hospital and home - Which supported the patient through discharge and handed over to community services. Hospital occupational therapists were felt to be in a position to carry out this role because they had established relationships with patients, and issues "identified in hospital could be taken into the home situation."

b) To provide a realistic service that is relevant to patients needs - The home was viewed as a more realistic environment to treat stroke patients. Community integration which assisted patients to get back to "things they did before their stroke" and involved using community resources was emphasised. Client-centredness through which patients could judge their own performance and set their own goals was viewed as important and one group member suggested that the service should be "socially and not medically focused." Reducing "dependence", so that "you can withdraw" was also highlighted.

c) To provide treatment as well as equipment provision - the new service should do more than provide equipment, it should involve assessment and treatment.

d) Integration with existing services - This would involve linking the patient up with other services and training staff such as homehelps. This was described by the basic grade as "a mixed role" - of purchasing services from other people and providing therapy services. Links could be made with the hospital service by setting joint home programmes, verbal handover including the patients notes and joint therapy/homevisit sessions.

Service operation

- Who should provide the service? - hospital occupational therapists and occupational therapy assistants.
- Where should the intervention occur? - the patients home and the community e.g. visiting the shops, going for a walk, doing a leisure activity.

- When should the intervention happen? - No consensus was reached on when to start the service. Suggestions ranged from starting on day of discharge to avoid crisis, to a week after discharge to allow patients' time to adjust to life at home. All agreed that the service needed to be slowly withdrawn, possibly once the community services or day hospital services were established or when the plans from the in-patient homevisit had been carried out. The time scale varied from two to six months.
- How should the intervention be carried out? The use of flexible, individualised structured programmes which continued hospital intervention, established new goals and graded intervention were proposed.
- What should the intervention consist of? - Assessment, motor relearning, maintaining activities of daily living, upper limb programmes, vocational advice, activities outside of the house, leisure activities, using community resources, joint work with community staff, provision of education/information, support to patients/carers, changing the patients environment.

Potential limitations

These included limitations in resources such as staff to carry out the intervention, the time consuming nature of community intervention and the lack of specialist rehabilitation facilities for some patients. The day hospital OT pointed out that the day hospital with its access to the multi-disciplinary team might be more appropriate for some patients. Role conflict with other professionals such as the liaison health visitors and the bureaucracy of community services were also discussed. These limitations however were not presented as insurmountable and the group did offer some solutions such as increasing staffing levels and decreasing in-patients caseload, finding relevant, realistic local community resources.

Appendix E

INFORMATION FOR PATIENTS, THEIR FAMILIES AND FRIENDS

Many people continue to need support from hospital services after they have returned home after a stroke. One such service that is sometimes offered is occupational therapy. At the moment we are not certain of the best way to provide occupational therapy after you go home. Until we know we cannot properly organise help for people who have suffered a stroke.

We are therefore planning to carry out a study at the Glasgow Royal Infirmary to test the usefulness of occupational therapy. To do this we will compare the experiences of groups of people with a stroke who receive occupational therapy either at the clinic or through visits at home.

We would like you to help us with this study. To do this we would first like to find out how your stroke has affected you. We will then provide you with one of the occupational therapy services already mentioned. After a period of time we will contact you again and ask you about your experiences.

Joining this study will not affect your right to any other treatment or care you need. You can withdraw from the study at any time. All the information we collect will be kept safely and confidentially and will only be used for research purposes.

We hope that you will help us as we try to improve the care for people who have had a stroke by joining this study.

THANKYOU

If you would like more information please contact Louise Gilbertson (Research Occupational Therapist) by phone on 0141-211-1514.

Consent form

I agree to help with this study, the purpose of which is to find out what type of occupational therapy is best for people who have suffered a stroke.

I understand that I am free to leave this study at any stage and need to give no explanation if I choose to do so. If I leave the study this will not influence any other or future treatment that I might need.

I understand that all the information gathered about me will be kept confidentially and only used for research purposes.

Consent

I,(name)..

of(address)..

