Occupational therapy to improve outdoor mobility after stroke

by

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CONTRIBUTION BY AUTHOR and ACKNOWLEDGEMENTS

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ABSTRACT

People who have suffered a stroke can become housebound and miserable because they cannot access suitable transport. They can have difficulty getting to the shops, doctors and hospital and this can have an effect on their quality of life. Occupational therapists routinely aim to help these people overcome their outdoor mobility problems by providing information and verbal instructions but these interventions do not appear to be effective. The aim of this research was to design and evaluate a new occupational therapy outdoor mobility intervention. The intervention was modeled on travel training that is provided for other conditions and the outdoor mobility experiences and needs of people with stroke.

Qualitative semi structured interviews were used to investigate 24 peoples experiences of both using transport and their outdoor mobility after they had suffered a stroke. It was found that people wanted to travel for a variety of reasons; shopping, work, getting to the doctors, social reasons, meeting friends, visiting family and just for the sake of traveling. People were prevented from traveling because of physical difficulties such as stepping onto the bus, psychological problems such as confidence and environmental barriers such as the weather or lack of information. The results were used to define the main components of an Occupational Therapy Outdoor Mobility Intervention.

A randomised controlled trial was used to evaluate the effects of this Occupational Therapy Outdoor Mobility Intervention (OTOMI) by comparing it to the routine occupational therapy intervention. Participants with stroke in

the last 36 months were recruited from primary care services and randomly allocated to receive either the OTOMI or the routine occupational therapy. Participants in the OTOMI received up to seven individualised occupational therapy sessions. The sessions aimed to increase confidence, encourage use of different types of transport and provided tailor-made information. Outcomes were measured by postal assessment 4 and 10 months after recruitment. The primary outcome measure was a yes/ no question, Do you get out of the house as much as you would like? Secondary outcomes included the number of journeys, mood, performance of activities of daily living and leisure.

168 participants who had had a stroke in the last 36 months were recruited into the study over eighteen months, 82 in the control group and 86 to the OTOMI group. 10 people were unable to provide follow-up information at the four month assessment and 21 people at the ten month assessment. Intention-to-treat analyses were undertaken. For the principal outcome measure, participants who were dead at the point of assessment were allocated the worst outcome, and for others lost to follow up their baseline or last recorded responses were used. For the other analyses all missing values were imputed using baseline values.

Participants in the treatment group were more likely to get out of their house as often as they wanted at 4 months (RR 1.72, 95% CI 1.25 to 2.37) and at 10 months (RR 1.74, 95 CI 1.24 to 2.44). The treatment group recorded more journeys outdoors in the month prior to assessment at 4 months (intervention group median 37, control group median 14, Mann-Whitney $p<0.01$) and at 10 months (intervention group median 42, control group median 14, Mann-

Whitney: $p<0.01$). At 4 months the NEADL mobility scores were significantly higher in the intervention group, but there were no significant differences in the other secondary outcomes. There were no significant differences in these measures at 10 months.

The interview study demonstrated that participating in outdoor mobility is a major problem for people who have had a stroke. The randomised controlled trial demonstrated that a relatively simple and feasible, individualized, properly organised, focused and adequately resourced occupational therapy outdoor mobility intervention can increase participation in outdoor mobility activities, allowing people to get out of the house as much as they wish.

Chapter 1

Introduction

1.1 SUMMARY OF CHAPTER

Stroke can have a devastating effect on people's lives, leaving them physically and psychologically damaged and often unable to continue with their normal activities. Activity or occupation is essential for a good quality of life, yet people who have had a stroke can find it difficult to maintain activity due to a lack of suitable transport. There is evidence that elderly people can find it difficult to participate in outdoor mobility because of inaccessible services, an inability to carry heavy loads whilst using transport and a fear of crime. For people who have suffered a stroke, these barriers may be exacerbated by physical or cognitive limitations. This diminution of quality of life provides the justification for interventions aimed at enhancing outdoor mobility for those with mobility restrictions.

Travel Training, Travel Awareness and Travel Blending are interventions used in both the United States of America and in Australia to increase participation in outdoor mobility activities for people who have mobility restrictions. These interventions have not been formally evaluated, but generally follow a programme of practice using one route and one type of transport. Studies of mobility restricted people in the United Kingdom have shown that this type of mobility intervention may not be appropriate, as the barriers to, and needs of outdoor mobility are diverse.

Occupational therapists are responsible for providing interventions aimed at improving participation in the occupation of outdoor mobility after stroke. Occupational therapy uses a combination of purposeful activities to restore

physical function, reduce psychological barriers and tackle social issues with the aim of improving task performance. Occupational therapists may provide equipment, information and adaptations to a person's environment to enable participation in activities of daily living. There is evidence that at present, occupational therapists provide written and verbal information for outdoor mobility problems, but these interventions do not appear to improve performance in outdoor mobility.

It is hypothesised that if an occupational therapy intervention in the United Kingdom were to be effective at improving outdoor mobility it needs to be modeled on a combination of published information, experiences and requirements of potential users and occupational therapy core skills. Using this process the best intervention for evaluation can be produced. This was the remit of the work contained in this thesis.

1.2 LITERATURE SEARCH HISTORY

A variety of search techniques were employed to identify published studies of the barriers to outdoor mobility and the therapeutic interventions aimed at improving performance in outdoor mobility activities. An initial search included only people who had had a stroke, but this produced few studies. The search was widened to include older people and people with a disability other than that resulting from a stroke. Searches were performed using Medline (1966–2003), Allied and Complementary Medicine Database (AMED) (up to 2003), Cumulative Index for Nursing and Allied Health Literature (CINAHL) (1982–2003), ASSIA (Applied Social Sciences Index Abstracts), Web of Science, Sociological Abstracts and the Cochrane Library. The database searches were limited to articles published in the English language using the following combinations of keywords:

Stroke	Stroke patients Cerebrovascular accident Cerebrovascular disorders Stroke
Rehabilitation	Rehabili$ International Classification of Functioning Disabilities Therapy Home$ Occupational Therapy Aids and appliances Activities of Daily Living Occupational Therapy process Physiotherapy Occupational Science Caregiver Burden Caregiver support

Mobility	Physical mobility Mobili$ Automobile driving Driving Transport$ Transport alternatives Public services Cars Buses Community transport Travel Training
Social aspects	Community living Isolation Leisure activities Leisure Social adjustment Social isolation Social integration Social reintegration Social performance Independence Community reintegration Community participation Community access Social support Quality of life Rural deprivation Accessibility GP services

The reference list of each article found was checked for new citations and these papers were obtained. In order to make research findings of transport studies more accessible to the public, they are often disseminated through less formal academic avenues. Information was therefore also collected from reports, email and personal communications with the Department of Transport, charity and local transport publications and non-indexed journals.

1.3 BACKGROUND

This section examines the definition of stroke, the effects of stroke on people and carers and the rehabilitation available. The literature chosen for presentation is that which relates to outdoor mobility.

1.3.1 Stroke

1.3.1.1 Definition of stroke

The World Health Organisation (WHO) defines a stroke as:

Rapidly developing clinical signs or symptoms of focal (or global) disturbance of cerebral function, lasting more than 24 hours, or that leads to death, with no apparent cause other than vascular origin. (Aho et al, 1980).

There are several clinical sub-types of stroke, but the pathology of the stroke is usually an infarction (80%), where an artery serving the brain is blocked, disrupting the blood supply, or sometimes a haemorrhage (20%) where a blood vessel in or around the brain bursts. A clinical diagnosis of stroke as provided by a General Practitioner was used in this thesis. However, the research does not rely on the cellular damage caused by stroke, but the limitations in every day activities experienced.

1.3.1.2 Incidence and prevalence of stroke

Globally, stroke is the second leading cause of death (World Health Organisation, 2002) and in the UK it is the fourth highest cause of death (Royal

College of Physicians, 2002). Thirty three percent of people who have a stroke will die (Wade and Langton-Hewer, 1987) and 53% will still be dependent on other people six months later (Feigin et al, 2003). The NHS spends 4% of its financial resources on stroke (Wade, 1992) and with stroke being the biggest single cause of major disability in the community, there are hidden costs to carers, families and community services (Wade, 1992).

1.3.1.3 Effects of stroke

The physical damage to the brain caused by a stroke can produce a wide range of effects that will depend on the type of stroke, the part of the brain affected and the extent of brain damage. The effects may include:

- *Weakness (hemiparesis) or paralysis (hemiplegia)* – leading to difficulties in walking, movement or coordination usually affecting one side of the body.
- *Lack of sensation* – problems with tactile sensation and the feeling of where the limbs are in space.
- *Swallowing difficulties* – the mechanisms to assist with eating or drinking can be effected.
- *Speech or language difficulties* – such as difficulties in understanding, speaking, reading, writing and calculation known as dysphasia or aphasia.
- *Problems of perception* – difficulties in recognising or being able to use everyday objects e.g. a kettle or teapot, difficulties in telling the time, and problems interpreting what the eyes see, even when vision is not affected.

- *Cognitive difficulties* - these include problems caused by damage to areas of the brain controlling mental processes such as thinking clearly and logically, sequencing activities, learning, paying attention, memory, decision-making and forward planning.
- *Behaviour changes* - these may include being slower to react than before the stroke, caution, disorganisation, finding it difficult to adjust to change, becoming confused or irritated and loss of inhibition or inappropriate behaviour.
- *Fatigue* – this may include people feeling too tired to undertake activities they would have previously enjoyed.
- *Mood changes* – a variety of symptoms, irritability, anxiety and depressive illness.

Stroke can be recurrent and the deficits cumulative, leaving people with difficulties when they try to regain their pre-stroke life. Shortly after the initial stroke event people may delay getting back to a normal life even though they may have made a good physical recovery (Parker et al, 1997a). This continuing limitation can cause a failure to resume occupations or activities, including those which involve social contact outside the home, such as outdoor mobility and leisure activities (Viitanen et al, 1988).

1.3.1.4 Stroke and an elderly population

Stroke is an example of an age-associated disabling illness (Langton Hewer, 1993) and is the most common cause of severe disability in community

dwelling adults (Martin et al, 1998). Stroke often causes mobility problems (Collen and Wade, 1991) and therefore, as people live longer, there will be more people with stroke and more people living in the community with mobility limitations.

The number of people aged over 65 in Britain has doubled in the last seventy years, and the number of people over 90 will double in the next 25 years (Department of Health, 2001a). Between 1998 and 2021, the percentage of the population aged 65 years and over will increase from 15.8% to 19.2% (Mitchell, 1995). By the year 2021 one in three people will be 60 years of age or older (Age Concern, 1998).

Even though older people expect and want to remain healthy, the incidence and prevalence of chronic illness increases almost exponentially with age, especially over 75 years of age (Martin et al, 1998). The number of people with some form of mobility limitation will rise correspondingly.

Unsurprisingly, for those with specific impairments, leading to performance limitations, transport use is a particular problem. Phrases such as 'imprisoned' 'housebound' and 'cooped up' have been linked with a lack of outdoor mobility for older and mobility restricted people (Cutler, 1975; Feibel and Sringer, 1982; Laurence, 1994; Pound et al, 1998). These people have problems using outdoor mobility to attend social events (Legh-Smith et al, 1986), GP appointments (Lovett et al, 2002), and the dentist (Cragg et al, 1994).

All types of travel declines with age and mobility restrictions. People aged 80 years of age and over make half the number of journeys and travel less than one-quarter of the distance of those aged 50-54 (Department of Transport, 2000a) . People who are dependent on walking frames to mobilize, are on average getting out of the house less than twice each week (Oxley and Alexander, 1994). Outdoor mobility is usually achieved by a combination of using a car, walking and public transport with very few people using specialist transport such as Dial –A- Ride (Rabbitt et al, 1996; Department of Transport, 2000a).

1.3.1.5 Carers of people with stroke

Current estimates suggest that 80% of stroke survivors are living in the community one year after stroke, with more than a third being dependent on an informal carer (Kerr and Smith, 2001). Carers may have to provide personal care, including assistance with washing, dressing, bathing, incontinence and physical help such as getting up and down stairs. In a study of carers of people with stroke it was found that the carer is most often the spouse (Blake and Lincoln, 2000) and may themselves be elderly and have activity restrictions. These carers are experiencing a burden that is associated with care giving (Pound et al, 1993; Anderson et al, 1995; Low et al, 1999) while also expressing fears about their spouse having another stroke and being anxious if they feel their partner's progress is too slow (Robinson, 1983).

As well as the burden of care giving, carers of people with stroke are more likely themselves to suffer activity restrictions and stress (Blake and Lincoln, 2000) than a similar group of people without stroke. Research examining the effect that carers make on participation in outdoor mobility has found that people with mobility restrictions are more likely to use the bus if they have a carer (Oxley and Alexander, 1994). Although Oxley studied a general population, the findings may be applicable to people who have a stroke and mobility restrictions. In the largest UK study (Gilhooly, 2001; Gilhooly et al, 2003) of the impact of different types of transport on quality of life, 304 elderly people were interviewed, 5000 people surveyed and transport providers, policy makers and car manufacturers were interviewed. One of the main results from this study was that having a carer who could drive was directly related to a better quality of life, and this was not associated with the wealth of the family. It would therefore appear that by helping the carer to continue to drive then the quality of life of people who have had a stroke could be maintained.

The research into caring for a person with a stroke demonstrates that it is not only important to support people who have had a stroke but also to provide empathy, assistance and advice for the carer (Kerr and Smith, 2001).

1.3.1.6 Occupation and activity limitations of stroke

To understand how a stroke may affect people it is essential that we understand the theories about human occupation. Human occupation as used in this thesis describes participation in a broad range of pursuits, not only those that are paid

or regarded as employment (Christiansen and Townsend, 2004). Occupations are understood to be activities that are invested with a sense of purpose, meaning, vocation and cultural belief.

The College of Occupational Therapists defines occupation as:

'daily activities that reflect cultural values, provide structure to living and meaning to individuals, these activities meet human needs for self care, enjoyment and participation in society' (Creek, 2002)

Occupational therapists have always been interested in the activities humans complete in their lives but have produced few theories. Since the 1960's the study of human occupation has been described by Occupational Scientists, who are at the same time mostly occupational therapists (Wilcock, 1991). They refer to occupation simply as the activities that comprise our life experience and can be named in our culture. They have a defined start and end point, are repeatable, intentional and consciously executed. They tend to be meaningful and can contribute to identity. They may not all be healthy activities and are understood to be units of doing something which are more substantial than scratching an itch but smaller than leading a Buddhist life (Hinojosa et al, 2003).

Although occupational science developed within the field of occupational therapy, the theories are not only studied by occupational therapists but, social scientists, psychologists and anthropologists. The science has contributed towards the understanding of why, what and where people undertake the

occupations that make up their daily lives. Occupational sciences highlight the importance to peoples well being of occupation as well as demonstrating the effect that disability, disease or ill health can have on participation in occupations (Wilcock, 2001).

The differences between occupational therapy and occupational science are often misunderstood. Occupational therapy is a profession and occupational sciences are an academic discipline. Occupation is the central focus of occupational therapy and the unit of analysis considered in occupational science. Occupational science focuses on human behaviour. It should be thought of as a social science and not as a single theory, model, perspective or frame of reference for occupational therapy. Occupational therapy draws its theoretical basis from a number of approaches and models; occupational science is the main body of knowledge that describes occupation, but other models describe why occupational therapists use certain techniques in their practice. The models of occupational therapy will be presented later in this chapter.

Understanding the meaning of occupation is important when occupational therapists proceed to improve people's lives after they have had a stroke. People who have had a stroke may be unable to continue with their normal occupations, they may be unable to remain in paid employment, they may be unable to pursue leisure activities and they may be restricted in their outdoor mobility. They may be constrained by a number of factors. Firstly the changes that have occurred to their bodily structures and functions for example muscle

weakness leading to an inability to walk to the shops. Secondly they may be restricted by their capacities; do they have the knowledge? the information? the skills and the cognitive ability to complete the occupation? Thirdly have the contextual or environmental factors been addressed in order that the occupation may be achieved: has equipment been provided, is there assistance to undertake the task and is it available in their location.

To explain these activity limitations caused by stroke a recognized form of terminology is needed. The original World Health Organisation International Classification of Impairments, Disability and Handicap (ICIDH) (Wood, 1980) was developed to help people use the same terminology when describing the limitations experienced after a medical incident such as stroke.

The ICIDH was replaced with the International Classification of Functioning, Disability and Health (ICF) (World Health Organisation, 2001). This classification system provides a standard language and framework for the description of health related states. It has a greater emphasis than the ICIDH on the personal, social and environmental contexts of health and describes positive states of participation, as well as negative states or limitations. The terminology was changed to reflect these changes; 'Handicap' was replaced with 'restriction' and 'disability' with 'limitation'. The ICF changed to a focus on health, i.e. how people live with their health conditions and how these can be improved to achieve a productive, fulfilling life. It has been promoted as encouraging consistency and understanding among health professionals. Whilst it is not yet routinely used in the analysis of rehabilitation interventions, the

ICF terminology will be used in this thesis when describing functioning, disability and health. Where there is a discrepancy from this terminology, attention will be drawn to the reason.

The ICF is split into two parts:

1. Functioning and Disability which has two components

- Body Functions and Structures
- Participation and Activity

2. Contextual Factors which has two components

- Environmental Factors
- Personal Factors

The theories of occupational science and the terminology of the ICF will be used in this thesis to describe how the effects of a stroke can cause people to have problems with their bodily functions, producing restrictions in activity or occupations which are compounded by environmental and personal factors.

1.3.2 Rehabilitation

Due to the aftermath of stroke, rehabilitation is commonly prescribed with the aim of reducing the impact of stroke on the participant and their carer.

The World Health Organisation (World Health Organisation, 2001) describes rehabilitation as:

"the combined and co-ordinated use of medical, social, educational and vocational measures for training and re-training the individual to the highest level of functional ability"

The rehabilitation team can consist of physiotherapists, occupational therapists, doctors, nurses, speech and language therapists, psychologists, social workers and rehabilitation engineers (Turner-Stokes et al, 2001). More recently, with the National Service Framework for Older People (Department of Health, 2001a) introducing Intermediate Care, rehabilitation is being provided by health and social care multidisciplinary teams that can include home care staff.

Rehabilitation is a complex intervention (Langhorne and Legg, 2003) that is best described by following the framework of the International Classification of Functioning and Health (ICF). Using the ICF, people who have underlying changes in their body functions and structures may have participation and activity restrictions, which are also influenced by their personal environment.

The rehabilitation process refers to both interventions that aim to reduce the underlying impairments through improving body functions and structures and to those interventions that enable participation and performance of activities (Wade and A de Jong, 2000). Rehabilitation aims to maximize the participation of people in their social setting, while minimizing the pain and distress

experienced by people and their carers after a change in their health. It focuses on physical, psychological, social and environmental aspects of people lives and the process is educational, active, reiterative and problem solving (Wade and A de Jong, 2000).

The skill of the rehabilitation process is being able to assess and apply the techniques in a way that the necessary conditions for task performance have been met. By grading tasks, the participant can successfully perform a series of small tasks leading to a more complex activity, or by applying simultaneous techniques the necessary conditions can be achieved and the participant can progress to the next task. For example, a person may be unable to get out of their front door, due to a fear of falling, poor balance and insecure handrails. Rehabilitation will have to satisfy all these necessary conditions if the person is to get out of the door safely. Therapists may instruct the person in the correct technique to step out of the door, while also practicing the technique to build confidence and have the handrail repaired.

In practice, a rehabilitation intervention such as occupational therapy involves a number of techniques. These include the assessment of the barriers to task performance, goal setting, interventions such as dressing practice and the iterative process of review. The information in Figure 1.1 below has been taken from Wades' work (Wade and A de Jong, 2000) and depicts how the concept of rehabilitation can be translated into a deliverable service with defined activities.

Figure 1.1 Description of rehabilitation (Wade 2000)

The rehabilitation process

Structure

A rehabilitation service comprises a multidisciplinary team of people who:

- Work together towards common goals for each patient
- Involve and educate the patient and family
- Have relevant knowledge and skills
- Can resolve most of the common problems faced by their patients

Process

Rehabilitation is a reiterative, active, educational, problem solving process focused on a patient's behaviour (disability), with the following components:

- Assessment - the identification of the nature and extent of the patient's problems and the factors relevant to their resolution

Goal setting

Goal setting can be a process that is both:

- Intervention, which may include either or both of *(a)* treatments, which affect the process of change; *(b)* support, which maintains the patient's quality of life and his or her safety
- Evaluation to check on the effects of any intervention

Outcome

The rehabilitation process aims to:

- Maximise the participation of the patient in his or her social setting
- Minimise the pain and distress experienced by the patient
- Minimise the distress of and stress on the patient's family and carers

1.3.2.1 Stroke as a rehabilitative sensitive condition

There is growing research evidence that rehabilitation is of benefit for people who have had a stroke. Studies completed in hospital stroke units, reviewed by the Stroke Unit Trialists' Collaboration (Stroke Unit Trialists' Collaboration, 2002), provide evidence that people who have their post stroke care on a stroke

unit have better outcomes. They are more likely to be alive, independent and living at home one year after the stroke. The stroke units provided multiple interventions by multidisciplinary teams and it is therefore difficult to assign the benefits to one particular profession. Further analysis of the results (Langhorne et al, 2002) has suggested that the provision of therapeutic techniques such as careful positioning and handling, discharge planning and early goal setting can make a difference. These are activities often undertaken by occupational therapists.

Evidence that community rehabilitation is effective for people with stroke has also been completed by individual professions such as occupational therapists (Walker et al, 2004) and physiotherapists (Young and Forster, 1991). In the occupational therapy study 185 people who had had a stroke and then not gone to hospital were randomly allocated to either of two groups. One group received the normal medical care plus occupational therapy at home for up to five months; the other group received the normal medical care. The study demonstrated that occupational therapy could significantly reduce the levels of restrictions in activities of daily living six months after entry to the study. The physiotherapy randomised controlled trial compared the effectiveness of physiotherapy provided in a day hospital with that provided at home over an eight week period. The people who were treated at home were more capable of using a flight of stairs and were more capable in functional activities of daily living. This gives rise to the idea that although the separate rehabilitation professions work as a team, the overall intervention packages they provide are quite different. For example, the physiotherapist may work with a person who

has had a stroke to enable them to walk, but they may still need handrails on the stairs, as provided through the occupational therapist, if they are to get to the bathroom. It may also indicate that training for activities of daily living may be more successful and appropriate if carried out at home as opposed to training in the hospital.

There have been a number of randomised controlled trials of rehabilitation in the community which has lead to a systematic review (Outpatient Service Trialists, 2004) of trials that have evaluated rehabilitation of people with stroke living at home. The main conclusion from the systematic review was that therapy based rehabilitation can reduce the risk of deterioration in abilities to undertake activities of daily living. Fourteen studies with a total of 1617 stroke patients were included. The trials evaluated eight occupational therapy interventions, two physiotherapy interventions and four multidisciplinary team interventions. Although a systematic review of this kind can provide evidence that rehabilitation does have a positive effect for a significant group of people with stroke, it does not tell us which components of the therapy are the most successful and which people are most agreeable to the rehabilitation offered.

An individual patient meta-analysis of the occupational therapy trials alone (Walker et al, 2004) collected data from 1143 people with stroke. These data were combined from eight randomised controlled trials of occupational therapy. The review found that targeted interventions produced better outcomes. People who received interventions aimed at improving activities of daily living were significantly more able to participate in activities of daily

living, after the intervention had ceased than those who had received the control intervention. Those who received leisure interventions were more able to complete leisure activities. This individual analysis provides us with some evidence that occupational therapists should be targeting treatment to specific restrictions in people's lives. However the studies did not evaluate all components of occupational therapy and those that provided a comprehensive occupational therapy service did not describe how much time was spent on various activities.

The systematic review and meta-analysis provide evidence that occupational therapy is a beneficial treatment for people who have had a stroke, and that targeted interventions are more successful than global interventions. However, the majority of these trials did not include people who were living in residential and nursing homes, which is unfortunate as stroke is the second most common cause of disability in a nursing home population (Martin et al, 1998). A study carried out in Nottingham (Sackley et al, 2001) of the rehabilitation provided in residential homes concluded that people did not appear to be receiving the occupational therapy advised by Clinical Guidelines (Royal College of Physicians, 2002) and the NHS (Department of Health, 2001a). A randomised controlled trial (Sackley et al, 2003) which evaluated an occupational therapy intervention in residential homes for people with stroke found that the intervention group maintained their independence in activities of daily living while the control group deteriorated. This study provides evidence that people who are normally excluded from rehabilitation services due to their locality would benefit from occupational therapy services.

The studies evaluating rehabilitation for people with stroke provide little information regarding the exact nature of the interventions. For clinicians this makes it difficult to organise services and implement evidence based practice. The Clinical Stroke Guidelines (Royal College of Physicians, 2002) have produced guidelines which combine research evidence, clinical expertise, and patients' views. They advise that rehabilitation of people with stroke should consist of:

- *Assessment*- both the collection of data and the interpretation of those data in order to inform a decision. There is evidence that a structured assessment helps to identify problems (Wade, 1998a).
- *Teamwork* - a definition of a team is a group of individuals working together towards a single goal or set of goals (Parsloe, 1981). All members of the healthcare team should work together with the patient and family, using an agreed therapeutic approach.
- *Goal setting* – this refers to the identification of, and agreement on, a target which the patient, therapist or team will work towards over a specified period of time. Goals should be meaningful and challenging, but achievable, and there should be both short-term and long-term goals (Wade, 1998b).
- *Therapy approaches* - focus on the modification of impairment and improvement in function within everyday activities. At present there is no evidence that any one technique is better that any other techniques (Nelson et al, 1996; Dean and Shepherd, 1997; Edmans et al, 2000) and therefore

the guidelines suggest that any of the current exercise therapies should be practiced within a neurological framework.

- *Intensity of therapy* - patients should see a therapist each working day if possible, they should receive as much therapy as can be given and that they find tolerable, and they should be given as much opportunity as possible to practice skills (Kwakkel et al, 2002).

The Department of Health has also recognized that people who have had a stroke require well-organised, client centered services. They have produced the National Service Framework for Older People 2001 (Department of Health, 2001a) which sets health and social care standards for people who have had a stroke, including the provision of rehabilitation in the community.

1.3.2.2 Stroke used as an indicator for other conditions

Stroke is a complex condition and therefore the results from stroke rehabilitation research are often used to provide evidence that the intervention under investigation may work for people with other conditions. This makes the research more useful in the clinical setting. The arguments to support this concept are that stroke is common and affects a large proportion of the population. It can affect people of all ages, both genders and from all social classes. It is a condition that can leave people with both physical and psychological limitations, which are the target for rehabilitation interventions.

The majority of rehabilitation interventions do not aim to change the underlying pathology of the stroke but to act on the health consequences

(activity and participation). Therefore any results gained in stroke rehabilitation studies may be applicable to other conditions such as Parkinson's or multiple sclerosis where people experience similar activity restrictions.

1.3.3 Occupational Therapy

Occupational Therapy is one of the Allied Health Professions (AHP) in the UK and is usually part of the rehabilitation multidisciplinary team that would be treating people after stroke. Occupational therapy is described as a complex rehabilitation intervention, as it involves several components and the components are not easily defined. (Campbell et al, 2000).

The College of Occupational Therapists define Occupational Therapy as:

'enabling people to achieve health , wellbeing and life satisfaction through participation in occupation' (Creek, 2002)

Occupational therapy originated in the Second World War when the ideas of rehabilitation, as opposed to convalescence, were essential to help servicemen return to military service (McDonald, 1964). The profession has since developed into a service that is employed in acute hospitals, primary care trusts, schools, charities, prisons, residential homes and social care settings. Occupational Therapists are trained to provide rehabilitation for all physical and psychological conditions in all ages of people.

The main aim of occupational therapy is to maintain, restore or create a compromise, beneficial to the individual, between the abilities of the person, the demands of the task and the demands of the environment. Ideally, occupational therapy is a partnership between the participant and the therapist in which both are actively involved. If the participant is unable to make decisions about the intervention, the occupational therapist will act on their behalf, but will continue to work towards the participant's understanding by providing choices. To the observer an occupational therapy intervention is a recognizable series of sequential actions by the therapist that hopefully lead to actions by the participant. Creek (Creek, 2002) has described eleven different actions that an occupational therapist might use. The first two, referral and information gathering, and the last, review, are not usually carried out in partnership with the participant. The other eight: initial assessment, problem formulation, goal setting, action planning, action, ongoing assessment and treatment, evaluation, outcome measurement and discharge, take place in collaboration with the participant. Together with this list of actions the occupational therapist brings to the process his/her beliefs, values, culture, language, goals, knowledge, skills, tools, methods and experience.

It is expected that occupational therapists will not follow a strict recipe of actions for a particular condition, but will draw on their own professional beliefs about the nature of people and beliefs about the nature of health, before thinking about the situation and determining what action should be taken in a particular context.

During the occupational therapy process, the therapist shifts his/her attention from occupation to activity to task to skill and back again. Occupation, activity, task and skill are related to each other in a hierarchy, in which the lower categories of skill and task must be achieved before the activity can be successful. By relating several activities together, an occupation can be achieved. For example, to achieve the occupation of shopping, people have to learn the skills of communication and motor control; they have to achieve the task of getting out of the house, and the activity of say, driving, before they can enjoy the shopping experience.

The process usually starts with an assessment of the current and expected occupations of the participant. Having identified the performance restrictions, the therapist will work on skills, tasks and activities to mitigate the restrictions. While working on these areas the occupational therapist will draw on their core skills. These have been described as the ability to: collaborate with the participant, assess and observe, enable, problem solve, educate, use activity as a therapeutic tool, analyse activities, grade activities, organize group work and adapt environments (Hagedorn, 2000a).

Throughout each occupational therapy session an experienced therapist may use all their core skills, they may move from working at the occupation level to the skills level and back again and will bring to the process their own beliefs, values and experiences. It is for these reasons that it is difficult, when evaluating occupational therapy interventions, to document the exact nature of what the participant received.

In the last three decades there has been work towards trying to provide a theoretical base for occupational therapy through a number of different approaches and models. Although there have been papers published describing the models there is very little research to evaluate or compare the models. Confusion has also occurred between the terms used, such as paradigm, model, frame of reference and approach which are used dependent on the author's viewpoint (Kortman, 1995). Some models are designed to guide the intervention process and display the sequence or process of actions or activities used in the intervention or treatment process. Other models show the link between theories and frames of reference. These models do not show application of one treatment technique and can be used in a number of different areas of practice.

Most occupational therapists would use a combination of models and approaches when deciding on a treatment programme. As people who have had a stroke often have restrictions in both physical and psychological function, models from both the physical and psychiatric settings are used. The most commonly used models and approaches for the treatment of people with stroke during occupational therapy will be described.

1.3.3.1 The Neurodevelopment approach

This term can cover a number of distinct but related models that share the common link of being based on the principals of neuromuscular facilitation and sensory integration. The primary techniques associated with this approach were evolved by physiotherapists, but the adapted forms are incorporated into activity based occupational therapy programmes. The origin of this approach is that the participant has shown developmental delay due to congenital or acquired damage to the brain, genetic abnormalities or the effects of other illness or injury. This approach uses techniques that aim to work through the stages of neurodevelopment in the normal sequence allowing the participant to gain function. The main techniques used by occupational therapists are Bobath, Rood, Conductive education, Proprioceptive Neuromuscular Facilitation (PNF), Sensory Integration.

Bobath (Bobath, 1986) is a bilateral approach for the treatment of hemiplegia utilising positioning, weight bearing, reflex inhibition and sensory facilitation. It has gained a following in both physiotherapists and occupational therapists but research comparing this techniques with a functional approach has not found either to be more successful than the other (Dickstein et al, 1986).

The Rood technique (Pedretti, 1985a) emphasizes the use of icing, tapping, pressure and stretch reflexes to stimulate sensory input with the aim of increasing motor output.

Conductive education (Macdonald, 1990) is a highly structured and formal system based on both cognitive and neurodevelopmental principals. The therapist works with the client on goal planning, facilitating movements by using verbal prompts, which the client repeats as they are completing the movement. Conductive education principals are often used by occupational therapists whilst the client is in hospital but it is not used routinely for treatment in the community due to the intensity required.

Proprioceptive Neuromuscular Facilitation (PNF) (Pedretti, 1985b) is another technique that aims to improve motor output by stimulating sensory input. Positioning and patterns of movement in developmental sequences are used with verbal and visual cues.

Sensory Integration (Ayres, 1972) stresses the integration of all sensory inputs. Touch vibration, sound, smell, and colours are geared to stimulate the sub cortical level of the brain. The aim is to promote vestibular stimulation, bilateral integration and the integration of primitive postural reflexes.

1.3.3.2 Compensatory or Functional model

The compensatory or as it is sometimes known the functional model is one of the most popular approaches to occupational therapy. (Walker et al, 2000). It combines medical, social, education and vocational measures for training or retraining the person to the highest level of function. It strongly focuses on the restoration of sensory-motor function. The techniques most commonly used

involve practice of activities to restore functional ability, equipment to compensate for residual deficits and ongoing therapy to maximize retained ability.

There has been some criticism of this model for inhibiting the person's full recovery by providing equipment before they have acquired skills, but research does not find this approach any less successful than other approaches and the Clinical Guidelines for stroke suggest using a variety of approaches to rehabilitation (Royal College of Physicians, 2002).

1.3.3.3 The Model of Human Occupation (Kielhofner and Forsyth, 1997)

This model was first published in the United States of America in 1980. It views a person as an open system interacting with the environment and continually being affected by it and affecting it. It focuses on the occupational areas of self care, leisure and work and has its own battery of assessments. The model has a wide following throughout the United States of America, but the terminology makes it difficult for practicing occupational therapists in the United Kingdom to use in everyday work.

The main theory that underpins the model conceptualizes human behaviour into three subsystems: volition being the will by which we choose what to do, habituation being the roles and rules that organise our lives and performance being the skills we need to carry out human behaviour. The environment is important in this model as the author feels that people seek to explore and

master their environments and that any feedback from the environment is crucial to furthering improved occupational performance.

Some of the difficulties when using this model lie in the fact that the theory does not deal with any physiological explanations of dysfunction but explains the client's difficulties through a volitional explanation. It is therefore a difficult model to use with people who have had a stroke if the rest of the multidisciplinary team is working with a neurodevelopmental approach. However as research evidence for either approach has not been published then the Model of Human Occupation may have a more appropriate application in the community setting.

1.3.3.4 The Cognitive frame of reference (Creek, 1990)

This model was originally designed as an approach for treating mental illness but has more lately been applied to any person with a cognitive limitation such as caused by stroke or traumatic brain injury. The basic premise of this approach is that neurological problems can produce limitations in cognitive capacity that can affect performance in activities.

Cognitive theories seek to understand memory, perception and conceptualization and how the individual forms relationships between concepts and makes sense of the environment. An understanding of these theories is essential if a therapist is to present effective information or improve cognitive skills. There are a number of different cognitive approaches aimed at a range of

limitations. The most commonly used for people who have had a stroke are those that aim to improve perception, memory, logic and sequencing. Cognitive models can also be used to help people understand thoughts, behaviours and emotions and develop healthy positive and effective cognitive strategies to cope with stress and anxiety.

1.3.3.5 The Adaptive skills model (Mosey, 1986)

This model was developed in the late 1960's and early 70's. It aims to deal with problems in the psychosocial function and was developed mainly for use in the psychiatric setting and is concerned with 'wellness' rather than 'illness'. The main premise of this model is that people have a learned maladaptive response or lack of skill, affecting task planning and performance, interactions or ability to identify and satisfy needs. The author has identified six adaptive skills, which are further split into skill components. The skills have been analysed as a developmental sequence and therefore enable a developmental age to be determined for an individual for each skill. This enables activities and interactions to be selected at the correct level so that early skills can be learnt before later ones are tried. Experiential learning through activity, interactions and group work is seen as a means of producing adaptive responses or improving skills and is one of the main techniques applied. Although this model is used mainly in the psychiatric setting the strong psychosocial emphasis makes it a useful model for people who have suffered a stroke and may have cognitive and perceptual deficits.

1.3.3.6 Evaluation of models and approaches

There has been some work evaluating the different approaches and techniques. A survey of current practice of 61 senior occupational therapists (Walker et al, 2000) found that the functional or compensatory approach and the Bobath approach were reported to be the most commonly used , with equal numbers using them, often or sometimes. The choice of approach used in stroke treatment sessions was based on the clinical situation rather then on education. Although this appears to be a small study the result is most likely representative of other occupational therapists as the population was sampled from a typical Health Region of the UK and probably representative of other Health regions.

There have been some studies that have compared approaches but there is no strong evidence that one approach is superior to any other approach (Dickstein et al, 1986; Langhammer and Stanghelle, 2000). The Royal College of Physicians' National Clinical Guidelines for Stroke (Royal College of Physicians, 2002) advocate that for rehabilitation to be successful, therapists should use one of the current movement re-education approaches together with the opportunity to practice functional (task specific) activities.

In the clinical setting occupational therapists are expected to assess a client in all areas of activity limitation and plan their treatment depending on the problems encountered. Most occupational therapists use a combination of models and approaches in their treatment sessions (Walker et al, 2000). This

thesis concentrates on occupational therapy which is aimed at activities and interventions related to outdoor mobility but may use a variety of models and approaches. Therefore, before reporting on occupational therapy interventions aimed at outdoor mobility, a number of different types of outdoor mobility available will be described.

1.3.4 Outdoor mobility

Participation in outdoor mobility usually involves the use of one or more types of transport. This has been described as the 'mobility chain' (Cornwell, 1996) and if one link of the chain is missing then people can become housebound. For example if people are suddenly unable to walk, then getting to the bus stop is almost impossible. To understand how occupational therapists might best help people with stroke participate in outdoor mobility then the different types of transport available need to be understood.

1.3.4.1 Transport policy

Current United Kingdom government transport policy recognises the needs and requirements of different social groups. The White Paper, 'A New Deal for Transport: Better For Everyone' (Department of Transport, 1998) notes that public transport should be accessible, affordable and personally safe. The government's 10 year plan 'Transport 2010' (Department of Transport, 2000b) states that improving public transport is key to reducing social exclusion. This

is particularly aimed at people who generally have less access to a car. This includes women, older people and people with a mobility restriction. Central government also controls financial benefits that may be used towards personal transportation such as the Mobility Allowance. This benefit is available to people less than 65 years of age that are unable to walk. The money can be used for transport costs, or to purchase a car or an electric scooter.

The Disability Discrimination Act 1995 (HMSO, 1995) requires all new land based public transport vehicles, together with hackney cabs, to be accessible to people with a mobility restriction, including those who need to remain in their wheelchairs. Technological inventions include vehicles such as the "kneeling bus" for those with limited physical ability, and "speaking timetables" for people with restricted vision. In addition, the Act requires modifications to the transport and pedestrian infrastructure, such as making pavements smoother and wider, providing adequate lighting on pavements, placing seats in bus stops and making it possible to move easily from one type of transport to another. As well as changing structures and vehicles the Act recommends that information and if needed, training is available to help people use the new types of transport.

Local Authority policies dictate the type of specialist transport services for people with mobility restrictions that are provided locally. They determine the level of concessionary fares given on public transport, the provision of Community Transport, the implementation of voucher schemes for taxis and the number of charity controlled schemes such as Shop-Mobility and voluntary

drivers. However, due to Local Authority control the services are inconsistent across geographical areas and people are often only eligible for the services provided in their own locality.

1.3.4.2. Driving

The car is the most favoured and used means of transport (Department of Transport, 2001c). There are currently over 2 million people over the age of 70 years who hold a driving license. Longer life expectancies, longer 'healthy' life expectancies and more women drivers mean that in 15 years it is expected that there will be 4.5 million people over 70 years holding a driving license (Department of Transport, 2001c). Car ownership is directly related to a better quality of life (Gilhooly, 2001; Gilhooly et al, 2003), an increase in social participation (Cornwell, 1996; Barnes, 1997) and less depression (Marottoli et al, 1997). A lack of a car is considered by the general public to be a sign of a 'disability' (Barnes and Hoyle, 1995). People are obviously keen therefore to keep their driving license and their car.

Of people over 55 years of age, 77% of men and 55% of women who had given up driving said it was due to some form of 'disability' (Department of Transport, 2001c). The terminology 'disability', used in the National Travel Survey (Department of Transport, 2001c) may have disguised why people gave up driving, as these decisions are not only influenced by physical restrictions, but by a complicated mixture of a reduced finance, increased cost of insurance, cognitive deficits, family pressures and lack of confidence (Campbell et al, 1993; Rabbitt et al, 1996; Mollenkopf et al, 1998). In a study of older people,

those who chose to give up driving were found to be more positive about the benefits of not driving than those who were still driving (Gilhooly, 2001). It has to be remembered that they were people who had chosen to give up driving, whereas people with stroke often have to give up their license suddenly (Cornwell, 1996).

1.3.4.3 Public Transport

People who do not have access to a car are almost twice as likely to say they face difficulties in getting to the local chemist or hospital (Department of Transport, 2001c). Older people, over 75 years of age, have more difficulties using public transport than the rest of the population. In the National Transport Survey (Department of Transport, 2001c), nine out of ten people thought that public transport was important or extremely important in community life. Although people felt in principle, that public transport was a good thing, 60% did not like using it, 80% found it difficult to get where they wanted to go, 70% found using it difficult and 50% found it difficult to understand the timetables. If people with no mobility limitations have reservations about using public transport then elderly and people who have had a stroke may have additional problems.

It is difficult to obtain accurate figures for how many older people can use public transport and the existing figures are confused by the definition of 'public transport'. In some areas of the United Kingdom, elderly and mobility restricted people are issued with travel vouchers to use for a taxi journey and

this is considered public transport. Of people aged 50-74 years, 46% of women and 24% of men are regular bus users (Age Concern, 1994), and of people over 65 years who use public transport, 62% of female and 54% of men needed assistance (Department of Transport, 2000a).

Personal security at night, difficulty carrying heavy loads, the driver's attitude, confusion over use and boarding and alighting vehicles were all deterrents to using the bus for older people (Help the Aged, 2000; Gilhooly, 2001). For people who have had a stroke the deterrents may not only be physical limitations such as the height of the step on to the bus, but also psychological such as a lack of confidence. This was evidenced in pilot work undertaken before this thesis, where a group of participants who had made a good physical recovery after their stroke were still unable to travel alone (Logan et al, 2001).

1.3.4.4 Walking

The proportion of trips made on foot in the United Kingdom is falling (30% in 1991 to 26% in 2001) (Department of Transport, 2001c). Walking decreases with age. Half of all journeys taken by people over 60 years of age are by foot; more than any other group apart from teenagers, but by 75 years of age they are walking less than any other group (Morton, 1994). Older people are discouraged from walking because of fear of crime, fewer other people walking, broken pavements, not enough time to use Pelican crossings and pavements covered in ice (Morton, 1994).

1.3.4.5 Specialist transport

There is very little research regarding the use of the specialist transport services. Dial-A-Ride, Community Transport and private adapted minibus companies provide a door to door service for a fee. Dial –A- Ride and Community Transport are subsidised services, with the user paying about the same as for a bus journey (Robertson, 2001). These services can transport people who need to remain in their wheelchairs plus a helper but they have been criticized for the organisational effort needed to book a journey (Department of Transport, 2000a). To overcome these problems, a 'hail and ride' system, for people with mobility restrictions, has been tried in the UK, called a 'Plus Bus'. The passengers position themselves anywhere along the bus route and indicate to the driver to stop. The driver can then assist the passenger to get onto the bus in their wheelchair and no prior booking is needed. Literature would suggest that people find the service excellent but to the providers it is more expensive than standard buses (Tyler, 2002).

Shop-mobility is a free service, usually in town centres, which provides daily use of wheelchairs and electric pavement scooters for use around the town. The use of powered vehicles or 'Scooters' (three or four wheeled) is thought to have increased by 50% over the last three years amongst the mobility limited and elderly population (Day, 2002). These scooters can bridge the gaps in transport between home and local facilities (Kelsall, 1996) which would normally be achieved by walking or using a car.

Commercial literature (Tapping and McDonald, 1994) suggests that scooters can promote independence in activities of daily living (ADL) outside of the home, such as shopping, health care appointments, visiting friends and dog walking, but there are also anecdotal accounts of accidents and damage to property (Day, 2002). As well as using Shop-Mobility scooters are available for purchase direct from the suppliers, shops, via the internet and through second hand sales. Guidelines on the sale and purchase of scooters (Department of Transport, 2001a; Travis et al, 2001) suggest that the purchaser should be assessed as to their suitability to purchase a vehicle but at present there are no guidelines about how or what to assess to define suitability.

1.3.4.6 Interventions aimed at enhancing outdoor mobility

Travel Training, Travel Blending and Travel Awareness Programmes are in existence in the United States of America (Action Research, 2002) and Australia (Ampt, 2003).

The USA Travel Training Scheme's provide a number of different types of training. They have been in existence for the last 15 years. Some training is undertaken in groups; this is usually for elderly people, over six sessions and teaches a set route by public transport. A number of states have formal travel training for people with learning disabilities which is undertaken by trainers who have undertaken a Masters qualification. These schemes have not been evaluated using an experimental design but are part of the transport policy supported by central government. The schemes are aimed at different types of participants for example elderly, young people and school leavers. Participants

are assessed before the training on both physical and cognitive abilities but there are no standarised assessments and the schemes have not been compared.

The Australian Travel Blending again is a large well funded centrally supported scheme. It provides verbal and written information for a population within a geographical area with the aim of changing transport behaviour. The emphasis is a change from using the car to using public transport in the form of the bus. All people in a population are targeted with the idea that the local bus services are wheelchair accessible and there is no need for a specialist transport service.

A number of Travel Training schemes and Travel Awareness schemes have been started in the United Kingdom aimed at older and mobility restricted adults. Unfortunately they have all been short lived usually due to limited financial support and no central organisation, plus there is very little published information about the schemes. Interventions in the UK tend to have been targeted at training transport providers; bus drivers and taxi operators, following findings that driver attitude deterred people from using public transport (DPTAC, 2002).

