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Life after Stroke: A Comparative Study

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Abstract

Stroke is a chronic illness and is the leading cause of disability globally in the adult population. The effects of stroke are wide ranging and impact on the stroke survivor's daily functioning and quality of life. To date, most research has focused on short-term outcomes in a clinical setting, rather than examining the longer term consequences of stroke in those who live in the community. To address this, the current study explored daily functioning and participation in a community based stroke sample aged 55-85 years (>2 years post-stroke), compared to a control sample of the same sex and age. Participants completed a battery of questionnaires, (modified Rankin Scale, Barthel Index, Hospital Anxiety and Depression Scale, EuroQol-5 Dimension, and the Short Form-36), and two brief cognitive screening tests (Mini Mental State Examination and the Montreal Cognitive Assessment). A semi-structure interview was also conducted with participants, and a qualitative data analysis was carried out and findings integrated with the quantitative results.

Stroke survivors reported greater disability and reduced health related quality of life across all measures, and they also demonstrated higher rates of anxiety and depression. In addition, they showed higher levels of cognitive impairment. Findings from the qualitative interview revealed that stroke survivor participated in fewer activities both inside and outside the home, and activities were less physically demanding.

The results obtained from this study demonstrated the long term effects of stroke present challenges for stroke survivors which impact on their HRQoL, significantly more than difficulties experienced from the ageing process. Finally,

the MoCA is more sensitive and detecting cognitive impairment in both a stroke and non-stroke population. Implications of the research are discussed.

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Table of Contents

Abstract.....	i
Acknowledgments	ii
Table of Contents.....	iii
List of Tables and Figures.....	v
CHAPTER 1.....
Introduction.....	1
What is a stroke?	1
Epidemiology of stroke.....	3
Demographic characteristics.....	6
Acute effects of stroke.....	9
Long-term stroke outcomes.....	10
Life after stroke: A review of the literature.....	14
Summary.....	28
CHAPTER 2.....
Methodology.....	31
Sample.....	31
Demographic information.....	32
Measures.....	33
Questionnaire.....	33
Disability.....	34
Cognitive functioning.....	37
Anxiety and depression.....	40

Health related quality of life.....	41
Qualitative interview.....	46
Procedure.....	48
Quantitative data analysis.....	49
Qualitative data analysis.....	49
Integration of quantitative and qualitative data.....	50
CHAPTER THREE.....	
Quantitative results.....	52
Demographic characteristics.....	52
Co-morbid conditions.....	52
Comparison of Stroke Group and Control Group on Outcome Measures	58
Relation between HRQoL and Outcome Measures Post-Stroke.....	58
Relation between Age and Outcome Measures.....	62
Comparison of the MMSE and the MoCA.....	62
Summary.....	66
Qualitative results.....	67
Participation in activities.....	67
Health and wellbeing.....	77
Summary of participants' experiences from the stroke group and control group.....	83
Support and services post-stroke.....	84
Limitations in support and services.....	87
Summary of participants' experiences with support and services post- stroke.....	88

CHAPTER FOUR.....	
Discussion and integration of findings.....	90
Age.....	91
Co-morbidity.....	93
Disability.....	94
Cognitive impairment.....	99
Sensitivity of the MMSE and the MoCA.....	102
Depression and anxiety.....	103
Health related quality of life.....	105
Support and services.....	109
Strengths and limitations.....	112
Conclusion.....	114
Implication of the research.....	115
REFERENCES.....	117
APPENDICES.....	137
Questionnaire.....	138
Information sheet.....	155
Consent.....	159

LIST OF TABLES

Table 1:	Distribution of demographic characteristics between the stroke group and control group.....	53
Table 2:	Co-morbid Conditions reported in the stroke and control groups.....	54
Table 3:	Mann-Whitney U test comparing outcome measures of the stroke and control Groups including medians and interquartile range.....	57
Table 4:	Spearman's Correlations Coefficient between total SF-36 and stroke outcomes.....	59
Table 5:	Spearman's Correlations Coefficient between domains of SF-36 and disability outcomes in the stroke group.....	61
Table 6:	Correlations Coefficient between age at time of interview and outcome measures.....	62
Table 7:	MMSE scores in comparison with MoCa scores.....	63

LIST OF FIGURES

Figure 1:	A comparison of the MMSE and MoCA scores for the stroke group.....	65
Figure 2:	A comparison of the MMSE and MoCA scores for the control group.....	65

Introduction

Stroke, or cerebral vascular accident, is a broad term which is used to describe abnormalities in blood supply to the brain (Caplan, 2009). Described as a chronic illness (Kirkevold, 2002), stroke is the second most common cause of death and the foremost cause of disability globally in the adult population, and as such results in extensive physical, psychological, and financial difficulties (Barker-Collo, Feigin, & Dudley, 2007).

Stroke can affect people of any age, however its occurrence is relatively uncommon for young people, with three quarters of first ever stroke affecting those aged 65 years and over (Bonita, 1992; Bonita, Solomon, & Broad, 1997). Subsequently, the population most affected by stroke is the elderly (Hackett, Duncan, Anderson, Broad, & Bonita, 2000) who are potentially already dealing with other issues that arise as a consequence of the ageing process (Bagg, Pombo, & Hopman, 2002; White et al., 2007). The number of stroke survivors is predicted to increase in the future as the size of the ageing population increases (Bonita, 1992; Eilertsen, Kirkevold, & Bjork, 2010). Consequently, the long-term effects of stroke is of significant public health concern (Bonita, et al., 1997), and it becomes essential that stroke research focuses on the long-term disability of stroke survivors to enable accurate planning, and allocation of health services and resources (Anderson et al., 2004; Hackett, et al., 2000).

What is a stroke?

There are two broad types of strokes, ischaemic stroke and haemorrhagic stroke. Ischaemic and haemorrhagic strokes differ according to the course of disruption in blood flow to the affected site in the brain. Ischaemic strokes are

characterised by a decrease in blood supply to the brain, whereas haemorrhagic strokes are characterised by an increase in blood supply to the brain (Robinson, 1998). Around 80% of total strokes are ischaemic, it is haemorrhagic strokes that are most likely to result in poorer post-stroke outcomes (Hardie, Hankey, Jamrozik, Broadhurst, & Anderson, 2003). When a stroke occurs, infarction (cellular death) results within minutes, causing damage which is irreversible, even if blood flow is restored (Sabate & Wimalaratna, 2004).

Ischaemic strokes typically occur as the result of disease, most commonly Arteriosclerosis, where plaques form narrowing the arterial walls, reducing blood supply, and causing the blood to clot. This most commonly occurs in an artery in the neck which leads directly to the brain, known as a thrombosis. Blood clots can also form in an artery elsewhere in the body and travel to the brain via the bloodstream, which is referred to as an embolism (Caplan, 2009). Embolisms can occur without warning and develop at a rapid speed (Robinson, 1998).

A number of embolic strokes occur as a result of an irregular heartbeat condition known as atrial fibrillation. Atrial fibrillation is one of the most common heart conditions, occurring in 0.4% of the population. This is caused by a blood clot which has formed in the heart, and once dislodged, travels to the brain (Caplan, 2009). Another high risk factor for experiencing ischaemic strokes is the occurrence of transient ischaemic attacks (TIA), also known as mini strokes, which increases the risk of a stroke by up to 30% within the first month (Donnan, Fisher, Macleod, & Davis, 2008). TIAs are caused by a temporary disruption of blood flow to the brain, and symptoms are similar to an ischaemic stroke, however symptoms only last from a few minutes to 24 hours (Caplan, 2009). This definition is currently under revision as research has highlighted that an arbitrary

time criteria was too general, and 30-50% of TIAs showed cell damage on a diffusion-weighted Magnetic Resonance Imaging (MRI) (Easton et al., 2009). It has been proposed that a TIA is defined by clinical symptoms lasting <1 hour with no evidence of infarction (Albers et al., 2002).

There are also varying types of haemorrhagic strokes which are identified by their location in the brain. An intra-cerebral haemorrhage occurs when a blood vessel bursts and bleeds into the brain, commonly due to high blood pressure. A sub-arachnoid haemorrhage is when the bleeding occurs between the brain and skull, most commonly due to an aneurysm. This bleeding may also occur outside of the arachnoid but inside the dura mater, which is referred to as a subdural haemorrhage, and when the bleeding is outside of the dura mater but inside the skull it is known as an epidural haemorrhage. Subdural and epidural haemorrhages occur mostly as a consequence of trauma to the brain (Caplan, 2009).

Epidemiology of Stroke

Every year, 15 million people worldwide experience a stroke; as a result, 5 million people will die, and 5 million people will experience permanent disability (Mackay & Mensah, 2004). According to a report by the Ministry of Health in New Zealand, stroke is the second leading cause of death, after ischaemic heart disease, occurring in 45.2 per 100,000 males and 41.6 per 100,000 females (Ministry of Health, 2004)

The primary measure of stroke outcome is survival, and although the initially high fatality risk gradually declines over time, previous stroke history has been found to predict a reduced life expectancy (Anderson, et al., 2004). The

prospect of surviving the acute phase of a stroke varies according to factors such as: severity of stroke (Macciocchi, Diamond, Alves, & Mertz, 1998), stroke subtype (Donnan, et al., 2008; Sacco, Wolf, Kannel, & McNamara, 1982), extent of tissue damage (Anderson, et al., 2004), and age of first stroke (Macciocchi, et al., 1998; Sabate & Wimalaratna, 2004).

Studies have found however, that the foremost predictor of stroke survival is stroke type. In a Perth 10 year follow up study, Hardie et al. (2003) reported that the mortality rate within the first month for stroke patients was 22%, although this increased to 38% for those who experienced an intra-cerebral and subarachnoid haemorrhage compared to 9% for patients with ischaemic stroke. Over the 10 year period of the study the cumulative risk of death overall was found to be 79%, however the greatest period of fatality risk was found to be during the first year post-stroke at 36%. Feign, Lawes, Bennett, Barker-Collo and Parag (2009) identified similar trends in their worldwide review with first month case fatality ranging from 17-30%, ischaemic stroke ranged from 13-23%, and intracerebral and subarachnoid haemorrhage ranging from 25-35% in high income countries.

Stroke mortality rates, over recent decades, have been reported to be steadily declining (Donnan, et al., 2008; Sabate & Wimalaratna, 2004). However, despite a decline in mortality rates, the incidence of stroke in New Zealand is not decreasing at the same rate, resulting in a rise of stroke survivors living with the effects of their stroke thus creating an ever increasing burden on our healthcare system (Tobias, Cheung, Carter, Anderson, & Feigin, 2007). Global trends are similar to New Zealand, with high-income countries demonstrating a decrease in mortality rates and incidence of stroke, while low to middle income countries

have experienced an increased incidence, exceeding that of high-income countries (Feigin, et al., 2009).

Understanding changing trends in stroke mortality and incidence rates is complex, however the most plausible explanation for any decreasing trends in stroke incidence has been advances in understanding risk factors associated with stroke, i.e. hypertension and smoking, alongside improved standards of living (Bonita, 1992; Donnan, et al., 2008; Feigin, et al., 2009), and better access to health care (Sabate & Wimalaratna, 2004). In developing countries, adopted aspects of Western lifestyles such as dietary changes, alcohol consumption and smoking are found to be a significant factor associated with the increase in stroke risk factors, thus leading to an increase in incidence of stroke at a rate which exceeds that of Western countries (Fang, Zimmer, Kaneda, Tang, & Xiang, 2009; Feigin, et al., 2009).

In New Zealand, studies have reported that mortality and incidence trends are consistent with studies from Australia, United States, Asia, Europe & China which show a decline in both mortality and stroke incidence (Feigin, Lawes, Bennett, & Anderson, 2003). However, whether this decline is due to a decrease in associated risk factors or better public awareness of the risk factors for stroke is unclear. According to the Ministry of Health (2004), the top five risk factors for mortality in the New Zealand population are tobacco smoking, blood cholesterol, blood pressure, body mass index and insufficient activity. These risk factors are known as modifiable risk factors which can affect health in many ways, one of which is increasing the risk of stroke (Donnan, et al., 2008; World Health Organisation, 2004).

Demographic characteristics

Demographic characteristics are related to the incidence of stroke and stroke outcomes (Barker-Collo & Feigin, 2006). Feigin et al. (2006) examined ethnic disparities in incidence of stroke subtype between 2002-2003 as part of the Auckland Regional Community Stroke Study. According to their findings, incidences of ischaemic stroke were 1.5-3.0 times higher for Māori, Pacific, Asian, and other non-European people compared with European. In addition, non-Europeans experienced stroke at a younger age across all stroke subtypes compared to those of European descent. A possible reason for the ethnic disparity has been linked to the overrepresentation of risk factors associated with stroke, and the adoption of Western lifestyles. Maori and Pacific Islanders are overrepresented in relation to stroke risk factors such as high blood pressure, smoking, diabetes, (Ministry of Health, 2008) and possibly the greatest influence of long term outcomes, a lower socio-economic status (Feigin et al., 2010; McNaughton, Weatherall, McPherson, Taylor, & Harwood, 2002).

The research into ethnic disparities in post-stroke outcomes yields contrasting findings. McNaughton et al. (2002) compared community outcomes for European and non-European survivors of stroke in New Zealand, and found that non-Europeans experienced more severe strokes and poorer health outcomes 12 months post-stroke, compared to Europeans. More recently (Feigin, et al., 2010) found poorer outcomes 5 years post-stroke were only observed in Māori and Pacific and Asia/other stroke survivors, in the domains of cognitive functioning and higher rates of dementia.

In contrast, age is a widely accepted risk factor associated with stroke, with three quarters of first ever stroke occurring in those aged 65 and over (Bonita, 1992; Bonita, et al., 1997). This age group is also at a higher risk of experiencing a severe stroke with permanent disability (Sabate & Wimalaratna, 2004) and higher mortality rates (Bonita, et al., 1997), therefore the population most affected by stroke is the elderly (Hackett, et al., 2000). The literature yields little consensus as to the effects of age on post-stroke outcomes, suggesting age alone cannot be considered in isolation, and characteristics such as premorbid functioning need to be considered (Bagg, et al., 2002). Other findings suggest that increased age is associated with impairment in activities of daily living (ADL) (Macciocchi, et al., 1998; Nakayama, Jorgensen, Raaschou, & Olsen, 1994), greater disability (Aprile et al., 2006), and cognitive impairment (Patel, Coshall, Rudd, & Wolfe, 2002).

Gender is also considered a variable associated with incidence of stroke. In a systematic review of the literature (Appelros, Stegmayr, & Terent, 2009) found that although incidence of stroke were higher for men (33%), and age of first stroke was younger, (68.6 years, compared with 72.9 years for women), severity of stroke was greater for women. Their findings were similar to Feigin et al. (2006) who found that the mean age of onset for first ischaemic stroke was 69 years for men and 75 years for women. Estimates regarding incidences of stroke in New Zealand from the Auckland Regional Community Stroke Study (ARCOS), report that from age 75+ incidences of stroke are greater for women than men, with a lower life time risk for males (16%) compared to females (18%) (Tobias, et al., 2007).

The higher incidence of stroke in females as they age is considered to occur as a result of women living longer than men, this is why elderly women are

the fastest growing stroke population (Nakayama, et al., 1994; Reeves et al., 2008). Petrea et al. (2009) found that although women developed first ever stroke on average 5 years later than men, they had a greater life time rate of stroke due to their higher life expectancy, and experienced greater post-stroke disability.