....agree to take part in the research project described above. Mrs Gilbertson has explained to me what I have to do, how it might affect me and the purpose of the research project.

Signed........................ Date ....

Witness .... Date ....

Appendix G
BASELINE INFORMATION FORM

Patient Details

Hospital No.
Name
Address
Postcode (DEPCAT grouping) ☐ 1
Date of Birth ☐☐☐☐☐☐☐ 2
Age ☐☐ 3
Telephone No.
Marital Status Single/widowed = 1 Separated/divorced = 2 Married = 3 ☐ 4

GP Details

Name
Practice Address
Tel. Number

Carers Details

Living with another 0 = No 1 = Yes ☐ 6
Presence of carer at home. 0 = No 1 = Yes ☐ 7

Status of main carer

1. Partner (male)	6. Partner (female)
2. Brother	7. Sister
3. Son (in-law)	8. Daughter (in-law)
4. Grandson	9. Granddaughter
5. Friend/Neighbour	10. Professional
	11. Other family member

Name................................
Address..........................
....
Tel:...................................
8.

Admission Details

Date of CVA ☐☐☐☐☐☐ 9
Date of Admission ☐☐☐☐☐☐ 10
Date of Baseline Assessment ☐☐☐☐☐☐ 11
Date of Discharge to Home ☐☐☐☐☐☐ 12

Pre-Stroke Status

Previous CVA 0 = No 1 = Yes ☐ 13

Pre-stroke Oxford Handicap Scale "Rankin"
0 = well, no symptoms
1 = Minor symptoms affecting lifestyle
2 = minor handicap but independent in selfcare
3 = moderate handicap, needing a little help with ADL
4 = needing a lot of help with ADL
5 = needing constant attention day and night ☐ 14

Pre-stroke mobility
1 = able to walk 200m outside   2 = able to walk indoors
3 = unable to walk without help   ☐ 15

Home-help
0 = No   1 = Home-help (1-2 times per week)
2 = Homehelp (>twice per week)   3 = Other   ☐ 16

Meals on wheels
0 = No   1 = yes   ☐ 17

Regular district nursing input
0 = No   1 = yes   ☐ 18

Employment
1 = paid work   2 = unemployed
3 = retired (previously employed)   4.= housewife (unpaid)   ☐ 19

Characteristics at study entry

Side of lesion	0 = Right	1 = Left	☐	20
Hemiparesis	0 = No	1 = Yes	☐	21
Hemisensory loss	0 = No	1 = Yes	☐	22
Visual/spatial inattention	0 = No	1 = Yes	☐	23
Hemianopia	0 = No	1 = Yes	☐	24
Dysphasia	0 = No	1 = Yes	☐	25
Brain-stem/cerebellar	0 = No	1 = Yes	☐	26
Cognitive impairment	0 = No	1 = Yes	☐	27
Anxiety	0 = No	1 = Yes	☐	28
Depression	0 = No	1 = Yes	☐	29

Relevant problems which might influence completion of assessments

……………………………………………………………………………………………………

……………………………………………………………………………………………………

……………………………………………………………………………………………………

……………………………………………………………………………………………………

STRATIFICATION CRITERIA

REFERRAL TO DAY HOSPITAL   0 = No   1 = Yes   ☐ 30
GENDER   0 = Male   1 = Female   ☐ 31

APPENDIX H

PATIENT DISCHARGE QUESTIONS

Before discharge patients were asked two questions:

1. "Would you agree with this statement, I think I will be able to cope at home".

Patients chose one of four responses. Strongly agree, agree, disagree and strongly disagree.

2. "How do you think you will be able to carry out your normal everyday activities once you are at home?".

Patients chose one of four responses. Well, Okay, Poorly, Don't know.

At seven weeks after discharge to home, patient were asked:

1. "Would you agree with this statement, I think I am coping at home."

Patients chose one of four responses. Strongly agree, agree, disagree and strongly disagree.

2. "How well do you think you are able to carry out your normal everyday activities."

Patients could choose one of four responses. Better than expected, as expected, worse than expected, much worse than expected.

