Exploring Family Functioning Post Stroke

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Abstract

Objectives: The aim of this study was to explore the impact of an older person's stroke on family functioning. Stroke patients, aged 65 and over, and members of their family were compared to a control group of older people without stroke and members of their family. The researcher was also interested in how individual functioning may act as possible contributory factors, consequently affecting family functioning as a whole.

Design & method: A cross sectional between groups design was employed. Stroke patients (aged 65 and over) and family members were compared to a healthy control group of older adults and family members. The participants completed assessments measuring family functioning, perceived quality of life, perceived social support, and current mood.

Results: The main result was that, in families where an older person had a stroke, the stroke did not negatively impact on family functioning. Group comparisons revealed that the stroke and control group did not differ on measures of family functioning, perceived social support and mood. However, older people with stroke reported a lower perceived quality of life than older people without stroke. The latter result suggests a possible area for intervention for clinicians working with older people with stroke.

Conclusions: Interpreted within a family life cycle and individual developmental perspective, the results suggest that older people suffering strokes may be expected, and as such this expectation may act as a coping mechanism for dealing with the illnesses and losses that people are faced with in their later life. Methodological limitations of the study and suggestions for further research are discussed.

Chapter 1: Introduction

Cerebrovascular accident, or stroke as it is more commonly known, is the leading cause of disability and the third most common cause of death world wide (Warlow, 1998). Although people of any age can have a stroke the majority of people who do are over the age of 65 (Chief Medical Office (CMO), 2002; Westcott, 2000). As with other types of chronic illness, stroke not only has an impact on the individuals themselves but can also have consequences for other members of their family, particularly in cases when there are apparent residual effects of the stroke. It is therefore essential for clinicians to have a good understanding of the implications of stroke for patients and their families.

This thesis will initially present information from research literature regarding demographic change and the consequences this has for the frequency of stroke among older people. It will then describe the physical and psychosocial consequences resulting from stroke. Since the primary focus of the study is that of the psychosocial implications of stroke both for the individual who has a stroke and their relatives, it will then discuss stroke in the context of family functioning. Although people aged 65 and above are more likely to suffer stroke than other age groups the consequences of stroke on older people and their families has not received extensive attention in the literature. Therefore the current study focuses on individuals over the age of 65 who experience stroke and their family members. As a result of population ageing, the number of older adults suffering strokes is set to increase.

1.1 Demographic changes in society

Demographic change is a global phenomenon occurring in the developing and the developed world (Kinsella & Velkoff, 2001). Worldwide, the proportion of people aged 60 and over is growing at a faster rate than any other age group (World Health Organisation (WHO), 2002). A useful indicator of this changing age structure is that of the ageing index (Kinsella & Velkoff, 2001). This index is defined as the number of people aged 65 and over per 100 people under the age of 15 years old. In 2000 the UK had an ageing index of 82, meaning that for every one hundred young people there were 82 people aged over 65 (Laidlaw et al., 2003). All developed countries have a projected ageing index of at least 100 by the year 2030. This means that for every one hundred young people under the age of 15, there will be 100 people aged over 65. The proportional increase for the ageing index in developing countries is said to be greater still (Kinsella & Velkoff, 2001).

This change in age structure is apparent worldwide. Therefore in the United Kingdom, as with the rest of the world, there is an increasing proportion of older people in the population who are living longer and healthier (Council of Europe, 2003; WHO, 2002). The United Kingdom had a population of just over 59 million at the start of 2003 and the proportion of people aged 65 and over in the UK population is expected to grow from about 16 per cent in 2003 to an estimated 21 per cent in 2030 (Council of Europe, 2003). Therefore by 2030, 1 in 5 people in the United Kingdom will be aged 65 or over.

A decline in birth rates since the late 1970s, coupled with the large birth cohorts of the late 1940s (the baby boomers) approaching retirement age, are the main reasons for the increase in the proportion of older people relative to the younger population (Kinsella & Velkoff, 2001). Old age dependency ratios, also known as support ratios, are defined as the number of people aged 60 and over per 100 people of working age (aged 15 to 60), in a given population. The dependency ratio in North America and in European countries was 0.26 and 0.36 respectively in 2002. Due to the increase in the older adult population these figures are expected to increase to 0.44 and 0.56 by the year 2025 (Laidlaw et al., 2003). That is, for every one hundred people aged 15 to 60, there will be 56 people aged over 60 in Europe.

The term 'dependency' ratio perhaps suggests that all those over 65 years of age will become dependent on those aged 15 to 60 years, who comprise the majority of those in employment. However, this is not the case. Older people, in both developed and developing countries are considered an important resource both to their families and their communities (WHO 2002), and will not necessarily become 'dependent' on younger people for any type of assistance. Therefore, although the idea of dependency ratios has been a useful indicator for economists predicting the financial implications of pension policies (WHO 2002), it is perhaps less useful for predicting the personal, physical and psychological needs of an ageing population. Individuals over 65 comprise of an extremely diverse group. Therefore, indices which more accurately reflect the nature of 'dependency' for older adults are needed (WHO 2002). These other indices would avoid grouping all healthy older adults with those in poor health as these different groups will have different needs in terms of their dependency and need for support.

Longer life expectancy is generally regarded as representing the improved health status of the population (WHO 2002). However, longer life expectancy is also recognised as presenting challenges to countries health systems, as rates of chronic illness and disability, for example, stroke, increase dramatically with age (Wood & Bain, 2001). As such an interest in health expectancy, defined as living longer and healthier lives, has emerged as an important consideration of today's ageing population (WHO 2002). Health expectancy is widely thought of as being equal to a disability-free life expectancy.

Although poor health is not an inevitable consequence of ageing, older people do experience relatively high levels of illness and disability. The likelihood of experiencing serious cognitive and physical disabilities dramatically increases in very old age (WHO 2002). This would suggest that perhaps some of the increase in life expectancy observed in recent years has resulted in an increase of time spent in poor health (Wood & Bain, 2001), and therefore has not necessarily reflected a corresponding increase in health expectancy for all older adults.

Women continue to have a higher life expectancy than men; 80.5 years and 75.8 years respectively in UK populations (WHO 2003). As women outnumber men in the older age groups (Wood & Bain, 2001), there is a corresponding increase in chronic illness, disease and disability for older women relative to older men, perhaps negating some of the potential benefit of their higher life expectancy (WHO, 2003; Wood & Bain, 2001).

The current study took place the Highland region of Scotland, which has a population of approximately 211, 340. It is estimated that 16 per cent of this population is aged 65 and over. This figure is expected to rise to 24 per cent by the year 2016 (Wood and

Bain, 2001, CMO, 2002). The proportion of older people in the Highland population is higher than the national average (NHS Highland, 2005). Therefore, it is perhaps expected that if there is a high proportion of older adults in the Highlands, (as in the rest of the UK and worldwide) then there will be an increased number of older adults suffering strokes. It is important, therefore, to better understand the consequences of stroke for older individuals and their families.

1.2 Stroke and implications

The World Health Organisation has defined stroke as

> *'a clinical syndrome of rapidly developed clinical signs of focal or global disturbance of cerebral function, lasting more than 24 hours with no other apparent cause other than vascular origin'* (WHO, 1978)

Stroke is due to an interruption of the blood flow to part of the brain. Effects of stroke are dependent on the part of the brain affected and the amount of damage caused. The European Stroke Initiative has recommended that the term stroke should be changed to 'brain attack' (Kaste, Skyhoj-Olsen, Orgogzo, Bogousslavsky & Hacke, 2000). This recommended change in terminology aims to highlight that, similar to having a heart attack, having a stroke should be considered a medical emergency.

1.2.1 Types of stroke

The fundamental classification is between ischemic or haemorrhagic strokes, although different subtypes of stroke exist. Ischemic stokes are said to account for approximately 88 per cent of strokes while haemorrhagic strokes for the remaining 12 per cent (Baldwin, 2006). This study explored the effects of both ischaemic and haemorrhagic strokes on family function.

Ischaemic stroke occurs when a clot blocks an artery carrying blood to the brain. This type of stroke has three main causes; a cerebral thrombosis, when a blood clot (thrombus) forms in a main artery to the brain; a cerebral embolism, when a blockage caused by a blood clot, air bubble or fat globule (embolism) forms in a blood vessel somewhere else in the body and is carried in the bloodstream to the brain; or by a blockage in the tiny blood vessels deep within the brain (lacunar stroke) (The Stroke Association).

Haemorrhagic strokes occur when the blood vessel in or around the brain ruptures, causing bleeding. Blood presses on the brain damaging the delicate tissue while other cells are starved of blood and die. (www.bbc.co.uk/health/conditions/stroke). Intracerebral haemorrhage refers to bleeding in the brain while subarachnoid haemorrhage refers to a bleed in the subarachnoid space between the brain and the skull (www.stroke.org.uk).

A transient ischaemic attack (TIA) is sometimes referred to as a 'mini-stroke' and occurs when the blood supply is interrupted for a shorter period of time, anything from a few minutes to 24 hours. The symptoms are very similar to a stroke (such as weakness on one side of the body, loss of sight and slurred speech) but they are temporary. A TIA is a sign that part of the brain is not getting enough blood and that there is a risk of a more serious stroke in the future (www.stroke.org.uk). The current study focuses solely on individuals who have experienced a stroke; therefore people who had transient ischaemic attacks were excluded from the study.

The tissue within many parts of the brain is unable to survive more than several minutes of oxygen deprivation. Therefore irreversible damage to the brain can occur very quickly following a stroke (Lezak et al., 2004). The specific types of problems resulting from stroke depend on the area of brain damaged, the type and severity of the stroke and the extent of the damage to the area. In some, but not all, cases the surrounding brain cells can take over the functions of the dead or damaged cells over time.

1.2.2 Symptoms of stroke

Recognition of early signs and symptoms of stroke have been shown to be poor within members of the community (Parahoo et al., 2003, Yoon & Byles, 2002). This may be because the symptoms of stroke can vary between individuals. People might experience drowsiness or loss of consciousness, limb weakness or paralysis, which can lead to; poor balance, loss of co-ordination, change in vision and loss of feeling in the face, arm or leg. They may also experience difficulties with communication, for example slurred speech. The Stroke Association recommends using the FAST test to diagnose a possible stroke, which represents Facial weakness, Arm weakness, and Speech problems - Test all three! (The Stroke Association, 2005; Fact sheet 4). It is hoped that by identifying the symptoms of stroke early this will enable more people to attend hospital when they suspect a stroke and perhaps within the important three hour time window necessary for a drug called tissue plasminogen activator (t-PA), which dissolves blood clots obstructing blood flow to the brain. T-PA is only of benefit for ischaemic strokes and is contra-indicated for haemorrhagic strokes. Administering t-PA for haemorrhagic strokes would cause further bleeding. Some ischaemic stroke patients who received t-PA within three hours of the start of stroke symptoms were at least 30 percent more likely to recover with little or no disability after three months (National Institute of Neurological Disorders and Stroke [NINDS]).

1.2.3 Incidence and prevalence of strokes

Stroke incidence is said to be relatively similar across developed countries at approximately four first time strokes per 1000 per annum in people aged 45-84 (Warlow, 1998). Someone in the UK has a stroke every five minutes and 48 per cent are either dead or disabled at six months (Mant, 2004).

As described above stroke mainly affects older people, with two thirds of strokes affecting people over 65. In addition, the prevalence rate for people over the age of 85 is set to increase from 2 in every 1000 to 2 in every 100 of the population (Smithard, 2005). Stroke recurrence is said to be approximately 12 per cent in the first year and 6 per cent in the second year (Topic Working Group, 1999) and there is thought to be a 25 per cent risk of a recurrent stroke over five years (NINDS, 2007).

Stroke is a major health problem in Scotland. It is the third most common cause of death and the most frequent cause of severe adult disability. Seventy thousand individuals are living with stroke and the consequences of stroke each year in Scotland and there is an estimated 15,000 new stroke events annually (Scottish Intercollegiate Guidelines Network 64 (SIGN 64), 2002). Within Highland, it is estimated that there are approximately 1,800 people who have suffered a stroke living in the region (NHS Highland, 2005). Clearly, stroke is a major health problem for the population but particularly for older people.

1.2.4 Risk factors for stroke

There are numerous causes of stroke, which have implications for the preventative strategies recommended as well as influencing prognosis and the type of treatment people require (Warlow, 1998). There are both modifiable and non-modifiable risk factors for stroke.

Modifiable risk factors include lifestyle factors such as smoking, drinking alcohol to excess, having a poor diet and a lack of exercise. In addition having high blood pressure is considered one of the major risk factors for stroke (The Stroke Association, 2005; Fact Sheet 6). An individual with hypertension is thought to have four times higher risk of having a stroke than someone who is normotensive (Baldwin, 2006). High blood pressure is seen to be common in older people (Hildick-Smith, 2000), and rather than asking healthy people having to take medication for years, it is recommended that some people may be able to lower their blood pressure using other methods, for example losing weight, eating properly and getting the right amount of physical exercise (American Stroke Association, 2007).

Non-modifiable risk factors for stroke include additional considerations such as male gender, older age, ethnic origin, as well as certain medical conditions such as diabetes mellitus, high cholesterol and heart disease. A previous stroke or transient ischaemic attack (TIA) is also considered a risk factor for further strokes. Male gender has been identified as a non-modifiable risk factor for stroke, especially in the under 65s. Women are said to have strokes later in life and therefore due to age, these women are at greater risk of disability (Kelly-Hayes, Beiser, Kase, Scaramuci & Agostino, 2003). Age is considered the most important risk factor for stroke as the risk of stroke doubles every ten years when people reach 65 (Laidlaw, Gallagher-Thompson, Thompson & Siskin-Dick, 2003). However, despite the increased risk of stroke with age it should be noted that stroke is not an inevitable consequence of ageing (Michael & Shaughnessy, 2006).

1.2.5 Implications of stroke

Outcome after stroke varies between individuals. Although survival rates have risen in recent years, Jorge and Robinson (2004) suggest that following a first stroke approximately one third of people will die within one year, one third will make a good recovery and one third will be left with some residual disability. Recent SIGN guidelines suggest that about 30 per cent of stroke patients will be fully independent within three weeks, a figure that increases to almost 50 per cent by six months (SIGN 64, 2002). However, Warlow (1998) cautioned that these averages conceal huge individual variations, dependent on stroke type, stroke severity and pre-stroke disability.

The consequences of stroke can be varied and wide ranging depending on the location and severity of the brain lesion. The following presents the common physical and cognitive effects of stroke in separate sections but it should be noted that they likely interact and in combination contribute to the level of disability and response to treatment.

Common physical disabilities resulting from stroke are paralysis (hemiplegia) or weakness (hemiparesis) on one side of the body, which can lead to difficulties with walking and co-ordination as well as affecting an individuals' ability to carry out activities of daily living. Other physical effects of stroke include visual impairment, incontinence and difficulty swallowing (Clarke, Black, Badley, Lawrence & Williams, 1999), as well as fatigue and post stroke pain.

Cognitive difficulties resulting from stroke include problems with perception, attention and concentration, memory, planning, problem solving, difficulty understanding or forming speech (aphasia) (Westcott, 2000) as well as neglect and lack of insight. Changes to personality or behaviour may also occur, either as a result of cognitive impairments or because of emotional difficulties post stroke. Commonly reported changes include; becoming more impatient or irritable, experiencing a loss of confidence and becoming more withdrawn (The Stroke Association, 2005; Fact Sheet 4). A great number of stroke patients experience emotional, cognitive and personality changes following stroke, which can be problematic for the patients themselves and their family members (SIGN 64, 2002).

Since the current study is focused on the emotional and psychosocial impact of stroke on family functioning, a more comprehensive review of this particular literature will follow.

1.3 Psychological implications of stroke

1.3.1. Post stroke depression

Angelelli et al. (2004) assessed individuals in their first year post stroke and compared them to a healthy control group. Their results revealed a wide range of difficulties in the post stroke group, for example depression, irritability, eating disturbances, agitation, apathy and anxiety. Symptoms of post traumatic stress disorder have also been found in individuals in the first year following a mild stroke (Bruggimann et al., 2006).

Depression, however, is considered the most common emotional disorder associated with stroke (House, 1987; Starkstein & Robinson, 1989) and can present a major obstacle to rehabilitation (Gall, 2005; Thomas & Lincoln, 2006). Depression has been associated with a longer length of stay in hospital and increased mortality (Turner-Stokes & Hassan, 2002). Prevalence estimates for post stroke depression (PSD) have ranged from 25 to 79 per cent (Kneebone & Dunmore, 2000). This variation in prevalence rates has been linked to differences in assessment measures, the populations sampled, age differences of participants and time since stroke (Robinson, Starr & Price, 1984; Thomas & Lincoln, 2006; Turner-Stokes & Hassan, 2002). Incidence rates of depression have been recorded as being higher in hospital studies than community studies (Robinson, Schultz & Paradiso, 1998).

Individuals with post stroke depression have been said to experience remission of their symptoms without treatment within the first year following onset (Robinson, 2002). However, other studies have reported that post stroke depression has a chronic course. Frequent and persistent mild depressive symptoms have been found in first time stroke patients up to 18 months post stroke, with male gender being the most significant indicator of negative change in depressive symptoms over time (Berg, Palomaki, Lehtihalmes, Lonnqvist & Kaste, 2003). Berg et al. (2003) concluded that stroke severity and functional impairment were also associated with depression, particularly after the acute stage when patients were becoming more aware of the complexities of their problems post stroke. The greater association between male gender and depression found by Berg et al. (2003) may be linked to age as all participants were under the age of 70. It has previously been suggested that men are more likely to experience depression if they have a stroke when younger and women are more likely to experience depression if they are older when they have a stroke (Burvill, Johnson, Jamrozik, Anderson & Stewart-Wynne, 1997)

A study investigating the frequency of depressive symptoms seven years after the onset of a first stroke found that 20 per cent of stroke patients met the criteria for minor or major depression compared to 11 per cent of patients with an exclusively physical illness, in this instance a prolapsed intervertebral disc (slipped disc). In addition, stroke patients experienced more emotional lability and irritability in the previous seven years than did the participants with the slipped disc (Dam, 2001). However, in the study by Dam (2001) all participants were under the age of 65 and therefore the chronicity of the post stroke depression might be different in older stroke participants.

Depression can have a negative impact on longer term recovery of physical function (Chemerinski, Robinson & Kosier, 2001) and social function (Clark & Smith, 1998). The relationship between depression and functional disability in older adults is complex. Folstein, Maiberger & McHugh, (1977) found that stroke patients were significantly more depressed than orthopaedic patients matched for level of disability suggesting that depression post stroke is not solely linked to adjustment to disability and suggests that it is something specific to stroke itself.

There is evidence of a link between symptoms of depression reported one month post stroke and mortality at 12 and 24 months post stroke (House, Knapp, Bamford & Vail, 2001). The results from the study by House et al. (2001) reported that impaired mood post stroke was an independent predictor of increased mortality, even after controlling for the effects of age, cognitive status and known physical predictors such as previous stroke.

The question of whether a biological mechanism causes post stroke depression remains unclear (MacHale, O'Rourke, Wardlaw & Dennis, 1998). MacHale et al. (1998) found depression was significantly associated with larger lesions involving the right anterior hemisphere. However, they suggest that the wide confidence intervals found in the data might suggest that the significant result may be due to chance. Robinson, Kubos, Starr, Rao and Price (1984) reported an association between depression and left anterior lesions while other studies have found no association between depression and lesion location (Gottlieb, Salagnik, Kipnis and Brill, 2002; Sinyor, Jacques, Kaloupek, Becker, Golderberg and Coopersmith, 1986). Perhaps future research will clarify whether there is such an association and more importantly if this association has any relevance regarding how best to treat post stroke depression in these individuals.

The mixed findings regarding biological mechanisms and post stroke depression have led researchers to query whether PSD is a result of psychological adjustment to stroke, particularly with regards to the increasing prevalence of depressive symptoms over time, which may suggest the heightened importance of psychological adjustment factors rather than organic factors (Berg et al., 2003). Patients with a lowered sense of perceived control over recovery have been found to experience longer lasting depressive symptoms (Thomas and Lincoln, 2006). These authors suggest that the psychological mechanism of locus of control might be related to the coping strategies of an individual and affect whether or not they develop depressive symptoms. Regardless of whether post stroke depression has a biological or psychological causation, perhaps the treatment, as with other types of depressive illness, should be both biological and psychological.

1.3.2 Anxiety symptoms post stroke

Symptoms of anxiety are also common post stroke and are often co-morbid with depressive symptoms. Indeed, anxiety has been associated with a greater severity of depression up to two years post stroke (Schultz, Castillo, Kosier & Robinson, 1997). Castillo, Starkstein, Fedoroff, Price and Robinson (1993) reported that 20 per cent of stroke patients in their study met the criteria for generalised anxiety disorder (GAD) co-morbid with depression and 7 per cent met the criteria for generalised anxiety disorder without associated depression. Anxiety following stroke is often untreated or inappropriately treated at the acute stage and can therefore become chronic (Voelker, 1996; Angstrom, 1996). Similar to depression, anxiety can have a significant negative impact on functional recovery and on people's interaction with their social network as well as impairing the prognosis of any co-morbid depression (Angstrom, 1996).

A gender difference for symptoms of anxiety has been found in some studies with women reporting more symptoms of anxiety and depression during the initial 2 year period following stroke (Schultz et al., 1997). A recent study suggested that gender was not associated with depression, but female gender was consistently associated with higher anxiety up to three years post stroke (Morrison, Pollard, Johnston & MacWalter, 2005). Shultz et al. (1997) reported that younger patients in their study experienced more anxiety symptoms but that no age difference was found for depressive symptoms.

1.3.3 Emotionalism

Emotionalism, or emotional lability, which is uncontrolled laughing or crying, following stroke, can lead to difficulties in assessing for depression. Morris, Raphael and Robinson (1993) reported a prevalence rate for emotional lability post first time stroke at 18 per cent. This occurred independently of post stroke depression.

In summary, depression and anxiety are said to be a frequent consequence for patients post stroke (House, 1987; Schultz et al., 1997; Starkstein & Robinson, 1989). If an individual experiences psychological difficulties post stroke, it can have consequences not only for themselves, but also for others in their family system. Symptoms of anxiety and depression in acute stroke patients have been shown to influence the psychosocial burden on their family members (Fure, Wyller, Engedal & Thommessen, 2006).

As a result of the many factors influencing life for patients post stroke, the rate and degree of recovery for physical and psychological factors is hard to predict. The first 3-6 months following stroke have been said to be most important for recovery of physical function but some recovery has been seen to occur up to 18-24 months following stroke (Laidlaw et al., 2003). The rate and degree of recovery for cognitive and emotional difficulties are less well known.

As the effects following stroke are complex, stroke rehabilitation is usually multidisciplinary, focusing both on improving the stroke patient's physical function and their emotional functioning and quality of life (Baldwin, 2006). Specialist stroke care in stroke rehabilitation units are said to result in better outcomes for patients than stroke care on a general medical ward (Stoke Unit Triallists Collaboration, 1997). However, 'better outcome' may be defined in various ways. Using the framework of the International Classification of Functioning, Disability and Health (ICF WHO, 2001b) stroke rehabilitation aims to maximise the individual's physical activity as well as their participation in social roles in order to enhance their quality of life (SIGN 64, 2002). As quality of life has been deemed an important part of stroke rehabilitation, it is necessary to understand more about how a stroke event may impact on quality of life.

1.4 Stroke and quality of life

There has been conceptual and methodological difficulties related to quality of life research with varied measurements of quality of life being utilised in different studies (Kim Warren, Madill & Hadley, 1999). Glozman (2004) suggests that it is the multidimensional nature of quality of life which makes it difficult to define and that different definitions highlight different aspects of this concept. The current study uses the definition developed by the World Health Organisation Quality of Life Group (WHOQOL group) who define quality of life as

> *'an individual's perceptions of their position in life in the context of their culture and value systems in which they live and in relation to their goals, expectations, standards and concerns'*
>
> (Harper & Power, 1998)

This definition is said to reflect the view that quality of life refers to a subjective evaluation embedded in a cultural, social and environmental context (Harper & Power, 1998).

In recent years quality of life assessment, measuring both physical and mental domains, has become an important measure of outcome for both patients and family members post stroke, perhaps especially as a result of a hypothesised link between quality of life ratings and depressive symptoms (Jonsson, Lindgren, Hallstrom, Norrving & Lindgren, 2005). In a study of Turkish stroke patients, Gokkaya, Aras and Cakci (2005) report that stroke patients had a lower health related quality of life than a healthy control group. They found this difference to be related to those patients in particular with lower functional status, female gender and depressed mood. A study by Kim et al., (1999) reported that depression was the best predictor of low levels of quality of life 1 to 3 years post stroke.