Women have also been found to experience poorer post-stroke outcomes than men (Feigin, et al., 2010), and experience greater dependency in ADL (Bonita, et al., 1997). When reviewing sex differences in the stroke literature Reeves et al., (2008) found functional outcome and quality of life post-stroke was less favourable for women than men, and higher incidence of depression were also reported in women. The authors propose that as women experience stroke later in life they are subsequently more likely to experience higher levels of pre-stroke disability. Women are also at an increased risk of experiencing subsequent strokes due to their longevity, and as they tend to outlive their husbands', lack of social support is also identified as impacting on post-stroke outcomes for women.

These findings are of concern, as research suggests that as the elderly population increases, subsequently the number of stroke survivors will increase within the ageing population (Barker-Collo & Feigin, 2006; Bonita, 1992). Feign et al. (2006) reported that incidences of stroke increased as populations aged for both genders, across all stroke subtypes and ethnic groups. This may have a big impact on health care costs as stroke is a major cause of disability worldwide, consuming 2-4% of the total healthcare costs globally (Donnan, et al., 2008). For the stroke survivor, the impact of stroke is not only financial; it often leads to psychological distress and restricted participation in activities across various areas of functioning (Doyle, 2002). Stroke survivors are also at a high risk of

experiencing further vascular events and on-going morbidity (Anderson, et al., 2004).

Acute Effects of Stroke

Symptoms of a stroke can occur without warning and their presentation can vary depending on the severity of stroke and location of lesion (Sabate & Wimalaratna, 2004) leaving the survivor with impairment in physical, psychological and social functioning (Kim, Warren, Madill, & Hadley, 1999). Common symptoms include weakness or numbness of face, arm, leg, typically on one side of the body. Other symptoms that may occur are confusion, trouble speaking or understanding speech; problems with vision, walking, dizziness, and loss of balance or co-ordination. The person may also experience a severe headache, fainting or loss of consciousness (World Health Organisation, 2011).

The immediate effects of stroke depend on stroke subtype, location of lesion, and the extent of damage (Sabate & Wimalaratna, 2004). For example, right hemisphere cell damage can lead to: paralysis, weakness, loss of feeling on the left side of the body, loss of vision and loss of awareness to the left, excessive or slurred speech, eating or swallowing difficulties, difficulty recognising faces, visual spatial relationships and interpreting sound, memory problems, and difficulties with abstract reasoning. Damage to the left hemisphere can result in: paralysis, weakness, loss of feeling on the right side of the body, loss of vision and loss of awareness to the right, difficulties speaking and understanding speech, inability to read or write, disconnected thoughts, verbal memory loss, difficulty performing purposeful actions, difficulty with numbers and left and right, and slow, clumsy movement. (The Stroke Foundation New Zealand, 1998).

Long-term Stroke Outcomes

As the number of stroke survivors increase over time, particularly in developed countries with rapid population improvement and changing lifestyles (Hardie, et al., 2003), stroke survivors will be living longer (Bonita, et al., 1997). After surviving the initial effects of stroke, stroke survivors are then faced with the long term outcomes and recovery (Hankey, Jamrozik, Broadhurst, Forbes, & Anderson, 2002). The stroke literature makes a distinction between short-term and long-term outcomes which Barker-Collo and Feigin (2006) note that short term is considered to be the first three months post-stroke, whereas long term outcomes refer to one year post-stroke onwards.

As noted previously, the decline in stroke mortality rates results in an increase in the number of stroke survivors living within a diverging range of post-stroke outcomes. This is characteristic of the pathophysiological effects of stroke varying for each individual, and stroke outcomes being dependent on the area of the brain in which the cell damage occurred (Collins, 2007). The effects of a stroke can be severe, leaving the survivor with major residual restrictions resulting in high levels of impairment and disabilities (D'Alisa, Baudo, Mauro, & Miscio, 2005), or mild, resulting in minor functional deficits (Eilertsen, et al., 2010).

At least half of stroke survivors are left with some form of long term disability which can include physical, cognitive, emotional, social or vocational difficulties (O'Sullivan & Chard, 2010). The outcome and disability experienced as a consequence of a stroke is determined by factors associated with the brain lesion such as: location, size, type of lesion (Donnan, et al., 2008; Macciocchi, et al., 1998), age (Barker-Collo & Feigin, 2006; Sabate & Wimalaratna, 2004) ,and

premorbid functioning (Hankey, Jamrozik, Broadhurst, Forbes, & Anderson, 2002). Long term outcome is predicted by factors such as residual disability (Hankey, et al., 2002), cognitive functioning (Haacke et al., 2006), physical functioning (Patel et al., 2006), and psychological functioning (Haacke, et al., 2006).

Stroke survivors then go on to face various challenges which are not limited to their overall functioning, but extend to the modification of identity and re-establishing role capabilities, whilst accommodating to acquired deficits in functioning (Salter, Hellings, Foley, & Teasell, 2008). Within the ageing population, this is of a particular concern as many elderly are also dealing with various other comorbidities (Sabate & Wimalaratna, 2004; White, et al., 2007) and other forms of disability prior to their stroke (Bonita, 1992), which could possibly be further exacerbated by post-stroke issues such as loss of motor and sensory functioning.

Therefore, the impact of stroke is a major health concern (D'Alisa, et al., 2005), and despite advances in medical technology, improved health care and education (Gunaydin, Karatepe, Kaya, & Ulutas, 2010), many survivors require continuing support in the community, despite living independently (White, et al., 2007). Being able to regain the ability to walk and function independently in everyday activities is a major concern for stroke survivors (Muren, Hutler, & Hooper, 2008), and deficits in functioning and mobility in everyday life has an huge impact on psychological functioning and wellbeing of the stroke survivor (White, et al., 2007). However, the effects of stroke are not limited to the person who experienced the stroke; the burden of disability extends to families and friends, health-care professionals and the community (O'Sullivan & Chard, 2010).

Although survivors of stroke can often continue to live independently in the community, Hackett et al. (2000) found when looking at health related quality of life in stroke survivors six years after stroke that although 77% were living at home, 46% still required support in at least one aspect of their daily living.

There is now recognition in the literature that when looking at post-stroke outcomes, measures need to extend beyond severity, mortality, and functional status to include physical, psychological and social functioning (Doyle, 2002). Furthermore, the residual effects of stroke go on to restrict an individual's ability to participate in hobbies, leisure, social, and physical activities, and it is understood that having the ability to participate in these activities improves both physical and mental wellbeing (O'Sullivan & Chard, 2010). With this in mind it becomes vital that rehabilitation programmes focus not only on promoting the stroke survivor's capabilities in physical functioning, but also to facilitate the adjustment process in order to maintain a level of participation in activities that promote their health and wellbeing (Gadidi, Katz-Leurer, Carmeli, & Bornstein, 2011; Kirkevold, 2002; O'Sullivan & Chard, 2010; Robison et al., 2009).

Another concern is the high prevalence rates of psychological disorders in stroke survivors (Robinson & Spalletta, 2010) which can lead to further decline in physical impairment, and can have a negative effect on the recovery process. (Pohjasvaara, Vataja, Leppavuori, Kaste, & Erkinjuntti, 2001; West, Hill, Hewison, Knapp, & House, 2010). Depression has been reported as the most common psychological symptom, with a systematic review carried out by Hackett, Yapa, Parag and Anderson (2005) which reported a pooled estimate of 33% of stroke survivors experiencing depression which was considered to occur most commonly in the first few months post-stroke. Incidences of post-stroke

anxiety have shown a different trend to depression although not as extensively researched. When looking at anxiety and depression 3 years post-stroke, Morrison, Pollar, Johnston, and Walter (2005) found that episodes of depression decreased overtime, whereas the experience of anxiety remained stable 3 years after a stroke.

Impairment in cognitive functioning after a stroke is also common, however deficits in functioning can vary according to age (Viscogliosi et al., 2011), ethnicity, (Feigin, et al., 2010), lesion site, and severity of stroke (Patel, et al., 2002). Deficits in cognitive function have also been associated with impairment in activities of daily living (ADL) (Feigin, et al., 2010), depression (Hackett & Anderson, 2005), the ability to participate in activities (Viscogliosi, et al., 2011) and poorer long term outcomes (Patel, et al., 2002). Rates of cognitive impairment after a stroke vary in the literature as often those with severe cognitive impairment are excluded (Patel, et al., 2002; Rasquin et al., 2004). There is a lack of standardised cognitive assessments for stroke (Gottesman & Hillis, 2010), and furthermore the studies typically focus on short term outcomes (Hochstenbach, den Otter, & Mulder, 2003).

Despite the growing population of stroke survivors living with the effects of their stroke, there is limited research into the challenges and difficulties this population continue to face long term (Eilertsen, et al., 2010). A benefit of long term outcome research is that the enduring impact that stroke has on survivors is most accurately measured after maximum clinical and functional recovery has occurred, and community-based studies that follow stroke survivor populations enable the functional status of these populations to be assessed (Gresham et al., 1975). To help understand the actual impact the stroke has on an individual's life,

these samples can be matched with age and sex control groups to enable a comparison of functioning and experience (Gresham et al., 1998; Hackett, et al., 2000), and changes that may occur due to other conditions (Haley, Roth, Kissela, Perkins, & Howard, 2011). In order to obtain a more comprehensive understanding of the effects of stroke and the experiences of a stroke survivor, it is beneficial to apply multiple outcomes measures.

Life after Stroke: A Review of the Literature

There are an extensive number of studies within the literature that explore post stroke outcomes, some of which will be discussed in the following review. Research in this area predominantly focuses on the short term post-stroke outcomes (Feigin, et al., 2010), and is biased towards participants associated with hospital and rehabilitation settings (Hackett, et al., 2000). Currently there is an under representation of community-based stroke research looking at long-term outcomes for stroke survivors (Barker-Collo, Feigin, Parag, Lawes, & Senior, 2010). Long term post-stroke research is crucial in helping stroke survivors, families and healthcare providers to more adequately prepare for the future, as well as creating evidence based long term rehabilitation and educational programmes that provide better outcomes for stroke survivors (Feigin, et al., 2010; Gadidi, et al., 2011).

New Zealand research has made a considerable contribution to the post-stroke outcome literature (Barker-Collo, et al., 2010; Barker-Collo, et al., 2007; Bonita & Beaglehole, 1988; Bonita, et al., 1997; Feigin, Barker-Collo, McNaughton, Brown, & Kerse, 2008; Gottesman & Hillis, 2010; Hackett, et al., 2000; McNaughton, et al., 2002). Stroke trends in New Zealand are considered

similar to those of Australia, United States, Asia, Europe & China (Feigin, et al., 2009), however a study by McNaughton, DeJong, Smout, Melvin and Brandstater (2005) found significant differences in rehabilitation practices and outcomes for stroke survivors between New Zealand and United States, with US stroke survivors experiencing more favourable outcomes. These outcomes were considered to be the result of more intensive rehabilitation practices in the U.S, with less time spent in assessment and non-functional activities than in New Zealand practice.

The largest incidence and outcome study in New Zealand is the Auckland Stroke Outcomes Study (ASTRO) (Feigin, et al., 2010) where in the most recent study, 418 participants were followed up from the previous Auckland Regional Community Study (ARCOS III). The authors found that at five years post-stroke, neuropsychological functioning and level of participation in activities greatly influenced outcomes. Two thirds of stroke survivors demonstrated good functional outcomes, with 70.6% demonstrating independence in ADL, although two-thirds of participants self-reported an incomplete recovery.

Ethnicity and gender differences were also explored. Women were found to have experienced poorer outcomes than men, and Māori and Pacific Islanders were severely disadvantaged in economic self-sufficiency. Non- Europeans (Maori, Pacific Islander and Asian/other) developed symptoms of dementia double that seen in European stroke survivors, which is possibly associated with education and socio-economic status. However, no disparities were found between European and non-European in terms of other functional outcomes. The authors concluded that the association between neurological deficits and the various outcomes found to be associated with stroke highlight the benefits of a

multidisciplinary approach to both research and structuring rehabilitation programme.

Examining long term stroke outcome studies can be challenging as studies tend to be cross-sectional and participants are assessed during varying stages of post-stroke recovery (Patel, et al., 2006) and samples often are not community based (Nakayama, et al., 1994). Also because most stroke survivors are >65, separating the effects of stroke from the ageing process can also prove difficult, as the negative effects of ageing and other comorbidities can also impact negatively on functional outcomes (Bagg, et al., 2002; Haley, et al., 2011; White, et al., 2007).

Co-morbidity is considered common in stroke survivors with hypertension, hyperlipidaemia, diabetes and cardio vascular disease frequently being reported (Karatepe, Gunaydin, Kaya, & Turkman, 2008), further complicating the recovery process (Studenski, Lai, Duncan, & Rigler, 2004). In exploring, this Karatepe et al. (2008) found a negative correlation between functional gain and co-morbid disease. Arnold et al. (2008) also reported similar findings with looking at outcomes of acute ischaemic stroke. Studenski et al (2004) found co-morbidity to be a strong predictor of functional outcomes when taking into account age and baseline functioning.

Premorbid functioning may provide an explanation in the variation of post-stroke functional outcomes (Bagg, et al., 2002), although research into this area has yielded mixed finding. Hankey et al. (2002) found premorbid functioning to be a prognostic factor for post-stroke outcomes, and the only amendable predictor of these outcomes. In contrast, Macciocchi et al. (1998) found, when

looking at ischaemic stroke survivors, age was a predictor of poor functional outcome, whereas premorbid conditions were found to be a poor predictor.

To determine whether outcomes are influenced by the effects of the stroke or difficulties that arise from the ageing process and associated medical conditions, incorporating age and sex-matched control populations into the study design can help separate the effects of stroke from the ageing process. Using this study design, Gresham et al. (1998) compared stroke survivors from the original 1972-1974 Framingham cohort to an age and sex-matched control group.

Although this was a small sample size, the functional status of stroke survivors was found to be higher than the control group. Anderson et al. (2004) also found that long term post-stroke outcomes in stroke survivors were comparable to a normal population. In a similar study design participants were followed up 21 years after their participation in a previous study. Although this stroke cohort had a mortality rate twice as high as the New Zealand population (70%), of the 50 stroke survivors, more than half reported they had recovered, and findings from the Short Form-36 demonstrated comparable level of dependency when compared to a standardised New Zealand sample.

Kirkvold (2002) described the trajectory of stroke as having an acute onset, followed by an initial rapid improvement which gradually slows to a stable rate of recovery, suggesting a likelihood that many will adjust to the residual effects of their stroke. Hackett et al. (2000), when comparing six year stroke survivors to an age and sex-matched control group found that although the stroke survivors scored lower in areas of physical functioning and general health, no differences were found in domains for mental health and bodily pain. From their findings, the authors concluded that despite on-going physical disabilities, stroke

survivors had adjusted well to their disabilities. However, when White (2007) compared function and health related quality of life in stroke survivors at 1, 3 and 5 year intervals they found that although function remained stable, a high number relied on community support and despite needs being met; emotional wellbeing was reported to be low. Similar to Patel et al. (2006) who found that at 3 years post-stroke, disability in stroke survivors was still prevalent and perception of health status was low, however this study found mental health to be satisfactory.

Research has shown age to influence post-stroke outcomes in ADL (Feigin, et al., 2010; Macciocchi, et al., 1998; Nakayama, et al., 1994), increased dependency (Feigin, et al., 2010), participation in activities (Gadidi, et al., 2011), and health related quality of life (Aprile, et al., 2006; Haacke et al., 2006; Haley, et al., 2011). Bagg et al. (2002) found age to have the most effect on functional outcomes in relation with functional status at time of admission. At ten years post-stroke, Wolfe et al. (2011) found increased age to be associated with greater disability, inactivity, and cognitive impairment, but poorly associated with anxiety, depression and HRQoL. Similarly, in a 3 month follow-up study after observing low quality of life (QoL) in stroke patients compared to a general sample, Gunaydin et al (2010) divided the stroke group into ≥ 65 years and < 65 years and found little difference between the geriatric patients and non-geriatric, suggesting that age did not affect QoL. Work/productivity was found to be the most influenced subscale of QoL in both the geriatric patients and non-geriatric patients.