Appendix L

THE CANADIAN OCCUPATIONAL PERFORMANCE MEASURE

Ask the patient to choose their 5 most important problems at this present time in self-care, productivity and leisure and record them below. Use the scoring cards, ask the patient to rate their performance and satisfaction of each problem out of ten points. Calculate the total scores.

1. Performance Scoring Card - How would you rate the way you do this activity now?

1 2 3 4 5 6 7 8 9 10

Not able to do it at all — able to do it extremely well

2. Satisfaction Scoring Card - How satisfied are you with the way you do this activity?

1 2 3 4 5 6 7 8 9 10

Not satisfied at all — extremely satisfied

Occupational Performance Problems	Performance Score	Satisfaction Score
1.		
2.		
3.		
4.		
5.		

Total performance score
(Total of performance scores divided by number of problems)

Total satisfaction score
(Total of satisfaction scores divided by number of problems)

Appendix I
OCCUPATIONAL THERAPY DISCHARGE PLAN

1. Was a home visit carried out before discharge? 0 = No 1 = Yes ☐ 1
2. Did the patient go on home leave before discharge? 0 = No 1 = Yes ☐ 2

3. Have any discharge arrangements been made for:

OT home therapy programme	0 = No 1 = Yes	☐	3
Hospital OT/A to fit equipment	0 = No 1 = Yes	☐	4
District nurse	0 = No 1 = Yes	☐	5
GP	0 = No 1 = Yes	☐	6
Physiotherapist	0 = No 1 = Yes	☐	7
Speech Therapist	0 = No 1 = Yes	☐	8
Health Visitor	0 = No 1 = Yes	☐	9
Day hospital	0 = No 1 = Yes	☐	10
Chiropodist	0 = No 1 = Yes	☐	11
Community OT	0 = No 1 = Yes	☐	12
Social Worker	0 = No 1 = Yes	☐	13
Homehelp organiser	0 = No 1 = Yes	☐	14
Homehelp	0 = No 1 = Yes	☐	15
Meals on wheels	0 = No 1 = Yes	☐	16
Day Centre	0 = No 1 = Yes	☐	17
Living with a stroke	0 = No 1 = Yes	☐	18
Stroke Clinic	0 = No 1 = Yes	☐	19
Other (name)	0 = No 1 = Yes	☐	20

4. Has adaptive equipment been requested from the COT? 0 = No 1 = Yes ☐ 21

List *1.*	*4.*	
2.	*5.*	*Total*
3.	*6.*	

5. Have alterations to property been requested from the COT? 0 = No 1 = Yes ☐

List *1.*	*4.*	
2.	*5.*	*Total*
3.	*6.*	

6. Has a referral been made to ALAC wheelchair services for equipment to be provided after discharge home? 0 = No 1 = Yes ☐

List 1.	*3.*	*Total*
2.	*4.*	

7. Do you think this patient would benefit from a domiciliary OT service? 0 = No 1 = Yes ☐

Appendix J
THE BARTHEL INDEX

1. In the last week, have you managed to get in **and** out of the bath or shower **and** wash yourself:

without any help	1
only with help or have not managed	0

2. In the last week, have you managed to go up and down the stairs:

without any help (must carry walking aid)	2
with a walking aid or help (including help to carry walking aid)	1
Unable to manage	0

3. In the last week, have you managed to get your clothes out, put them on **and** fasten them:

without any help	2
with help, does half, can put on some garments alone (help with buttons)	1
unable to manage without help	0

4. In the last week, have you managed to walk around your home:

without any help, or with the help of a walking aid only	3
with one persons help/supervising you	2
uses a wheelchair on the ward without any help, able to negotiate corners and doors	1
immobile/uses wheelchair with help	0

5. In the last week, have you managed to get from your bed and back again:

without help	3
with help from one person to supervise or assist	2
with a lot more help from one or more people, can sit	1
unable, no sitting balance	0