Similar to studies investigating the prevalence of depression and anxiety, gender differences have been examined with regards quality of life post stroke. Kuroda, Kanda and Sakai (2006) recently reported that male stroke patients quality of life scores were significantly higher than women stroke patients in their study. A close relationship was noted between quality of life scores and activities of daily living in both genders. In particular poor walking ability was associated with lower scores for quality of life. The difference between genders in relation to quality of life in this study was suggested to be influenced by the poorer outcome of ADL's and the higher anxiety and depression recorded in women post stroke in their study. Gokkaya et al.

(2005) also found in their study that women reported lower scores for health related quality of life.

King (1996) reported that the stroke patients in her study had a relatively high quality of life up to two years post stroke and the results were comparable to that of a normal population. However, 23 per cent of participants in her study reported dissatisfaction with their quality of life. 30 per cent of participants in this study were depressed and this, along with low levels of social support and poor functional status predicted their low scores for quality of life. Difficulty with physical functioning only explained three per cent of the overall variance of patient's quality of life. Therefore, in this study at least, functional status was not the biggest predictor of a patient's quality of life, rather it was psychosocial factors which appeared to exert a greater influence.

Clarke, Marshall, Black and Colantonio (2002) reported that, compared with healthy community dwelling older adults, the older adults in their study who had experienced a stroke reported a low sense of well being. Functional disabilities and cognitive difficulties reduced their sense of well being while good social support networks were found to moderate the subjective burden they expressed. The authors concluded by stating that social support not only helped the stroke patient in reducing their subjective burden of stroke, but that supportive social systems also indirectly reduce the burden of stroke on the healthcare system. This is an important finding if individuals experiencing stroke do not have good quality, informal social support networks to rely on, then perhaps these individuals will rely more heavily on professional support from the government. A discussion of the influence of social support for stroke patients and their families will take place later in this chapter.

Clarke and Black (2005) utilised a qualitative methodology to assess patient's quality of life post stroke. All participants reported that their lives had changed since their stroke and some respondents reported a reduced quality of life as a result. However, other individuals had found ways to adapt to their functional disabilities and reported a high quality of life. Patients in this study were all over 60 years of age and living in the community. Time since stroke ranged from seven months to nine years, post stroke, which the authors acknowledged as having an influence on the results. Individuals who had their stroke more than six years previously were said to be less focused on the changes stroke had brought into their lives, and tended to be more accepting and less inclined to talk about being frustrated with their lives than those individuals who had their stroke more recent than six years. Clarke and Black (2005) reported that the adaptive processes take time to become evident in people's lives and therefore wondered if people who were less than six years post stroke would have had sufficient time to fully adjust to their stroke in this way. The current study placed a time limit of five years post stroke for inclusion in the study and therefore will go some way to being able to answer Clarke and Black's query about time since stroke and its effect on quality of life.

One of the difficulties apparent in stroke research has been the use of family members or carers as proxies when completing assessments of quality of life. The use of proxies becomes necessary when cognitive and communication difficulties make it problematic to obtain information from the patients themselves (Sneeuw, Aaronson, de Haan & Limberg, 1997). Williams et al. (2006) compared patient and family proxy health related quality of life responses one to two months post stroke. They concluded that the family proxies reported more dysfunction in various aspects of health related quality of life than the stroke patient did themselves. Level of agreement between patients and family members was higher for objective domains like physical functioning and lower for more subjective domains, for example patient's mood. However, Sneeuw et al. (1997) commented that the benefits of using proxy ratings for non-communicative patients far outweigh the limitations. This is a difficult issue to resolve completely. Obviously, if individuals are unable to express their views because of impairment resulting from stroke, it may be better to have a proxy assessment of quality of life than none at all. This is perhaps particularly true within clinical practice when working with stroke patients and their family members but is an important issue for research as well. That said, if family members are in conflict or if the proxy members are experiencing significant depression or burden, as a result of the new family situation (Williams et al., 2006), the proxy assessments may not present a true picture on the patient's behalf. Each individual situation must therefore be judged independently with perhaps additional assessments of family functioning and conflict included to try to minimise any difficulties with proxy ratings.

A recent study in the UK found that although patient's perceptions of their physical health remained low up to three years post stroke, the perception of their mental health was satisfactory at this time (Patel et al., 2006). This study looked at all age groups of people who had experienced first time strokes. The authors reported that health related quality of life assessment was mainly carried out by the patient themselves but that for those who were 'too weak or dysphasic' their carers or close family members completed their assessments. They do not indicate on how many occasions this happened but research has shown that carer perceptions do not always coincide with patient's views. Therefore this may affect the conclusions drawn about the quality of life of stroke patients from this study.

In addition to influencing the patient's quality of life, stroke may also have an impact on the patient's family's quality of life. Schlote, Richter, Frank and Wallesch (2006) assessed family members of stroke patients at admission to inpatient rehabilitation as well as 6 months and 1 year after discharge. Results revealed that family members rated their health related quality of life as lower during their relative's rehabilitation stage, followed by an improvement when their relative comes home but that this was followed by deterioration at one year post stroke. The authors reported that changes in the family member's perceived health-related quality of life suggested that individuals go through different stages while adjusting to the chronic illness of their relative, during rehabilitation and in the first year after discharge. As this study only looked at the first year post discharge, it is difficult to know if this pattern of improvement and deterioration would continue or whether the family member would come to adjust to life with their relative's chronic illness.

Systems theory assumes that any major event affecting an individual within a system will impact on the relationships between all members of that system (Altschuler, 1997). Therefore the physical and mental sequelae after stroke and the family's response to this event can have negative effects on the individual who has the stroke, as well as on other individuals within the family. With this in mind, an exploration of family systems and their response to chronic illnesses such as stroke will follow.

1.5 Family systems

Families are unique social systems. Entry into families occurs by birth, adoption, fostering or marriage and members can only leave through death (Carr, 2006). Similar to any other system, the whole is more than the sum of its parts. Therefore knowledge of an entire family system cannot be gained solely from information regarding individual family members (Carr, 2006). The family has qualities of its own which exist over and above the qualities possessed by its individual members (Neidhardt & Allen, 1993), and the systemic view of the family allows people to have an identity as individuals but also to have an identity as being part of a family. The rules and expectations of being a member of a family are of great importance to the family unit, perhaps especially at times of transition, such as the transition required to adjust to one family member having a chronic illness such as stroke.

Despite the many and varied family structures now evident in today's society, most models still utilise the traditional nuclear family structure as a basis, with other family forms being viewed as a deviation from the norm (Carr, 2006). However, Bengtson (2002), in a paper pertinent to the current study, hypothesised that multigenerational family relations are becoming more important than the nuclear family structure due to population ageing, which is leading to a greater number of four and five generation families (Neidhart & Allen, 1993). Bengtson (2002) suggested that the increase in life expectancy leads not only to strong and resilient intergenerational solidarity within families, but also that for some families, these multigenerational bonds may become more important than nuclear family ties for the well being and support of individual family members. For example, he cites the increasing importance of grandparents to fulfil family functions due to the changes in family structure as a result of divorce and step family relationships.

Erik Erikson (1963) conceptualised a psychosocial theory of human development consisting of 'eight ages of man'. This theory highlighted personal psychosocial crises to be resolved at each of the eight stages, beginning at birth where the main crisis to resolve is that of basic trust vs. mistrust and ending in old age where the search for resolution is regarding that of ego integrity vs. despair (Erikson, 1963). Although addressing an individual's development throughout the lifespan, the emphasis in Erikson's earlier works was on the childhood stages. However, Erikson's wife, Joan Erikson (1997) revised the life cycle and added a ninth stage where the psychosocial crisis to resolve was that of despair and disgust vs. integrity: wisdom. The positive resolution of the eighth stage, in favour of integrity rather than despair has been said to lead to the development of wisdom (Carr, 2006). The emphasis Joan Erikson places on the ninth stage is for less retrospective analyses of one's life and more focus, although not exclusive, on the crises within day to day life. Both Erik and Joan maintained that an individual life cycle could not be fully understood unless it was placed in the appropriate social context, as throughout life, the individual and society are intricately linked (Erikson, 1997). Erikson's model of development focused on an individual's life cycle in relation to their social world and their interactions within it. It was not a model of the development and crises an individual experiences as being part of a family system. However, the individual life cycle will occur in the context of the family life cycle. Models for whole family development have been proposed by other researchers.

The family lifecycle model proposed by Carter & McGoldrick (1999) outlines the main developmental tasks to be completed by the family at each stage of development. This model also has eight stages of development, beginning with experiences within the family of origin and progressing to leaving home, the pre-marriage stage and the childless couple stage. The latter stages of the model include having a family with young children, having a family with adolescents, launching children and ends with the last stage of later life. Of the eight stages of development proposed, the latter three stages of the family lifecycle model make reference to beginning to take responsibility to care for members within the families of origin and dealing with disabilities and death in the family of origin. The model identifies the tasks of later life as, among other things, dealing with the loss of spouse and peers and preparing for death. This useful model highlights the progression of the family throughout the lifespan and for the purposes of this study, highlights the expectation or norm regarding caring for family members with disabilities, especially for members in their later life and older adults being cared for by younger members, thus the cycle continues.

A particular strength of this model in terms of this study is the dual focus on individual and family growth throughout the lifespan. In the last stage of later life, the model assumes that the whole family must adjust to any transitions for the older adult, such as illness and impending death while also benefiting from the wisdom and experience of the elderly (Carr, 2006). This process echoes Erikson's ninth stage. Family members having to deal with disability and illness is regarded as a normal process within the family life cycle rather than being fundamentally different from the norm (Neidhardt & Allen, 1993).

In times of stress, it is their family members that people turn to for physical and psychological protection (Altschuler, 1997). The individual variations in how families cope in times of stress may be a result of the differences in the quality of relationships within families, as these relationships are central to the overall functioning of the family (Carr, 2006). It is assumed that families exhibiting healthy family functioning move from one stage of the family life cycle to the next, adapting their rules, roles and routines in a flexible manner to meet the demands of the subsequent life cycle stage (Carr, 2006). However, it may be that moving from one stage to the next, whether in Erikson's model of individual development or the family lifecycle model, does not occur in a linear fashion.

1.6 Chronic illness and family systems

Stroke can be seen as a post-acute acquired impairment with chronic consequences for an individual's functioning and disability and for family systems (Laidlaw, in press). Stroke therefore requires families to adapt in a short period of time. Issues associated with adaptation include the ability to endure high levels of emotion, to flexibly shift clearly defined roles, to problem solve and to perhaps obtain external supports (Neidhardt & Allen, 1993). Other chronic illness such as Alzheimer's disease and Parkinson's disease are progressive whereas a stroke is not. Families adapting to the former can experience little relief from the constant adaptation and role change required. Indeed the progressive nature of these illnesses can contribute to the strain experienced by family members. Stroke, on the other hand, is a single event requiring a significant readjustment followed by a period of stabilisation and adjustment to any residual impairment (Altschuler, 1997). It has been suggested once the initial adjustment has been made, there is no need for further adjustment to family roles although the family might face exhaustion as a result of living with the effects of stroke (Neidhardt & Allen, 1993), perhaps especially if there is considerable disability resulting from stroke.

Chronic illness creates increased stress and requires adjustment from families (Newby, 1996). There are three hypothesised phases of chronic illness; crisis, chronic and terminal. Rolland (1987) provided a description of each phase and a suggestion of the tasks to be completed by the family at each of these phases. Each phase and their tasks can be seen in table 1.1.

Table 1.1 Phases of chronic illness

Phase	Description of phase	Tasks family have to complete
Crisis	Symptomatic phase preceding diagnosis as well as the beginning of the adjustment period during initial treatment	-Trying to create a meaning for the illness event that maximises preservation of a sense of mastery and competency -Grieving for the loss of the pre-illness family identify -Moving towards a position of acceptance of permanent change - Pulling together to undergo short term crisis reorganisation - Developing a system of flexibility regarding future goals, in the face of uncertainty.
Chronic	Follows the initial diagnosis and readjustment. The time period of this phase varies considerably and consists of the day to day living with the specific characteristics of the chronic illness	-Maintain normal functioning while managing the uncertainty that the chronic illness brings. -Goal for each family member of obtaining maximal autonomy despite the need for dependency and care giving.
Terminal	Begins when death is inevitable	- Grieving - Resolution of grief as the family assumes a life that incorporates the loss

Visser-Meily et al. (2005) reported that when a parent has a stroke, a child's functioning can be affected. These authors found that in the crisis and initial adjustment phase following their parent's stroke, children reported clinical levels of depressive symptoms and exhibited behaviour problems. Those children who experienced problems immediately following stroke, were more likely to be experiencing problems one year post stroke. The authors queried whether this suggested an enduring impact of their parent's stroke. This might be the case, or perhaps a one year time frame was not long enough for the family to have adjusted to life post stroke. In this study, the severity of the stroke seemed to be of minor importance as family routines still had to change as they adjusted to life post stroke. The authors recommended assessing a child's functioning, as well as measuring the healthy parent's depressive symptoms and the quality of the marital relationship as these three factors were found to contribute to family adaptation post stroke. This study highlights the importance of applying a family centred approach in stroke rehabilitation as the event affects everyone in the family, not just the patient.

A family systems approach to stroke recovery suggests that the stroke patient and their family members are part of one inter-related system with pre-existing patterns of relationships, rules, communication styles and roles (Palmer & Glass, 2003). A stroke challenges the whole system and each part of the system must adjust to any effects that the stroke might have.

Most stroke patients will rely on family members to assist them with the physical, cognitive, behavioural and emotional changes commonly associated with stroke. As a result stroke can have a negative impact on members of the patient's family with regards their physical and psychological well being (Han & Haley, 1999; King, Shade-Zeldow, Carlson, Feldman & Philip, 2002), as well as possibly affecting their overall family functioning.

1.6.1 Models of family functioning

A number of models of family functioning have been developed by researchers including the Beavers Systems Model of Family Functioning (Beavers & Hampson, 2000), the Circumplex Model (Olson, 2000) and the McMaster Model (Miller, Ryan, Keitner, Bishop & Epstein, 2000). Each of these models conceptualises family functioning as varying along certain dimensions. All three models are said to focus on the strengths a family may possess rather than deficits, although an absence of strength on any particular dimension indicates dysfunction (Carr, 2000). In addition, all three models have led to the development of assessment instruments, based on one specific model, for use with families both in research and clinical practice.

The two central dimensions of the Beavers Systems Model of Family Functioning are family competence and family style (Beavers & Hampson, 2000). Healthy functioning families are said to adopt a systems approach to relationships, appreciating the interchangability of cause and effect which occurs within systems. Nine family groupings can be developed on the basis of a family's poisitioning along the dimensions of competence and style, ranging from optimal families to severely dysfuntional families (Beavers & Hampson, 2000). Olson's Circumplex model focuses on the dimensions of cohesion, flexibility and communication within family systems. Family cohesion is defined as the 'emotional bonds that family members have toward one another' and it focuses on how the system balances the needs of the individual with the needs of the family system. The flexibility dimension refers to how the family system manages stages of stability and change, and the communication dimension is considered a means of facilitating cohesion and flexibility (Olson, 2000). Based on the circumplex model, extreme (either very high or very low) levels cohesion or flexibility is thought to indicate difficulty with regards family functioning.

Utilising assessment techniques based on either of the above models of family functioning in this research would have provided the researcher with useful information about how families function. However, a previous study comparing the rating scales derived from the above two models, with the rating scale based on the McMaster model revealed that although all scales permitted families to be classified as clinical or non clinical, the McMaster scale provided the greatest detail regarding specific family strengths (Drumm, Carr & Fitzgerald, 2000). In addition to this positive finding with regards the McMaster model, previous studies have utilised the McMaster assessment scales with stroke patients and their family members (Bishop, Epstein, Keitner, Miller & Srinivasan, 1986; Clark & Smith, 1999), suggesting that use of this model as a base to view family functioning with this group is valid.

The McMaster Model of Family Functioning has evolved over a period of thirty years with reformulations of the model appearing over time but the core dimensions remain the same (Miller et al., 2000). The model identifies six dimensions of family functioning.

Table 1.2 The dimensions of family functioning in the McMaster model

Dimension	**Definition**
Problem solving	the families ability to resolve problems
Communication	the exchange of information among family members
Roles	whether the family has established patterns of behaviour for specific family functions
Affective responsiveness	the extent in which family members experience appropriate affect
Affective involvement	the extent in which family members are interested and place value on each other's activities and concerns
Behaviour control	the way families express and maintain standards of behaviour

This model does not imagine any one dimension to be the cornerstone for conceptualising family behaviour, but rather that a more comprehensive picture of the family can be gained from assessing several dimensions of functioning (Epstein et al., 1980). The model utilises a general systems theory approach in an attempt to describe the structure, organisation and transactional patterns of the family unit (Epstein, Bishop & Levin, 1978). Table 1.3 contains the aspects of systems theory underlying the McMaster model.

Table 1.3 The aspects of systems theory underlying the McMaster model

All parts of the family are inter-related
One part of the family cannot be understood in isolation from the rest of the system
Family functioning is more than just a sum of its parts; it cannot be fully understood by simply understanding each individual family member
A families structure and organisation are important factors that strongly influence and determine the behaviour of family members
Transactional patterns of the family system strongly shape the behaviour of family members

Adapted from Miller et al. (2000)

Families are thought to have to deal with basic, developmental and hazardous tasks throughout the lifespan. Basic tasks include the provision of food and shelter. Developmental tasks occur along with family growth and can be divided into individual and family stages. Hazardous tasks include how families respond to crises, such as accidents and illness (Epstein, Bishop & Levin, 1980), and it is these tasks that the current study is focusing on. Families that function well within the key dimensions are thought to be more likely to have fewer problems and be more able to deal effectively with any problems once they arise. It is proposed that healthy family functioning would better enable families to deal with adjusting to chronic illness and disability while ensuring the continuity of meaningful family relationships whereas family dysfunction would potentially exacerbate the difficulties involved in dealing with disability and chronic illness. Indeed a number of previous studies have utilised the McMaster model and in particular the Family Assessment Device instrument with families of patients with chronic illnesses. Studies focusing on stroke patients and their families have illustrated that family functioning, based on the McMaster model, has been shown to predict adherence to treatment following stroke (Evans, Bishop, Matlock, Stranahan, Green-Smith & Halar, 1987), as well as predicting a family's adjustment post stroke (Evans, Bishop, Matlock, Stranahan, Halar & Noonan, 1987). A more thorough overview of family functioning post stroke is detailed in the section below.

1.6.2 Stroke and family functioning

Family function has been said to affect stroke rehabilitation (Palmer and Glass, 2003), treatment adherence (Evans, Bishop, Matlock, Stranahan, Green-Smith & Halar, 1987), and has predicted re-hospitalisation of patients (Evans, Bishop, Matlock, Stranahan, Halar & Noonan, 1987). Prior to a stroke, 25 per cent of families are said to function at a level that may potentially negatively affect stroke outcome and another 25 per cent will fall to this level following a stroke (Bishop & Evans, 1995).

Bishop, Epstein, Keitner, Miller and Srinivasan (1986) assessed stroke patients and their spouses at least one year post stroke and found indications of high levels of morale, general health and family functioning (as measured by the FAD). Their sample did not differ from an age matched community sample. Husbands and wives were found to have similar views about the level of their functioning. The stroke couples did report decreased socialisation (and poor transport) but these specific difficulties did not negatively impact health or family functioning. An increase in time since stroke was correlated with improved family functioning, giving support to the idea that families adjust to life with chronic illness over time as suggested by Rolland (1987).

However, Bishop et al. (1986) assessed couples more than one year after stroke, with a large time scale since stroke onset, ranging from 11 months to 10 years 2 months. The study had a sample size of 22 stroke patients and their spouses. Given the large time scale of the study it makes it difficult to know whether family functioning was good after the initial first year or whether adaptation to stroke took longer than this. If stroke does influence how families function it may be important for those working clinically with stroke patients and their families to know what stage post stroke might be more problematic. The study by Bishop et al. (1986) had a wide age range for patients from 54 to 77 years. The researcher is particularly interested in how older adults and their family members adjust to life following a stroke, however it is difficult to know if Bishop et al.'s (1986), results would be replicated with a solely older adult patient group. Only those patients who had spouses would have been eligible for the study and therefore we do not have any information from patients without spouses, but those who may have children who could have felt an effect of the stroke. The authors suggested that the positive results arising were a result of optimal levels of functioning returning, which was to be expected. They hypothesised that, had couples been assessed earlier the results may have been different. However, the authors chose to exclude all those who were less than one year post stroke in order to minimise the crisis effects of stroke and to maximise the time given for functional ability to return. Therefore, it is impossible to know from the results of this study whether family functioning was affected post stroke in these families or if the positive results would have been found in the first year, post stroke. The current study has included stroke patients who are in their first year post stroke which may provide much needed information about how families function during this crisis period.

Clark and Smith (1999) carried out a longitudinal study charting changes in family functioning over time with a group of stroke rehabilitation patients and their families. Patients were one-year post stroke and family members were 46 spouses, and 25 other family members. Family functioning was assessed using the McMaster Family Assessment Device. Clark and Smith (1999) reported that family functioning deteriorated when patient and family members were assessed one year post discharge. These changes in family functioning were observed in specific areas of functioning, namely within the problem solving, communication, roles, behaviour control and affective involvement sub-scales of the Family Assessment Device. Thus, there was a noticeable deterioration in the family's ability to resolve problems, a lack of clarity in the communications between family members and difficulties adjusting to new roles and responsibilities post stroke.

There were no significant differences between the family functioning ratings provided by patients and their spouses suggesting high levels of agreement between family members. Clark and Smith (1999), highlighted that previous research into family functioning, following onset of a stroke had only asked carers to provide reports on how their family functions. A concern about only asking a family member to act as proxy with regards family functioning is that the patient and family member would not agree in their evaluations of how the family was functioning following a stroke. Although in the study by Clark and Smith (1999) broad agreement was found between family members, they reported that the perceptions of patients and their carers differed over time. Therefore it may be more appropriate to ask both members of the family about their perceptions of how they work and interact together rather than solely relying on one person's perceptions of events. The age range of patients in this study was 43 to 92 years, making it difficult to know if there are any types of family function more difficult for younger or older stroke patient and their families.

A further study by Clark (1999) suggested that family functioning was poorer when the patient developed psychological morbidity, was less satisfied with their recovery, and when the health burden of the stroke was great. Thus, implying that if the patient was less satisfied with their life post stroke, this may have had an effect on the rest of their family, negatively impacting on family functioning.

King, Shade-Zeldow, Carlson, Feldman and Philip (2002) assessed adaptation to life up to two years post stroke. They ascertained that although improvement occurred with regards patient's depressive symptoms, the rate of depression did not change overall. In fact the rate of depression did decrease within the first year but increased again in year two. This result may indicate that there are ongoing difficulties, not necessarily linked to the initial stroke onset but perhaps more to the enduring nature of families living post stroke. Indeed levels of family functioning as rated by both patients and family members were found to become less healthy over the two year period, which may support the hypothesis that living with stroke as a chronic illness caused difficulties for a longer period than the initial year, as was hypothesised by Bishop et al. (1986). An interesting finding in this study by King et al. (2002) was, despite reporting an increase in health problems over time, the majority of stroke participants subjectively rated themselves as being in good or very good health which may suggest the decline in family functioning is not necessarily related to poor physical health as implied by Clark (1999). There were 53 stroke patients included in this study with an age range from 32 to 85 years. Perhaps as a result of this larger sample size, analyses revealed that older age predicted depression post stroke. Previous studies with a smaller sample size and a wide age range may have missed this finding. The current study focuses solely on stroke patients over 65 and therefore will ascertain whether this link between age and post stroke depression will be replicated.

Family relationships can be vehicles for social support. It is widely held that social support decreases the effects of stress (Woods, 1999). Therefore, the researcher thought it beneficial to explore the findings regarding the effect of social support for stroke patients and their families in more detail.