Ween Alexander, D'Esposito and Roberts found age to be a relevant predictor of stroke recovery in the young and very elderly population (as cited in (Barker-Collo & Feigin, 2006)). With one quarter of strokes occurring in those

under 65 years, the on-going needs and outcomes for this age cohort may differ from the older population. Given the financial impact of stroke, the focus on returning to work generally becomes the benchmark for recovery (Daniel, Wolfe, Busch, & McKeivitt, 2009). However, employment also provides a means from which a person sees themselves in society, and as such, also provides an emotional and functional motivation for recovery (Hartke, Trierweiler, & Bode, 2011). Daniel et al. (2009) in their systematic review, found that the social consequences of not being able to return to work not only negatively impact on social participation but also extend to family life, financial status, and sex life. Hartke et al. (2011) also explored the potential for employment to greatly influence post-stroke outcomes. The authors identified several themes which focused on barriers such as stroke survivors' perception of their work potential, support, impairment, psychological issues, and organisational influences. This study indicated that by addressing factors such as these, stroke survivors can increase the potential for employment opportunities after stroke.

Considering the significant life changes brought about by stroke, survivors are more likely to experience psychological disorders than the general population (Barker-Collo, 2007; Hackett, et al., 2005), and the effects of mood disorders go on to influence long term recovery (Pohjasvaara, et al., 2001; West, et al., 2010). Reported rates of depression vary according to the setting of the stroke population, and length of time post-stroke. After reviewing the literature, Robinson and Spalletta (2010) found rates of symptoms associated with major depression were reported by 21.7% of stroke survivors, and mild symptoms reported by 19.5% of stroke survivors. Wolfe et al. (2011) identified that over a

10 year period, rates of depression fluctuated with an average of 31% of stroke survivors experiencing depression.

Research has noted various relationships between stroke and depression. Studies have shown that depressive symptoms in stroke survivors have been associated with greater cognitive impairment (Robinson & Spalletta, 2010), ADL (Feigin, et al., 2010; Robinson & Spalletta, 2010), psychosocial difficulties (Feigin, et al., 2010; Teoh, Sims, & Milgram, 2009), greater disability (Aprile, et al., 2006), restriction in activity participation (D'Alisa, et al., 2005; Feigin, et al., 2010), QoL (Choi-Kwon, Choi, Kwon, Kang, & Kim, 2006; Feigin, et al., 2010) and health related quality of life (HRQoL) (Haacke, et al., 2006). However, despite the range of impact, episodes of depression have been shown to decrease over time (Hackett & Anderson, 2005; Morrison, et al., 2005; Patel, et al., 2006; Teoh, et al., 2009).

Unlike depression post-stroke, rates of anxiety have been found to be more stable (Åström, 1996; Morrison, et al., 2005). Prevalence rates of anxiety have been found to be less than that of depression. Barker-Collo (2007) found that at 3 months post-stroke, rates of depression and anxiety (from mild to severe) were 45.6% and 38.6% respectively. Between 2-5 years post-stroke, Bergersen, Frosli, Sunnerhagen and Schanke (2010), found that of 162 respondents, 36% had possible anxiety disorder, 27.8% had possible depression, and 17.3% reported comorbid symptoms. At three years post-stroke, Morrison et al. (2005) noted stable rates of anxiety with female gender, and earlier anxiety predicting a greater likelihood of anxiety post-stroke. Åström (1996), also identified similar trends in acute stroke patients, demonstrating no significant decrease of anxiety by 3 years post-stroke.

Similar to depression, the experience of anxiety post-stroke has been associated with poorer functional outcomes and social relationships (Åström, 1996; Barker-Collo, 2007). Shimoda and Robinson (1998) found between 3- 24 months post-stroke, when anxiety was experienced alongside depression, there was greater impairment in ADL than depression alone, and depressive symptoms lasted longer and were more severe. However, there was no relation between anxiety and cognitive impairment, whereas depression was found to influence cognitive functioning. In contrast, Barker-Collo (2007) found that at 3 months post-stroke, mood disturbances were more likely to affect cognitive functioning than physical functioning. At 3 years post-stroke, Åström (1996) found anxiety to be associated with dependence in ADL and reduced social networks.

Cognitive impairment is also considered to be an issue post-stroke (Patel, et al., 2002) further influencing functional outcomes (Barker-Collo & Feigin, 2006; Barker-Collo, et al., 2010). Stroke survivors may experience progress in physical functioning, but still be unable to resume previous activities and employment due to cognitive deficits (Gottesman & Hillis, 2010; Viscogliosi, et al., 2011). To explore the frequency of cognitive impairment post-stroke, Rasquin et al. (2004) found that in a sample of 198 stroke survivors 65% presented with mild cognitive impairment, and 10% were found to present with post-stroke dementia. Mental speed and calculation were shown to be the most affected, whereas memory showed little deterioration. At 1 year post-stroke, improvement was noted for some, and to a lesser extent deterioration was also detected, however for most, cognitive functioning remained stable.

Hochstenbach, de-Otter and Mulder (2003) also identified similar rates of improvement at 2 years post-stroke, although this was predominantly in attention

and language, and only some demonstrated improvement in memory. At 5 years post-stroke, Barker-Collo et al. (2010) found neuropsychological deficits were independently associated with poor functional outcomes more so than gender, age, education, and depression.

Cognitive deficits following stroke have also been shown to influence participation in activities. Viscogliosi et al. (2011), found that at 3 weeks after being discharged home deficits in memory, visual perception, and language were associated with restriction in participation. This was most notable in those aged 65 and over. Cognitive impairment was found to result in more restrictions in social roles than in ADL.

As a long-term predictor of post-stroke outcomes, Patel, Coshall, Rudd and Wolfe et al. (2002) found that cognitive impairment 3 months post-stroke was negatively associated with long term survival, disability, and increased dependency up to 4 years post-stroke. The authors suggested that those with cognitive impairment were more likely to experience more severe cerebrovascular disease, be non-compliant with medication, and more likely to have relationship difficulties with family and careers due to their decreased ability to manage their physical impairment.

Impairment in physical and cognitive functioning post-stroke, as well as psychological distress, go on to influence the stroke survivors QoL (Kim, et al., 1999). For the stroke survivor, a decline in HRQoL is the most significant effect of stroke (Aprile, et al., 2006). Although QoL and HRQoL appear at times to be used interchangeably in the literature, they are two separate constructs (Doyle, 2002). QoL is considered a broad concept which incorporates whole aspects of an

individual's life that may or may not be related to health, such as standard of living, spirituality, education (Doyle, 2002). HRQoL refers to aspects of people's lives that are associated with health and health related outcomes (Salter, Moses, Foley, & Teasell, 2008).

Outcome measures of HRQoL within the stroke literature are most commonly explored by using measures of ADL, typically the Barthel Index and the modified Rankin Scale (*see methodology for a description of these measures*) (Haacke, et al., 2006; Kim, et al., 1999). However, as the effects of stroke go beyond physical functioning, it is crucial to consider the possible multi-determinants that predict HRQoL and QoL post-stroke (Haacke, et al., 2006; Teoh, et al., 2009). To achieve this it is necessary for QoL and HRQoL measure to incorporate a multidimensional framework, and consider global aspects of functioning in multiple areas (Salter, Moses, et al., 2008).

In order to predict QoL and HRQoL in stroke survivors, the association between disability and QoL are often considered, with greater disability predicting a reduced QoL. When exploring this, Aprile et al. (2006), reported that stroke survivors who demonstrated high levels of disability according to their physician, also reported themselves restricted in daily activities. Furthermore, domains of mental health were associated with greater disability and negatively predicted QoL for subsequent years after stroke.

Similarly, Gunaydin et al (2010) found at 3 months post-stroke, depression negatively affected QoL alongside stroke severity, functional status, and ability to walk. Choi-Kwon, Choi, Kwon, Kang and Kim (2006) identified dependency in ADL, depression, and pain as predictors of QoL post-stroke. These domains

continued to be related to QoL post-stroke at 3 years alongside low socio-economic status. Even stroke survivors with mild residual disabilities have demonstrated a reduced HRQoL. Muren et al. (2008) identified a decrease in functional capacity and HRQoL particularly in areas related to physical activity in mild stroke survivors between 60-104 months post-stroke. Patel et al. (2006) also found the relationship between disability and HRQoL to be evident up to 3 years post-stroke, whereas mental health was found to be satisfactory.

Although the physical effects of stroke are considered a key determinant in both QoL and HRQoL, there is an increased awareness that psychosocial factors also influence QoL (Gunaydin, et al., 2010). Therefore, although it is understood that dependency in mobility and self-care are the most acute issues, psychosocial and environmental issues have been found to be more prevalent in the stroke population (Gresham et al., 1979). Psychosocial factors that predicted HRQoL 6-24 months post-stroke were explored by Teoh, Sims, and Milgram (2009). Their findings highlighted factors such as depression, self-esteem, and perceived control as predictors of HRQoL, with those who reported high levels of depression reporting lower levels of HRQoL. Kim et al. (1999) also sought to identify the key predictors of QoL between 1-3 years post-stroke. Psychosocial predictors such as depression and social support were also found to predict QoL, as well as improvement in functional status although this was not considered necessary for effective rehabilitation.

The ability to accommodate acquired disabilities is also another consideration in QoL. Darlington et al. (2006) found that stroke survivors who were able to adjust their goals to accommodate their disabilities reported higher levels of QoL in the first year post-stroke, whereas functioning as measured by the

mRS became less associated with QoL after time. Likewise, Kirkevold (2002) identified a gradual evolving process of adjustment. The development of hope and optimism preceded a gradual understanding of the actual impact as survivors become accustomed to the effects of their stroke. Focus becomes less on physical concerns, and more about practical concerns, alongside an altered understanding of their stroke.

Long-term outcomes also suggest that a reduced HRQoL can continue to be an issue for stroke survivors. At seven years post-stroke, Leach, Gall, Dewey, MacDonell, and Thrift (2011) found that HRQoL was poor for a large number of stroke survivors with reduced ability in ADL predicting poorer HRQoL. Whereas Wolfe et al. (2011) reported a favourable comparison of HRQoL to non-stroke populations in regards to the domain of physical functioning from 3 months post-stroke to 10 years post-stroke. The mental health domain however, demonstrated more a fluctuating trend over this time period that could not be explained.

Perhaps the most significant impact that physical limitations impose on a stroke survivor is the effect they have on their level of participation in activities. Participation and the ability to participate is considered to extend beyond impairment and functioning (Dijkers, 2010); it is understood to be a dynamic interaction between health status, functional status, and environmental factors within the individual's life (D'Alisa, et al., 2005). Participation as an outcome measure provides information regarding the impact of stroke on stroke survivors' lives (Gadidi, et al., 2011). Almborg, Ulander, Thulin and Berg (2010) found that after discharge, stroke patients who were unable to participate in hobbies and social activities reported lower HRQoL, whereas patients who were able to participate in hobbies and social activities reported higher HRQoL. Kwok, Pan,

Lo and Song (2011) also found participation in activities to be independently associated with HRQoL with regards to both short-term and long term recovery. Independence was associated with HRQoL both short-term and long-term, whereas participation in leisure activities was found to be associated with only long term outcomes.

The aspects of stroke that restrict the participation in activities for long-term stroke survivors was examined by D'Alisa et al., (2005). After comparing stroke survivors >2 years two years post-stroke and <2 years post-stroke, they found that restriction in areas of mobility, physical independence and occupation was greatest for both groups, however it was most severe for the group <2 years post-stroke. Activity restriction was mostly determined by functional disability followed by emotional well-being and social integration. At 4 years post stroke Gadid et al. (2011) found limitations in activities and participation to be prevalent, with age and functional ability being the most significant predictors. Similarly, Danielsson, Willen and Sunnerhagen (2011) found walking ability, activity and participation continued to impaired long-term after stroke.

Robison et al. (2009), in their qualitative study, found that by 12 months post-stroke there was only a marginal resumption of valued activities despite attempts. The inability to resume previous activities impacted on sense of self and the QoL of the participants, despite many accepting that they would not be able to perform at the same level as before. Activity was not resumed, not only as a result of physical disability; fatigue and dizziness were also a factor. Not knowing what services to engage in for support, and confidence in self and body were highlighted to be relevant factors.

A qualitative perspective was also applied by O' Sullivan and Chard (2010) who identified four themes: re-engaging in leisure activities, acceptance of physical limitations post-stroke, gratitude for help and support, and looking forward to the future in resumption of leisure activities. Participants identified limitations in physical and social activity, and spent more time engaging in passive and less social activities such as watching TV, listening to the radio and reading. Re-engagement in many activities required dependency on others, mostly around driving. Physical limitations were cited as the main reason for not engaging in leisure activities as well as a decline in mobility, leg/hand functioning, balance, and fatigue.

Most relevant to the current study is research by McKenna, Liddle, Brown, Lee and Gustafsson (2009), who found that compared to non-stroke participants, stroke survivors spent less time sleeping, engaging in ADL's, and in volunteer work. More time was spent at home, with others, and engaging in solitary leisure activities. The stroke survivors were also less likely to be in roles of hobbyist/amateur, volunteer, caregiver, student, or to be involved in organisations. However, both the control and stroke samples reported engaging in fewer roles than they had prior to their stroke. Satisfaction in life was found to correlate with the greater number of roles.

Life satisfaction is considered to be an aspect of QoL which is related to the self-appraisal of one's life (Muldoon, Barger, Flory, & Manuck, 1998). Boosman, Schepers, Post and Visser-Melly (2011) explored the relationship between life satisfaction and social activity 3 years post-stroke. The authors found a significant association between life satisfaction and social activities as well as ADL. To a lesser extent, social support and cognitive functioning was also

related. Overall social activity was found to predict life satisfaction three years post-stroke. Similarly, Bouffioulx, Arnould, and Thonnard (2011) identified that satisfaction was associated with an interaction between functional, support, and environmental factors.

Although managing the effects of stroke is a complex issue, research findings illustrate the significance of increasing the activity levels in both the elderly and post-stroke population to reduce the likelihood of experiencing poor stroke outcomes (Hankey, et al., 2002). The expanding range of recovery outcome measures within literature to include health, status, participation in activities, HRQoL and QoL reflects the growing trend moving away from primarily focusing on physical functioning towards considering a more global understanding of functioning and impairment (Salter, Hellings, et al., 2008). Improving participation in social activities, leisure activities, domestic, and vocation activities is recognised as a key determinant of effective rehabilitation programmes (Boosman, et al., 2011; Dijkers, 2010)

Summary

Stroke is a chronic disease with long-term complications for survivors (Caplan, 2009). Although extensively researched, the studies are often looking at short-term outcomes, in a rehabilitation setting (Feigin, et al., 2010; Hackett, et al., 2000). Long term outcome is crucial, as the most at risk stroke population is the elderly. As stroke mortality rates are decreasing, the population of elderly stroke survivors living with the residual effects of stroke is increasing (Haacke, et al., 2006).