6. In the last week, once your meals are prepared (by yourself or someone else) and placed in front of you, have you managed to **feed** yourself:

without help	2
with help to cut or spread only	1
have you needed more help than this	0

7. In the last week, when you used the toilet or commode, have you managed to get to the toilet or commode, get on and off, undress and dress, and clean yourself:

without help	2
with help to undress/dress or get on or off (able to clean self without help)	1
have needed more help than this	0

8. In the **last two days,** have you managed to do **all** of the following (even if someone has handed you the things you need): clean your teeth, wash your face, brush your hair, fit your false teeth and shave (men only):

without help.. 1
help needed to do one or more of the tasks............. 0

9. In the last **week,** have you had full control of your bladder?

Yes (manages catheter without help)................................ 2
Occasional accident (not more than once a day)................. 1
Frequent accident (more than once a day) or manages catheter with help... 0

10. In the last **week,** have you had full control of your bowels?

Yes... 2
Occasional accident (not more than once a week)............... 1
Frequent accident (more than once a week).......................... 0
Required enema/suppositories to open bowels..................... 0

11. TOTAL BARTHEL ☐☐

Appendix K

THE NOTTINGHAM EXTENDED ACTIVITIES OF DAILY LIVING

For the following activities please record only what you have actually done since your stroke and not what you think you could do, ought to do or would like to do. **PLEASE TICK ONE BOX FOR EACH QUESTION**

	No	I need help	On my own but with difficulty	Alone easily
1. Can you walk around outside?				
2. Can you climb stairs?				
3. Can you get in and out of the car?				
4. Can you walk over uneven ground?				
5. Can you cross roads?				
6. Can you travel on public transport?				
7. Can you feed yourself?				
8. Can you manage to make yourself a hot drink?				
9. Can you take hot drinks from one room to another?				
10. Can you do the washing up?				
11. Can you make yourself a hot snack?				
12. Can you manage you money when you are out?				
13. Can you wash small items of clothing?				
14. Can you do your own housework?				
15. Can you do your own shopping?				
16. Can you do a full clothes wash?				
17. Can you read newspapers or books?				
18. Can you use the telephone?				
19. Can you write letters?				
20. Can you go out socially?				
21. Can you manage your own garden?				
22. Can you drive a car?				

Appendix M

Dartmouth Coop Function Charts

(Reproduced, with permission, from Nelson, E. C., Landgraf, J. M., Hays, R. D., Kirk, J. W., Wasson, J. H., Keller, A., and Zubkoff, M. (1990). *Functional Status Measurement in Primary Care*, WONCA Classification Committee. New York, Springer)

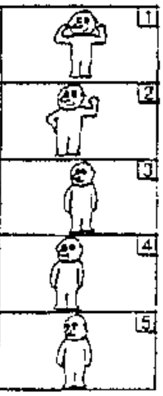
PHYSICAL CONDITION

During the past 4 weeks...
What was the most strenuous level of physical activity you could do for at least 2 minutes?

Very heavy, e.g. Run, fast pace Carry heavy bag of groceries upstairs	1
Heavy, e.g. Jog, slow pace Climb stairs at moderate pace	2
Moderate, e.g. Walk, fast pace Garden, easy digging Carry heavy bag of groceries	3
Light, e.g. Walk, regular pace Golf or vacuum Carry light bag of groceries	4
Very light, e.g. Walk, slow pace Drive car Wash dishes	5

EMOTIONAL CONDITION

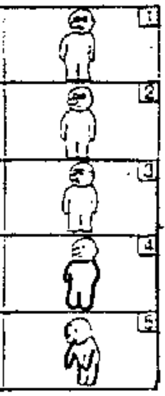
During the past 4 weeks...
How much have you been bothered by emotional problems such as feeling unhappy, anxious, depressed, irritable?



Not at all	1
Slightly	2
Moderately	3
Quite a bit	4
Extremely	5

DAILY WORK

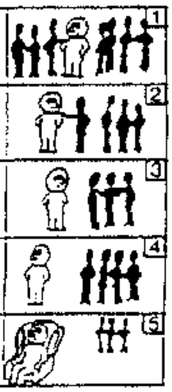
During the past 4 weeks...
How much difficulty did you have doing your daily work, both inside and outside the house, because of your physical health or emotional problems?