1.7 Stroke and social support

Definitions of social support vary and therefore conceptual difficulties are apparent throughout the literature. Kaplan, Cassel and Gore (1977) defined social support as the degree to which the needs for affection, approval, belonging and security are met by others. Sarason (1987) extended this, claiming that social support is the;

> *'existence or availability of people on whom we can rely, people who let us know they care about us, value us and love us'.*

These definitions focus on the cognitive or emotional element of support, whereas other definitions focus more on the behavioural or practical aspect of support. For example;

> *'being able to count on others when the need arises'* (Turner & Noh, 1983)

Barrera (1981) highlighted the importance of reciprocal relationships and the fact that only social support which is perceived to be effective is effective. A large number of other definitions exist in the literature, between various aspects of social support, although all aspects are said to be subcategories of either emotional or practical support (Barrera & Ainley, 1983). A recent study by Reinhardt, Boerner and Horowitz (2006) found that receiving practical support had a negative impact on older adult's well being, whereas receiving emotional support had a positive effect on well being. This study, with a group of older adults with vision loss may suggest that receiving practical help from people may highlight to patients what they cannot do for themselves. This finding supports a distinction being made between the different components of social support, in order to further understand how social support affects older people's adaptation to chronic health conditions.

A consistent finding in the social support literature has been that the availability of emotional and practical support from family members and friends can greatly enhance an individual's ability to cope with the acute and chronic phases of an illness (Schultz, Tompkins & Rau, 1988). Who supports the support person is therefore also going to be of interest. Previous studies report that one of the most frequent consequences of caring for a frail elder is having to give up or restrict social activities (Horowitz, 1985). These activities are said to be closely related to social support (Woods, 1999) and restricting activities might mean carers losing a vital source of social support. Studies suggest that the needs of stroke patients assume priority within families, therefore social activities frequently become severely restricted and relationships with families and friends may change (Thommessen, Wyller, Bautz-Holter, & Laake, 2001).

Social support has been regarded as the most important modifiable variable for family caregivers (Zarit & Edwards, 1999). However, one study addressing the protective nature of social support against the development of a mood disorder, reported that social support could help prevent the onset of a mood disorder after a stroke. This appeared to be less effective in lessening the severity of a mood disorder that was in existence prior to the stroke (Knapp & Hewison, 1998). This finding may suggest that social support would be an important variable for intervention with some individuals, but not all.

Murphy (1982) reported that the absence of a confiding relationship increases vulnerability to depression in older adults. Higher levels of social support have recently been associated with lower levels of depressive symptoms and higher levels of well being and general health (Grant et al., 2006).

Different role relationships are said to lead to different ratings on measures of actual and ideal support (Power, Champion & Aris, 1988). In addition, different patient groups may have differing problems relating to social support. Lam and Power (1991) found that depressed participants in their study were more dissatisfied with their level of emotional and practical support than non depressed participants. However, age seemed to influence participant's perception of social support. Older participants with depression reported being satisfied with the level of social support they received, as they did not rate their ideal support as higher than the actual support they received. This was in contrast to what has been found with younger participants (Power, Champion & Aris, 1998). Lam and Power (1991) suggest that although older adults may have fewer close relationships than younger adults, they do not appear to be any less satisfied with this situation.

Previous research has shown that social support can protect individuals experiencing negative events and thus prevent many psychological symptoms, including those related to depression. This is known as the stress buffering theory (Cobb, 1976). This theory suggests that the greater the number of support members, the greater the opportunity to be protected, or buffered, from the stressor. However, Power et al. (1988) suggest it is the quality of relationships rather than the quantity that is an important measure of whether support is effective or not.

Some studies have proposed that the support provided by family member relationships is more likely to have an impact on outcome post stroke rather than relationships out with the family. Knapp and Hewison (1998) supported this hypothesis but also found that other social network relationships acted as a protective buffer against depression and anxiety. These authors therefore concluded that it may be as important to maintain friendships with acquaintances following stroke, as it is to maintain the quality of the closest, confiding relationships. This study by Knapp & Hewison (1998) provided support for the buffering effect of social support post stroke.

A study by Glass, Matchar, Belyea and Feussner (1993) reported that level of perceived social support significantly predicted change in functional status in a sample of older, first time stroke survivors. Specifically, higher levels of social support predicted a more rapid rate of recovery and a greater amount of improvement overall, even in individuals who had experienced severe strokes. Additionally, those participants who reported low levels of social support appeared to decline in functional status over time. This latter finding was found to occur in the context of milder stroke, perhaps, as the authors suggested, because friends and family members underestimated the patient's need for support following a mild stroke.

Other studies on the importance of social support following stroke have been carried out but have mainly focused on the availability of caregivers for stroke patients. The current study is not a caregiver study, but rather is interested in the impact on all family members, whether providing care or not. The researcher did not want to include studies carried out with caregivers of stroke patients, as the findings of these studies may differ from how stroke impacts on family members not providing care. In the letter inviting people to participate in the study, older adults were prompted to ask the family member whom they felt closest to and who they saw often, provided they were over the age of 18. Nevertheless, although the current study does not have caregivers as its main focus there is much in the caregiving literature that is applicable to family members of individuals who experience a stroke, due in part to the fact that it is usually members of a patient's family who act as caregiver. With this in mind, the researcher wanted to complete the literature review by presenting a broad overview of some of the significant findings from the caregiver literature as it applies to families post stroke.

1. 8 Caregiver stress and burden

Caregiving develops in the context of ordinary family relationships but the pattern and process of caregiving is subject to individual variation within families. Some caregivers adapt successfully to chronic debilitating conditions whereas others are said to become increasingly burdened (Aneshensel, Pearlin, Mullan, Zarit, & Whitlach, 1995). Caregiver burden is a complex construct with many studies using different measures to assess burden. Vitaliano, Russo, Young, Becker, & Maiuro (1991) distinguishes between objective and subjective caregiver burden, with the former relating to the demands and disruptions caused by caregiving and the latter referring to the distress experienced. Cousins, Davies, Turnball and Playfer (2002) suggest that 'caregiver burden' is a psychological concept and therefore there can be clear individual differences in outcomes in what may appear similar caregiving situations. Rather than a direct link between situation and outcome, they suggest that a caregiver's appraisal of their caregiving situation has a mediating effect on their psychological well being. Caregiving situations share some commonalities but each individual situation is also unique to the family in which the caregiving situation occurs. Caregiving for a disabled elder has been identified as one of the most stressful and disruptive events in the family life cycle (Zarit & Edwards, 1999) and it has been suggested that approximately one third of family caregivers will experience difficulties with psychological adjustment over time (Hodgson, Wood & Langton-Hewer, 1996).

Caregiver strain has been found in stroke studies, irrespective of whether the stroke patients were living at home, in the hospital or in another setting (Bugge, Alexander & Hagen, 1999). Depression is also very common in people caring for stroke patients (Han & Haley, 1999). Indeed some studies report a higher rate of depression and a lower reported quality of life in carers, than in their family member who experienced the stroke (Berg, Palomaki, Lonnquist, Lethihalmes & Kaste, 2005, Rees O'Boyle & MacDonagh, 2001)). In some cases, depression may be associated with factors to do with their family member, for example if the stroke patient is severely dependent or emotionally distressed themselves as a result of stroke (Dennis, O'Rourke, Lewis, Sharpe & Warlow, 1998). Other studies have found depression to be associated with carer characteristics, for example, having a negative orientation towards solving problems, a lack of caregiver preparedness and impaired social functioning (Grant et al., 2004). Caregiver depression has been associated with poor response in rehabilitation for the stroke patient (Scholte op Reimer, de Haan, Pijnenborh, Limburg, & van den Bos, 1998), and higher levels of depression in the patient (Carnwath & Johnson, 1987).

The negative implications of caregiving have been well documented. More recently however, research into the positive side of caregiving has been carried out. In a study by Cohen, Colantonio and Vernich (2002), 70 per cent of respondents reported positive feelings about caring and these positive feelings about caring were found to be significantly related to less caregiver depression and burden. Other studies have also reported that caregiver burden and anxiety can gradually decrease, despite no change to patient dependency (McCullagh, Brigstocke, Donaldson & Kalra, 2005). The authors suggested this finding may indicate a shift towards normalisation of the situation in time.

Some or all of the findings from caregiver studies may be replicated in studies concentrating on the impact of stroke on family. However, the researcher is of the opinion that by solely focusing on these individuals providing care to stroke patients, valuable information about how stroke affects the rest of the family may be lost. The current study chose, as its focus, stroke patients over 65 and one family member whom they nominated to take part. It was hoped that this would allow a comprehensive picture of the impact of stroke from both the perspective of the patient themselves and a close family member. The particular research aims and hypotheses of the study are detailed in the section below.

1.9 Research aims, questions and hypotheses

1.9.1 Research aim

The main aim of the study was to ascertain whether family functioning was different in families where one member had had a stroke. Family functioning can be defined as a measure of how well families interact and work together. The study was interested in how a stroke would impact on life within the family system. In order to do this, the study looked at the subjective perceptions of life from the perspective of older adult stoke patients (aged over 65) and one of their family members. A community group, of older adults without stroke and their family members, was utilised as a comparison control. Increased knowledge about the psychosocial consequences of stroke for this age group is necessary to inform the clinical management of stroke patients and their families.

1.9.2 Research questions and hypotheses

The research question underpinning this study is what impact a stroke has on the lives of older adults who experience stroke and their family members. In order to answer this question the researcher wanted a comprehensive view of what life was like for this group of people. In addition to looking at two family members' perceptions of how their family functions post stroke, it was also of interest to the researcher to investigate how a stroke event might have impacted on individual functioning, with particular reference to perceived quality of life, perceived social support and current mood. The researcher was interested in these individual characteristics as possible contributory factors which affect how the family functions as a whole. Both the stroke patient and their family member were assessed for each of these variables. It was expected that if the stroke patients themselves or their close family members experienced difficulties in any of these individual domains this would significantly contribute to problems for their individual and family functioning.

Hypothesis 1. Older adults and family members in the stroke group will have higher scores on the family functioning measure than older adults and family members in the control group (higher scores indicate poorer family functioning).

Hypothesis 2. Control group participants (older adults and family members) will report increased levels of quality of life compared to those from the stroke group.

Hypothesis 3. There will be a lower perceived social support in the stroke group (older adults and family members) compared to the control group.

Hypothesis 4. There will be a higher incidence of depression and anxiety in older adults and family members from the stroke group compared to the control group.

Chapter 2: Methodology

2.1 Design

A cross sectional independent group design with two groups was employed. The experimental group (hereafter referred to as the stroke group) comprised older adults (>65 years) who had experienced a stroke, and one family member. The comparison control group comprised of healthy older adults who had never had a stroke, and one family member. The purpose of the design was to examine group differences in relation to family functioning, quality of life, perceived social support and mood in the context of cerebrovascular accident. All participants completed five self report questionnaire measures relating to the above variables.

2.2 Participants

2.2.1 Stroke group; older adult participants

Twenty eight individuals who had experienced a stroke within the last five years were recruited from local health and voluntary services, within the Highland region of Scotland. The researcher initially met with nurses from the voluntary organisation, Chest, Heart and Stroke Scotland (CHSS-Highland Branch) and latterly with members of staff from the Stroke Unit in Raigmore Hospital, Inverness, the York Day Hospital, Inverness and Speech and Language Therapists from the Ross-shire area of the Highlands to discuss the purpose and design of the study. All three CHSS nurses covering Highland and several NHS Highland employees agreed to tell suitable patients about the research and ask if they could pass their details on to the researcher who would then provide them with further information about this study. One hundred and three older adults were referred to the study and twenty eight agreed to take part and met criteria for the study. The average age of the stroke group older adult participants was 75 years (standard deviation of 6.4 years) with an age range of 65 to 90 years.

2.2.1.1 Stroke group; family member participants

Older adults agreeing to participate in the stroke group were asked to nominate a family member to participate also. They were asked to nominate the family member they felt closest to and whom they saw often. Thus, there were twenty eight family members recruited to the stroke group with an average age of 67 years (standard deviation of 11.3 years) and an age range of 37 to 84 years.

2.2.2 Control group; older adult participants

A group of older adults, who had never had a stroke, were recruited from local community groups from Inverness and Ross-shire. The researcher initially met with representatives of Contact the Elderly (Highland Branch), a Bowling club (Ross-shire) and a Senior Citizens group (Inverness-shire) to discuss the purpose and design of the study and request to speak to members of their respective community groups in order to identify potential participants for this study. The researcher then attended eight groups within the community to explain the nature and purpose of the study and answer any questions about the study. Each individual attending the group was presented with an information sheet about the study at this time. The researcher then attended all eight community groups on a second occasion to invite people to participate in the study. One hundred and twenty seven healthy older adults were asked to participate in the study and twenty eight agreed and met the criteria for the study.

The average age of the control group older adult participants was 73 years (standard deviation of 5.8 years) with an age range of 65 to 85 years.

2.2.2.1 Control group; family member participants

Older adults agreeing to participant in the control group were asked to nominate a family member to participate also. They were asked to nominate the family member they felt closest to and whom they saw often. Thus there were twenty eight family members recruited to the control group with an average age of 54 years (standard deviation of 17.6 years) and an age range of 27 to 83 years.

2.2.3 Inclusion and exclusion criteria

Older adult participants in both the stroke and control groups had to satisfy the following inclusion and exclusion criteria. They had to be aged 65 years and above, live in the community in the Highland region, be able to give written consent and have a family member, over the age of 18, also willing and able to take part in the research. Additionally, the older adults in the stroke group had to have had only one stroke within the last five years. All participants were unpaid volunteers. Individuals who had a transient ischemic attack or a stroke more than five years ago, those with dementia or severe mental illness (for example psychosis) and individuals who did not have a family member willing to take part were excluded from the study. Twenty four older adult participants were excluded based on these criteria.

2.3 Measures

All older adult and family member participants were asked to complete five self report questionnaires on one occasion only. These were;

- A demographic questionnaire (appendices 1 & 2)
- The Family Assessment Device (FAD) (Epstein, Baldwin & Bishop, 1983) (appendix 3)
- World Health Organisation Quality of Life Short Measure (WHOQOLBref) (The WHOQOL Group, 1998) (appendix 4)
- The Significant Others Scale (SOS) (Power, Champion & Aris, 1988) appendix 5)
- Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith, 1983) (appendix 6)

Details of all the above measures follow.

2.3.1 Demographic Questionnaire (appendices 1 & 2)

Participants were asked to complete a questionnaire regarding demographic information on gender, age, marital status, level of education attained, occupation, living arrangements and the nature and quality of their relationship with the family member also completing the questionnaires. The demographic questionnaire used in this study is based on the device used in a large multinational quality of life study (Power, Quinn, Schmidt & the WHOQOL –OLD Group, 2005). In addition, information regarding subjective and objective health status was collected as participants were asked to say whether they considered themselves currently healthy or unhealthy and were also asked to provide details of any medical conditions they had as well as any medication they took for medical conditions. Participants were also asked

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to rate whether they (if they were the older adult participant) or their older adult family member (if they were the family member participant) had experienced any changes to their memory, ability to concentrate, problem solving or speech ability as well as other personality changes, for example if they were more irritable or impatient. These questions asked about changes occurring since their stroke (group A; stroke patient group) or since the start of 2006 (group B; community control group). Participants were all asked whether they had had a stroke and if so, the date of their stroke.

2.3.2 Family Assessment Device (FAD) (Epstein, Baldwin & Bishop, 1983) (see appendix 3)

The FAD was developed to measure how families interact, communicate and work together. It has been widely used in clinical and research domains. Internal reliability and validity has been established in previous research (Epstein et al., 1983). In addition it is said to have moderate correlations with other self report measures of family functioning which provides concurrent validity for the scale (Miller, Epstein, Bishop & Keitner, 1985), as well as discriminative validity, demonstrated by clinician ratings, good test-retest reliability and low correlations with social desirability (Miller et al., 1985). The FAD has been widely used in stroke research (Gresham et al., 1995), and found to be a reliable and valid instrument with this population. It is regarded as one of the most researched family assessment tools available (Ridenour et al., 1999).

The Family Assessment Device is a 60 item scale which measures overall family functioning in seven key areas, one measuring general family functioning and six measuring the six dimensions of the McMaster Model of Family Functioning (Epstein et al., 1980). This model is based on a systems approach and state that the six dimensions of family functioning are problem solving, communication, roles, affective responsiveness, affective involvement and behaviour control. These dimensions are said to be consistently found by researchers and clinicians to be associated with healthy family relationships (Epstein, Baldwin & Bishop, 1993; Olson et al., 1989). Additionally, factor analyses have confirmed that the structure of the FAD corresponds well to the theoretical structure hypothesised by the McMaster model of Family Functioning (Kabacoff, Miller, Bishop, Epstein & Keitner, 1990).

Participants were asked to read 60 statements about families and rate their level of agreement or disagreement with each item, on a four point Likert scale ranging from 'strongly agree' to 'strongly disagree'. Each of the 60 items corresponds to only one of the seven scales. Each individual item is given a value of 1 to 4, with higher scores indicating increasing dysfunction. Items on the FAD depict both healthy and unhealthy family functioning but the scoring system transforms unhealthy items into positive ones. When all the scores are summed and averaged, each of the seven scales has a scale score ranging from 1 (healthy) to 4 (unhealthy). Participant's scores then indicate a level of family functioning for each of the seven scales, expressed numerically where a higher number indicates poorer family functioning. The questionnaire can be self or verbally administered.

Miller et al. (1985) provided clinically derived cut off scores to indicate which scores are in the healthy or unhealthy range for each of the seven scales. These clinically derived cut off scores are said to have adequate sensitivity and specificity (Miller et al., 1985). Descriptions of the seven scales and the cut off scores for each scale are shown in table 1. Scores at or above the cut off on any particular scale suggests dysfunction.

Table 2.1 The Family Assessment Device: Description of Scales & Cut Off Scores

Scale;	**Measures;**	**Cut off;**
Problem solving	The family's ability to resolve problems at a level that maintains effective family functioning	2.2
Communication	Whether communication in the family is clear and direct or indirect and vague	2.2
Roles	The extent to which families have established patterns of behaviour for handling family tasks	2.3
Affective Involvement	The degree to which family members are involved and interested in the activities of other family members	2.1
Affective Responsiveness	The ability of family members to respond to a range of situations with appropriate quality and quantity of emotion	2.2
Behaviour Control	The ways in which a family expresses and maintains standards of behaviour for family members	1.9
General Functioning	Overall health of the family	2.0

Miller, Epstein, Bishop & Keitner, 1985

2.3.3 World Health Organisation Quality of Life – Revised (WHOQOL-Bref) (The WHOQOL Group, 1998) (appendix 4)

The WHOQOL Bref measures participants' perceived quality of life. The World Health Organisation Quality of Life Assessment, the WHOQOL 100 was developed simultaneously in 15 international field centres in order to develop a reliable and valid assessment of quality of life that is applicable across cultures (The WHOQOL Group, 1998). The WHOQOL Bref is a 26 item abbreviated version of the WHOQOL 100 and was developed using data from the field trial of the WHOQOL 100 (Harper, Power & the WHOQOL group, 1998).

Both the WHOQOL 100 and the WHOQOL Bref generate four domain scores. These domain scores relate to physical health, psychological health, social relationships and environment. 24 items from the WHOQOL Bref make up the four domains, one item from each of the 24 facets contained within the WHOQOL 100. These 24 facets can be seen in table 2 below. The remaining two items ask about overall quality of health and general health. The questionnaire can be self administered or verbally administered and measures quality of life within a time frame of two weeks. Three of the 26 questions are framed negatively so are reverse scored. Scores for each item are summed to give a total score for each domain. These raw scores are then converted to a score between 0-100 where a higher number indicates a better-perceived quality of life (WHO, 1996).

Domain scores on the WHOQOL Bref have been shown to correlate highly with the WHOQOL 100 domain scores (0.89 or above) (based on a four domain structure), indicating good convergent validity (Harper, Power & The WHOQOL Group, 1998). The WHOQOL Bref is recommended for use in research when quality of life is only one of the variables of interest and therefore using the WHOQOL 100 may be considered too lengthy for practical use (Harper et al., 1998). The WHOQOL Bref is said to have good discriminant validity, content validity, internal consistency and test-retest reliability (Harper, Power & the WHOQOL Group, 1998). More recent studies have confirmed that the WHOQOL Bref has good reliability and validity and conclude that it is a cross culturally valid assessment of perceived quality of life (Skevington, Lofty, O'Connell & The WHOQOL Group, 2004).

Table 2.2; Facets of WHOQOL Bref Domains of Quality of Life

Domain	**Facets incorporated within domain**
Physical Health	Pain and discomfort Sleep and rest Energy and fatigue Mobility Activities of Daily Living Dependence on medicinal substances and medical aids Work capacity
Psychological Health	Positive feelings Thinking, learning, memory and concentration Self-esteem Bodily image and appearance Negative feelings Spirituality/religion/personal beliefs
Social Relationships	Personal relationships Social support Sexual activity
Environment	Freedom, physical safety and security Home environment Financial resources Health and social care: accessibility and quality Opportunities for acquiring new information and skills Participation in and opportunities for recreation/leisure activity Physical environment (pollution/noise/traffic/climate) Transport

Harper, Power & the WHOQOL Group, 1998

2.3.4 Significant Others Scale – Short Form (SOS) (Power, Champion & Aris, 1988) (appendix 5)

The Significant Others Scale is a measure of perceived social support. It measures the different functional resources of social support that may be provided by a number of significant role relationships within an individual's social network. It examines the quality of an individual's most significant relationships and focuses on the individual's perception of support received. Crucially the SOS asks participants to rate their perception of the actual support they receive as well as their ideal level of support from the significant people in their network. The authors of this scale suggest it is often the discrepancy between these two scores which can be the most revealing (Power et al., 1988).

The Significant Others Scale was originally developed by Power et al. (1988) in order to assess five emotional and five practical support functions in 12 people. There is also a SOS Short Form, developed to assess two emotional, and two practical support functions in 7 people. Additionally, there are also two versions of the SOS available; SOS(A) in which all 7 individuals are specified on the questionnaire and SOS(B) in which the respondent selects the key individuals to be rated. Version B was used in this study with participants asked to name three people who were significant in their life. The authors suggest asking a minimum of seven key relationships in an individual's life. However due to social support being only one of the variables of interest in this study, a maximum of three possible relationships was chosen. This follows the advice of Power et al. (1988) who advocate the use of the short SOS when there are several measures to be administered.

Each participant was asked to rate each relationship against each of the four support functions on a 7 point Likert scale, where 1 indicates never (gives this type of support) and 7 indicates always (gives this type of support). Raw scores are then summed to give scores for emotional support, practical support and overall social support (emotional and practical combined) for each significant relationship. In addition, scores can be summed and averaged to give a mean score for each type of support for that participant. In all cases, the higher the number, the more actual or ideal support perceived. With regards emotional, practical and overall social support, scores are provided for actual support perceived, ideal support wished for and the resultant discrepancy between these scores. Again these can be seen for individual relationships or across a person's social network.

The SOS has been shown to have good criterion group validity and test-retest reliability (Power et al., 1988). It has been used widely in research with a variety of medical, clinical and non-clinical populations (Cresswell et al., 1992; Lam & Power, 1991; Lovestone & Palmer, 1993; Power, 1988; Tiller et al., 1995)

2.3.5 Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith, 1983) (appendix 6)

The HADS comprises of two subscales, measuring anxiety and depression, within one questionnaire. The scale comprises 14 items, 7 addressing anxiety symptoms and 7 addressing depressive symptoms. All items are rated on a scale of 0 to 3 with higher scores indicating increased severity. The scores for the 7 questions are then added to give two separate scores for depression and anxiety. It can be self or verbally administered and measures a time frame of one week.

The HADS is commonly used in both clinical and research domains and has been found to be a reliable instrument for detecting states of depression and anxiety. The anxiety and depressive subscales are also valid measures of the severity of the emotional disorder (Zigmond & Snaith, 1983). It is said to have good discriminant validity, internal consistency, and good to very good concurrent validity (Bjelland, Dahl, Tangen Haug & Neckelmann, 2002). It has been used in the context of stroke and found to be a valid instrument for use with population (Johnson et al., 1995; O'Rourke, MacHale, Signorini & Dennis, 1998). In addition, it does not ask about somatic symptoms thus making it useful for an older population who may suffer physical symptoms not related to anxiety. It looks instead at the emotional and cognitive aspects of anxiety while the depression subscale focuses largely on the concept of anhedonia (loss of pleasure). The HADS is thought to correctly assess the symptom severity and caseness of anxiety disorders and depression in psychiatric and primary care populations as well as the general population (Bjelland et al., 2002, Flint & Rifat, 2002).