Deficits in functional outcomes are often reported in the stroke literature, with many studies highlighting the various domains of impairment experienced as a consequence of stroke. These include physical and neurological limitations (Barker-Collo & Feigin, 2006; Barker-Collo, et al., 2010; Patel, et al., 2002), cognitive impairment (Viscogliosi, et al., 2011), psychological distress (Robinson, Starr, Kubos, & Price, 1983; West, et al., 2010; White, et al., 2007), QoL and HRQoL (Aprile, et al., 2006; Patel, et al., 2006), and participation in activities (D'Alisa, et al., 2005; Robison, et al., 2009). Studies that explore these areas enable us to have a multidimensional understanding of the impact of stroke (Haacke, et al., 2006), as well as provide a measure to assess patient reported outcomes in a rehabilitation setting (Salter, Moses, et al., 2008). Contradictory findings in the research highlight how untangling the relationship between impairment and functioning can be complicated. It also reflects the complexity of the recovery process after stroke.

Previous research has identified several factors associated with outcomes after a stroke which include age, cognitive impairment, functional status, level of disability, psychological wellbeing, and participation in activities. However, many of these studies focus on short-term outcomes, are restricted to hospital or rehabilitation based settings, apply a limited range of outcome measures, and do not use an age-sexed matched group. Ageing is also considered to negatively influence recovery, although research in this area has produced mixed findings. Therefore, the aim of this study is to investigate long-term post-stroke outcomes in a community based stroke sample, and explore how much (if any) of impairment in functioning is a consequence of stroke or whether it is simply the

effects of ageing, and determine whether findings differ from a comparable group that have not experienced a stroke.

As the ability to participate in activities provides an outcome measure of the impact a stroke has on an individual's life (Gadidi, et al., 2011) a more detailed qualitative analysis of participation in activities will be carried out in order to explore themes associated with participation in activities, and determine whether they differ from a comparable group that has not experienced a stroke.

A secondary aim of this study is to explore the sensitivity to two cognitive measures, the Mini Mental State Examination and the Montreal Cognitive Assessment, commonly used to detect cognitive impairment. Research suggests the Mini Mental State Examination should be used with caution when detecting cognitive impairment, and the Montreal Cognitive Assessment is a more sensitive measure (Appelros, 2005; Dong et al., 2010; Nys et al., 2005; Pendlebury, Cuthbertson, Welch, Mehta, & Rothwell, 2010). This study will apply both measures to a stroke and control population to determine if the Montreal Cognitive Assessment is more sensitive at detecting mild cognitive impairment.

The purpose of this study is to investigate factors that affect the life of New Zealand stroke survivors, and to explore how they believe their stroke has affected their lives. To separate the impact of stroke from the ageing process, the stroke sample was compared with a control population of similar age range on various outcome measures including disability, ADL, cognitive functioning, mood, and HRQoL. In addition; this study will examine the sensitivity of the neuropsychological tests which are used to detect cognitive impairment in a stroke population.

Method

Sample

Recruitment

Participants were recruited through their involvement in the Hamilton Stroke Club, the Te Awamutu Stroke Club, their association with the Stroke Foundation, poster distribution through the community, by being approached by the researcher, and snowball sampling. Snowball sampling refers to a method of recruitment where participants are recruited through their association with others in regards to the subject of the study (Biernacki & Waldorf, 1981).

Eligibility

As the focus of the study was to examine the longer term outcomes of stroke, participants needed to be at least two years post-stroke, aged between 55 and 85, living independently in the community, and able to comfortably converse in English. The control sample was recruited on the basis that they could be age and sex matched to the stroke population. Inclusion criteria for the control sample were the same as the stroke sample, except they had to never have experienced a stroke. A total of 26 stroke participants were recruited and 26 control participants were recruited, however 1 stroke participant was excluded as they did not meet the >2 years post-stroke criteria, and 1 control participant was excluded on the basis that they could not be matched to a stroke participant.

Of the stroke population, 13 had experienced an ischaemic stroke, 9 had experienced a haemorrhagic stroke, and 3 were unsure of their type of stroke. Three reported that they had experienced a TIA, and one reported that they had

experienced mild stroke. These participants were included, as the criteria for including stroke participants did not specify severity of stroke.

Demographic Information

Twenty five stroke participants (mean age = 69.88 years, SD = 8.14) were interviewed. Eleven (44%) were male and 14 (56%) were female. Of this sample 22 (88%) identified as European, 2 identified as Māori (8%) and 1 as Asian (4%). Sixteen participants (64%) were married at the time of the interview, 1 (4%) was single, 2 were divorced (8%) and 6 were widowed (24%). Of this sample, 8 (32%) lived alone and 17 (68%) lived with either with a spouse or family members. Nine (36%) reported no formal qualification (school certificate or higher) and 16 (64%) reported a formal qualification. At the time of the interview 2 (8%) were currently in paid employment and 23 (92%) were currently not in paid employment.

Twenty five control participants were interviewed (mean age = 69.52 years, SD = 7.84). Eleven (44%) were male and 14 (56%) were female. Of this sample, 24 identified (96%) as European and 1 as Samoan (4%). Seventeen participants (68%) were married at the time of the interview, 2 (12%) were single, one (4%) was divorced and four (16%) widowed. Of this sample 1 (4%) lived alone and 24 (96%) lived with a spouse or family members. Four (16%) reported no formal qualifications (school certificate or higher) and 20 (80%) reported a formal qualification. At the time of the interview, 16 (64%) were currently in paid employment and 9 (36%) were currently not in paid employment.

Measures

A range of measures were used in the current study in order to collect demographic information, and to determine the participants' level of disability, current cognitive functioning, their health related quality of life, and participation in activities. The stroke samples were also asked about their experience with support and services post-stroke. Measures were chosen on the basis of their validity and reliability, and their previously use on a stroke population. The interview process consisted of questionnaire, cognitive screening, and a semi-structured interview.

Questionnaire

Participants first answered questions from a structured interview where screening information was collected to ascertain eligibility for the study. Demographic information was collected in order to gather relevant background which included date of birth, sex, ethnicity, marital status, living arrangements, prior or current occupation, main income earner, and highest qualification (see Appendix 1).

Medical history was also collected by means of self-report. Stroke participants were asked if they knew the type of stroke they experienced (ischaemic/haemorrhagic), and if they knew which side of the brain their stroke occurred. Both groups were asked if a doctor or medical person had ever told them they had any of the following medical conditions: elevated blood lipids (cholesterol), diabetes, coronary artery disease, angina (heart attack), irregular pulse (arrhythmia), atrial fibrillation/valvular heart disease, heart failure, migraine, epilepsy/seizures, hypertension, or head injury. Participants were also

asked if they had received a diagnosis that was not mentioned (see Appendix 1). A series of measures were used to assess disability, cognitive functioning, mood, and health related quality of life.

Disability

Two measures, the modified Rankin Scale (mRS) and the Bartel Index (BI) were used to determine the level of disability for both groups.

Severity of disability was assessed using mRS (Rankin, 1957) which is a derivative of the original Rankin Scale (Swieten, Koudstaal, Visser, Schouten, & Gijin, 1988). The mRS is a 6-point category scale consisting of six items containing graded responses of 0-6 according to level of disability (New & Buchbinder, 2006). This measure was selected as it is a primary measure used to assess the functional recovery of stroke survivors (Swieten, et al., 1988; Tate, 2010).

There are no specific guidelines for administering the mRS (Tate, 2010), and descriptor categories that classify level of function are recorded as: 0: No symptoms at all, 1: No significant disability, despite symptoms, able to carry out all usual duties and activities, 2: Slight disability, unable to perform all previous activities but able to look after own affairs without assistance, 3: Moderate disability: requiring some help but able to look after own affairs without assistance, 4: Moderately severe disability: unable to walk without assistance and unable to attend to own bodily needs without assistance, 5: Severe disability: bedridden, incontinent and requiring constant nursing care and attention, 6: Death (Banks & Marotta, 2007).

In a literature review Banks & Marotta (2007) reviewed 224 articles and found test-retest reliability to be strong ($k=0.81-0.95$) and inter-rater reliability to be moderate ($k=0.56$ versus 0.78). In regards to construct validity, the mRS was reported to be related to severity of stroke, and convergent validity was found to be high in relation to other disability scales. Similarly, Kwon, Hartzema, Duncan and Lai (2003) also found a high correlation between the Functional Independence Measure (.89) and the Barthel Index (.89).

Although primarily used as a global outcome scale in stroke (Wilson et al., 2005), the mRS has also been applied to measuring disability in both chronic idiopathic axonal polyneuropathy patients, as well as a control sample (Vrancken, Franssen, Wokke, Teunissen, & Notermans, 2002), and head injury patients (Schaefer, Huisman, Sorensen, Gonzalez, & Schwamm, 2004).

Critics have suggested that the mRS demonstrates limitations for use as a measure of disability. The mRS does not include domains of communication and cognitive difficulties which are often identified in stroke patients, and there is some confusion of language used, such as the phrases 'usual duties and activity' (New & Buchbinder, 2006).

Disability was also measured using the BI (Mahoney & Barthel, 1965). The BI was developed as a measure for clinicians to assess the progress of rehabilitation for people with neuromuscular and musculoskeletal disorders (Mahoney & Barthel, 1965). It has since been extensively used to measure functional outcomes for older people, and people with stroke (Aprile, et al., 2006). Lack of improvement on the BI during the treatment phase suggests limited potential for rehabilitation (Mahoney & Barthel, 1965). The BI was selected for

this study as it has been widely used as a functional measure for both older people, and those who have experienced a stroke (Tate, 2010). The BI differs from the mRS as a measure of disability as it focuses on disability in regards to ADL, whereas the mRS provides a global outcome scale of disability (Huybrechts & Caro, 2007).

The BI consists of ten items which examine ADL such as: feeding, bathing, grooming, continent with bowels and bladder, toilet use, transference from bed to chair, and mobility. A score of 0 indicates complete dependence and the highest score indicates independence, with a maximum total score of 100 (Mahoney & Barthel, 1965).

Reliability and validity of the BI was assessed in stroke patients 6 months post stroke (Hsueh, Lee, & Hsieh, 2001). The authors found that inter-rater reliability for individual items was moderate to excellent ($k = 0.53-0.94$), with intraclass correlation at .92. Internal consistency was found to be excellent at four separate time stages (Cronbach $\alpha = .89-92$). The score of the BI was found to correlate with Fugl-Meyer motor assessment ($r = .78$) and the Frenchay activities index ($r = .59$).

To compare its validity and reliability between a stroke sample and a non-stroke sample, Laake et al. (1995) carried out a factor analysis on eight of the ten items on the BI. The authors found the items to be a uni-dimensional measure in a stroke population, but when applied to geriatric and hip fracture population, mobility and bodily functions were found to be not uni-dimensional. Similarly, Sainsbury et al., (2005) found, when looking at the reliability of the BI on older people, fair to moderate inter-rater reliability. Total score agreement was higher

(ICC $k=.89$) and inter-rater agreement (ICC $k=.95-.97$). Both authors suggest that cognitive impairment may affect reliability when obtained by patient interview.

The sum-score structure of the BI requires the items reflect that same construct (Laake, et al., 1995), and despite being a validated measure, the use of an ordinal value has made interpretation of the total score difficult (Kwon et al., 2004). However, as suggested by Mahoney & Barthel (1965) the BI is designed as a brief measure of ADL, and a sum-score of 100 does not indicate the individual's total independence, but it suggests the level of care needed. Therefore, outcome scores of the BI need to be interpreted as highlighting areas of difficulty for which the patient may require support.

Cognitive Functioning

Two measures were used to assess cognitive functioning, the Mini Mental State Examination (MMSE) and the Montreal Cognitive Assessment (MoCA). Findings in the literature has reported concern regarding the sensitivity of the MMSE compared to the MoCA (Appelros, 2005; Dong, et al., 2010; Nys, et al., 2005; Pendlebury, et al., 2010) consequently cognitive functioning was also measured by the Montreal Cognitive Assessment (MoCA). As both measures are used to detect cognitive impairment in stroke survivors, a secondary aim of this study is to explore the sensitivity of the MMSE compared to the MoCA on both a stroke and non-stroke population.

The MMSE was originally developed to detect dementia and delirium in a clinical setting (Folstein, Folstein, & McHugh, 1975), and has since has become the mostly commonly used brief cognitive screen measuring to assess cognitive impairment (Tate, 2010). The MMSE was chosen for use in this study due to its

frequent application in various clinical settings, which also includes a stroke population (Nys, et al., 2005).

The MMSE contains 11 questions which measure cognitive functioning in orientation to time (year, season, month, date, day), orientation to place (region, country, town, building, house number), registration which is later followed by recall of three words (apple, penny, table), attention, (5 responses to serial 7s or spelling “world” backwards), five aspects of language (naming, repetition, following a 3-stage command, reading, writing a self-initiated sentence), and construction (copying two pentagons which are overlapping) (Folstein, et al., 1975). Each correct response is given a score of 1, with a total score ranging from 0-30 determined by the number of correct responses. Administration of the MMSE takes between 5-10 minutes (Folstein, et al., 1975), and typically a cut off score of ≤ 24 is applied to detect cognitive impairment (Tate, 2010).

The MMSE has been extensively tested on various clinical populations. In its initial test of validation, Folstein, et al. (1975) administered the MMSE to a dementia, depressive, schizophrenia and non-clinical population. The MMSE was found to be a valid test of cognitive function, with scores correlating with the Wechsler Adult Intelligence Scale tests of verbal IQ ($r=.77$) and performance IQ ($r=.66$). Reliability was observed when administered after 24 hours by single examiner ($r=.89$) and multiple examiners ($r=.83$) and 28 days ($r=.98$).

Research into the use of the MMSE for detecting cognitive impairment in stroke survivors has produced findings that suggest caution is necessary with interpreting results, particularly with concern to the domains of abstract reasoning and executive functioning (Appelros, 2005; Dong, et al., 2010; Nys, et al., 2005).

Nys et al. (2005) found that when differentiating between cognitively impaired and cognitively intact stroke patients, the sensitivity of the MMSE was no better than chance ($p=0.13$). Appelros et al. (2005) found that subjective memory difficulties correlated poorly with MMSE ($k=0.21$). When comparing with scores with the MoCA, Pendlebury, Cuthbertson, Welch, Mehta and Rothwall (2010) found the MMSE scores were skewed towards higher scores, whereas the MoCA scores were normally distributed.

The MoCA (Nasreddine et al., 2005) was developed as a brief screening tool for detecting mild cognitive impairment in older people who have measured as cognitively intact according to the MMSE. The MoCA covers eight cognitive domains: orientation (month, year, day of the week, place and city), attention/calculation (4 items for digit span forwards and backwards, a brief vigilance task, and serial 7s subtraction task), memory (5 minute recall of 5 nouns), executive/visuo-construction (3 items for alternating trails, copy of a cube, and clock drawing), two items of language (3 items naming: lion, rhinoceros, and camel, repetition of two sentences), and two executive/language tasks (similarities between train and bicycle, and a clock and ruler, and a letter fluency task (Nasreddine et al., 2005).

Administration of the MoCA takes 10 minutes, and correct responses are given a score of 1, with a total score ranging from 0-30. As initial findings indicated that those with less than 12 years education tended not to perform as well, an extra point is added to a score of less than 30 when the respondent has less than 12 years education. A cut off score of 26 is applied to identify mild cognitive impairment (Nasreddine, et al., 2005; Tate, 2010)

In a validation study, Nasreddine et al. (2005) looked at the performance of 94 mild cognitively impaired, 93 Alzheimer's disease and 90 healthy control participants. The MoCA detected mild cognitive impairment in 90% of participants, whereas the MMSE detected 18%. The MoCA demonstrated a high test-retest reliability (.92) and good internal consistency ($\alpha=.83$) across all three groups

To compare the sensitivity of the MoCA after acute stroke to that of the MMSE, Dong et al. (2010) examined the performance of 100 post-stroke patients with vascular cognitive impairment on both measures. Fifty seven patients were found to have unimpaired scores on the MMSE, whereas 18 of these patients were found to be cognitively impaired with the MoCA. However, only 2 of the 41 patients with unimpaired MoCA scores were detected with cognitive impairment using the MMSE.