There is a longer history of travel training for people who are visually impaired and those people with learning disabilities. Orientation and mobility training schemes are provided for visually impaired to help them maintain travel independence, but a Cochrane review did not find any randomised trials of this type of intervention (Virgili and Rubin, 2003). These schemes provided the

programme for one person at a time with the travel trainer designing the intervention to suit the participant.

1.3.4.7 Occupational therapy aimed at enhancing outdoor mobility

There is strong evidence from meta-analysis, described in section 1.3.1.6, that occupational therapy is beneficial for people with stroke by helping people improve their abilities in everyday activities (Outpatient Service Trialists, 2004; Walker et al, 2004). The randomised controlled studies that were included in these systematic reviews evaluated one of two occupational therapy approaches. Occupational therapy provided with the aim of improving activities of daily living or with the aim of improving leisure based activities. Participation in outdoor mobility performance was most likely assessed by therapists for participants in both intervention groups. Getting to the shops involves outdoor mobility and can be categorised as both activities of daily living and as leisure. However, restrictions in outdoor mobility were not specifically addressed. There are reasons this may have occurred. The first is that, at the time these studies were being undertaken, most therapists were hospital based and possibly did not have the skills to tackle outdoor mobility problems or recognise its importance. The second is that, of the outcome measures used in these studies, only a small sub-section of the Nottingham Extended Activities of Daily Living Scale (Nouri and Lincoln, 1987) measures outdoor mobility. Again, this is most likely due to the legacy of most occupational therapy researchers being hospital based and not dealing on a day-to-day basis with people living at home. Thirdly the occupational therapists in the research projects may have had time restrictions which

prohibited them from taking people outside their homes. With an increasing emphasis on rehabilitation as a community based activity it is hoped that occupational therapy research will include issues that are relevant to the participant's restrictions and environment and that this will include outdoor mobility.

A research project, measuring participation in outdoor mobility completed prior to the project in this thesis, surveyed people who had received occupational therapy following a stroke, and examined their therapy notes. Of the 90 people studied, all had been assessed for outdoor mobility, 22 (24%) had been given verbal and written advice and 2 (2%) had been taken by the therapist to practice getting on and off the bus (Logan et al, 2001). The study concluded that the interventions used by the therapists to overcome outdoor mobility restrictions did not achieve the desired outcome, as only two people had been able to use the specialist transport available and half the sample still wished to get out of the house more often (Logan et al, 2001).

Occupational therapists have been involved with studies of improving occupational performance through the use of powered wheelchairs (Burning, 2001), transport safety for children who use wheelchairs (McMillen, 1992) and driving after a stroke (Nouri and Lincoln, 1993). Most of the driving research focuses on the assessment of ability to drive and the provision of car adaptations (Radford and Lincoln, 2004). It has been recommended that programmes should be established to help those who are unable to drive safely

make the transition to alternative mobility, such as the bus or specialist transport (Eberhard, 1998).

1.4 THE TRAVEL RESEARCH PROGRAMME

The literature provides evidence that people who have had a stroke cannot get out of the house as much as they want and that specialist transport is underused. There is little information why this is the case. Occupational therapy interventions have been shown to increase participation in activities of daily living for people with stroke by using targeted interventions and there is evidence that functional task orientated rehabilitation is successful. Although physiotherapists have evaluated mobility training for people with stroke no research has been undertaken to understand how an occupational therapy intervention might improve outdoor mobility or to evaluate occupational therapy interventions aimed at enhancing outdoor mobility.

The aim of the current research was to design and evaluate an occupational therapy outdoor mobility intervention. The intervention would be modeled before evaluation, following the Medical Research Councils recommendations for evaluating complex interventions (MRC, 2000). These recommendations suggest that qualitative, informative work completed prior to a randomised controlled trial can produce a better intervention for evaluation and therefore a more useful clinical trial.

1.4.1 The research question

Can an occupational therapy outdoor mobility intervention help people who have had a stroke improve their outdoor mobility performance?

1.4.2 Aims of the study

The aims of the two studies reported in this thesis are:

- To understand the barriers to, and experiences of, outdoor mobility including transport use after having a stroke and use the information to model an occupational therapy outdoor mobility intervention.
- To evaluate the effect of the occupational therapy outdoor mobility intervention.

Chapter 2

Experiences and barriers to outdoor mobility after having a stroke: A qualitative interview study to inform an occupational therapy intervention

2.1 SUMMARY OF CHAPTER

Many people who have had a stroke want to get out of their house more often.

This study used qualitative methodology in the form of a semi-structured interview to elicit the barriers to, and experiences of, outdoor mobility and transport for people who had suffered a stroke. The aim of the study was to gather information that could be used to inform the development of an occupational therapy intervention aimed at enhancing participation in outdoor mobility.

Community-dwelling people who had had a stroke were purposively sampled to include people with a variety of recent experiences of transport. Twenty-four were recruited and gave consent to be interviewed. They were interviewed at home and their comments audio taped and transcribed. Analysis was by constant-comparative methodology. Emerging themes and concepts were developed by two researchers. The data were stored using a computer package especially designed for qualitative research.

It emerged from the interviews that the participants wanted to travel for specific purposes such as shopping or to get to the hospital, but also just for the sake of it. Many who could no longer use their car found that they had less travel flexibility and that their autonomy had been diminished. Barriers to using alternative forms of transport were fear of injury or embarrassment from falling, an associated lack of confidence, inadequate information about

transport services, poor perceptions regarding the cost of taxis and pavement vehicles (scooters) and environmental factors such as the weather. Those who could drive, or who lived with someone who did, gave the most positive descriptions of transport use. Those reliant on family or friends felt they could ask only for help in order to meet health- related appointments and those who used specialist transport services provided the most negative descriptions of transport.

Many of the barriers to outdoor mobility after stroke may be amenable to an intervention. This study therefore provides support for the development of an occupational therapy intervention capable of re-enabling people to walk outside, drive or be driven, to use a pavement scooter safely, to provide information about the alternatives and to encourage best use of public transport.

2.2 BACKGROUND

Chapter 1 reported evidence from the literature of transport and outdoor walking restrictions in people who have had a stroke. There was very little evidence to tell us why these people were unable to participate in outdoor mobility, or whether the interventions aimed at helping people get out of the house and use transport were effective. Occupational therapists were found to provide therapy to overcome outdoor mobility restrictions as part of other activities, but their interventions had not been evaluated.

The research question posed at the end of the Chapter was: could an occupational therapy intervention dedicated to improving outdoor mobility performance be effective? Before evaluating such an intervention the barriers to outdoor mobility need to be understood and the components of the intervention defined.

The aims of this study are to elicit the barriers to outdoor mobility and transport use, to understand the experiences of people when regaining their independence traveling outside the home and to use the results to inform an occupational therapy intervention.

Ethical approval was approved by the Queens Medical Centre Ethical Board (HCO60001). Appendix1. At the time of the study planning there was no requirement to obtain R&D approval from the NHS Trust. Research Governance principals were followed (Department of Health, 2001b).

2.3 METHOD

2.3.1 Design

Qualitative methodology was considered the most appropriate way to answer the research question, as it allowed experiences to be viewed from the participants' perspective. This type of research was chosen to illuminate and shed light on the barriers to outdoor mobility, whilst permitting exploration of concepts not easily measured or quantified (Murphy et al, 1998). The approach favoured was to learn from the participant's experiences, as opposed to studying them (Spradley, 1979). To be able to design a travel promotion programme it was important to gain an understanding of how people behaved in their own environments, how their impairments had affected their outdoor mobility, and how their social situation had influenced their ability to get out of the house. It was essential to gather the information in the context of their community. To complement the qualitative approach it was considered appropriate to gather some quantitative data about the participants using standarised assessments of activities of daily living. The qualitative aspects will be described first.

The methodology employed to complete this study of outdoor mobility was informed by two approaches. Grounded theory techniques (Strauss and Corbin, 1999) and the concepts of symbolic interactionism (Blumer, 1969) were influential in the design of the study, but not followed as a step by step research methodology. The two approaches are described below.

Grounded theory is an analytic inductive technique (Murphy et al, 1998) that stresses an iterative process between the researcher and participant to create an understanding of the experience of complex phenomena. It should be used to generate theories as opposed to confirming opinions or testing a hypothesis. The underpinning theories of Grounded theory evolved to assist the completion of research in areas where little previous investigation had taken place and leads the researcher to focus on the day-to-day life of people as it is actually happening using small-scale everyday life situations. The founders of the theory purport the belief that the researcher should approach the research subject without any prior beliefs or expectations and be wary of uncritically accepting prior beliefs. At the same time, a benefit of qualitative research is precisely this issue. The researcher may possess knowledge and skills that necessarily and valuably dissect the analysis and interpretations drawn. This requires careful, analytic, explicit analysis and the use of iterative approaches to confirm or refute emerging ideas as they shape into themes. The use of more than one researcher and the presentation of findings to other researchers in an attempt to confirm or refute ideas is all part of the process.

The standpoint of the researcher is important. The philosophical position of symbolic interactionism (Blumer, 1969) was used in this study to help guide the analysis of the findings rather than as research method. Essentially, symbolic interactionism is concerned with the self, how it is constructed through communication with shared symbols (e.g. words), and how social activity functions through a role-taking process. It was useful in as much as it provided the social philosophy to link human experience and individual

behaviour with the world of social interaction. It was also important as it emphasized the position of people as users of the environment, as problem solvers, in control of their own actions and how people's behaviour can shape society. This approach or attitude encourages the researcher to listen to the respondents, rather than be tempted to impose a pre-existing meaning on what the respondents are saying. This is important when the researcher has a professional background where clinical experience could influence the analysis.

To gather useful and reliable qualitative data, certain research techniques need to be employed. These design considerations shall be discussed before the study is presented.

2.3.2 Design considerations

2.3.2.1 Interviewing

Postal questionnaires and surveys have been used in previous studies (Kershaw, 2001) to measure the number of times a participant has used a particular type of transport, but it is very difficult using these tools to measure experiences and personal accounts (Britten, 1995). Due to the nature of stroke, people may have reading difficulties, an inability to write and poor concentration. Therefore asking patients to write comments, narrative or keep a diary, was likely to yield a poor and biased response rate. Focus groups, where people are interviewed collectively rather than individually, were another option for data collection (Kitzinger, 1995). They have the advantage of

getting a group discussion, allowing people to share experiences, but the very nature of the study, being a study of transport difficulties, would preclude a number of the key informants getting to a venue.

Taking these deliberations into mind, one-to-one interviews in the participants' own homes were considered to be the best way to elicit the barriers and the experiences of outdoor mobility that could include both transport and walking.

2.3.2.2 Type of interview

Qualitative interviews are often described as being unstructured to contrast them with the verbal administration of a quantitative questionnaire with closed, numerical responses. There are three main types of one-to–one interviews: structured, semi-structured and unstructured. (Britten, 1995)

Structured interviews

Structured interviews consist of administering a pre-defined questionnaire. The interviewers are trained to ask questions (mostly fixed choice) in a standardised manner and the response categories are limited and set. For example, interviewees might be asked: "Do you get out of the house as much as you would like, Yes or No?" The same questions are asked in the same order to maintain consistency. This type of interview was considered inappropriate for this study, as this was an exploratory investigation and existing literature did not provide concepts that were quantifiable, making it difficult to create a set of questions.

Semi-structured Interviews

Semi-structured interviews are conducted on the basis of a 'topic guide' or 'interview schedule' consisting of open-ended questions that define the area. The interviewer is free to probe and explore each area and may diverge in order to pursue an idea in more detail. Continuing with the same example, interviewees might initially be asked; "Can you tell me how you feel about your ability to get out of the house?

Semi-structured interviews were chosen as the most appropriate methodology for this study as there was pervious literature available and with the aim of the study being to collect specific information that could be used to define an intervention the interviews needed a structure.

In-depth Interviews or unstructured interviews

In-depth or unstructured interviews, where there are no predefined questions, may cover only one or two issues, but in greater detail. This technique requires greater interviewing skills to tease out information, keep within time and keep within the focus of enquiry, while listening and responding appropriately. Such an interview might begin with the interviewer saying, "This research study is about how people think about their ability to get out of the house. Can you tell me about your experiences when you go out of the house?" Further questions from the interviewer would be based on what the interviewee said and would consist mostly of clarification and probing for details.

2.3.2.3 Interview Schedule

To complete a semi-structured interview a schedule or topic guide is produced before the first interview (Bowling, 2000). A schedule was developed for use in this study of outdoor mobility, to maintain focus and steer the interview around topics, as opposed to getting answers to a set of questions. The schedule was piloted on colleagues and participants. The schedule was used during the interviews to enquire into participants' needs for transport, their experiences of transport and the barriers they had experienced. A copy of the schedule can be seen at Appendix 2. At all times the researcher had freedom to follow the participant's lead if the topic was relevant to the interview. Open-ended rather than closed questions were used so that the participant was given the opportunity to respond in their own words and expand on the issues raised in the interview. There is evidence that if the questions are open-ended, neutral, sensitive, and clear to the interviewee, then responses will be of greater use to the researcher (Patton, 1990; Britten, 1995). As the initial interviews were analysed the emerging themes helped direct the subsequent interviews.

The topics covered were:

- Activities undertaken that involved going out of the house, before and after stroke.
- Transport used before and after stroke.
- Barriers to and experiences of participating in outdoor mobility.
- Ideas and suggestions for better outdoor mobility.

It was expected that the interviews would take no longer than one hour to complete.

2.3.2.4 Recording the interview

The interviews were tape recorded and transcribed as this was considered the best method to achieve an accurate account of each interview that could be studied by more than one researcher (Maykut and Morehouse, 1994). For most people talking while being taped is not a problem, unless the topic is very sensitive, and there is evidence that they feel their comments are being taken more seriously (Stewart, 1992). The transcripts could be re-read and manipulated in small sections as well as analysed as a whole. Other methods of recording the interview were considered, but taking notes during the interview was considered to be distracting for the participants and the interviewer and videoing the interview thought not to add anything to answering the research questions (Stewart, 1992). Field notes were made following the interviews on key points and ideas to be developed, context, interruptions, non-verbal communications and general mood.

2.3.2.5 Gaining trust and establishing rapport

Gaining trust and establishing rapport is essential for an interviewer's success (Fontana and Frey, 1994). For participants, to be open and honest they need to trust that the interviewer will be sensitive to their situation and respect their comments. Having sensible information sheets, contact telephone numbers and processes for keeping data anonymous, helps participants trust the interviewer. Interviewers need to try to be interactive and sensitive to the language and

concepts used by the interviewee (Britten, 1995) whilst keeping the schedule flexible. They have to consider how their characteristics, such as race, gender and age influences the interview. It has been suggested that it is best not to interview one's own patients if the interviewer is a clinician because patients are likely to want to please the clinician and feel unable to speak honestly (Fontana and Frey, 1994). However, to gain trust and establish rapport it is considered appropriate to be honest with the participant and introduce the interviewer and explain their clinical background (Murphy et al, 1998).

The researcher who undertook the interviews in the patients' own homes was also an experienced stroke occupational therapist and introduced herself as a research occupational therapist. It was considered essential to be honest with the participants, plus evidence (Hoddinott, 1997) suggests that, using a trained clinical professional encourages participants to talk about sensitive subjects such as incontinence. A limitation of the researcher being a medical professional was that the participants may have felt happy to talk about medical and health service issues but not other environmental or social issues.

As stroke patients can have speech, memory or physical difficulties it was accepted that the carer or spouse may be present at the interview. Although it was possible that a carer or spouse may interrupt the participant or substitute their views, the benefits were in the increased trust which was established between the researcher and the family unit. The topic of research in this study was not deemed to be personally sensitive and it was considered that the carer could add a great deal to the research data. Although this technique has been

used with success in previous studies (Pound et al, 1998), it has to be acknowledged that the participant may not be willing or able to voice concerns about the carer /spouse, or things that might impact upon them.

2.3.2.6 Measuring activity limitation in the sample

To describe the sample and the individuals quantitative data was collected. Two standarised assessments of participation were used. The Barthel Index (Collin et al, 1988) and the Nottingham Extended Activities of Daily Living Scale (NEADL) (Nouri and Lincoln, 1987) were used to measure how much participants were able to participate in activities of daily living. These two assessment measures have been well used in other studies (Logan et al, 1997; Walker et al, 1999). They have been tested for reliability and validity and have been previously administered by post (Nouri and Lincoln, 1987; Collin et al, 1988; Yeo and Lincoln, 1995). The information obtained from the two assessments was used in conjunction with the analysis of the interview data to help describe the participants living situation and functional ability.

The Barthel Index

The Barthel Index is a self care assessment covering ten areas: continence of bowels and bladder, grooming, toileting, feeding, transfers, mobility, dressing, stairs and bathing. The version standarised by Collin (Collin et al, 1988) was used in this study and it provided a score for each participant of between 0 and 20.

The Nottingham Extended Activities of Daily Living Scale (NEADL)

The NEADL (Nouri and Lincoln, 1987) was developed to detect how people who have suffered a stroke carry out instrumental activities needed for daily life, alone, that are beyond self care or personal activities of daily living (P-ADL). It is a 22 item questionnaire designed for people living in the community. The 22 items cover four sections and include mobility (six items), kitchen (five items), domestic (five items) and leisure (six items). Each item is scored on the response to four options:

No	0 points
With help	1 point
On my own with difficulty	2 points
On my own easily	3 points

A total score for each sub section can then be calculated. The four subsections can be combined to give a score out of 66.

2.3.2.7 Ethical Issues and confidentiality

Ethical issues and confidentiality are important when researching people under any circumstances but more complicated when the population to be studied is frail, elderly, may have speech and communication problems and is in receipt of the services under consideration. Participants were first contacted by their clinical occupational therapist and replied directly to the researcher. They were asked for signed consent, but were informed that they could stop the interview at any time without giving a reason. The participants were told that the tape

recordings would be destroyed at the end of the study and for the duration of the study they would be kept in a locked filing cabinet.

Participants were reassured that anything they said would be treated as confidential and that any quotes from the interview would be anonymous. Names were replaced by a numerical code and once the interviews were transcribed the codes were used when referring to the transcripts. Any names quoted here have been substituted with false ones.

2.3.2.8 Sampling

As there is very little information about which people find using transport difficult and there is evidence that it is not only physical attributes that stop people from traveling (Logan et al, 2001) it was decided to include a variety of participants from different environments.

To gain the depth of experiences when using transport needed in this study it was decided to use purposive sampling (Murphy et al, 1998) to select the people to interview. Using this technique participants are chosen because they satisfy a number of pre-defined criteria. Although this technique allows the researcher to interview fewer people as it is hoped that the sample will be informative, it relies on prior knowledge about the factors that are going to be important. This is difficult to define before the interviews and it has to be acknowledged that there may be some parts of a population that are difficult to access. For example people who do not speak English or those who are not known to the Health Authorities and do not get asked to be in a study.

Two criteria were chosen to define the participants: participation in outdoor mobility and frailty / vulnerability, which was assessed by age and living circumstances. People who were older and living alone were considered to have higher levels of frailty (Martin et al, 1998). Participation in outdoor mobility was categorised into: house bound, using public transport, car driving, using specialist transport. Frailty was categorised by age, under / over 65 years old, and whether the person was living alone. The aim of the sampling was to have at least one participant from each level of frailty in each transport group. The sampling framework can be seen in Figure 2.1.

Figure 2.1 Sampling Framework used to recruit participants

	Travels alone	Travels with someone	Housebound
< 65yrs, living alone	X	X	X
< 65yrs, living with someone	X	X	X
65yrs, living alone	X	X	X
65yrs, living with someone	X	X	X

X denotes an eligible participant

2.3.2.9 Inclusion Criteria

Participants were included if they had suffered a stroke using the World Health Organisation clinical definition (Aho et al, 1980) at least six months ago, satisfied the sampling framework above and gave consent. The cut off of six

months was used because after this time it was hoped that the participants would have settled into routine that included outdoor mobility.

2.3.2.10 Exclusion Criteria

People were excluded if they had communication problems such as dysphasia or dementia recorded in their occupational therapy notes, or were unable to speak English. They were excluded as it would have been difficult for them to complete a verbal interview.

2.3.3 Procedure of the study

2.3.3.1 Recruiting primary care services

Managers of three primary care occupational therapy services were approached and the study explained. These services covered city, suburban and rural addresses. They gave approval for their staff to help recruit patients and provided a named contact in each of the departments. The named contact was visited, the study explained and a practice briefing supplied. This can be seen in Appendix 3. The services were able to provide patient information about outdoor mobility, functional ability, as well as clinical and demographic data.

2.3.3.2 Recruiting participants

Participants who had suffered a stroke within the last twelve months were recruited between September 2000 and May 2001. The named contact in the primary care service sent an introductory letter to any patient who satisfied the

eligibility criteria and purposive sampling framework. The letter introduced the researcher to the potential participant, provided information about the study and a reply slip that the participant could return if they wished to take part in the study. The reply slips were returned directly to the researcher. An example can be seen in Appendix 4 and 5. The primary care service added the name of each potential participant to the pre-printed letters and the reply slip making it easy for participants to return the slip if they had writing difficulties. The recruiting services were provided with stationary and stamps to send the letters.

2.3.3.3 The interview

The researcher contacted all the participants who had returned a reply slip immediately and made an appointment to visit them at home. It has been found that participants are more likely to continue in a study if they are contacted quickly after they have agreed to take part (Bowling, 2000). At the initial appointment the study was explained, the exclusion and inclusion criteria were applied and, if satisfied, consent was obtained. The consenting participants were interviewed during the initial visit. If they wished, or if it was necessary the interview was completed on a second visit.

A phased approach to the interviews and analysis allowed the sampling of the later stages to be guided by the initial findings. Recruitment was stopped when all the cells in the sampling framework were represented by participants who had been interviewed, and the stories began to repeat themselves. This is a concept known as saturation (Maykut and Morehouse, 1994).

Age, gender and residence data were collected from the participants at the end of the interviews. Activity limitation was measured using the Barthel Index and the Nottingham Extended Activities of Daily Living Scale as described in Section 2.3.2.6.

2.3.4 Data organisation and analysis

2.3.4.1 Analysis of the transcripts

The transcripts were analysed straight after the interview and checked for errors. This provided a way to modify interviews, allowing common themes and areas for exploration to be followed in depth. New ideas could be explored as they emerged with subsequent participants. The development of the concepts and themes was continuous (Fitzpatrick and Boulton, 1994) as it is generally considered that qualitative data analysis is not a discreet operation conducted at the end of the field work (Sage, 1994).

The transcripts were read thoroughly by two researchers (PL and JD) and analysis began. The two researchers regularly confirmed the consistency and accuracy of the coding, the development of the themes and understanding of the interpretation. To manage and interpret the data, the text was split into identified units for analysis. Small units of meaningful text were identified in line with the broad areas listed in the topic guide. The interview schedule and the participants' own words were used to highlight the relevant meaningful text units. A system of coding was applied so that each mention of a particular issue or meaningful text was easily identifiable and was cross-referenced with other

issues. Concepts in the transcripts and the text units were developed to capture recurring phenomena and these became the emergent themes. Broader categories were used to link these themes. The coded text was then organised by these themes. Some of the coded text units were placed in more than one theme. The presence of these categories was systematically checked across each of the transcripts using the method of constant comparison (Strauss, 1987; Maykut and Morehouse, 1994). Disconfirming and confirming data were actively sought throughout the process in an attempt to refute or support the emerging findings. The conclusions and verifications were drawn from the linkage between themes and the search for disconfirming cases. The N5 (Non-numerical Unstructured Data Indexing, Searching and Theorising) (Richards, 2000) computer programme was used to store and organise the data from the transcripts.

2.3.4.2 Examples of the coding

The process of coding began with categories generated directly from the text. For example, here is a brief extract from an interview with a woman who traveled alone, lived alone and was over 65 years of age.

"When we went on holiday I used to drive. So it was quite a blow when I had to give it up. I have got my licence back now. But I haven't got that confidence back to go any distance. I just sort of go down to the supermarket."

The text was split into text units that related to the topic of why people wanted to travel, and coded into categories. This sentence was also coded within the topic of experiences of travel. The categories were placed in themes and an example can be seen in Figure 2.2 below.

Figure 2.2 Examples of coding of the reasons for travel

Text unit	**Category**
When we went on holiday I used to drive	Holidays
So it was quite a blow when I had to give it up.	Loss of personal choice
I just sort of go down to the supermarket.	Shopping

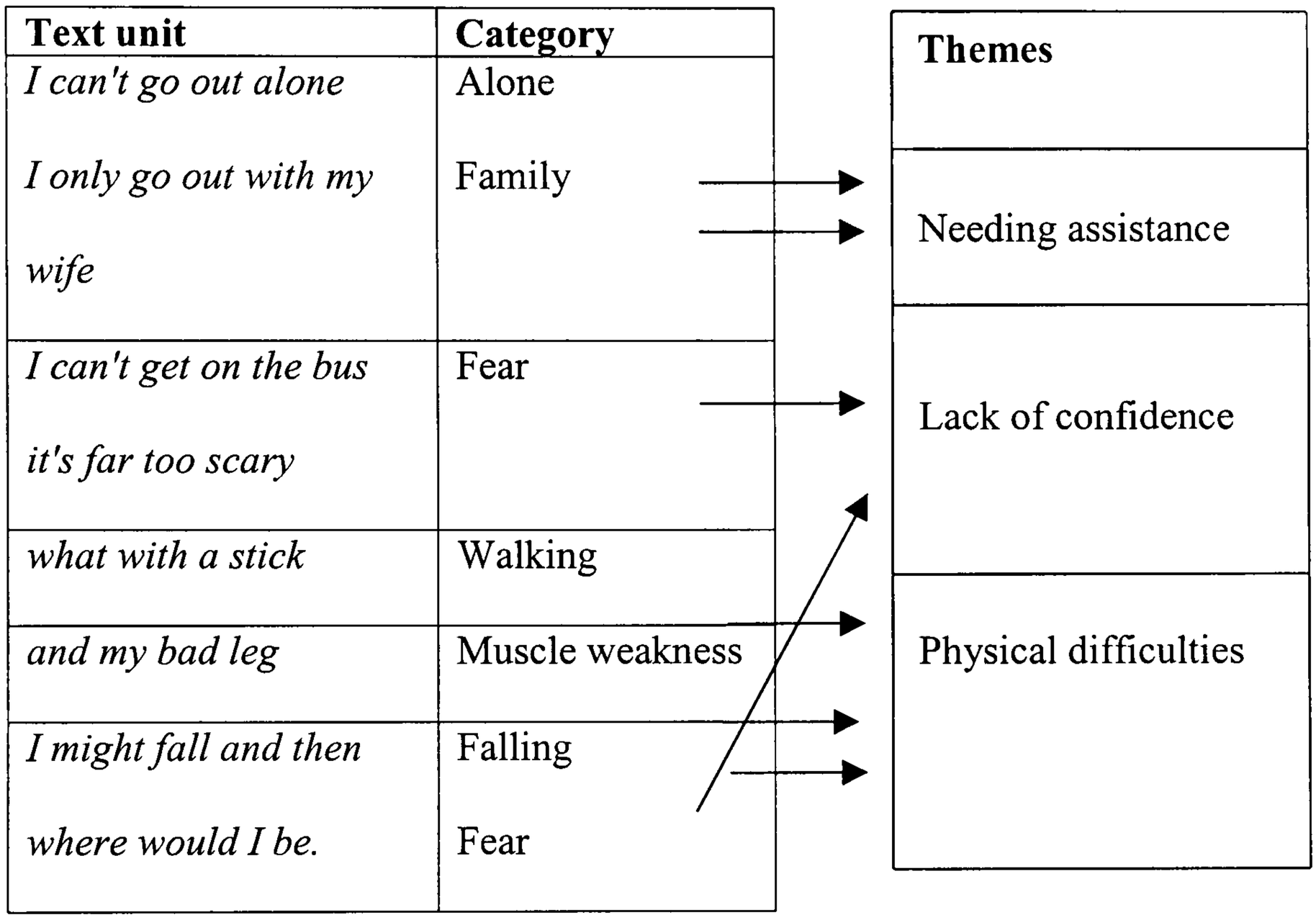
Themes
Social and family roles
Maintaining autonomy
Every day activities

An example of coding of the experiences of outdoor mobility is presented below. Participant 123, who said he was housebound, living with somebody and under 65 years of age said:

"I can't go out alone, I only go out with my wife because I can't get on the bus. It's far too scary what with a stick, and my bad leg I might fall and then where would I be?"

The text was split into text units and coded into categories. The categories fall together into themes; these can be seen in Figure 2.3.

Figure 2.3 Example of coding of barriers to travel



Where necessary, text units were coded under more than one category.

2.3.4.3 Presentation of the findings

Firstly, a small amount of demographic information about the sample is presented. Secondly, analytic accounts of the data are presented. In the discussion the findings will be compared to previous findings. Quotations are used sparingly to illustrate the analysis. The discussion centres on the most frequently appearing issues and highlights any areas that need to be incorporated into the occupational therapy outdoor mobility intervention.

2.4 RESULTS

2.4.1 Recruitment

Thirty-two letters were sent from three primary care occupational therapy departments over a period of six months. As the cells in the purposive sampling framework were filled, the occupational therapists were asked to send letters to specific people, such as a lady over 65 years, who could travel on public transport and who was living alone. Over the six month period twenty-eight replies were received and twenty-four participants interviewed. The purposive sampling framework can be seen in Table 2.1 showing how the sample was spread across the cells. The numbers in the boxes relate to the participants study number.

Table 2.1 Results of the sampling framework

	Travels alone	Travels with someone	Housebound
< 65yrs, living alone	117,	112	122,
< 65yrs, living with someone	118, 116,	101	123
65yrs, living alone	102, 120, 124	107, 108	111, 119
65yrs, living with someone	121, 110, 106 104	113, 103 105,115	114, 109

2.4.2 Characteristics of the sample group

Nearly three-quarters of the sample were male (71%), they were mostly white (94%) and older (median age 71years), although one participant was 43 years of age. Participants were recruited from rural, suburban and city addresses, and 25% described themselves as housebound. Although the inclusion criteria requested participants who had had their stroke over six months before the interview, when the demographic data were analysed one participant had experienced another stroke a month before interview. His further stroke did not invalidate him as a source as it had been a minor stroke that had not changed his ability in activities of daily living.

Participants scored a median of 18, with a range of 12 to 20 (IQR 15.25 -20) on the Barthel Index indicating that most of them were walking indoors, independently dressing, feeding and getting to the toilet alone. They had a median score of 13, with a range of 3 to 32 (IQR 9 -16) on the NEADL indicating needing help to fulfill some outdoor activities such as crossing the road, using public transport or driving a car. The characteristics of the patients are summarised in Table 2.2 over leaf.

Table 2.2 Characteristics of the participants

Age: median (range)	71 (43-91)
Male	17 (71%)
Residence: City Suburban Rural	 7 (29%) 11(46%) 6 (25%)
Ethnicity: White Black Caribbean Pakistani	 22 (94%) 1 (4%) 1 (4%)
Living alone	10 (42%)
Time since stroke in months: median (range)	11 (1-46)
Nottingham Extended ADL score (maximum possible 66): Median (IQR) Mean (SD)	 13 (9-16) 12.88 (6.82)
Barthel Index (Maximum possible 20): Median (IQR) Mean (SD)	18 (15.25-20) 17.54 (2.54)
Self reported transport use: Housebound Travelled independently Travelled accompanied	 6 (25%) 10(42%) 8 (33%)

The duration of the interview ranged between 25 –75 minutes (mean 41 minutes).

2.4.3 Interview Analysis

The findings are presented using the emerging themes and the interview schedule topics as a guide. Quotes are in italics with:

m - male

f - female

h - housebound

ta -travelled alone

ts - travelled with someone

age in years

c- city resident

s - suburban resident

r – rural resident

Ishikawa 'Fish Bone' Figures (Ishikawa, 1986) have been used to summarise the themes derived from analysis of the data. These cause-and-effect diagrams were developed by Kauro Ishikawa of Tokyo University in 1943. They are known as fishbone diagrams because of their appearance. Cause-and-effect diagrams are used to systematically list the different causes that can be attributed to a problem (or an effect). A cause-and-effect diagram can aid in identifying the reasons why a process goes out of control. Although these diagrams were originally used for management of shipyards and factories they provide a visual view of how many different factors can influence an outcome. In these diagrams the main backbone of the fish depicts the issue under investigation, the spurs off the backbone the overarching themes linking related categories together and the smaller 'bones' the units of text.

2.4.3.1 Why the participants wanted to travel

Figure 2.4 gives a pictorial representation of the need to travel. All participants reported that getting out of the house was very important and 18 (75%) wanted to get out more often.

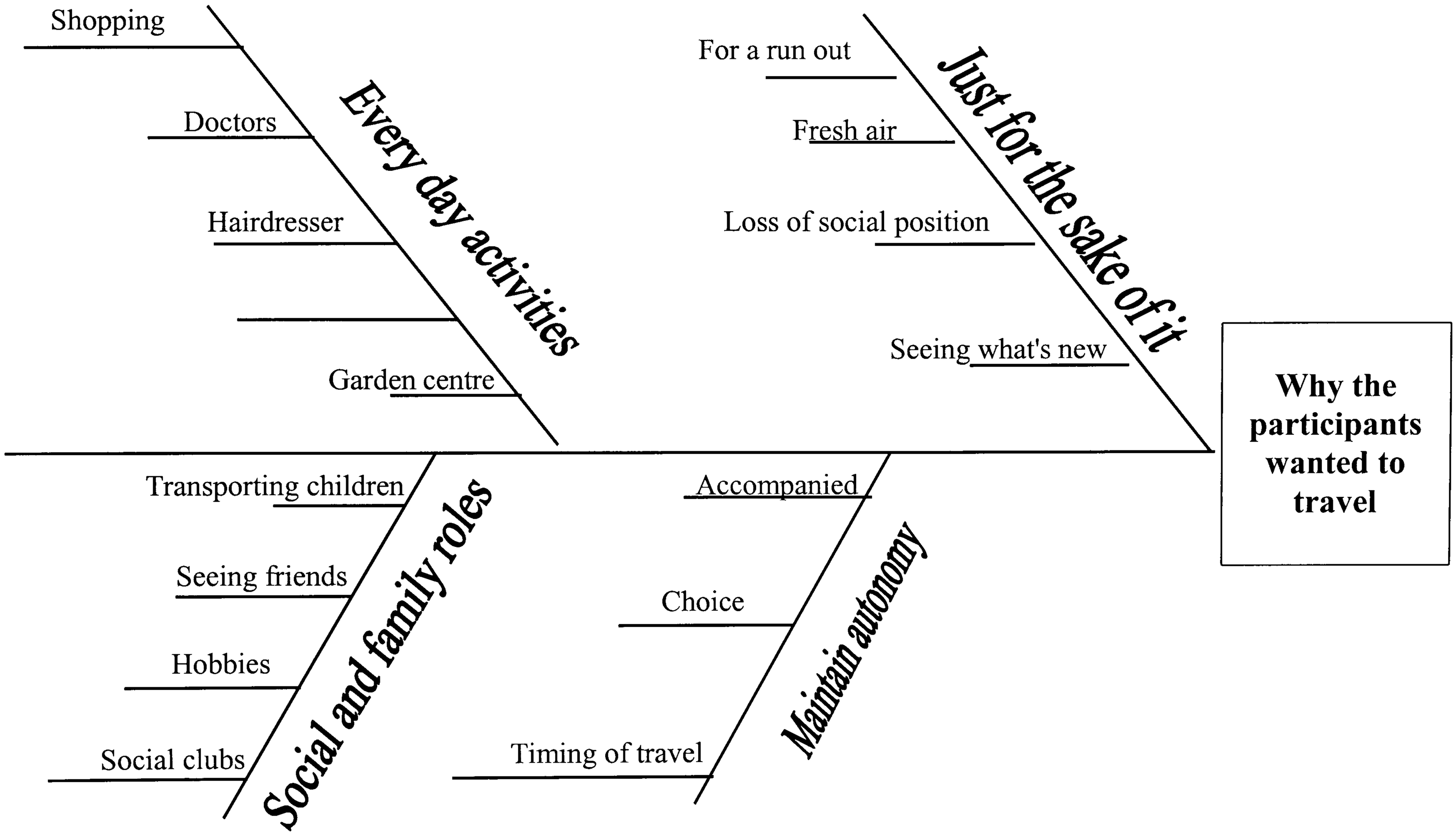


Figure 2.4: A Fishbone diagram to show why participants needed outdoor mobility. An analysis of interview data. (n = 24)

The emergent themes are presented below with quotes to support the findings.

The participants wanted to travel:

2.4.3.1.1 To maintain autonomy

Most (20, 83%) participants wished to travel when and where they wanted, but not necessarily on their own. They wanted to be able to choose for themselves. They felt this was best served by having use of a car because of its convenience.

"The car, it's there on the drive and I can just pop out, everyday if I want to."

(m, ta, 73, r)

Most retained their cars for as long as possible. Three who had stopped driving wanted to get their driving license back. Participants who did not have immediate use of a car found the other transport services curtailed their independence because they had to plan ahead, and often book to travel at a certain time.

"I can't go out when I want to I have to wait till someone come to pick me up."

(m, ts ,73 ,s)

2.4.3.1.2 To participate in social and family roles

Participants were involved in a variety of hobbies such as bowls, painting, and the use of computers.

"Two friends just say are you playing bowls this Saturday and I say yes and they come and pick me up. I couldn't get there on my own". (m, ts, 65, s)

Religious observation, voluntary work, going to the cemetery and commitments such as child minding were all mentioned as activities that the participants still enjoyed but had been affected by a reduction in the use of transport.

"'I used to pick up the kids from school to help the daughter but it's had to stop because I can't drive". (m, ts, 65, s)

Maintaining social connections by attending a social club, a club attached to a previous employer, a daily visit to the betting shop were activities that required transport to get to the venue, but also meeting people, friends and neighbours whilst using the transport was important.

"I always meet somebody I know, when I catch the number 37...we have a chat and catch up on the gossip". (f, ta, 73 ,c)

2.4.2.1.3 Just for the sake of it

It was important to most of this population (17, 70%) to travel for the sake of it, they wanted to be able to enjoy the activity in its own right.

"let's go for a ride today". (m, h, 91, r)

Participants who had given up their car found this one of the most frustrating aspects. They wanted to be

"able to go out just for the sake of going out". (m, h, 70, c)

"to enjoy the ride and to get some fresh air". (m, ta, 72,r)

and felt public transport, friends and specialist services (such as Dial-A –Ride) did not cater for this need. There was a feeling amongst the group who had

given up their cars that they had also given up part of their social standing that others would perceive them less favourably now that they were unable to drive.

"No I don't know anybody who uses the bus. They all have cars and when you have worked for it you want to keep hold of it. I don't know what I will do if they say I can't have my car back. ..... Then I suppose I will have to use the bus or taxi". (f, 59,r ,h)

Three participants spoke about using the actual traveling time to see what was going on in their neighbourhood. The information they gathered about their environment was used in conversations with other people, especially partners at home and for making plans for further journeys.

"I like to get out to see around and about you know what's been knocked down and what's changed". (f, h, 59,r)

2.4.2.1.4. To continue with usual activities of daily living

Getting to the GP's, the hairdressers and shopping were important to all the participants and they were hesitant to ask for home visits or assistance.

"The daughter usually takes me down to the doctors or the hospital, but she has to take time off work and I don't like to ask". (m, ts, 69, r)

Two participants who had been at work before their stroke had not gone back to their previous employment because they said they needed transport to get to work. However, when questioned further there were also problems with the actual skills needed to complete the posts. Garden centres were mentioned by more than half of the participants as places they would like to visit but as they

are situated out of town, and not usually on a bus route, they were reliant on being taken in a car.

"This is the bitter pill that you have to swallow, there is no transport to say the garden centre or retail parks and you miss out on all these things you see advertised on the tele and you look and think, Oh you can't get there". (m, ts, 73, r)

2.4.3.2 Experiences and barriers to transportation

Although six (25%) participants described themselves as housebound at the baseline assessment, during the interviews it was found that all participants got out of the house in some way. One was pushed in a wheelchair once a week and one drove a car every day. Most (16, 66%) had used one type of transport exclusively but experiences and barriers cited were similar for the different types of transport. The experiences of transport use are shown pictorially in Figure 2.5. The emergent themes are described following the diagram, again using quotes to emphasise these themes.

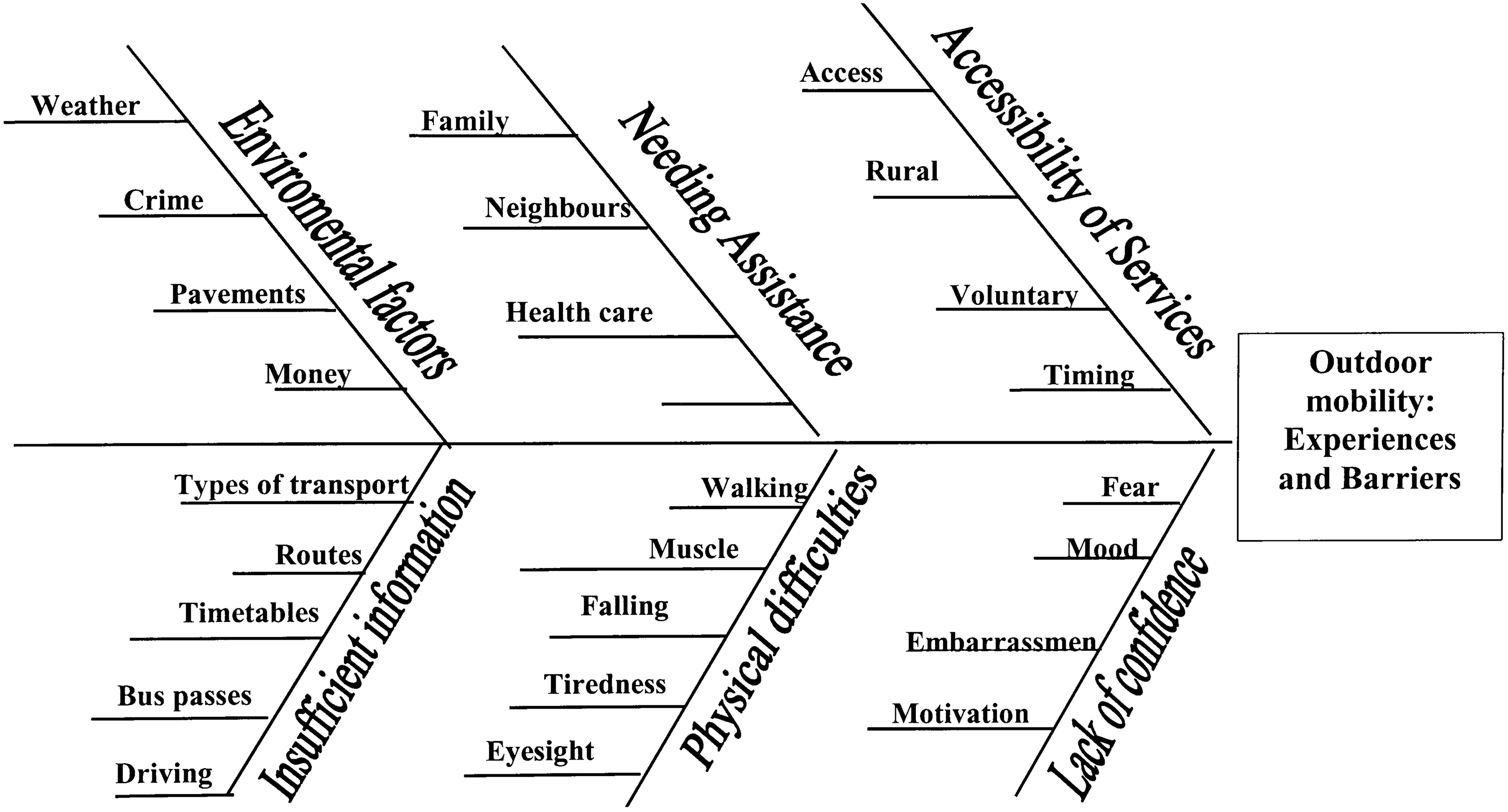


Figure 2.5: A Fishbone diagram to show the barriers and experiences of participating in outdoor mobility (n = 24)

2.4.3.2.1 Being afraid and lacking confidence

Falling was one of the main concerns for a number of participants, 18 (75%). They were afraid of injury or embarrassment from falling, for example when using a bus or tripping on a paving stone.

"I fell my length and the driver didn't even get out his cab, it's put me off trying again". (f, ta, 81, s)

A small number, 3 (12%), were afraid they would have another stroke outside the house and embarrass themselves or show themselves up by being incontinent. Eleven, 11 (46%), said they wanted to use transport but had lost their confidence

"After my stroke I lost my confidence I wanted to use the bus but didn't dare". (m, ts, 69, r)

Ten participants had changed their mode of transport and did not feel that they could learn a new skill.

"I don't think I could manage a scooter, I've always been able to walk and I think I would rather wait till the family come to take me out". (f, h, 67,c)

While one participant had overcome this problem and started to use transport after trying it with family members, half of the sample felt they should have had more encouragement from health professionals.

"I was scared at first to use the bus, then I went with the wife and then with my daughter and finally I went on my own, now it's fine". (m, ts, 69, r)

"Nobody motivates anybody. Chivvy but not motivate. When you are out on your own you need someone in the community, someone who is trained in motivation to encourage people to get on with things". (m,65, ta, c)

A third of the sample mentioned being low in mood and miserable. It was impossible to attribute the misery totally to a lack of transport but it was obvious that the two are related in some way. The miserable periods fluctuated for most people and they had good and bad days. They adjusted their activities depending on how they felt each day.