2.4 Ethical Approval

Ethical approval was granted for this study by the Highland Research Ethics Committee on May 24th 2006 (appendix 7). In addition, approval was given by the Highland Research and Development department (appendix 7a). Initially, the researcher had solely approached the CHSS nurses to access potential participants. However, this approach resulted in low numbers of participants being referred to the study. Given this challenge to recruitment, the researcher approached the Highland Research Ethics Committee to propose a change to the search criterion for the study. The amendment consisted of asking staff members within the National Health Service to identify possible participants for the study. This approval was granted on October 4th 2006 (appendix 7b).

The main ethical considerations for this study were potential distress to participants, heightened scores for anxiety and depression, confidentiality and informed consent. Each of these issues were considered and addressed to ensure that this study was carried out to the highest ethical standards expected by both the University of Edinburgh and the British Psychological Society code of conduct. Further details about each of these issues are highlighted in the procedure section below (section 2.6).

2.5 Preparation of Questionnaires and Pilot Study

Before any participants were approached, the researcher met with the Stroke Nurse for Inverness and the Deputy Director of Advice and Support from the Chest, Heart and Stroke Scotland organisation in order to discuss the layout and structure of the questionnaires in detail. The discussion centred on changing the layout of the questionnaires to make them more accessible for patients with aphasia. Following this meeting, the researcher modified each questionnaire in accordance with the style utilised by the Chest, Heart and Stroke organisation for their literature. Examples of the changes are; highlighting important information in colour and including pictures to aid comprehension. In addition, all documentation was increased from 12 to 14 font in order to maximise readability for individual's with a possible visual impairment.

A pilot study was carried out to identify exactly how long it would take participants to complete the five questionnaires, in addition to using the pilot to identify any issues previously not envisioned by the researcher, with particular relevance for understanding instructions and materials.

Four participants known to the researcher took part in this pilot, comprising two older adults (1 male, 1 female) age 68 and 65 respectively and two nominated family members (1 female, 1 male) age 62 and 63. Participants took between 25 and 60 minutes to complete the questionnaires, with a mean of 41 minutes. This data was incorporated into the information sheet for potential participants for the study proper (appendix 8). The data collected from the pilot study was not utilised for the analysis but rather information regarding the layout and structure of the questionnaires was utilised to highlight any changes to be made before the main study began.

2.6 Procedure

The following section of this chapter outlines procedural information necessary to permit a replication of this study. This section contains information about how participants were contacted by study personnel and allows an understanding of the procedures that were used with participants.

2.6.1 Implementation of Research Protocol.

2.6.1.1 Stroke group

The researcher met with relevant members of staff from the health and voluntary organisations covering the geographical regions in the Highlands (Inverness-shire, Ross-shire, Caithness and Sutherland, and Lochaber) to discuss the project and clarify their understanding of the research purpose and design. Each staff member identified potential families for participation in the project based on the research inclusion/exclusion criteria (see appendix 9) and sent a referral form containing details of interested parties to the researcher (see appendix 10). Family member participants were recruited via nomination by their older relative when they were considering taking part. Suitable patients referred to the study for inclusion, as stroke group participants, either met with the researcher or were posted the relevant information about the study. Each individual family chose which method they would prefer. Either in their home or by post, both the older adult and family member participants were given a letter inviting them to participate (appendix 11), an information sheet detailing the nature and purpose of the study (appendix 8) and a consent form (appendix 12) indicating that they understood the nature and purpose of the study and that they agreed to take part. Upon receiving consent, each participant was given a pack containing the five questionnaire measures. If the participants were sent the questionnaires packs by post they were given a stamped addressed envelope in which to return them.

2.6.1.2 Community Control Group

Relevant groups were identified through local sources and consent to approach groups was sought from the individual management bodies for these groups. The researcher attended eight group meetings on two occasions, initially to introduce the study, answer any questions about taking part and give people a letter inviting them to participate (appendix 11) as well as an information sheet (appendix 8) and a consent form (appendix 12). A second visit was arranged to provide interested parties with packs of questionnaires for themselves and their family member. All participants in this group completed the five questionnaires at home and returned them in a stamped addressed envelope provided. Unfortunately, the time scale of each of the community groups precluded people being able to complete the questionnaires with the researcher present but all were told that they could contact the researcher with any questions and that she would be happy to visit people in their homes in order to aid completion of the questionnaires.

All participants were thanked for their participation and informed that they could obtain a summary of the findings by contacting the researcher at the end of February 2007.

2.6.3 Potential Distress to Participants

It was considered that some participants might experience discomfort while completing the questionnaires due to the potentially sensitive issue of discussing the impact of illness on their family or just discussing their family in general, particularly if family conflict was apparent. All participants were provided with contact details for the researcher who was available to offer advice and support and discuss any issues arising, either during or directly after participation if present or by telephone contact. In addition, participants were advised that they could stop completing the questionnaires at any time if they became distressed.

2.6.4 Elevated scores of emotional distress

Another possibility was that older adults or their family members in either the stroke or control group would have elevated scores on the depression or anxiety questionnaires. All participants were given an information sheet before taking part in the study with the advice that if anything contained in the questionnaires highlighted any issues for them, they had the opportunity to discuss this with the researcher. The researcher offered to either provide support herself or direct participants to appropriate professional support should they wish or need it. In the event of ascertaining an individual had elevated scores of anxiety and/or depression (defined as score of more than 11 on the HADS, indicating moderate-severe level of anxiety or depression), the researcher informed the participant of her concern and advised the participant to seek support. If the participant refused then their wishes were respected, however contact details for the researcher were provided in the event that they wanted to discuss this further.

2.6.5 Confidentiality

The confidential nature of participating was emphasised on the information sheet each participant was given. In addition, each older adult-family member dyad was given a single identification number in order to ensure anonymity while still linking the family members together. Participants were given the label 'OA' (older adult) or 'FM' (family member) along with the number to identify which member of the dyad had completed which pack. All consent forms containing individual's names, addresses and identification numbers were stored in a locked cabinet in the Department of Psychological Services, New Craigs, Inverness. The numbered questionnaires were stored separately. No identifiable information was entered onto a computer database, therefore ensuring strict confidentiality.

2.6.6 Informed consent

All participants were required to provide written, informed consent prior to participating in this study. It was important that participants understood the nature and purpose of the study they were taking part in, as well as being fully aware that their participation was voluntary and that they could withdraw at any time, without explanation. Potential participants were given time to digest this information before being asked to complete any questionnaires. This allowed time to consider whether they wanted to participate and also provided them with the opportunity to discuss the study and seek further information. The voluntary and non–detrimental effect of choosing to participate in the study was emphasised and all potential participants were asked to sign a written consent form participating in the study.

2.7 Sample size estimation

Cohen's tables (1992) were used to determine the sample size necessary to detect a large effect size using independent t-tests at a power of 0.8 with an alpha of 0.05. This revealed that a sample of twenty six in each group was required to ensure the study had sufficient statistical power. Equal numbers were obtained, with 28 participants within each of the four groups.

2.8 Approach to Analysis

Data analysis was carried out using SPSS for Windows (version 10). The demographic characteristics of the sample were explored prior to conducting formal statistical analyses. Analysis of the data was undertaken using parametric methods thus independent t-tests were used for between group comparisons. However, on the occasions when the data deviated significantly from the assumptions of normality and equal variance, the non parametric counterpart of the independent t-test, the Mann Whitney U test was used in its place. All comparisons compared the older adults in the stroke group with the older adults in the control group and compared the family members in the stroke group with the family members in the control group. The analysis of the data was guided by the aims and research questions of this study therefore analyses was not completed comparing all four groups as the results would be meaningless for this study.

Chapter 3: Results and analyses

The analytical strategy will be presented initially, followed by an assessment of the descriptive characteristics of the sample. Following this preliminary exploration, the data will be examined in line with the main hypotheses using independent t-tests as the main statistical analysis.

3.1 Analytical strategy

Within the stroke and the community control group, four separate sub groups exist. For the purposes of this study the researcher is interested in how older adults who have a stroke compare to older adults who have not had a stroke and how family members of someone who has had a stroke compare to members of families where no one has had a stroke. Therefore all exploratory analysis and hypothesis testing was carried out using separate comparisons between the older adults in the stroke group and the older adults in the control group and between family members in the stroke group and family members in the control group. The only exception to this is when exploring relationship factors within families. Other than relationship factors there are no comparisons which look at all four groups together.

Independent t-tests were used to identify any differences between the two groups (stroke group and community control group). An important assumption underlying the use of the independent t-test is that the data does not deviate significantly from the normal distribution. All data was therefore checked for normality by utilising the Kolmogorov-Smirnov and the Shapiro-Wilkes tests of normality. However, Field (2005) suggests that a significant result from the Kolmogorov-Smirnov and Shapiro-

Wilkes test does not necessarily tell us whether the deviation from normality is large enough to bias any statistical procedures. Field therefore suggests looking at the data in more detail to try and assess the extent of non-normality. The researcher therefore undertook further exploration of the assumption of normality by evaluating the extent of skewness of the data. The skew index was divided by its standard error and if the result was less than 1.96, the data was deemed to be within the bounds of normality necessary for utilising parametric tests. However, if the results of the skew index divided by its standard error was greater than 1.96, this suggested a significant deviation from normality. In these instances, the non-parametric counterpart of the independent t-test, the Mann Whitney U test was performed. Unless stated in the text, the data met the assumption of normality.

Another important assumption underlying the use of t-tests is the assumption of homogeneity of variance. The independent t-test is said to be fairly robust when there are equal numbers in each condition and therefore a violation of this assumption is not considered too severe (Dancey & Reidy, 2004; Kinnear & Gray, 2000). However, results from the independent t-test provide data for Levene's test of homogeneity of variance which reports an F-ratio and two test statistics with different degrees of freedom. If the assumption of homogeneity of variance is violated, as seen by Levene's F-ratio, this violation is corrected by reporting the test statistic with the adjusted degrees of freedom, which does not assume equal variance. Unless stated in the text the data met the assumption for homogeneity of variance.

3.2 Sample characteristics

3.2.1 Whole Sample Participants

Two hundred and thirty people over 65 were invited to take part in the study. Fifty six older adults agreed to take part in the study, giving a response rate of 24 per cent. In addition, fifty six family members of the older adults agreed to take part. Thus, the total sample in this study comprised one hundred and twelve individuals. This low response rate occurred as a result of individuals being excluded from the study on the basis of the inclusion and exclusion criteria as well as people declining participation.

3.2.2 Stroke group

One hundred and three individuals over 65 who had experienced a stroke within the last five years were invited to take part in the study. Twenty eight individuals agreed to take part, giving a response rate of 27 per cent. To be eligible for participation in the study, these twenty eight people were asked to nominate a family member to take part in the research also. This gave a total of fifty six in the stroke group.

3.2.3 Community control group

One hundred and twenty seven individuals aged over 65 who had never had a stroke were invited to participate in this study. Twenty eight people agreed to take part, a response rate of 22 per cent. In addition, twenty eight family members were nominated to take part, thereby increasing the number in this group to fifty six in total.

3.3 Demographic characteristics

3.3.1 Stroke group

With regards the twenty eight older adult participants in this group, there were sixteen males (57%) and twelve females (43%) The mean age of the stroke participants was 75.00 years (SD, 6.4; range 65 -90). The median age of the stroke participants was 76 years and the modal age was 77 years. Neugarten (1974) coined the terms 'young old' and 'old old' to represent different age bands within the older adult population. Within this group twelve older adults (43%) were between the age of sixty five and seventy four (young old) and sixteen older adults (57%) were over the age of seventy five (old old). The time elapsed since having a stroke was on average 14.7 months (SD, 12; range 2 - 61).

The family members in the stroke group consisted of twelve males (43%) and sixteen females (57%) The mean age of the family members in this group was 66.90 years (SD, 11.3; range 37 -84). The median and the modal age of family members was 70 years old. Eleven family members (39%) were aged sixty five to seventy four (young old), nine (32%) were over the age of seventy five (old old) and eight (29%) were younger than sixty five. Further demographic information for both the older adults and the family members in the stroke group can be seen in Table 3.1.

3.3.2 Community control group

With regards the twenty eight older adult participants in the healthy control group there were eleven males (39%) and seventeen females (61%). The mean age of the control group participants was 73.10 years (SD, 5.8; range 65 -85). The median age of the stroke participants was 72.50 years and the modal age was 75 years. Sixteen older adult participants (57%) were in the young old category and twelve (43%) were in the old old category.

The family members in the control group consisted of 10 males (36%) and 18 females (64%) The mean age of the control group participants' nominated family members was 54.30 years (SD, 17.6; range 27 - 83). The median age of the stroke participants was 52 years and the modal age was 36 years. Two family members (7%) in this group were young old, six family members (21%) were old old and twenty (71%) were under the age of sixty five. Further demographic information for both the older adults and the family members in this group can be seen in Table 1.

3.3.3 Group comparison for demographic characteristics

As can be seen from the mean values in table 3.1 there was no significant difference between older adults in the stroke group and older adults in the control group in terms of age ($t(54) = 1.153$; $p = 0.254$). There were also no significant associations between older adults in the stroke group and older adults in the control group in relation to Neugarten's age bands ($x^2(1) = 1.143$, $p = 0.285$), gender ($x^2(1) = 1.788$, $p = 0.181$) or education ($x^2(1) = 0.299$, $p = 0.584$). This suggested that the two older adult groups did not differ from each other in terms of age gender or education. Significant associations were found between the two older adult groups in relation to marital status($x^2(2) = 7.547$, $p = 0.023$) and living situation ($x^2(1) = 9.524$, $p = 0.002$). As can be seen from table 3.1, a higher percentage of older adults in the stroke group were married and lived with their family than older adults in the control group.

Table 3.1. Demographic characteristics of participants by group (stroke or control) and member (older adult or family member)

Demographic variable	**Stroke group**		**Control group**		**Stroke group**		**Control group**	
	Older adult (n=28)		**Older adult (n=28)**		**Family member (n=28)**		**Family member (n=28)**	
Characteristic	*Mean*	*SD*	*Mean*	*SD*	*Mean*	*SD*	*Mean*	*SD*
Age	75	6.4	66.9	11.3	73.1	5.8	54.3	17.6**
	N	*%*	*N*	*%*	*N*	*%*	*N*	*%*
Age category								
• Young old (65-74)	12	42.9	16	57.1	11	39.3	2	7.1*
• Old old (75+)	16	57.1	12	42.9	9	32.1	6	21.4
• Under 65					8	28.6	20	71.4
Gender								
• Male	16	57.1	11	39.3	12	42.9	10	35.7
• Female	12	42.9	17	60.7	16	57.1	18	64.3
Marital status								
• Married/partnered	25	89.3	16	57.1*	26	92.9	22	78.6
• Single/divorced	2	7.1	6	21.4	1	3.6	5	17.9
• Widowed	1	3.6	6	21.4	1	3.6	1	3.6
Education								
• High school	18	64.3	16	57.1	18	64.3	8	28.6**
• Higher/Further education	10	35.7	12	42.9	10	35.7	20	71.4
Living arrangements								
• Living with family	26	92.9	16	57.1**	27	96.4	23	82.1
• Living alone	2	7.1	12	42.9	1	3.6	5	17.9

*P<0.05, **p<0.01

With regards to comparisons between family member in the stroke group and family members in the control group there was a significant difference in relation to age (t(54) = 3.174; p = 0.003). This suggested that the two family member groups differed in terms of their age. It was therefore expected that there would be a significant association between different age bands for this group ($x^2(2) = 74.933$, p = 0.03). The frequency values in table 3.1 suggest that more family members in the control group were under the age of 65 than the family members in the stroke group. There was also a significant difference between the two family member groups in terms of education

($x^2(1) = 7.179$, $p = 0.007$). The frequencies in table 3.1 suggest that more family members in the control group attended higher education than the family members in the stroke group. There was no significant association between family members in terms of gender ($x^2(1) = 0.299$, $p = 0.584$), marital status ($x^2(2) = 3.000$, $p = 0.223$) or living situation ($x^2(1) = 2.987$, $p = 0.084$).

3.4 Health of participants

3.4.1 Stroke group

As can be seen from Table 3.2, 71 per cent of older adult participants in this group rated themselves as healthy while 25 per cent rated themselves as unhealthy. The WHOQOL Bref contained one question asking how satisfied individuals are with their health. This data revealed that 50 per cent of older adults in this group were satisfied with their health while 25 per cent were neither satisfied nor dissatisfied and the remaining 25 per cent were dissatisfied with their health. 96 per cent of participants took medications and reported an average of 2.2 medical conditions (SD, 1.1; range 1 - 4) and 6.8 types of medication (SD, 3.8; range 1 - 15). The median number of medications was 6 and the mode was 5.

Data from family members in the stroke group revealed that 86 per cent thought of themselves as healthy while the remaining 14% did not. 68 per cent of this group were either satisfied or very satisfied with their health, 18 per cent were neither satisfied nor dissatisfied and 14 per cent were dissatisfied. 75 per cent of this group were taking medications for an average of 2.1 medical conditions (SD, 0.9; range 1 - 4) and 2.8 different medications (SD, 2.1; range 1 - 10). Due to the large age range of this group, the group is not homogenous. Therefore, the researcher decided to split the group between those under 65 and those older 65 to assess if there is a difference in health status according to this age split. Seventeen (85%) family member participants aged over 65 years rated themselves as healthy compared to three (15%) family member participants over 65 years who rated themselves as unhealthy. This compared with seven (87.5%) family member participants aged less than 65 years who rated themselves as healthy and one (12.5%) family member aged less than 65 who rated themselves as unhealthy. The results suggested that there is not an age difference for health status. The majority of family members in the stroke group rated themselves as healthy regardless of age.

3.4.2 Community control group

89 per cent of older adult participants in this group rated themselves as healthy and 75 per cent were satisfied or very satisfied with their health. Only 7 per cent rated themselves dissatisfied with their health. These participants had an average of 0.9 medical conditions (SD, 1.2; range 1 – 5), and 75 per cent of older adult participants in the control group took medications, with an average of 2.9 different types (SD, 2.8; range 1 - 12). The median number of medications was 2 and the mode was 1.

96 per cent of family members in the control group rated themselves as healthy with only 4 per cent reporting that they were dissatisfied with their health. 50 per cent of this group took medications for an average of 1.6 medical conditions (SD, 1.1; range 1 - 4). These family members took an average of 3.3 types of medication (SD, 3.7; range 1 - 14). Due to the large age range of this group, it is not homogenous. Therefore the researcher separated the group into adults aged less than 65 and older adults aged 65

and over. The data for subjective health status revealed that seven (87.5%) family member participants aged over 65 years rated themselves as healthy compared to one (12.5%) family member over 65 who rated themselves as unhealthy. In addition, all twenty (100%) family members aged less than 65 rated themselves as subjectively healthy. Therefore the majority of the family members in the control group rated themselves as subjectively healthy regardless of age.

Table 3.2. Subjective and objective health ratings

Health rating	**Stroke group Older adult (n=28)**		**Control group Older adult (n=28)**		**Stroke group Family Member (n=28)**		**Control group Family member (n=28)**	
Characteristic	**N**	**%**	**N**	**%**	**N**	**%**	**N**	**%**
Subjective Health								
• Healthy	20	71.4	25	89.3	24	85.7	27	96.4
• Unhealthy	7	25	3	10.7	4	14.3	1	3.6
WHOQOL Health question								
• Dissatisfied	7	25	2	7.1**	4	14.3	2	7.1
• Neither satisfied nor dissatisfied	7	25	5	17.9	5	17.9	6	21.4
• Satisfied	14	50	14	50	11	39.3	14	50
• Very satisfied			7	25	8	28.6	6	21.4
Objective health								
• Take medications								
- yes	27	96.4	20	71.4*	21	75	14	50
- no	1	3.6	8	28.6	7	25	14	50
	Mean	**SD**	**Mean**	**SD**	**Mean**	**SD**	**Mean**	**SD**
• Number of medical conditions	2.2	1.1	1.9	0.9	2.1	1.2	1.6	1.1
• Number of medications	6.8	3.8	2.9	2.8**	2.8	2.1	3.3	3.7

*$p<0.05$, **$p<0.01$

3.4.3 Comparison of health characteristics by group

No significant association was found between older adults in the stroke group and older adults in the control group and subjective health rating ($x^2(1) = 2.138$, $p = 0.144$)

suggesting the groups did not differ on this variable. Independent t-tests revealed a significant difference between older adults in the stroke group and older adults in the control group with regards to the health satisfaction question in the WHOQOL Bref ($t(54) = 2.984$, $p=0.004$) suggesting older adults in the stroke group were less satisfied with their health. No significant difference was found with regards to the number of medical conditions the older adults in either group reported ($t(40) = 0.782$; $p = 0.439$). However, there was a significant association reported regarding how many individuals took medication in either group ($x^2(1) = 6.847$, $p = 0.011$) and the number of medications people took ($t(43 = 3.706$; $p = 0.001$). The mean values and frequencies in table 3.2 suggest that older adults in the stroke group take more medication than the older adults in the control group and comparing all older adults who take medications; those in the stroke group took a higher quantity of different types of medication.

With regards comparing the family members from the stroke and control group no difference was found for their subjective health rating ($x^2(1) = 1.976$, $p = 0.160$) or for the health satisfaction question in the WHOQOL Bref ($t(54) = 0.142$, $p=0.887$). As can be seen from table 3.2 not every family member had a medical condition or took medications. Of those that did, there was no significant difference found when comparing family members from the experimental group to family members in the control group in relation to number of medical conditions ($t(28) = 1.144$; $p = 0.262$) or number of medications ($t(33) = 0.440$; $p = 0.663$) or quantity of medications ($x^2(1) = 3.733$, $p = 0.053$).

3.5 Cognitive and personality characteristics

Table 3.3 contains data regarding the changes to cognitive and personality characteristics by group (stroke and control) and by member (older adult and family). For each question, older adults were asked to report on changes they have noticed in themselves while family members were asked to record changes they had noticed in the older adult.

Exploratory analysis of the data revealed that there was a significant relationship between older adults (stroke and control group) and memory changes ($x^2(1) = 14.000$, $p = 0.000$), changes in concentration ($x^2(1) = 12.876$, $p = 0.000$), changes in problem solving abilities ($x^2(1) = 6.095$, $p = 0.014$) and changes to speech ($x^2(1) = 13.689$, $p = 0.000$). There was also a significant relationship found between older adults in the stroke and control group and irritability ($x^2(1) = 6.842$, $p = 0.009$), less confidence ($x^2(1) = 10.500$, $p = 0.001$), less sociable ($x^2(1) = 7.791$, $p = 0.005$), less interest in things they enjoyed previously ($x^2(1) = 9.333$, $p = 0.002$). Although older adults in the control group did report some cognitive and personality changes the frequencies in table 3.2 indicate that the older adults in the stroke group reported more changes than the older adults in the control group. There was however no significant relationship found between older adult group (stroke and control) and feeling more inpatient ($x^2(1) = 3.818$, $p = 0.051$), more weepy ($x^2(1) = 2.504$, $p = 0.114$), or more stressed ($x^2(1) = 2.333$, $p = 0.127$). This suggests that the two groups of older adults did not differ on these variables.