No difficulty at all	1
A little bit of difficulty	2
Some difficulty	3
Much difficulty	4
Could not do	5

SOCIAL ACTIVITIES

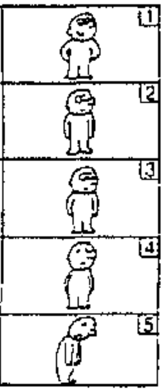
During the past 4 weeks...
To what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbours or groups?



Not at all	1
Slightly	2
Moderately	3
Quite a bit	4
Extremely	5

PAIN

During the past 4 weeks...
How much bodily pain have you generally had?



No pain	1
Very mild pain	2
Mild pain	3
Moderate pain	4
Severe pain	5

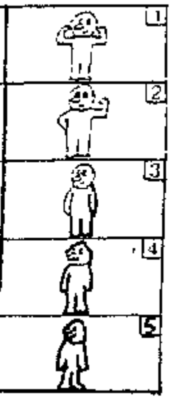
CHANGE IN CONDITION

How would you rate your physical health and emotional condition now compared to 4 weeks ago?

Much better	++	1
A little better	+	2
About the same	±	3
A little worse	−	4
Much worse	−−	5

OVERALL CONDITION

During the past 4 weeks...
How would you rate your overall physical health and emotional condition?



Excellent	1
Very good	2
Good	3
Fair	4
Poor	5

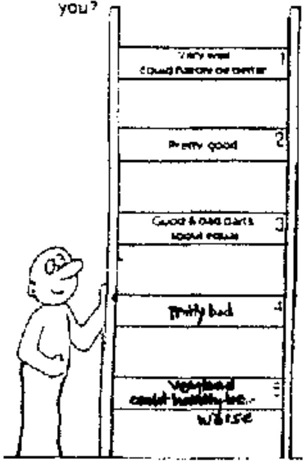
SOCIAL SUPPORT

During the past 4 weeks...
Was someone available to help you if you needed and wanted help? For example if you
—felt very nervous, lonely, or blue
—got sick and had to stay in bed
—needed someone to talk to
—needed help with daily chores
—needed help just taking care of yourself

Yes, as much as I wanted	1
Yes, quite a bit	2
Yes, some	3
Yes, a little	4
No, not at all	5

QUALITY OF LIFE

How has the quality of your life been during the past 4 weeks? i.e. How have things been going for you?



Appendix N
THE EUROQUOL

Mobility

I have no problems in walking around = 0
I have some problems in walking around = 1
I am confined to bed = 2 ☐

Self-care

I have no problems with self-care = 0
I have some problems with self-care = 1
I am unable to wash or dress myself = 2 ☐

Usual activities

I have no problems with performing my usual activities = 0
I have some problems with performing my usual activities = 1
I am unable to perform my usual activities = 2 ☐

Pain/discomfort

I have no pain or discomfort = 0
I have moderate pain or discomfort = 1
I have extreme pain or discomfort = 2 ☐

Anxiety/Depression

I am not anxious or depressed = 0
I am moderately anxious or depressed = 1
I am extremely anxious of depressed = 2 ☐

Compared with my general health level over the past 12 months, my health state today is:

Better = 0
Much the same = 1
Worse = 2 ☐

To help people say how good or bad a health state is I have drawn a scale (rather like a thermometer) on which the best state you can imagine is marked by 100 and the worse state you can imagine is marked by 0.

I would like you to indicate on this scale how good or bad is your health today, in your opinion. Please do this by drawing a line from this box below to whichever point on the scale indicates how good or bad your current health state is.

Current health state score ☐☐

Appendix O
THE LONDON HANDICAP SCALE

This questionnaire asks six questions about your everyday 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 can do with what someone like you who is in good health can do

Getting Around (Mobility)

Think about how you get from one place to another, using any help, aids or means of transport that you normally have available

Does you health stop you from getting around ?