"There's times when I don't feel like going out, you know, I, err, I have to pick me time right. If I start to feel a bit miserable then I don't go anywhere". (m, 75, ta, r)

2.4.3.2.2 Physical Abilities

Nearly half of the population complained of difficulties with bodily functions such as muscle weakness, poor eyesight and incontinence. Many of the participants could walk but some where unable to walk the distance needed to complete their journey since they were unable to stand for long periods, some needed to rest and others needed seats at the bus stops.

"Yes I can get to the stop and sit down. But it's just a matter of getting on and getting off. Getting enough rest before I have to get off and walk wherever I am going". (m, ta, 44, c)

Others had trouble with equipment or appliances that were supposed to help with mobility or had asked for equipment that they had never received, such as walking sticks or wheeled walking frames.

"Oh, they made a splint for me but it's so awkward I've got to wear trousers all the while and wear these special shoes. Bit awkward. So if I go out without trousers I can't wear the splint". (m, ts,79,s)

Tiredness was a concern for half of the sample, and this was mostly the people who complained about having 'good days' and 'bad days'. The participants did not want to leave their homes when they were having a 'bad' day.

"Since I have had my stroke I have no energy. I used to be able to get up and do all sorts of things and now I am tired. ....I don't go out as much as I should because I am tired, it's like a great burden trying to get ready that sometimes I think it's not worth the effort". (m,82 ta ,r)

2.4.3.2.3 Insufficient information

All participants had a good knowledge of the local concessionary bus travel schemes, but five (20%), did not know how to use buses.

"I think I would use the bus if I knew which one to get". (m, ta, 76,c)

Most, 22 (92%), participants had heard of local and national schemes (disabled person's car badges, Mobility Allowance, Dial-A-Ride, Shop

Mobility) but had not used them because they didn't know if they were eligible.

"I suppose I should have applied for a car badge but I didn't know how to go about it, and if I would be eligible". (f, h, 67,c).

People who had given up their cars were generally critical of health care professionals for not providing correct information about car driving or getting assessed for driving. This group was also dissatisfied with the information provided about other types of transport once they had been told that they could no longer drive. A few participants had received correct and appropriate information. One gentleman, who mourned the loss of his car when his GP said he was no longer fit to drive, admitted that the information given to him by his GP was suitable for the situation.

"the doctor said 'I don't want you to drive anymore. Which was a bit of a shock.....She gave me some information about the disabled persons travel card and the voluntary drivers. Now I'm used to using public transport. I feel as though she was right and with me thinking about it already, so it wasn't to hard. Don't get me wrong it was hard but I was more or less adjusted to in that time frame and I knew it was something that I would have to pack in soon, So yes it was hard". (m, ts, 73, r)

2.4.3.2.4 Accessibility of services

Six participants found public transport services unsatisfactory because bus stops were too far away, services were infrequent and geographical

coverage was inadequate. Nevertheless, the public bus was the most widely used service in this group, used by ten of the participants. Three participants who had used the bus before the stroke and had returned to their regular journeys reported few differences in their lives.

"I still use the same bus, but now I give myself longer to get to the stop and I wait till the driver has stopped before I get out my seat". (f, ts, 76, c)

Three participants had had to give up their cars since their stroke and were reliant on the public bus: they were the most despondent about the services that were available.

"I've always relied on the car and now I'm having to use the bus. They don't always come when you want one and then they don't go to the places I want to go like the garden centre". (m, ta, 79, c)

Three other participants had sold their cars after their stroke and purchased an electric pavement scooter. Another was intending to do so. They found that their scooters met their transport needs in the way that their cars had previously done.

"I'd be stuck in doors all the time... with this I can get to the shop, down to the canal, just around and about". (m, ta, 73, s)

Two participants were regular users of Dial-A-Ride, a community transport service where adapted vehicles and trained drivers can be booked for specific journeys. They were supportive of the scheme but reported patchy

services dependent on location, booking difficulties, restrictions on use and a heavy demand on the service.

"They are great if you can plan two days in advance and then book for the time you need a ride, but it's not good when you just fancy a trip to the shops because it's a nice day and you are having a good day". (m, ts, 43, c)

Three had used voluntary drivers. These are volunteers who are registered with the Council of Voluntary Services and give services similar to a taxi but the user only has to pay for the petrol. The users were happy with the service, but it does not exist in all areas and has to be booked in advance.

"I use the same voluntary driver every week to get to church, if it wasn't for him I would never go". (f, ta, 63, s)

2.4.3.2.5 Needing assistance

Most of the participants relied on family members to take them to hospital appointments. They were hesitant to ask for help with transport but would take a lift if it was offered. They rarely asked for lifts for what they perceived as social events or hobbies. Some of the participants had regular lifts from friends or neighbours and compensated them by buying them gifts. Only one woman had been able to persuade her neighbour to accept money for petrol. This situation worked well, but for others the money offered had been refused and the participants felt unable to ask again.

Most of the sample would have liked more professional assistance to help them get 'back to normal'. This phrase was used in three quarters of the

interviews. This ranged from professionals to help with motivation, confidence and fear, to practical help such as form filling and getting a new ferrule for a walking stick.

"when I had my therapy they fixed up the rails and things in the bathroom but they never took me out". (m, ta, 68, s)

A number of participants wanted extra therapy to help with walking, muscle weakness and tripping over paving stones. Some felt they had been discharged from the therapy services too early or that rehabilitation had focused on their personal activities of daily living and had ignored this aspect of instrumental activities of daily living.

"Nobody talked about going outside. Somebody did come to see if I could get in the bath and that sort of thing but not outside. I don't need the seats, we still have them , but we don't use them what I want to do now is walk to the shops". (f, h, 67,c)

Two participants spoke positively about the assistance they had received to help them get out more often. These were participants who were younger, lived with a partner and were hoping to get back to work. They had received community rehabilitation from occupational therapists and physiotherapists. The therapists had taken one gentleman on the bus with the aim that he would learn how to use the bus on his own.

"It's been since he came home that he has had the chance to try the bus and things I think the help he has had has been excellent".(m, ta, 44, c)

2.4.3.2.6 Environmental factors

A lack of money was a perceived barrier to transport for half of the participants. When asked what they would use extra money for, the main requirements were to keep the car and buy an electric pavement scooter.

"I know it's expensive to keep the car but it's my independence, I'd be lost with out it". (m, ta, 79, r)

Two participants said they would use more taxis if they had more money, the rest expressed a thrifty attitude.

"our generation have always walked or used the bus, the taxis are too expensive". (f, h, 76, r)

People who used voluntary drivers, public transport and community transport felt the costs were acceptable. All the participants felt happier going out in the summer than in the winter, and avoided rain, ice, snow, wind and the dark.

"When the weather's better I will venture into town, if I can still manage the bus". (f, h, 76, r)

Most of the participants were afraid of falling or being blown over, and a few of being mugged in the dark. Two people mentioned practical difficulties such as carrying an umbrella whilst using a walking stick or walking across uneven pavements.

2.5 INTERPRETATION

2.5.1 Overall outcomes and relationship to other studies

These participants who had had a stroke wanted to get out of the house, not just for specific purposes, but to participate in and resume the activities they associated with normal daily living, and for the enjoyment of the journey. Loss of the use of a car was particularly associated with loss of autonomy and this supports other research (Gilhooly, 2001; Gow et al, 2001) where the car was found to be the single biggest factor in older people maintaining a good quality of life. People wanted to maintain a car for the flexibility of being able to travel when and to where they wanted. The ex-car drivers were hardest hit by having to change travel behaviour and did not find it easy to use public or specialized transport. This does not support the findings of other research (Gilhooly, 2001; Gilhooly et al, 2003), that found the people who had given up driving to be the most positive about using public transport, but it may account for the results of an earlier study where people with few impairments were unable to participate in outdoor mobility (Logan et al, 2001). These may have been people who had given up their car suddenly in response to having a stroke and had never learnt how to use the bus.

Barriers to mobility included body functions (e.g. walking ability), psychological status (e.g. confidence) and environmental factors (e.g. position of bus stop). Several factors facilitated transport use, including

prior transport use, finances, and access to a car. These barriers and facilitators rarely existed in isolation but interacted in a complex way for each individual. These results mostly support other research (Help the Aged, 2000; Gilhooly, 2001) which studied 'relatively fit' older people. Both of these studies confirmed the findings of this current research that people worry about money when using a taxi, that bus drivers are not very helpful and that specialist services are difficult to arrange and not always available. In these previous studies the main barriers to using public transport were people's concerns about personal security and difficulty carrying loads. Whereas, in this study of people who had limitations due to a stroke, the most frequent barriers were personal restrictions such as walking, psychological restrictions such as a lack of confidence to try a new type of transport and environmental restrictions such as being blown over by the wind. It would appear that people with stroke experience additional personal or intrinsic barriers to outdoor mobility when compared with a population of older people. If the model of rehabilitation is followed, then these personal necessary conditions will need to be met before people with stroke can be mobile outdoor as much as an age matched population without stroke. Environmental issues like the position of the bus stop or low levels of social support may be barriers to outdoor mobility for people that an intervention could not address but education, confidence and physical ability are all areas an intervention can tackle.

The majority of this largely urban population used the public bus services. The people who had always used the bus were the people who spoke most positively about public transport. Those who were forced to use the bus because of giving up their car were the most negative. These results provide evidence that it may be beneficial for people to be encouraged to use public transport before they have to give up their cars due to disability, therefore making the transition, when needed, easier.

Preparation to travel, (timetables, bus pass and position of bus stop) hindered some people as did confines regarding destination, and the behaviour of the bus drivers. Again this mostly supports other research (Age Concern, 1994; Gilhooly, 2001) but this group of participants emphasized the need for assistance for the whole traveling activity, from understanding the timetable to stepping onto the bus. Many of the participants wanted to travel with somebody for the companionship as well as the physical and psychological support. Again these barriers are areas that an occupational therapy intervention could address. It maybe that by meeting the necessary conditions of having the correct timetable a person is able to use the local bus.

Electric pavement scooters appear to be popular (Day, 2002) because they provide independence similar to the car, although there are no published figures to say how many scooters are being used. These powered three or four wheeled vehicles are personally financed (£2,000 -£4,000). It is not

legally necessary in the UK to have any form of insurance for these vehicles, nor is there legislation about who should not use them, nor are there any tests of proficiency or safety (Department of Transport, 2001a).

This study identified some key problem areas that need to be overcome or solved if people with mobility restrictions due to stroke are to get out of their houses more often. The ease with which the participants talked about their difficulties and acknowledged the need for help from health professionals implies that rehabilitation in this area is feasible.

2.5.2 Limitations and strengths of the study

The people who agreed to take part in this study were selected to satisfy the sampling framework. There were no difficulties recruiting participants who were already interested in outdoor mobility and who could provide written consent. People with severe communication disorders or those in institutional care were not recruited. These people may have further difficulties due to their environment, but due to the nature of recruitment and data collection they were deemed not suitable. Nevertheless, the purposive sampling achieved a group of people with a wide range of activity limitations, as detailed by the range in the Barthel and NEADL. This indicates that people in institution care, who also have an activity limitation, may have similar experiences to this sample and may benefit from a therapeutic intervention.

The main researcher was an occupational therapist (PL) with an interest in the topic, which may have biased the findings through reducing the expression of criticism of rehabilitation and the health services, and her previous experience may have affected the recognition of themes. However, the focus of enquiry was not on rehabilitation services, and by using a second researcher to check findings in the analysis stage, interviewer bias was minimised. The strengths of this double checking of the results is that the results can be considered internally valid, in that they are true and externally valid in that the results can be used for the intended purpose. The strengths of using an interview study over a questionnaire study are that it can reveal potentially unexpected findings and can illuminate real world issues in sufficient detail for them to be understood. This was important when a feasible, and potentially effective, intervention aimed at outdoor mobility was developed.

2.5.3 Implications for an occupational therapy outdoor mobility intervention

A rehabilitation intervention aimed at increasing participation in outdoor mobility in people who have had a stroke should take into account several of the findings from this study. An effective intervention should be individualised. It should aim to alleviate physical difficulties and develop skills to maximize the individual's potential to outdoor mobility performance. It should aim to overcome psychological barriers and it should acknowledge the impact of environmental factors. In developing the

intervention or programme, transport use should be valued in its own right, rather than simply as a means of achieving some other task. As others have also advised, (Barnes, 1997) emphasis should be given to restoring car driving. For some this will be impossible. For these, help is needed to make the transition to the use of other forms of transport, perhaps using the financial resources released when car driving has to cease. The package of intervention suggested here is feasible and is similar to interventions provided by occupational therapy for problems such as reduced leisure activity (Parker et al, 1997a) and dressing (Walker and Walker, 2001). Due to the associated lack of confidence in overcoming barriers with using public transport and accessing specialist transport services, an outdoor mobility intervention would need to combine information-giving with skills training given by a therapist who could facilitate necessary behavioral changes, motivational training and anxiety management.

There will be limitations to the success of any outdoor mobility rehabilitation programme, even if it fulfils the specification implied. Some people will be too poor, or feel themselves to be, to make use of transport opportunities. Poor weather remains a limitation, as does the present state of public transport services and infrastructure. Nevertheless, rehabilitation interventions that take an individualised approach, that recognise transport use as of value in its own right, that encourages a return to driving or explore the use of a scooter or facilitates the use of alternative forms of transport should be developed and evaluated.

2.6 CONCLUSION

Transport is an issue for people with a mobility limitation caused by a stroke. People want autonomy and freedom to choose how, when and with whom they travel. This is at present best provided by the use of a car and increasingly an electric pavement scooter. Public transport is patchy, often difficult to use and restricted in its destinations. People who have had a stroke may lack the personal skills needed to use public transport, especially for those who have had to give up their car since having the stroke. A targeted occupational therapy outdoor mobility intervention using the findings of this study may allow people with mobility limitations to regain the confidence and skills needed to travel, as much as they want, away from their house and to utilize transport services.

Chapter 3

A randomised controlled trial to evaluate the effectiveness of an occupational therapy outdoor mobility intervention

3.1 SUMMARY OF CHAPTER

Many people who have had a stroke cannot get out of their house as much as they would like. They have difficulties participating in outdoor mobility activities such as walking and using the local bus. The barriers to outdoor mobility have been found to vary from person to person and can be a combination of a lack of information, never having experienced certain outdoor mobility activities and psychological distress such as a fear of falling. An occupational therapy outdoor mobility intervention, which assesses these barriers and acts to remove those that are identified, may increase outdoor mobility performance.

A randomised controlled trial was used to evaluate this occupational therapy outdoor mobility intervention (OTOMI) with people with stroke by comparing it to routine occupational therapy interventions provided for outdoor mobility limitations. Routine interventions were understood to include an assessment of outdoor mobility and provision of verbal and written literature about transport options.

Participants who had had a stroke in the last three years were recruited from primary care services and randomly allocated into two groups. Participants in the routine occupational therapy group received one intervention visit from an occupational therapist and were provided with verbal and written outdoor mobility information. The OTOMI group received up to seven intervention visits from an occupational therapist. In this group, participants

were supplied with appropriate information, prescribed remedial exercises, given equipment and adaptations if needed and provided with psychological support. They were encouraged to perform outdoor mobility tasks with the therapist with the aim of improved future independent performance.

Outcomes were measured at four and ten months after recruitment by postal assessment. The principal outcome measure for the trial was a single yes/no question: "Do you get out of the house as much as you would like?" The secondary outcome measures were the number of journeys, the Nottingham Extended Activities of Daily Living Scale, the Nottingham Leisure Questionnaire and a 12-item General Health Questionnaire. Carer mood was measured at 4 and 10 months using the 12-item General Health Questionnaire.

158 participants at 4 months and 147 participants at 10 months returned completed questionnaires. Intention-to-treat analyses were undertaken. To deal with missing data two techniques were used. For the principal outcome measure, participants who had died prior to the point of assessment were allocated the worst outcome, and for others lost to follow up, their baseline or last recorded responses were used. For the other analyses all missing values were imputed using baseline values.

Participants in the treatment group were more likely to get out of their house as often as they wanted at 4 months (RR 1.72, 95% CI 1.25 to 2.37) and at

10 months (RR 1.74, 95 CI 1.24 to 2.44). The treatment group recorded more journeys outdoors in the month prior to assessment at 4 months (intervention group median 37, control group median 14, Mann-Whitney $p<0.01$) and at 10 months (intervention group median 42, control group median 14, Mann-Whitney: $p<0.01$). At 4 months the NEADL mobility scores were significantly higher in the intervention group, but there were no significant differences in the other secondary outcomes. There were no significant differences in these measures at 10 months.

In conclusion, this occupational therapy outdoor mobility intervention increased outdoor mobility. The intervention increased the proportion of people who reported that they got out of the house as much as they wanted and increased the number of journeys undertaken.

3.2 INTRODUCTION

Evidence was presented in Chapter 1 that people wish to travel for a variety of reasons including shopping, education, social, health needs and just for the enjoyment of the journey (Department of Transport, 2000a). People wish to travel when they want, with whom they want and where they want (Gilhooly, 2001). Literature presented in Chapter 1 found that for elderly people, those with physical impairments such as caused by a stroke or psychological difficulties, outdoor mobility can be very difficult and some times impossible (Cornwell, 1996). Why people with stroke found it difficult to participate in outdoor mobility was investigated using a qualitative interview study which has been presented in Chapter 2. The barriers to outdoor mobility were found to be individualised but usually included a lack of knowledge, lack of confidence, never having experienced available transport, lack of equipment and physical inability.

The evidence documents an association between activity restrictions and depressive symptoms (Feibel and Sringer, 1982; Ebrahim et al, 1987) after stroke and a relationship between a lack of outdoor mobility and misery (Gilhooly, 2001). A qualitative interview study by Pound (Pound et al, 1998) of forty people with stroke explored the consequence of stroke and found that the main problem raised by the sample was that of a difficulty leaving the house or being completely housebound. These people found a lack of accessible transport and difficulties walking the main barriers. This study recommended that environmental obstacles that were contributing to

isolation and a loss of social role needed to be tackled. The authors acknowledge that this work has been in the past the remit of occupational therapists but could be extended to other members of the rehabilitation team.

Evidence from the literature would suggest that occupational therapy has been administered in the UK with the aim of improving performance in outdoor mobility and promoting adaptation to life changes. The interventions provided consisted mainly of the provision of leaflets and verbal advice (Logan et al, 2001) and this study suggested that giving information alone does not necessarily change behaviour, particularly when there are other conditions governing that behaviour. Whereas, published models of occupational therapy suggest that occupational therapy works best when repetition of an activity is used to establish a new behaviour (Hagedorn, 2000b). Undertaking repeated activities forms the basis of the Travel Training provided in the in the USA (Action Research, 2002), which is usually aimed at independent use of one bus route. These programmes are documented but have not been formally evaluated.

An occupational therapy intervention aimed at increasing outdoor mobility was designed using the results from the qualitative study presented in Chapter 2. The main aim of the intervention was to enable people to get out of the house as much as they want by increasing the number of journeys, increasing the modes of transport used and improving performance in

mobility related activities. The intervention was based on the models of occupational therapy that consider that understanding that human behaviour is influenced by the interactions of the human system, the task and the environment (Reed and Sanderson, 1983; Kielhofner and Nicol, 1989). It incorporated the core skills of occupational therapy, those of assessment, activity analysis, goal setting and problem solving with a rehabilitation model (Walker and Gladman, 2004) that explains how people will be able to undertake activities only when certain necessary conditions have been met. For example to use the bus, people need to be able to understand a timetable and tell the time, have a bus stop within walking distance, be physically able to get on and off the bus and have the confidence to complete the activity. If anyone of these necessary conditions were lacking then the activity would fail. The intervention was designed to let the participants experience the use of transport and outdoor mobility with the therapist before undertaking the task on their own or with a friend/carer. Although the occupational therapy outdoor mobility intervention aimed to improve performance and participation in outdoor mobility activities it was hoped that mood would also improve by getting out of the house more often. The converse to this is that the intervention may cause extra psychological distress to either the participants or the carers due to the fear of going outside.

The aim of this chapter was to evaluate this new occupational therapy outdoor mobility intervention (OTOMI), by comparing it with what was considered an appropriate control condition for an occupational therapy

intervention, that of providing one visit and issuing leaflets and verbal advice.

As the main aim of the intervention was to help people get out of the house as much as they wanted: the principal research question was, does the occupational therapy outdoor mobility intervention (OTOMI):

- Increase the proportion of people who get out of the house as much as they want?

Secondary research questions were, does this intervention:

- Increase the number of journeys undertaken?
- Improve task performance in outdoor mobility activities?
- Reduce psychological distress?
- Enhance task performance in other activities of daily living?
- Improve task performance in leisure activities?

In this chapter, the study design and design considerations are presented first, followed by the procedure for the study and the method of data analysis. The results are presented before the interpretation and conclusion.

3.3 METHOD

3.3.1 Design

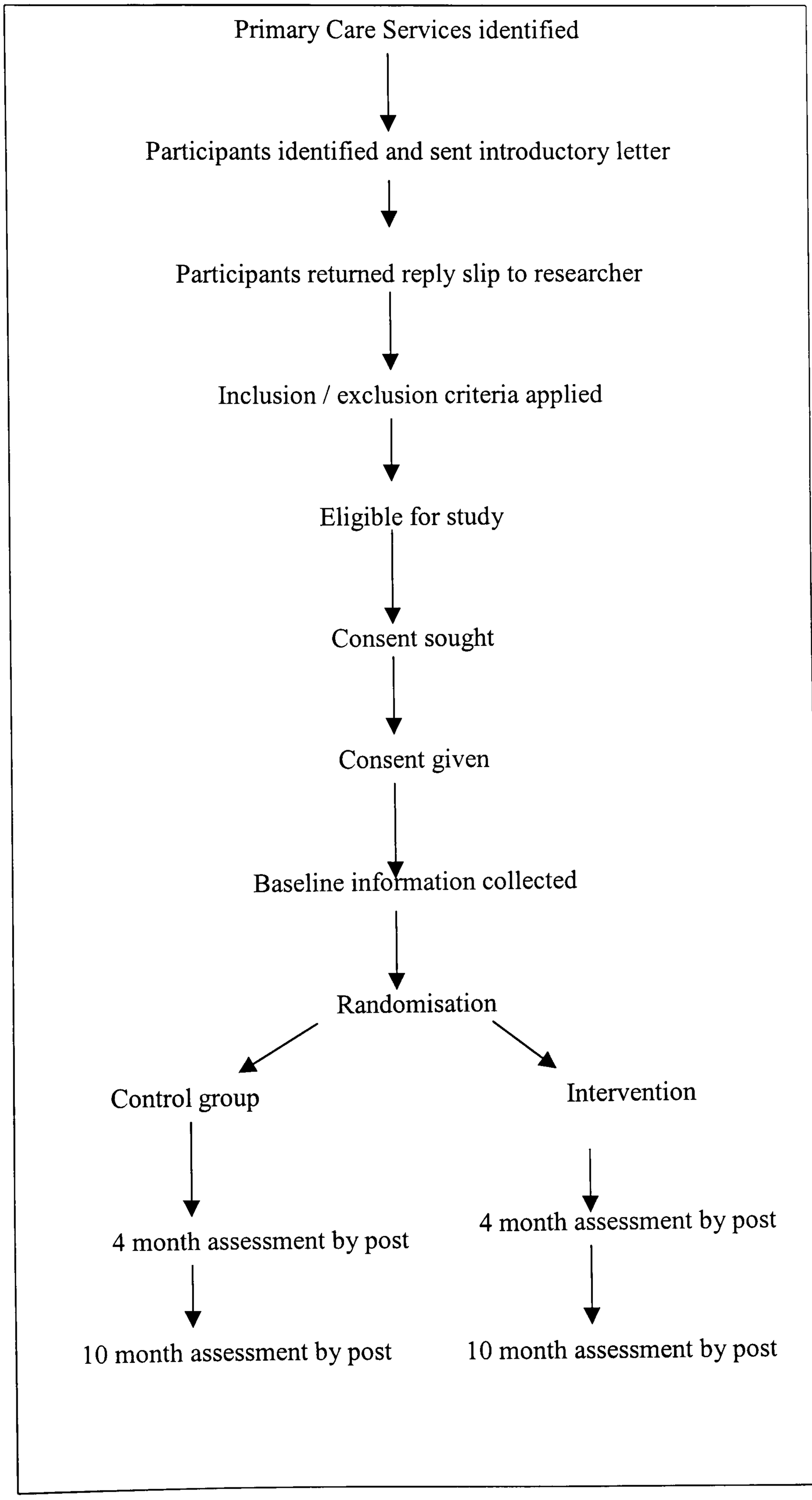
A randomised controlled trial was used to evaluate the occupational therapy outdoor mobility intervention (OTOMI). The implementation of a two group design was chosen as the most appropriate method of comparing the intervention with routine practice (Britton, 1998). This design has been recognised as a particularly strong design in its ability to examine benefits and hazards of a specific intervention while avoiding allocation bias that may be seen in non-randomised controlled studies (MRC, 2000) .

Randomised controlled trials (RCT) are appropriate for use if the issue under investigation is well–known, unambiguous and amenable to measurement. The OTOMI satisfied these criteria as occupational therapy is recognised as a standard form of rehabilitation, the intervention has been defined and it is possible to measure outdoor mobility activity. Randomised controlled trials are useful to verify or establish causality and provide results that are reliable and can be applied to other settings. The collection of numerical data in a randomised controlled trial allows the results to be more easily combined with other studies. This is especially useful for systematic reviews and meta-analyses, which combine the results of a series of smaller studies.

Randomised controlled trials demand that for valid information to be obtained then certain methodologies, or design considerations, have to be

followed (Moher et al, 2001). The recommendations of the CONSORT group for completing and reporting randomised controlled trials have been applied to this study (Begg et al, 1996). A plan of the study can be seen overleaf, Figure 3.1.

Figure 3.1 Plan of the study



3.3.2 Design considerations

3.3.2.1 Interventions under evaluation

Randomised controlled trials (RCT) require that the interventions under evaluation are un-ambiguous, well defined and amenable to measurement. Two interventions were evaluated in this RCT.

Intervention 1: Control or routine occupational therapy intervention

Routine occupational therapy for outdoor mobility restrictions was considered to consist of one therapy session from an occupational therapist. During the therapy session outdoor mobility performance is assessed and written and verbal information on outdoor mobility activities are provided. This level of intervention has been reported in another study of outdoor mobility (Logan et al, 2001).

Intervention 2: Occupational Therapy Outdoor Mobility Intervention

The occupational therapy outdoor mobility intervention (OTOMI) aimed to increase the proportion of people who got out of the house as much as they wanted, by increasing the number of journeys undertaken and increasing the number of different types of transport used.

It involved the provision of the same verbal and written information as in the routine intervention but with an additional six occupational therapy sessions administered at home over a four month period. The OTOMI followed the core skills and principals of occupational therapy (Creek,

2002), including assessment of outdoor mobility restrictions, setting realistic goals with the participant, providing knowledge and information, psychological support and equipment and adaptations. It followed the models of occupational therapy that recognise that a person is affected by their impairments, their social situation, their psychological position and their environment (Reed and Sanderson, 1983; Kielhofner and Forsyth, 1997). The intervention included supported practice and planning of outdoor mobility activities. It recognised the need to assist changes in travel behaviours, with practice of new skills and psychological support through encouragement, techniques to overcome fear and anxiety while increasing motivation.

The OTOMI was able to provide small pieces of equipment to assist with mobility such as walking sticks. Larger pieces of equipment were provided by the Wheelchair Service and Home-Loans. Money was available to introduce participants to using taxis and to register them with the Dial-A-Ride Scheme. Occupational therapy was provided Monday to Friday in normal working hours 9 a.m. – 5 p.m. Data on the number and duration of visits, visit goals, tasks undertaken and whether the task was achieved were collected for each therapy session.

3.3.2.2 Measuring outcomes

Randomised controlled trials demand that the interventions evaluated are amenable to measurement and that outcome measures are, where possible,

standarised, relevant, reliable, valid and sensitive (Wade, 1992). Before considering the measures available for use in the trial, it was important to understand the criteria by which the assessments were measured.

Measurement systems have properties that allow the user to make decisions about the quality or goodness of a measurement technique. A property of a measurement system deals with the extent that the relationship which exists between the attributes of objects in the real world is preserved in the numbers which are assigned these objects by the measurement tool (Bowling A, 1997).

Standardisation

Using established standardised measures with well defined and comprehensive instructions reduces ambiguity (Gladman, 1991) and improves consistency. Results obtained from measures that are familiar to those in the field:

- provide a trial with meaningful results
- allow them to be communicated more easily
- allow them to be compared with other trials
- allow them to be used in subsequent studies such as meta-analysis and systematic reviews.

Relevance

Measurements should be appropriate to the population being studied and to the data that are actually required to answer the question posed (Wade, 1992). Measures should provide the information wanted, no more and no less. They should be simple to administer and easy to complete. A balance was required to ensure that the measurements were not so simple so that they did not elicit sufficient information to produce worthwhile data, while not being overly complicated or lengthy.

Reliability

Reliability refers to the reproducibility and consistency of a measure and can be tested in a variety of ways (Wade, 1992). Test re-test reliability is a test of the stability of the measure over a period of time in which it is not expected to change, by making repeated administrations of it. The instrument is administered once and then again under the same conditions. The relationship between the test and the re-test scores is an indication of the reliability. The main advantage of this procedure is that the instrument is compared to itself, but the disadvantage is that the respondent may recall the question and give the answer given the first time round without considering any changes. To overcome this problem the time between first and second posting can be increased, but for people with stroke this may mean their condition has changed and therefore invalidates the test. Intra-rater reliability is the extent to which the results obtained agree when the same assessor repeats the measure on different occasions.

Validity

Validity is an assessment of whether an instrument measures what it aims to measure (Wade, 1992). This judgment is primarily based upon the logical link between the questions and the objectives of the study. Each question must have a link with the objectives and this is known as face validity. It can refer to different ideas and one measure can be valid for one purpose and invalid for another. The following four terms of validity are widely used to test measures:

- Face validity refers to whether the measure appears to be sensible, relevant, reasonable and clear.
- Construct validity refers to the extent of concurrence between the results from the measure and results from the underlying theoretical construct.
- Content validity refers to the components of the measure. They should not only relate to each other but should cover the full scope of the domain that it is intended to measure.
- Criterion validity refers to the testing of a measure against some other measure that is known to be valid or may be referred to as the 'gold standard'.

Sensitivity

To detect the change expected from the trial intervention it was necessary to choose either very sensitive measures (ones that could perceive a small change) or use several complementary measures. A number of

complementary measures were chosen to gain an understanding of how the intervention may have affected the participants

3.3.2.3 Outcomes measured in the randomised controlled trial

In this trial the participants were assessed after providing consent, which is described later, on three occasions; at baseline by an assessor, and at the end of intervention (four months after recruitment) and ten months later by postal assessment.

3.3.2.3.1 Measuring baseline demographic and clinical characteristics

The demographic information of age, gender, ethnic origin, living circumstances, occupation, hemisphere of the brain affected by the stroke and duration since the stroke was collected during the baseline visit by PL.

The Office of Population, Census and Survey guidelines (Office of Population Censuses and Surveys, 1990) were used to classify social status based on current occupation or occupation before retirement or stroke. The occupations of the participant and their spouse/partner were recorded and the higher score used as an indication of standard of living in the household. This measure places occupations into six different categories, professional, Managerial/technical, skilled non-manual, skilled manual, partly skilled and unskilled.

3.3.2.3.2 Measuring outdoor mobility

Outdoor mobility is not easily defined. It can include the distance traveled, how long it has taken, how many times the journey is taken, how it was undertaken, the purpose of the journey and the value (to the participant) of the journey. Findings from the interview study and previous research have highlighted that one of the most important aspects of outdoor mobility is the ability to get out of the house as much as people want (Logan et al, 2001).

The main aim of the occupational therapy outdoor intervention under evaluation was to address this finding, while increasing the number of journeys taken, the types of transport used and performance of transport related activities. The occupational therapy intervention was aimed at the participation level of outdoor mobility and was therefore interested in social, and environmental factors as well as the medical or physiological factors.

The outcome measures used to evaluate this intervention needed to be sensitive to changes in these areas. The principal outcome measure for the evaluation had to assess whether people got out of the house as much as they wanted. Measures of the number of journeys and the types of transport used were needed to support this primary outcome measure. A literature search revealed a number of published mobility questionnaires (Collen et al, 1990; Wade, 1992) but all measured walking and gross motor function and not the use of mobility in its wider sense, such as by wheelchair, bus or

electric pavement scooter. The importance of this issue was recognised by policy makers in 2001 as this research was underway as evidenced by the Department of Transport, Help the Aged and the Disabled Persons Transport Advisory Committee (DPTAC) (Department of Transport, 2001b) organizing a conference to discuss the topic. This group of interested parties concluded that at that time there was not an ideal way of measuring participation in outdoor mobility for people with mobility restrictions.

The following mobility scales were reviewed for any items that could be used as outcome measures.

- The Timed Walking (Wolfson et al, 1990) test is a simple, reliable way of measuring how fast an individual can move across a 10 m space. It measures a single activity and does not account for any other factors that may influence participation in walking outside. It was unsuitable for use in this study as it has to be administered by an assessor, making it costly and it measures only walking not how people move around their environment. The OTOMI was aimed at all outdoor mobility.

- The Rivermead Mobility Index (Collen et al, 1991) concentrates on the personal activities of mobility such as walking and going up and down stairs, but does not assess the use of mobility outside the house or performance in activities such as driving. Again this is a measure

of activities and not a measure at the level of participation which was required in this randomised controlled trial.

- The Rivermead Motor Assessment (Lincoln and Leadbitter, 1979) was originally validated for use by physiotherapists. Further work on reliability demonstrated that the participant's verbal account of what they do is as reliable as the observed account and that it does not have to be a physiotherapist to complete the assessment (Collen et al, 1990). It has three sections: gross motor function, upper limb function and leg and trunk control. The gross motor function section would be most appropriate for use in this study of outside mobility as it includes questions about walking and running. However the assessment needs to be completed face to face, has not been used as a postal questionnaire and again concentrates on mobility activities and not on participation or occupation which this intervention aimed to influence.

- The London Handicap Scale (Harwood et al, 1994) contains one mobility question, but this measures handicap and not task performance and is therefore inappropriate for use in this study of participation in activities.

- Measures of participation in activities of daily living such as the Nottingham Extended Activities of Daily Living (NEADL) (Nouri

and Lincoln, 1987) and the Frenchay Activities Index (Holbrook and Skilbeck, 1983) contain mobility sub-sections. The mobility sub section from the NEADL, which contains six mobility questions, was chosen to measure outdoor mobility as the questions include walking, the use of public transport and driving. Plus the activities do not need to be completed independently for people to gain a score. This was important as a finding from the interview study was that some people prefer to travel accompanied even when they can travel alone. The total NEADL was used to measure participation in activities of daily living. The reliability and validity of this scale is described later in full in Section 3.3.2.3.4

- The National Transport Survey (Department of Transport, 2001c) is a very large questionnaire, devised for general populations who may use a wider variety of transport modes than people with mobility restrictions. It measures the level of participation in outdoor mobility. It contains only a handful of questions for people related to mobility restrictions caused by impairments and contains no references to services such as voluntary drivers or Dial-A-Ride. It was inappropriate to use in the RCT due to the number of questions it contained, but one question was useful. It contained an item that measured the number of 'trips' or journeys undertaken each day.

- The Transport Survey used in a previous study of outdoor mobility (Logan et al, 2001) is a 20-item checklist, which was based on studies of transport use (Oxley and Alexander, 1994). It lists different types of transport, such as using the bus, driving a car, being pushed in a wheelchair and asks about possessing a bus pass, disabled persons car badge and receiving Mobility Allowance. It contains one question asking if people get out of the house as much as they want and another asking whether they have enough transport. All items have yes/ no responses. Unfortunately prior to this RCT it had not been tested for reliability, nor did it measure the frequency of journeys.

As the principal aim of the intervention was to help people get out of the house as much as they wanted, the following question was chosen as the principal outcome measure.

- The 'yes/no' question from the transport survey, 'Do you get out of the house as much as you want?'(Logan et al, 2001). This question represents the findings of the qualitative interview study that not all people want to go out the same number of times and that gait speed is not that important to this population.

The following outcome mobility measures were chosen to compliment the principal outcome measure.

- Number of journeys in the last month, as measured in the NTS (Department of Transport, 2001c) was used to evaluate whether people who received the intervention went out more times or just became more satisfied with the number of journeys they were making..
- Use of different modes of transport, as measured in the travel survey (Logan et al, 2001) was used to evaluate which types of transport were effected by the intervention.
- Performance of mobility activities, as measured in the NEADL mobility sub-section (Nouri and Lincoln, 1987) was used as a standarised measure of mobility related activities.

With the exception of the NEADL this combination of mobility questions had not been assessed for validity and reliability. The questions were placed together in a questionnaire format and reviewed for face validity by health care colleagues and test-retest reliability by people with stroke living at home. Ethical approval to undertake this small study was granted by the Nottingham Queens Medical Centre (No HC060001). The letter can be seen in Appendix 1.

To test for face and content validity ten health professionals (occupational therapists, medical doctors, physiotherapists and health psychologists) were

recruited. They checked the questions for relevance to clinical practice, clarity, ambiguity and whether they included the full scope of outdoor mobility. Following these consultations the presentation and wording of the questions were amended.

To test for test re-test reliability, 25 people with stroke living at home provided consent to be in the study. They were sent the first questionnaire with a covering letter and a stamped addressed envelope. If a completed questionnaire was returned a second questionnaire was sent with a request that it be completed within one week and returned. No attempt was made to follow up any participants who did not send back either the first or second questionnaires and if the second questionnaire was sent back after two weeks or longer it was discarded.

The results from the validity testing indicated that the health professional considered the questions to be sensible, concise and appropriate. Eighteen sets of questionnaires were returned for the reliability testing. The proportion of agreement for each question, between first and second questionnaires was analysed using Cohen's Kappa Coefficient (Cohen, 1960) and the results interpreted with the guidelines identified by Fleiss (Fleiss, 1981). There was Fair (0.455) to Excellent (1.00) agreement for the questions between first and second posting. The principal outcome measure had test-retest reliability, kappa 0.91, and indicating excellent agreement. The other questionnaire items and Kappa results can be seen in Appendix 7.

This study indicated that the mobility questions had face and content validity and administered by post results were reliable over time.

3.3.2.3.3 Measuring mood

A variety of questionnaires were considered for use in this trial. The three well-known measures, Beck inventory (Beck et al, 1961) Wakefield inventory (Snaith et al, 1971) and Hamilton inventory (Hamilton, 1967) were discarded as they were developed for use in mentally ill patients to detect depression. The 12 point General Health Questionnaire was chosen (Goldberg and Williams, 1992) (GHQ 12 point) and it is described below.

The General Health Questionnaire –12

The General Health Questionnaire (GHQ) was developed to detect psychological distress and is a widely used reliable measure (Wade, 1992). It has been used by post (Parker et al, 2001) and with carers of people who have had a stroke (Carnwath and Johnson, 1987; Blake and Lincoln, 2000). The 12-item version was chosen for this study over the 28 item, 30 item, 60 item versions because it was simple to read and quick to complete plus it lacked the direct questions related to suicide present in the other versions. Each question is scored zero to three, with zero denoting the least distressed. To classify the cases and non-cases of psychological distress the answers for each question can be scored 0,0,1,1 and a recommended cut off threshold of 2/3 indicates a case (Goldberg and Williams, 1992).

3.3.2.3.4 Measuring activities of daily living

There is evidence that occupational therapy interventions can improve personal and extended activities of daily living (Walker et al, 2004) and people are prevented from engaging in instrumental daily activities due to a lack of outdoor mobility (Department of Transport, 2000a). It was considered that an occupational therapy intervention aimed at increasing outdoor mobility may also increase participation in other activities of daily living.

It was therefore appropriate to measure the effect of the intervention on 'extended' or instrumental Activities of Daily Living (ADL), such as shopping and domestic chores. To measure extended activities of daily living three well-known measures were considered. The Nottingham Extended Activities of Daily Living (Nouri and Lincoln, 1987)(NEADL) was chosen over the Rivermead ADL Index (Whiting and Lincoln, 1980) and the Frenchay Activities Index (FAI) (Holbrook and Skilbeck, 1983). The FAI was discarded because it asks what a participant has done in the last three or six months and these times would have not corresponded with the intervention period. The Rivermead ADL Index was inappropriate to use in this trial as it has to be completed by an assessor and to reduce observer bias the assessments were administered by post.

The Nottingham Extended Activities of Daily Living Scale

The NEADL was developed to detect how people who have suffered a stroke can carry out complex every day tasks such as outdoor mobility and shopping. It has been used in rehabilitation and occupational therapy studies (Drummond and Walker, 1995; Logan et al, 1997; Walker et al, 1999), was designed for use by post and has been tested for reliability and validity. The 22 items cover four sections and include mobility (six items), kitchen (five items), domestic (five items) and leisure (six items).

The NEADL can be scored in two different ways. Either by each response obtaining a score (0,1,2,3) with a maximum total score of 66 or a (0,0,1,1) dichotomous scoring system with a maximum of 22. This allows each activity to be scored dependent or independent giving greater sensitivity.

The 0,1,2,3 scoring system was used in this trial of outdoor mobility as results from the semi-structured interviews provided evidence that people often travel with somebody for social reasons even if they are able to travel alone. By using this scoring it was possible to measure whether participants had started to travel on their own.

3.3.2.3.5 Measuring leisure activities

A lack of outdoor mobility can affect the ability to complete leisure activities (Parker et al, 1997a). It was therefore appropriate to measure participation in leisure activities, in this RCT, after providing an

intervention aimed at increasing outdoor mobility. There are few measures of leisure participation that have been developed for use with people who have had a stroke, which can be administered by post. The Nottingham Leisure Questionnaire fulfills these criteria and was therefore chosen.

The Nottingham Leisure Questionnaire

The Nottingham Leisure Questionnaire (Drummond and Walker, 1994) with 38 items, was developed to collect information on the leisure activities of people who had suffered a stroke. A shortened questionnaire containing 30 activities has been adapted from the original questionnaire and tested for reliability when used in postal assessments (Parker et al, 1997b). People are asked to read the activity list and respond to each activity by ticking whether they complete the activity 'regularly', 'occasionally' or 'never'. A total leisure score can be formulated from this questionnaire representing the frequency of participation in leisure pursuits.

3.3.2.3.6 Measurements to aid comparison with other studies

As well as measuring performance in activities that may have been affected by the intervention the Barthel Index (Collin et al, 1988) was chosen as an measure used in most randomised controlled trials of rehabilitation. The Barthel Index measures personal activities of daily living, providing a score between 0 -20. It is well known and used, has been tested for validity and

reliability (Collin et al, 1988) and published results can be used in meta-analysis (Wade, 1992).

3.3.2.4 Postal questionnaires or assessment by independent interview

Postal questionnaires were used to collect outcome data. The advantages of postal outcome measures over an assessor visiting the participant at home are: they reduce the chance of bias, they are practical to use for large trials and they are relatively inexpensive for the researcher and unobtrusive for the participant (Parker and Dewey, 2000). However, there is a possibility that some participants are unable to complete the questionnaire due to physical limitations, eyesight or inability to read English. Participants who were unable to complete and return the questionnaires were offered the help of an independent assessor who would visit them at home. Participants who were sent a questionnaire but who did not return it were contacted by the independent assessor and offered a second posting or a visit at home. When questionnaires were returned with questions missing or ambiguous answers given, the independent assessor contacted the participant by telephone and asked about individual questions. There is evidence that if post alone is used then all these steps are needed to prevent bias arising from higher response rates in those given active treatment. (Parker and Dewey, 2000). The study presented in this thesis used all the recommended steps making response bias unlikely.

3.3.2.5 Sample size

As stated the primary outcome measure was a single question: Do you get out of the house as much as you want? Yes / No. To calculate sample size the primary outcome measure should be used but in the absence of pilot data using this measure, it was decided to use a well used measure of activities of daily living. It was estimated that the total sample needed to detect a 3 point difference on the Nottingham Extended Activities of Daily Living Scale was 200, were alpha = 0.05, power 80%, and standard deviation = 5 taken from previous rehabilitation trials (Drummond and Walker, 1995; Logan et al, 1997; Walker et al, 1999). A 3 point difference on the EADL scale was set as this was considered to show a clinically significant effect. For example a participant may move from being unable to cross road at all to crossing roads with someone, using public transport with someone and walking outside with someone. As well as providing a sample large enough to show a statistically significant difference between the groups if present, and avoid a type two error , information from 200 participants would afford a worthwhile description of the outdoor mobility options used by stroke patients in the community.

To examine the effects of the sample size on the primary outcome measure it was decided to complete a power calculation for the primary outcome after the study had been completed.

3.3.2.6 Duration of the study

Previous studies (Logan et al, 1997; Walker et al, 1999; Cunliffe et al, 2004,) of people who have had a stroke in Nottinghamshire have shown that the community occupational therapy and GP practices receive in the region of four hundred new strokes per year. The limiting factor for recruitment in this RCT was not the number of potential participants but the number of occupational therapy hours available to implement the intervention. It was estimated that if twelve participants could be recruited each month, with approximately six receiving the occupational therapy outdoor mobility intervention then at anyone time 24 participants could be receiving the intervention. This was considered a reasonable clinical case load.

To recruit the 200 participants, necessary for the power of the study, at 12 patients per month, eighteen months of recruitment was required.

3.3.2.7 Ethical consideration and obtaining consent

Ethical Approval was sought and granted by The Queens Medical Centre Ethics Committee (No HC060001). A copy of this letter can be found at Appendix 1. The principles of research governance were followed (Department of Health, 2001b). Participants were first contacted by their GP or occupational therapist. They replied to the researcher (PL), and by doing so the participants were under no obligation to take part in the study. The researcher (PL) contacted the participants and completed the baseline assessments. Verbal consent to visit the participant was requested by

telephone. At the first visit the purpose and nature of the study was explained and signed consent obtained. All participants were provided with the contact details and information about the study. It was explained at the first visit that they were free to withdraw from the study at anytime without giving a reason and that their normal medical care would not be affected.