Table 3.3 Changes noticed in older adult since stroke (stroke group) or since beginning of 2006 (control group)

Characteristic	**Stroke group**		**Control group**		**Stroke group**		**Control group**	
	Older adult (n=28)		**Older adult (n=28)**		**Family member (n=28)**		**Family member (n=28)**	
	N	%	N	%	N	%	N	%
Memory changes								
• Yes	21	75	7	25**	23	82.9	8	28.6**
• No	7	25	21	75	5	17.9	20	71.4
Changes in concentration								
• Yes	17	60.7	4	14.3**	20	71.4	7	25**
• No	11	39.3	24	85.7	8	28.6	21	75
Changes in problem solving								
• Yes	11	39.3	3	10.7*	16	57.1	2	7.1**
• No	17	60.7	25	89.3	12	42.9	26	92.9
Changes to speech								
• Yes	11	39.3	0**		14	50	0**	
• No	17	60.7	28	100	14	50	28	100
More irritable								
• Yes	13	46.4	4	14.3**	16	57.1	3	10.7**
• No	15	53.6	24	85.7	12	42.9	25	89.3
More inpatient/impulsive								
• Yes	9	32.1	3	10.7	9	32.1	4	14.3
• No	19	67.9	25	89.3	19	67.9	2	85.7
More weepy								
• Yes	9	32.1	4	14.3	8	28.6	0**	
• No	19	67.9	24	85.7	20	71.4	28	100
More stressed/restless								
• Yes	6	21.4	2	7.1	10	35.7	4	14.3
• No	22	78.6	26	92.9	18	64.3	2	85.7
Less confident								
• Yes	18	64.3	6	21.4**	18	64.3	5	17.9**
• No	10	35.7	22	78.6	10	35.7	23	82.1
Less sociable								
• Yes	9	32.1	1	3.6**	13	46.4	4	14.3**
• No	19	67.9	27	96.4	15	53.6	24	85.7
Less interest in things								
• Yes	8	28.6	0**		12	42.9	0**	
• No	20	71.4	28	100	16	57.1	28	100

*$p < 0.05$, **$p < 0.01$

Chi square analyses for family member comparisons revealed a significant relationship between group and memory ($x^2(1) = 16.258$, p = 0.000), concentration ($x^2(1) = 12.087$, p = 0.001), problem solving abilities ($x^2(1) = 16.047$, p = 0.000), speech ($x^2(1) =$

18.667, $p = 0.000$), irritability ($x^2(1) = 13.462$, $p = 0.000$), weepiness ($x^2(1) = 9.333$, $p = 0.002$), confidence ($x^2(1) = 12.469$, $p = 0.000$), sociability ($x^2(1) = 6.842$, $p = 0.009$) and less interest in things previously enjoyed ($x^2(1) = 15.273$, $p = 0.000$). The frequency values in table 3.2 suggest that the family members in the stroke group reported more changes in their older adult relative than did the family members in the control group. There was no significant relationship found between family member group (stroke and control) and impatience ($x^2(1) = 2.504$, $p = 0.114$) or stress ($x^2(1) = 3.429$, $p = 0.064$).

What is interesting to note from table 3.2 and the above chi square comparisons is the seemingly high agreement between older adults and family members in the stroke and control groups respectively. Although not of principal interest to the study, the researcher performed chi square analyses looking at the relationship between older adults and family members in the same group and all the cognitive and personality variables asked about. Results revealed no significant association between member of family and any variable cited. This was true both for the stroke group and the community control group. This suggests that members of the same family did not differ significantly on any variables and thus suggests high agreement between older adults and family members regarding any changes occurring in the older adults either since their stroke (stroke group) or since the beginning of 2006 (control group).

3.6 Relationship information

3.6.1 Stroke group

Twenty four (86%) participating family members were spouses of older adults while one (4%) was a sibling and two (7%) were adult children. 100 per cent of older adults rated this relationship as good or very good while 93 per cent of family members agreed. The remaining 7 per cent said this relationship was neither good nor poor or very poor. 75 per cent and 71 per cent of older adults and family members respectively said their relationship had not changed while 10 per cent of older adult said this relationship was better before the stroke and 14 per cent said the relationship was better since the stroke. 4 per cent of family members said they thought the relationship was better now while 25 per cent said they thought it had been better before the stroke.

3.6.2 Community control group

10 family members were spouses of the older adult (36%) in the control group while 3 were siblings (11%) and 15 (54%) were adult children. 97 per cent of older adults in this group rated this relationship as good or very good and 92 per cent of family members agreed. 96 per cent and 86 per cent of older adults and family members respectively thought their relationship had not changed while 4 per cent of older adults and 11 per cent of family members thought their relationship was better at the time of taking part in the study than it had been previously. One family member participant in the control group rated their relationship with the older adult participant as worse than it had been before. See Table 4 for detailed information across groups.

Table 3.4 Information about family relationships

Relationship Information	**Stroke group**				**Control group**			
	Older adult (n=28)		**Family member (n=28)**		**Older adult (n=28)**		**Family member (n=28)**	
	N	**%**	**N**	**%**	**N**	**%**	**N**	**%**
Relationship								
• Spouse			24	85.7**			10	35.7
• Sibling			1	3.6			3	10.7
• Adult child			2	7.1			15	53.6
Quality of relationship								
• Very good	27	94.6	24	85.7	22	78.6	20	71.4
• Good	1	3.6	2	7.1	5	17.9	6	21.4
• Neither good nor poor			1	3.6	1	3.6	2	7.1
• Very poor			1	3.6				
Changes to relationship								
• Better before	3	10.7	7	25				
• Better now	4	14.3	1	3.6	1	3.6	3	10.7
• Not changed	21	75	20	71.4	27	96.4	24	85.7
• Worse now							1	3.6

*p<0.05, **p<0.01

3.6.3 Between group comparison for relationships

Chi square analyses revealed a significant association between family member (stroke and control) and type of relationship with older adult ($x^2(2) = 17.370$, $p = 0.000$). The frequencies in table 3.4 suggest that family members in the stroke group primarily spouses of the older adults whereas family members in the control group were primarily the older adult's adult children. The different composition of these two family member groups may have an impact on how comparable these family members groups are to each other.

3.6.4 Within group comparison for relationships

With regards to relationship characteristics, it was of interest to the researcher to explore the quality of family relationships and whether these relationships had changed. Poor relationships may affect how families function and so need to be taken into account. Chi square analyses between older adults in the stroke group and family members in the stroke group revealed no significant associations between either the quality of their relationship ($x^2(3) = 2.510$, $p = 0.474$) or their perception of whether their relationship had changed ($x^2(2) = 3.424$, $p = 0.180$). Frequency values in table 3.4 suggest that the majority of older adult and family members agreed that their relationship was either good or very good and had not changed since the stroke.

With regards to older adults and family members in the control group, no significant relationship was found for the quality of their relationship ($x^2(2) = 0.519$, $p = 0.771$) or their perception of whether it had changed ($x^2(2) = 2.176$, $p = 0.337$). Frequency values in table 3.4 suggest the majority of older adults and their family members agreed that they had a good relationship and that this had not changed.

3.7 Interim summary

3.7.1 Summary for older adult comparisons

The data suggests that a greater number of older adults in the stroke group were married and therefore living with family members than older adults in the control group. In addition, older adults in the stroke group were taking more medications and were less satisfied with their health than older adults in the control group. Although older adults in the stroke group were less satisfied with their health than older adults in the control group, there was no difference recorded with regards to subjective health rating. That is, the majority of older adults rated themselves as healthy, regardless of group.

With regard to cognitive and personality changes occurring in older adults, those from the stroke group reported experiencing more changes than older adults in the control group. Specifically older adults in the stroke group rated higher for changes in memory, concentration, problem solving abilities, speech ability as well as rating themselves as experiencing changes leaving them more irritable, less confident, less sociable and as having less interest in things they used to enjoy prior to their stroke.

3.7.2 Summary for family member comparisons

These two sub-groups of family members are not homogenous in terms of age or education. In addition, family members in the stroke group tended to be spouses of the older adults while family members in the control group were primarily children of the older adults. These differences may affect whether the community group of family members is an adequate control for the family members in the stroke group. Bearing that in mind, the data revealed differences between the two family member groups with regards to any cognitive and personality changes occurring in their older adult relative. However, within families there appeared to be a high level of agreement about these changes. That is, older adults and family members in the stroke group agreed there had been many cognitive and personality changes occurring since the stroke and older adults and family members in the control group agreed they had noticed few changes since the time period they were given (beginning of 2006). This agreement occurred irrespective of whether family dyads were husband and wife or parent and adult child.

3.8 Data analysis – between groups

3.8.1 Tests of Hypothesis one

It is hypothesised that the older adults and family members in the control group will have healthier family functioning when compared to older adults and family members from the stroke group.

Family functioning was measured by the Family Assessment Device (Epstein, Baldwin & Bishop, 1983). All participants rated their agreement with 60 statements encompassing seven domains of family functioning, detailed in table 3.5. This table shows by means and standard deviations for each scale for all participants and is separated by into experimental and control group and older adult and family members. The means represented in the table for each of these four groups can be compared to the clinical cut off scores developed for the FAD by Miller et al. (1985). If scores are equal to or larger than the cut off scores the family is said to be experiencing dysfunction in that particular domain. It is useful to know if any of the groups in this study reported dysfunction before analysing if there differences between the experimental and control groups in relation to family functioning.

Table 3.5 Mean and standard deviations of FAD subscale scores by group and member

FAD* sub-scale (cut off score)	**Stroke group**		**Control group**		**Stroke group**		**Control group**	
	Older adult (n=28)		**Older adult (n=28)**		**Family member (n=28)**		**Family Member (n=28)**	
	Mean	SD	Mean	SD	Mean	SD	Mean	SD
• Problem solving (2.20)	1.91	0.35	1.87	0.27	1.87	0.35	2.00	0.36
• Communication (2.20)	2.15	0.33	2.09	0.32	2.11	0.38	2.18	0.46
• Roles (2.30)	2.17	0.29	2.12	0.29	2.19	0.34	2.11	0.38
• Affective responsiveness (2.20)	2.13	0.43	2.16	0.42	2.16	0.54	**2.29**	0.56
• Affective involvement (2.10)	2.03	0.35	1.87	0.41	1.94	0.38	1.91	0.57
• Behaviour control (1.90)	**1.96**	0.31	**1.99**	0.36	1.84	0.39	1.89	0.45
• General functioning (2.00)	1.82	0.30	1.81	0.33	1.85	0.43	1.90	0.40

*FAD is the Family Assessment Device (Epstein, Baldwin & Bishop, 1983)
Scores in bold exceed clinical cut off scores

As shown by table 3.5, the majority of sub-scale scores are within the healthy functioning range for all groups when compared to the clinical cut off scores as determined by Miller et al. (1985). The exceptions to this are older adults from both the stroke and the control group exceeded the cut off scores for behaviour control and the family members in the control group exceeded the cut off for affective responsiveness. This suggests these groups reported family dysfunction for each of these subscales.

Whether or not the group's scores exceed these clinical cut off points informs the reader about the extent of any family dysfunction as measured by the FAD. However, to test the hypothesis it is necessary to utilise inferential statistics to ascertain any differences between the stroke and control groups in terms of family functioning. As with all the exploratory analysis, all comparisons completed were comparing older adults in the stroke group with older adults in the control group and family members in the stroke group with family members in the control group.

Table 3.6 Sub-group differences for family functioning as measured by the FAD

Family Assessment Device sub-scale	**Older adult comparison**			**Family member comparison**		
	t / U	**p**		**t / U**	**p**	
Problem solving	353.500	0.404	#	338.500	0.369	#
Communication	343.000	0.416	#	0.608	0.546	
Roles	0.028	0.978		0.790	0.433	
Affective responsiveness	0.277	0.783		0.846	0.401	
Affective involvement	284.500	0.076	#	376.000	0.792	#
Behaviour control	0.360	0.720		0.551	0.584	
General functioning	0.114	0.910		0.458	0.649	

Mann Whitney U test performed due to data deviating from normal distribution

The data was checked to investigate the assumption of normality underlying the use of t-tests as tested by the Kolmogorov-Smirnov test (K-S), the Shapiro Wilkes test (S-W) and by exploring the data for skewness. This analysis revealed that the data for older adults in the stroke group was out with the bounds of normality for the subscales of communication (K-S(28) = 0.165, p = 0.000, S-W(28) = 0.904, p = 0.017) and affective involvement (K-S(28) = 0.253, p = 0.000, S-W(28) = 0.868, p = 0.010) and the data for older adults in the control group deviated from normality with regards the problem solving subscale (K-S(28) = 0.295, p = 0.000, S-W(28) = 0.819, p = 0.010).

The data for comparing family members from the stroke group with family members from the control group revealed that data for family members from the stroke group deviated from normality for the problem solving (K-S(28) = 0.247, p = 0.000, S-W(28) = 0.859, p = 0.010) and affective involvement subscales (K-S(28) = 0.209, p = 0.003, S-W(28) = 0.880, p = 0.010). As a result of these deviations from normality, non parametric statistics were employed to confirm the results these sub-scale analyses.

As can be seen in table 3.5 there were no significant differences between older adults from the stroke group and older adults from the control group in relation to problem solving (U = 353.500, p = 0.404; 2 tailed), communication (U = 343.000, p = 0.416; 2 tailed), roles (t(54) = 0.028, p = 0.978; 2 tailed), affective responsiveness (t(54) = 0.277, p = 0.783; 2 tailed), affective involvement (U = 284.500, p = 0.076; 2 tailed), behaviour control (t(54) = 0.360, p = 0.720; 2 tailed) or general family functioning (t(54) = 0.114, p = 0.910; 2 tailed) as measured by the Family Assessment Device.

In addition, there were no significant differences found between family members in the stroke group and family members in the control group for problem solving (U = 338.500, p = 0.546; 2 tailed), communication (t(54) = ,0.608 p = 0.546; 2 tailed), roles (t(54) = 0.780, p = 0.433; 2 tailed), affective responsiveness (t(54) = 0.846, p = 0.401; 2 tailed), affective involvement (U = 376.000, p = 0.792; 2 tailed), behaviour control (t(54) = 0.551, p = 0.584; 2 tailed) or general family functioning (t(54) = 0.458, p = 0.649; 2 tailed) as measured by the Family Assessment Device.

3.8.1.2 Interim Summary; hypothesis one

The results showed that older adults in both the stroke and control groups reported unhealthy family functioning within the behaviour control subscale as indicated by their scores being higher than the clinical cut off scores developed by Miller et al.

(1985). The behaviour control subscale measures the ways in which a family expresses and maintains standards of behaviour for members of their family. In addition, family members in the control group had higher scores than the clinical cut off scores for affective responsiveness. This subscale measures the ability of family members to respond to a range of situations with appropriate quality and quantity of emotion.

Despite these scores being higher than the clinical cut off scores, there were no differences found between older adults in the stroke group and older adults in the control group and no differences between family members in the stroke group and family members in the control group with regards any of the seven subscales of the Family Assessment Device. Thus, older adults and family members in the control group were not found to have healthier family functioning than those in the stroke group. Therefore, hypothesis one was not supported.

3.8.2 Tests of Hypothesis two

It is hypothesised that older adults and family member participants in the control group will report increased levels of quality of life compared to older adult and family member participants in the stroke group.

3.8.2.1 Quality of life comparison between older adults in the stroke group and older adults in the comparison group.

Table 3.7 Comparison of older adults from stroke and control group with regards quality of life

WHOQOL	**Older Adults with Stroke (n=28)**		**Older Adults without Stroke(n=28)**		
QOL Domain	Mean	SD	Mean	SD	Sig. level
Psyc. health	66.5	13.9	76.2	12.2	p = 0.008
Phys. health	55.7	17.5	74.5	19.4	p = 0.000
Social Rels.	67.9	17.3	78	10.1	p = 0.011
Environment	73.1	17	82.1	10.9	p = 0.023

When checking the assumption of homogeneity of variance, the data for the social relationships and environment domain were found to have significant F ratios for Levene's test of homogeneity. Therefore, the Levene correction of adjusted degrees of freedom (df) was employed for these two analyses.

3.8.2.2 Establishing significance levels

The second domain within the WHOQOL Bref, Psychological health, was chosen as the initial focus of interest and as such was analysed using the accepted statistical convention of 0.05 as suggesting statistical significance. However, as a result of the multiple comparisons being done using this data, the Bonferroni correction technique was employed to analyse the remainder of the quality of life data. Therefore the 0.05 statistic was divided by the remaining three domains to give a new significance level of 0.016 for the remaining three domains.

As can be seen in table 3.6, there is a significant difference between the older adults in the stroke group and the older adults in the control group in terms of psychological health (t(54) = 3.802, p = 0.000; 2 tailed), physical health (t(54) = 2.755, p = 0.008; 2

tailed) and social relationships (t(53.026) = 2.657, p = 0.011; 2 tailed). In all three cases, the mean values in table 3.6 suggest that older adults from the control group report a higher quality of life than older adults from the stroke group. No difference was found between the two older adult groups with regards to environment (t(45.984) = 2.353, p = 0.023; 2 tailed).

3.8.2.3 Quality of life comparison between family members in the stroke group and family members in the comparison group.

The Mann-Whitney test U was utilised for the psychological health domain as the data for this comparison was found to be out with the accepted bounds of normality (K-S(28) = 0.194, p = 0.008, S-W(28) = 0.888, p = 0.010). When using non-parametric tests such as the Mann Whitney U, the median and range are considered to be more appropriate measures of central tendency and dispersion than the mean and standard deviation (Bruce, Kemp & Snelgar, 2003).

Table 3.8 Quality of life comparison of family members in the stroke and control groups

WHOQOL domain	**Family members in stroke group (n=28)**		**Family members in control group (n=28)**		**Significance level**
	Median	*Range*	Median	Range	
Psychological functioning	81	63	69	62	p = 0.324*
	Mean	*SD*	*Mean*	*SD*	
Physical health	74.7	17.4	76	15.8	p = 0.560
Social Relationships	78	16.1	75.5	16.2	p = 0.565
Environment	81.8	12.2	78.9	11.8	p = 0.378

* Non parametric test – Mann-Whitney U performed

As seen in Table 3.7, there are no significant differences with regards the psychological domain (U = 323.500, p = 0.324; 2 tailed), the physical health domain (t(54) = 0.586, p = 0.560; 2 tailed), the social relationships domain (t(54) = 0.579, p = 0.565; 2 tailed) or the environment domain (t(54) = 0.889, p = 0.378; 2 tailed). This suggests that family members in the stroke group and family members in the community control group did not differ with respect to their perceived quality of life.

3.8.2.4 Interim Summary; hypothesis two

Overall, the second hypothesis was found to be true in the comparisons between older adults in the stroke group and older adults in the control group. The older adults in the control group reported a better quality of life in relation to the psychological, physical health and social relationship domains when compared to those older adults in the stroke group. However, no differences were found in relation to the environment domain when comparing the older adults from each group. In addition, no differences were found on any of the quality of life domains when comparing the family members from the stroke group with the family members in the control group. Thus the hypothesis was partly but not wholly supported.

3.8.3 Tests of Hypothesis three

It is hypothesised that there will be a lower perceived social support reported by participants in the stroke group compared to the control group.

Social support was assessed using the Significant Others Scale (Power, Champion & Aris, 1988). This scale produces scores for social support which are separated into emotional and practical support. All participants completed the Significant Others Scale which asks about the actual emotional and practical support people receive. This scale also asks people to rate how much support people would like if things were exactly as they hoped for in their relationships. The discrepancy between these scores can therefore show whether individuals are happy with they support they receive or whether they wish they had more or less support. In relation to social support, participants who had experienced a stroke were compared with older adults from the control group. The family member participants from the experimental group were compared with the family members from the control group.

3.8.3.1 Comparison of perceived social support for older adults in the stroke group and older adults in the comparison group

All results are based on non parametric Mann-Whitney U tests as all conditions showed the data for older adults in the stroke group deviated from the normal distribution for actual emotional support (K-S(28) = 0.314, p = 0.000, S-W(28) = 0.709, p = 0.010), ideal emotional support (K-S(28) = 0.333, p = 0.000, S-W(28) = 0.562, p = 0.010), and the discrepancy between the actual and ideal (K-S(28) = 0.407, p = 0.000, S-W(28) = 0.652, p = 0.010). The data also deviated from normality for the actual practical support perceived (K-S(28) = 0.201, p = 0.005, S-W(28) = 0.785, p = 0.010), the ideal practical support wanted (K-S(28) = 0.236, p = 0.000, S-W(28) = 0.721, p = 0.010) and the discrepancy between these (K-S(28) = 0.314, p = 0.000, S-W(28) = 0.570, p = 0.010).

Table 3.9 Social support comparison of older adults by group using Mann Whitney U tests

Significant Others Scale	**Older adults in stroke group(n=28)**		**Older adults in control group (n=28)**		
Type of support	*Median*	*Range*	*Median*	*Range*	*Significance level*
Actual emotional support	13.5	6.50	12.7	4	p = 0.168
Ideal emotional support	13.7	6.50	13	2.67	p = 0.121
Discrepancy	0.00	3	0.16	4.67	p = 0.267
Actual practical support	12.7	8.50	12.7	6.33	p = 0.459
Ideal practical support	13.3	8.50	12.5	1.30	p = 0.262
Discrepancy	0.00	4.33	0.16	4.34	p = 0.284

As shown in table 3.8, there are no significant differences when comparing older adults from the stroke and control groups in terms of actual emotional support (U = 309.500, p = 0.168), ideal emotional support U = 301.000, p = 0.121) or the discrepancy between these scores (U = 331.000, p = 0.267). There were also no significant differences between the older adults by group (stroke and control) in terms of actual practical support received (U = 334.500, p = 0.459), their ideal practical support (U = 325.000, p = 0.262) or the discrepancy between these scores (U = 332.000, p = 0.284). Both groups report similar median scores across both emotional and practical support. In addition, the discrepancy between the actual emotional or practical support received and the ideal emotional and practical support hoped for does not yield a statistically significant result, meaning that neither older adult group wish they received more emotional or practical support from their social network than they receive currently.

3.8.3.2 Comparison of perceived social support for family members in the stroke group and family members in the comparison group

Table 3.10 Comparison between family members in the stroke group with family members in the control group with regards social support

Significant Others Scale	**Family members in stroke group(n=28)**		**Family members in control group (n=28)**		
Type of support	*Median*	*Range*	*Median*	*Range*	*Significance level*
Actual emotional support	12.8	13	12.2	6	p = 0.908 p = 0.894
Ideal emotional support	13.3	12	13.3	2.67	p = 0.434
Discrepancy	0.00	13	0.67	3.33	
Actual practical support	11.6	12	11.8	7.67	p = 0.599 p = 0.882
Ideal practical support	12.3	12	12.5	5	
Discrepancy	0.67	5	0.67	4.33	p = 0.926

All results are based on non parametric Mann-Whitney U tests as the data for family members in the stroke group deviated from the normal distribution for actual emotional support (K-S(28) = 0.256, p = 0.000, S-W(28) = 0.697, p = 0.010), ideal emotional support (K-S(28) = 0.301, p = 0.000, S-W(28) = 0.484, p = 0.010), and the discrepancy between the actual and ideal (K-S(28) = 0.309, p = 0.000, S-W(28) = 0.536, p = 0.010). The data also deviated from normality for the actual practical support perceived (K-S(28) = 0.149, p = 0.113, S-W(28) = 0.863, p = 0.010), the ideal practical support wanted (K-S(28) = 0.230, p = 0.001, S-W(28) = 0.641, p = 0.010) and the discrepancy between these (K-S(28) = 0.228, p = 0.001, S-W(28) = 0.809, p = 0.010).

There were no significant differences found between family members from the stroke group and family members from the control group in terms of actual emotional support (U = 385.000, p = 0.908), ideal emotional support U = 384.000, p = 0.894) or the discrepancy between these scores (U = 346.500, p = 0.434). There were also no significant difference between the older adults by group (stroke and control) in terms of actual practical support received (U = 360.000, p = 0.599), their ideal practical support (U = 383.000, p = 0.882) or the discrepancy between these scores (U = 386.500, p = 0.926).

3.8.3.3 Interim Summary; hypothesis three

The third hypothesis relating to social support was not supported. No difference was found between in the stroke group when compared to those in the control group with regards to their level of perceived social support. This result occurred irrespective of older adult or family member comparison.

3.8.4 Tests of Hypothesis four

It is hypothesised that the there will be a higher incidence of anxiety and depression in older adults and family members from the stroke group compared to the control group

Depression and anxiety is assessed using the Hospital Anxiety and Depression Scale (HADS) This measure provides separate scores for anxiety and depression and this data is summarised in table 3.10 below.

Table 3.11 Independent t-test comparison of older adults from the stroke and control group

	Older adults in stroke group (n=28)		**Older adults in control group (n=28)**				
	Mean	SD	Mean	SD	t	df	Sig. level
Anxiety	6.6	3.66	4.46	3.53	2.23	54	p = 0.030
Depression	5.36	3.27	3.39	2.47	2.54	54	**p = 0.014**

3.8.4.1 Comparison of older adults from the stroke group with older adults from the control group

There was a significant difference between older adults in the stroke and control group in relation to depression (t(54) = 2.54, p = 0.014). The result for anxiety (t(54) = 2.23, p = 0.030) is not deemed significant as a Bonferroni correction on this data meant a new significance level of 0.025. Therefore the result for anxiety was not significant.