1. Not at all: You go every where you want to, no matter how far away
2. Very slightly: You go most places you want to, but not all
3. Quite a lot: You get out of the house, but not far away from it
4. Very much: You don't go outside, but you can move around indoors
5. Almost completely: You are confined to a single room, but can move around in it.
6. Completely: You are confined to a bed/chair. You cannot move around at all. There is no-one to move you

Looking after yourself (Physical independence)

Think about things like housework, shopping, looking after money, cooking, laundry, getting dressed, washing, shaving and using the toilet

Does your health stop you looking after yourself?

1. Not at all: You can do everything yourself
2. Very slightly: Now and again you need a little help
3. Quite a lot: You need help with some tasks (heavy housework, shopping), but no more than once a day
4. 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
5. Almost completely: You need help available all the time, you cannot be left alone safely
6. Completely: You need help with everything. You need constant attention, day/night

Work and Leisure (Occupation)

Think about work (paid or not), housework, gardening, sports, hobbies, going out with friends, travelling, reading, looking after children, watching television and going on holiday

Does you health limit your work or leisure activities?

1. Not at all: You can do everything you want to do
2. Very slightly: You can do almost all the things you want to do
3. Quite a lot: You find something to do almost all the time, but cannot do some things for as long as you would like
4. Very much: You are unable to do a lot of things, but can find something to do most of the time
5. Almost completely: You are unable to do most things, but can find something to do some of the time.
6. Completely: You sit all day doing nothing. You cannot keep yourself busy or take part in any activities

Getting on with people (Social integration)
Think about family, friends and the people that you might meet in a normal day

Does your health stop you getting on with people?
1. Not at all: You get on well with people, see everyone you want to and meet new people
2. Very slightly: You get on well with people, but your social life is slightly limited
3. Quite a lot: You are fine with people you know well, but you feel uncomfortable with strangers
4. 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
5. Almost completely: Apart from the person who looks after you, you see no-one. You have no friends and no visitors
6. Completely: You don't get on with anyone, not even people who look after you

Awareness of your surroundings (Orientation)
Think about taking in and understanding the world around you. finding your way around in it

Does your health stop you understanding the world around you?
1. Not at all: You fully understand the world around you. You see, hear, speak and think clearly and you memory is good
2. Very slightly: You have problems with hearing, speaking, seeing, your memory, but these do not stop you doing most things
3. Quite a lot: You have problems with hearing, speaking, seeing, your memory which make life difficult a lot of the time. But, you understand what is going on
4. Very much: You have great difficulty understanding what is going on
5. Almost completely: You are unable to tell where you are or what day it is. You cannot look after yourself at all
6. Completely: You are unconscious, completely unaware of anything going on around you

Affording the things you need (Economic self-sufficiency)
Think about whether health problems led to any extra expenses, or have caused you to earn less than you would if you were healthy

Are you able to afford the things you need?
1. Yes, easily - You can afford everything you need. You have easily enough money to buy modern labour-saving devices, that you may need because of ill-health
2. Fairly easily - You have just enough money. It is fairly easy to cope with expenses caused by ill health
3. Just about - You are less well off than other people like you; however, with sacrifices you can get by without help
4. 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
5. No - You are dependent on state benefits, or money from other people or charities. You cannot afford things you need
6. Absolutely not -you have no money at all and no state benefits. you are totally dependent on charity for your most basic needs

Appendix P

GENERAL HEALTH QUESTIONNAIRE (GHQ 12)

Name:..Date:..................

Please read this carefully.

We should like to know if you have had any medical complaints and how your health had been in general, over the last few weeks. Please answer the questions simply by underlining the answer which you think most nearly applies to you. Remember that we want to know about present and recent complaints, not those that you had in the past.

It is important that you try to answer ALL the questions.
Thank you very much for your co-operation.