Participants were also reassured that all information would be treated as confidential and stored securely. Carers were asked to provide consent for participants who were unable to give consent, due to reduced cognitive function.

All information obtained from participants was coded with a subject number to ensure confidentiality. Identifiable personal details and consent forms were kept in a locked filing cabinet. All computer records and data sets were password protected.

3.3.2.8 Stratification and randomisation

Stratification was used in this trial to facilitate balanced groups of participants using known prognostic factors. Participants were stratified on age and transport used prior to recruitment. The participants' age was important as age is directly related to impairment due to illness (Martin et al, 1998), and older people are less mobile outdoors (Age Concern, 1994).

Since outdoor mobility was the outcome domain then it was reasonable to stratify for baseline outdoor mobility as mobility at baseline was likely to be predictive of mobility at the end of the trial. Transport activity limitation was stratified as follows, those who could travel alone, those who needed help to travel and those who were housebound.

Participants were randomly allocated, using the Trent Institute for Health Services Research telephone randomisation service, either to receive the control intervention or the occupational therapy outdoor mobility intervention. A computer generated sequence was used.

3.3.3 Procedure of the study

3.3.3.1 Recruitment of Primary Care Services

To comply with research governance and provide the best information for the participants, Primary Care clinicians known to the participants were used to make the first contact by letter. GP practices that were registered with the Trent Focus for Primary Care Research, Collaborative Research Network (CRN), Social Service Occupational Therapy departments, a Health Care of the Elderly Day hospital and a primary care rehabilitation service were approached by the research (PL) and agreed to take part in the study. These services were asked to identify people who had had a stroke in the last year and send them an introductory letter. By identifying participants from multiple sources it was envisaged that a range of

participants would be recruited from a variety of social and environmental backgrounds and it would mimic clinical practice.

Eighteen primary care services were visited by the researcher (PL) over the period of 12 months (June 2001 to July 2002) and provided with information about the study and what would be involved if the agreed to take part. One GP practice felt they were unable to take part because of staff shortages. The information given to the services can be found at Appendix 3. Recruitment of the primary care services was staggered so that recruitment of the participants was spread over the study period, making an even work load and avoiding a waiting list. Services were contacted regularly during the study to avoid any problems with recruitment. GP practice managers used computerised records to identify people with a diagnosis recorded of a stroke, the occupational therapy departments, day hospital and primary care rehabilitation service managers used paper records to identify people with a diagnosis of stroke, as they do not keep diagnosis on their computerised records.

3.3.3.2 Recruitment of primary care participants

The 17 primary care services that agreed to take part were used to recruit participants. Services were asked for the number of people who they had registered as having a stroke in the last year. Letters, information sheets, stamped addressed envelopes and reply slips for the number of potential participants identified by each service were produced and delivered to the

service. The primary care service managers added the name of the potential participant to the printed letters and the reply slip making it easier for the participants to return the slip. The letters introduced the researcher (PL) to the potential participant, provided information about the study and directions about how they could take, by returning the reply slip. An example can be seen in Appendix 4. The service managers were provided with stationary and stamps. The first six services who recruited participants into the study were approached one year after their first involvement and asked to complete the same procedure. The managers checked their records for incidence of new stroke.

3.3.3.3 Inclusion criteria

Participants were eligible for inclusion if they had suffered a stroke in the last year, which had been clinically diagnosed by their GP, were known to one of the 17 recruiting centres, and gave signed consent or their carer gave consent. As there were no priori reasons why an intervention aimed at getting people out of their houses could not be applied in a residential and nursing home population these participants were included. All people who felt they had a problem with outdoor mobility were included even if at the first assessment they said they got out of the house as much as they wanted. Information from the interview study had shown that people may want to change their mode of transport from being reliant on family or friends

3.3.3.4 Exclusion criteria

Participants were not eligible for the study if they or their carer did not provide consent.

3.3.3.5 Consent and baseline data collection

Interested participants who returned their reply slips were contacted by telephone or letter and an appointment at home was arranged. At this initial visit, the study was explained by the researcher (PL), written consent was obtained and participants were assessed on baseline descriptive measures. If participants wished to have time to make a decision a second appointment was made, and for those with cognitive or speech problems their next of kin was always present. The areas measured at the baseline assessment are listed below and have been described in detail in section 3.3.2.3. The assessment can be seen in Appendix 6

Baseline information / data collected:

- Demographic information, age, gender, ethnic origin, social classification
- Clinical characteristics – side of stroke, duration from stroke
- Living circumstances – alone, warden aided, nursing home, residential home
- Identification of General Practitioner
- Measurement of outdoor mobility performance
    - Do you get out of the house as much as you want? Yes / No
- Measurement of participation in outdoor mobility activities

  - Number of journeys in the last month
  - Types of transport used
  - Mobility section, Nottingham Extended Activities of Daily Scale

- Measurement of mood –
  - General Health Questionnaire 12- point
- Measurement of participation in activities of daily living
  - Nottingham Extended Activities of Daily Scale.
  - Barthel Index
- Measurement of leisure activity
  - Nottingham Leisure Questionnaire

After the baseline data were collected, time was allowed to discuss transport needs, provide verbal and written information in the form of leaflets and encouragement to try outdoor mobility. All participants received this therapy session, for people allocated to the control group this session was their intervention. Following the baseline visit participants were stratified on age and transport activity limitation and randomised to one of the two intervention groups. All participants recruited into the study received a letter of thanks and written information about transport services and leaflets after the first visit. Those allocated to the intervention group received the same information with an extra paragraph informing them that an occupational therapist would be contacting them to visit at home. The intervention was mainly provided by PL, a senior occupational therapist with 15 years

experience in stroke rehabilitation. A second senior occupational therapist (MW) provided less than 5% of the interventions.

3.3.3.6 Four and ten month data collection

Four and ten months after recruitment to the study, patient records were checked for deaths or change of address. Participants and carers were followed up at four and ten months by postal questionnaire and asked to complete the following measures. A copy can be seen in Appendix 8.

For participant

- State who completed the questionnaire – self, spouse, family
- Living circumstances – alone, warden aided, nursing home, residential home
- State where the participant was completing the questionnaire – home , hospital, relatives home
- A measurement of outdoor mobility performance
  - Do you get out of the house as much as you want? Yes / No
- A measurement of participation in outdoor mobility activities
  - Number of journeys in the last month
  - Types of transport used in the last month
  - Mobility section, Nottingham Extended Activities of Daily Scale
- A measurement of mood –

  - General Health Questionnaire 12- point.

- A measurement of participation in activities of daily living
  - Nottingham Extended Activities of Daily Scale.
  - Barthel Index
- A measurement of participation in leisure activity
  - Nottingham Leisure Questionnaire

For the carer

- A measurement of mood –
  - General health Questionnaire 12- point.

Returns were recorded and checked weekly to identify non-returns and respond to them accordingly.

3.3.4 Data organisation and analysis

3.3.4.1 Intention to treat analysis

An intention to treat analysis was used to analyse the data in this trial as it has been recommended that this type of analysis should be used for pragmatic randomised controlled trials (Roland and Torgerson, 1998; Hollis and Campbell, 1999; Campbell et al, 2000). It follows the premise that participants will be followed up as part of the group they were first assigned to at randomisation, regardless of whether the participant continued in the trial, complied with the intervention, received the wrong intervention or died.

The reasons why it is advised to use an intention to treat analysis are:

- It guards against any attempts to influence the results of the study by excluding odd outcomes or extreme outcomes. For example older, severely physically impaired people who are more likely to die are also more likely to be unable to get out of the house. If a greater number of people died from one group then it may be possible that these people were also the ones who found it difficult to participate in outdoor mobility and this would affect the outcomes. An intention to treat analysis would address this problem by including values for all people.

- If participants are stratified on baseline data and then randomised, intention to treat analysis maintains these comparable groups at outcome.

- Intention-to-treat reflects the way an intervention would have affected a similar population. This analysis used data from all participants even those who may not have received the full intervention.

It is only possible to complete an intention to treat approach if complete outcome data are available for all randomised participants. However there is no consensus (Hollis and Campbell, 1999) about how to deal with missing data.

3.3.4.2 Handling missing data

Missing values are a problem in randomised controlled trials because the sample size can be reduced and if more people drop out from one group, bias may be introduced. Missing values in data are due to different reasons. Participants may not have responded because they withdrew consent or they may have died, it may be impossible to trace them or they are too ill at the time of the assessment. Even when questionnaires are returned individual items may have been missed. To reduce missing values at the study design stage the following actions were taken:

- The questionnaire was kept as short as possible and the layout and wording were checked for ease of use before the study started
- Each question was checked for a wide enough range of response options
- Assessments were administered by post, but an independent assessor was available to visit at home for those people who needed help.
- An independent assessor was available to telephone participants who returned the questionnaire with incomplete or inaccurately filled in questions.

By following these practices it was hoped to reduce the amount of missing data. However it was acknowledged that there would be some missing data due to deaths and the following techniques for dealing with missing data were considered.

- Complete Case Analysis or Listwise deletion- using this technique all cases with missing values are left out of the analysis; however this is not suitable for an intention to treat analysis where all participants need to have a value.
- Assume no change in score – using this technique the missing values are substituted with the last observed response. This is perhaps the least arbitrary of the techniques and was used in this study for people who had not died as it was assumed that their scores where unlikely to have changed.
- Assume poor outcome for all drop outs – missing values are given the worst outcome measure possible. Using this technique depends on the setting. This technique was used in the present study for the primary outcome measure with participants who had died, but it was considered inappropriate to assume that those who had withdrawn had suddenly become much worse.
- Assume good outcome for all drop outs – missing values are assigned the best outcome measure possible. This technique again depends on the setting but in this study of people with stroke it was not realistic to assume that all those who had withdrawn had become much more able in their outdoor mobility.
- Extreme case analysis – Using this technique all drop outs in intervention group would assume a poor outcome and all drop outs in control group would assume a good outcome. Again this technique

depends on the setting, but it is not appropriate for routine use and is best used as a sensitivity analysis to test the dependency of findings on imputation assumptions.

- Assign group means (or median) – using this technique the missing value is assigned the group mean or median, which ever is more appropriate for the data

Having considered the different techniques for dealing with missing data it was decided that for the principal outcome measure, participants who were dead at the point of assessment were allocated the worst outcome, and for others lost to follow up their baseline or last recorded responses were used. For the other analyses all missing values were imputed using baseline values.

3.3.4.3 Analysis

Data were stored and analysed using the SPSS-X (2002, Version 10.1) computer programme and Microsoft, Access Database. Statistical significance was tested at the 5% level. Two sided tests were used.

The baseline data were checked for balance of baseline characteristic to ensure the groups were matched and the postal returns were checked for bias response.

The groups were compared using the four and ten month data and analysed depending on how it had been measured.

Categorical data

Data are categorical data if the values or observations belonging to it can be sorted according to category. Each value is chosen from a set of non-overlapping categories. The categories may be nominal or ordinal.

Data are nominal when the values given are a code and do not relate to a measurement or order. Nominal data sets in this study were:

- Do you get out of the house as much as you want – Yes / No
- Different modes of transport used –Yes / No
- General Health Questionnaire -12 - Case / Not a case

The data were described with frequencies and percentages. Contingency tables and the Relative Risk test with 95% Confidence Intervals were used to compare the groups. The principal outcome measure was analysed using contingency table analysis. The Relative Risk test was used to compare the proportions of people who were able to participate in an activity if they had received either of the interventions.

Ordinal data

Data are said to be ordinal if the values can be ranked (put in order) or have a rating scale attached. You can count and order, but not measure, ordinal data. Ordinal data sets in this study were:

- GHQ – 12 point, psychological distress - using the score out of 36
- NEADL – score out of 66
- Nottingham Leisure Questionnaire – score out of 60
- Barthel Index - score out of 20

They were analysed using descriptive statistics. The mean, standard deviation, median and inter-quartile ranges are given. As the results were not normally distributed univariate analysis using the non-parametric Mann-Whitney U test was used to compare groups.

Interval data

Data are interval if observations can be ranked and their ranks are considered to be of equal intervals. Interval scales in this study were:

- The number of journeys

The distribution of the numbers of outdoor trips was skewed and analysed using the Mann-Whitney U-tests. The mean, standard deviation, median and inter-quartile range is given.

Ancillary analyses

Ancillary analyses examined the effect of baseline variables on the outcome and included a within-subjects analysis of the effect of the intervention over time. Multivariate linear regression analysis was used to analyse the secondary outcome measures - NEADL, NLQ and GHQ-12 scores. This analysis was adjusted for baseline variables (sex, ethnic origin, age, prior transport use). The model for linear regression requires that certain assumptions are necessary. These were checked before the test was applied. The assumptions are that the relationship between the residuals has to be approximately linear and that the residuals about the fitted line are normally distributed (Campbell and Machin, 1999).

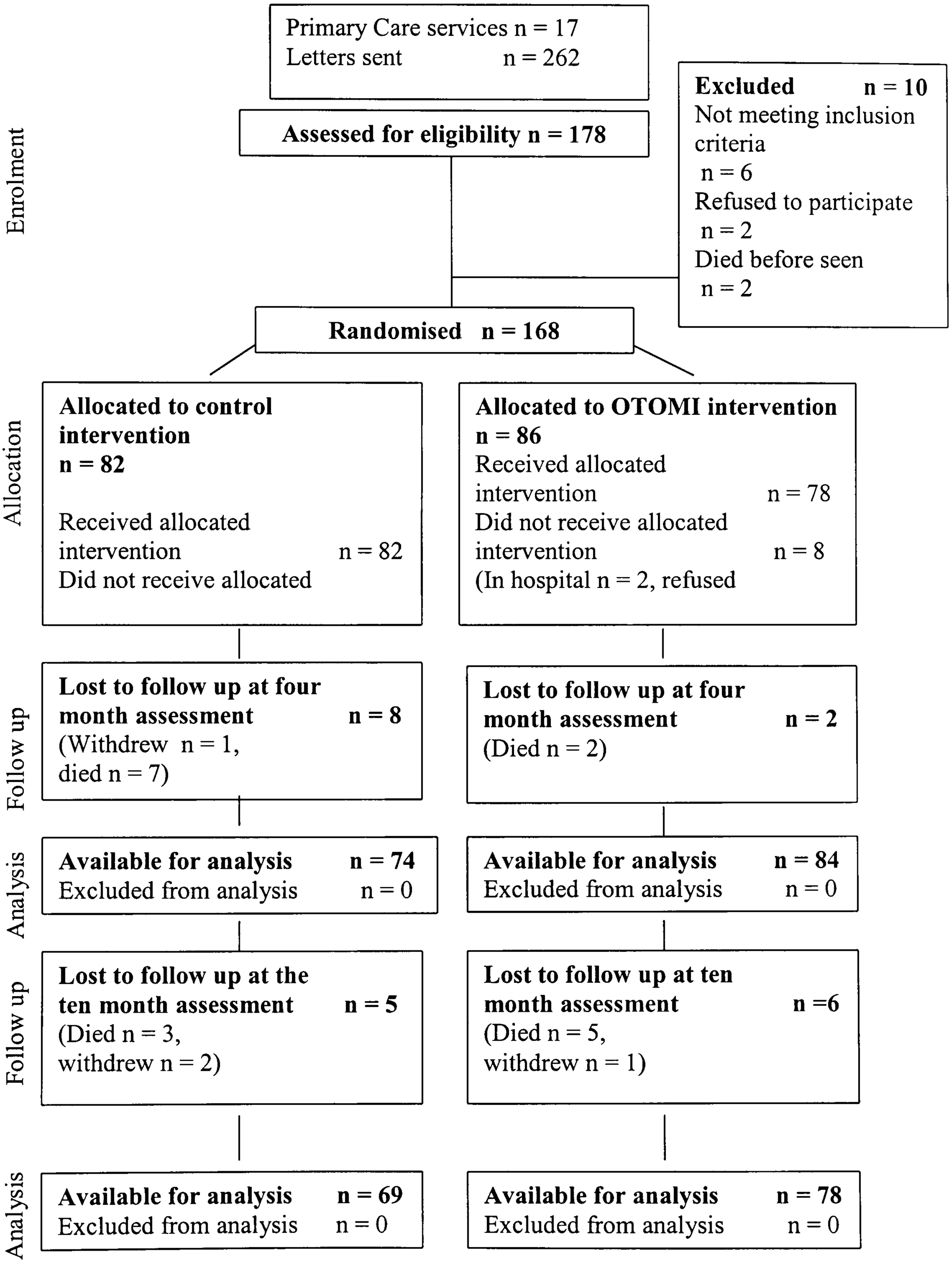
3.4 RESULTS

3.4.1 Flow of participants through the study

Figure 3.2 on the next page shows the flow of participants through the study. It follows the recommendations for reporting randomised controlled trials stated in the Consort Statement (MRC, 2000)

Over eighteen months 262 letters were sent by 17 primary care service managers to people who had had a stroke in the last year. 178 (67.9%) participants replied and 168 (64%) people gave consent to be in the study. Of the ten who did not give consent, 3 were too ill to be seen, 2 were too confused to give consent and 1 was a duplicate referral. 158 (94%) were available to provide information at the four month follow up and 147 (87.5%) at the 10 month follow up. Of the 86 allocated to the occupation therapy outdoor mobility intervention, 78 (91%) received the intervention as intended and all 82 (100%) allocated to the control group received the intervention as intended.

Figure 3.2 Flow of participants through the study



3.4.2 Recruitment rates

3.4.2.1 Recruitment rate of primary care services

Primary care General Practitioner services were contacted in the first instance by the Trent Focus for Primary Care Research Collaboration Network. Six General Practice's agreed to take part. The four Nottingham social services, the Nottingham primary care rehabilitation team and the Queens Medical Centre Day Hospital were contacted by the researcher (PL). Six additional General Practices requested information about the study after a research presentation. The researcher visited all services and provided information. Seventeen services agreed to take part and they can be seen in Table 3.1.

Table 3.1 Primary care services and numbers recruited in each service

Centres OT = Occupational Therapy	**No of letters sent**	**No of replies**
Ludlow Hill Surgery (pop 4,000)	5	5
East wood Health Centre (pop 12,000)	15	10
Aspley Medical Centre (pop 8,000)	8	5
Derby Road Health Centre	15	11
Radford Health Centre	3	2
The Manor Surgery(15,000)	19	13
Compton Acres Medical Centre	5	1
Linden Medical group	12	6
Family Medical Centre	12	6
Stapleford Health Centre	20	12
Ruddington Medical Centre	13	11
Sub -total	127	82
City Social Services OT West	51	31
Rushcliffe, Social Services OT	45	34
Broxtowe, Social Service OT	19	15
City Social Services East	15	11
Sub -total	130	91
Rushcliffe Primary Care OT	3	3
Leen Gate Clinic	2	2
TOTAL	262	178

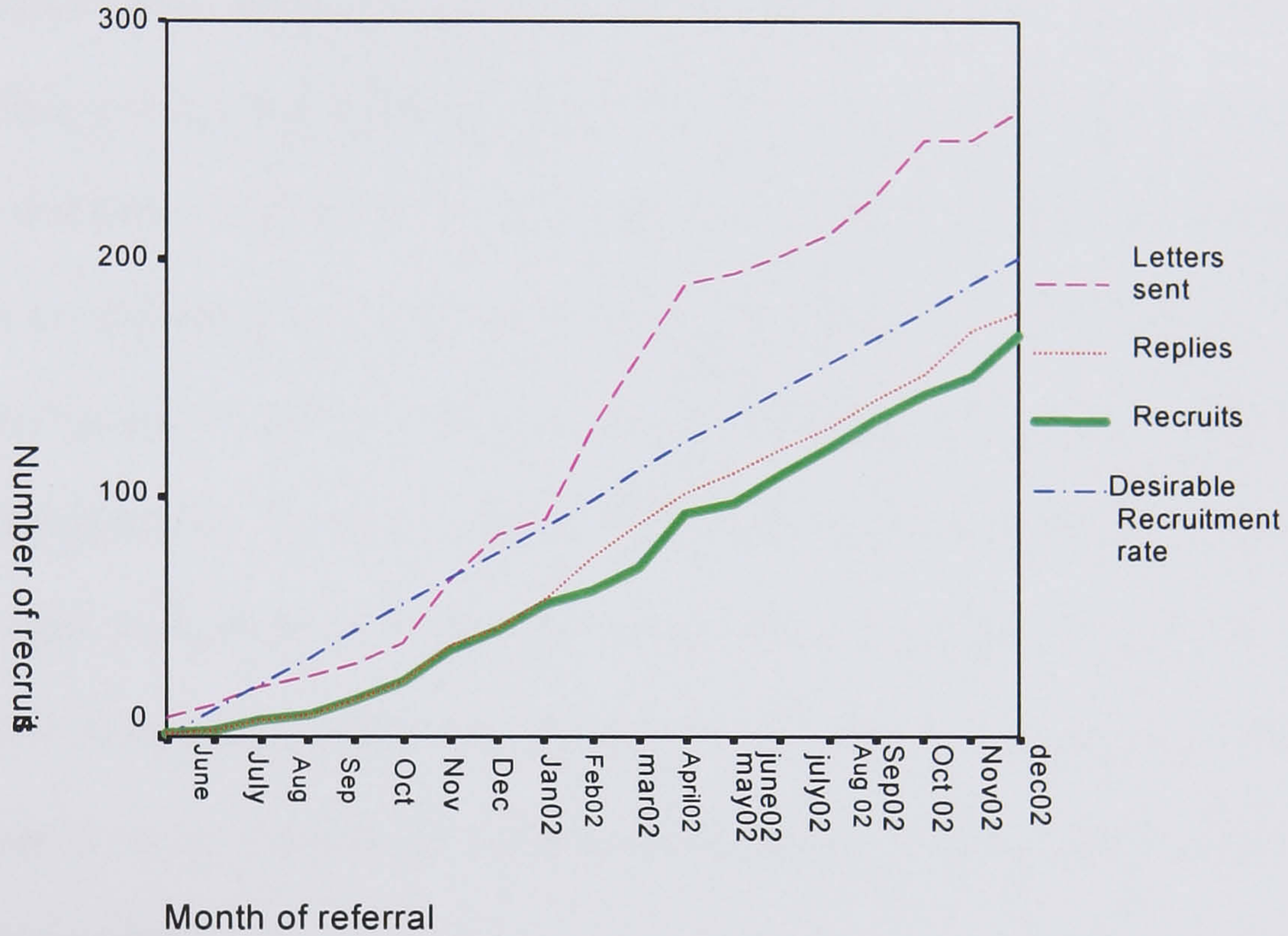
3.4.2 2 Recruitment rate of primary care participants

As each service agreed to take part, they were asked to search their records for people who had suffered a stroke in the last year regardless of their home location. The 17 primary care services identified 262 people as having had a stroke in the previous 12 months using their computerised or hand written records. They sent an introductory letter to each person they identified containing a reply slip and pre-paid envelope. The eleven General Practices sent 127 letters, the four social service departments 130 letters, the primary care rehabilitation service 3 letters and the day hospital 2 letters. The numbers of letters sent by each service and the number of returns can be seen in Table 3.1.

One hundred and seventy eight (67.9%) people returned their reply slip stating an interest in the study. Each potential participant was visited at home by the researcher (PL), the study was explained and 168 (94.3%) people provided consent to take part in the study. For people who were unable to read or write, a next of kin was asked to be present to provide consent if needed. The rate of recruitment can be seen in Figure 3.3. The solid thick line shows the rate of recruitment, the dashed line the number of letters sent, the fine dotted line the replies and the dot and dashed line indicates the rate of recruitment needed to recruit the original sample size of 200 participants, at a rate of 11 per month. This graph demonstrates that although the recruitment rate was slow to start, once procedures were in place, 11 new participants per month were recruited and provided with the

interventions. 168 participants were recruited over 18 months. It would have taken an extra four months to recruit the additional 32 and unfortunately financial support to extend the recruitment period was not available.

Figure 3.3 Rate of participant recruitment over time



Ten people in total returned the reply indicating an interest in the study but did not supply consent. Two of these did not want to be in the study when visited and eight were excluded. The reasons are shown in Table 3.2

Table 3.2 Reasons for not giving consent

Reason for non inclusion	n
Did not want to be in study	2
Too ill to be seen	3
Too confused to give informed consent	2
Duplicate referral	1
Died before being consented	2
Total without consent	10

3.4.3 Characteristics of participants at baseline

3.4.3.1 Demographic characteristics

The baseline characteristics can be seen in Table 3.3. The sample as a whole had a mean age of 74 years (S.D. 8.47, range 47 – 92 years), 91 (54%) were male and 67 (40%) lived alone. 8 (4%) participants were recruited from nursing or residential homes. Social status was measured with the Office of Population, Census and Survey guidelines and the participants were placed in the six categories depending on their occupation or past occupation. As can be seen in Table 3.3 the groups were well matched for most baseline characteristics. The most marked imbalances were in gender and ethnic origin. More men and more people from a black Caribbean background were recruited into the control group. The impact of factors were taken into consideration when the groups were compared at the four and ten month assessments.

Table 3.3 Baseline characteristics

Characteristic		Both groups n 168	Control n 82	Intervention n 86
	Age, mean (S.D)	74 (8.47)	74 (8.61)	74 (8.36)
Gender	Male (%)	91 (54%)	51 (62%)	40 (46%)
	Female (%)	77 (46%)	31 (38%)	46 (54%)
Marital status	Single	9 (5.4%)	4 (4.9%)	5 (5.8%)
	Married/cohabiting	90 (53.6%)	46 (56.1%)	44 (51.2%)
	Widowed	58 (34.5%)	25 (30.5%)	33 (38.4%)
	Divorced	11 (6.5%)	7 (8.5%)	4 (4.7%)
Living	alone not WA	44 (26.2%)	19 (23.2%)	25 (29.1%)
	alone & WA	23 (13.7%)	12(14.6%)	11(12.8%)
	someone not WA	89 (53%)	44(53.7%)	45(52.3%)
	someone & WA	4 (2.4%)	3(3.7%)	1(1.2%)
	Nursing Home	7 (4.2%)	3(3.7%)	4(4.7%)
	Residential Home	1 (0.6%)	1(1.2%)	0
Ethnic origin	White UK	150 (89.3%)	72 (87.8%)	78 (90.7%)
	White other	8 (4.8%)	3 (3.7%)	5 (5.8%)
	Black Caribbean	6 (3.6%)	6 (7.3%)	0
	Black African	1 (0.6%)	0	1 (1.2%)
	Asian Indian	3(1.8%)	1 (1.2%)	2 (2.3%)
Social status	Professional	6 (3.6%)	4 (4.9%)	2(2.3%)
	Managerial/technical	36 (21.4%)	13(15.9%)	23(26.7%)
	Skilled non- manual	23 (13.7%)	12(14.6%)	11(12.8%)
	Skilled manual	53 (31.5%)	30(36.6%)	23(26.7%)
	Partly skilled	32 (19%)	15(18.3%)	17(19.8%)
	Unskilled	18 (10.7%)	8(9.8%)	10(11.6%)

WA = Warden Aided

3.4.3.2 Clinical characteristics at baseline

The clinical characteristics of the sample were examined and can be seen in Table 3.4. The groups were well matched for the side of the brain affected by the stroke and the time from the day of the stroke to when they were recruited into this study. The range for the total sample was 3 days to 39 months. Although the primary care services were asked to only send letters to participants who had had a stroke in the last year, 39 participants said they had their stroke over a year before. These people were included in the results as they had indicated transport problems and asked to be in the study and there is no a priori reason why this type of intervention cannot benefit people late after stroke. There were equal numbers of right and left hemisphere strokes recruited into the study and 23 (13.7%) participants felt unable to confirm which side of the brain had been affected. Six (3.6%) had bilateral strokes.

Table 3.4 Clinical characteristics at base line

	Both groups n 168	Control n 82	Intervention n 86
Side of stroke No lateralisation Right Left Bilateral	 23(13.7%) 60 (35.7%) 79 (47%) 6 (3.6%)	 11(13.4%) 34(41.5%) 36(43.9%) 1(1.2%)	 12(14%) 26 (30.2%) 43 (50%) 5 (5.8%)
Time from stroke to recruitment Mean in months (S.D)	11 (8.68)	10 (8.98)	11 (8.41)

3.4.3.3 Outdoor mobility participation at baseline

The results from the assessment of participation in outdoor mobility activities can be seen in Table 3.5 and Table 3.6.

Table 3.5 shows that fifty six (33%) people said they got out of the house as much as they wanted, 56 (33%) people said they had enough transport and 40 (24%) said yes to both. It was considered appropriate to include these 40 people even though they already said they went out of the house as much as they wanted, as they had asked to take part in the study as they considered they had outdoor mobility problems. This may have been that they wanted to change how they travelled or wished to learn to travel independently. The sample as whole used a form of outdoor mobility a median of 13 times per month. This does not mean they went out of the house on 13 different days, as participants could have walked to the bus stop, used the bus to the shops and caught a taxi home accounting for 3 of the 13 journeys. Over a third, 62 (37%) perceived themselves as being housebound. The Mobility section of the NEADL show that the groups were matched on their ability to completed outdoor mobility activities when measured with a standardized assessment. They were scoring a median of 4 out of a possible score of 18 indicating that this sample were not regularly driving cars or travelling on public transport.

The number of times each type of transport was used in the last month can be seen in Table 3.6. Being a passenger in a car was the most frequently used mode of transport, 109 (65%). Walking was very popular, with 81(48%) people walking accompanied and 66 (39%) walking alone. 27 (16%) people had managed to use the bus alone and 19 (11%) had used an electric pavement scooter in the month before recruitment. Very small numbers of people had used the specialist transport services; 8 (5%) had used Shop - Mobility and 4 (2%) a voluntary driver. The groups were well matched at baseline on all the measures.

Table 3.5 Participation in outdoor mobility at baseline

Mobility activity measure		Both groups n 168	Control n 82	Intervention n 86
Self reported	Housebound	62(37%)	30 (37%)	32 (37%)
	Accompanied travel	45 (27%)	20 (24%)	25 (29%)
	Travelled alone n (%)	61 (36%)	32 (39%)	29 (34%)
Mobility participation	Yes I get out of the house as much as I want n (%)	56 (33.3%)	32 (39%)	24 (27.9%)
	Yes I have enough transport n (%)	56 (33.3%)	30 (36.6%)	26 (30.2%)
No. of journeys in last month	Mean, (S.D)	21, (22.3)	20, (21.0)	22, (23.6)
	median (IQR)	13 (3-32)	15 (4-30)	12 (3–35)
	Range	0 – 92	0-91	0-92
Mobility section NEADL	Median (IQR)	4 (1-8)	4 (1-8)	3.5 (1-9)
	Mean (S.D)	5.23 (4.96)	5.21 (4.13)	5.23 (5.01)

Table 3.6 Type of transport used in the month before recruitment

	Both groups n 168	Control n 82	Intervention n 86
Passenger in car	109 (64.9%)	58 (70.7%)	51 (59.3%)
Walk outside accompanied	81 (48.2%)	39 (47.6%)	42 (48.8%)
Walk outside alone	66 (39.3%)	31 (37.8%)	35 (40.7%)
Pushed in wheelchair	36 (21.4%)	16 (19.5%)	20 (23.3%)
Taxi accompanied	31 (18.5%)	16 (19.5%)	15 (17.4%)
Bus accompanied	30 (17.9%)	14 (17.1%)	16 (18.6%)
Bus on own	27 (16.1%)	12 (14.6%)	15 (17.4%)
Taxi on own	25 (14.5%)	9 (11%)	16 (18.6%)
Driven self	21 (12.5%)	8 (9.8%)	13 (15.1%)
Used Electric scooter	19 (11.3%)	12 (14.6%)	7 (8.1%)
Used Shop mobility	8 (4.8%)	6 (7.3%)	2 (2.3%)
Dial–A-Ride accompanied	7 (4.2%)	4 (4.9%)	3 (3.5%)
Dial-A-Ride on own	5 (3%)	2 (2.4%)	3 (3.5%)
Used Voluntary driver	4 (2.4%)	2 (2.4%)	2 (2.3%)
Used Bicycle	4 (2.4%)	3 (3.7%)	1 (1.2%)
Accessories to transport			
Owns disabled persons parking permit	70 (41.7%)	31 (37.8%)	39 (45.3%)
Receiving Mobility Allowance	23 (13.7%)	15 (18.3%)	8 (9.3%)
Had a bus pass	53 (31.5%)	25 (30.5%)	28 (32.6%)

3.4.3.4 Activities of daily living, leisure activity and mood limitation at baseline

The groups were well matched at baseline on their mood, their ability to participate in activities of daily living and their leisure activity. Results can be seen in Table 3.7. One participant did not want to complete the General

Health Questionnaire and therefore there is one missing set of scores from the intervention group. The groups were compared on the proportion of participants classified as a 'case' of non-psychotic psychiatric disorder using the scoring for the GHQ -12, where responses are scored 0,0,1,1. This gives a possible total score ranging from 0 to 12, with the recommended cut – off threshold of 2/3 indicating a case.

Table 3.7 Activities of Daily Living, leisure and mood at baseline

Assessment	Both groups n 168	Control n 82	Intervention n 86
Barthel total score Mean (S.D)	16 (4.92)	15 (5.36)	16 (4.44)
Median IQR	18 (15-20)	17 (13 –20)	18 (16 –20)
NEADL total score Mean (S.D)	23 (14.98)	23 (15.80)	23 (14.25)
Median (IQR)	22 (11-33)	21 (9 – 35)	23 (12 – 31)
NLQ total score Mean (S.D)	13 (7.83)	13 (7.74)	13 (7.95)
Median (IQR)	12 (7-18)	12 (7-19)	11 (7 – 18)
	n 167	n 82	n 85
GHQ patient No (%) with psychological distress	34 (20.4%)	18 (22%)	16 (19%)

3.4.4 Randomisation and stratification by age and outdoor mobility

Using age (64 years and under / 65 years and over) and independence in outdoor mobility the participants were placed in one of six groups for stratification. The stratification was used in the randomisation process and the results can be seen in Table 3.8

Table 3.8 Randomisation and stratification

	Control n 82	Intervention n 86
Aged ≥ 65 years, housebound	28	27
Aged ≥ 65 years, travels with someone	20	20
Aged ≥ 65 years, travels alone	23	23
Aged < 65 years, housebound	3	4
Aged < 65 years, travels with someone	1	4
Aged < 64 years, travels alone	7	8

3.4.5 The intervention provided

The number of sessions of intervention and the type of activity undertaken with the participants was collected and the results can be seen in Table 3.9 and 3.10. A vignette of a participant and a sample of the documentation used by the occupational therapists can be seen in Appendix 9. All participants received a 60-minute assessment from an occupational therapist plus written and verbal information about transport in the local area before they were randomised. This first session acted as the comparison intervention for those subsequently randomised to the control group.

Of those allocated to the outdoor mobility intervention eight participants did not receive the intervention after the initial assessment. Two of these were admitted to hospital before the programme could commence and six decided they did not want any visits from an occupational therapist after the first hour session. No information was collected as to why these people did not

want any further occupational therapy. The majority of participants had the full six sessions and three participants had seven sessions.

Table 3.9 Duration and number of intervention sessions

	Intervention n 78
Total duration of intervention in minutes Median (IQR) Mean (SD)	 240 (180 -310) 230.27 (113.32)
Number of visits per participant Median (IQR) Mean (SD	 6 (4 – 6) 4.73 (1.92)

Table 3.10 shows a breakdown of the activities undertaken in occupational therapy outdoor mobility intervention (OTOMI). As can be seen the main goals of the intervention as agreed at the first assessment are very similar to the tasks undertaken. 407 separate visits were provided over an 18-month period mostly by PL, a senior occupational therapist with 12 (3%) visits being provided by a second senior occupational therapist (MW). It was documented in the notes that 18 participants did not achieve the goal of the intervention: six participants refused to leave the house during the intervention, even though they had given consent to the trial, two would not go outside as it was too cold and the other ten had individual reasons. The number of applications to other services was documented and can be seen in Table 3.10. The other category includes single applications such as referral to the British Legion for financial assistance, referral to Social Services for grab handles on the front door and referral to the local stroke club.

Table 3.10 Activities provided in the OTOMI.

		n = 78
Main mobility mode for which treatment goals were set	Walking	17 (22 %)
	Bus	13 (17 %)
	Dial A Ride	10 (13 %)
	Driving	8 (9 %)
	Shop Mobility	6 (8 %)
	Scooter of own	6 (8%)
	Voluntary drivers	5 (6%)
	Push in wheelchair	4 (5%)
	Electric wheelchair	3 (4%)
	Passenger in car	3 (4%)
	Taxi	3 (4%)
Achieved goal:	Yes	60 (77%)
Reason for not achieving goal:	Refused to leave house	6 (8%)
	Weather too cold	2 (2%)
	Other reasons	10 (13%)
		407 visits
Tasks undertaken	Walking	135 (33%)
	Bus	53 (13%)
	Shop mobility	32 (9%)
	Pushed in wheelchair	31 (8%)
	Dial –A-Ride	29 (7%)
	Driving	26 (7%)
	Scooter	25 (6%)
	Voluntary driver	24 (6%)
	Electric wheelchair	12 (3%)
	Passenger in car	11 (4%)
	Taxi	10 (4%)

Table 3.10 continued

Applications to services:	Voluntary	16 (19%)
	Dial –A –Ride	16 (19%)
	Parking permit	13 (16%)
	Shop Mobility	12 (15%)
	Bus pass	4 (5%)
	Befriending service	4 (5%)
	Other applications	17 (21%)

3.4.6 Four month results

3.4.6.1 Lost to follow up at four month assessment

Computerised hospital records were checked to ascertain whether the participant was alive before the four-month questionnaire was sent. Seven (8.5%) of the control group had died by the 4 month assessment compared to 2 (2.3%) of the intervention group. This difference between deaths did not reach a statistically significant level (RR 1.65, 95% CI 1.12 to 2.43, p = 0.07). One hundred and fifty nine four month questionnaires were sent by post to the participants. One participant returned the questionnaire saying she did not want to be in the study. The results can be seen in Table 3.11

Table 3.11 Reasons for not completing the four month questionnaire

	Total group n = 168	Control n = 82	Intervention n =86
Completed questionnaire	158 (94%)	74 (90%)	84 (97.6%)
Withdrew consent	1 (0.5%)	1 (1.2%)	0
Died before assessment	9 (5.3%)	7 (8.5%)	2 (2.3%)

3.4.6.2 Characteristics of responders and non-responders at four months

The characteristics of the four-month responders were compared to those who did not respond using the baseline data. Table 3.12 illustrates that non-responders tended to be older, more likely to be living alone, have poorer functional ability and had completed less journeys in the previous month than responders. The non- responders category included those who died before or around the time of follow up as these where the greatest number of non- responders.

Table 3.12 Characteristics of responders and non-responders

	Responders n 158	Non-responders n 10
Gender male	85	6
female	73	4
Age, mean (S.D)	74 (8.6)	78 (4.9)
Barthel score at baseline, median (IQR)	18 (15-20)	16.5 (9-18)
Living alone	62 (39.2)	5 (50%)
Number of journeys median	14 (3-33)	4.5 (2 - 23)
Number who went out as much as they wanted	53 (34%)	3 (30%)

3.4.6.3 Who completed the four month assessment

The four month questionnaires were mostly completed by the participants 103 / 158 (65%), but there was 16 / 158 (10%) that needed a visit by an

independent assessor. No further interventions were offered for the intervention or control group after the four month assessment. Table 3.13 shows information about who completed the other questionnaires.

Table 3.13 Person who filled in the questionnaire

	Both groups n 158	Control n 74	Intervention n 84
Patient	103 (65.2%)	47 (63.5%)	56 (66.7%)
Husband, wife	26 (16.5%)	14 (18.9%)	12 (14.3%)
Other relative	8 (5.1%)	3 (4.1%)	5 (6%)
Friend	2 (1.3%)	1 (1.4%)	1 (1.2%)
Paid carer	3 (1.9%)	2 (2.7%)	1 (1.2%)
Independent assessor	16 (10.1%)	7(9.5%)	9 (7%)

3.4.6.4 Accommodation at the four month assessment

Nearly half of the participants were living alone and 9 (6%) were living in residential or nursing care. One participant (intervention group) who stated that they were living alone completed the questionnaire whilst in hospital. Where participants were living at the time of the four month assessment can be seen in Table 3.14.

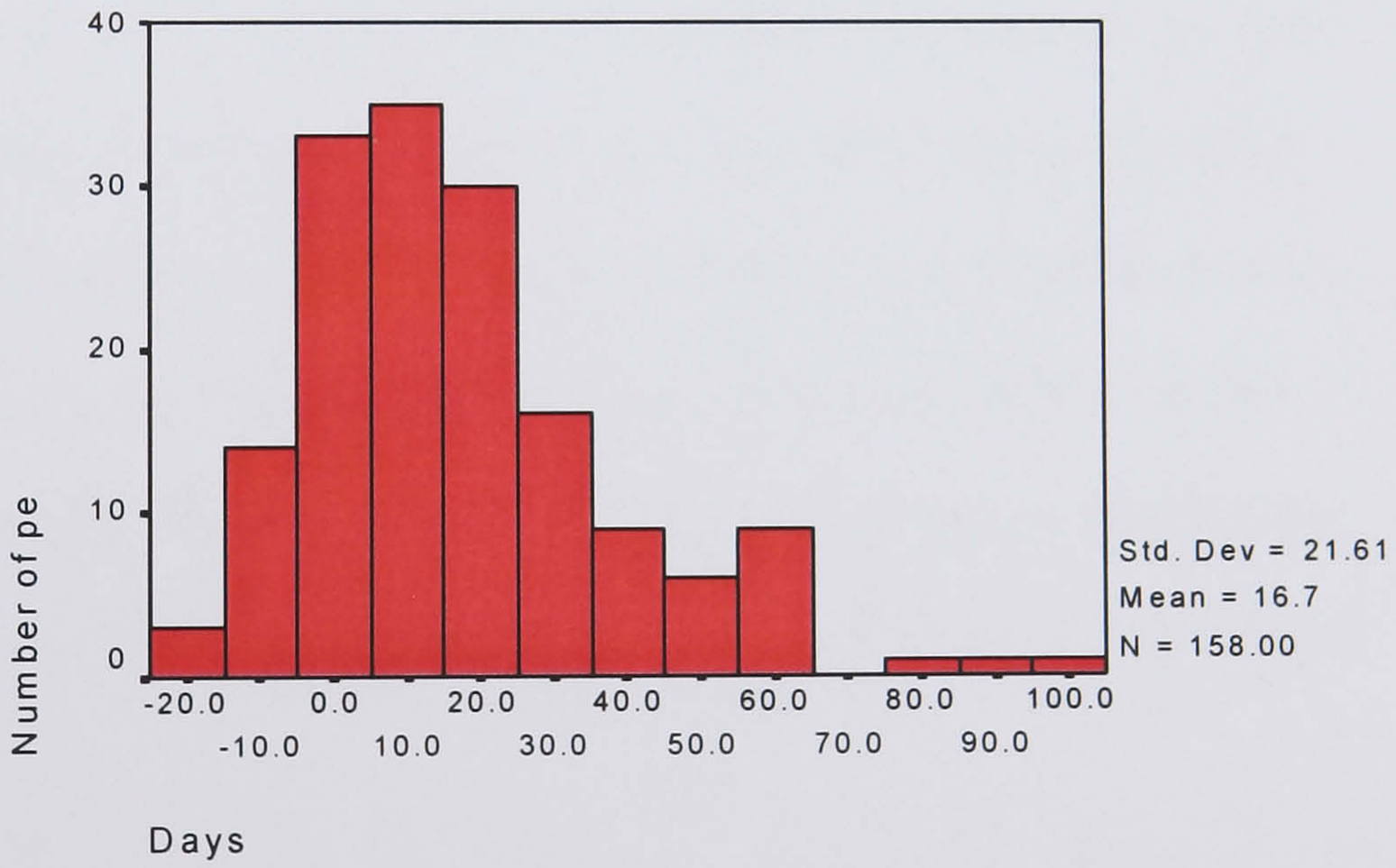
Table 3.14 Accommodation at four months

	Both groups n 158	Control n 74	Intervention n 84
Living alone	76 (48.1%)	33 (44.6%)	43 (51.2%)
Living with someone	73 (46.2%)	37 (50%)	36(42.9%)
Nursing Home	8 (5%)	3 (4.1%)	5 (6%)
Residential Home	1 (0.6%)	1 (1.4%)	0

3.4.6.5 Nearness to four month assessment due date

The four-month assessment was sent a median of 2 days, IQR - 4 to 10 days (mean 11 days, S.D. 55 days) before the date it was due to be completed. There were a median 12 days, IQR 2-26days, (mean 17 days, range 20 days prior to 103 day after it was due) from the date the questionnaire was first administered to the date it was completed. The results are skewed by home visits and can be seen in Figure 3.4.

Figure 3.4 Distribution of days from the 4 month assessment being due and being completed



3.4.6.6 Missing /ambiguous data

Of the 158 questionnaires returned, 123 (78%) were returned complete and unambiguous. Participant or carers who returned questionnaires with missing or ambiguous answers e.g. a text answer where a tick was expected or where two ticks were given instead of one, were telephoned by the

independent assessor for clarification. If they were unable to complete the questionnaire over the phone they visited at home. Table 3.15 gives details of missing or ambiguous data/collection.

Table 3.15 Missing/ambiguous data collection

	Both groups n 158	Control n 74	Intervention n 84
No missing data	123 (77.8%)	65 (87%)	58 (69%)
Telephoned, questionnaire completed	35 (22.2%)	9 (12.2%)	26 (30.9%)

To complete an intention to treat analysis, complete data sets for all participants who gave consent to be in the study were required. To deal with missing data a number of techniques were used. For the principal outcome measure, participants who were dead at the point of assessment were allocated the worst outcome, and for others lost to follow up their baseline or last recorded responses were used. For the other analyses the baseline value was or last recorded value was used (Hollis and Campbell, 1999).