Table 3.12 Independent t-test comparison of family members from the stroke and control group

	Family members in stroke group (n=28)		**Family members in control group (n=28)**				
	Mean	SD	Mean	SD	t	df	Sig. level
Anxiety	5.53	3.68	5.71	3.79	0.189	54	p = 0.851
Depression	4.53	3.67	3.25	3.09	1.419	54	p = 0.162

3.8.4.2 Comparison of family members from the stroke group with family members from the control group

There were no significant differences between family members in the stroke group and family members in the control group with regards to either anxiety (t(54) = 0.189, p = 0.851) or depression (t(54) = 1.419, p = 0.162).

Although, a significant difference was found for the comparison of older adults from the stroke and control group, the group means, shown in table 3.10, reveal low scores. The cut off scale for the HADS depression scale and the HADS anxiety scale counts all scores below 7 to be within the 'normal' range and therefore the mean scores show that all participants were below clinical 'caseness' for anxiety and depression. This suggests that all four groups have minimal scores for depression and anxiety, thus the fourth hypothesis is not supported.

3.8.4.3 Interim Summary; hypothesis four

There is a significant difference between older adults in the stroke and control group for depressive symptoms. However, mean scores indicate minimal scores for all groups with regards to depression and anxiety. Therefore, there is not a higher incidence of anxiety and depression in the stroke group when compared to the control group when analysing data from this study. Cut off between normal and pathological functioning in HADS-A was set at 8 points and in HADS-D at 6 points (Zigmond and Snaith, 1983).

3.9 Summary of findings

In sum, there are differences between the stroke and control group for some of the variables investigated but not all. More specifically the data revealed that;

- There is no difference in relation to family functioning across the four groups and the majority of family functioning for all groups fell within the healthy functioning range.
- There is a difference between older adults in the stroke and control group with regards psychological and physical health and social relationships but not environment.
- Family members from both groups report similar levels of quality of life.

- Individuals across all four groups' report a similar perceived social support and a large discrepancy does not exist between the actual and ideal support reported.
- Older adults in the stroke group do report a higher incidence of depressive symptoms than older adults in the control group. However, their scores, as with all the group scores for anxiety and depression fall within the normal range and as such do not suggest 'clinical caseness' of either depression or anxiety.

These findings will now be interpreted in light of the current literature for this topic, taking into account the limitations of this study.

Chapter 4: Discussion

4.1 Interpretation of results

4.1.1 Family Functioning

The main aim of this study was to ascertain whether families in which an older adult member had experienced a stroke, differed from families where no-one had had a stroke. In both the stroke group and the control group, older adult and family member participants reported similar levels of family functioning as measured by the Family Assessment Device. Additionally, the results showed that families in this study scored within the healthy functioning range on most dimensions, regardless of group.

The dimensions in which participants were seen to exhibit dysfunctional functioning were behaviour control and affective responsiveness. Older adult participants in both the stroke and control group reported higher scores, indicating poorer family functioning, with regards behaviour control. This dimension is defined as the pattern a family adopts for behaving in three types of situations. These situations are physically dangerous situations, situations which involve meeting and expressing psychobiological needs and situations involving interpersonal socialising behaviour, both within and outside the family (Miller et al., 2000). The apparent dysfunction for behaviour control is not specific to stroke but was apparent for both groups of older adults. It is difficult to know what aspect of maintaining appropriate standards within these situations is perplexing for the family, from the older adult's perspective. It may be that this is a cohort finding, indicating their dissatisfaction with the standards of behaviour which other family member's exhibit. This hypothesis would need investigated further before any conclusions could be drawn about older adults and their views of how members of their family behave.

Family members in the control group had higher scores, indicating dysfunction, for the affective responsiveness subscale. This measures the ability of family members to respond to a range of situations with appropriate quality and quantity of emotion. The more effective a family's functioning, the wider the range and the more appropriate their emotional responses will be in terms of quantity and quality for any given situation (Epstein et al., 1980). Although family members in the control group scored above the clinical cut off for affective responsiveness, the difference between groups was not statistically significant. However, the fact that family members in the control group reported dysfunction regarding their family's ability to respond with the appropriate emotion required in a situation, may in fact suggest a positive aspect of having a family member with a chronic illness. That is, the fact that members of the stroke group rated their family as functioning within the healthy range for expressing appropriate emotion, may suggest that the stroke event precipitates the family system having to deal with the emotion of this event, as well as dealing with any physical effects resulting from it. This hypothesis again would need to be substantiated by further investigation.

Despite the apparent dysfunction for two dimensions of family functioning, there were no statistically significant differences found between older adults in the stroke group and older adults in the control group and no statistically significant differences between family members in the stroke group and family members in the control group with regards any of the seven subscales of the Family Assessment Device. Thus, older adults and family members in the control group were not found to have healthier family functioning than those in the stroke group. Indeed, the majority of participants reported healthy family functioning, suggesting that an older member of the family experiencing a stroke does not necessarily result in poor family functioning.

The findings in the current study are similar to that of Bishop et al. (1986) who found that stroke patients and spouses in their study reported healthy family functioning, comparable to that of a community control group. However, Bishop et al. (1986) reported that they thought their findings could be explained by the fact that all families in their study were more than one year post stroke and therefore past the crisis stage of living with stroke. The current study included families where stroke patients were less than one year post stroke suggesting that perhaps adjusting to living with this particular form of chronic illness does not take as long to adjust to as Bishop et al. (1986), suggested. This is supported by Neidhardt and Allen (1993), who suggested that once the initial adjustment to stroke has taken place, there is no need for further adjustment; thereby suggesting family functioning may not be unduly affected. In addition, Altschuler (1997) postulated that a significant period of adjustment must take place when a person has a stroke, but that this is then followed by a period of stabilisation and adjustment to living with the consequences of stroke.

The findings in the current study contradict those from other research studies, such as the longitudinal study by Clark & Smith (1999), who reported that family functioning deteriorated when patient and family members were assessed one year post discharge and King et al. (2002), who observed that family functioning for the stroke patients and family members in their study also became less healthy over time. The reason why some families appear to function well after a stroke and some families do not is a complex issue. Clark (1999) suggested some reasons why some families may adjust less well than others. Families in her study tended to experience poorer family functioning when the stroke patient developed psychological morbidity and when the health burden of the stroke was great. Although in the current study, stroke patients reported dissatisfaction with their health status and their health related quality of life, this difficulty with their individual functioning did not necessarily lead to problems for overall family functioning.

One of the differences between the current study and previous studies on stroke and family functioning is that the current study focused exclusively on stroke patients aged over 65. It may be that by including all people who have stroke, regardless of age, differences in family functioning become apparent which may not be obvious if different cohorts are looked at separately. Teasell, McRae and Finestone (2000) reported that rehabilitation of younger stroke patients is associated with a variety of problematic social factors, such as marital break-up, problems with caring for young children and difficulties in returning to employment, which may have financial implications for young families. If these types of problems occur, it is to be expected that difficulties in how families function may occur. However, these problems are much less likely to be apparent in an older adult stoke population and may be part of the reason why family functioning in the current study did not appear unduly affected by the stroke event.

4.1.2 Quality of Life

In line with theoretical expectations, the evidence from the current study suggests that there is an association between having a stroke and reporting a lower perceived quality of life. Older adults in the stroke group reported a lower perceived quality of life in relation to the psychological, physical health and social relationship domains when compared to older adults in the control group. The finding regarding dissatisfaction with their physical health is perhaps to be expected given the high prevalence of physical effects that can result from stroke. The finding that older adults in the stroke group are less satisfied with their quality of life with regards to psychological factors and social relationships suggests that stroke has a wider impact than exclusively physical effects for the stroke patient.

The stroke event did not appear to create the same differences on the quality of life ratings for family members from the stroke group. When compared with family members from the control group, both groups of family member participants reported similar levels of quality of life with scores indicating they both groups of family members were satisfied with their perceived quality of life in all domains assessed.

The finding that stroke patients report low levels of quality of life is supported in the literature. Previous studies have proposed a relationship between functional status of patients, female gender, and depressed mood (Gokkaya et al., 2005; Kanda & Sakai, 2006; King, 1996), as well as the availability of social support (King, 1996). In the current study, stroke patients did not report depression or dissatisfaction with the social support they received. They did report dissatisfaction with their physical health which may be related to their functional status. No gender subgroup analysis was carried out due to the numbers in this study. However, there were more men than women in the older adult stroke patient group, suggesting that both sexes reported a reduced quality of life post stroke.

Several studies have suggested an association between quality of life scores and depression (Gokkaya et al., 2005; Jonsson et al., 2005; Kim et al., 1999). Naumann and Byrne (2004) used the WHOQOL Bref in their study with older adults with depression. They reported that the quality of life scores were strongly correlated with severity of depression thereby raising the issue of measurement redundancy. However, it might be that older adults who are depressed report reduced levels of quality of life and that older adults who are not depressed could also report low levels of quality of life, independent of depressive symptoms. The current study found that older stroke patients had low scores for perceived quality of life without depression. This suggests that assessing quality of life as well as assessing mood in an essential part of evaluating how patients adjust to life post stroke.

Clarke and Black (2005) postulated that the process of fully adjusting to life post stroke is gradual. Older adult participants in their study, who were less than six years post stroke, reported more frustration with their lives and were more focused on the changes since their stroke than older adults who had their stroke more than six years prior. It may be that the findings in the current study are similar to those found by Clarke and Black (2005). All stroke patients in the current study had their stroke within the last five years and therefore may not have fully adjusted to their changed lives, post stroke, which could be negatively impacting on how they view their quality of life.

The fact that older adults in the current study rated their quality of life as low despite their family functioning, perceived social support and mood appearing unaffected is interesting. It perhaps suggests that the facets incorporated within the quality of life questionnaire are tapping into areas of the patient's life, which have been altered by the stroke, which the other measures do not assess. Further investigation of this possibility may yield clinically relevant information about how best to work with stroke patients who report reduced satisfaction with their quality of life.

With regards the family members in the stroke group having similar satisfaction levels as family members in the control group, this may suggest that family members take less time to adjust to life post stroke than patients do. Schlote et al. (2006) found that family members in their study reported changes in their perception of quality of life over the course of their relatives first year, following discharge from hospital. The current study looked at family members of stroke patients up to five years post discharge and the results regarding family member's good quality of life may suggest that family members had already adjusted to life with their relative's chronic illness.

4.1.3 Social Support

The hypothesis relating to social support suggested that those older adults and family members in the stroke group would report lower levels of social support than those in the control group. The data, however suggested that this was not the case. No differences were found between the older adult participants or the family member participants in the stroke group when compared to their respective controls in the community group with regards their level of perceived social support. The results for the comparison of older adults from the stroke and control groups suggest that neither group had higher levels of perceived emotional or practical support than the other. Additionally, there were no differences between the older adult groups in terms of ideal emotional or ideal practical support, although there was a tendency for the ideal support to score higher than the actual support received for older adults in both groups. These results suggest that older adult participants in both groups were equally satisfied with the support they perceived to be available from their support networks and therefore stroke did not impact on patients perceptions of social support. One possible explanation for this finding may be the design of the study. In accord with the inclusion criteria for this study, older adult stroke patients were only eligible for participation in the study if they had a family member who would also be able to take part in the study. Although a necessary feature of a study addressing issues with family functioning, this design did result in stroke patients who did not have family members being excluded from taking part. Therefore the finding that older adults in the stroke group did not differ from older adults in the control group with regards perceived social support may be explained by the fact that they all had at least one close family member nearby who might have provided them with support. In addition, the majority of the older adults in the stroke group were married which may suggest there spouse was a valuable source of support for them.

Similar findings were reported for the family member's comparison. Family members in the stroke and control group reported similar levels of perceived support and neither group had higher expectations than the other with regards ideal support. This finding suggests that family members of stroke patients do not necessarily experience difficulties with the people in their social networks providing adequate support.

Previous research into social support post stroke, has suggested that social activities become restricted and relationships with family and friends change as a result of stroke (Thommessen et al., 2001). Additionally, low levels of social support have been found to predict a decline in functional status over time (Glass et al., 1993). Other studies have provided evidence for a stress buffering theory of good quality social support, both in stroke studies (Knapp & Hewison, 1998) and in studies with other older adult populations (Lam & Power, 1991). Results have been mixed regarding whether the quality or quantity of relationships is more important for this hypothesised buffering effect (Cobb, 1976; Power et al., 1998). Participants in the current study were asked to nominate three individuals from their social network. Not all participants named three individuals, preferring instead to name only one or two important individuals in their social network. Regardless of the quantity of the relationships assessed, findings show that they were satisfied with the support they received. As a result, it may be that the good quality social support reported by older adults and family members in the stroke group in this study suggests a stress buffering effect against problems for both individual and family functioning.

4.1.4 Anxiety and Depression

Older adults in the stroke group reported higher scores on the depression subscale when compared to older adults in the control group. The data suggest that older adults who have had a stroke experience more depressive symptoms than older adults who have not experienced stroke. Despite this difference in depressive symptoms, older adults in both the stroke and control groups had scores below the clinical cut off, determined by Zigmond and Snaith (1983) for indicating problems with depression. No differences were recorded between the older adult groups with regards anxiety and older adults in both groups had low scores for anxiety, which were below clinical cut offs. Therefore, in this study, having a stroke did not lead to elevated scores of depression or anxiety for patients. The cut off between normal and pathological functioning recommended for use in research was set at the lower end of the borderline range for both subscales. That is, scores of 7 or less were taken to indicate the probable absence of a mood disorder, while scores of 8-10 highlighted a 'borderline' case and scores of 11 and above suggested the probable presence of a mood disorder (Zigmond and Snaith, 1983). In the current study, both the older adult and family members had mean scores indicating the probable absence of a mood disorder, suggesting that, in this sample, stroke did not lead to elevated scores of depression and anxiety.

These findings contradict previous research. Stroke patients in this study were not found to have clinical symptoms of depression or anxiety. Berg et al. (2003) previously reported that stroke severity, functional impairment and male gender were associated with depression. Stroke patients in previous studies have been younger than the participants in the current study (Berg et al., 2003; Dam, 2001), and it has been suggested that the relationship between male gender and depression may be more apparent in younger men who have stroke (Burvill et al., 1997). Similarly Schultz et al. (1997) found that younger patients in their study experienced more anxiety symptoms than older patients in their sample. Taking these previous research findings into account, it may be that when younger people experience a stroke this can lead to anxiety and depression, which may not be the case when older adults experience stroke. However, to suggest age as the explanatory factor regarding why stroke patients in the current study did not have depression or anxiety difficulties appears too simplistic. There may be some age related factors which influence how people respond to stroke and this possibility needs further investigation in studies focusing specifically on older adults who experience stroke.

With regards the finding that family members in the stroke group reported low levels of anxiety and depression, a previous study suggested that symptoms of anxiety and depression in stroke patients are seen to influence the psychosocial burden of their family members (Fure et al., 2006). Therefore, if stroke patients are not experiencing difficulties with anxiety and depression, then perhaps their family members will not report any difficulty in this area. If poorly adjusted individual functioning can lead to difficulties for other members of the family system, then perhaps positive aspects of one members individual functioning can have a positive affect on the rest of the system.

4.1.5 Demographic variables

4.1.5.1 Older adult comparisons

The older adults in the stroke and control group were comparable in terms of age, gender and education. This suggests the community group were an adequate control group for the older adults in the stroke group. There were differences with regards marital status and living situation as a higher proportion of older adults in the stroke group were married and therefore living with their spouse. A higher number of older adults in the control group were single or widowed and therefore living on their own. This difference in martial situation may, in part, explain the difference between quality of life scores between these two groups of older adults, as perhaps being married led to a reduced level of quality of life. However, stroke patients in this study most often chose their spouse to take part in the research and reported a good quality relationship with them, one that had not changed as a result of stroke. The fact that patients reported a good relationship with their spouses suggests that their marital status would not explain their dissatisfaction with their quality of life.

4.1.5.2 Family member comparisons

The family member participants from the stroke and control group differed with regards age as more family members in the control group were under the age of 65 than family members in the stroke group. This can be explained by the fact that married older adults in the stroke group nominated their spouse to take part in the research whereas older adults in the control group asked their children. As stated above, fewer older adults in the control group were married compared to those in the stroke group. However, this difference does question whether the family members in the control group acted as an adequate control group for family members in the stroke group. No differences on any variable assessed were found between family members in the two groups suggesting that neither the stroke event nor the age difference contributed to any differences being recorded between the two groups. Additionally, there were no differences between the groups for other demographic variables such as gender, marital status or living situation.

4.1.5.3 Personality and cognitive changes

Older adults and family members within the stroke group reported many personality and cognitive changes in the older adults as a consequence of their stroke and there was a high level of agreement reached between the older adult and their family member regarding the presence of these changes. A correspondingly high level of agreement was found between the ratings for the older adult and family member participants in the control group although, in this group, both members agreed there had been fewer personality and cognitive changes compared to the changes noted in the stroke group. This agreement occurred irrespective of whether family dyads were husband and wife or parent and adult child. This difference is perhaps to be expected as a result of these types of changes being more common in a post stroke patient population, than in a healthy older adult population. Specifically, a greater number of older adults in the stroke group rated changes in memory, concentration, problem solving abilities and changes to speech ability as well as rating themselves as experiencing changes leaving them more irritable, less confident, less sociable and as having less interest in things they used to enjoy, prior to their stroke.

The high level of agreement reached for both groups between older adult and their family members provides evidence for the possible usefulness in asking family members to act as proxies for patients, with cognitive or communication difficulties, when it comes to assessing outcomes following stroke. It must be noted that this good agreement occurred in relation to personality and cognitive changes which are possibly more objective dimensions to measure than a patient's perception of their quality of life, which may represent more subjective feelings, and therefore be more challenging for family members to determine.

4.1.5.4 Health characteristics by group

Older adults and family members in the stroke group reported more cognitive and personality changes than older adults and family members in the control group. In addition, older adults in the stroke group reported lower levels of quality of life with regards their physical health, as well as reporting dissatisfaction with their current health status than the older adults in the control group. Older adults in the stroke group also took more medications than older adults in the control group, both in terms of number of people taking medication and the quantity of medications being taken. Given these findings, it is therefore somewhat unexpected that there was no difference found in the comparisons between the groups for subjective health ratings. Older adults in the stroke group rated themselves as subjectively healthy despite being dissatisfied with their physical health and reporting a high number of residual effects from stroke. Family members from both groups also rated themselves as subjectively healthy. King et al. (2002) also found that stroke patients in their study rated themselves as subjectively healthy, despite reporting an increase in health problems over time. It might be of interest to further investigate what individuals think about when rating themselves as healthy, despite physical implications of stroke being reported.

One recent qualitative study found that patients undergoing inpatient rehabilitation were able to identity some positive consequences of their stroke. Among the main themes regarding positive consequences of stroke were increased social relationships, and increased health awareness. Within an inpatient environment, stroke patients have been found to utilise social comparison to ascertain how severe their stroke was. This may lead to an increased awareness of health for some people as well as an appreciation that their stroke was not more severe. This greater awareness of their current health status may in part explain why the stroke patients in the current study and in the study by King et al. (2002) rated themselves as subjectively healthy.

To summarise the findings of this study, an older adult having a stroke did not negatively impact on their family's functioning. This is borne out by the data in the current study which suggests that older adult and family member participants in the stroke group did not differ from an older adult and family member control group with regards to family functioning as measured by the Family Assessment Device. Additionally, individual functioning of the family members of stroke patients did not differ from that of the control group, in terms of quality of life, perceived social support or current mood. Older adults who had had a stroke reported similar levels of perceived social support to healthy older adults as well as non-clinical levels of anxiety and depression.

One difference between the older adult groups was that older adults in the stroke group were less satisfied with their perceived quality of life in relation to their physical health, social and psychological functioning.

4.2 Theoretical implications

With regards Rolland's (1987) three hypothesised phases of chronic illness, it may be that the families in this study have passed the crisis stage and are now living with the chronic illness, as part of their daily family life. Tasks of the chronic phase in Rolland's model include, working to maintain normal functioning, while managing the uncertainty that chronic illness can bring. In the context of this study, this suggests that despite the physical health difficulties resulting from stroke and the various personality and cognitive changes that older adults and family members reported, they had maintained normal functioning, both for their own individual functioning and overall family functioning. It is highly likely that there was a crisis phase for each family following the onset of stroke, but the time scale of this stage would vary for different families. It is hypothesised that this study provides evidence for families adjusting well to stroke if the family member who has the stroke is an older adult. Possible reasons for this are detailed below.

Hurwicz et al. (1992) explored the quantity and influence of salient life events for individuals and their wider family in three generation families. Results suggested that older adults experienced fewer life events than younger individuals and appeared less vulnerable to strain if transitions or events were appropriate to their developmental life stage. Additionally, major life events were associated with depressive symptomatology in younger and middle aged adults but no event was found to be related to depressive symptomatology in older adults. This suggests that if the same event happens to individuals over 65 and to those under 65, perhaps older adults would not experience the same negative effects as younger adults, especially if the event fits in with their stage of development. Thus, stroke could be seen as an event which people might anticipate as being a more likely event in later life which may explain why the individual functioning of older adults and their family members was not negatively influenced by stroke. Similar findings exist in the bereavement literature, suggesting that older people may accommodate to the loss of their loved ones better than younger people (Norris & Murrell, 1987; Zisook & Schuchter, 1991). One explanation for these findings are that illness, loss and bereavement occur in later life within the expected developmental sequence whereas illness, loss and bereavement in younger adults do not.

Family responses to chronic illness vary according to the age and developmental stage of the individual with the illness as well as the family life cycle stage (Newby, 1996). Within the model of the family life cycle, it is suggested that there is an underlying order of the life course and that illness occurs within an unfolding time sequence (Newby, 1996). Therefore chronic illnesses which occur at unusual or unexpected times of the family life cycle may be more problematic for family functioning than those which occur within the expected times scales of the developmental family stage. However, this is not to suggest that an older adult having a stroke is not an important and difficult event for the family to deal with or an attempt to minimise the impact that a stroke can have on individual and family functioning.

The family life cycle proposed by Carter & McGoldrick (1999) indicates that there is an expectation that family members in their later years will experience physical decline and that younger members of the family may have to become involved in caring for or supporting these older members. In addition, family members are expected to adjust to the inevitability of death and of possible disability in the later years of people's lives. The family life cycle suggests that older adults themselves will begin to prepare for the losses of their peers and spouse as expected consequences of ageing. It therefore seems reasonable to assume that older adults may come to expect that their own physical health may decline with the onset of illness. However, rather than this resulting in a negative outlook on life, it may act as a protective mechanism for dealing with the illness and losses that occur in later life.

The 'understandability phenomenon' (Blanchard, 1992) refers to the false belief that depression in later life is an understandable consequence of getting older and is therefore to be expected. However, it is possible that a more realistic belief is in operation with regards the expectations of physical illness in later life. If older people and their family members expect that people might experience a chronic illness as they get older, then perhaps this knowledge will help prepare them for this event if it does occur. This hypothesis is perhaps again too simplistic and does not account for the distress experienced in families where older adults experience other chronic illnesses, for example dementia. Further research investigating the cognitive processes involved in families adjusting to different chronic illnesses in later life is required.

4.3 Strengths and limitations of study

4.3.1 Statistical power analysis

In the design stage of this study, a power analysis was performed regarding required sample size. Cohen's tables (1992) were used to determine the sample size necessary to detect a large effect size using independent t-tests for a power of 0.8 with an alpha of 0.05. This revealed that having twenty six participants in each group was necessary to achieve sufficient statistical power. There were twenty eight participants recruited to each of the four groups in this study, ensuring that sufficient power had been met. However, sample size and therefore statistical power was too low for analyses of any subgroups regarding types of stroke or gender or age groups. A replication of the study, with a bigger sample, is needed to assess if there are differences between subgroups with regards family functioning post stroke.

4.3.2 Recruitment

Previous studies looking at stroke and family functioning have included all adults who have experienced stroke (Bishop et al. 1986; Clark & Smith, 1999; Evans et al., 1987). However the researcher is of the opinion that different cohorts may have different experiences resulting from stroke. Older adults tend not have to leave employment or to care for their young children and so the changes to family functioning may differ significantly in both populations. There may be cohort specific effects for younger adult and for older adults so a possible strength of the current study is that it focuses exclusively on older adults who have had a stroke to ascertain whether any cohort specific effects do indeed apply to this population of stroke patients. Additionally, most previous studies do not have a control group which proved invaluable in this study as it provided a comparison group as a context in which to view the findings of this study. The fact that the older adults in the stroke group did not differ significantly on the variables in this study, with the exception of quality of life, suggests that having a stroke as an older adult perhaps does not have the same negative consequences often seen in younger populations of stroke patients.