Have you recently…				
1. Been able to concentrate on whatever you're doing?	Better than usual	Same as usual	Less than usual	Much less than usual
2. Lost much sleep over worry?	Not at all	No more than usual	Rather more than usual	Much more than usual
3. Felt that you are playing a useful part in things?	More so than usual	Same as usual	Less useful than usual	Much less useful
4. Felt capable about making decisions about things?	More so than usual	Same as usual	Less so than usual	Much less than usual
5. Felt constantly under strain?	Not at all	No more than usual	Rather more than usual	Much more than usual
6. Felt you couldn't overcome your difficulties?	Not at all	No more than usual	Rather more than usual	Much more than usual
7. Been able to enjoy your normal day to day activities?	More so than usual	Same as usual	Less than usual	Much less than usual
8. Been able to face up to your problems?	More so than usual	Same as usual	Less so than usual	Much less than usual
9. Been feeling unhappy and depressed?	Not at all	No more than usual	Rather more than usual	Much more than usual
10. Been losing confidence in yourself?	Not at all	No more than usual	Rather more than usual	Much more than usual
11. Been thinking of yourself as a worthless person ?	Not at all	No more than usual	Rather more than usual	Much more than usual
12. Been feeling reasonably happy, all things considered	More so than usual	About the same as usual	Less so than usual	Much less than usual

Appendix Q
PATIENT SATISFACTION WITH SERVICES

We are keen to know about your experiences when you returned home after your stroke and would be grateful if you could complete this questionnaire. All the information is strictly confidential and will only be used to help improve our services.

Please read each statement and tick the answer which is nearest your view. There is no right of wrong answer, it is your opinion we are interested in.

I am happy with the amount of recovery I have made	Agree ☐	Disagree ☐
I am satisfied with the amount of treatment the therapists have given me	Agree ☐	Disagree ☐
I was given all the information I needed about the allowances or services I might need	Agree ☐	Disagree ☐
Things were well prepared for my return home	Agree ☐	Disagree ☐
I get all the support I need from services such as meals-on-wheels, homehelps, etc	Agree ☐	Disagree ☐
I am satisfied with the out-patient services provided by the hospital	Agree ☐	Disagree ☐
I am satisfied with the practical help I have received since I left hospital	Agree ☐	Disagree ☐
I have received enough information about recovery and rehabilitation	Agree ☐	Disagree ☐
Somebody has really listened and understood my needs and problems since I left	Agree ☐	Disagree ☐
I have not felt neglected since I left hospital	Agree ☐	Disagree ☐
I have received enough special equipment	Agree ☐	Disagree ☐
I know who to contact if I have problems related to my stroke	Agree ☐	Disagree ☐

Appendix P
Number Needed to Treat

At Seven Weeks

$$\text{NNT} = \frac{\text{No. of control patients died or deteriorated (Barthel Index) at 7 weeks}}{\text{Total population of control patients}}$$

$$\frac{30}{71} = 0.42 = 42\%$$

$$\frac{\text{No. of treatment patients died or deteriorated (Barthel Index) at 7 weeks}}{\text{Total population of treatment patients}}$$

$$\frac{16}{67} = 0.24 = 24\%$$

A home based occupational therapy service is associated with an 18% reduction in death and deterioration at seven weeks after discharge.

That means that for every 100 patients treated, 18 are prevented from deteriorating.

So to prevent one patient deteriorating $\frac{100}{18}$ = (5.5) six patients would be needed to be treated.

At Six Months

$$\text{NNT} = \frac{\text{No. of control patients died or deteriorated (Barthel Index) at 6 months}}{\text{Total population of control patients}}$$

$$\frac{41}{67} = 0.61 = 61\%$$

$$\frac{\text{No. of treatment patients died or deteriorated (Barthel Index) at 6 months}}{\text{Total population of treatment patients}}$$

$$\frac{33}{66} = 0.50 = 50\%$$

A home based occupational therapy service is associated with an 11% reduction in death and deterioration at six months after discharge.

That means that for every 100 patients treated 11 are prevented from deteriorating.

So to prevent one patient deteriorating $\underline{100}$ = (9.1) nine patients would be needed to be treated.

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