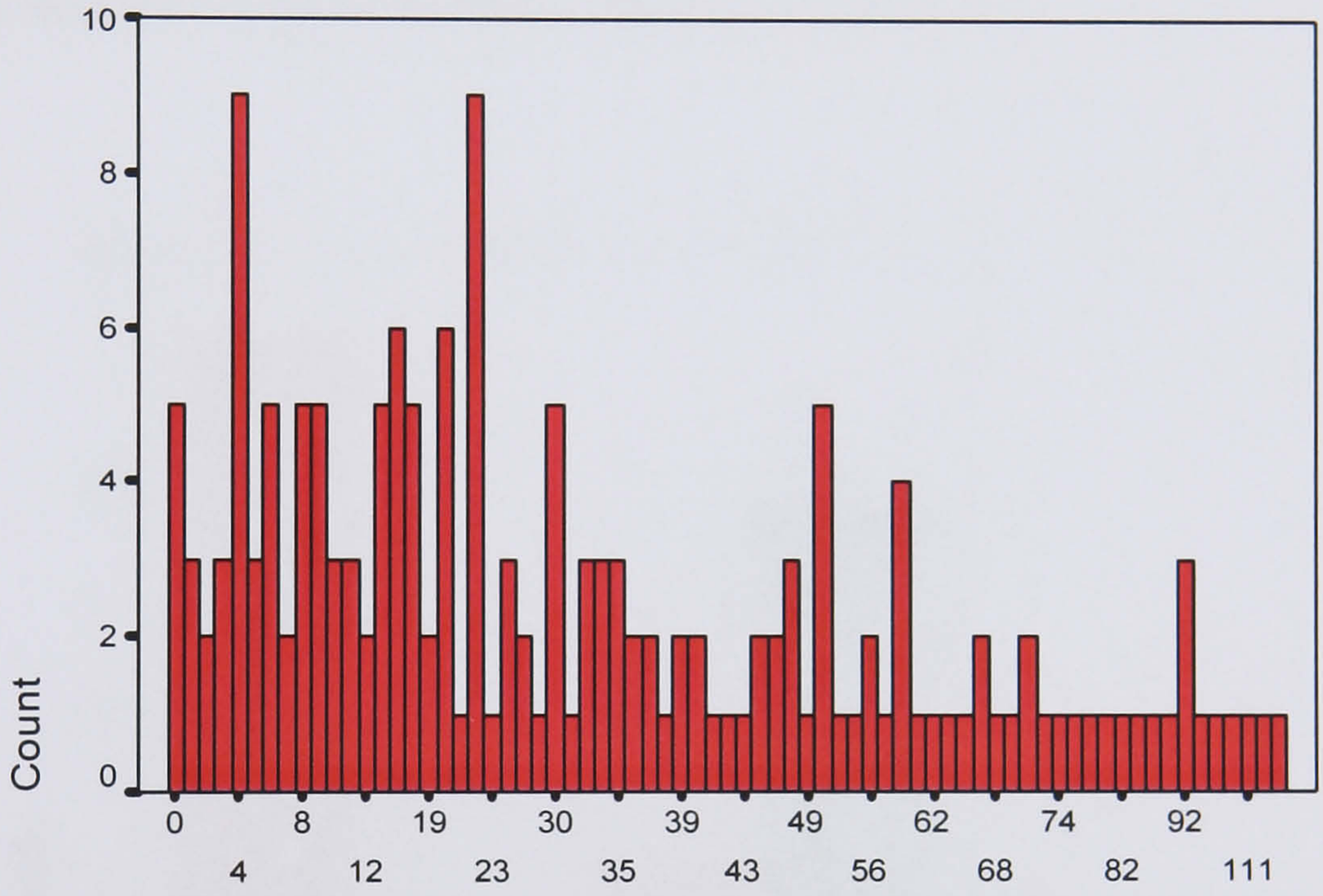
3.4.7 Principal outcome measure at the four month assessment

3.4.7.1 Outdoor mobility performance

Table 3.16 shows a comparison of outdoor mobility performance between the intervention group and the control group using an intention to treat analysis. Given the skewed distribution shown in Figure 3.5 of the data for

the number of journeys undertaken non-parametric statistics were used to compare the two groups for this variable.

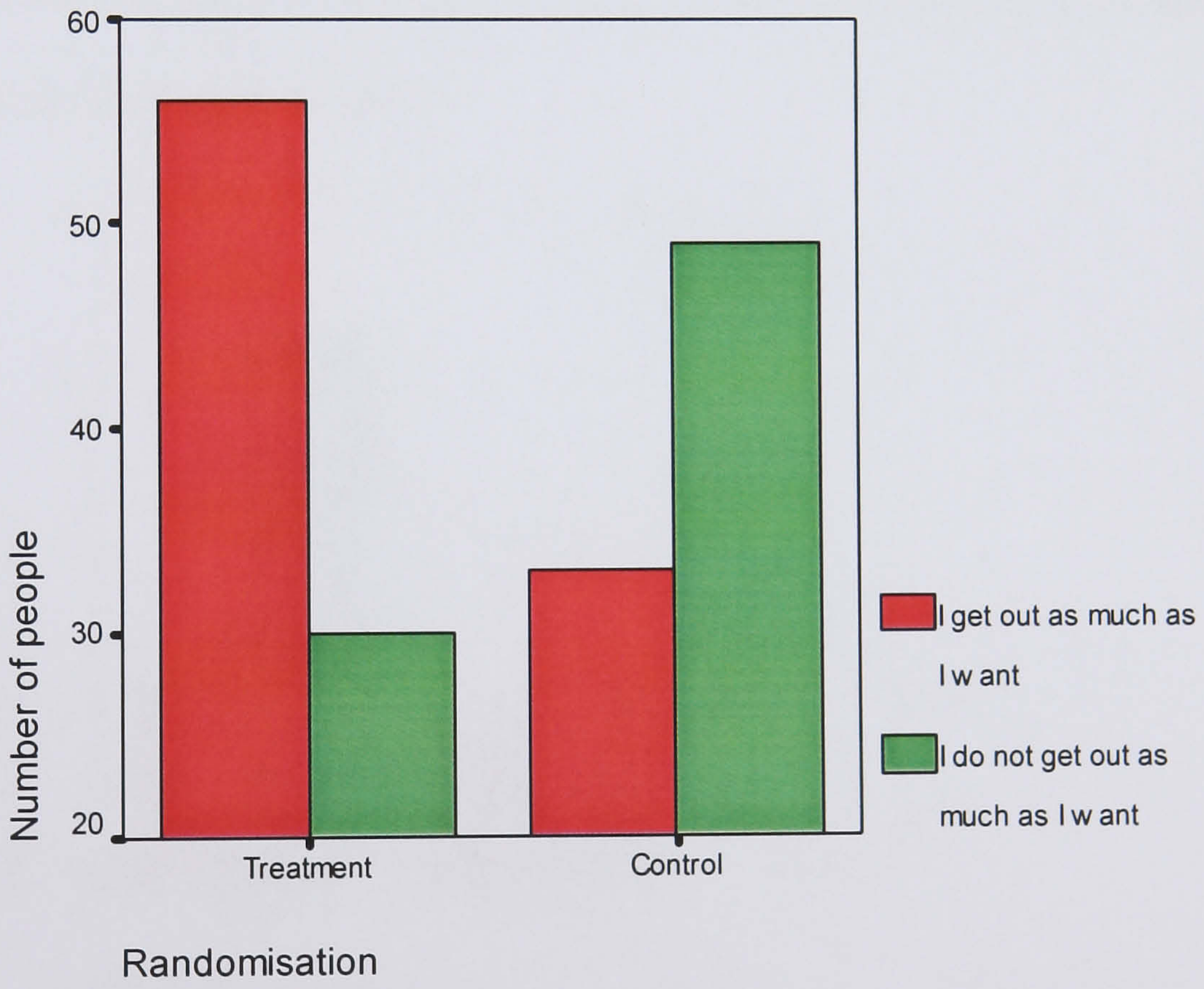
Figure 3.5 A graph to show the distribution of the number of journeys undertaken by the total population studied



The principal outcome measure; Do you get out of the house as much as you want? indicated that 56 (65%) participants in the intervention group compared to 30 (35%) in the control group said yes to this question. The results can be seen in Figure 3.6. This demonstrates a difference of 33%, equivalent to a numbers needed to treat (NNT) of 3.3 participants receiving the intervention to get one participant to change their outcome from 'No' to 'Yes'. Fifty two (61 %) participants in the intervention group compared to 32 (39%) in the control group said they had enough transport, again this

showed a statistically significant difference between the groups (RR 1.53, 95%CI 1.12 to 2.08) as shown in Table 3.16.

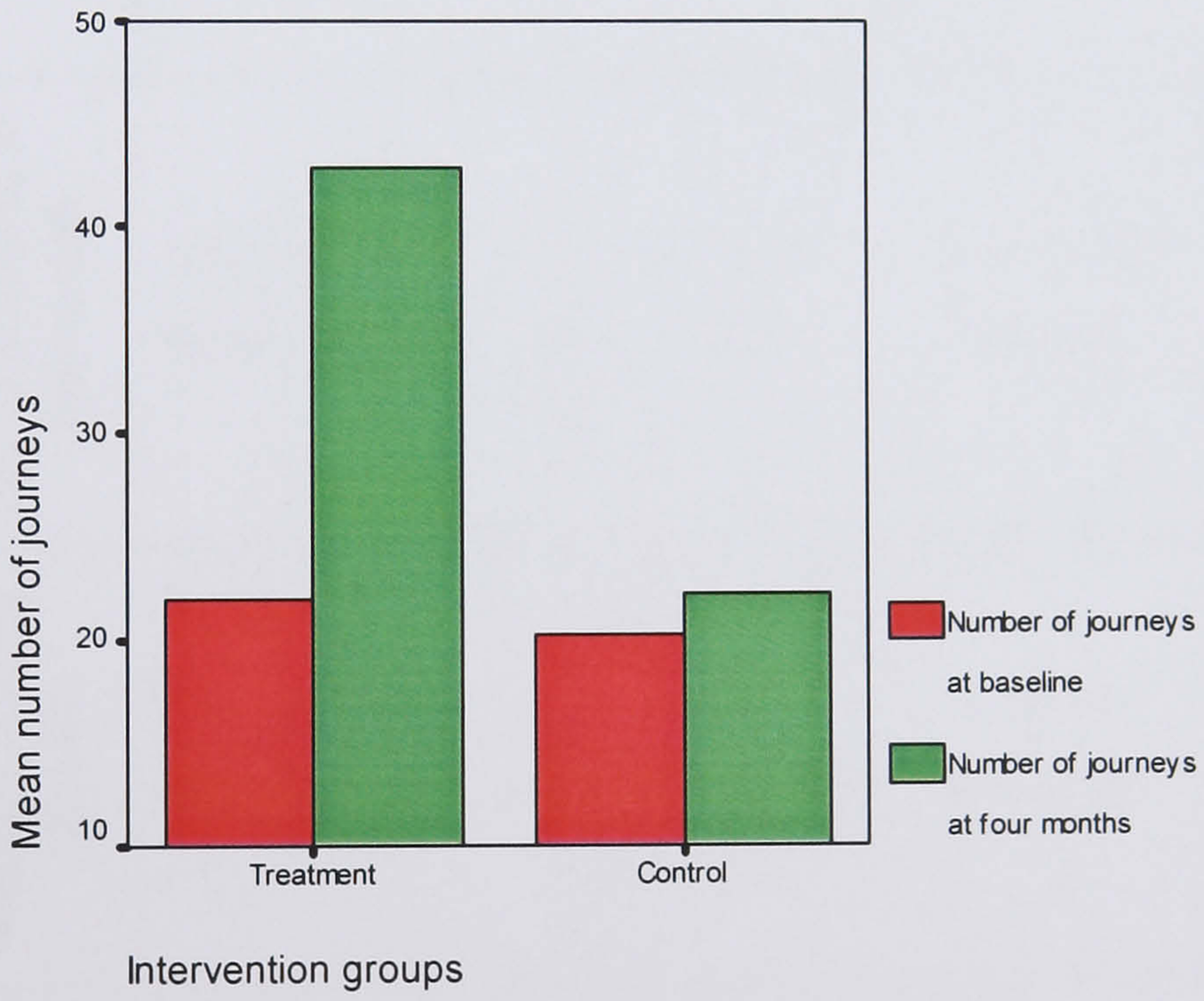
Figure 3.6 A graph to depict the difference in the number of people who said they got out of the house as much as they wanted



At the four month assessment there was a statistically significant difference between the number of journeys taken by the intervention group and the control group. (Mann Whitney U test, $Z = -4.923$, $p < 0.001$). The participants reported that a median of 37 journeys per month were taken by

the intervention group compared to a median of 14 in the control group. A graph can be seen to show the difference pictorially in Figure 3.7. It has to be remembered that these were self reported journeys and a walk to the bus stop, a ride on a bus and a trip home in a taxi would have accounted for three journeys. The number of journeys was calculated in the same manner as at the baseline assessment.

Figure 3.7 A graph to show the change in number of journeys from baseline to the four month assessment.



The mobility section of the NEADL measured participation outdoor mobility activities. Participants in the intervention group scored a mean of 9 (out of a possible 18 points) compared to 6 in the control group. This indicated that the intervention group was more likely to be able to complete activities such as crossing roads and using public transport.

Table 3.16 Outdoor mobility at four months

Measure		Control n 82	Intervention n 86	Comparison of groups
Mobility participation	Yes I get out of the house as much as I want n (%)	30 (35%)	56 (65%)	RR= 1.72 (95% CI 1.25 to 2.37) NNT = 3.3
	Yes I have enough transport n (%)	32 (39%)	52 (60.5%)	RR= 1.49 (95% CI 1.10 - 2.03) p = 0.013
No. of journeys in last month	Median (IQR) Mean, (S.D)	14 (5-34) 21 (22)	37 (17 -61) 42 (30)	Mann Whitney U test, Z = -4.923, p<0.001
Mobility section NEADL	Median (IQR) Mean (S.D.)	7 (2-10) 6.67 (5.31)	9 (4-13) 8.7 (5.48)	Mann – Whitney U test, Z=-2.533, p = 0.011

RR = Relative risk, NNT = number needed to treat

A sensitivity analysis using data from the responders only (n = 158) was completed to examine the dependency of the findings upon the techniques used to replace the missing data. For the primary outcome measure, 56 (66%) people in the intervention group and 30 (40.5%) in the control group said they got out of the house as much as they wanted. The statistical

comparison of the groups detected a similar difference to the intention to treat (RR 1.64, 95% CI 1.20 to 2.25). The number of journeys was also subjected to a sensitivity analysis for the responders only. The intervention group undertook a median of 37 journeys and the control group a median of 14 journeys (Mann- Whitney $p<0.01$).

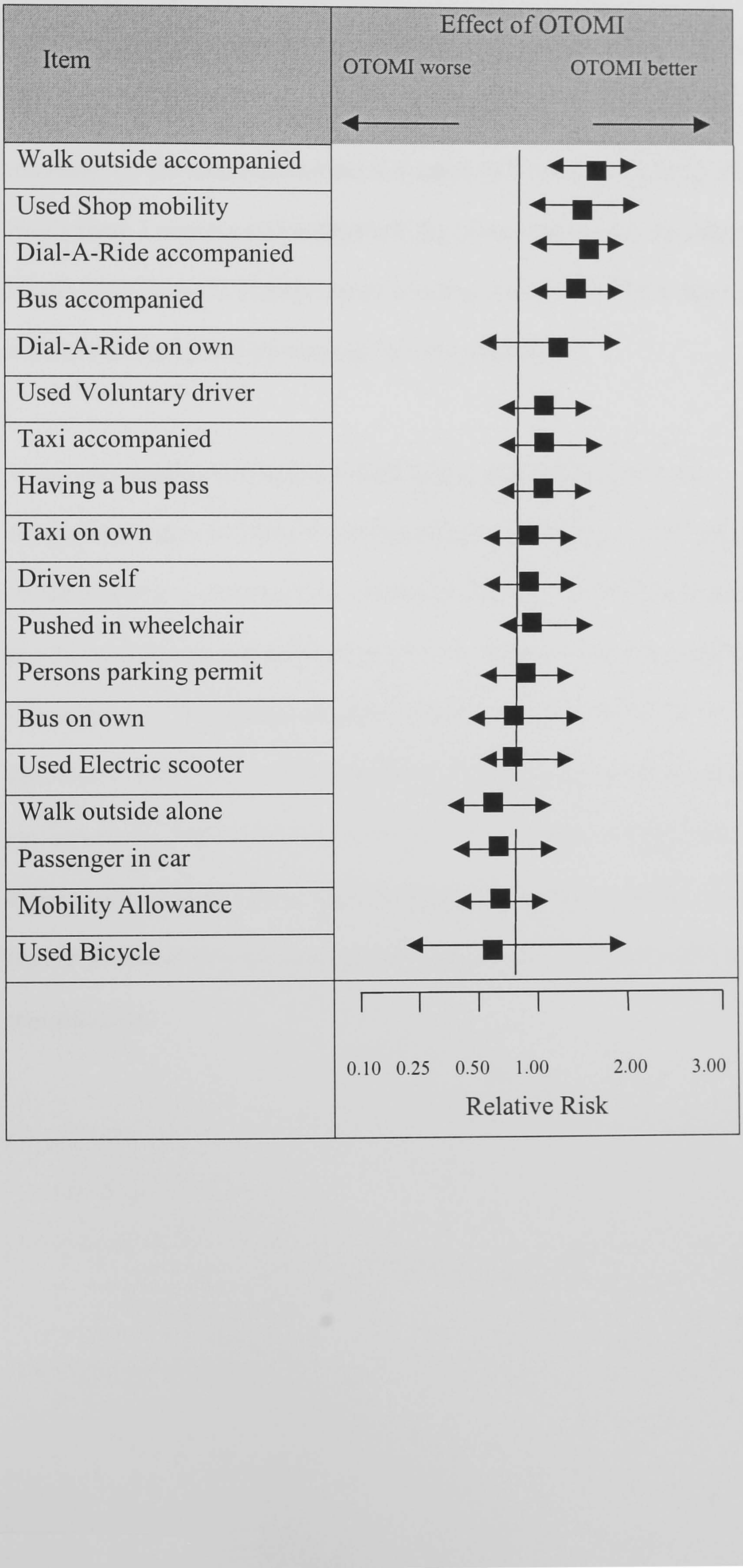
A comparison of the different types of transport used by the two groups can be seen in Table 3.17. The data were examined using the Relative Risk test and showed a positive trend towards people in the OTOMI group for participating in most types of outdoor mobility except for being a passenger in a car and riding a bike. The people in the OTOMI group were one and half times more likely to use the bus accompanied, walk outside accompanied or uses shop mobility than those people in the control group.

The results are shown pictorially in Figure 3.8. The boxes depict the R-R and the arrows the 95% CI.

T able 3.17 Types of transport used at four months

Activity	Control n 84	Intervention n 86	R-R test
Passenger in car	59	61	0.84
Walk outside accompanied	41	62	1.50
Walk outside alone	40	45	0.99
Pushed in wheelchair	24	29	1.04
Taxi accompanied	18	24	1.10
Bus accompanied	15	30	1.40
Bus on own	14	16	1.00
Taxi on own	12	16	1.06
Driven self	11	14	1.06
Used Electric scooter	11	12	0.98
Used Shop mobility	5	15	1.50
Dial-A-Ride accompanied	3	9	1.46
Dial-A-Ride on own	4	5	1.05
Used Voluntary driver	4	8	1.28
Used Bicycle	3	2	0.75
Accessories to Transport			
Parking permit	34	48	1.17
Mobility Allowance	21	17	0.71
Having a bus pass	29	45	1.31

Figure 3.8 Effect on individual different types of transport used



3.4.8 Secondary outcome measures

3.4.8.1 Activities of daily living, leisure and mood limitation at four months

The mean and median scores of outcomes for activity limitation and mood measured by the total Nottingham Extended ADL index (NEADL), the Nottingham Leisure questionnaire (NLQ), Barthel Index and the General Health Questionnaire (GHQ) can be found in Table 3.18. There were no statistically significant differences between the groups.

Mood was measured in both the participants and carers. Data were compared using two different scoring methods. The groups were compared on the proportion of participants classified as a 'case' of non-psychotic psychiatric disorder using the scoring for the GHQ -12, where responses are scored 0,0,1,1. This gives a possible total score ranging from 0 to 12, with the recommended cut – off threshold of 2/3 indicating a case. The results can be seen in Table 3.18. One participant did not want to complete the questionnaire and 88 carers returned the completed questionnaire. Secondly the scores out of 36 were used in a linear regression procedure which is reported later.

Table 3.18 Activities of daily living, leisure and mood at four months

	Control n 82	Intervention n 86	Comparison of groups
NEADL total Median (IQR) Mean (S.D.)	26 (11 - 44) 26.00 (18.16)	31 (20 - 49) 33.27 (17.30)	M-W P = 0.089
NLQ Median (IQR) Mean (S.D.)	12 (7 - 18) 13.98 (8.86)	14 (10 - 20) 16.20 (8.81)	M-W P= 0.144
Barthel Median (IQR) Mean (S.D.)	17 (13-19) 15.28 (4.94)	18 (15-20) 16.07 (4.77)	M-W P = 0.192
	n 82	n 85	
GHQ patient No (%) with psychological distress	30 (40.5%)	31 (36.9%)	OR = 0.86 (95% CI 0.43 - 1.71) p = 0.76
	n 47	n 41	
GHQ carer No (%) with psychological distress	18 (38.2%)	12 (29.2%)	OR = 0.67 (95% CI 0.25-1.78) p = 0.50

M-W = Mann Whitney U test, OR = Odds Ratio, CI = Confidence Interval

Activity limitation, mood and leisure outcomes satisfied the conditions for analysis by linear regression. All models were adjusted for baseline characteristics of gender, ethnic origin, and the two stratification factors (age and transport used before study). Examinations of the residuals for each outcome measure, (apart from the Barthel score) showed no serious

departures from the model assumptions. Plots of residuals can be found in Appendix 10. The results of the linear regression are shown in Table 3.19. The diamonds show the best estimate of effect, at the centre, and the 95% confidence intervals, at the ends. The scales have been converted into a percentage to make the diamonds easier to view pictorially. If the diamonds lie completely to the right or left of the '0' line this indicates a statistically significant difference between the groups. As can be seen there is an overall trend towards a better outcome as measured by these scales for participants in the intervention group. Only the mobility scale of the NEADL reached a statistical significant difference. Table 3.19 indicates that the study may have been under powered to detect small changes in the NEADL total score and the NEADL sub sections.

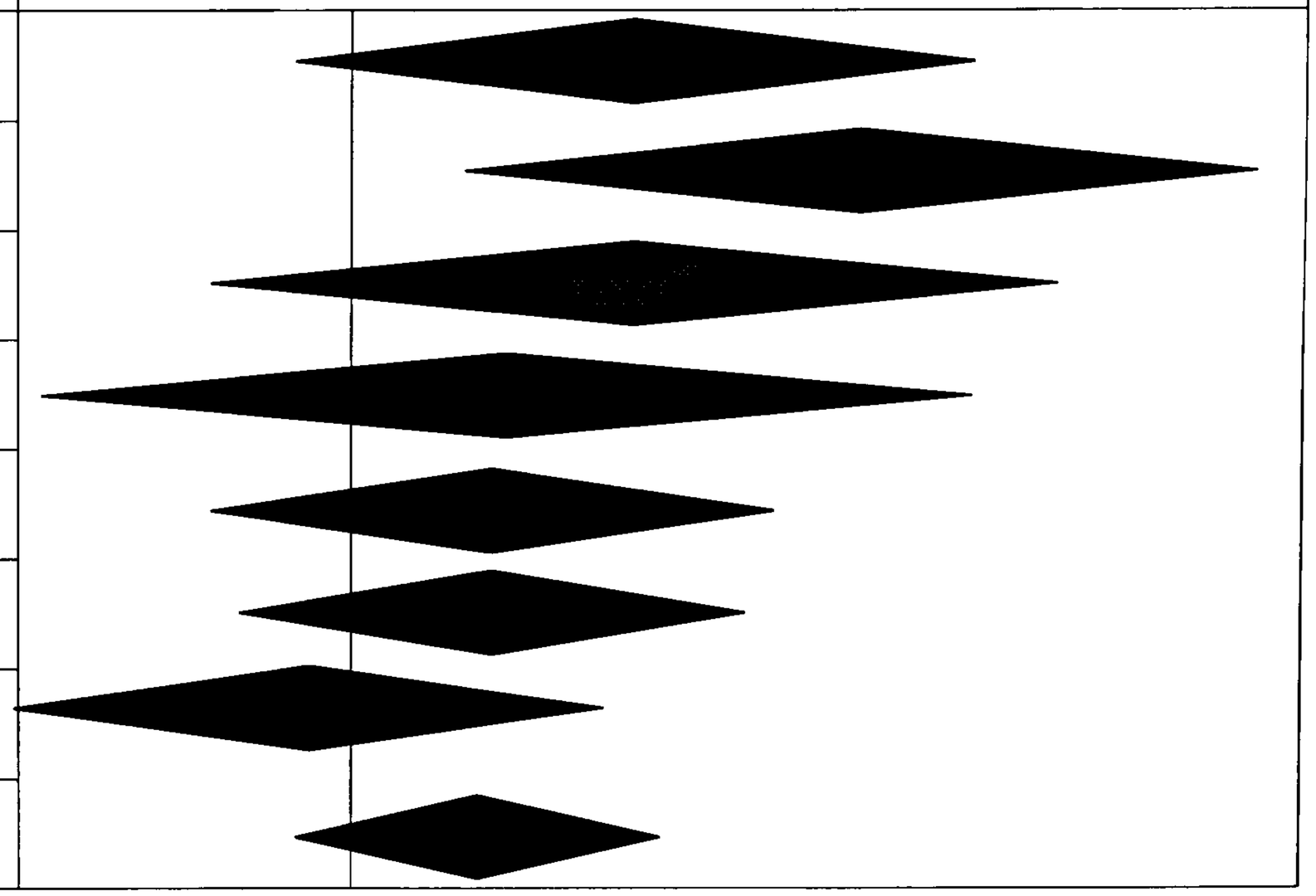
	Range worst - best	Mean difference	95% CI	Difference: % of the scale range Intervention worse ← → Intervention better -6 -4 -2 0 2 4 6 8 10 12 14 16 18 20
ADL (NEADL)	0 - 66	4.54	-0.74 to 9.839	
Sub-scales: Mobility	0-18	2.08	0.67 to 3.93	
Kitchen	0-15	1.19	-0.51 to 2.68	
Domestic	0-15	0.74	-0.99 to 2.14	
Leisure	0-18	0.56	- 0.73 to 2.00	
GHQ (patient)	36 - 0	-1.30	-1.02 to 3.77	
GHQ (carer)	36 - 0	-0.32	-2.83 to 2.18	
Leisure (NLQ)	0 - 60	1.73	- 0.95 to 4.62	

Table 3.19 – Activities of daily living, leisure and mood by multivariate linear regression at 4 months

3.4.9 Ten month results

3.4.9.1 Lost to follow up at 10 month assessment

The 158 participants who completed the four month assessment were considered for the ten month assessment. Computerised hospital records were checked to ascertain whether the participant was dead before the ten-month questionnaire was sent by post. Eight people had died, therefore 150 ten month assessments were sent. 147 completed 10-month assessments were available for analysis. Table 3.20 shows the total number of participants and how they were lost from recruitment to the ten month assessment.

Table 3.20 Reasons for not completing the ten month questionnaire

	Total group n = 168	Control group n = 82	Intervention group n =86
Lost to follow up at the 4 month assessment	10	8	2
Withdrew consent at ten month	3	2	1
Died between four month and ten month assessment	8	3	5
Completed ten month questionnaire	147	69	78

3.4.9.2 Characteristics of responders and non-responders

Ten-month responders were compared to those who did not respond using the baseline data. Table 3.21 illustrates that non-responders tended to be people that had been living in nursing or residential homes, were older, had less independence in activities of daily living and did not go out of the house much at the baseline assessment. Four of those that had died were from nursing or residential home accommodation.

Table 3.21 Characteristics of responders and non-responders

	Responders n 147	Non-responders n 11
Gender male	79(54%)	6 (55%)
female	68 (46%)	5 (45%)
Age, mean (S.D)	74 (8.65)	78 (6.65)
Barthel score at baseline, median (IQR)	18 (16-20)	5 (2-19)
Living alone	60 (41%)	2 (18%)
Living with someone	84 (57%)	5 (46%)
Nursing/ residential	3 (2%)	4 (36%)
Number of journeys Median (IQR)	15 (4-34)	2 (0-2)

3.4.9.3 Who completed 10 month assessment

Two thirds of the questionnaires were completed by the participant. The independent assessor completed 18 (12%) of the assessments. This was similar to the numbers at the four month assessment. Table 3.22 shows who completed the ten month assessments.

Table 3.22 Person who filled in the questionnaire

	Both groups n 147	Control n 69	Intervention n 78
Participant	91 (61.9%)	40 (58%)	51 (65.4%)
Husband, wife	27 (18.4%)	15 (21.7%)	12 (15.4%)
Other relative	7 (4.8%)	4 (5.8%)	3 (3.8%)
Friend	2 (1.4%)	1 (1.4%)	1 (1.3%)
Paid carer	2 (1.4%)	1 (1.4%)	1 (1.3%)
Independent assessor	18 (12.2%)	8 (11.6%)	10 (12.8%)

3.4.9.4 Accommodation at 10 months assessment

As can been seen in the Table 3.23 there were no significant differences between the groups as to where the participants were living at the ten month assessment. However the number of participants who were in nursing and residential homes had dropped from the start of the study due to deaths. One participant had moved into residential care since the four month assessment. 145 participants completed the forms at home; one (control) completed the forms whilst in hospital and one (control) whilst at a relative's home.

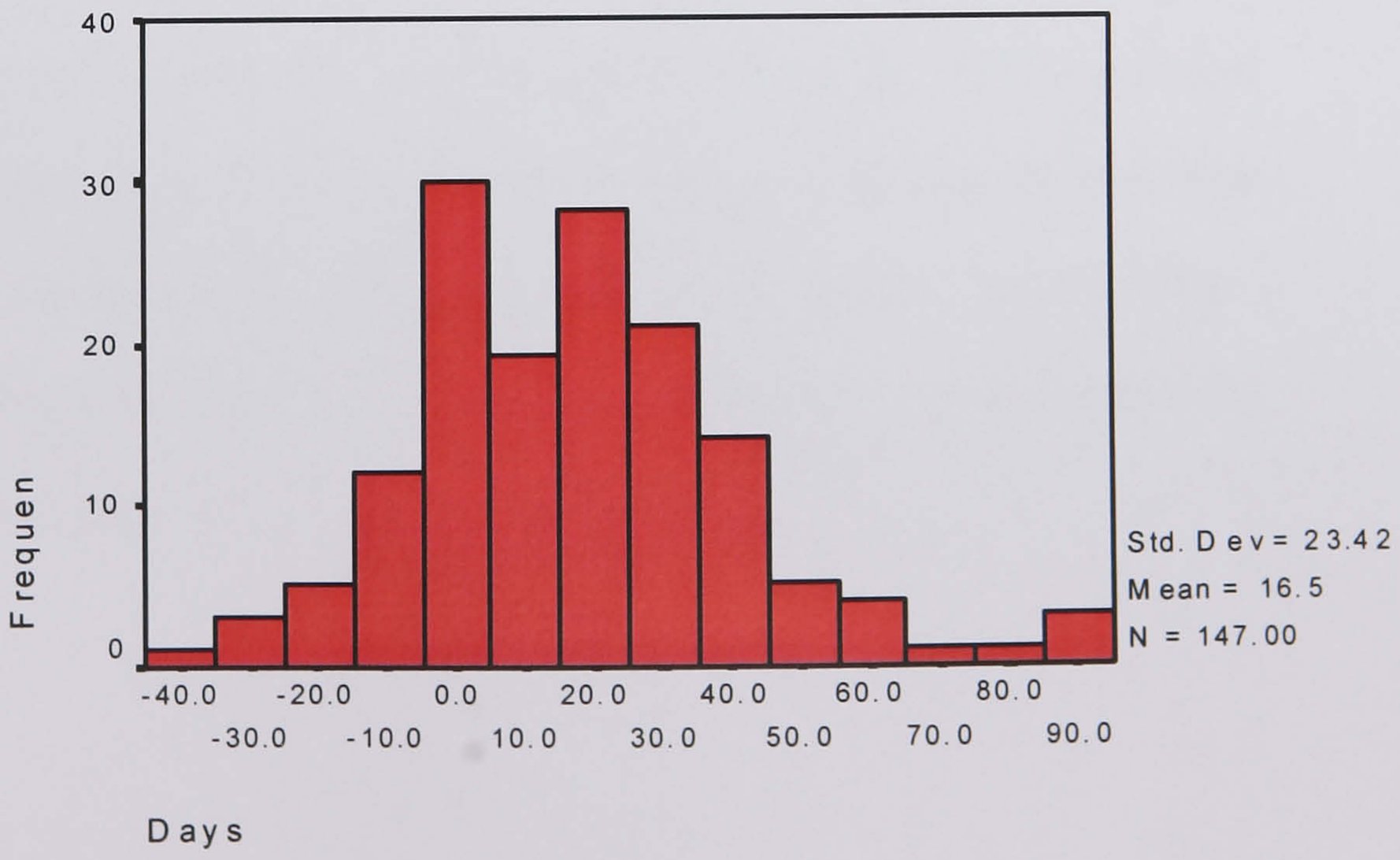
Table 3.23 Accommodation at ten months

	Both groups n 147	Control n 69	Intervention n 78
Living alone	66 (44.9%)	30 (43.5%)	36 (46.2%)
Living with someone	77 (52.3%)	37 (53.6%)	40 (51.3%)
Nursing Home	2 (1.4%)	1 (1.4%)	1 (1.3%)
Residential Home	2 (1.4%)	1 (1.4%)	1 (1.3%)

3.4.9.5 Nearness to 10 month date

There was a median of 15 days (IQR 0-30) from the date the questionnaire was due to the date it was completed. Figure 3.9 shows the distribution of the days

Figure 3.9 Distribution of the 10 month assessment being due and being completed



3.4.9.6 Missing /ambiguous data

Of the 147 questionnaires returned, 92 (62%) were returned complete and unambiguous. As with the four month data, where the answer was incomplete or not clear the participant was telephoned by an independent assessor for clarification. Table 3.24 gives details of missing or ambiguous data/collection.

Table 3.24 Missing/ambiguous data collection

	Both groups n 147	Control n 69	Intervention n 78
No missing data	92 (62.5%)	45 (65%)	47 (60%)
Telephoned, questionnaire completed	55 (37.5%)	24 (35%)	31 (40%)

Intention-to-treat analyses were undertaken. The same principals as at the four months assessment were applied for missing data. For the principal outcome measure, participants who were dead at the point of assessment were allocated the worst outcome, and for others lost to follow up their baseline or last recorded responses were used. For the other analyses all missing values were imputed using baseline values.

3.4.10 Principal outcome measures at ten months

3.4.10.1 Outdoor mobility performance at ten months

Table 3.25 shows the results when the groups were compared on outdoor mobility performance at the ten month assessment, using an intention to treat analysis. Given the skewed distribution of the data non-parametric statistics were used to compare the two groups.

The principal outcome measure; Do you get out of the house as much as you want? indicated that 53 (62%) participants in the intervention group compared to 33 (38%) in the control group said yes to this question. This demonstrated a statistically significant difference. The results were similar when a responder's only analysis was completed on 147 participants (RR1.67, 95%CI 1.21 to 2.31). 58 (67%) participants in the intervention group compared to 43 (52%) in the control group said they had enough transport, again this showed a statistically significant difference between the groups.

A median of 42 journeys was made by the intervention group compared to a median of 14 in the control group. This was statistically significant when tested with the Mann- Whitney U test ($Z -4.337$ $p< 0.01$). A responders only analysis with 147 participants was similar (intervention 46 journeys, control 15 journeys, Mann-Whitney $p<0.01$).

The mobility section of the NEADL scale did not show any significant differences between the intervention and control group (Mann Whitney U test Z –1.148, p =2.51).

Table 3.25 Outdoor mobility at ten months

Mobility activity measure		Control n 82	Intervention n 86	Comparison of groups
Mobility participation	Yes I get out of the house as much as I want n (%)	33 (38)	53 (62)	RR 1.74, 95% CI 1.24 to 2.44 NNT = 4
	Yes I have enough transport n (%)	28 (40.6)	53 (67.9)	RR1.37, 95% CI 0.99 to 1.91
No. of journeys in last month	Median (IQR) Mean, (S.D)	14 (7-32) 21 (22)	42 (13-69) 42 (30)	MW p < 0.01
Mobility section, NEADL	Median (IQR) Mean (S.D.)	7 (3-14) 8.28 (5.72)	6 (2 –12) 7.39 (6.04)	MW p = 0.251

RR = Relative risk test, MW = Mann-Whitney U test, NNT = numbers needed to treat

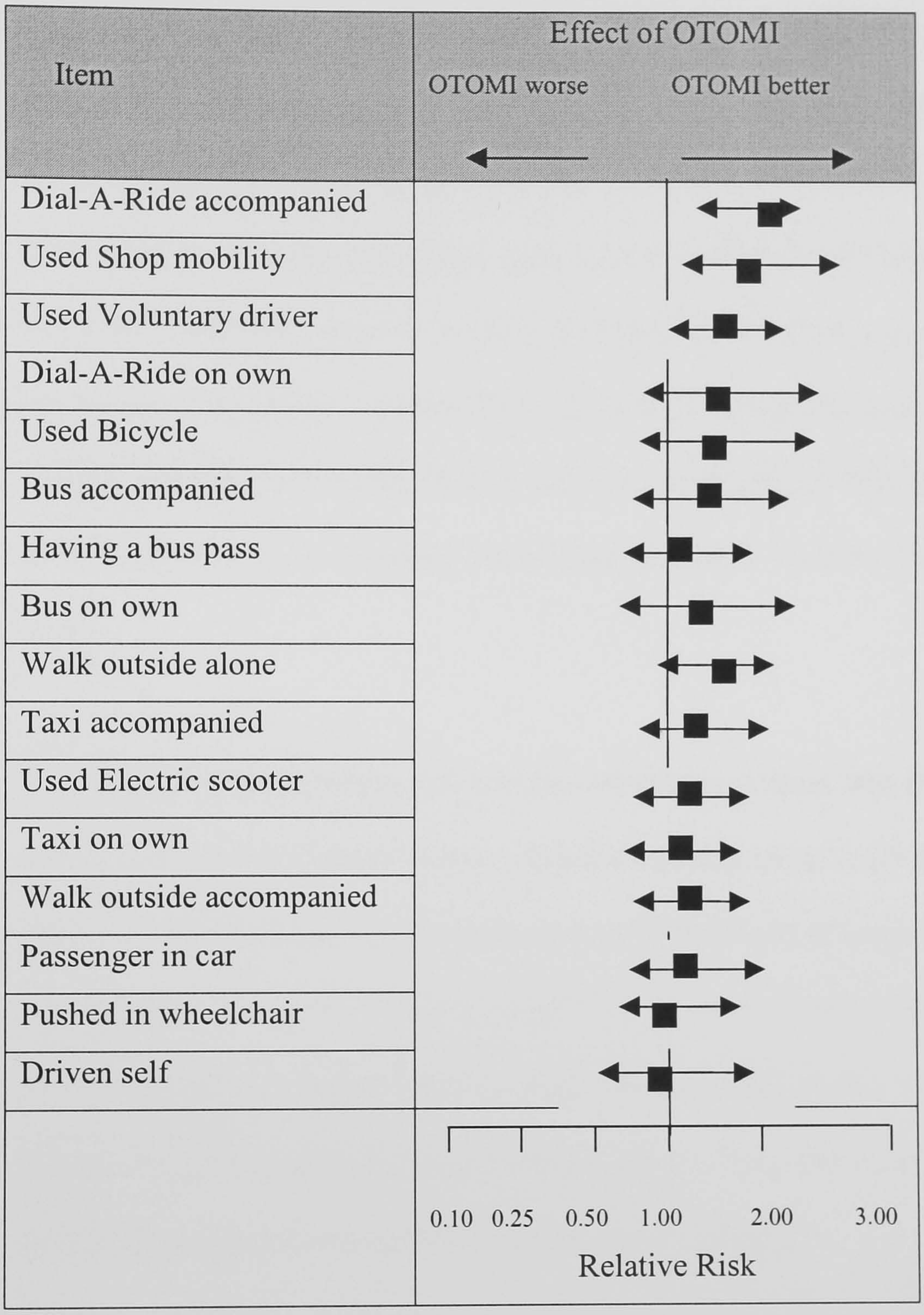
A comparison of the different types of transport used by the two groups can be seen in Table 3.25. The Relative Risk test was used to determine the relationship between receiving the OTOMI and whether different types of out door mobility were used. Overall the people in the OTOMI group had used more types of transport but only Shop-Mobility, Dial-a-Ride and the voluntary drivers showed a strong positive relationship. A pictorial representation of the results can be seen in Figure 3.10.

Table 3.26 Types of transport used at the ten month assessment

Activity	Control n 69 (%)	Intervention n 78 (%)	R-R Test
Passenger in car	55 (79.7)	65 (83.3)	1.13
Walk outside accompanied	45 (65.2)	57 (73.1)	1.20
Walk outside alone	33 (47.8)	43 (55.1)	1.15
Pushed in wheelchair	23 (33.3)	26 (33.3)	1.00
Taxi accompanied	14 (20.3)	23 (29.5)	1.24
Bus accompanied	14 (20.3)	26 (33.3)	1.34
Taxi on own	17 (24.6)	19 (24.4)	0.99
Driven self	15 (21.7)	12 (15.4)	0.81
Bus on own	9 (13.0)	15 (19.2)	1.22
Used Electric scooter	12 (17.4)	15 (19.2)	1.06
Used Shop mobility	4 (5.8)	17 (21.8)	1.67
Used Voluntary driver	7 (10.1)	10 (12.8)	1.12
Dial-A-Ride accompanied	4 (5.8)	10 (12.8)	1.40
Dial-A-Ride on own	2 (2.9)	6 (7.7)	1.45
Used Bicycle	1 (1.4)	4 (5.1)	1.54
Accessories to Transport			
Parking permit	36 (52.2)	44 (56.4)	1.08
Mobility Allowance	15 (21.7)	20 (25.6)	1.10
Having a bus pass	28 (40.6)	44 (56.4)	1.35

R-R = relative risk test

Figure 3.10 Effect on individual different types of transport used at ten months



Ancillary analyses were completed to examine the effect of the baseline variables on the outcome and the effect of the intervention over time. Only two baseline factors were significantly associated with getting out of the

house as much as wanted at 4 or 10 months: residential status and self-reported outdoor mobility dependency which was one of the stratification variables. At 4 months all 8 in care homes did not get out of the house as much as they wanted, compared to 50/93, 54%, living with others and 37/67, 55%, living alone (Chi-square p=0.01): 24/62 (39%) of those rating themselves as "housebound", 39/61 (64%), of those who travelled alone, and 24/45 (53%) who travelled accompanied got out of the house at 4 months as much as they wanted (Chi-square p=0.02). An intention to treat analysis adjusting for baseline factors associated with outcome was similar to the main analysis at 4 months (Mantel Haenszel RR 1.71, 95%CI 1.26 to 2.33).

The effect of the intervention at 4 months was greater in those who did not get out of the house as much as they wanted at baseline (n=112, RR 2.1, 95%CI 1.32 to 3.34) than in those who got out of the house as much as they wanted at baseline (n=56, RR 1.42, 95%CI 0.92 to 2.18). Twenty three participants who, at baseline, got out of the house as much as they wanted (23/56, 41%) did not get out of the house as much as they wanted at 4 months (7 in the treatment group, 16 in the control group).

Twenty seven participants who got out of the house as much as they wanted at 4 months reported that they did not at 10 months (17 in the treatment group, 10 in the control group) and 22 participants who did not get out of the house as much as they wanted at 4 months reported that they did at 10

months (14 in the treatment group, 8 in the control group). These differences were not statistically significant (Chi-square, $p>0.1$).

The treatment group made a median of 16 more outside journeys between the month before baseline and the month before the 4 month assessment, compared to a median change of 0 in the control group (Mann-Whitney, comparing group changes, $p<0.01$). The median change in the number of journeys between 4 and 10 months was 0 for both groups (Mann-Whitney $p<0.01$).

3.4.11 Secondary outcome measures at ten months

3.4.11.1 Activities of daily living, leisure and mood limitation

The mean and median scores of outcomes for activity limitation and mood measured by the Nottingham Extended ADL index (NEADL), the Nottingham Leisure questionnaire (NLQ) and the General health Questionnaire – 12 (GHQ) for both participant and care can be found in Table 3.27. The Barthel ADL Index results have been added for comparison with other studies and future meta-analysis,

As with the four month data the General Health Questionnaire was scored using the 0,0,1,1, scoring scheme to provide information about cases and non-cases of psychological distress. The results can be seen in Table 3.27. There were no statistically significant differences between the groups.