A possible limitation of the study with regards recruitment is the low response rate of potential participants who then agreed to take part in the study. There may have been a self selection bias in that perhaps those older adult-family member dyads who agreed to take part in the research were the families who were doing well post stroke and the families doing less well declined participation. The other possibility is that the individuals who took part in the research did so as a way of ensuring the continuity of stroke services in this area.

All participants in the study lived within the community. Therefore the results of the study cannot be generalised to families where the older adults are in long term care, for example, nursing home placements. It is possible that the older adults in this environment report more negative psychosocial consequences of stroke which may have a negative impact on the overall functioning of their families. Further research is needed to replicate this study to assess if this is indeed the case, or if the age effect proposed in this study is found with an older adult population of people who do not live in the community.

This study focused on how chronic illness, in this case, cerebrovascular accident or stroke impacted on the family members of those who experienced stroke. Therefore, family members, but not necessarily those providing care, were included in the study. There is the possibility that asking people to identify themselves as caregivers would exclude people who did not regard themselves in this way and the primary interest of the study was the family and how they responded to chronic illness, not necessarily only those family members who provide care. The term 'caregiver' and 'care receiver' can suggest a possible power imbalance within the family with the care receiver dependent on the overburdened and stressed care giver for assistance. One hypothesis is that if the study stipulated that only caregivers of stroke patients should participate then perhaps individuals who agreed to take part would have been those who felt overburdened in their situation, leading to a possible skewed result towards highlighting the negative impact of stroke. However, the family members in the stroke group mainly consisted of spouses and adult children, who represent the people who most often act as caregivers for stroke patients. Therefore although this study did not ask if care was provided, it can be postulated that it would most likely be these family members who would be giving the care, if they do not do so already. These results may have been found whether the researcher had stipulated that 'family members' or 'caregivers' take part in the research. This change in language is an important one so the study would need to be replicated exactly changing only the terminology from family member to caregiver in order to assess if the same results are found.

The older adult participants had different relationships with the various family members who agreed to take part in this study. The majority, but not all, of older adults in the stroke group were married and therefore asked their spouse to participate. However, the older adults in the community group more often asked their adult children to participate. These different family relationships may have affected the results found. A positive bias may have been reported from those family members not living with their older adult family member as they were not privy to exactly how their life post stroke has changed. It might therefore have been of interest to analyse the different subgroups in terms of their family functioning ratings in order to assess whether differences existed between the dyads when two spouses were the respondents compared to when a parent and child were participating. Unfortunately, the numbers in this study precluded any subgroup analysis. However, it may be important to bear in mind for future research projects that the nature of different family relationships may have a notable impact on the results found.

4.3.3 Design of study

The study employed a cross sectional design. The data provides information for 28 individual families at a specific point in time. The design does not allow for follow up of these families to assess if the findings remain constant or whether they change over time. However, a cross sectional design was considered the optimal choice for a project of this nature.

In addition, this study looked only at those stroke patients who were living in the community with the support of family members. The participants in this study were deemed physically independent enough to be discharged home instead of being referred to a long term care facility. In addition, going home after stroke often depends on whether there are people in the patient's family network able and willing to provide support to the patient. As a result, it might be that those families with unhealthier family functioning were unable to maintain the patient in the community. Therefore future research should assess the family functioning and social support within families where the stroke patient resides in a nursing home to assess if there are significant differences when compared to a community control group or even to a group of stroke patients within the community.

Participants in this study were not excluded if they had a chronic illness, other than stroke. Therefore the noted reduction in quality of life may be a result of these other disabilities, not necessarily related to stroke. With a population of older adults the measurement of stroke related disability is said to be extremely difficult because of the overlapping disabilities caused by other illnesses such as osteoarthritis (Warlow, 1998). However, older adults from the stroke and control groups did not differ regarding the number of medical conditions they reported having and the difference between groups was still recorded, suggesting that the difference in quality of life was due to stroke related disability in the stroke group.

An important aspect of the design of any research project is deciding whether to adopt a quantitative or qualitative methodology. The current study utilised a quantitative methodology. This study was the first of its kind to focus exclusively on the lives of older adults post stroke and the lives of their family members. All previous stroke research has included stroke patients of all ages. As this study was the first to focus on the older adult age group, the researcher decided to adopt a broad-brush approach to collecting data. That is, the researcher was interested in many facets of older people's lives following stroke. The researcher wished to collect data from a large group of people regarding these various aspects of their lives post stroke and to compare their responses to that of a large community control group.

Although qualitative data would provide a richness of detail regarding individuals taking part in the study, it is not generalisable to other people or families in similar situations. A quantitative approach may not fully record the contextual detail of the situation but it does provide clear and reliable data with which the researcher can test out different hypotheses. The researcher of the current study was particularly interested in testing out whether previous literature findings would be replicated with an older adult population. Therefore, a quantitative design was the most appropriate for the current study. However, given the possible cohort effect found in this study it may be of interest in the future to conduct a study utilising a qualitative design in order to further investigate how older adults and their family members adjust to life post stroke.

Based on previous literature on stroke and family functioning, the researcher chose one tailed research hypotheses to predict that the lives of older stroke patients and their family members would be negatively affected by the stroke event. Prior research has found that family functioning is different in families where one member has had a stroke. Specifically that stroke patients and their family members report a higher level of unhealthy family functioning than families where no-one has had a stroke. In addition, research has suggested that the individual functioning of patients and family members can also be negatively impacted by the stroke event. Some examples of this impact are; reduced levels of quality of life, reduced access to social support and heightened levels of anxiety and depression. Given this previous literature, the researcher chose the specific one-tailed hypotheses outlined in section 1.10 as being the most likely outcomes of the current study. In retrospect, however, it may have been prudent to choose more exploratory hypotheses given the fact that no study has looked exclusively at older adult stroke patients and therefore it is not certain that the findings from previous literature would map onto the findings for this age group. Indeed, the results of this study suggest that the adjustment experience of older adults and their family members does in fact differ from that of younger stroke patients and their families. In fact, the results of the study allude to the strength and resilience of the older adult population, and this perhaps is the way forward for clinical and research practice when working with older stroke patients and their families. In hindsight, therefore, the researcher may not have chosen one tailed research hypotheses and will bear this in mind for future research projects.

4.3.4 Questionnaire measures

The use of self report questionnaires could be thought of as a limitation; however this research was interested in people's own perceptions of their current life situation, therefore these measures appeared suitable for the task. Some older adults and family members in the stroke group stated that the questionnaires failed to capture the complete experience associated with living their lives post stroke. It may therefore be appropriate to include a qualitative aspect in future research to ensure detailed information about the family's circumstance is adequately conveyed.

The measures chosen were not necessarily specific for research with either stroke patients or with older adults which could be perceived as a limitation of the study. For example, a stroke specific quality of life assessment, such as the Stroke Impact Scale (Lai et al., 2003) and an older adult specific quality of life assessment such as the WHOQOL OLD (Power, Quinn & Schmidt, 2005) may have been employed to provide a comprehensive picture of quality of life for the patient population of this study. However, this study comprised of a healthy control group as well as stroke patients and some of the family members were under the age of 60, which is below the recommended age for use with the WHOQOL Old (Power et al., 2005).

Given the different relationships that stroke patients and their family members had, it is apposite to reflect on the assessment tool used to investigate family functioning. The Family Assessment Device (FAD) has been used within previous stroke research and was therefore chosen for the current study as a means to adequately compare the results of this study with previous literature on this topic. However, the FAD contains numerous questions which are best answered by family members still living with each other, which was not the case for all of the families taking part in this study. In addition, there are other assessment tools which can be utilised with specific family relationships, for example, the Dyadic Adjustment Scale (Spanier, 1976) which is a measure of couple relationships and therefore may be more appropriate for spouses to complete than the FAD. Future research into the adjustment of families post stroke should consider the nature of the relationships of participants before deciding on which assessment tool to use.

4.4 Future research

Suggestions for future research have been proposed throughout the discussion so shall not be repeated here. A further suggestion for any replication study is the possible inclusion of the WHOQOL 100 (The WHOQOL Group, 1998) quality of life assessment to replace the WHOQOL Bref. This would perhaps provide a more in depth analysis of perceived quality of life and help extrapolate the exact nature of perceived quality of life which older stroke patients find difficult, which may provide useful information for clinical working with older adults who experience stroke.

4.5 Clinical Implications

Although the majority of findings in the current study indicate that families in which an older adult has had a stroke do not differ significantly from families where no one had a stroke, the finding that older adults in the stroke group reported a lower perceived quality of life should not be overlooked. This finding provides support for clinicians asking stroke patients about their quality of life, independent of mood assessment, and regarding quality of life as a possible focus for intervention in working with stroke patients.

In addition, the finding that families appear to adapt well to life post stroke should be highlighted when working with patients and their families post stroke. It is understandable and expected that families will experience a crisis reaction to stroke and the many and varied residual effects of stroke that may occur. With this in mind, all individuals experiencing stroke and their family members may benefit from emotional support from clinicians involved in their care. Although stroke participants in this study did not exhibit clinically significant symptoms of depression or anxiety, it remains the case that these difficulties are known to be common post stroke (Angstrom, 1996; House, 1987; Starkstein & Robinson, 1989; Voelker, 1996,). Therefore, all stroke patients and their family members should be assessed for the presences of mood disorders and, if a disorder is identified, individuals should be referred for treatment of this mood disorder.

In light of the findings in this study suggesting that negative psychosocial consequences for the family system do not necessarily follow from stroke, it may prove useful to spend time identifying and discussing the various strengths a family has. This might be in relation to the quality of their family relationships (pre-morbidly or currently), how effectively they communicate or solve problems as a family or the quality of their social support networks. A systemic assessment regarding families' coping strategies post stroke would provide the clinician with valuable information for use within therapy.

Erikson (1963), suggested a psychosocial model regarding individual development which, to be fully understood, has to be viewed in the context of people's social relationships. Carter and McGoldrick (1999) developed the family life cycle model as a framework for understanding how family systems progress throughout the lifespan. Both models agree that individuals are also part of wider family systems. Therefore, it has been suggested that if individuals are experiencing difficulties with their daily functioning, this may have an impact of the rest of their family and negatively impact the overall functioning of the family. This study provides tentative evidence for the beneficial impact that positive individual functioning may have on overall family functioning in the context of an older adult family member having stroke as a chronic illness. If this positive relationship is found to be substantiated, then clinicians working with stroke families would be best placed to build on family strengths, and the strengths of individuals within the family, instead of focusing solely on the difficulties that stroke can have for individual and family functioning.

4.5 Conclusion

The aim of this exploratory study was to ascertain whether family functioning was different in families where an older adult member had experienced a stroke. In order to do this, the study assessed the subjective perceptions of life from the perspective of the stroke patient and one of their family members. A control group of older adults and family members was also included in order to view the results of the study in the context of healthy functioning families. Results revealed that stroke did not negatively impact on either the individual functioning of older adults or their family members or the overall functioning of the family. The only exception to this was that older adults from the stroke group reported lower levels of quality of life than the older adults in the control group, suggesting that focusing on quality of life issues may be an important topic for clinicians to assess and focus on when working with older adult stroke patients. Results of the study were interpreted as suggesting a cohort finding with regards adjusting to life post stroke. The stroke event is perhaps an expected consequence of ageing, and one that is in accord with the developmental sequence highlighted in both individual and family life cycles. However, rather than this expectation leading to a negative outcome for patients and their family members, it may in fact be a valuable coping mechanism for dealing with the illnesses and losses that people are faced with in later life.

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Appendices

Appendix 1

Demographic Questionnaire (older adults)

Demographic Questionnaire-OA Participant Information Number……………………

Demographic Questionnaire - About you

Before you begin we would like to ask you to answer a few questions about yourself. **Please respond by circling or ticking** the correct answer **or by filling the space provided.**

1. What is your **gender**? Male Female

2. What is your **date of birth**? ______ / ________ / ________

Day Month Year

3. What is your **marital status**?
   - Single (never married)
   - Married
   - Partnered (other that married)
   - Separated / Divorced (not currently partnered)
   - Widowed

4. What is the **highest level of education** you received?
   - Primary school
   - High school
   - Trade or technical certificate
   - College diploma or degree
   - University degree
   - Other: Please specify

____

5. What is/was your **occupation**?

____

____

6. What are your **living arrangements?**
   - Living alone
   - Living with partner/spouse
   - Living with partner/spouse and family
   - Living with family in their home
   - Living in residential care
   - Other: Please specify

____

6. In general do you consider yourself to be currently **healthy or unhealthy?**
   - Healthy
   - Unhealthy

7. Please provide details of any **medical condition(s)** you have which you feel might affect your quality of life

9a. If you have any medical conditions, do you use **any medication** for it?

- Yes
- No

- 9b. If yes, please provide details of the medications you use:

In order to answer the following questions, please read these two statements

- If you have had a stroke, please answers questions as being related to any changes occurring since your stroke
- If you have never had a stroke, please answer questions in relation to the beginning of this year (2006)

10. Have you noticed **any changes** in your **memory?** (please circle)

YES **NO**

- If yes, how much do these changes affect your everyday life?

0	+	++	+++	++++
Not at all	very little	somewhat	moderately	severely

11. Have you noticed **any changes** in your **ability to concentrate?**

YES **NO**

- If yes, how much do these changes affect your everyday life?

0	+	++	+++	++++
Not at all	very little	somewhat	moderately	severely

12. Have you experienced **any changes** in your **problem solving abilities?**

YES **NO**

- If yes, how much do these changes affect your everyday life?

0	+	++	+++	++++
Not at all	very little	somewhat	moderately	severely

13. Any **changes in speech?**

YES **NO**

- If yes, how much do these changes affect your everyday life?

0	+	++	+++	++++
Not at all	very little	somewhat	moderately	severely

14. Have you noticed **any other changes?**

More irritable?	**YES**	**NO**
More impatient/impulsive?	**YES**	**NO**
More weepy?	**YES**	**NO**
More stressed/restless?	**YES**	**NO**
Less confident?	**YES**	**NO**
Less sociable?	**YES**	**NO**
Less interest in things that you used to enjoy?	**YES**	**NO**

15. Have you **ever had a stroke**?

- Yes
- No

If yes, **when** did you have this stroke? __________ / ____________

Month Year

16. What is the nature of your relationship with the family member also completing these questionnaires?

- Husband / Wife
- Brother / Sister
- Daughter / Son
- Daughter in-law / Son in-law
- Other: Please specify

____

17. What is your relationship like with this family member?

- Very good
- Good
- Neither good nor poor
- Poor
- Very poor

18. Has your relationship always been like this or has it changed?

- Better before
- Better now
- Relationship has not changed
- Worse before
- Worse now

Thank you for your time.

Appendix 2

Demographic Questionnaire (family members)

Demographic Questionnaire - About you

Before you begin we would like to ask you to answer a few questions about yourself. Please respond by circling or ticking the correct answer or by filling the space provided.

1. What is your gender? Male Female

2. What is your date of birth? ______ / ________ / ________

Day Month Year

3. What is your marital status?

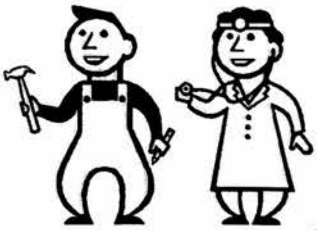
- Single (never married)
- Married
- Partnered (other that married)
- Separated / Divorced (not currently partnered)
- Widowed

4. What is the highest level of education you received?

- Primary school
- High school
- Trade or technical certificate
- College diploma or degree
- University degree
- Other: Please specify

____

5. What is/was your **occupation**?



____

____

6. What are your **living arrangements**?
   - Living alone
   - Living with partner/spouse
   - Living with partner/spouse and family
   - Living with family in their home
   - Living in residential care
   - Other: Please specify

____

7. In general do you consider yourself to be currently **healthy or unhealthy?**
   - Healthy
   - Unhealthy

8. Please provide details **of any medical condition(s)** you have which you feel might affect your quality of life

9a. If you have any medical conditions, do you use **any medication** for it?

- Yes
- No

- 9b. If yes, please provide details of the medications you use:

In order to answer the following questions, please read these two statements and answer about the family member also completing these questionnaires

- If your family member has had a stroke, please answers questions as being related to any changes occurring since their stroke
- If they have never had a stroke, please answer questions in relation to the beginning of this year (2006)

10. Have you noticed **any changes** in your **family members' memory?** (please circle)

YES **NO**

- If yes, how much do these changes affect their everyday life?

0	+	++	+++	++++
Not at all	very little	somewhat	moderately	severely

11. Have you noticed **any changes** in their **ability to concentrate?**

YES **NO**

- If yes, how much do these changes affect their everyday life?

0	+	++	+++	++++
Not at all	very little	somewhat	moderately	severely

12. Have you experienced **any changes** in their **problem solving abilities?**

YES **NO**

- If yes, how much do these changes affect their everyday life?

0	+	++	+++	++++
Not at all	very little	somewhat	moderately	severely

13. Any **changes in speech?**

YES **NO**

- If yes, how much do these changes affect their everyday life?

0	+	++	+++	++++
Not at all	very little	somewhat	moderately	severely

14. Have you noticed **any other changes in your family member**?

More irritable?	**YES**	**NO**
More impatient/impulsive?	**YES**	**NO**
More weepy?	**YES**	**NO**
More stressed/restless?	**YES**	**NO**
Less confident?	**YES**	**NO**
Less sociable?	**YES**	**NO**
Less interest in things that they used to enjoy?	**YES**	**NO**

15. Have **YOU** ever had a stroke?

- Yes
- No

If yes, **when** did you have this stroke? _________ / ____________

Month Year

16. What is the **nature of your relationship with the family member** also completing these questionnaires?

- Husband / Wife
- Brother / Sister
- Daughter / Son
- Daughter in-law / Son in-law
- Other: Please specify

____

17. What is your **relationship** like **with** this **family member**?

- Very good
- Good
- Neither good nor poor
- Poor
- Very poor

18. Has your relationship **always been like this or** has it **changed**?

- Better before
- Better now
- Relationship has not changed
- Worse before
- Worse now

Thank you for your time.

Appendix 3

Family Assessment Device (FAD)

Participant Information Number………………..

Family Assessment Device (FAD)

The following pages contain a number of statements about families. Please **read each statement carefully,** and **decide how well it describes your own family.** You should **answer according to how you see your family.**

For each statement there are **four possible** responses:

1 = Strongly Agree	Select 1 if you feel that the statement describes your family very accurately.
2 = Agree	Select 2 if you feel that the statement describes your family for the most part.
3 = Disagree	Select 3 if you feel that the statement does not describe your family for the most part.
4 = Strongly Disagree	Select 4 if you feel that the statement does not describe your family at all.

Try not to spend too much time thinking about each statement, but respond as quickly and as honestly as you can. If you have trouble with one question, **answer with your first reaction.** Please be sure to **answer *every* statement** and **please circle one number only** for your response.

1 2 3 4

Strongly Agree Disagree Strongly

Agree
Disagree

- Planning family activities is difficult because we misunderstand each other.

1 2 3 4

- We resolve most everyday problems around the house.

1 2 3 4

- When someone is upset the others know why.

1 2 3 4

Participant Information Number………………

Strongly Agree	Agree	Disagree	Strongly Disagree

- When you ask someone to do something, you have to check that they did it.

1 2 3 4

- If someone is in trouble, the others become too involved.

1 2 3 4

- In times of crisis we can turn to each other for support.

1 2 3 4

- We don't know what to do when an emergency comes up.

1 2 3 4

- We sometimes run out of things that we need.

1 2 3 4

- We are sometimes reluctant to show our affection for each other.

1 2 3 4

- We make sure members meet their family responsibilities.

1 2 3 4

- We cannot talk to each other about the sadness we feel.

1 2 3 4

- We usually act on our decisions regarding problems.

1 2 3 4

- You only get the interest of others when something is important to them.

1 2 3 4

- You can't tell how a person is feeling from what they are saying.

1 2 3 4

- Family tasks don't get spread around enough.

1 2 3 4

Strongly Agree	Agree	Disagree	Strongly Disagree

- Individuals are accepted for what they are.

1 2 3 4

- You can easily get away with breaking the rules.

1 2 3 4

- People come right out and say things instead of hinting at them.

1 2 3 4

- Some of us just don't respond emotionally.

1 2 3 4

- We know what to do in an emergency.

1 2 3 4

- We avoid discussing our fears and concerns.

1 2 3 4

- It is difficult to talk to each other about tender feelings.

1 2 3 4

- We have trouble meeting our bills.

1 2 3 4

- After our family tries to solve a problem, we usually discuss whether it has worked or not.

1 2 3 4

- We are too self-centred.

1 2 3 4

- We can express feelings to each other.

1 2 3 4

- We have no clear expectations about toilet habits.

1 2 3 4

Participant Information Number……..……….

Strongly Agree	Agree	Disagree	Strongly Disagree

- We do not show our love for each other.

1 2 3 4

- We talk to people directly rather that through go-betweens.

1 2 3 4

- Each of us has particular duties and responsibilities.

1 2 3 4

- There are lots of bad feelings in the family.

1 2 3 4

- We have rules about hitting people.

1 2 3 4

- We get involved with each other only when something interests us.

1 2 3 4

- There's little time to explore personal interests.

1 2 3 4

- We often don't say what we mean.

1 2 3 4

- We feel accepted for what we are.

1 2 3 4

- We show interest in each other when we can get something out of it personally.

1 2 3 4

- We resolve most emotional upsets that come up.

1 2 3 4

- Tenderness takes second place to other things in our family.

1 2 3 4

Strongly Agree **Agree** **Disagree** **Strongly Disagree**

- We discuss who is to do household jobs.

1 2 3 4

- Making decisions is a problem for our family.

1 2 3 4

- Our family shows interest in each other only when they can get something out of it.

1 2 3 4

- We are frank with each other.

1 2 3 4

- We don't hold to any rules or standards.

1 2 3 4

- If people are asked to do something, they need reminding.

1 2 3 4

- We are able to make decisions about how to solve problems.

1 2 3 4

- If the rules are broken, we don't know what to expect.

1 2 3 4

- Anything goes in our family.

1 2 3 4

- We express tenderness.

1 2 3 4

- We confront problems involving feelings.

1 2 3 4

- We don't get along well together.

1 2 3 4

Strongly Agree	Agree	Disagree	Strongly Disagree

- We don't talk to each other when we are angry.

1	2	3	4

- We are generally dissatisfied with the family duties assigned to us.

1	2	3	4

- Even though we mean well, we intrude too much into each other's lives.

1	2	3	4

- There are rules about dangerous situations.

1	2	3	4

- We confide in each other.

1	2	3	4

- We cry openly.

1	2	3	4

- We don't have reasonable transport.

1	2	3	4

- When we don't like what someone has done, we tell them.

1	2	3	4

- We try to think of different ways to solve problems.

1	2	3	4

Thank you.

Appendix 4

World Health Organisation Quality of Life – Revised (WHOQOL-Bref)

WHOQOL Bref (adapted) Participant Identification Number……………………….

This questionnaire asks how you feel about your quality of life, health, or other areas of your life. Please answer all the questions.

If you are unsure about which response to give to a question, please choose the one that appears most appropriate. This can often be your first response.

Please keep in mind your standards, hopes, pleasures and concerns. We ask that you think about your life in **the last two weeks**.
FOR EXAMPLE, thinking about the last two weeks, a question might ask:

	Not at all	**Not much**	**Moderately**	**A great deal**	**Completely**
Do you get the kind of support from others that you need?	1	2	3	4	5

You should **circle the number that best fits** how much support you got from others over the last two weeks. So you would circle the number 4 if you got a great deal of support from others.