Anxiety and Depression

Anxiety and depression was measured by the Hospital Anxiety and Depression Scale (HADS).

Levels of anxiety and depression were measured using the HADS (Zigmond & Snaith, 1983). The HADS is a brief measure for the recognition of emotional disorders which has been designed to distinguish between symptoms of anxiety and depression. The HADS consists of seven depression items and seven anxiety items with four point (0-3) responses. A score of 0-7 of either subscale is considered within normal range, 8-10 suggests the presence of either or both emotional disorders, and a score of 11 or higher suggests probable presence (Snaith, 2003).

The HADS has been extensively applied within the literature as a measure of anxiety and depression. A review by Bjelland, Dahl, Haug and Necklemann (2002) reported a mean Cronbach $\alpha=.83$ for the anxiety subscale and a mean Cronbach $\alpha=.82$ for the depression subscale. The correlation between the HADS and other measures ranged between .49 to .83. Overall, the HADS was found to assess the both the presence and severity of anxiety and depressive symptoms in both clinical and general populations.

Although the HADS is used as a measure of anxiety and depression in stroke survivors (Bergersen, et al., 2010; D'Alisa, et al., 2005), there was little found in the literature of reliability and validity data regarding its use with a stroke population. However, in one study, Aben, Verney, Lousberg, Lodder and Honig (2002) found the HADS to be an acceptable screening measure for depression with both subscales demonstrating a high sensitivity and a high correlation ($r=.67$). Internal consistency was high but a decrease was noted in patients who met the criteria for cognitive impairment according to the MMSE, suggesting it by applied with caution to those with cognitive impairment.

Health Related Quality of Life

HRQoL was measured by the EuroQol Quality of Life Scale-5D (EQ-5D) and the Medical Outcome Study 36-Item Short Form Health Survey (SF-36).

HRQoL was measured by using the EQ-5D (EuroQol Group, 2009). This is a standardised measure of health outcomes and is often used to measure quality of life in both general and clinical populations (Pinto, Maso, Vilela, Santos, & Oliveira-Filho, 2011), (*for more information see www.euroqol.org*). It was chosen

for use in this study as it is a brief measure of HRQoL which has been applied to both stroke and non-stroke populations, as well as a New Zealand population

The EQ-5D is a two-part measure. The first section contains a descriptive system with questions relating to five dimensions: mobility, self-care, usual activities, pain/discomfort and anxiety/depression. Each item has 3 statements that represent 3 levels of difficulty with a 3 point response (1-3). The second section is a visual analogue scale (VAS); the respondent is asked to rate his/her perceived current health state where 0 represents worst imaginable and 100 is the best possible health state (Salter, Moses, et al., 2008). A health profile can be generated in three ways. Firstly from responses from the descriptive system where a score of 11111 represents full health, 21211 represents someone who has some problems with mobility and usual activities, and a score of 33333 represents extreme difficulty in all domains. Secondly by a score on the VAS (EQ-5D_{VAS}), with a score of 100 representing best imaginable health state, and a score of 0 representing worst imaginable health state; and thirdly by a single weighted summary index score (EQ-5D_{INDEX}) (EuroQol Group, 2009). Results in this study will be presented as an EQ-5D_{VAS} overall self-rated health status and as a descriptive system weighted index EQ-5D_{INDEX}. Scoring of the EQ-5D summary weighted index score was calculated on the EQ-5D calculator as recommended by the developers

(see www.economicnetwork.ac.uk/health/EQ_5D_index_calculator.xls). This calculated the scoring algorithms of value sets for a New Zealand population.

To assess the validity of the EQ-5D as a quality of life measure in a stroke population, Dorman, Waddell, Slatter, Dennis and Sandercock (1997) administered the EQ-5D to 152 stroke survivors. Discriminant validity was

demonstrated by the EQ-5D when outcomes discriminated between stroke subtypes and severity of stroke. The EQ-5D correlated moderately well with other standardised measures in all domains except psychological functioning and the depression subscale of the HADS. The visual analogue scale was found to demonstrate discriminant validity, as scores correlated with stroke subtypes and severities. Similar findings were observed by Pinto, et al. (2011) with Brazilian stroke survivors. The EQ-5D correlated with stroke severity ($r=-0.404$) and impairment of daily activities, according to the modified Barthel Index ($r=0.512$). Interobserver agreement of all domains was also found to be good ($k=0.60$).

The validity of the EQ-5D on a New Zealand Māori was explored by Perkins, Devlin and Hansan (2004). The authors investigated the content, construct validity, and test-retest reliability of the EQ-5D. Sixty six Māori were recruited via cultural networks. Of this sample, 76% felt it was an adequate measure of health, suggesting content validity; however a high rate of missing values and inconsistencies in scoring by participants resulted in low construct validity. Test-re-test reliability was observed by calculating intraclass correlation coefficients for the descriptive scoring values of 11111 (0.85) and 33333 (0.96).

HRQoL was also measured by the SF-36 (Ware & Sherbourne, 1992). The SF-36 is a widely used measure which has been applied across various populations to assess HRQoL (Okazaki, Sonoda, Suzuki, Saitoh, & Okamoto, 2008). A comprehensive guide and scoring can be found at www.sf-36.org.

This measure stemmed from the Medical Outcomes Study (MOS), and was designed to include the most frequently applied health concepts measured in health surveys (McHorney, Ware, & Raczek, 1993). It was developed to assess a

patient's perspective of their health, and is widely used on populations with varying medical conditions. The SF36 is an extensively used measure in various population studies, and is used for a range of medical conditions (Tate, 2010), and as a result of this it has been chosen as a measure for HRQoL in this study.

The SF-36 consists of 36 items which are grouped into two areas of physical functioning and mental functioning. The physical functioning component includes 21 items from four scales. Physical functioning (10 items), where low scores indicate limited performance in all activities and high scores indicate no difficulty; role-physical functioning (4 items) where high scores indicate problems with work or other daily activities due to physical health and high scores indicate no difficulty; bodily pain (2 items), where low scores indicate severe bodily pain and high scores indicate no pain or limitations; general health (5 items) where a low score indicates a personal evaluation of poor health and belief that health will deteriorate, and a high score indicates evaluation of health as excellent; and vitality (4 items) where low scores indicate tiredness and worn out all of the time and high scores indicate feeling full of energy all of the time.

The Mental functioning component includes social functioning (2 items) where low scores indicate extreme interference in everyday activities due to physical and emotional problems, and high scores indicate the ability to perform everyday activities without interference; role emotion (3 items) where low scores indicate difficulty with work or other daily activities due to emotional problems, and high scores indicate no difficulties; mental health (5 items) where low scores indicate feelings of nervousness and depression all of the time and high scores indicate feelings of peacefulness, happiness and calm all of the time.

The two areas of functioning are then summed to yield component summary scores. Low scores for the physical component summary indicate limitations in self-care, physical, social, and role activity, severe bodily pain, frequent tiredness and a poor evaluation of health. High scores indicate no difficulties or decreased wellbeing, high energy, and evaluation of health as excellent. Low scores for the mental component summary indicate frequent psychological distress, social and role disability due to emotional problems, and health evaluated as poor. A high score indicates frequent positive affect, no psychological distress and limitations in social and role activity due to emotional problems and health evaluated as excellent (Ware, 2004).

Scoring of the SF-36 is based on a method of summated ratings and standardised SF-36 scoring algorithms, where all items in the same domain can be aggregated without score standardisation or item weighing (Ware, 2004). A Microsoft Excel 97 programme designed using the above mentioned guidelines, developed by Kalantar-Zadeh, Kopple, Block and Humphreys (2001), was used to calculate the results of the SF36 (*see www.nephrology.rei.edu/qol/htm*).

In a SF-36 Health Survey update study, Ware (2004) reported that reliability statistics have exceeded the minimum standard of .70 in more than 25 studies and replicated over 24 patient groups. To assess the validity of the SF-36 in measuring physical and mental health constructs on a clinical population, McHorney et al. (1993) applied the SF-36 to four groups ranging from minor chronic, to both serious medical and mental health conditions. Observed differences were found on outcome profiles between the groups which correlated with physical and/or mental health. In a New Zealand sample, Scott, Tobia,

Sarfati and Haslet (1999) found the SF-36 was an acceptable measure of HRQoL, and demonstrated a satisfactory performance

To validate the SF-36 on a stroke population, Anderson, Laubsher and Burns (1996) administered it to 90 Australian stroke survivors one year post-stroke. Validity was observed by a decline in scores across eight scales for stroke patients with physical disability as measured by the Barthel Index, and psychological distress as measured by the General Health Questionnaire-28. However, low scores on the social functioning items did not correlate with low levels of social activity on the Adelaide Activity Profile. Internal consistency was found to be satisfactory for all scales except vitality (Cronbach's $\alpha > 0.7$)

Qualitative Interview

The effects of stroke extend beyond physical impairment as the experiences faced by the stroke survivor go on to challenge their identity, concepts of self, and role in life which cannot be understood for a single approach (Salter, Hellings, et al., 2008). Stroke research tends to focus on impairment in functioning rather than the experience of stroke (Clarke, 2009) which can provide crucial to informing the success of rehabilitation services. In order to move beyond the frequency of events, qualitative research produces contextual as opposed to numerical data, which enables an analysis of meaning and concepts behind the events (McKevitt, Redfern, Mold, & Wolfe, 2004). Qualitative research provides a lens through which the stroke survivor's experiences can be viewed, and how they made sense of those experiences can be explored through analysis (Clarke, 2009; Robison, et al., 2009).

Exploration of qualitative data enables investigators to examine how people make sense of their lived experiences, and how they interpret the meaning of those experiences (Wilkinson, Joffe, & Yardley, 2004). Furthermore, exploring participation in activities provides a way in which to understand the interaction between health, physical function, activities, and external factors associated with a person's life (D'Alisa, et al., 2005).

A qualitative interview was conducted with participants in order to expand on their experiences participating in activities, the difficulties they experience due to their health, and for the stroke sample, their experience with support and services post-stroke. A qualitative approach was chosen to enable a thematic analysis of the data to be carried out and was conducive in identifying repeated patterns of meaning within participants responses (Braun & Clarke, 2006). In thematic analysis both manifest themes, which are observed in the transcripts, and latent themes, which are referred implicitly, are identified. The aim of thematic analysis is to interpret the latent meanings taken from the observed manifest themes within the data.

A semi-structured interview was carried out where participants were asked questions regarding their ability to participate in employment, sporting and physical activities, hobbies, leisure and social activities. Participants were also asked to describe their health, identify any areas of difficulty, and where they would attribute any difficulties experienced. Stroke participants were asked questions in regards to what services or support they found most helpful, what they would have liked to have known but were not told, and what services or support did they feel were missing. (See Appendix A).

Procedure

Approval for this research was obtained from the University of Waikato's School of Psychology Ethical Review Committee.

In order to recruit participants for this study, talks were given at the Hamilton Stroke Club and Te Awamutu Stroke Club. Participants who had expressed an interest to take part in the study were approached by the researcher and an appointment was made to meet with the participant at their own home for a one off interview. A brief explanation of the study was provided over the phone and the participant was given the opportunity to ask any questions.

The researcher met with the participant on a mutually agreed day and time at the participant's home. The researcher explained the purpose of the study and went through the information sheet with the participant (See Appendix B) and the consent form was signed (See Appendix C).

The right to refuse to answer any questions and to withdraw from the study at any time was explained to the participants. No participants expressed any desire not to answer any questions or to withdraw from the study.

Most visits lasted 60 minutes; however overall sessions with the stroke participants took longer than the control group, as often the stroke participants took the opportunity to talk about their stroke. The stroke survivors also elaborated further on responses.

Each visit started with an informal talk to allow for rapport to be established and then demographic and medical information was collected. The participants were then administered the self-reported questionnaires in the

following order: Modified Rankin Scale, Barthel Index, Mini Mental State Examination, The Montreal Cognitive Assessment, The Hospital Anxiety and Depression Scale, the EuroQol-5D, and the Medical Outcomes Study 36-Item Short Form Health Survey. The final part of the interview was a qualitative interview which was recorded on a Dictaphone (with the participants agreement) to ensure accurate transcribing.

Quantitative Data Analysis

Data analysis was carried out by using SPSS (version 19) and the statistical significant level was set at 0.05 (two-tailed). Descriptive statistics were used to assess the demographic characteristics of participants, and chi-square analysis (X^2) was carried out to determine differences in distributions between the stroke and non-stroke samples for demographic characteristics and co-morbid conditions.

A Shapiro-Wilks test was conducted to determine normality of the data as well as data plotted on graphs. As normality could not be assumed for some of the variables, Mann-Whitney tests were carried out to explore differences between the groups, and Spearman rank correlation coefficients were carried out to investigate relations between the measures.

Qualitative Data Analysis

All participants were interviewed in regards to their ability to participate in employment, domestic activities, physical and leisure activities, and their views regarding their health and wellbeing. The stroke participants were interviewed about their experiences with services and support post-stroke (see Appendix 1). Each interview was recorded and responses were transcribed verbatim. Each

transcript was read and analysed separately, and themes were identified that related to each topic area. This process involved the coding of each transcript in order to identify similarities and differences in themes across transcripts. Themes were highlighted and checked with another independent person, and as themes emerged they were then entered on to an Excel spread sheet under categories established from the structure of the interview.

Through the process of thematic analysis, patterns of meaning were identified across data sets (Braun & Clarke, 2006) and used to analyse the interview data. This involved coding of the data that was guided by topic areas covered in the interview. Themes were identified and then used to explain, from the perspective of the stroke survivor, their ability to participate in activities, as well as their perceptions of their health and wellbeing in contrast to the control participants. An iterative analytic process was applied to coding and modification of coding until themes could no longer be identified. Dominant themes were then used to describe the experience of a stroke survivor compared with a non-stroke survivor.

Integration of Quantitative and Qualitative Data

The use of both the qualitative and quantitative data was then integrated in order to generate a more comprehensive account of the actual impact of stroke. This approach was used by Clarke (2003), where a quantitative approach was taken to explore patterns and correlations of wellbeing after stroke, and qualitative methods were used to understand the meaning and processes underlying the effects of stroke and impact on wellbeing.

In this study, the quantitative measures of disability, cognitive functioning, and mood were used to explore patterns and correlations associated with HRQoL after a stroke. The qualitative data was then used to explore patterns and meanings across data sets associated with participation in activities, health and wellbeing, and for the stroke survivors, services and support post-stroke. The purpose of integrating these two data sets was to explore correlations in objective data, and the meanings underlying the experiences. Furthermore, by exploring areas of participation, a context from these experiences has arisen in can be established.

Quantitative Results

Demographic Characteristics

Twenty five stroke participants and 25 control participants were recruited and matched with regard to age and gender. A summary of the demographic characteristics of the stroke and control groups are shown in Table 1. A chi squared analysis was carried out to explore whether distributions between demographic characteristics differed between the stroke and non-stroke samples. A Fisher's exact test was used when cells had an expected value below five. As shown in Table 1, results from this analysis suggested the only significant difference in distributions between the two samples related to current employment status ($p < .0001$), revealing that fewer members of the stroke group were in current employment.