Table 3.27 Comparison of activity limitation and mood at ten months

	Control n 82	Intervention n 86	Comparison of groups
NEADL total Median (IQR) Mean (S.D.)	29 16-41) 29 (17.6)	32 (20-48) 33.83 (16.82)	Mann-Whitney U Z = -0.17 p = 0.116
NLQ Median (IQR) Mean (S.D.)	11 (7-20) 14.28 (9.07)	13 (5-20) 15.15 (8.57)	Mann-Whitney U Z = -1.570 p = 0.349
GHQ patient No (%) with psychological distress	41(51)	35 (40.7)	Chi- squared p = 0.278
Barthel Median (IQR) Mean (S.D.)	17 (14-18) 15.99 (4.44)	17 (14-19) 16.22 (8.57)	Mann-Whitney U Z = -0.17 p = 0.864
	n 37	n 33	
GHQ carer No (%) with psychological distress	11 (29.7%)	10 (30.3%)	Chi –squared p = 1.00

A linear regression analysis was completed to look at the effect of the intervention when the base line characteristics were taken into account. The residuals can bee seen in Appendix 11 and they showed no serious departures from the model assumptions. The models were adjusted for

baseline characteristics of, gender, ethnic origin and the two stratification factors. The results of the linear regression are seen in Table 3.28. As can be seen the effect of the OTOMI is the same as at the four month assessment, but the confidence intervals are larger and the statistically significant difference seen at four months on the mobility section of the NEADL has been lost. To read the Table please refer to section 3.4.8.1.

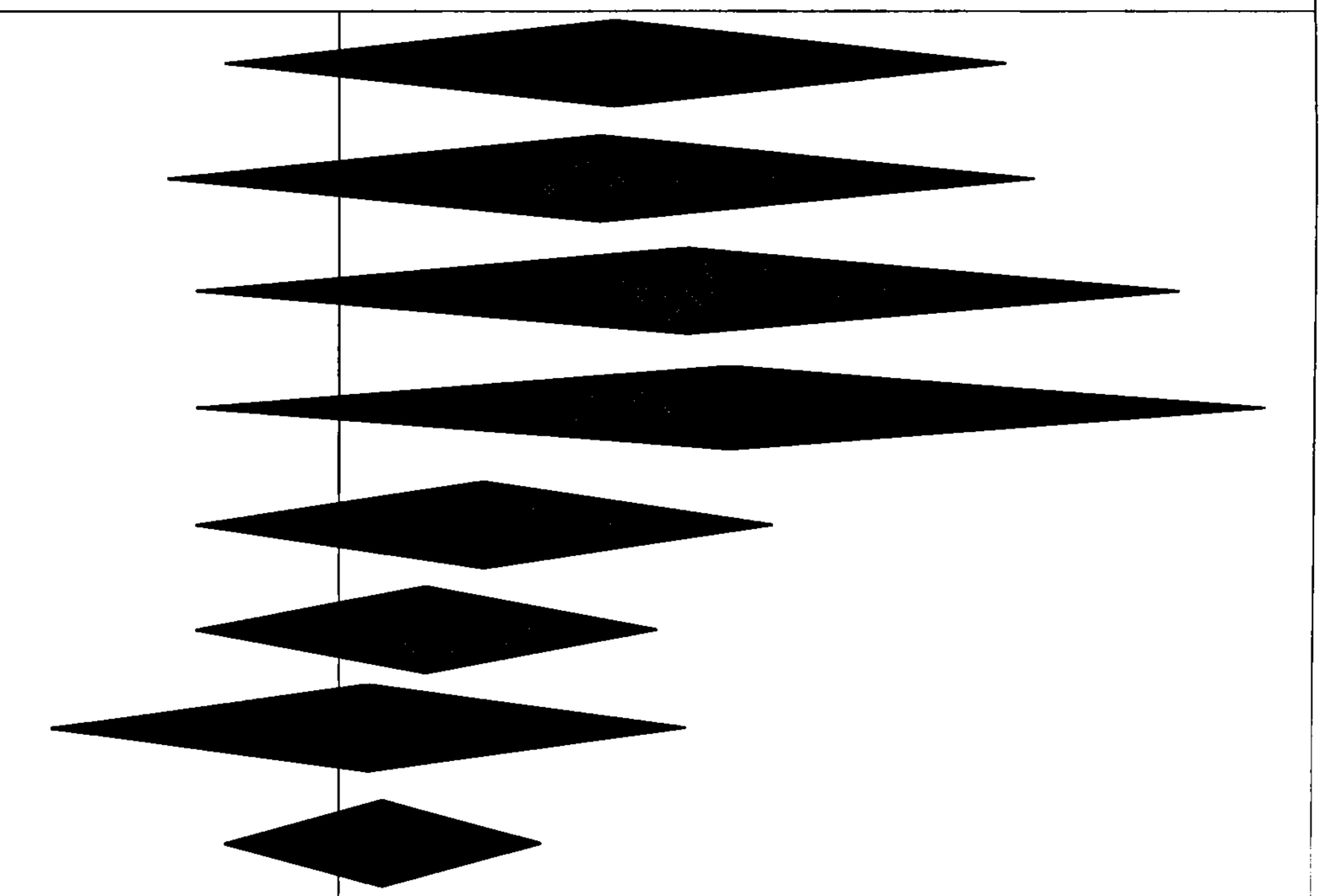
	Range worst - best	Mean difference	95% CI	Difference: % of the scale range Intervention worse ← → Intervention better -6 -4 -2 0 2 4 6 8 10 12 14 16 18 20
ADL (NEADL)	0 - 66	3.94	-1.52 –10.30	
Sub-scales: Mobility	0-18	0.89	-0.63 – 3.05	
Kitchen	0-15	1.14	-0.52 – 2.85	
Domestic	0-15	1.41	-0.46 – 3.27	
Leisure	0-18	0.66	-0.73 –2.29	
GHQ (patient)	36 - 0	-1.19	- 1.14 - 3.54	
GHQ (carer)	36 - 0	-0.22	-2.41 – 3.28	
Leisure (NLQ)	0 - 60	0.88	-1.75 – 4.00	

Table 3.28 – Activities of daily living, leisure and mood by multivariate linear regression at 10 months

3.4.12 A power calculation after the study had ceased

A post-hoc power calculation was completed on the data obtained from the primary outcome measure.

In this study a positive difference of 33% was observed between the intervention group and the control group at the four month assessment. A power calculation with significance level of 0.05 and a two sided test at 80% power indicates that 68 participants are needed in each group. This study had 82 and 86 participants in each group, fortunately the effect size was large and these group sizes were adequate.

3.5 INTERPRETATION

3.5.1 Overall findings

The results from this study indicate that an occupational therapy outdoor mobility intervention (OTOMI) given to people with stroke, over a maximum of seven sessions can improve participation in outdoor mobility activities. These results were maintained over time but the OTOMI did not have a statistically significant effect on other activities of daily living, mood or leisure activity.

The main benefit for the group of receiving the OTOMI compared to the group receiving routine occupational therapy was an increase in the proportion of

people who said they got out of the house as much as they wanted. The primary outcome results were maintained from the four month assessment to the ten month assessment, but by the ten month assessment the positive difference in performance of mobility related activities had ceased to be apparent. This occurred even when the participants were taking the same number of journeys. The intervention group also participated in more outdoor journeys and outdoor mobility activities, such as crossing the road, than the control group.

Even though there is evidence from other studies that a lack of outdoor mobility can make people miserable (Feibel and Sringer, 1982; Department of Transport, 2000a)and stop them from completing everyday activities, the increase in outdoor mobility participation observed in this OTOMI evaluation did not have a statistically significant effect on psychological distress, activities of daily living or leisure activities. Carers of the participants who received the OTOMI did not have any less psychological distress than those of participants in the control group.

Before discussing what these results mean in relationship to other studies and to clinical practice it is essential to understand the trial limitations.

3.5.2 Limitations and strengths of the study

3.5.2.1 The size of the sample

This trial of an occupational therapy outdoor mobility intervention is comparable in size to other recent trials of occupational therapy (Corr and Bayer, 1995; Walker et al, 1999; Gilbertson et al, 2000). With a sample size of 168 participants this trial has produced evidence that targeted occupational therapy can improve participation in outdoor mobility.

In absence of pilot data using the primary outcome measure it was estimated that the sample size of 200 was needed. The sample size, calculated using previous NEADL data (Clarke and Ahern, 1994; Walker et al, 1999) indicated that 100 participants in each group would be needed to show a clinical difference. Due to time restraints the sample size of 200 was not reached, but by completing a post hoc calculation it was evident that the study was adequately powered to show a reliable treatment effect on the principal outcome measure. The principal outcome measure was a single question; Do you get out of the house as much as you want? This question was used to measure what the intervention aimed to achieve. It was fortunate that the difference between the groups was large (33%) as a smaller effect (say 10%) that still may have been clinically worthwhile, might have been missed.

Although the study was large enough to provide reliable evidence of an improvement in the primary outcome measure a limitation of the study is that it may have been too small to make any reliable deductions about the interventions effect on mood, activities of daily living or leisure activity. The

95% CI's shown in the linear regression provide some evidence that for the NEADL scores the study was underpowered to show an effect, but that a 10% difference was seen. To evaluate whether this type of outdoor mobility intervention can have an effect on other areas of activity participation and mood, a larger trial is needed or if other trials have been completed since this trial the results could be combined and a meta-analysis could be completed.

The main reason the sample size was not reached was due to participant recruitment taking longer than expected in the first three months. The services (all apart from one) were keen to take part but needed time to send out letters. The recruitment rate was slow to start, as can be seen in figure 4.2, but once established the target of 11 participants per month was achieved and was maintained over the remaining study period. This indicates that this type of research is feasible in the primary care setting if given time to become established and a pilot phase of months rather than weeks is applied. As indicated by the number who wished to take part the methodology used targeted appropriate primary care services and participants. The number of participants recruited was less than first planned, but the number lost to follow up was very low, 6% at four months and 12% by the ten month assessment. The sample size was restricted only because of time, and not because the study excluded a large number of people or that people dropped out due to the intervention or follow up procedures being inappropriate.

3.5.2.2 The population

Older, white people, who were married and living with their spouse, dominate this population. Over half were in non-manual professions before retiring and almost all had been well before their stroke. They had mostly suffered their stroke a few months before entering the study and were therefore settled into a mobility routine. For those who went outside, being a passenger in a car was the most favoured mode of transport with few using specialist transport. Slightly more men than women came forward to take part in the research and one third of the population said they got out of the house as much as they wanted at the start of the study. Information about why people volunteered or why the study attracted more men was not collected. One consideration is that men are historically more likely to be the drivers and the topic of the research may have attracted the car drivers. The second issue maybe explained by the fact that the participants wanted to change their transport behaviours or travel more alone. Although this is a limitation of the study that has to be taken into consideration when reflecting on the results, it was considered that as this was an exploratory study it was important to include all those who wished to take part. In future studies of this kind a more detailed account of the participant's goals at the start of the intervention may overcome this limitation by being clear what the participants wanted to achieve.

As well as reduced mobility this sample had other activity limitations before the study commenced, with a large proportion not being able to bath alone or complete outdoor activities alone such as shopping. They participated in few

leisure activities and over half were suffering from psychological distress when they volunteered to take part in this study.

To try and understand whether this population is typical of the wider population of people with stroke the recruitment process was examined.

The sample in this study was not complete, as General Practitioners and Occupational Therapists were relied upon to send initial letters to potential participants. The services identified people by either searching computerised databases or paper referrals by hand. These techniques did not identify all people with stroke in a geographical area because some people are not registered with a GP or the services do not have a record of a stroke for the individual. However there is no reason to believe that the services did not send a letter to all people they identified and as multiple sources were used to recruit participants it was considered that most of the potential participants were approached. The only people that appeared to be under represented were those living in nursing and residential homes. Only 5 % of the population who volunteered for this study lived in residential care. This is lower than what would be expected, as it has been estimated that 20% (Rudd and al., 1999) of people who have a stroke and survive are living in residential homes. As the researcher was unable to check who the initial letters were sent to it is impossible to know whether people in residential and nursing care did not respond or were not sent a letter by the primary care service.

To check further the population size covered by each GP and the number of strokes they would expect to see in one year, was compared to the number of letters they sent. The Oxford Community stroke trial (Bamford et al, 1988) stated that a GP with a population of 2,000 patients could expect to see five new cases of stroke per year and four of these would be admitted to hospital and one die. It would appear from the surgery's population sizes that the majority but not all of the potential stroke patients were receiving a letter. For example one surgery, with 8,000 patients, identified 12 new strokes in a six month period. The Oxford calculations would have forecast 20 in the same time with four dying leaving a possibility of 16 people. There probably was some selection bias in the primary care services as they were able to choose which participants received a letters and it would be understandable for the GP to withdraw a participant if he felt they were medically unstable or a danger to the researchers.

The trial was offered to most of the potential participants, but not all chose to take part. They were self-selecting, in that they were free to choose if they wanted to return the reply slip. This may have encouraged the more able and motivated to reply as they had to post the reply slip. On the other hand, as the study information asked for participants who felt they had difficulties with outdoor mobility the more able may have discarded the letter. It was indicative of the effects of stroke that 64% of the general population of community dwelling people with stroke felt they had mobility problems and asked to take part.

In the absence of a complete sample it is not possible to state whether certain groups of patients were missed, but by looking at the baseline characteristics the sample can be compared to samples in other trials. Results from the Barthel Index and NEADL scale would suggest that there was a wide spread of activity restriction scores in the sample, which were slightly lower than those seen in similar trials of community rehabilitation (Gladman et al, 1993; Corr and Bayer, 1995; Logan et al, 1997; Walker et al, 1999). This was most likely due to inclusion criteria that included people from nursing and residential care. The mean age of 74 years for this population was very typical for a population of community stroke patients (Logan et al, 1997; Walker et al, 1999; Gilbertson et al, 2000) and with the other characteristics it was considered that the participants were typical of the wider population of people who have had a stroke in primary care.

3.5.2.3 Outcome measures

The measures used in the present trial were selected after reviewing several relevant scales, considering the literature, the research questions and the population being studied. Their strengths and weaknesses have already been described. It could be argued that the primary outcome was measured by a single question designed for the study and not by a standardised well known assessment, making the positive results of increasing the number of people who said they went out as much as they wanted, difficult to support. In defense of using this question, the findings of the qualitative interview study in Chapter 2 highlighted to need to measure whether people got out of the house as much as they wanted as some people like to go out three times a day and others once a

week. The results had explicitly found that people also liked to travel for the sake of the journey and not always with a destination in mind and that they wanted to make the decision to travel for themselves. The OTOMI was an intervention based on these findings and therefore the question, 'Do you get out of the house as much as you want?' acknowledges the aims of the intervention. Measures of journeys undertaken, types of transport used and the mobility section of the NEADL have been used in other studies with success and were applied to support the primary outcome measure. The measures were tested on professionals and people with stroke and were deemed sensible, reliable, sensitive to change and suitable for this study.

3.5.2.4 Follow-up rate

The efforts made to reduce missing data throughout the study gave rise to high follow-up rates. Consent was obtained carefully, participants knew the details of the study and had the chance to ask questions. Following recruitment the participants were thanked by letter and reassured that the information they were providing was valuable and confidential. To add to this the participants were obviously interested in the topic of the research as indicated by the number who wished to take part.

Postal questionnaires were used to collect outcome data about the participants and carers. They were timed to measure participation in activities and the mood of participant and carer, four and ten months after recruitment. That is one and seven months after the intervention had ceased. The first assessment was

planned to measure any immediate benefits of the intervention and the later assessment to check that the effects were maintained.

Postal assessment has been used successfully in other studies (Parker and Dewey, 2000) but naturally there are concerns about follow-up rates. To overcome these, postal assessments were used in the first instance and then an assessor who was masked to allocation contacted those who needed help to complete the questionnaire. Although the number of participants who required assistance was equal between groups, this approach can lengthen the time from the date due to the date the assessment is completed. Every effort was made to pass participant information to the assessor as soon as it was known a visit was needed.

The assessor also contacted participants by telephone to check ambiguous data. The assessor took as many steps as possible to maintain masked conditions. To check for bias, the assessor guessed to which group the participant had been allocated. She guessed correctly only a little more frequently than would have occurred by chance (54%). One of the main findings of this exercise was that the participants would often mention the name of the researcher (PL) but as she had recruited all the participants and provided both interventions, the assessor was unable to confirm to which group they had been allocated. By following this combination of postal and assessor techniques, a very successful follow-up rate was achieved at both the four and ten month assessments.

Participants lost to follow- up were mainly due to death. These people were older, more disabled and more likely to be living in a nursing or residential home when they were recruited. The death rates were distributed across both intervention and control group and similar to other community rehabilitation studies (Gladman et al, 1993; Gilbertson et al, 2000). Four participants withdrew consent, three from the control group and one from the OTOMI group. The measures taken to reduce missing data most likely encouraged people to remain in the study and return their questionnaires.

3.5.2.5 The interventions provided

The positive results of this randomised controlled trial were obtained by providing six extra sessions of occupational therapy. For clinicians to be able to use the results of this trial they will need to be able to understand what the interventions entailed.

In this type of pragmatic trial it was impossible to blind the participants to the intervention they were receiving, as it was essential to the success of the rehabilitation that they engaged in the rehabilitation. Therefore the participants knew they had a 50/50 chance of receiving the OTOMI and those who were allocated to the OTOMI group may have been keener, because of this, to participate in the activities. This was not considered to be a weakness of the study, but more an indication that when people can choose to take part in rehabilitation then they may be more motivated to achieve their goals, a concept that has been documented in other studies (Maclean and Pound, 2000).

The participants in the control group received what was considered to be a reasonable control intervention that had been reported in an earlier study (Logan et al, 2001). This served two purposes, the first, so the participants received an intervention that involved interaction with an occupational therapist and thereby reduced the limitation that the affect of the OTOMI was only due to a person visiting at home. The second, if leaflets, a verbal assessment and information were enough to change outdoor mobility then the extra six sessions would not have been needed. The control intervention was provided for all participants before randomisation. This was essential to allow the participants in the control group to receive the intervention before randomisation.

The OTOMI was modeled on the findings of the earlier interview study (Chapter 2), published literature and occupational therapy skills. This process of defining the intervention, before the RCT, has been recommended when evaluating complex interventions (MRC, 2000). The OTOMI has been described earlier, but in brief, the intervention applied occupational therapy core skills using both physical and psychological therapeutic techniques, to provide a detailed assessment and delivery of the intervention, information, experiences of outdoor mobility, equipment and environmental adaptations. These techniques are in-line with the recommendations for stroke rehabilitation (Royal College of Physicians, 2002) and occupational therapy principles (Creek, 2002). One of the main differences between this intervention and an occupational therapy service is that the OTOMI was targeted at one area of deficit whilst occupational therapists would be expected to assess and treat

multiple outcome domains. It may be, as other trials have suggested that targeted interventions produce better results (Walker et al, 2004) and that this OTOMI needs to be used when people have been assessed and diagnosed with limitations in outdoor mobility.

The interventions were provided by two senior occupational therapists that were experienced and trained to work with people with stroke in the community. They had an experienced knowledge about outdoor mobility. This type of information is available for a motivated occupational therapist to acquire.

3.5.3 Relationship to other studies

This RCT of an occupational therapy outdoor mobility intervention has added to the growing body of knowledge endorsing the practice of occupational therapy. A recent individual patient meta-analysis of occupational therapy for people with stroke living in the community concluded that targeted occupational therapy interventions can improve both personal and extended activities of daily living (Walker et al, 2004). This trial of outdoor mobility confirms this finding and it is hoped this trial will be included in future meta-analysis and systematic reviews.

As well has having an effect on activities of daily living, occupational therapy has been seen to affect the mood of people with stroke and their carers (Walker et al, 1999; Gilbertson et al, 2000). Mood is also affected by the availability of transport (Gilhooly, 2001) and the ability to resume social activities after stroke

(Feibel and Sringer, 1982). It had been hypothesised that as more people were able to get out of the house and the number of journeys increased then people would have less distress. This effect was not seen in this trial of an occupational therapy outdoor mobility intervention. This does not negate the main findings, but shows that getting out of the house is not a simple solution to mood disturbance. The association between occupational therapy and mood for people with stroke needs further investigation.

People who lived in residential and nursing homes were readily accepted into this trial and although the numbers were very small and therefore sub- group analysis not possible, people did ask to take part in the study, indicating a need for some form of intervention. Evidence for occupational therapy in these locations is limited but one recent RCT (Sackley, 2004) has shown that people who received occupational therapy maintained their level of activity in daily tasks while those who received the control intervention of normal nursing care were less able to carry out activities of daily living. Further research is needed to evaluate the OTOMI in a larger group of people living in residential care.

3.5.4 Implications for clinical practice

The occupational therapy outdoor mobility intervention (OTOMI) evaluated in this RCT is a feasible service to offer in the primary care setting. To observe the effects seen in this trial of OTOMI it is proposed that the following items are required.

- Participants with stroke who want to get out of the house more often.

- A well defined targeted intervention that is based on information gathered from descriptive studies and qualitative research. This must include the elements of education, information, practice sessions, small pieces of equipment, psychological support and the ability to refer to other agencies. The intervention must have a small money resource for use when the participants are experiencing accompanied transport options, for example using Dial-A-Ride for the first time.
- An experienced motivated occupational therapist to provide the intervention.
- Resources to provide at least seven sessions of occupational therapy aimed at outdoor mobility limitations for each participant.

3.6 CONCLUSION

The results of this study indicate that a high proportion of stroke patients outdoor mobility restriction can be met by an occupational therapy intervention, and the changes in outdoor mobility participation can be measured.

Chapter 4

Discussion

4.1 SUMMARY OF CHAPTER

This thesis contains two research studies in separate chapters. As the studies are related and follow a logical sequence each study has been presented with an interpretation of results section at the end of the chapter. The limitations and strengths of each study has been described in detail, therefore this concluding Chapter provides a summary to the programme of research. Firstly the limitations and strengths of the two studies are reviewed. Then the results are compared to other studies and finally recommendations are provided for occupational therapists, transport providers and researchers. The chapter finishes with the main conclusions of the study and ideas for possible future research.

4.2 Overall findings

Our society has a growing proportion of older and activity restricted people who are more likely to be on low incomes due to retirement and less likely to have access to a private car than other sections of the population (Gilhooly et al, 2003). Their independence and autonomy depends on sustaining their personal mobility which may be limited by bodily functions and structures, social or environmental factors (Logan et al, 2001). Occupational therapists are often responsible for providing rehabilitation for people who have health changes and who wish to maintain their independence in outdoor mobility activities. Past research (Logan et al, 2001) has indicated that people who received occupational therapy following a stroke were being provided with verbal and written information for outdoor mobility difficulties but no practical

re-training. Although this study based its findings on a survey of only 42 people, the research questioned whether these techniques were effective as over half of the population still wanted to get out more often. This study suggested that future research should be undertaken to learn from participants about the barriers to transport use and to use the findings to devise an intervention that may have an effect.

In the United States of America (Action Research, 2002) and Australia (Ampt, 2003), and with some special groups, such as learning disabilities or visually impaired people (Virgili and Rubin, 2003), travel training packages are available. The United States of America provides travel training in a number of states. Although these programmes have not been formally evaluated there is anecdotal evidence (Action Research, 2002) that by undertaking a detailed assessment of need and providing an individually designed intervention they have helped mobility limited elderly people to travel independently. There are no such travel programmes in the UK, but there is evidence from occupational therapy trials (Walker et al, 2004)that targeted interventions can help people increase their activities of daily living after a stroke. It was the aim of the studies in this thesis to develop an occupational therapy intervention based on people experiences and to then evaluate the intervention.

Before the intervention could be evaluated it needed to be defined. To produce a travel promotion intervention suitable and of best quality, the needs of the participants and the environmental issues were explored. This process, to understand and evaluate complex intervntions is recommended by the Medical

Research Council (MRC, 2000). The process begins with exploration of the theory behind the intervention, and then recommends a modeling phase where the components of the intervention are identified. To complete this theory and modeling phase a qualitative semi-structured interview study collected information about experiences of travel, barriers to travel and models of good practice. The findings were that participants wanted to travel when they chose, with whom they chose and to where they chose. One of the findings of the research was that the participants liked to travel just for the experience of the journey. This goes against the traditional view of travel behaviour, which measures the value associated with the destination at the end of the journey. The present research advocates that there are psychological benefits of traveling, health benefits from walking and social benefits from involvement in the local community. Any intervention aimed at outdoor mobility needs to acknowledge the benefits associated with the actual movement, quite independent of the destination. This was an important finding as occupational therapy is dedicated to improving activity and occupation, which could either mean the destination or the travel itself.

As well as enjoying the journeys the participants produced a long list of activities they were unable to participate in because they had problems with travel. Getting to the shops, doctors, friend's houses and leisure activities were among the list. There were obvious benefits lost when outdoor mobility was restricted from both the travel activity and the destination. It was concluded that the main outcome of an outdoor mobility intervention should be an

increase in travel, whether by foot or transport and this had to be the main focus of the therapy.

Safe, accessible and affordable public transport was clearly an important issue for people with stroke. Participants who were most satisfied with their travel were those having the immediate use of a car and driver. People were prepared to hang onto their cars even if they could no longer drive far or into the town centre. Most of the participants found using mainstream public transport difficult, if not completely impossible and not all these people had mobility restrictions. This confirms findings of the earlier study by Logan (Logan et al, 2001) that found that a small group of people who had made a good physical recovery from their stroke were unable to use public transport and other with considerable physical limitations were able to travel alone.

The results of the present stroke study indicated that people who had always used the bus found returning to bus use after a stroke easier and more satisfactory than those who had to change from being a car user. This could have been due to a number of reasons. People may not have known which bus to catch or how to use public transport. They may have been unable to walk to the bus stop or have been scared of falling. But there was also evidence that owning a car symbolized an achievement in life which could be seen by others. People were reluctant to give up their cars as they felt people would relate to them differently. These findings relate well to the theories of symbolic interactionism (Blumer, 1969) which provide an understanding of the self being constructed through shared symbols and a role taking process. For an

intervention to work these psychological and behavioral positions needed to be understood and incorporated into the rehabilitation package.

The barriers to outdoor mobility were complex and related to each person's physical abilities, psychological abilities and the environment where they lived. They included activities such as stepping onto the bus, poor self confidence to try a new type of transport, poor information about bus times and environmental factors such as uneven pavements. Anyone of these things could prevent someone from leaving their house and most people had a combination. The research findings indicated that a person's ability to travel was a question of whether the barrier existed for them and how they had satisfied all the necessary conditions to overcome the barriers. Of course two people may address the same problem in a different manner. To enable better outdoor mobility the participants recommended the provision of better information about local transport services, support to try out new forms of transport whilst regaining confidence and a reduction in environmental barriers. They suggested assistance with retaining car licenses, applications for disabled parking permits and bus passes, getting appropriate equipment and adaptations to their homes. The combination of retraining, goal setting and compensatory equipment was comparable to the components of the rehabilitation process.

During the rehabilitation process people are assessed and a programme of personal changes depending on their needs is designed. This is complimented with environmental adaptations, education and learning new skills (Wade,

2002). Occupational therapists provide interventions in this manner by assessing the individual, identifying the occupations or activities to be addressed and producing a treatment programme. They provide therapy for physical, psychological and environmental problems (Creek, 2002). It was therefore appropriate for the outdoor mobility intervention to be provided by occupational therapists. The participant's recommendations and occupational therapy skills were combined and the components of the intervention were identified. The intervention was a combination of information provision, practice completing activities, equipment and referral to other agencies. Techniques used included confidence building, motivational skills, assessment and goal setting.

A randomised controlled trial was completed to measure the effect of this intervention on outdoor mobility performance. The results from the randomised controlled trial found that the people in the intervention group were a third more likely to be able to get out of the house as much as they wanted and took double the number of journeys of those in the control group. The increase in the number of people who got out of the house as much as they wanted was maintained over time and even after a gap of six months without intervention these people were still taking more journeys than those in the control group. The intervention was most successful with people with the worse self reported mobility at the start of the study.

The randomised controlled trial was completed with the utmost care to reduce bias and as the limitations of this study have already been explored and

discussed it is considered that a cause and effect relationship exists between the intervention and the improvement in outcome. These results were not only statistically interesting they were clinically meaningful. It was encouraging that the intervention caused an effect on the primary outcome measure but it was disappointing that there were no significant or persistent effects on the secondary measures of instrumental activities of daily living ability, leisure activity or psychological well-being. There was a 10% change for the better in the intervention group in these areas and although this did not reach statistical significance it may have been because the effect was too small to be identified in the sample size. Therefore larger studies or the findings of a meta-analysis will be required to confirm or refute whether an increase in outdoor mobility effects post stroke depression.

In conclusion, the main findings were that many people with stroke find outdoor mobility difficult and that an occupational therapy intervention aimed at outdoor mobility can increase outdoor mobility in both the shorter and longer term.

4.3 Critical evaluation of research methods

To allow the results of the research presented to be useful and credible to occupational therapists, transport providers and other researchers, the methodologies were scrutinized for areas of weakness. By supplying the reader with this information they are then able to make a decision about the validity of the results, understand the interventions provided and consider whether similar

results would be achievable in their location or whether they want to change their policies or practice. For researchers who may be interested in adding to the body of knowledge with future research a critical review of the methodologies used allows them learn from the experiences of this study.

4.3.1 Limitations and strengths of the programme

The limitations for each study have been discussed in the individual chapters. However, there are some limitations that are relevant to the whole programme of research.

There are three questions which need to be answered before any research findings can be used by other people. How valid are the findings, e.g. are they true? How reliable were the instruments used to measure the findings? and how generalisable are the finding?

These three questions have been discussed in the interpretations of chapter 2 and 3 but to recap. The targeted intervention had been prepared for the evaluation and was expected to overcome many of the barriers to mobility that exist in people with stroke. In the trial the number of outdoor journeys was measured, as it was this that was expected to be affected by the intervention, but the principal outcome measure was a person centre outcome assessment, measuring at the level of participation rather than activity. Both these measures indicated a positive gain for the people in the intervention group and it is therefore considered that a cause and effect relationship exists between the

intervention and the improvement in outcome, and also that the findings are clinically meaningful.

One of the difficulties when evaluating rehabilitation interventions is being able to find the appropriate principal outcome measure that is both reliable and sensitive to the changes hypothesised in the research question. By using a simple single question which had been developed from previous research and the findings of the qualitative study it was considered that the measure was targeted at the main outcome the intervention would effect. That of changing peoples experience of whether they got out as much as they wanted to. This question was checked for reliability over time and supported by a more objective and well used measure of number of journeys. By using postal outcome assessment was used to reduce the likelihood of inducing bias through face to face assessment, and think it unlikely that the magnitude, consistency and persistence of the effect seen on the principal outcome measure could be explained by response bias.

Whether the research findings are generalisable to other locations is important if research is going to be used clinically. One of the limitations of this programme of research not already discussed was that the interview study and the evaluation of the intervention was undertaken by the same occupational therapist (PL) who provided the majority of the intervention. She was also using the results for this PhD dissertation. The worry could be that only an occupational therapist who is interested enough in the topic to complete a PhD in the area can replicate the results. A review of the activities undertaken in the

intervention indicates that they are sensible goal orientated tasks that relate directly to the rehabilitation process and the College of Occupational therapists definition of an occupational therapy intervention. Therefore the findings are likely to apply to the delivery of the intervention by other motivated Occupational Therapists who have been trained to provide the sorts of interventions used in this study. The findings may not apply to services delivered by untrained staff, treatment packages that are considerably shorter than in this study, or where one or more elements of the intervention cannot be provided (for example lack of access to aids and equipment).

Another concern for people interested in applying the results to their clinical setting is: are there enough people who have had a stroke to make the intervention viable? The recruitment rate indicates that there is likely to be a sufficient number of people in other health districts to make it worthwhile setting up services to deliver the intervention elsewhere. The high adherence to the trial protocol and the relatively small number of occupational therapy visits suggests that the intervention is feasible within a NHS or similar healthcare setting (for example, by a community rehabilitation team).

One of the main strengths of the research was that the research idea came from clinical experience and focused on a pragmatic issue for people with stroke. It was evident by the number of people who agreed to take part that participants, GP's and occupational therapists felt that it was a valid topic area. Although the research idea came from the clinical field and the research was applied in the clinical field the mixed methodologies of a qualitative interview study and

a randomised controlled trial followed strict research principals recommended by the Medical Research Council (MRC, 2000). The MRC guidance for completing an evaluation of an intervention, recommend that a qualitative investigative research study is completed prior to the randomised controlled trial to produce an intervention of the best quality. By using the MRC recommendations very few people were excluded from the trial allowing men and women of all ages, living in rural, city, suburban and residential localities and from all social classes to take part. A strength of the study was that as very few people were excluded that the population studied is most likely representative of the wider population and thus makes the results applicable to other settings.

So to answer the three questions stated at the start of this section: the occupational therapy outdoor mobility intervention did cause an effect on the outdoor mobility of the people in the study. The intervention is feasible for an occupational therapist to undertake in other locations and the effect seen was measured with a simple, reliable client centred question which focused on outdoor mobility participation.

4.4 Where the results fit in the literature

The research of transport use and barriers to outdoor mobility compares well to other transport studies. It confirms the results from larger studies (Age Concern, 1994; Oxley and Alexander, 1994; Gilhooly, 2001), in that elderly people are prevented from using transport due to a combination of factors. All three of these studies used large postal surveys of a general elderly population

and although they have not been published in journals normally associated with health issues, the findings they present are relevant to people who have suffered a stroke. Darkness, poor pavements, fear of falling and nobody to travel are all reasons given for not traveling by people with stroke and the general elderly group. However, whereas Gilhooly (Gilhooly, 2001) found that people start to make arrangements for lifts and start using public transport occasionally as they get older, the present study of stroke found that these people may have to make a rapid change in their mobility options due to physical changes caused by the stroke. It is this required change of behaviour which has emerged as one of the reasons for a change in the frequency of participation in outdoor mobility activities. People are either waiting for things to 'get back to normal' or don't want to acknowledge that they may never be able to move around the community as they did before the stroke. They are reluctant to change their travel behaviour and by the time they have adjusted to their new limitations the rehabilitation services have discharged them from care. People then find it difficult to get the help needed to try outdoor mobility. This finding confirms Parker's finding (Parker et al, 1997a) that people put their lives on hold waiting for things to get back to normal before they changed their daily activities It is important therefore for therapists and transport providers to understand that people with stroke may need time to change their behaviour and time to acquire the confidence to try a new type of transport, whether it is new to them or new to the environment.

The evaluation of the occupational therapy outdoor mobility intervention (OTOMI) is comparable in size and outcome to other studies of occupational

therapy interventions (Corr and Bayer, 1995; Drummond and Walker, 1995; Walker et al, 1996; Logan et al, 1997; Gilbertson et al, 2000). Systematic reviews and individual meta-analysis (Steultjens et al, 2002; Outpatient Service Trialists, 2004; Walker et al, 2004) of therapy trials indicates that occupational therapy increases participation in activities of daily living. Most of these trials have evaluated a comprehensive package of occupational therapy so it is difficult to compare them directly to occupational therapy aimed at outdoor mobility. However, one of the main findings of the systematic reviews has been that the success of these interventions is in part due to the provision of a well organised, defined and targeted intervention. This type of intervention is comparable to the OTOMI. The OTOMI was a single profession intervention that was goal orientated, using a number of techniques to increase outdoor mobility. The findings add to the belief that by providing a targeted intervention a measurable change in a participant's life can be detected. This study was not completed as part of a multi-disciplinary trial and although it is recognised that stroke is a complex condition that requires a complex intervention provided by a number of professionals, it may be the individual professions that target activities can change people's lives.

4.5 What can we learn?

4.5.1 For occupational therapists and rehabilitation teams

The results of this research show that the intervention provided was a relatively simple straight forward package. However, in order to achieve the desired outcomes there are necessary skills and procedures.

The level of interest and the recruitment rate indicate that outdoor mobility is a major issue for people with stroke. Therapists or others providing an intervention need to recognise that there could be a large demand for such an intervention. This incurs time and costs. Although no economic evaluation of the intervention was completed, each participant received on average six sessions from a senior occupational therapist. This is a feasible amount of therapy to provide in a community setting. The intervention was successful by providing a trained occupational therapist. The results may be achievable with a similar trained professional but research would need to confirm this hypothesis. The professional would need to be able to assess the requirements of the participant and plan a travel programme, motivate, provide confidence building activities, assess for equipment, advice and refer to transport services, as well as accompanying the participant on outdoor mobility activities.

The randomised controlled trial of the OTOMI included people who had had their stroke 36 months previously but who still had outdoor mobility difficulties. It is therefore important that occupational therapists are able to accept referrals from people late after stroke. This is in line with other research recommendations which indicate people may improve in walking and activities of daily living late after stroke (Jackson et al, 2000).

4.5.2 For transport providers and policy makers

The results of this research will be of interest to transport providers and those Government departments who have to implement the Disability Discrimination Act (HMSO, 1995). This Act has stated that all people should have access to public transport and that help and training should be offered to help people use public transport. The main messages from the research findings were that people with stroke need flexible, safe, reliable and not segregated transport. This is compatible to other research by the Department of Transport (Department of Transport, 2000a) who commissioned research into older people's travel needs and found that people do not like to book in advance for specialist transport. The value of the journey itself is important and not just the destination and this is confirmed by the number of people who wish to keep their cars, irrespective of the cost so they can 'have a ride out' whenever they wish. Money to travel is important to people who have had a stroke and further research is needed to understand the complexities and cost of owning a car, access to a car and driver and access to a known taxi driver.

Pavement scooters were very popular and a prized resource for users both in the intervention study and indicated by an increase in the intervention group of the RCT from 5 to 15 users. There has been an increase in the use of scooter across all populations (Day, 2002) and this has implications for pavement design, roads, shopping areas, general public health and safety and legal highway implications. The Department of Transport is considering licensing of electric pavement scooters (Day, 2002) due to a number of accidents and damage to property, which could have a detrimental effect on people with

stroke accessing this mode of transport. This is an area that needs further research to evaluate scooter benefits and limitations.

Even when the public transport systems have been made accessible to people with mobility difficulties by the implementation of accessible buses the public have to have the confidence and skills to use the transport. The travel training and travel blending schemes in the USA (Action Research, 2002) and Australia (Ampt, 2003) have recognised that people need to be introduced to the public transport system, especially if they have been a car user from birth. By increasing transport use, these travel training schemes aim to improve health and reduce social exclusion. The Department of Transport in the UK (Mobility and inclusion unit, 2004) is committed to travel training, but there are no programmes at present for people with stroke. It seems timely that with the findings of the research presented in this thesis that the intervention should be available to people with stoke, even late after stroke. Transport providers and policy makers should be talking to health professionals with the aim of providing this type of programme. Further research needs to be undertaken to evaluate further travel training programmes in different settings and organised in collaboration between the Department of Health and the Department of Transport.

4.5.3 For researchers

The results from these studies indicate that the topic of outdoor mobility is an area of interest to clinicians and service users. It is an area that deserves further research to improve services and therapy techniques. The occupational therapy

outdoor mobility intervention worked well for people with stroke but the principals of the intervention may apply to other people in a primary care setting such as elderly fallers. Similarly the intervention was evaluated in one location. A multi-centre research programme using clearly defined interventions and outcomes would be a logical next step to further support the results.

General Practitioners and community occupational therapists were keen and willing to recruit participants and this indicates an enthusiasm to engage in the research process. The use of postal questionnaires has demonstrated that they can be administered with success to people with stroke, but that it is advisable to also have an independent assessor who can visit those people who are unable to complete the questionnaires. Most rehabilitation, such as this outdoor mobility intervention, is classified as a complex intervention and it is best evaluated using a combination of research methodologies. This current stroke study has highlighted the importance of defining the intervention under investigation before the evaluation by gathering information from potential recipients of the intervention. There are no clear guidelines how best occupational therapy interventions should be formally documented for clinical trials. A recently published study (Sackley, 2004) documenting an occupational therapy intervention provided in a randomised controlled trial, suggested that although it was possible to provide targeted interventions the validity of intervention recording methods needs to be examined. One way forward should be for occupational therapists to start using the common terminology as stated in the International Classification and Functioning. This

is an area that needs further research to enable researchers to commit to paper the rehabilitation intervention provided.

It is envisaged that this piece of research will be included in systematic reviews of occupational therapy intervention research and if in the future there are further evaluations of travel promotion programmes it could be included in a meta-analysis.

4.6 Conclusion

In conclusion, it is not inevitable that people after a stroke have to suffer from limited outdoor mobility: outdoor mobility can be improved by a practicable and relatively simple occupational therapy intervention.

4.7 Dissemination of this research

The publications from this thesis can be seen in Appendix 11

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APPENDIX

APPENDIX 1 Ethical approval

Queen's Medical Centre
Nottingham

Research and Development Directorate

Please ask for: Janet Boothroyd, Business Manager, Ext. 44307
Ruth Doyle, Data Manager, Ext. 44771
Linda Ellis, Administrative Assistant, Ext. 41049
Debbie Cocks, Secretary/Administrator Ext. 35117

Our Reference: **HC060001**

13th July 2000

Mrs PA Logan
ADRU
B Floor
Medical School
UHN

Dear Mrs Logan

Re: **An Investigation of the Transport Use by Stroke Patients In A Primary Care Setting and Evaluation of an Occupational Therapy Intervention**

The Ethics Committee met on 3rd July 2000 and approved the project subject to your providing of some information, or clarification. We are now in receipt of this, and the project is now fully approved, including the protocol, patient information sheet and consent form.

The Ethics Committee requires that:

i) Serious adverse reaction/events, which occur during the course of the project, are reported to the Committee.

ii) Changes in the protocol are submitted as project amendments to the Committee.

iii) Yearly reports and a final report on the project to be submitted. (Forms will be sent to Lead Investigator for completion).

Kind regards

Yours sincerely

Dr I M Holland
Honorary Secretary
Ethics Committee

University Hospital
Nottingham NG7 2UH
Telephone (0115) 9249924
External (0115 8493295) Internal 35295
olland, Honorary Secretary, Ethics Committee
Centre, Nottingham, University Hospital NHS Trust

APPENDIX 2 Interview schedule

Interview Schedule

Aims of the interviews:

- To understand the issues behind 'getting out and about'
- Gain an insight into the factors that affect the use of transport by stroke patients.
- To help develop a postal questionnaire.
- To develop a therapy intervention package.

The interview will be no longer than one hour in the participant's home at their convenience and will be tape-recorded. The interviewer will introduce themselves and explain the study. The participant will have had time to read the information sheet, ask questions and sign a consent form. The types of phrases to be used are in bold and the prompts and probes are in non-bold.

Probes: How did it feel

How has that affected you.

What sort of things could you do about that.

Can you tell me a little more about that.

Thank you for agreeing to see me, we understand that people who have suffered a stroke may find it difficult to get out of their houses and to get to where they want to go. I'd like to start with talking about the time before your stroke.

TOPICS	QUESTIONS
Activities before stroke Transport before stroke	**Can you tell me about the sort of thing did you do outside the house before you had your stroke and how you used to get there?** Leisure, household tasks, working, friends, family, money. Just going out for a drive? How many times per week.
Activities after stroke Barriers to Transport since stroke activities	**Can you tell me about what sort of things/ activities you do now outside the house?** Frequency, enjoyment, work, holidays. What about the ones from before the stroke. Why not? Environment, fear, loss of skills, money, loss of friends. **How do you get to ……. now?** Frequency, ease of use, getting to the doctors, dentist. Has it changed since before the stroke?
Barriers to transport	**Is there anything that is stopping you from using transport?** Walking, money, using the bus, frequency of driving, weather
Consequence of stroke	**Can you tell me how the changes in getting out and about have affected you?**

	Loss of hobbies, loss of job, loss of helping at home, not being able to go for a drive just for the sake of it. If patient has given up driving, discuss how it happened and the consequences, having to learn how to use the bus.
Acquisition of skills	**Can you tell me how you came to be able to (eg use the bus)……. since your stroke?** Therapy, family support, motivation.
Self help	**Is there anything that you feel you could do for yourself to make it easier for you to get out more often?** Contacting taxi companies, getting a bus pass, anything you wish you had done.
External help	**Is there anything that anybody else could have done for you?** Information, therapy, money.
Environmental issues	**Have you thought about using any of the specialist transport available in Nottingham?** Dial- a –ride, voluntary drivers, scooters, community transport.
Closure	**Is there anything else that you would like to tell me about to do with getting out of the house.**

Thank you for your time I shall now turn off the tape recorder.

Transportation for people who have suffered a stroke

Supported by
National Primary Care Researcher Development Award, NHS Exec R&D

Name of researcher: Pip Logan
Address: Ageing and Disability research Unit
B Floor, Medical School
Queens Medical Centre
Nottingham NG7 2UH

Tel (0115) 924 9924 Ext 35135
e-mail pip.logan@nottingham.ac.uk

Duration of Award: 1st March 2000 - 29th February 2004

Collaborators: Nottingham City and Community Council Social Services Occupational Therapy Department, Nottinghamshire PCT's, Trent Focus for Primary Care Research.

Background

Stroke patients often become housebound, miserable and in poor health because they cannot get out of the house to use community services, see family and friends and partake in leisure activities. Transportation is often cited as a reason for non-attendance at GP practice, dentists and hospital appointments. A pilot study of 90 stroke patients found that 70% had been assessed for transportation problems by an occupational therapist and 30% provided with written advice. Only one had used specialist transport and over half wished to get out more often. The problems of transportation faced by stroke patients are not fully understood or documented. Interventions to increase transport use have not been evaluated or explored.