Please read each question and circle the number of the scale for each question that gives the best answer for you

	Very poor	**Poor**	**Neither poor nor good**	**Good**	**Very good**
How would you rate your quality of life?	1	2	3	4	5

	Very dissatisfied	**Dissatisfied**	**Neither satisfied nor dissatisfied**	**Satisfied**	**Very satisfied**
How satisfied are you with your health?	1	2	3	4	5

The following questions ask about how much you have experienced certain things in the last two weeks

	Not at all	**A little**	**A moderate amount**	**Very much**	**An extreme amount**
To what extent do you feel that (physical) pain prevents you from doing what you need to do?	1	2	3	4	5
How much do you need any medical treatment to function in your daily life?	1	2	3	4	5
How much do you enjoy life?	1	2	3	4	5
To what extent do you feel your life to be meaningful?	1	2	3	4	5

	Not at all	**A little**	**A moderate amount**	**Very much**	**Extremely**
How well are you able to concentrate?	1	2	3	4	5
How safe do you feel in your daily life?	1	2	3	4	5
How healthy is your physical environment?	1	2	3	4	5

The following questions ask about how completely you experience or were able to do certain things in the last two weeks

	Not at all	**A little**	**Moderately**	**Mostly**	**Completely**
Do you have enough energy for everyday life?	1	2	3	4	5
Are you able to accept your bodily appearance?	1	2	3	4	5
Have you enough money to meet your needs?	1	2	3	4	5
How available to you is the information that you need in your day to day life?	1	2	3	4	5
To what extent do you have the opportunity for leisure activities?	1	2	3	4	5

	Very poor	**Poor**	**Neither poor nor good**	**Good**	**Very good**
How well are you able to get around?	1	2	3	4	5

The following questions ask you to say how good or satisfied you have felt about various aspects of your life over the last two weeks

	Very dissatisfied	**Dissatisfied**	**Neither satisfied nor dissatisfied**	**Satisfied**	**Very satisfied**
How satisfied are you with your sleep?	1	2	3	4	5
How satisfied are you with your ability to perform your daily living activities?	1	2	3	4	5
How satisfied are you with your capacity for work?	1	2	3	4	5
How satisfied are you with yourself?	1	2	3	4	5

	Very dissatisfied	**Dissatisfied**	**Neither satisfied nor dissatisfied**	**Satisfied**	**Very satisfied**
How satisfied are you with your personal relationships?	1	2	3	4	5
How satisfied are you with your sex life?	1	2	3	4	5
How satisfied are you with the support you get from your friends?	1	2	3	4	5
How satisfied are you with the conditions of your living place?	1	2	3	4	5
How satisfied are you with your access to health services?	1	2	3	4	5
How satisfied are you with your transport?	1	2	3	4	5

The following question refers to how often you have felt or experienced certain things in the last two weeks

	Never	**Seldom**	**Quite often**	**Very often**	**Always**
How often do you have negative feelings such as blue mood, despair, anxiety, depression?	1	2	3	4	5

Do you have any comments about the questionnaire?

THANK YOU FOR YOUR HELP

Appendix 5

Significant Others Scale – Short Form (SOS)

Participant Identification Number:..................

SIGNIFICANT OTHERS SCALE

Please list below **up to three people who are important in your life**. These could include your husband, wife, brother, sister, close friend(s) etc. **For each person** please **circle a number** from 1 to 7 to show **how well he or she provides the type of help that is listed. Please do not put their name - write down the relationship you have with them e.g. sister, wife, friend etc.**

The **second part of each question** asks you to **rate how you would like things to be** if they were exactly as you hoped for. As before please put a circle around one number between 1 and 7 to show what the rating is.

Person 1 – (e.g. sister).....................	*Never*			*Sometimes*			*Always*
1. a) Can you **trust, talk frankly and share your feelings** with this person?	**1**	**2**	**3**	**4**	**5**	**6**	**7**
b) What rating would your ideal be?	**1**	**2**	**3**	**4**	**5**	**6**	**7**
2. a) Can you **lean on and turn to this person in times of difficulty?**	**1**	**2**	**3**	**4**	**5**	**6**	**7**
b) What rating would your ideal be?	**1**	**2**	**3**	**4**	**5**	**6**	**7**
3. a) Does he/she give you **practical help?**	**1**	**2**	**3**	**4**	**5**	**6**	**7**
b) What rating would your ideal be?	**1**	**2**	**3**	**4**	**5**	**6**	**7**
4. a) Can you **spend time with him/her socially?**	**1**	**2**	**3**	**4**	**5**	**6**	**7**
b) What rating would your ideal be?	**1**	**2**	**3**	**4**	**5**	**6**	**7**

Person 2 –	*Never*			*Sometimes*			*Always*
1. a) Can you **trust, talk frankly and share your feelings** with this person?	**1**	**2**	**3**	**4**	**5**	**6**	**7**
b) What rating would your ideal be?	**1**	**2**	**3**	**4**	**5**	**6**	**7**
2. a) Can you **lean on and turn to this person in times of difficulty?**	**1**	**2**	**3**	**4**	**5**	**6**	**7**
b) What rating would your ideal be?	**1**	**2**	**3**	**4**	**5**	**6**	**7**
3. a) Does he/she give you **practical help?**	**1**	**2**	**3**	**4**	**5**	**6**	**7**
b) What rating would your ideal be?	**1**	**2**	**3**	**4**	**5**	**6**	**7**
4. a) Can you **spend time with him/her socially?**	**1**	**2**	**3**	**4**	**5**	**6**	**7**
b) What rating would your ideal be?	**1**	**2**	**3**	**4**	**5**	**6**	**7**

PLEASE CIRCLE ONE NUMBER ONLY FOR EACH QUESTION

Person 3 –	***Never***			***Sometimes***			***Always***
1. a) Can you **trust, talk frankly and share your feelings** with this person?	**1**	**2**	**3**	**4**	**5**	**6**	**7**
b) What rating would your ideal be?	**1**	**2**	**3**	**4**	**5**	**6**	**7**
2. a) Can you **lean on and turn to this person in times of difficulty?**	**1**	**2**	**3**	**4**	**5**	**6**	**7**
b) What rating would your ideal be?	**1**	**2**	**3**	**4**	**5**	**6**	**7**
3. a) Does he/she give you **practical help?**	**1**	**2**	**3**	**4**	**5**	**6**	**7**
b) What rating would your ideal be?	**1**	**2**	**3**	**4**	**5**	**6**	**7**
4. a) Can you **spend time with him/her socially?**	**1**	**2**	**3**	**4**	**5**	**6**	**7**
b) What rating would your ideal be?	**1**	**2**	**3**	**4**	**5**	**6**	**7**

Thank you for completing this questionnaire

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Appendix 6

Hospital Anxiety and Depression Scale (HADS)

Participant Identification Number..........................

HADS

Read each item below and **underline the reply or circle the number** that comes closest to how you have been feeling in the **past week**.

Don't take too long over your replies; **your immediate reaction** to each item will probably be more **accurate** than a long, thought out response.

I feel tense or wound up
3 Most of the time
2 A lot of the time
1 From time to time, occasionally
0 Not at all

I still enjoy the things I used to enjoy
Definitely as much
0 Not quite so much
1 Only a little
2 Hardly at all
3

I get a sort of frightened feeling as if something awful is about to happen
Very definitely and quite badly
3 Yes, but not too badly
2 A little, but it doesn't worry me
1 Not at all
0

I can laugh and see the funny side of things
0 As much as I always could
1 Not quite so much now
2 Definitely not so much now
3 Not at all

Worrying thoughts go through my mind
3 A great deal of the time
2 A lot of the time
1 Not too often
0 Very little

I feel cheerful
3 Never
2 Not often
1 Sometimes
0 Most of the time

I feel as if I am slowed down
Nearly all the time
Very often
Sometimes
Not at all

I get a sort of frightened feeling like 'butterflies' in the stomach
Not at all
Occasionally
Quite often
Very often

I have lost interest in my appearance
Definitely
I don't take as much care as I should
I may not take quite as much care
I take just as much care as ever

I feel restless as if I have to be on the move
Very much indeed
Quite a lot
Not very much
Not at all

I look forward with enjoyment to things
As much as I ever did
Rather less than I used to
Definitely less than I used to
Hardly at all

I get sudden feelings of panic
Very often indeed
Quite often
Not very often
Not at all

I can sit at ease and feel relaxed

0 Definitely
1 Usually
2 Not often
3 Not at all

I can enjoy a good book or radio or television program

Often
Sometimes
Not often
Very seldom

Now check that you have answered all the questions

Thank you.

Appendix 7

Ethics Committee Approval letter

Appendix 7a

Research Governance Approval letter

Appendix 7b

Ethics letter approving amendment to recruitment strategy

Highland Research Ethics Committee

Assynt House
Beechwood Park, Inverness, IV2 3HG
Telephone: 01463 717123
Fax: 01463 235189
Textphone users can contact us via
Typetalk: Tel 0800 959598
www.show.scot.nhs.uk/nhshighland/

NHS
Highland

Mrs Camilla Dyer
Trainee Clinical Psychologist
Department of Psychological Services
New Craigs
6 – 16 Leachkin Road
INVERNESS
IV3 8NP

Date: 24 May 2006
Your Ref:
Our Ref:

Enquiries to: Irene Robertson
Extension: 4844
Direct Line: 01463 704844
Email: irene.robertson@hhb.scot.nhs.uk

Dear Mrs Dyer

Full title of study: **Investigating the impact of chronic illness on family functioning**
REC reference number: **06/S0901/10**

Thank you for your letter of 12 May 2006 responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

Ethical review of research sites

The Committee has designated this study as exempt from site specific assessment (SSA). The favourable opinion for the study applies to all sites involved in the research. There is no requirement for other Research Ethics Committees to be informed or SSA to be carried out at each site.

Conditions of approval

The favourable opinion is given provided that you comply with the conditions set out in the attached document. You are advised to study the conditions carefully.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	*Version*	*Date*
Application, Parts A & B	1	13 April 2006
Investigator CV		13 April 2006
Summary CV for superviser		13 April 2006
Protocol and Summary	1	13 April 2006
Non-validated demographic questionnaire – older adults	2	12 May 2006
Non-validated demographic questionnaire – family members	2	12 May 2006

Letter of invitation to participants (management body)	1	13 April 2006
Letter of invitation to participants (family members)	1	13 April 2006
Letter of invitation to participants ((Group A)	1	13 April 2006
Letter of invitation to participants (Group B)	1	13 April 2006
Participant Information Sheet	2	12 May 2006
Information sheet for community groups	1	13 April 2006
Participant Consent Form (community group)	2	12 May 2006
Participant Consent Form (Group A & family members)	2	12 May 2006
Statement of indemnity arrangements		13 April 2006

Research governance approval

You should arrange for all relevant NHS care organisations to be notified that the research will be taking place, and provide a copy of the REC application, the protocol and this letter.

All researchers and research collaborators who will be participating in the research must obtain research governance approval from the relevant care organisation before commencing any research procedures. Where a substantive contract is not held with the care organisation, it may be necessary for an honorary contract to be issued before approval for the research can be given.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

06/S0901/10 **Please quote this number on all correspondence**

Yours sincerely

pp **Margaret Dakers Thomson**
Chair

Enclosure: *Standard approval conditions (SL-AC2)*

Copy to: *Dr K Laidlaw, clinical & Health Psychology, University of Edinburgh*
Dr C Sinclair. Research Manager, NHS Highland

Medical Director's Office
Raigmore Hospital
Old Perth Road
Inverness, IV2 3UJ
Telephone 01463 704000
Fax 01463 711322
E-mail: alison.graham@raigmore.scot.nhs.uk

NHS Highland

12 June 2006

Mrs Camilla Dyer
Trainee Clinical Psychologist
Department of Psychological Services
New Craigs
6-16 Leachkin Road
Inverness
IV3 8NP

Dear Mrs Dyer,

Research Governance Approval: Non-Commercial Research Project

I am pleased to tell you that you now have Management Approval for the project entitled **'Investigating the impact of chronic illness on family functioning.'** I acknowledge that:

- The project is sponsored by the University of Edinburgh.
- Costs for the project are covered by the Doctorate in Clinical Psychology course at the University of Edinburgh.
- Ethics approval for the project has been obtained from the Highland Research Ethics Committee (reference number: 06/S0901/10).
- The project involves questionnaires and surveys only and therefore has 'Site Specific Assessment exempt' status.
- NHS Highland will not bear any costs associated with carrying out this project.

Please direct all enquiries regarding this letter to the NHS Highland Research Manager (Dr Catherine Sinclair 01463 667317).

Yours sincerely,

Dr Alison Graham,
Medical Director

cc Dr Catherine Sinclair, Unit 18, The Green House, Beechwood Business Park, Inverness IV2 3ED

Highland Research Ethics Committee

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NHS
Highland

Mrs Camilla Dyer
Trainee Clinical Psychologist
Department of Psychological Services
New Craigs
6 – 16 Leachkin Road
INVERNESS
IV3 8NP

Date:	4 October 2006
Your Ref:	
Our Ref:	
Enquiries to:	Irene Robertson
Extension:	4844
Direct Line:	01463 704844
Email:	irene.robertson@hhb.scot.nhs.uk

Dear Mrs Dyer

Full title of study:	**Investigating the impact of chronic illness on family functioning**
REC reference number:	**06/S0901/10**

Thank you for your emails of 21 and 26 September 2006, notifying the Committee of the proposed amendment to the above study.

The amendment has been considered by the Chair.

The Committee does not consider this to be a "substantial amendment" as defined in the Standard Operating Procedures for Research Ethics Committees. The amendment does not therefore require ethical review by the Committee and may be implemented immediately, provided that it does not affect the research governance approval for the research given by the R&D Department for the relevant NHS care organisation.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

06/S0901/10 **Please quote this number on all correspondence**

Yours sincerely

Irene Robertson
Committee Administrator

Copy to: Dr C Sinclair. Research Manager, NHS Highland

Appendix 8

Participant information sheet

Information sheet - all participants

Department of Psychological Services
New Craigs
6-16 Leachkin Road
Inverness IV3 8NP
Telephone 01463 704683
Fax 01463 704686

Enquiries to: Jan Slupek, Secretary
Direct Line: 253697
Email: Camilla.Dyer@hpct.scot.nhs.uk

INFORMATION SHEET FOR PARTICIPANTS

Study Title: An Exploration of Family Functioning Post Stroke

Thank you for reading this.

You are being **invited to take part** in a **research project** to investigate the impact of chronic illness on family functioning. Before you decide whether or not you want to become involved in the research, it is important to understand why the research is being done, and what it will involve. **Please read this information sheet carefully** and discuss it with others if you wish. Please contact the main researcher if you would like to ask any questions or want something clarified regarding the study. **Take time to decide whether or not you wish to take part.**

What is the study about? Why is it important?

The prevalence of chronic illness is said to increase with age to the point where 50-86% of adults aged 65 or over report having at least one chronic illness. Cerebrovascular accident (CVA), or stroke as it is more commonly known, is one such chronic illness and is said to affect approximately 300 000 people a year in the UK. Stroke is said to mainly affect older people, with two-thirds of strokes affecting people over the age of 65. By comparing older adults who have had a stroke and their family members (group A) with older adults who have not had a stroke and their family members (group B) we hope to find out some of the differences between these two groups. **We hope that by finding out more about any difficulties that exist for those families where an older adult has had a stroke, this will lead to better help being available for the older adult themselves, and their families.**

Who is doing the research?

The research is being carried out by Mrs Camilla Dyer, Trainee Clinical Psychologist at the Department of Psychological Services, Inverness. The research is part of her qualification of Doctorate in Clinical Psychology at the University of Edinburgh. Dr Jim Law, Chartered Clinical Psychologist at the Department of Psychological Services in Inverness and Dr Ken Laidlaw, Chartered Clinical Psychologist in NHS Lothian and Senior Lecturer in the Clinical Psychology Department at the University of Edinburgh, will oversee the research.

Why am I being asked to take part?

Two groups of people are **being asked to take part in the study, individuals who have had a stroke** (aged over 65) **and one family member** whom they nominate (group A**) and individuals who have not had a stroke** (also aged over 65) and **one family member** whom they nominate to take part (group B). The family member can be a spouse, son, daughter, sister, brother, daughter in-law etc. but must be over 18. Having these two groups will allow us to compare them, to ascertain whether there are any differences between how families function depending on whether anyone in the family has had a stroke or not. **You have been asked to take part because**, at the moment, **you fit one of these categories.**

Do I have to take part?

It is completely **up to you whether or not you choose to take part.** In addition, if you do agree to take part you can also stop taking part at any time without giving a reason. **Deciding not to take part will not have any adverse effects.**

If I decide to take part, what will it involve?

If you decide to take part in the research study, **you will be asked to complete five short questionnaires**. The questionnaires should take between 40-60 minutes to complete. These questionnaires will ask you about how your family interacts and communicates together, how satisfied you are with your quality of life, how you perceive the level of support you receive as well as asking about your current mood. You will only be asked to complete each questionnaire on **one occasion only**. If completing any of the questionnaires raises any issues that you feel you want help with, please contact the principal researcher (Camilla Dyer) who will be able to discuss these issues with you and if you wish, she will be able to suggest appropriate sources of help.

Will my responses be kept confidential?

All information provided **will be kept strictly confidential.** The only people with access to this information will be the principal researcher and her two supervisors. All of the information gathered will have your name removed so you cannot be recognised.

What are the potential benefits of taking part in the study?

There are **no individual benefits for taking part** in the study. **However,** the **information provided might help those individuals who suffer a stroke, or other chronic illness, and their families.**

What will happen to the results of the study?

The results will be included in a thesis submitted to the University of Edinburgh by the principal researcher. You will <u>not</u> be identified in any publication that may be produced from this research. **You can be sent a summary of these results by contacting the principal researcher any time after February 2007.**

Who has reviewed this study?
The study has been reviewed by the Highland Health Board Research Ethics Committee.

Independent Advice
Dr Jim Law is available to offer independent advice about the project. If you have **any queries about the project or require further information** Dr Law can be contacted at the address below:

Dr Jim Law
Department of Psychological Services
New Craigs
6-16 Leachkin Road
Inverness
IV3 8NP
Telephone: 01463 704683

You can also contact the principal researcher, Mrs Camilla Dyer, at the above address and number.

Please keep this information sheet for your own records.

Thank you very much for considering taking part in this study.

Appendix 9

Inclusion criteria

Department of Psychological Services
New Craigs
6-16 Leachkin Road
Inverness IV3 8NP
Telephone 01463 253697
Fax 01463 704686

Enquiries to: Jan Slupek, Secretary
Direct Line: 253697
Email: Camilla.Dyer@hpct.scot.nhs.uk

Exploring Family Functioning Post Stroke

Inclusion Criteria for study

- Over 65
- Had a stroke in the last 5 years
- Only had one stroke
- Live in the community, in the Highland region
- Have a family member able to take part in the research also (could be wife, husband, son, daughter, son-in-law, grand-daughter etc as long as they are over 18)

Please contact me if you have any questions about this criteria or any other aspect of this study.

Thank you very much for your help in recruiting participants for this research. It is much appreciated.

Yours sincerely

Camilla Dyer
Principal Researcher
Trainee Clinical Psychologist

Appendix 10

Letter of referral to study

Department of Psychological Services
New Craigs
6-16 Leachkin Road
Inverness IV3 8NP
Telephone 01463 704683
Fax 01463 704686

NHS Highland

Enquiries to: Jan Slupek, Secretary
Direct Line: 703697
Email: Camilla.Dyer@hpct.scot.nhs.uk

Research Study: **An Exploration of Family Functioning Post Stroke**

This form is for those individuals who have agreed that Camilla Dyer can post them the letter of invitation to participate in the study, the consent form and the information sheet for the study. Please send this sheet back to Camilla Dyer in the addressed envelope provided.

If you are unsure about the next stage in the research process for individuals taking part or have any questions about the study, please contact me at the above phone number or email.

Details of individual agreeing that Camilla Dyer can contact them;

Name……………………………………………………………………………

Address…………………………………………………………………………
……………………………………………………………………………………
……………………………………………………………………………………
……………………………………………………………………………………
……………………………………………………………………………………

Post code ………………………………………………………………………

Phone number…………………………………………………………………

Thank you.

Appendix 11

Letter of invitation to participants (older adults)

Appendix 11a

Letter of invitation to participants (family members)

Invitation letter - OA

Department of Psychological Services
New Craigs
6-16 Leachkin Road
Inverness IV3 8NP
Telephone 01463 704683
Fax 01463 704686

Enquiries to: Jan Slupek, Secretary
Direct Line: 253697
Email: Camilla.Dyer@hpct.scot.nhs.uk

To Whom It May Concern,

I would like to invite you to consider becoming involved in a research study, which is investigating the impact of chronic illness on family functioning. We are looking for individuals over the age of 65 to participate in this study as well as wanting them to nominate one family member who will also take part in the research.

Before you decide whether or not to take part in the research it is important to understand why the research is being done, and what it will involve for you. I have enclosed an information sheet about the research study and a consent form. Please read these carefully. Talk about it with your family and friends if you want to. If you have any questions about the research, please do not hesitate to contact me, either by phone on (01463) 704683 or by email at Camilla.Dyer@hpct.scot.nhs.uk.

Please take time to decide whether or not you wish to take part. This is entirely up to you and deciding not to take part in the research will have no adverse effects.

If you are happy to take part in the research study, please complete the consent form attached and return in the stamped addressed envelope. The researcher will then contact you either by phone or post depending on whether you indicate on the consent form that you want her to send out the questionnaires by post or if you would like her to visit you, bringing the questionnaires with her.

In addition, could you please give the yellow letter, information sheet and consent form to one of your family members who we would also like to take part in the research. We would ask you to choose the family member you feel closest to and who you see often.

Thank you for considering taking part.

Yours sincerely,

Mrs Camilla Dyer
Principal Researcher
Trainee Clinical Psychologist

Invitation letter - Family members

Department of Psychological Services
New Craigs
6-16 Leachkin Road
Invemess IV3 8NP
Telephone 01463 704683
Fax 01463 704686

NHS
Highland

Enquiries to: Jan Slupek, Secretary
Direct Line: 253697
Email: Camilla.Dyer@hpct.scot.nhs.uk

To Whom It May Concern,

I would like to invite you to consider **becoming involved in a research study,** which is investigating the impact of chronic illness on family functioning. We are looking for individuals over the age of 65 to participate in this study as well as wanting them to nominate one family member who will also take part in the research. **Your relative has nominated you to take part.**

Before you decide whether or not to take part in the research it is important to understand why the research is being done, and what it will involve for you. **I have enclosed an information sheet about the research study and a consent form.** Please read these carefully. Talk about it with your family and friends if you want to. If you have **any questions about the research,** please do not hesitate to **contact me,** either by phone on (01463) 704683 or by email at Camilla.Dyer@hpct.scot.nhs.uk.

Please take time to decide whether or not you wish to take part. This is entirely up to you and deciding not to take part in the research will have no adverse effects.

If you are happy to take part in the research study, **please complete the consent form attached and return** in the stamped addressed envelope. **The researcher will then contact you** either by phone or post depending on whether you indicate on the consent form that you want her to send out the questionnaires by post or if you would like her to visit you, bringing the questionnaires with her.

Thank you for considering taking part.

Yours sincerely,

Mrs Camilla Dyer
Principal Researcher
Trainee Clinical Psychologist

Appendix 12

Consent form

Department of Psychological Services
New Craigs
6-16 Leachkin Road
Inverness IV3 8NP
Telephone 01463 704683
Fax 01463 704686

NHS
Highland

Enquiries to: Jan Slupek, Secretary
Direct Line: 253697
Email: Camilla.Dyer@hpct.scot.nhs.uk

Participant Identification Number:

CONSENT FORM

Study: An Exploration of Family Functioning Post Stroke
Main Researchers: Mrs Camilla Dyer (Trainee Clinical Psychologist)
Dr Jim Law (Chartered Clinical Psychologist)

Please initial

I have **read & understood** the information sheet for the above study. ⓘ ___________

I am aware that I can **contact the principal researcher** (Camilla Dyer) with any **questions** about the study. ___________

I understand that my participation is **voluntary** & I am **free to withdraw** at any time, without giving any reason and without my medical or legal rights being affected. ___________

I **agree** to take part in the study ☑ ___________

OR

I **do not want** to take part in the study ☒ ___________

Working with you to make Highland the healthy place to be

Chairman: Mr Gary Coutts
Chief Executive: Dr Roger Gibbins BA MBA PhD

NHS Highland, Assynt House, Beechwood Park, INVERNESS
IV2 3HG
Highland NHS Board is the common name of Highland Health Board

Your Name

…………………………………… **Your Signature**……………………………………………

Date …………………………………………..

If taking part in the study, **please complete** the following: **Please initial**

I would like Camilla Dyer to **post me the relevant questionnaires**, which I will complete and return in the stamped addressed envelope. __________

OR

I would like Camilla Dyer to **come to my home**, bringing the questionnaires with her. __________

My address is

____

____

____

____

My **phone number** to arrange the time of the visit is

☎ ____

■■

Researcher's name Mrs Camilla Dyer________ Date consent form received__________

Researcher's signature ______________________

Please return this form.