Co-morbid Conditions

Co-morbid conditions were recorded and are shown in Table 2. A chi squared analysis was conducted to determine if frequencies of co-morbid conditions differed between the stroke and control groups. A significantly higher number of the stroke group had high cholesterol, diabetes, coronary artery disease and angina, arrhythmia, atrial fibrillation/valvular heart disease, and migraine.

Table 1

Distribution of Demographic Characteristics between the Stroke Group and Control Group χ^2

Demographics	Stroke (25) <i>n</i> (SD)	Control (25) <i>n</i> (SD)	χ^2	df	<i>p</i>
Years since first stroke	9.88 (4.63)	N/A			
Age	69.88 (8.14)	69.52 (7.84)			
Gender	<i>n</i> (%)	<i>n</i> (%)			
Male	11 (44)	11 (44)			
Female	14 (56)	14 (56)			
Ethnicity			3.58 ^a		.360
European	22 (88)	24 (98)			
Māori	2 (8)				
Samoan	1 (2)				
Asian		1 (2)			
Marital Status			1.79 ^a		.679
Married/defacto	16 (64)	17 (68)			
Single	1 (4)	3 (12)			
Divorced	2 (8)	1 (4)			
Widow	6 (24)	4 (16)			
Current living arrangement			.01	1	1.000
Living alone	8 (32)	8 (32)			
Living with spouse/family	17 (68)	17 (68)			
Highest qualification			3.04 ^a		.274
None	12 (48)	7 (28)			
Secondary	5 (20)	4 (16)			
Tertiary	8 (32)	14 (56)			
Currently employed			17.01***	1	.001
Yes	2 (8)	16 (64)			
No	23 (92)	9 (36)			

Note. ^a: Fisher exact test **p*<0.05; ***p*<0.01; ****p*<0.001

Table 2

Co-morbid Conditions Reported in the Stroke and Control Group, (N50), p<0.05

	Stroke	Control	X^2	df	<i>p</i>
High cholesterol	19	12	4.16*	1	.041
Diabetes	9	0	10.98***	1	.001
Coronary artery disease, angina	13	4	7.22**	1	.007
Arrhythmia, atrial fibrillation/valvular heart disease	12	5	4.37*	1	.037
Heart failure	3	0	3.19	1	.074
Epilepsy/seizures	1	0	1.02	1	.312
Migraine	11	4	4.67*	1	.031
Head injury	6	3	1.22	1	.269
Hypertension	16	10	2.88	1	.089
Other	11	17	2.92	1	.087

Note: *p<0.05; **p<0.01; ***p<0.001

Comparison of Stroke Group and Control Group on Outcome Measures

Prior to carrying out further inferential statistical analysis, histograms were plotted in order to examine the distribution of the data, and Shapiro-Wilks tests of normality were carried out for each of the dependent variables. This test revealed data were not normality distributed for the mRS, BI, MMSE, HADS_{ANXIETY}, EQ-5D_{INDEX} and SF-36, so for consistency reasons non-parametric statistical analyses were carried out for all measures. A series of Mann-Whitney tests were conducted to evaluate the hypothesis that the stroke group would differ in levels of impairment compared to those who had not experienced a stroke.

Table 3 presents the descriptive statistics (median and 25th and 75th percentiles) of the stroke and control groups. Examinations of these data suggest that the stroke group obtained lower scores on all measures aside from

HADS_{DEPRESSION}, SF-36 role emotion, and mental health component summary. The results from the Mann-Whitney tests revealed that stroke sample reported a significantly higher level of disability (mRS), ADL (BI), cognitive impairment (MMSE and MoCa), and anxiety (HADS_{ANXIETY}). In regards to HRQoL there were significant differences between to two samples in health status (EQ-5D_{INDEX}), perception of health (EQ-5D_{VAS}), and for the SF-36 in the domains of physical functioning, role physical, bodily pain, general health, vitality, social functioning, mental health component summary, physical component summary, and the SF-36 total score where the stroke group reported lower scores. Overall as demonstrated by the EQ-5D and the SF36, the stroke group reported lower HRQoL than the control group.

In addition to examining differences between the groups, additional analyses were carried out to explore the number of participants in each group who met the cut off scores (score >7) for diagnosis of anxiety and/or depression HADS_{ANXIETY} and HADS_{DEPRESSION}. As shown in Table 3, neither group appeared to show particularly high levels of anxiety or depression. However, when comparing the number of participants who met the clinical diagnosis cut-off scores, a higher number of stroke participants met cut off scores for anxiety and depression. (stroke group median and SD for depression 5.48, \pm 3.42 and anxiety 5.20 \pm 2.83. control group depression 5.00 \pm 3.13 and anxiety 3.28 \pm 2.62).

On a case by case basis of the stroke group 32% (*n*25) met the criteria for possible depression of the stroke group (score >7) and 8% in the probable range (score >11), and 20% reported possible anxiety (score >7). In the control group (*n*25) 20% reported possible depression (score >7) with 8% in the probable range (score >11), and 4% reported probable anxiety (score >11). In the stroke group

12% meet the cut off score for both depression and anxiety and no-one scored above the cut off for both anxiety and depression in the control group. Thus, a greater number of people in the stroke group reported higher levels of depression and anxiety than the control group.

Table 3

Mann Whitney U Test Comparing Outcome Measures of the Stroke and Control Groups including medians and interquartile range.

Dependent (scaled)	Stroke [median (percentiles 25th-75th)]	Control [median (percentiles 25th-75th)]	U	Z	p	r
mRS	2 (1-3)	0 (0-1)	47.50	-5.32	.001***	-0.75
BI	95 (80-95)	0 (100-100)	94.50	-4.86	.001***	-0.69
MMSE	28 (26.5-29)	29 (28.5-30)	208.00	-2.10	.035*	-0.30
MoCa	24 (20.5-25)	25 (23-27.5)	190.50	-2.38	.017*	-0.33
HADS _{DEPRESSION}	4 (3-8)	4 (2.5-6.5)	182.00	-0.43	.667	-0.06
HADS _{ANXIETY}	5 (3-7)	3 (2-4.5)	290.50	-2.56	.011*	-0.36
EQ-5D _{INDEX}	63(.40-.61)	71 (.63-1)	129.00	-3.59	.001***	-0.51
EQ-5D _{VAS}	75 (54-85)	90 (72.5- 90.5)	169.00	-2.80	.005**	-0.40
SF36 PF	35 (15-67.5)	90 (80-95)	45.50	-5.20	.001***	-0.73
SF36 RP	50 (50-87.5)	100 (50-100)	187.00	-2.53	.011*	-0.36
SF36 BP	62 (41-74)	74 (68-92)	187.00	-2.46	.014*	-0.35
SF36 GH	60 (43.5-72)	72 (54-58.7)	199.00	-2.21	.027*	-0.31
SF36VT	55 (40-70)	70 (60-82.5)	164.00	-2.89	.004**	-0.41
SF36 SF	75 (63-100)	100 (88-100)	168.00	-3.01	.003**	-0.43
SF36 RE	100 (50-100)	100(100-100)	263.00	-1.33	.184	-0.19
SF36 MH	88 (70-92)	88 (78-96)	271.00	-0.81	.417	-0.11
SF36 PCS	51 (34.5-65.5)	73 (64.5-90.5)	102.00	-4.07	.001***	-0.58
SF36 MCS	71 (58.5-83.5)	83 (76.5-90.5)	158.00	-2.00	.003**	-0.42
SF36 (total)	60 (46-76)	81(73-93)	112.00	-3.89	.001***	-0.55

Note: *p<0.05; **p<0.01; ***p<0.001

PF= physical function, RP= role physical, BP= bodily pain, GH=general health, VT=vitality SF= social functioning, RE=role emotion, MH=mental health, PH=physical health, PCS=physical component summary score, MSC=mental component summary score.

Relation between HRQoL and Outcome Measures Post-Stroke

As there were significant differences between the stroke and the control group, subsequent analyses were conducted separately for each group in order to determine which factors influenced HRQoL post-stroke. As the sample size was too small to carry out regression analyses, Spearman's correlation coefficients were calculated to investigate the relation between outcome measures and the total score of the SF36 and are shown in Table 4.

To assist with interpretation of the correlations, higher scores on the mRS, and the HADS subscales were indicative of greater impairment, in contrast higher scores on the BI, MMSE, MoCa, EQ-5D and SF36 were indicative of better functioning.

In the stroke group Spearman's correlation revealed a negative correlation between the mRS and total score of the SF36 suggesting the greater the level of disability the lower reported HRQoL. There was a positive correlation between SF36 and BI suggesting that greater ability in ADL, the higher reported HRQoL. The total score of SF36 negatively correlated with HADS_{ANXIETY}, suggesting the higher reported anxiety the lower reported HRQoL. A negative correlation was also found between the total score of the SF36 and HADS_{DEPRESSION} suggesting the higher levels of depression is related to lower reported HRQoL. There was a positive correlation between the total score on the SF36 and EQ-5D_{INDEX} suggesting the higher reported health status the higher reported HRQoL.

For the control group the Spearman's correlation also revealed a negative correlation between mRS and the total score of the SF36, suggesting that higher levels of disability related to HRQoL, and a positive correlation between the EQ-5D_{INDEX} and the total score of the SF36 suggesting that greater difficulty with health is related to HRQoL. Similar to the stroke group there was a negative correlation between HADS_{ANXIETY} and the total score of the SF-36 suggesting that higher levels of anxiety is related to lower reported HRQoL. Also there was a negative correlation between HADS_{DEPRESSION}, and the total score of the SF-36 suggesting that higher levels of depression is related to lower reported HRQoL. There was a positive correlation between the EQ-5D_{VAS} suggesting that as health status increased HRQoL increased.

Table 4

Spearman's Correlations Coefficient between total SF-36 and Stroke Outcomes

Outcome	Total SF-36	
	Stroke (n25)	Control (n25)
	r_s	r_s
mRS	-.504*	-.427*
BI	.516**	.071
MoCa	.161	.212
MMSE	.199	-.028
EQ-5D _{INDEX}	.626**	.748***
EQ-5D _{VAS}	.366	.484*
HADS _{ANXIETY}	-.609**	-.451*
HADS _{DEPRESSION}	-.526*	-.432*

Note: *p<0.05; **p<0.01; ***p<0.001

Spearman's correlations were also used to examine how the mRS and the BI related to each of the subscale scores of the SF36 and the EQ-5D, and to investigate the relation between levels of disability (mRS), impairment in ADL (BI) and HRQoL (SF36 subscales and EQ-5D) as shown on Table 5. For the mRS, there was a significant negative correlation with SF36 physical functioning, vitality, mental health, mental component summary and physical component summary indicating higher levels of disability related to more difficulties in physical functioning, energy, mental health and physical health. The mRS also showed a significant negative correlation with EQ-5D_{VAS} suggesting that an increase in disability was associated with a decrease in perception of health. With regard to ADL, the BI showed a significant positive correlation with the SF36 subscale of physical functioning, role physical, mental health and mental health component summary indicating that an increased ability to ADL related to an increased ability in physical roles and mental health, and positive affect. The BI showed a positive correlation between the EQ-5D_{INDEX} indicating that an increased ability in ADL related to an increase in HRQoL.

For the control group the mRS negatively correlated with domains of physical functioning, general health and physical health component summary suggesting an increasing disability related to difficulties in physical functioning and general health. There was a negative correlation between mRS and EQ-5D_{VAS} indicating that as disability increased perception of health decreased.

Table 5

Spearman's Correlations Coefficient between domains of SF36 and Disability Outcomes in the Stroke Group

SF-36 Domains	Stroke (n25)		Control (n25)	
	mRS r_s	BI r_s	mRS r_s	BI r_s
Physical functioning	-.77***	.75***	-.42*	.17
Role physical	-.33	.48*	-.16	.08
Bodily pain	-.17	.31	-.14	.12
General health	-.19	.19	-.45*	.21
Vitality	-.51**	.25	-.36	.26
Social functioning	-.25	.28	-.19	-.14
Role emotion	-.27	.30	-.06	-.09
Mental health	-.46*	.45*	-.27	-.01
Mental component summary	-.53**	.58**	-.36*	.16
Physical component summary	-.47*	.39	-.43	.14
EQ-5D				
EQ-5D _{INDEX}	-.39	.52**	-.39	.00
EQ-5D _{VAS}	-.47*	.01	-.34**	.03

Note: *p<0.05; **p<0.01; ***p<0.001

Relation between Age and Outcome Measures

In order to determine whether an increase in age influenced post-stroke outcomes Spearman's correlations were also conducted between current age and each of the outcome measures as shown in Table 6. There were weak, non-significant correlations between age and all the outcome measures for both groups suggesting that age did not significantly influence outcomes.

Table 6

Spearman's Correlations Coefficient between Age at Time of Interview and Outcome Measures

Outcome measures	Age			
	Stroke		Control	
	r_s	P	r_s	p
mRS	-.11	.588	-.14	.491
BI	.14	.516	-.21	.307
MMSE	.09	.675	-.15	.485
MoCa	.08	.717	-.35	.084
HADS _{DEPRESSION}	.02	.927	-.05	.816
HADS _{ANXIETY}	.14	.494	.09	.668
EQ-5D _{INDEX}	-.04	.864	-.19	.360
EQ-5D _{VAS}	.12	.555	-.18	.404
SF36 Total	-.38	.060	-.36	.078

Comparison of the MMSE to the MoCA

Both the MMSE and MoCA are used to detect cognitive impairment in stroke survivors, however studies have suggested that the MMSE is not as sensitive at detecting cognitive impairment compared to the MoCA (Aggarwal & Kean, 2010; Dong, et al., 2010; Nasreddine, et al., 2005; Pendlebury, et al., 2010). To explore the sensitivity of the MMSE compare to the MoCA in both the stroke and control populations in this study Spearman's correlations were conducted to determine if the two measures were related. The correlation coefficient between the two scores was significant ($p < .05$) suggesting they are not measuring the same thing.

The sensitivity of the MMSE compared to the MoCa was then explored by looking at the number of participants in each group that met the cut off score for cognitive impairment for each of the measures (Table 7). The cut off scores were set according to recommendations by the literature (Kalantar-Zadeh, et

al., 2001; Nasreddine, et al., 2005) with a cut off score for the MMSE ≤ 24 indicating cognitive impairment and the cut off score for the MoCA < 26 indicating cognitive impairment. Table 7 shows that more people would be classified as cognitively impaired according to the MMSE than measured by the MoCA.

Table 7

MMSE scores in comparison with MoCa scores (n, %)

	r_s	Stroke		Control	
		Below cut off	Above cut off	Below cut off	Above cut off
MMSE	.255	2 (8)	23 (92)	0	25 (100)
MoCa	.307	20 (80)	5 (20)	15 (60)	10 (40)

Note: ≤ 24 cut off for MMSE, < 26 cut off for MoCa

The scores obtained by each participant on each of the two measures were plotted to further explore the variations in scores. Figure 1. presents the data of each individual MMSE and MoCa scores for the stroke group. The horizontal lines on the graphs signify the cut of scores for both measures (≤ 24 for the MMSE and < 26 for the MoCa). There is little consistency in scores between the two measures with a greater variation between the scores for the two measures, particularly in regards to low scores. More participants meet the criteria for cognitive impairment according to the MoCA than the MMSE with only two participants meeting the cut off score for both measures.

Figure 2. presents the data of each of the individual MMSE and MoCA scores for the control group. There was some consistency in the pattern of scores however; there was still a degree of variation between the scores for the two measures. There were no participants that meet the cut off score for both measures; however 15 meet the cut off score for the MoCA. More participants meet the criteria for cognitive impairment on the MoCa than the MMSE suggest the MoCA is more sensitive to mild cognitive impairment than the MMSE.