Aim

The aims of this study are to:

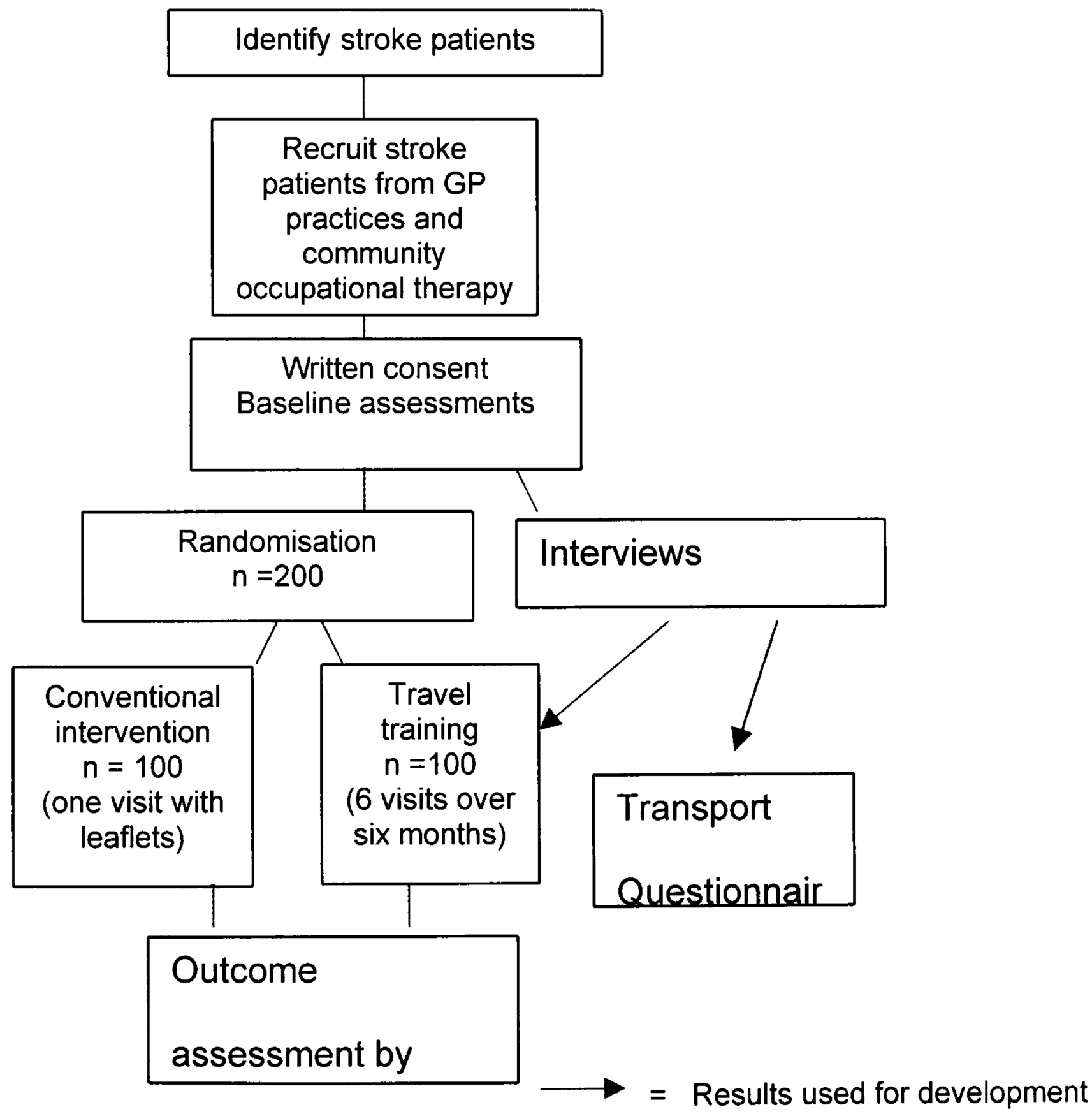
elicit the barriers, physical and mental which need to be overcome to enable transport use and

to evaluate an occupational therapist lead travel training programme.

Methodology

Qualitative semi- structured interviews will be used to elicit barriers. A mobility questionnaire will be tested for reliability and validity. The travel awareness package
will be evaluated by a randomised controlled trial.

This project has full ethical approval from the Queens Medical Centre, Research and Development Directorate. Ref: HC060001



What collaborators are being offered

- Opportunity to be involved with a primary care research project that will be recruiting patients from multiple sources, (GP's, Stroke Rehabilitation, Primary Care Groups, Social Services)
- Opportunity to be involved in a piece of research that is directly related to care in the community.
- Occupational Therapy for approx. half of the patients recruited.
- Transport Information in the community.

Implications for the patient

- The interviews will take approximately 1 hour
- The conventional intervention will take approximately one hour and offer the patient time to discuss local transport, and information to keep in the form of leaflets.
- The travel training will give the patient an opportunity to use different modes of transport with an occupational therapist. Any treatment related costs will be paid by the project.
- Patients in both the conventional group and the travel training group will be asked to complete a postal questionnaire (approx. 20 minutes) and return it in a pre-paid envelope, six and twelve months after randomisation.

What is expected of collaborators

- To send a prepared letter and information about the project to the patients asking them if they are willing to be contacted to discuss the study. A reply slip and SAE to be returned to the lead researcher will be supplied.
- To provide numbers of consultations for each patient (from the time of recruitment to the six month assessment).

(PL will be preparing the letters, consent form)

APPENDIX 4 Letter to participants

Dear

A STUDY OF HOW STROKE PATIENTS GET OUT AND ABOUT

A research occupational therapist called Pip Logan, from the University of Nottingham has contacted the surgery and asked if she may contact some stroke patients. She is interested in all stroke patients and how they get out and about, including those who do not go out at all and those who have returned to all activities, including driving.

She wants to ask if you would be in a study of stroke patients and she is happy to visit you at home to explain the study. If you agree to be in the study you may be offered some information and assistance to get out more often. The information collected will be entirely confidential and you will be able to withdraw from the study at any time.

If you are happy for her to come and see you at home or need further information, could you please complete the enclosed slip and return it in the stamped addressed envelope or phone Pip at the QMC, Tel **(0115) 924 9924 Ext 35135**

We hope the results of the project will be of great benefit to stroke patients in the future and may help to develop better transport systems for people who have a disability.

Thank you for your help.

Yours sincerely

Dr.....

A STUDY OF HOW STROKE PATIENTS GET OUT AND ABOUT

Yes, I am willing for Pip Logan to contact me at home to discuss this study

Name:.....

Address:.....

.....

.....

.....

.....

Telephone number:.....

Please return to: Pip Logan, Ageing and Disability research Unit, B Floor, Medical School, QMC, Nottingham NG7 2UH. Tel (0115) 924 9924 Ext 35135

Appendix 5 - Information for participants

GETTING OUT OF THE HOUSE STUDY

The background to the study:

- People can become house bound after a hospital admission or illness
  leading to poor health, isolation, and misery.
- Occupational therapists are often responsible for ensuring that a patient
  can get out of their house and use community services as well as transport.
- Our research studies show that 50% of all stroke rehabilitation patients
  would like to get out more often.

We wish to find out:

- what prevents stroke patients from getting out of the house?
- why do stroke patients find it difficult to use transport?
- if stroke patients have any suggestions that could help other stroke patients
  get out and about easier?
- if occupational therapy could help stroke patients get out more often?

We aim to do this by:

- interviewing stroke patients about their use and non-use of transport.
- using this information to help change the way occupational therapists help stroke patients.
- testing a new treatment programme with a group of stroke patients.

How you can help:

- We would like to interview 20 stroke patients and record their views of getting out of the house and using transport.
- We would like to recruit 200 stroke patients and offer them an assessment visit from an occupational therapist.

- **Some of the stroke patients we visit will be offered some extra therapy to assist them in using transport.**
- **Stroke patients who are in our study will be asked to complete a short questionnaire at home and send it back to the hospital in a pre-paid envelope.**

ALL INFORMATION WILL BE CONFIDENTIAL AND ONLY USED

FOR RESEARCH PURPOSES

For more information please contact

Pip Logan **Tel (0115) 924 9924 Ext 35135**

Research Occupational Therapist
Ageing and Disability Research Unit
QMC
Nottingham

Stn

Interview/Baseline participant characteristics

Referred by:

Title

Name First

Surname

Address

Telephone no

Post code

Date of birth: ☐☐ ☐☐ ☐☐☐☐

Age on entry to trial: ☐☐☐

Date of stroke ☐☐ ☐☐ ☐☐☐☐

Side affected ☐
1 = Right
2 = Left

Marital status: ☐
Single 1
Married 2
Widowed 3
Divorced 4

Sex: ☐
1 = male
2 = female

Living situation: ☐
Alone – independent 1
Alone – warden-aided 2
Do not live alone: 3
Details:
Do not live alone – warden-aided: 4
Details:

Occupation

Participant's previous main occupation:

Title:

Main duties:

Social class: ☐

1 (1)

2 (2)

3NM (3)

3M (4)

4 (5)

5 (6)

Spouse's previous main occupation:

Title:

Main duties:

Transport Used since stroke

Mostly house bound	Yes	No	Don't Know
Travels alone	Yes	No	Don't Know
Travels accompanied	Yes	No	Don't know

Current Barthel Score

Bowels	
Incontinent	0
Occasional accident (once a week)	1
Continent	2
Bladder	
Incontinent, or catheterised and unable to manage alone	0
Occasional accident (maximum once per 24h)	1
Continent	2
Grooming	
Needs help with personal care	0
Independent face/hair/teeth/shaving (implements provided)	1
Toilet use	
Dependent	0
Needs some help, can do something alone	1
Independent (on and off, dressing, wiping)	2
Feeding	
Unable	0
Needs help cutting, spreading butter etc.	1
Independent	2
Transfer (bed to chair and back)	
Unable, no sitting balance	0
Major help (1 or 2 people, physical), can sit	1
Minor help (verbal or physical)	2
Independent	3
Mobility	
Immobile	0
Wheelchair independent, including corners	1
Walks with help of 1 person (verbal or physical)	2
Independent (but may use aid e.g. stick)	3
Dressing	
Dependent	0
Needs help, but can do about half unaided	1
Independent (including buttons, zips, laces etc.)	2
Stairs	
Unable	0
Needs help (verbal, physical, carrying aid)	1
Independent	2
Bathing	
Dependent	0
Independent	1
Total:	☐☐

Extended Activities of Daily Living Scale

	Tick one box for each activity			
	not at all	**with help**	**on your own with difficulty**	**on your own easily**
1) Walk around outside?……..	☐	☐	☐	☐
2) Climb stairs?……	☐	☐	☐	☐
3) Get in and out of a car?…….	☐	☐	☐	☐
4) Walk over uneven ground?……..	☐	☐	☐	☐
5) Cross over roads?..…….. .	☐	☐	☐	☐
6) Travel on public transport?……...	☐	☐	☐	☐
7) Manage to feed yourself?……..	☐	☐	☐	☐
8) Manage to make yourself a hot drink?	☐	☐	☐	☐
9) Take hot drinks from one room to another	☐	☐	☐	☐
10) Do the washing up?	☐	☐	☐	☐
11) Make yourself a hot snack?	☐	☐	☐	☐
12) Manage your own money when you are out?	☐	☐	☐	☐
13) Wash small items of clothing?	☐	☐	☐	☐
14) Do your own housework?	☐	☐	☐	☐
15) Do your own shopping?	☐	☐	☐	☐

16) Do a full clothes wash?	☐	☐	☐	☐
17) Read newspapers or books?	☐	☐	☐	☐
18) Use the telephone?	☐	☐	☐	☐
19) Write letters?	☐	☐	☐	☐
20) Go out socially?	☐	☐	☐	☐
21) Manage your own garden?	☐	☐	☐	☐
22) Drive a car?	☐	☐	☐	☐

Interview Field Notes

Time of Interview

Duration of Interview

Distractions

Place of interview

Field notes, i.e. Did the interviewee appear relaxed? Non-verbal gestures.

Interview Field Notes

Time of Interview

Duration of Interview

Distractions

Place of interview

Field notes, i.e. Did the interviewee appear relaxed? Non-verbal gestures.

APPENDIX 7 - KAPPA scores

Question	Cohens Kappa Coefficient (n=18)	Level of agreement (Fleiss)
Walk with someone	0.679	Good
Walk on own	0.886	Excellent
Passenger in car	0.769	Excellent
Driven Self	0.870	Excellent
Bus with someone	0.550	Fair
Bus on own	1.000	Excellent
Dial-A-Ride with someone	*	*
Dial –A-Ride on own	1.000	Excellent
Taxi with someone	0.561	Fair
Taxi on own	0.455	Fair
Electric Scooter	1.000	Excellent
Shop Mobility	1.000	Excellent
Bicycle	*	*
Voluntary Driver	0.640	Good
Wheelchair	0.658	Good
Get out as much as want	0.906	Excellent
Have as much transport as want	0.814	Excellent
Has a bus pass	1.000	Excellent
Gets Mobility Allowance	1.000	Excellent
Has disabled parking permit	1.000	Excellent
	Pearson R (n=17)	
Total of trips	0.835	Excellent

* Indicates activities selected by no participants and therefore no test re-test data available

…. mths	No			

The

Getting out of the House

Study

confidential

QUESTIONNAIRE FOR PATIENTS

This is the questionnaire you kindly agreed to fill out. Thank you for filling it in. It will help us find out more about the way stroke patients get out of the house and will contribute to our knowledge of the best ways in which we can help people.

For each question, please choose the answer that applies to you and put a tick ✓ in the box next to it. If you are unsure which answer to choose, please tick the one that seems most applicable, rather than leaving the question blank.

You may feel that some of the questions don't apply to you, for example because you have made a full recovery, but please answer them all so that we can include you in our overall picture.

If someone is filling this in on your behalf, it is important that they tick THE ANSWERS YOU WOULD GIVE if you were able, even if these are not the ones they would choose for you.

Today's date:.....

Do we have your correct name and address? If not, please write them here:

.....

.....

Are you filling in the questionnaire yourself?
*Please tick **one** box*

Yes..... ☐ 1

No, it is being completed for me by:

my husband or wife..... ☐ 2

another relative (please specify in the box below) ☐ 3

[ ]

a friend..... ☐ 4

a paid carer..... ☐ 5

any other (please specify in the box below) ☐ 6

[ ]

At present do you live:
Please tick one box

in a house, flat or bungalow alone?..... ☐ 1

in a house, flat or bungalow, with someone?. ☐ 2

in a residential home?..... ☐ 3

in a nursing home?..... ☐ 4

Are you filling in the form:
Please tick one box

at home?..... ☐ 1

in hospital?..... ☐ 2

at a relatives home?..... ☐ 3

Mobility Section

These questions are about how you get about

Please indicate WHAT YOU HAVE DONE IN THE LAST **MONTH** by placing a tick in the boxes.

	NO	YES	number of times used
In the last month have you? *for example* Walked outside with someone?	☐ 0	☑ 1	
Walked outside with someone?	☐	☐	
Walked outside on your own?	☐	☐	
Been a passenger in a car?	☐	☐	
Driven yourself?	☐	☐	
Been on a bus with someone?	☐	☐	
Been on a bus on your own?	☐	☐	
Used Dial-a-Ride with someone?	☐	☐	
Used Dial-a-Ride on your own?	☐	☐	
Used a taxi accompanied?	☐	☐	
Used a taxi on your own?	☐	☐	
Used an electric scooter?	☐	☐	
Used Shop Mobility?	☐	☐	
Used a bicycle?	☐	☐	
Used a Volunteer Driver Scheme?	☐	☐	
Been pushed in a wheelchair?	☐	☐	
Do you have an orange or blue car badge?	☐	☐	**NA**
Do you get Mobility Allowance?	☐	☐	**NA**
Do you have a bus pass?	☐	☐	**NA**

These are statements other people have made about their recovery.
Please indicate if you agree or disagree with the statements.

	Tick one box for each statement **Agree**	**Disagree**
I get out of the house as much as I would like.	☐ 1	☐ 2
I have as much transport as I would like.	☐ 1	☐ 2

EVERYDAY ACTIVITIES SECTION

Please give answers based on **WHAT YOU HAVE ACTUALLY DONE IN THE LAST WEEK** OR SO. Please tick ONE box for EACH section.

In the bath or shower, do you:
Please tick one box

manage on your own?..... ☐ 1
need help?..... ☐ 0
never have a bath or shower?..... ☐ 0

Do you go up and down stairs:
Please tick one box

without any help?..... ☐ 2
with help (either supervision or assistance)? ☐ 1
not at all?..... ☐ 0

Do you get dressed:
Please tick one box

without any help (including buttons, zips, laces etc)?..... ☐ 2
with help, but you can do at least half on your own?..... ☐ 1
with help for almost everything?..... ☐ 0

Do you get about indoors:
Please tick one box

walking with no-one helping? (you may use a stick or frame).. ☐ 3
walking with the help or supervision of one person?..... ☐ 2
propelling yourself with a wheelchair?..... ☐ 1
not at all?..... ☐ 0

Do you move from bed to chair:
Please tick one box

on your own?..... ☐ 3
with a little help from one person?..... ☐ 2
with a lot of help from one or two people?..... ☐ 1
not at all?..... ☐ 0

Do you feed yourself:
Please tick one box

without any help?..... ☐ 2
with a little help (e.g. cutting up food)?..... ☐ 1
with a lot of help?..... ☐ 0

Do you use the toilet or commode:
Please tick one box

without any help?..... ☐ 2
with a little help (e.g. wiping)?..... ☐ 1
with a lot of help?..... ☐ 0

Do you wash your face, brush your hair and teeth, (for men, shave):
Please tick one box

without help?..... ☐ 1

with help?..... ☐ 0

Are you incontinent of urine (i.e. wet your bed or clothes):
Please tick one box

never?..... ☐ 2

occasional "accident"?..... ☐ 1

more often than occasional "accident"?..... ☐ 0

have a catheter which you manage yourself? ☐ 2

have a catheter which is managed by someone else ☐ 0

Are you incontinent of your bowels (soil yourself):
Please tick one box

never?..... ☐ 2

occasional "accident"?..... ☐ 1

more often than occasional "accident"?..... ☐ 0

need regular enemas?..... ☐ 0

More questions about everyday activities

Please answer these questions by ticking ONE box for EACH question. Please record WHAT YOU HAVE ACTUALLY DONE IN THE LAST WEEK OR SO.

	Tick **one** box for each activity			
	not at all	**with help**	**on your own with difficulty**	**on your own easily**
Do you…..	0	1	2	3
Walk around outside?…	☐	☐	☐	☐
Climb stairs?……	☐	☐	☐	☐
Get in and out of a car?	☐	☐	☐	☐
Walk over uneven ground?	☐	☐	☐	☐
Cross over roads?……	☐	☐	☐	☐
Travel on public transport?	☐	☐	☐	☐
Manage to feed yourself?…	☐	☐	☐	☐
Manage to make yourself a hot drink?	☐	☐	☐	☐
Take hot drinks from one room to another?	☐	☐	☐	☐
Do the washing up?……	☐	☐	☐	☐

Tick one box for each activity

Do you…..	**not at all** 0	**with help** 1	**on your own with difficulty** 2	**on your own easily** 3
Make yourself a hot snack?.	☐	☐	☐	☐
Manage your own money when you are out?	☐	☐	☐	☐
Wash small items of clothing?	☐	☐	☐	☐
Do your own housework?….	☐	☐	☐	☐
Do your own shopping?……	☐	☐	☐	☐
Do a full clothes wash?……	☐	☐	☐	☐
Read newspapers or books?…	☐	☐	☐	☐
Use the telephone?……	☐	☐	☐	☐
Write letters?……	☐	☐	☐	☐
Go out socially?……	☐	☐	☐	☐
Manage your own garden?…	☐	☐	☐	☐
Drive a car?……	☐	☐	☐	☐

GENERAL HEALTH SECTION

We should like to know if you have had any medical complaints and how your health has been in general **OVER THE LAST FEW WEEKS.** Please answer **ALL** the questions by putting a tick in the box which you think most clearly applies to you.

Have you recently…….

Been able to concentrate on whatever you're doing?

	Please tick one box
Better than usual……	☐ 0
Same as usual……	☐ 1
Less than usual……..	☐ 2
Much less than usual……	☐ 3

Lost much sleep over worry?

	Please tick one box
Not at all……	☐ 0
No more than usual…….	☐ 1
Rather more than usual…	☐ 2
Much more than usual…….	☐ 3

Felt that you were playing a useful part in things?

	Please tick one box
More so than usual……	☐ 0
Same as usual……	☐ 1
Less useful than usual…	☐ 2
Much less useful……..	☐ 3

Have you recently……

Felt capable of making decisions about things?

Please tick one box

More so than usual……	☐ 0
Same as usual……	☐ 1
Less so than usual……	☐ 2
Much less than usual……	☐ 3

Felt constantly under strain?

Please tick one box

Not at all……	☐ 0
No more than usual……..	☐ 1
Rather more than usual…	☐ 2
Much more than usual……..	☐ 3

Felt that you couldn't overcome your difficulties?

Please tick one box

Not at all……	☐ 0
No more than usual…….	☐ 1
Rather more than usual….	☐ 2
Much more than usual…	☐ 3

Been able to enjoy your normal day-to-day activities?

Please tick one box

More so than usual…	☐ 0
Same as usual……	☐ 1
Less so than usual……	☐ 2
Much less than usual…	☐ 3

Been able to face up to your problems?

Please tick one box

More so than usual……	☐ 0
Same as usual……	☐ 1
Less so than usual…….	☐ 2
Much less able……	☐ 3

Been feeling unhappy and depressed?

Please tick one box

Not at all……	☐ 0
No more than usual……..	☐ 1
Rather more than usual…	☐ 2
Much more than usual…	☐ 3

Been losing confidence in yourself?

Please tick one box

Not at all……	☐ 0
No more than usual……..	☐ 1
Rather more than usual…	☐ 2
Much more than usual…	☐ 3

Been thinking of yourself as a worthless person?

Please tick one box

Not at all……	☐ 0
No more than usual……..	☐ 1
Rather more than usual…	☐ 2
Much more than usual…	☐ 3

Been feeling reasonably happy all things considered?

Please tick one box

More so than usual……	☐ 0
About same as usual……	☐ 1
Less so than usual…….	☐ 2
Much less than usual…	☐ 3

LEISURE ACTIVITY SECTION
This section is about the hobbies and things you do. Please tick one box for each activity and every activity. PLEASE RECORD WHAT YOU HAVE DONE SINCE YOUR STROKE

Tick one box for each activity

	Regularly 2	**Occasionally** 1	**Never** 0
Watching TV……..	☐	☐	☐
Listening to radio/music…….	☐	☐	☐
Visiting family/ friends…….	☐	☐	☐
Reading books……..	☐	☐	☐
Singing……..	☐	☐	☐
Gardening……..	☐	☐	☐
Craft ……..	☐	☐	☐
Attending sports events….	☐	☐	☐
Attending classes…….....	☐	☐	☐
Collecting things……..	☐	☐	☐
Shopping for pleasure……....	☐	☐	☐
Cooking for pleasure……....	☐	☐	☐
Reading newspapers/magazines	☐	☐	☐
Walking……..	☐	☐	☐
Volunteer work……..	☐	☐	☐

	Tick one box for each activity		
	Regularly 2	**Occasionally** 1	**Never** 0
Indoor games eg cards, bingo	☐	☐	☐
Dancing……	☐	☐	☐
Looking after or exercising pets……..	☐	☐	☐
Eating out……	☐	☐	☐
Going out to pubs……	☐	☐	☐
Going to plays/museums/cinema	☐	☐	☐
Photography……..	☐	☐	☐
Exercise/fitness……..	☐	☐	☐
Attendance at day centre and clubs…..	☐	☐	☐
Going to parties……	☐	☐	☐
Entertaining at home…….	☐	☐	☐
Church activities……	☐	☐	☐
Meditation/relaxation……	☐	☐	☐
Driving……	☐	☐	☐
DIY……	☐	☐	☐
Sport……	☐	☐	☐
Holiday……	☐	☐	☐

Thank you for completing this questionnaire, please check your answers and put it in the attached pre-paid envelope and post back to

THE GETTING OUT OF THE HOUSE STUDY

B98

Ageing and Disability Research Unit

B Floor

Medical School

QMC

NG7 2UH

If there are any questions or you need help with the form please ring

(0115) 9249924 Ext 44048

As well as looking at how your own life has been affected by your stroke, WE WOULD LIKE TO KNOW HOW IT HAS AFFECTED YOUR CLOSE FAMILY OR FRIENDS.

If you have someone living with you, or if there is a relative or friend you depend on for help with day-to-day care, we would be grateful if you would ask them to complete the short WHITE CARER QUESTIONNAIRE enclosed.

Please return this questionnaire and the carer questionnaire, if completed, in the stamped addressed envelope provided.

Thank you once again for your help

APPENDIX 9
Occupational therapy to improve outdoor mobility

Educational and Treatment protocol

This treatment programme mainly followed the model of Human Occupation as described by Kielhofner. This model describes an approach where the needs of the participant are used to shape the interventions. However other models such the Bobath approach were used to facilitate walking and transfers and the compensatory approach to provide equipment where people were unable to complete a task unaided.

Occupational therapy also requires that therapists have a knowledge of physical and psychological deficits, occupational science, activity analysis and goal setting. The outdoor mobility intervention required that the therapist was skilled in communication both written and verbal to teach clients in the best format, motivational techniques to encourage people to have a go at a new activity and confidence training to overcome anxiety.

The following headings taken from the International Classification of Functioning were used to separate the treatment sessions into identifiable components.

Personal	-	Initial interview /assessment Goal Setting Review / Discussion
Environment	-	Information giving about transport Referrals for changes to the environment Assistive Equipment (Handrails)
Performance Areas - Activities and Participation		Retraining new skills Relearning old skills Repetitive practice Mobility training Participation in Transport Use Participation in using adaptive equipment Training on routes Training on routines Graded Tasks /Reporting Back/Homework
Impairments	-	Balance practice Muscle building exercises Assistive devices (Splint)
Social	-	Involvement of family/carers Referral to other agencies (Day centre, holidays)

The next three pages show the forms used to record the intervention. The ICF headings were used to produce a data collection form, which can be seen overleaf. This allowed the therapists to mark which items they had completed at each session. The goals of the treatment where set at the end of the first session and noted on the second form and the ongoing treatment sessions were recorded on the third form. Prior to the trial commencing the main outdoor mobility activities where subjected to an activity analysis by two occupational therapists. A sample of an activity can be seen below.

Catching the Bus

Getting the bus timetable
Deciding the time of travel
Getting a bus pass or correct change
Getting ready for a bus journey, shoes, umbrella, coat, walking stick.
Leaving the house and locking the door
Walking to the bus stop
Waiting at the bus stop
Hailing the bus
Boarding the bus
Paying or presenting bus pass
Sitting down
etc.....

The activity analysis allowed the occupational therapists to decide where the barriers to transport were and at which level treatment activities should begin. They also provided small goals, which the participants could achieve before the whole task was undertaken.

Following the forms there are two case vignettes to illustrate how two participants progressed through the treatment.

Outdoor mobility treatment record

Name and Address Telephone number:					DOB Age		DOS Side affected			Stn
		Participation / Activity			Environmental			Personal		Social
Date	**Dur**	**Task**	**Function Rehabilitation Training**	**Personal Devices**	**Adaptive Equipment**	**Referral to other Agencies**	**Information**	**Confidence/ Motivation**	**Goal setting**	**Involvement of families, hobbies or clubs**

Name……..

Stn no……

Goal No	Goals of Outdoor mobility Intervention	Date task completed

Other information that is important when away from the home
Medication/ fits/ incontinence

Outdoor mobility therapy records

Nmae .....

Stn.....

Date	**Task**	Subjective account of treatment session / **O**bjective account of activity/ **A**nalysis of the treatment session / **P**lan for the future

Outdoor mobility occupational therapy intervention

Case Vignette 1 - Mrs Jones

Initial Assessment
Assessed through discussion, observation and use of the baseline assessment scores for Barthel, Nottingham Extended Activities of Daily Living, primary outcome question, number of journeys in the last month and the types of transport used in the last month.

Clinical history
Date of Birth 05.07.1930
Date of stroke 11.12.2001, admitted to hospital with left sided weakness that was diagnosed as a stroke, discharged home after 7 days, following rehabilitation and a home visit. No follow -up and no community rehabilitation. Medication - Aspirin daily.
Entered trial 06.07.2002

Social situation
Lives alone since husband died one year ago from Alzheimer's Disease. Mrs Jones was the main carer for her husband. She had worked in a hosiery factory before retirement.

Environment
Lives in a two bedroomed owner-occupier mid terraced house. Local shops and doctors 500 metres away. Main shopping centre 2 kilometres. Bus stop 500 metres.

Mobility -
Types of transport used in last month
Walking - Walking inside house independently with furniture. Can walk 10 metres outside with one stick and wall but does not. On assessment Mrs Jones was very unstable and worried about falling when walking outside. Mrs Jones comments that before the stroke she was able to walk approx. 6 kilometres without any problems but rarely left her husband for long.
Driving - does not drive a car. Has a daughter who drives and collects Mrs Jones once a month for Sunday lunch.
Pubic bus - Unable to get on and off the bus as afraid of falling.
Electric pavement scooter - She has bought an electric outdoor scooter since her husbands death but is unable to get the scooter out of the garden shed as the door of the shed hits the garden fence. Has tried Shop-Mobility scooters in the past and thought it would be good for getting to the shops and the cemetery.
Voluntary driver - did not know service existed
Dial -a - ride - did not feel she would be eligible
Trains, planes, trams, bicycle - not tried in the last ten years

Mobility outcome score - Housebound

Number of journeys per month - 2
Primary outcome measure, Do you get out of the house as much as you would like - No

Stairs
Independent up and down stairs with the use of two handrails once a day.

Access to property
One 15cm step at front door straight onto street and therefore unsuitable for permanent ramps. One 15cm step at back door but door way too narrow for scooter.
Mrs Jones can get independently in and out of her house.

Transfers
Mrs Jones is independent in all transfers.

Personal activities of daily living
Independent in washing, dressing, grooming but unable to get in and out of the bath. Stated that she is continent but has occasional accidents. Barthel score of 18.

Domestic activities of daily living
Independent inside the home with cooking, cleaning and laundry but unable to shop or look after the garden since her stroke. Community care services visit twice a week to provide support with shopping. The next door neighbour visits daily and will do shopping.

Nottingham Extended Activities of Daily living score of 11/22 or 29 /66

Hobbies and leisure activities
Mrs Jones was a keen church member before her stroke. She walked to the local church (400 metres) twice a week for services and attended a luncheon club once a week. She has not attended church since her stroke, as she does not like to ask for a lift and can not walk to the church. She enjoyed shopping prior to the stroke but is unable to get to the shops at present.

Safety
Has Piper alarm and wears the pendent at all times. Has mobile phone but not always with the participant.

Goals identified

1. To get the shed door re-hung on the opposite side to allow the scooter to be driven out of the shed

2. To practice using scooter to enable Mrs Jones to get to the church and the local shops

3. To increase confidence when walking outside to allow Mrs Jones to walk around the shops once there on her scooter

Treatment sessions

Session 1 - 60 minutes

Subjective - Discussed the goals of the treatment, confidence and homework
Objective - Walked to the garden shed, opened shed door looked at scooter and started the engine. Walked down side passage to the front pavement and then back through the front door (20 metres) with one stick. Rang carpenter from participant's house arranged for shed door to be re - hung Mrs Jones to pay, as Social Services will not pay for this job.
Analysis - Mrs Jones is very keen to get outside and move around on her own, the door needs to be re- hung before the scooter can be used but Mrs Jones' walking can be improved with practise.
Plan - Participant to walk outside and around house to front door everyday and if possible twice a day. Participant to pay carpenter and supervise the door re-hanging

Session 2 - 50 minutes

Subjective - Discussed the goals of the treatment, confidence and homework. Mrs Jones has been able to walk outside only four times during the week as she has not been feeling well and it rained
Objective - Walked to the garden shed, opened shed door looked at scooter and started the engine. Walked down side passage to the front pavement along pavement to the end of road and returned (50 metres) with one stick. Rang carpenter to confirm that he would complete job this week.
Analysis - Mrs Jones has not been well but still keen to get outside.
Plan - Participant to continue with walking practice and try to extend walks to next door neighbours house.

Session 3 - 70 minutes

Subjective - Discussed the goals of the treatment, confidence and homework. The door has been re-hung and participant has taken scooter out of the shed and down the passage between the houses. Mrs Jones is very pleased with how she coped and is keen to go further.
Objective - Walked to the garden shed, opened shed door, started the engine, backed scooter out of shed and drove down passage and along pavement. Crossed road continued to next road and crossed road returned to house and put scooter back in shed. Walked back to house.
Analysis - Mrs Jones is very happy with the scooter and the shed.
Plan - Participant to walk outside and around house to front door everyday and if possible twice a day. Participant to take scooter out of shed and to the local shops. If feeling confident to get off scooter and go into shops.

Session 4 - 60 minutes
Subjective - Discussed the goals of the treatment, confidence and homework. Mrs Jones has been unable to use her scooter as she has been unwell all week. Discussed the treatment session and decided we would go to the shops using the scooter. Mrs Jones was very afraid but was persuaded to go accompanied.
Objective - Walked to shed got scooter out and used scooter to get to shops. Walked into shops and bought a paper and some fruit. Used scooter to get back from shops to house.
Analysis - Mrs Jones was very pleased with her trip outside and felt she would be able to now go on her own.
Plan - Participant to use scooter to get to shops at least once in the next week.

Session 5 - 20 minutes
Subjective - Discussed the goals of the treatment, confidence and homework. Mrs Jones has used the scooter three times, once to the shops and twice to the church. She is very pleased with her progress and feels she will be able to go out more in the next month. Discussed joining the AA in case of a breakdown, Mrs Jones agreed to contact the AA.
Objective - Walked outside with participant using one stick 100 metres. No problems.
Analysis - Mrs Jones should be able to use her scooter on her own and walk into church and the shops. She will need to practice her routes to use dropped kerbs.
Plan - Participant to use scooter to get to shops three times a week and church twice a week. Occupational therapist will telephone in one week to check progress.

Session 6 - 40 minutes
Subjective - Discussed the goals of the treatment and homework and discharge. Mrs Jones has been able to use her scooter everyday. She has joined the AA incase of breakdowns. She is very happy with the situation.
Objective - Discussed the future and provided information about Dial-a-ride in case Mrs Jones wishes to take her scooter into the city.
Analysis - Mrs Jones is now independent with her scooter she may have problems accessing Dial - a- Ride
Plan - Discharged

Case Vignette 2 - Mr Dent

Initial Assessment
Assessed through discussion, observation and use of the baseline assessment scores for Barthel, Nottingham Extended Activities of Daily Living, primary outcome question, number of journeys in the last month and the types of transport used in the last month.

Clinical history
Date of Birth 05.07.1957
Date of stroke 04.06.2001, admitted to hospital with severe right sided weakness that was diagnosed as a stroke, transferred to the stroke unit, discharged home after 3 months in hospital. Care transferred to community rehabilitation. At present not receiving any active rehabilitation but case still open. Weighs 18 stone. Entered trial 07.03.2002

Social situation
Lives with wife and two children who are still at school. Prior to stroke had worked as a park keeper for the local council. At present on sick leave. Wife works full time in the retail trade. In receipt of mobility allowance which is being used to buy a Motorbility Car.

Environment
Lives in a three bedroomed council owned house. Shops, doctors, bus stop 700 metres away. Bathroom and WC downstairs.

Mobility -
Prior to his stroke Mr Dent walked and drove.
Types of transport used in last month
Walking - Walking independently inside house with walking frame. Has not walked outside. Transferred to car with wheelchair.
Wheelchair - Has self propelling wheelchair which is mainly used outside the house, pushed by wife or children
Driving - Prior to stroke was the main car driver now wife drives. Daughter 17 years wishes to learn to drive.
Pubic bus - Not tried as not walking outside.
Electric pavement scooter - Not tried, but has tried electric wheelchair and had success in the hospital but house is not suitable.
Voluntary driver - Non available in location
Dial -a - ride - Not tried
Trains, planes, trams, bicycle - Prior to stroke used planes once and trains once a year.

Mobility outcome score - Travels with help
Number of journeys per month - 16 with wife in car
Primary outcome measure, Do you get out of the house as much as you would like - No

Stairs

Does not go upstairs at present, sleep downstairs.

Access to property
One 15cm step at front door has had grab handles fixed next to front door. Independent in and out of front door. Two 15cm steps at back door. Unable to use steps with out help.

Transfers
Mr Dent is independent in transfers from chair to wheelchair, on and off the WC and to standing but needs help with getting in out of the car and into bed.

Personal activities of daily living
Needs help with dressing and cutting up food. Independent in grooming and toileting although is occasionally incontinent of urine. Has not tried the bath. Barthel score of 13.

Domestic activities of daily living
Wife does all shopping, cleaning and cooking. Mr Dent is left with drinks and snacks if at home on his own. He can use the telephone, read the newspaper and manage money when out at the social club.

Nottingham Extended Activities of Daily living score of 6/22

Psychological situation
Mr Dent is very concerned about his appearance since the stroke and feels he is an embarrassment to his family. He has lost confidence in his abilities to walk and does not want to be seen outside with a walking frame. He feels he can not help his wife or children. His GP has prescribed anti-depressants for his mood.

General Health Questionnaire score of 26/36

Hobbies and leisure activities
Prior to his stroke Mr Dent was in full time employment and spent his leisure time with his family. His main hobbies were taking his son to football practice and matches, attending the local social club and using computers. Since the stroke he has used the computer but is unable to drive so finds it difficult to attend the football matches. He visits the social club once a week with his wife and goes shopping with the family once a week.

Safety
Has Piper alarm and wears the pendent at all times. Access to phone at home. Does not have mobile phone

Goals identified

1. To liase with community physiotherapists with the aim of replacing walking frame with Delta frame in first place and the then one stick.

2. To walk outside 100 metres to aid independence using car and dial -a-ride scheme

2. To be able to travel independently using the dial-a-ride scheme to attend local computing classes

Treatment sessions

Session 1 - 70 minutes
Subjective - Discussed the goals of the treatment, confidence and homework
Objective - Walked inside the property, opened front door and stepped outside. Mr Dent became very anxious and returned to house. Spoke to physiotherapist who said she would re-assess for a Delta frame or walking stick. Filled in forms for Dial-a-ride and trial to pay for membership (£5). OT to send application forms.
Analysis - Mr Dent is very concerned about walking outside. He maybe happier to have wife present at therapy sessions
Plan - Participant to walk around inside house, open front door and step outside, everyday with wife. If Mr Dent receives membership for Dial-a-ride he will contact OT and then OT will book a journey for next therapy session in two weeks.

Session 2 - 20 minutes
Subjective - Discussed the goals of the treatment, confidence and homework. Mr Dent has walked inside everyday but has fallen once and become scared of going outside. Dial-a-ride membership arrived but frightened of using the service as Mr Dent thinks it's only for old people. Mrs Dent has found out that the computer classes are at the local College and they have a Meet and Greet service for people in wheelchairs.
Objective - Walked to front door, opened door and stepped outside, walked to car with assistance of OT, but very concerned. Wife present. Rang Dial-a-ride and booked journey for next week. To go to local shops for a coffee and return.
Analysis - Mr Dent is very anxious but Mrs Dent is very keen to try Dial-a-ride .
Plan - Participant to continue with walking practice and try to walk to car for every journey.

Session 3 - 90 minutes
Subjective - Discussed the goals of the treatment, confidence and homework. Physiotherapist has visited and given Mr Dent a Delta frame with seat and brakes. She does not feel he is ready for a stick. Mr Dent. Mr Dent is very despondent with his progress and has been getting very tearful and moody. Discussed the stroke clubs who provide transport as a way of

getting out of the house and meeting other young people with a stroke. Agreed to send an application for Mr Dent.
Objective - Dial-a-ride to local shops with Mrs Dent, OT followed in car as transport will only take one helper. Used wheelchair for the total journey
Analysis - Mr Dent very anxious about how he will manage on his own to get to the computer classes. Says he doesn't want to bother.
Plan - Continue with walking, Mrs Dent to take Mr Dent in car to first weeks class, OT to pick Mr Dent up from Class. The next week Dial-a-ride will be used as the transport.

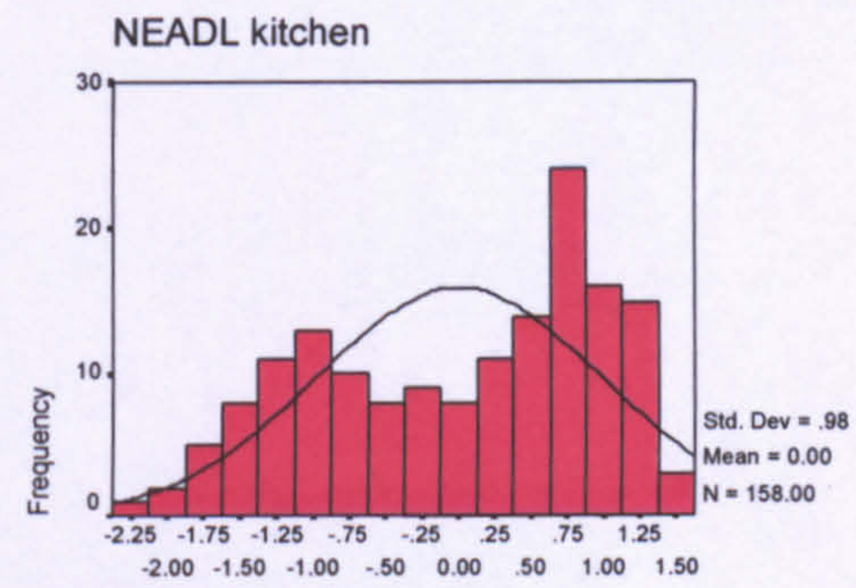
Session 4 - 20 minutes
Subjective - Discussed the goals of the treatment, confidence and homework. Mr dent went to computer class and really enjoyed the time away from home. The Meet and Greet system worked well.
Objective - OT collected Mr Dent from computer class and walked from car to house with Delta frame.
Analysis - Mr dent still not happy to use the Dial-a-ride as he feels it makes him look more disabled. He wants to try a taxi. Explained that it would be £10 round trip and he would have to get himself to the taxi. He wants to try.
Plan - Participant to try using taxi with a friend in the next two weeks.

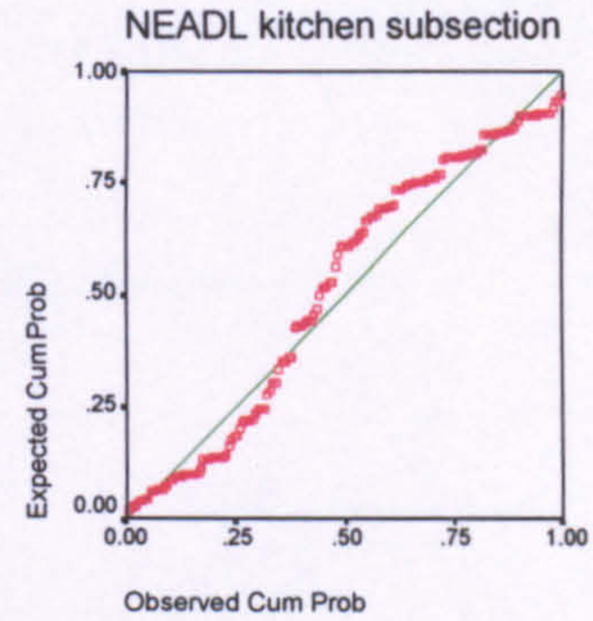
Session 5 - 20 minutes
Subjective - Discussed the goals of the treatment, confidence and homework. Mr Dent used taxi with friend who is happy to travel with Mr Dent on other journeys. Cost of taxi a problem but at present Mr Dent would rather use taxi.
Objective - Walked outside with participant using Delta frame.
Analysis - Mr Dent appears very happy with the prospect of using a taxi and this has encouraged him to walk outside. The cost of the taxi will put a strain on the family as the computer classes are once a week but Mrs Dent is happy to see her husband get out of the house.
Plan - Participant to walk to pavement each day and used taxi on own this week.