When comparing the two figures and Table 7 it is clear that more participants in the stroke group met the cut off score for mild cognitive impairment compared to the control group and the stroke group showed greater variability in the scores compared to the control group.

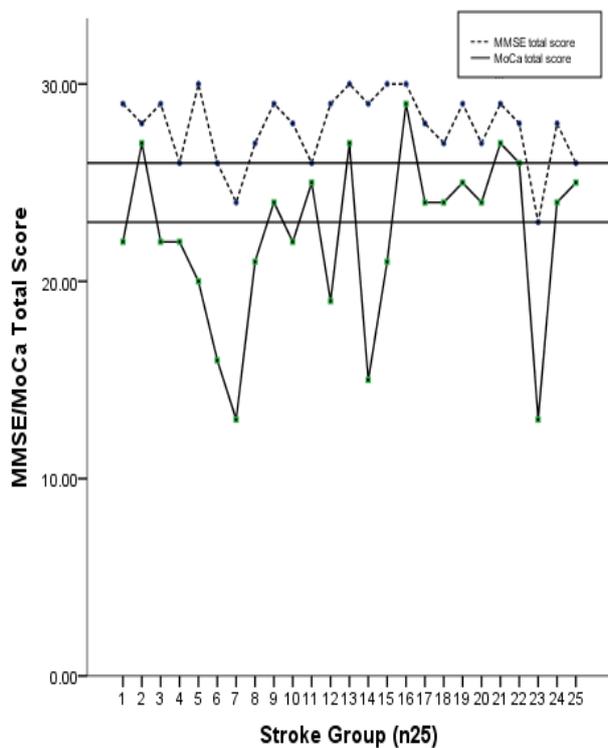


Figure 1. A comparison of the MMSE and MoCA scores for stroke group

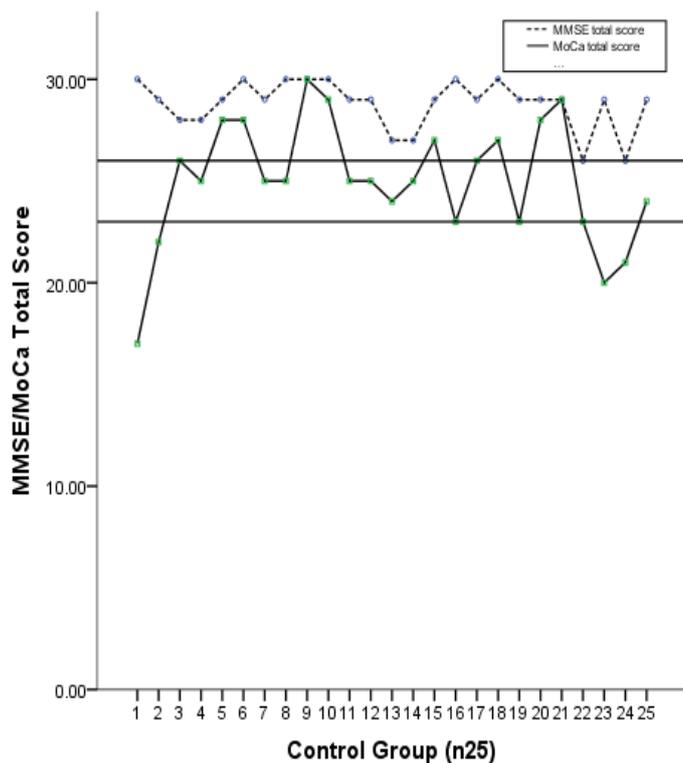


Figure 2. A comparison of the MMSE and MoCA scores for control group

Summary

Overall the stroke group demonstrated significantly higher levels of disability as measured by the mRS and the BI, greater cognitive impairment as measured by the MMSE and the MoCA, higher levels of anxiety as measured by the HADS, and lower HRQoL as measured by the EQ-5D and SF-36 than the control group. In addition, the MoCA was found to be more sensitive at detecting mild cognitive impairment than the MMSE for both the stroke and control groups.

Qualitative Results

Following the collection of the quantitative data, all participants completed a semi-structured interview regarding participation in activities, their perception of health and wellbeing, and for the stroke group, their experience with supports and services post-stroke. A thematic analysis was carried out (*see methods section for a description of analysis*), and emergent themes were identified from the interviews. These themes were coded and categorised according to specific aspects of the interview, and then entered on to an Excel spreadsheet. Dominant themes were then used to construct a comparison of experiences between the stroke group and the control group.

The results from the qualitative analysis have been grouped according to the structure of the interview in the categories: participation in activities, health and wellbeing, and support and services. Under each heading are themes which describe the experience of the stroke group in contrast with the control group, which is then followed by extracts of interviews.

Participation in Activities

Participation in activities included the areas of employment, domestic activities, and hobbies, leisure and social activities.

Physical limitations and restrictions

For the stroke survivors, physical limitations were frequently cited as barriers for not participating in employment, domestic activities, and leisure activities. The prospect of employment seemed to be unobtainable for most, with only two participants in the stroke group reporting being involved in employment. Both participants however, were no longer working in the field where they were previously employed. Being unemployed was not always due to the effects of stroke, some participants felt they were too old to work, and as one participant expressed:

'I think for me the problem is the institutional design, the design of the institution to create, to allow people to work'. (S11)

For this participant it was the structure of the workplace environment that was unable to accommodate to the needs of stroke survivors, rather than the lack of ability on the stroke survivors behalf.

In contrast, the control group were confident in their ability to participate in various activities. The focus here was more about what they did in regards to participation, as opposed to what they felt they could no longer do, or were restricted. A majority of the control group reported participating in some form of employment, and others were retired. Only two participants reported not being able to work due to their health. The response echoed by most participants in the control group was:

'Employment, yes I can participate' (C15)

Participation in activities for stroke survivors was not as straightforward as the control group. The residual effects of stroke altered their ability to participate in domestic activities and leisure activities, with hand paresis often being identified as a limitation for participating in activities, particularly domestic chores.

'Vacuuming, um cleaning the windows, cleaning and dusting, I find it difficult dusting. I can dust with difficulty you know cos I can't use both hands.' (S4)

Not having the use of both hands meant that tasks had become more difficult. For some this meant they could no longer participate in chores they previously could, as a result of restricted functioning.

'I'd find anything needing two hands, I can't use, I just use one hand.' (S2)

Also when considering activities, many have found there were activities they used to be able to do, but since their stroke they were incapable of doing.

'I use to be able to; I use to do vacuuming and clean toilets and all that sort of thing and I can't do it now' (S9)

For the control group, most felt they were capable of performing domestic activities with little to no difficulty. As tasks become more physically demanding some reported difficulty:

'Um cleaning windows, scrubbing and reaching up high, cleaning the ceiling and vacuuming I can't vacuum it's a bit hard for me.' (C4)

'Yes, like I mentioned before I just can't do my bathroom ceilings or high up on the walls or anything to get my mildew down'. (C15)

By most accounts domestic activities were simply chores that were completed with little consideration given to the physical requirements necessary to complete everyday tasks. Domestic activities that were considered difficult were typically chores that would not be considered every day basic chores. For example, as two participants reported:

'Window cleaning, that's about the only problem, um if they're low enough, cleaning around the eaves on the house and that sort of thing is a problem' (C01)

'Um, oh heavy, really heavy work I can't do, um like digging the garden is a bit of a strain but if I do a little bit at a time it's ok, um I don't like to get up on the roof anymore [laugh] and I most things I manage, moving heavy is... I need help with.' (C10)

For the stroke group, even daily domestic chores were seen as a struggle for many. However, despite their difficulties most were able to identify chores they could do. Although it was apparent that the range of chores were limited, and for some, the time it now takes to complete task was longer and required an adjustment of expectations.

'I can do most of the cooking and cleaning, all the stuff that I need to do. I might be a little slower.'
(S13)

Maintaining the ability to participate in domestic activities provides an opportunity for the stroke survivor to retain the role of caring for themselves and their environment. Therefore, it becomes important to find tasks that complement their capabilities to enable t to continue being involved in their own self-care.

'Inside I can cook and make the bed, um do the dishes um, look after myself.'(S4)

'I can still do the weeding outside and um inside I just, I clean things when they need cleaning.' (S21)

Although there was an awareness of their physical limitations, for some there was an underlying perseverance and determination to give things a go. Inventive strategies were incorporated in order to be less reliant on others, and to continue doing tasks for themselves. Resilience seemed a necessary requirement in maintaining a level of independence when faced with limitations in functioning.

'Things like taking out the rubbish, you use a cart now or something like that, you find other ways of doing stuff.' (S13)

'When hanging clothes with two hands up I take the clothes walker, when I go backwards the walker supports me back to front. So I have things that work...I found it very difficult to vacuum with the head up and down, but I take the end off and sit on the floor and do it crawling.' (S5)

Although domestic activities provided their own set of challenges for both the stroke and control groups, the stroke group reported a greater degree of restriction and limitation that extended to everyday tasks. However, most were able to continue to participate by modifying their performance and expectations. Leisure activities for the stroke group proved to be a greater challenge for some, when the effects of their stroke meant they were unable to resume previously valued activities. This was seen as occurring through a loss of functioning where it was considered a necessary requirement to participate in the task (Robison, et al., 2009).

'Well I feel like I'm living half a life, I just can't do what I use to do, I can't like say take the car and go to town or something, I can't play in my drama group anymore, what I use to love.' (S10)

'Use to do a lot of knitting and sewing, but I can't do anything like that now. Oh yes, it's the walking I miss that, I miss the most and driving' (S17)

'I used to do exercises over there but they were too fast and upset the balance, and especially the stand ups and downs and when I come I'd be worse, I hardly could walk. And I used to do line dancing and can't cope anymore, feel a bit thick when you can't cope.' (S5)

'I think it's the ability to participate in things really and ah like things that were just, natural phenomenon it's just a bit of an effort now or just unable to do it'. (S13)

Post-stroke, participants found that the loss in their ability to resume previously valued activities was difficult to accept and this was experienced as a sudden loss, rather than a natural progression associated with increasing age. Activities that they had taken for granted and considered they would always be able to do were now seen as a struggle, or something completely out of their capability. This evoked a sense of loss when reflecting back on what was previously enjoyed, and also demonstrated how stroke survivors made sense of the effects of their stroke according to what they valued (Clarke, 2009).

Most significant for the stroke survivors was the loss of ability to get around, making the once simple task of walking, now difficult.

'Motor dyspraxia, right side hemiplegia. I seem to walk, I walk um this is alright, but this one goes it's um, it's oh I'll have a stick, ah see (yes, your stick) and I walk cause when I walk outside it's um walking it's my leg you know, it's gonna stay.' (S14)

'I can't walk without an aid properly.' (S8).

'Walking for a start, walking is one of the main things.' (S9)

Mobility difficulties meant that stroke survivors were often confined to activities that were less physically demanding and within the home environment, often replacing the more physically challenging activities. For some, activities were also chosen for their therapeutic qualities in order to keep the momentum of functioning going.

'I spend a lot of time on the computer, and I love music and I read and I do jigsaws to try and keep my fingers going, picking up the pieces.' (S1)

'Play cards which is quite good, at least it keeps your brain going'. (S18)

'I do scrapbooks for rest homes, things like that. Um crossword puzzle.' (S6)

'Um I do my diary writing, writing things in my diary. Um watching TV and listening to the radio.'
(S4)

For the control group, the confidence in their capabilities to participate in activities around the home extended to activities outside the home, with most reporting enjoying a range of activities including. Most commonly the control group considered leisure pursuits to be more physical in nature, with less focus on passive activities. Only two participants reported no longer being involved in activities, and one participant reported experiencing a reduced capacity. Participation in leisure activities were often considered for their exercise value with the idea of maintaining physical health.

'Um well mainly we walk to keep fit, that's our main thing.' (C21)

'Well I have a gym membership which um, which I do participate in when I get there, so that involves um like rowing machines, steppers, um weights, um skipping, blah, blah, blah. I also am a walker so I go for regular walks around the block.' (C9)

'Yes I do, we are bright and active and on a Friday morning we go for a very vigorous walk. If there's a function on in the evenings we do a bit of dancing.' (C7)

Social activities were based around church groups, community networks, and hobbies

'I belong to our local garden club. Um, fellowship, church evening fellowship, and I belong to a friendship group, um and enjoy going to my children's school activities.'

'I've got a good network of friends and we go to movies and eat at one another's houses. Um I belong to garden club' (C01)

'Yes I belong to several things like Rural Women, Garden Club ... yeah I take part in whatever's going on, and church work.' (C18)

With most of the control group reporting little to no difficulty in activities, health outcomes were not seen as a barrier for participating in activities. Only two participants reported that physical difficulties have prevented them from participating in activities.

Getting involved

For the stroke group, although leisure activities were often confined to the home, social activities provided an opportunity to be involved, and socialise with others who had likeminded interests. Although there was an awareness regarding limitations with the more physically demanding activities, most were still able to participate in activities that were compatible with their physical capabilities. Many continued to enjoy the company of others, were able to participate in social activities that were not physical demanding. In a social context, stroke survivors were able to reflect on what they were able to do, and were less aware of their physical restrictions. The social activities that the stroke group were involved in included church groups and clubs that they had previous associations with prior to their stroke. Also, for most of the stroke group, particular social activities had been taken up since the stroke as recommended by support professionals.

'I go to stroke club, I go to Stewart Centre where activities are quite wide' (S13)

'I go to stroke club once a month, I go and read with the kiddies at school, I visit a lady now, that's older than I am and can't get to stroke club, um I like to go shopping.' (S20)

For many, social activities were based around interests and social networks.

'I go to a discussion group on once a week at the moment; I've just started a new group. And I've been going to lunch with people from the community and church people on a Wednesday' (S21)

'I play competitive scrabble all over New Zealand and I do quiz shows all in town everywhere, on Monday night mainly. I go to shows at the casino and play bingo.' (S16)

Social events were activities that most were able to participate in, and where the physical effects of their stroke were not as apparent. For those with aphasia, this was not always the case as social situations proved challenging when communicating with others.

Yeah well I talk, talk talking like now I could talk I cause I can't have a conversation I, so after a while I um, I can't say the words, say it, I can't. I can't um say and it's my, mine I hear it but I can't, every time I, in the end I get [merirl?] Um well what's the word?

I. You get frustrated?

P. Yeah and in the end I just..

I. Don't talk?

P. Yeah, yeah.

I. Is it just not being able to make conversation makes it difficult for you?

P. Yeah it's ah especially ah have I, you know sometimes you think, you think of something to say and then you go to say it, it's ah (gone?) no (it's not coming out?) yeah and you think oh god no, one day. (S14)

The difficulty of trying to be understood by others led to feelings of frustration and defeat. This example demonstrates the difficulty stroke survivors face when trying to reconcile their acquired deficits in functioning to situations where they once experienced no difficulty.

Overall, there was a stark contrast between the stroke and control groups when it came to participating in some activities. For the stroke group, activities were less physical demanding, often as a consequence of a loss of functioning in areas necessary to complete more physical task. The control group participated in a range of activities, particularly physical activities which were seen as an essential component to maintaining their physical wellbeing. Social activities however, were something that both groups reported relatively similar experiences in. Social activities were often seen as a means to associate with likeminded others, and for most physical functioning was not a barrier to participation.