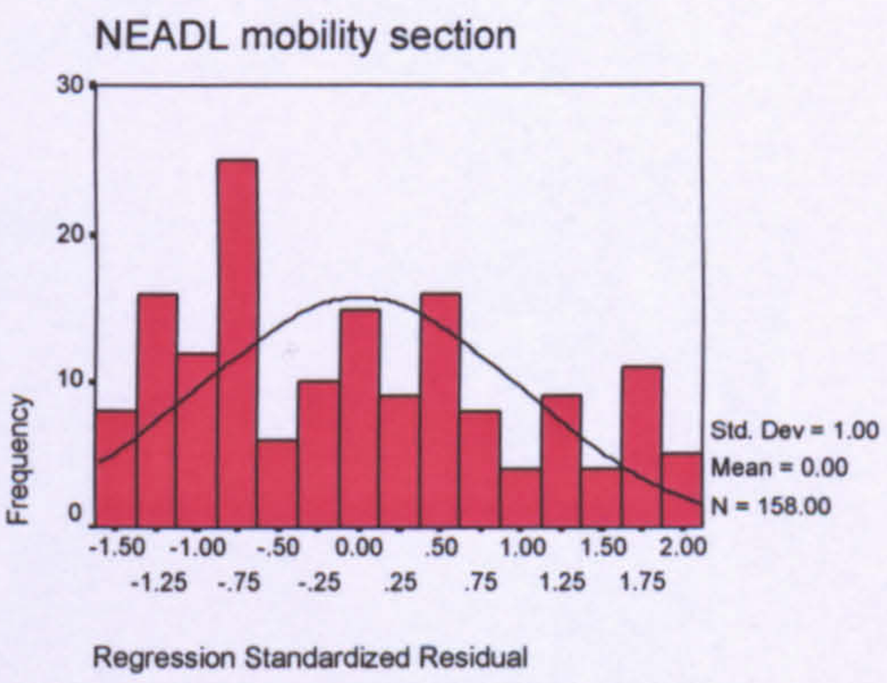
Session 6 - 20 minutes
Subjective - Discussed the goals of the treatment and homework and discharge. Mr Dent has used the taxi on his own for the computer class. The Dial-a-ride did not work in this situation because of the stigma attached to this form of transport. The cost of a taxi may prevent Mr Dent from travelling to other venues. It is unfortunate that there are no voluntary drivers.
Objective - Discussed the future. Mr dent is considering moving the Mobility Allowance from the Motorbility Scheme (which pays for the car) to having the cash for getting taxi's and then buying a car. This will also help the daughter, as Motorbility will not let people under 21yrs drive their cars. The stroke club has a waiting list for people who need transport but when a place becomes available Mr Dent will attend.
Analysis - Mr Dent is now independent using a taxi as long as it is to a venue where he will be assisted. Dial-a-ride did not work. Mr Dent can walk outside (20 metres)

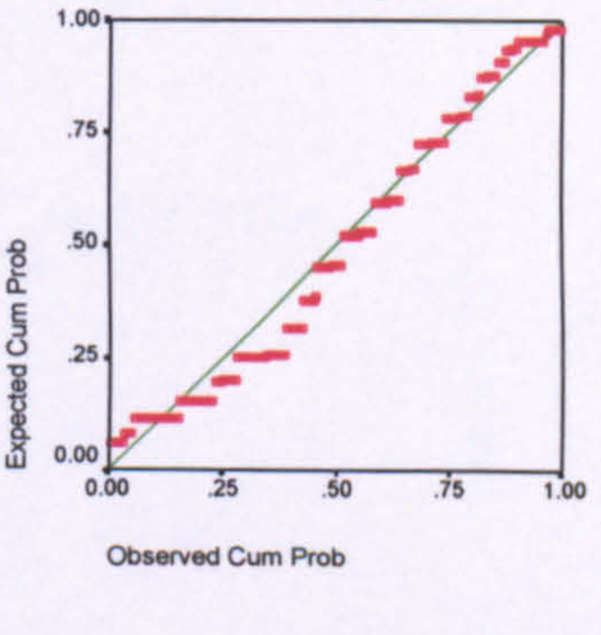
APPENDIX 10 Four month residual plots

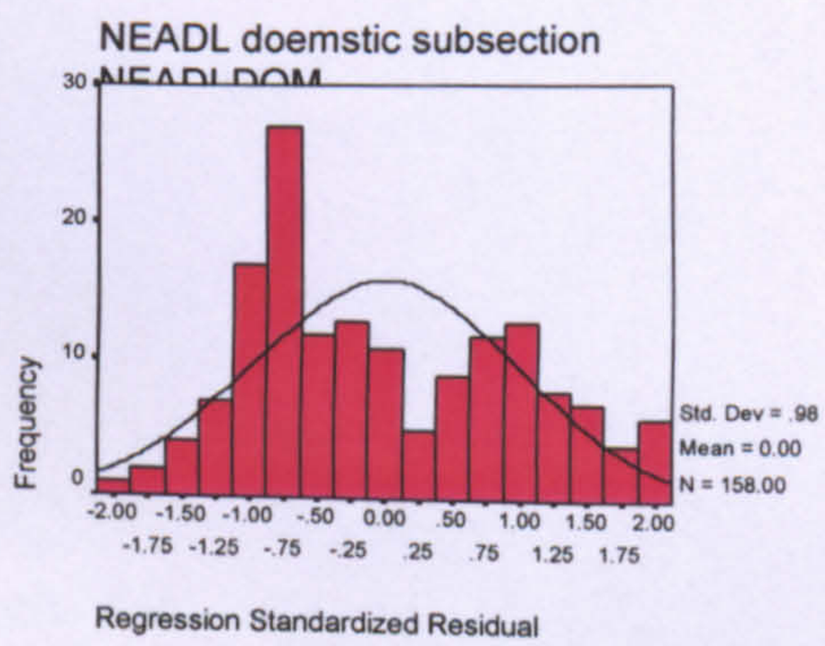
Four month residual plots

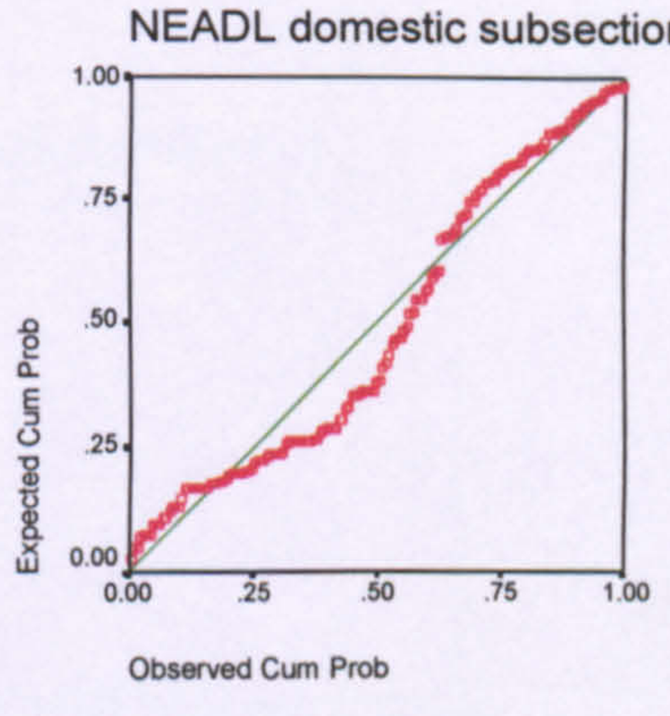


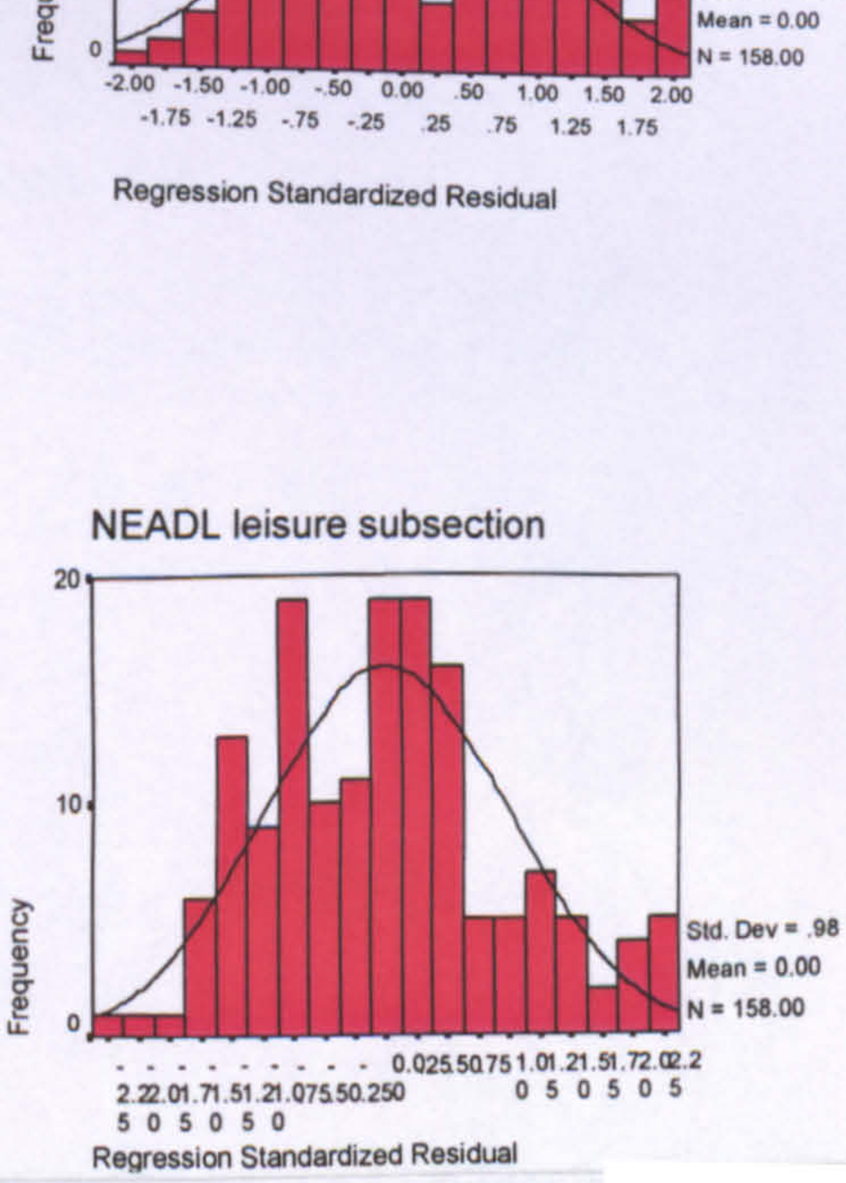


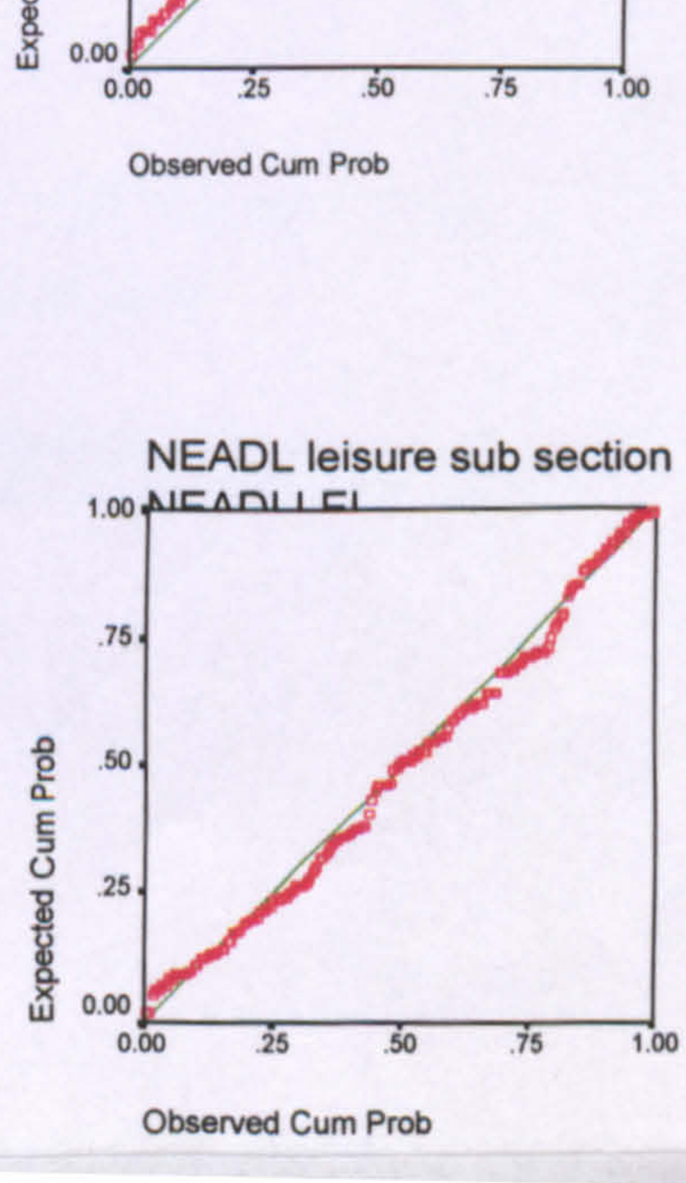




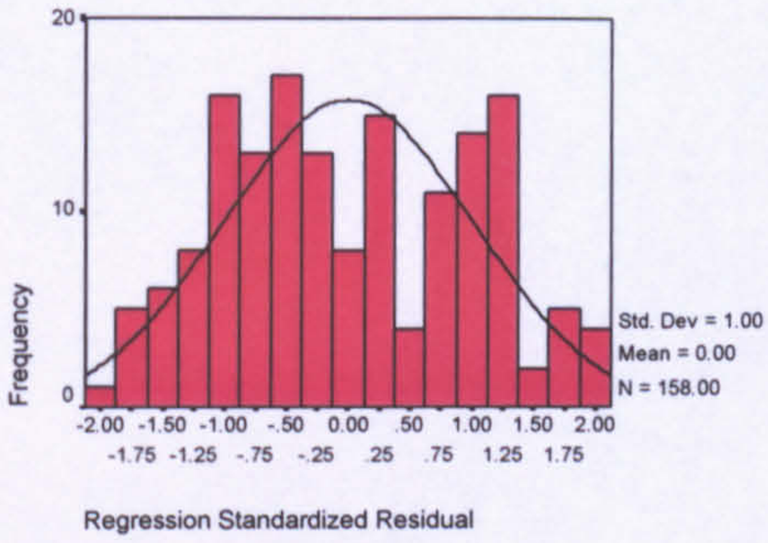






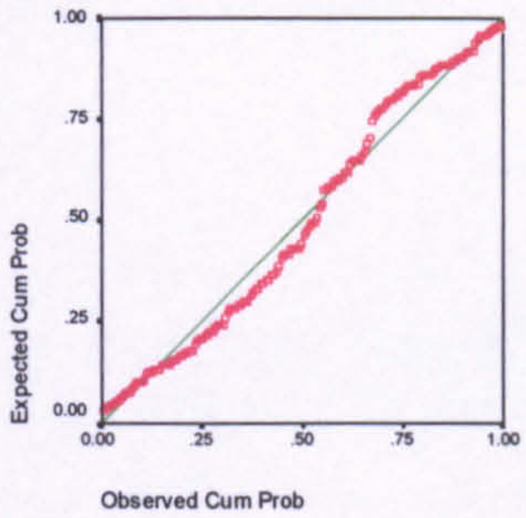


NEADL total 4 month

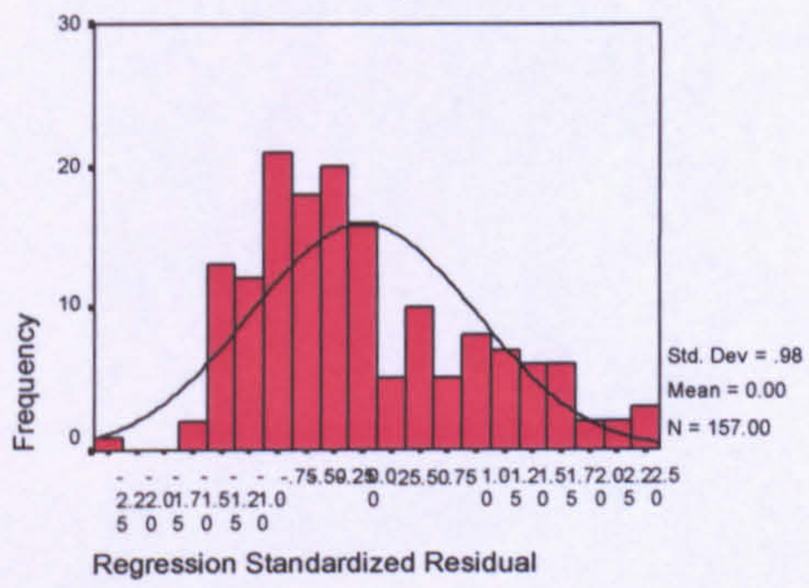


Plot of residuals

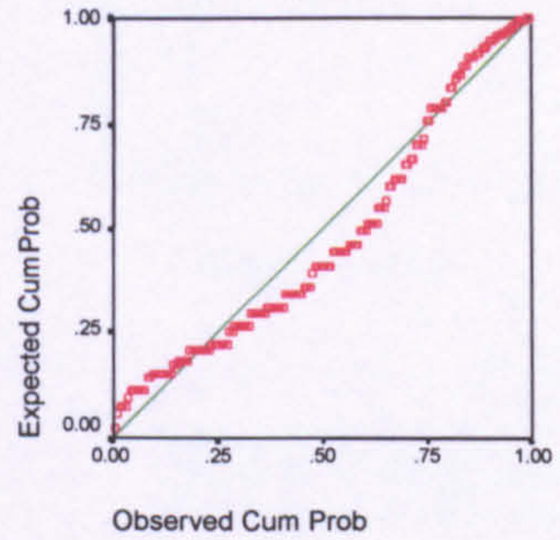
NEADL 4 month total



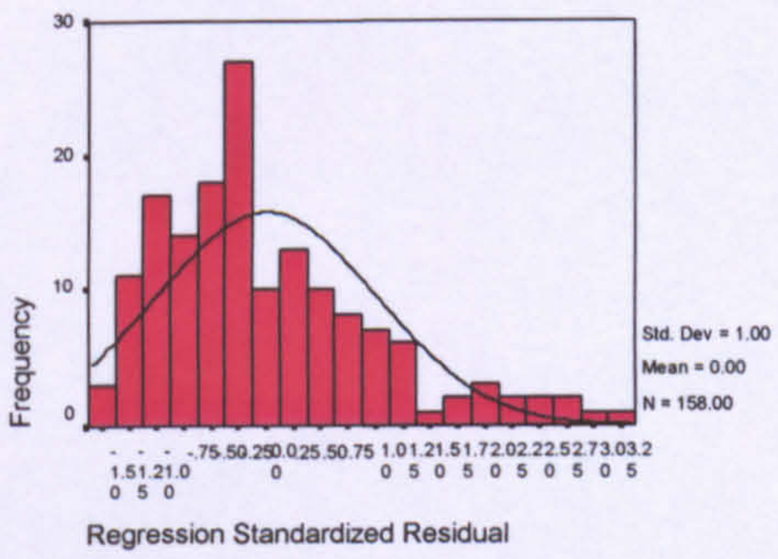
GHQ at 4 months patients



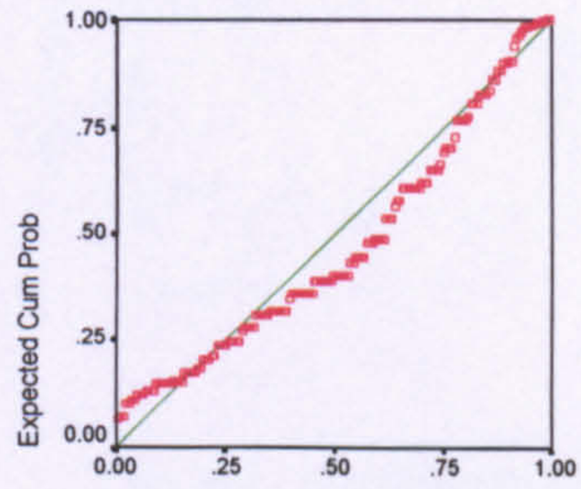
GHQ participant 4 months



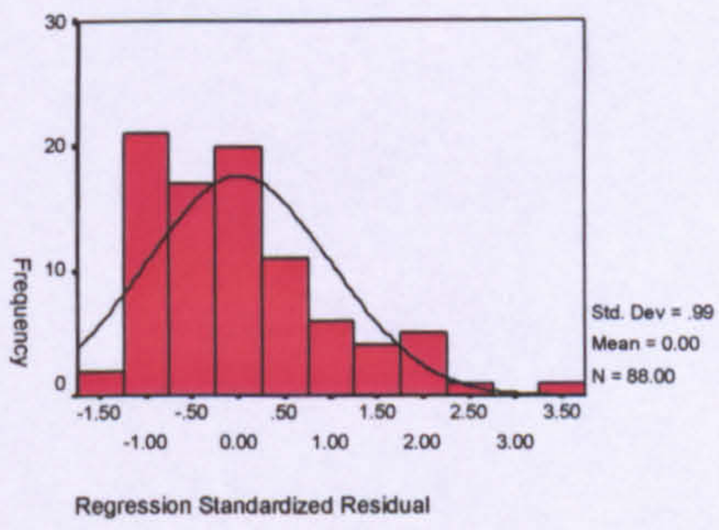
NLQ 4 month total



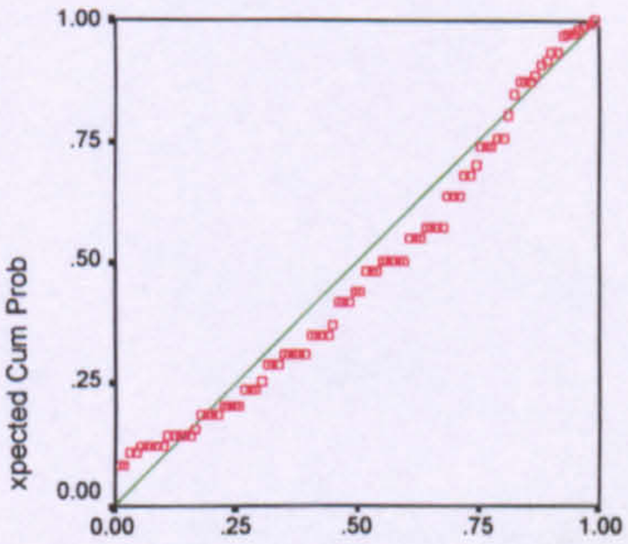
NLQ four months



GHQ carer 4 month

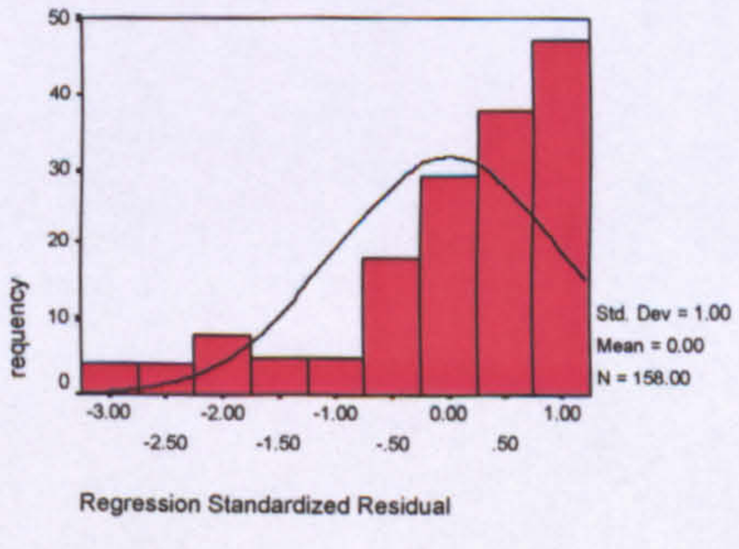


GHQ carer 4 month

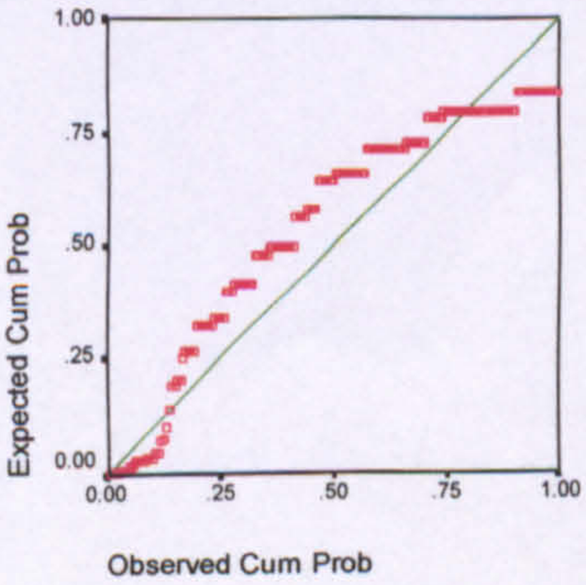


Barthel not used in linear regression

Barthel 4 month total

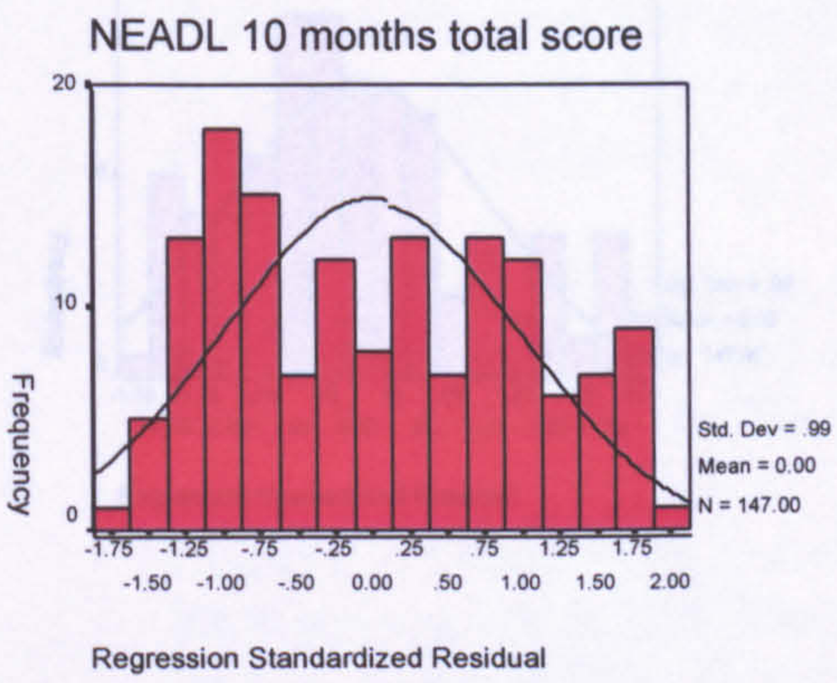


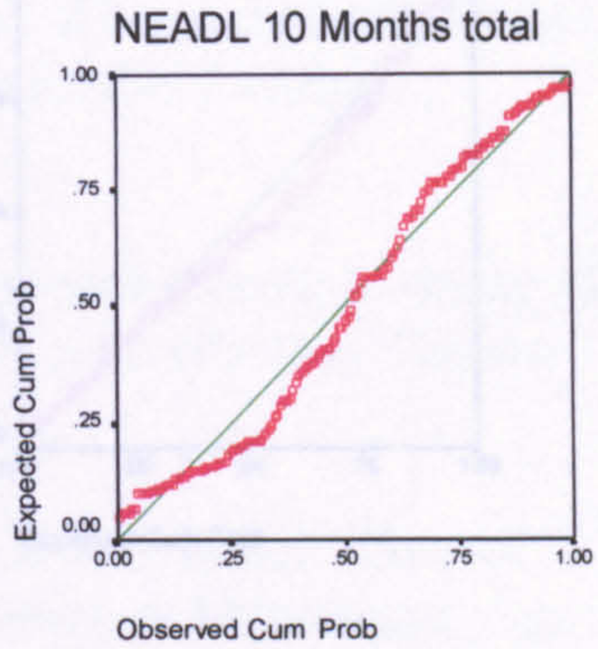
Barthel at four months

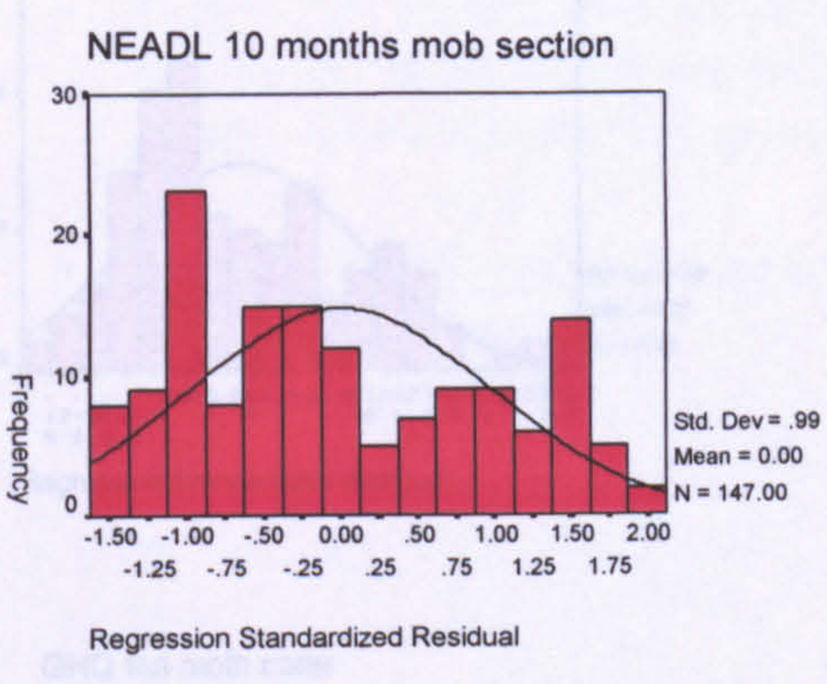


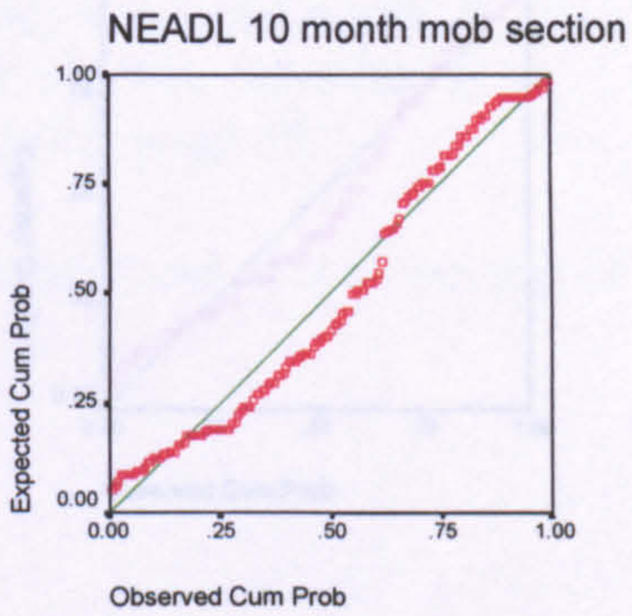
APPENDIX 11 Ten month residual plots

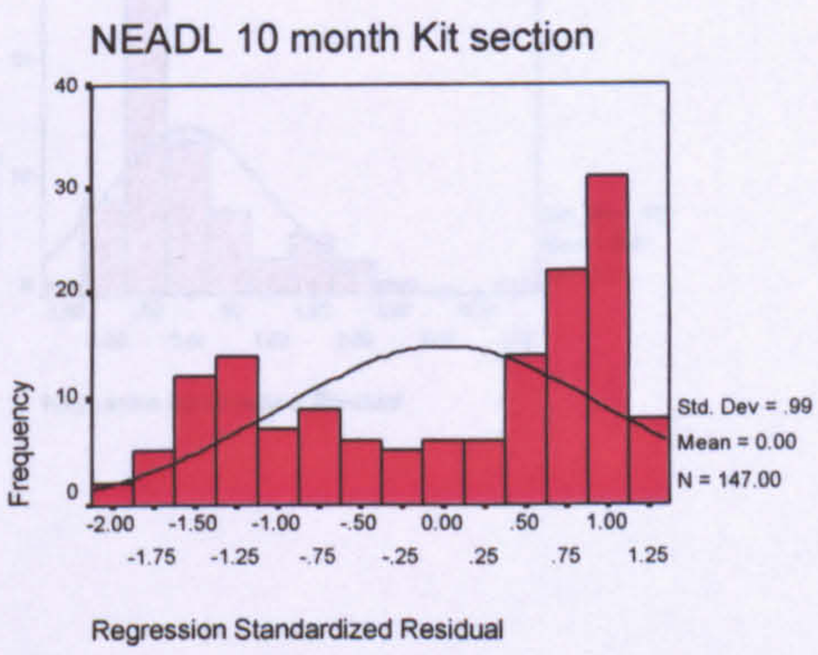
Ten months residual plots

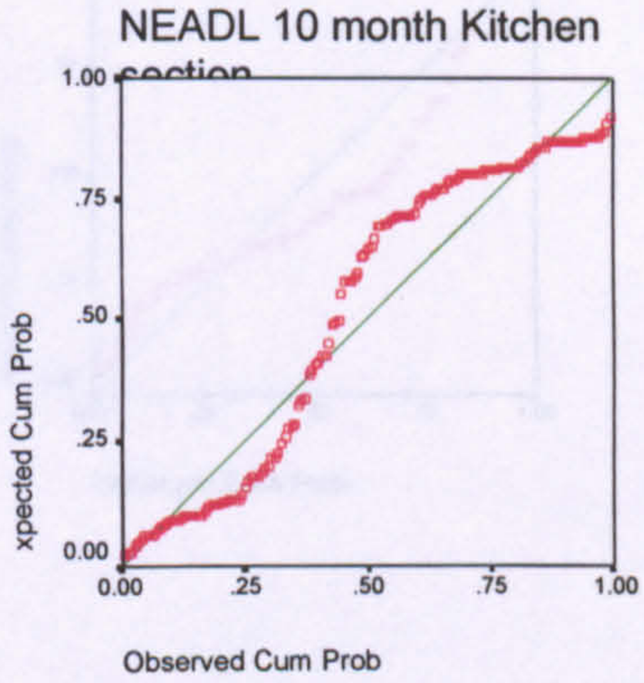


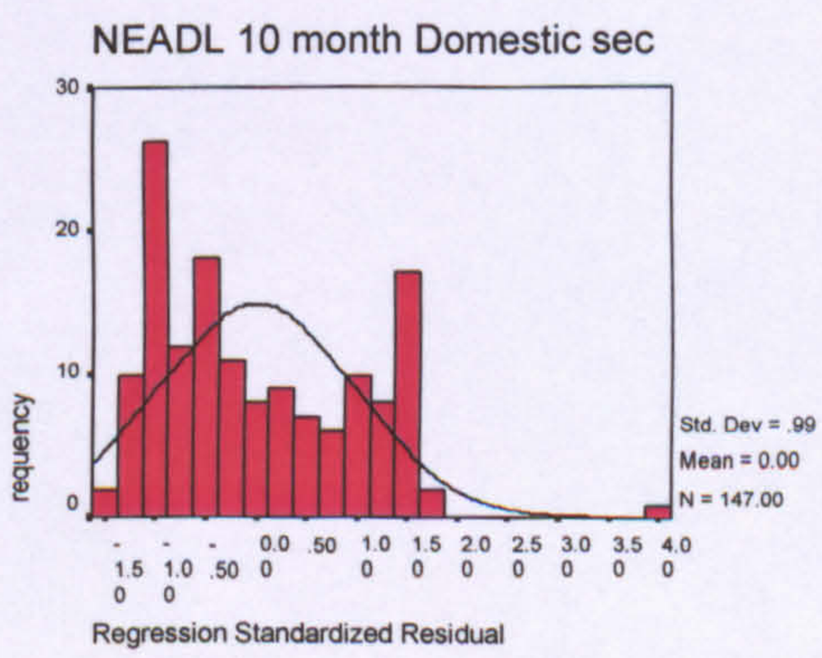


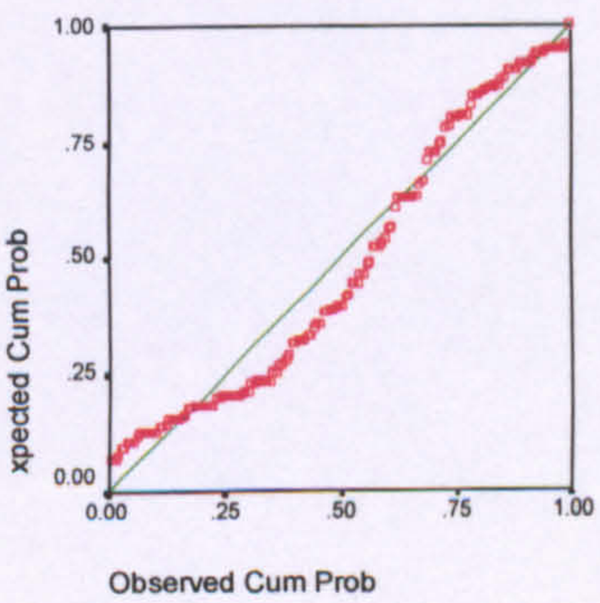




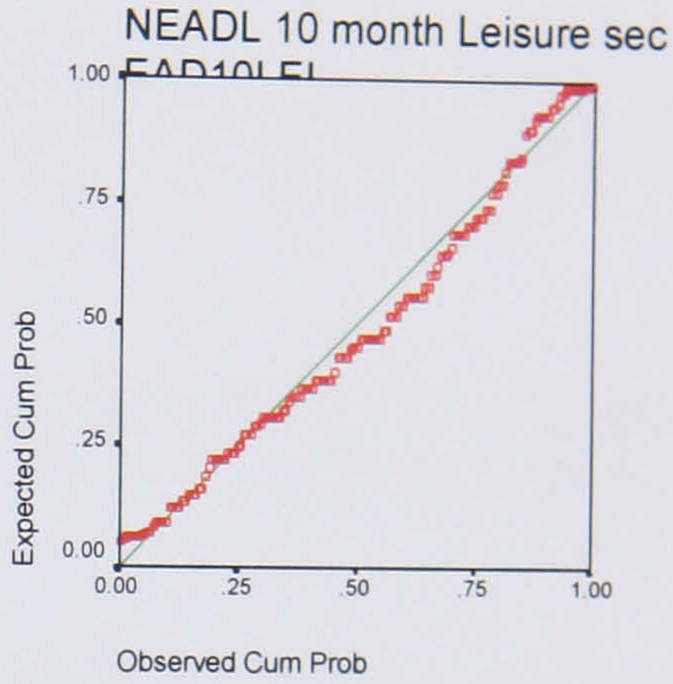


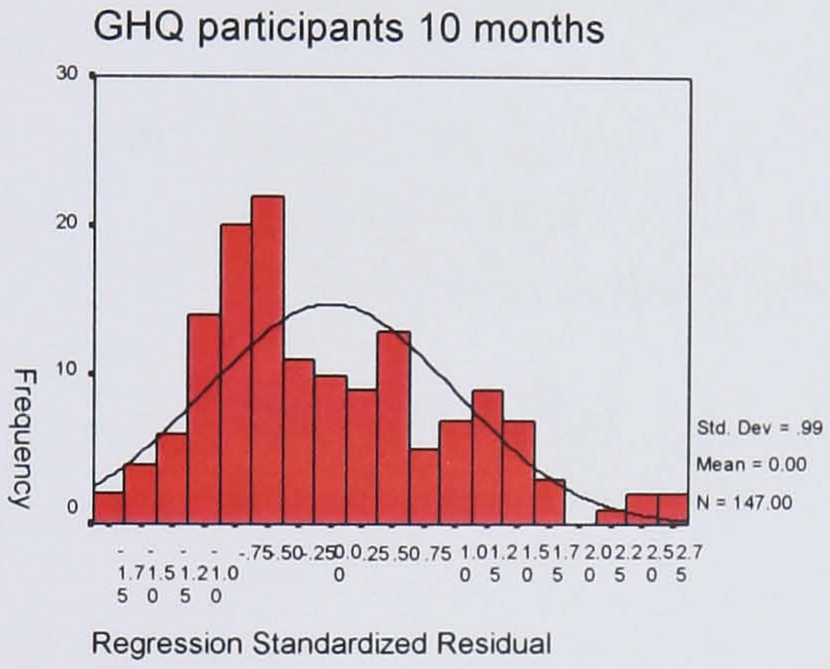


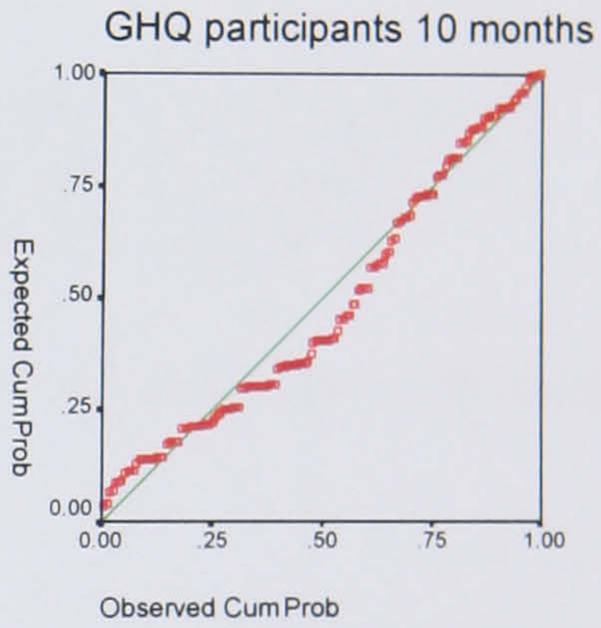


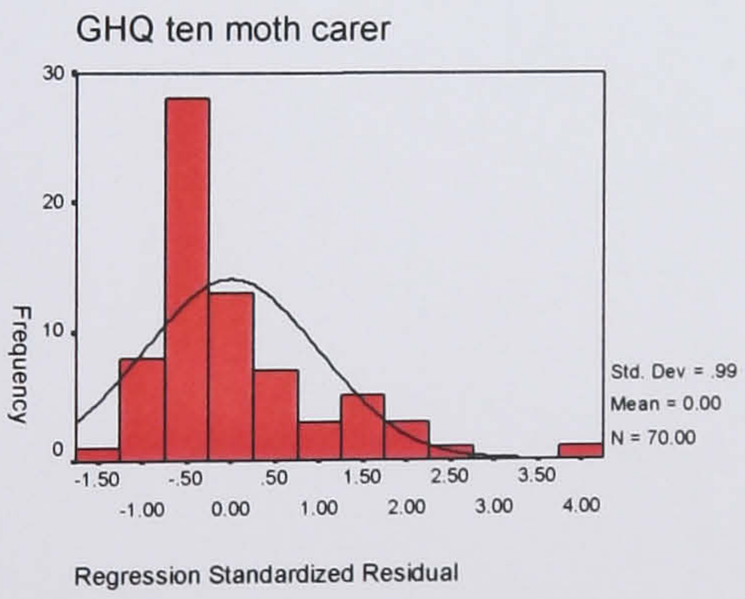


NEADL 10 month Leisure sub
Frequency
Std. Dev = .99
Mean = 0.00
N = 147.00
Regression Standardized Residual


NEADL 10 month Leisure sec
Expected Cum Prob
Observed Cum Prob


GHQ participants 10 months
Frequency
Std. Dev = .99
Mean = 0.00
N = 147.00
Regression Standardized Residual


GHQ participants 10 months
Expected Cum Prob
Observed Cum Prob


GHQ ten moth carer
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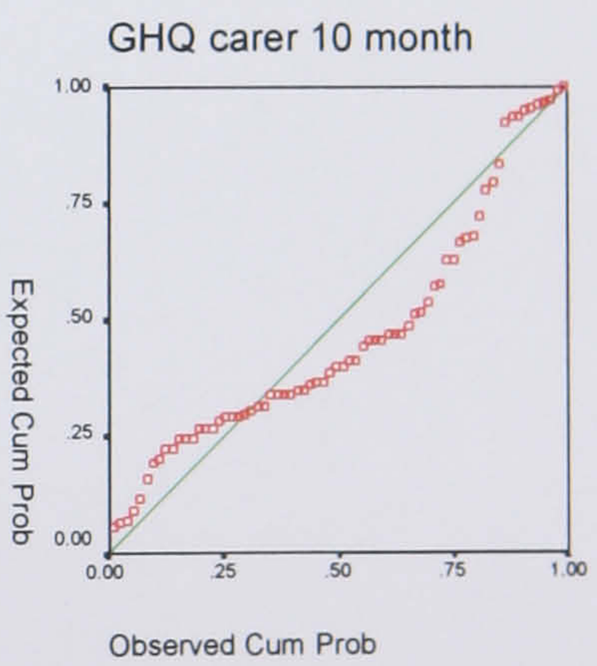
Regression Standardized Residual


GHQ carer 10 month
Expected Cum Prob
Observed Cum Prob

APPENDIX 12 - Publications and dissemination

- Logan PA, Gladman JRF, Avery AJ, Walker MF, Groom L, Dyas J. Randomised controlled trial of an occupational therapy intervention to increase outdoor mobility after stroke. British Medical Journal. Accepted for publication

- Logan PA, Dyas J, Gladman JRF. Using an interview study of transport use by people who have had a stroke to inform rehabilitation. Clinical Rehabilitation 2004; 18: 703-708

- Logan PA, Gladman JRF, Avery AJ, Walker MF, Groom L, Dyas J. A Randomised Controlled Trial of A Travel Promotion Programme. Age Ageing, October 2004;33 suppl 1:i11

- Logan PA, Dyas J, and Gladman J R F. Getting out of the house: a qualitative study of the use of transport by people who have had a stroke. SAPC Conference proceedings July, 2002, page 39

- Flyer (2004) for participants and primary care services sent at the end of the trial, see over leaf.

Getting out of the House

A study of people who have had a stroke

P.A. Logan, J.R.F. Gladman, A.J. Avery, M.F. Walker, L. Groom, J. Dyas, K.A. Radford
Division of Primary Care and Division of Rehabilitation and Ageing, University of Nottingham

Barriers to mobility in people who have had a stroke

We have previously found that, despite rehabilitation, 42% of people with a stroke want to get out of their house more often[1].

We interviewed them about their reasons, and to identify how the problems might be overcome. Getting out of the house was found to be very important, not only to get somewhere, but for its own sake. Issues such as physical limitations, fear, embarrassment and lack of information were important and many people found using transport extra difficult after giving up driving[2].

Evaluation of a travel promotion programme

Based on the findings of earlier studies we set up a travel promotion programme. This was delivered by an occupational therapist (OT). Participants were: encouraged and accompanied when using transport, provided with bespoke information, prescribed remedial exercises and equipment if needed. The OT helped them to return to driving or to use alternative modes of transport.

A randomised controlled trial was used to evaluate the travel promotion programme. 82 people were treated and 86 control participants (who received leaflets about transport) were recruited. Four months later the group which used the travel promotion programme went out twice as often as those who did not, and were nearly twice as likely to say that they went out as much as they wanted[3].

The travel promotion programme is a simple, feasible intervention that could help many disabled people. It deserves wider implementation and evaluation.

Mrs Bath went with the OT to try an electric pavement scooter at Shop Mobility. She then tried the service by herself. She can now get around the indoor shopping centres alone and is thinking about buying a scooter.

Mrs Clarke, 67 yrs of age, had to give up using her car when she had a stroke. She had never used the bus. She felt isolated, miserable and unable to continue with the activities she wanted because she couldn't face getting on the bus.

References
1 Logan PA, Gladman JRF, and. Radford KA (2001). A pilot evaluation of the transport used by stroke patients. British Journal of Occupational Therapy 64: 261-264
2. Logan PA, Dyas J, Gladman JRF. Using an interview study of transport use by people who have had a stroke to inform rehabilitation. Clinical Rehabilitation (in press)
3. Logan PA, Gladman JRF, Avery AJ, Walker MF, Groom L, Dyas J. A Randomised Controlled Trial Of A Travel Promotion Programme (platform presentation British Geriatrics Society October 2003)

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