Health and Wellbeing

Living in good health

For the stroke group, there was a distinct understanding that being healthy was not defined by the effects of stroke. Many stroke survivors saw themselves as otherwise healthy, their health and wellbeing as existing independently to their stroke. This reflected the process of acceptance and adjustment to stroke; the individual living with the consequences of stroke. As the stroke survivors were two years or more post stroke this also reflected the length of time post-stroke, with many stroke survivors having the time to live and adjust to the effects of their stroke.

'My health, my normal health, my physical health is pretty good, I don't get sick quite very often, I don't get colds, I don't do flu.' (S10)

'Good, very good, yes. No I think everything is ok as far as I'm concerned.' (S24)

'Well I can't complain, no, I reckon another year will make all the difference' (S17)

'Well I'm feeling good, very good today um I'm not feeling tired, I think my health is in good shape.'

(S12)

The theme of living in good health was echoed by the control group, with most viewing themselves as experiencing good health which they saw as being uncomplicated by medical concerns.

'Um slightly above average I would think. (C25)

'Well I'd say for my age it's pretty good, you know I can do most things you know that I need to do every day, and I can still bake and do things like that, so yeah it's pretty good really.' (C22)

'At the moment it's fine, no problems at all.' (C14)

'Um I'd say very good compared to what it has been like in the last few years, yeah at the moment it's probably the best it's been for the last four years.' (C23)

Despite an overall positive view of health, for some stroke survivors the physical effects of stroke were not as easy to ignore. The profound effect the stroke had on their life had altered their life trajectory to point where acceptance was difficult.

The struggle to accept life changes

For some, the struggle to fully reconcile the impact their stroke had on their lives continued to resonate. The residual effects of their stroke prevented them from engaging in activities, altering how they saw themselves. Being able to accept the outcome of their stroke was difficult, and the negative disruption the stroke played on their life course was experienced as a loss.

'Cos I thought at that particular time, I thought godfather, is this going to be the rest of my life?'(S9)

'My life just got cut, I'm now in wheelchair. We had everything going for us, a beautiful new home that I'd done all the work on. Beautiful family, all of the sudden it's all just taken away from you, all your investments, all your retirement dreams, everything is just gone, and it's very sad.' (S12)

'I use be able to do everything I could in my own life, but now I have my stroke it's very hard for me to explain myself and I want to be a normal person as much as I could.' (S7)

'I wanted black and white answers to when I would be mobile and didn't necessarily wanted to hear that I may not be, wanted to know when I could go back to work, not really accepting that I probably may not be able to, these sorts of things.' (S13)

But this was not always the case, the ebb and flow of making sense of life after stroke was also apparent in those who demonstrated a more stoic stance and were most resigned to their post-stroke outcomes.

Stoicism

Despite the struggle to accept the life changes from their stroke, for some there was also a tendency not to complain about one's own difficulties and see that there were others who were worse off. Their attitude towards negative life events enabled them view their stroke as something that had just happened and they might as well just accept it and move on.

'Oh yes, didn't worry me, you know it was done and I couldn't do anything about and that's it.'
(S2)

'All people have life changes and you have to accept you're not the only one and I've got very strong attitude, I've seen others suffering and I say I'm not the only one and push on.' (S5)

'Um and if I fall down on the ground, if I go down on the ground I use my hands to lift myself up. Some people have to use a heavy chair to lift themselves up, but I use my hands.' (S4)

Similarly, the control participants had an overall positive view of their health; however they were also not immune to ill health. For the control group, health tended to relate to episodes of illness, rather than permanent states. Even chronic conditions were considered to disrupt an otherwise healthy life. As one participant reported:

'Oh with my back I struggle a little bit sometimes, but it has stages that it um bugs you and then it seems to come right again. You've just got to nurse it.' (C17)

Physical difficulties for the control group were mostly experienced as bodily pain, and for many negotiating this was part of their everyday living.

Enduring

For many, the concept of enduring their pain and physical difficulties was clear. This did not prevent participation, but for some in the control group being aware of the pain was considered an important aspect in managing the effects. Ill health was not life altering, but the effects were not inconsequential. For instance, one participant was fearful that a seemingly benign pain could indicate something more serious.

'Physical problems um, yes in walking and in doing vigorous activities, ah I have a certain fear of having heart problems, and after following the bypass I was perfectly clear of any heart problems, but over recent years I have noticed that I do get tightness in my chest which the heart specialist says is angina, but I've got medication for that too. But also I have this retched hernia thing which if I eat cream or rich food I get trouble with that, which is in a way similar feelings for any heart problems as well, so I have to decide between the two.' (C6)

Most felt any difficulties they experienced were easily managed through simply being aware of them. Most reported that it did not have a huge impact on their lives and experienced little disruption.

'I do have difficulty if I have to walk any distance, my legs start to hurt, um or and I get shortage of breath and that, but other than that it's very manageable and I don't have a problem.' (C5)

'Only the osteo, when...sometimes because if I get down, kneel down or anything it takes me ages to get back up and, but no there's no huge impact, it's a bit of an impact but no huge impact.' (C15)

'Um I have a couple of things that I have to be mindful of like the onset of osteoporosis so I try to do things that are weight bearing, and keep up calcium intake um, I've got some osteoarthritis in my feet, um which causes some pain but it's quite manageable.' (C10)

For others, although they continued to participate in activities, it was in a more limited capacity than previously. Pain was seen as physical reminder of their limitations in functioning.

'Yep and that's through pain basically, you know restricting pain and that's what stops me from doing continuous work. I have to sit down and wait for a while before the pain dissipates and then go back and have another go, and that could be the day after or something like that, you know, so the pain barrier restricts me from doing as much as what I use to do. I use to go out and do the whole lot in one day, well now it takes a day and a half.' (C23)

'As I've said to you I had some osteoarthritis in my two thumb joints which means that some activities, such as gardening, the gripping, the secateurs, those kinds of things where there's a gripping, cutting movement, I can still do them, but not to the same capacity.' (C9)

'With lifting um cos of the shoulder that's been very painful so I try to avoid doing things with that, so I only try to garden with the left side, doesn't work very well, um mainly yeah.' (C1)

Summary of Participants' Experiences from the Stroke and Control Groups

Although both the stroke and the control group reported an overall positive view of their health, neither group escaped the physical reminders that required them to be mindful of their physical limitations. The residual effects of stroke had become something that most stroke survivors had adjusted to; similarly, although they were aware of health concerns, most of the control group managed the ill effects. The difference between the two groups lay in the severity of their physical impairment, and the adjustment of expectations, and accommodation required to participate in activities.

For the stroke group, challenges faced in everyday life exceeded that of the control group, and this was evident when looking at the types of activities the stroke group participated in compared to the control

group. A more passive range of activities now replaced physical pursuits, and the ability to participate in activities of daily living were limited, and required greater effort.

Support and Services Post-Stroke

An integral factor of life after stroke is engaging in support and services. As most required support after their stroke, stroke survivors were also interviewed about their experiences with support and services.

Positive regard for support and services

Most received inpatient care after their stroke and gave praise for the support they received. Many acknowledged the effectiveness of the rehabilitation therapies and felt it was an important factor in their recovery.

'In hospital I had to... they helped me to walk again cos I couldn't walk by myself, they helped me to walk again, and um my speech came back.' (S4)

'Speech therapist taught me how to cope, and how to speak back.' (S5)

'Yeah, they got others, organise people, they come over her and help me out, that, I'm grateful for that yeah, like I said I have to do it myself, the way I am.' (S7)

Services and support were instrumental in overcoming their disability and learning to manage their acquired deficits in functioning. For some however, there was a notable gap between inpatient services and the transition back into home life.

Abandonment

The transition from hospital to home was difficult and some felt there was an absence of support, and the skills developed in rehabilitation did not adequately match the environment outside of hospital. Support was not as readily available, and the inpatient care environment did not generalise to the outside settings.

The stroke survivors were left with a sense of abandonment when both they, and their spouse, were left to cope.

'I think once you get put out to pasture, from rehab, once you're reached your level of, all your level, they call it your level, you're not going to improve much more, they pass you out, they discharge you, and from that point you're on your own.' (S12)

'It was alright in the very beginning you know, the doctors visited me and blah, blah, blah, but then I just manage myself you know.' (S16)

'From the hospital perspective I was there a number of months and wasn't really prepared for the realities of. I mean you get into a comfort zone where you have um, an OT and a physio and a speech language therapist and all the support people are there, and you're in a cocooned environment where you have hand rails and everything set up for your disability, but when you get out into the real world...' (S13)

The transition to home after stroke emphasised for the stroke survivors how their stroke not only affected their lives, but the lives of others around them.

The ripple effect of stroke

There was awareness that the effects of stroke were not limited to the individual, but extended to others surrounding them. Life changes were not only experienced by the stroke survivor; their families were also expected to make adjustments to their own lives. As a wife of a stroke survivor commented:

'And I'll tell you another thing, something that never happened too, nobody ever asked me could I take care of him when I brought him home. Did I want my life to stop, did I want to take care of him for the rest of my life?' (S19)

The acquired role of caregiver for the wife of a stroke survivor meant that paid employment had to be given up for new role, which came with no training.

'And they're just told to give up their job, and that really sat Ann on her back side. Oh you will have to just take him home and give up your job and look after him. But no training, so we struggled doing things together for a long time didn't we? Yes. (S12)

The caregiver role also required a shift in identity when the functioning of the stroke survivor required the efforts of 'we' and opposed to 'me'

'Sally modernised herself to become part of me, a part of who I am.' (S01)

The affliction of stroke ripples through the family, and consequently the stroke survivor is left feeling the burden of guilt.

'You know even though I went through a bit of trauma my wife went through twice as much.' (S17)

'I think mainly it's been hard watching my wife have to struggle, that's been the biggest thing right from the word go, they might as well have had the stroke too.' (S12)

'But it wasn't fair on any of them there, they've all got too many children, you know and um, and let's face it when you've had a stroke you, it takes time to deal with you.' (S18)

It was apparent that many were unprepared for life after stroke and the impact that this would have on their families, as the burden of stroke extended to others around them. Expectations of their recovery were in stark contrast to their actual experiences, and there was an eventual realisation that what they felt they had been led to believe would happen, was not what they were experiencing.

Limitations in Support and Services

Need for information

Many felt there was an absence or lack of information given to them that enable them to them understand the actual impact the stroke would have, particularly with long-term outcomes.

'Ah the severity of it I guess, um see I had no idea what, what had happened or what they told me but they... I didn't realise I was that close to ending things I guess, maybe that sort of thing would have been helpful. I don't know.' (S9)

'I'd like to have known more about strokes, I really didn't know.' (S16)

'Well everything that I'm eligible for.' (S24)

'Yeah they explained everything, yeah, but they also said that I would come right, that my arm would start moving again.' (S10)

Rather than an absence of information this perhaps reflects the timing of the information, with many unable to fully comprehend what they have been told at their stage of recovery. Some felt that they were not explicitly given information about how likely they were to regain functioning.

'I would have like to have known how long I would have the stroke for but I was never told that, didn't say it was going to be all your life, um that hurt a little bit, but I got over it.' (S1)

Also there was a need for information to relate to their future plans. As one participant expressed:

'Um basically that um my goals were really unachievable, they said, people said to me you might not be able to achieve that. I would have rather they were honest and said no way would you be able to play golf for arguments sake.' (S12)

Summary of Participants' Experiences with Support Services Post-Stroke

Most stroke survivors that were spoken to had engaged in inpatient support after their stroke. They expressed a positive regard for the support and services they received after their stroke, with many reporting their rehabilitation was a crucial factor in regaining functioning. However, once discharged there was a sudden shift in support available, and many felt abandoned in the process as the inpatient environment failed to generalise to their real world setting. The ripple effect of their stroke became apparent once at home, affecting not only themselves but their families, and many felt they were unprepared for life after stroke.

Most felt they could have benefited from a more comprehensive understanding of the actual impact their stroke would have on their life.

Discussion and Integration of Findings

The aim of this study was to investigate factors that impact on long term outcomes in the lives New Zealand stroke survivors, and to compare their outcomes to a group who had not experienced a stroke, to help determine whether subsequent difficulties were a result of the stroke or the ageing process. Research suggests that recovery after stroke should not be limited to regaining functioning (D'Alisa, et al., 2005), therefore this study extended research outcomes to explore themes associated with participation in activities, and to see whether these differed from a population who had not experienced a stroke. Secondly, this study looked to investigate the sensitivity of two measures commonly used to detect cognitive impairment in a stroke population; the MMSE and MoCA.

In order to develop a more comprehensive understanding of how impairment in function is experienced, this study applied both qualitative and quantitative methodology to examine the relationship between functional outcomes and the participants' experiences in participating in activities, and their perception of their health and wellbeing. The quantitative results from this study indicate that community based stroke survivors report greater levels of disability, reduced ability in ADL, impairment in cognitive function, and higher levels of anxiety. Furthermore, impairment in these areas is associated with lower reported HRQoL compared to a sample that has not experienced a stroke. The qualitative research suggests that by exploring participation in activities, the extent to which impairment impacts on the life of a stroke survivor can be understood through their experiences (Clarke, 2009). The stroke group experienced greater restriction and disability in activities and as a result were less likely to participate in physical activities than the control group, however overall both groups viewed themselves as experiencing good health.

Age

In order to determine whether difficulties experienced by the stroke survivors could also be accounted for by the ageing process, the study looked the relation between age and functional outcomes. The results from this study found no correlation between any of the outcome measures and age. This finding was unexpected, but in comparison to other research is somewhat consistent after considering the potential for

other factors to influence outcomes. As Arnold et al. (2008) demonstrated after correcting for co-morbidity, age did not independently predict clinical outcomes 3 months after acute ischaemic stroke. At 3 months post-stroke Choi et al. (2006) found no association between age and QoL, however this study excluded stroke survivors with cognitive or speech impairments.

Aprile et al. (2006) also excluded stroke survivors with cognitive impairment and found age to be associated with higher disability, but found no association between age and QoL. Similarly, Wolfe et al. (2011) reported that at 10 years post-stroke age, was associated with higher rates of disability, inactivity and cognitive impairment, but increasing age was not associated with a reduced HRQoL. However, Nakayama et al. (1994) found age was only associated with impaired ADL, and that age had no influence on cognitive impairment at 3 months after discharge. Furthermore, Bagg et al. (2002) reported age to independently predict functional outcomes at the time of discharge, but found age did not predict functional improvement.

Contrary to the findings from this study, Feigin et al. (2010) reported age to be independently associated with most outcome measures at 5 years post-stroke. Haacke et al. (2006) also found increasing age was negatively associated with HRQoL at 4 years post-stroke, however when considering other variables age was found not to independently predict a reduced HRQoL.

Results from this study indicate that functional outcomes and HRQoL are better accounted for by stroke rather than the ageing process. The lack of association between age and functional outcomes found in this study could possibly reflect characteristics associated with the stroke group. Research has indicated that the degree to which age predicts outcomes can be influenced by other factors such as premorbid functioning, functional status at discharge (Nakayama, et al., 1994), and functional status at admission (Bagg, et al., 2002). Another consideration is the length of time post-stroke, most studies exploring the association between age and outcomes are short-term and are in a clinical setting (Arnold, et al., 2008; Bagg, et al., 2002; Gunaydin, et al., 2010; Macciocchi, et al., 1998). The participants in this study were >2 years post-stroke and in a community based setting, therefore their outcomes were more likely to be favourable than those from a clinical setting. Also some of the stroke group had experienced more than one stroke and this may have contributed to greater stroke related impairment.

Similar to the stroke group, there was no association found between any of the outcome measures and age, which suggests that difficulties experienced by the control group were not associated with the ageing process. A possible explanation for this could also reflect characteristics associated with the control group. As this group was also in a community based setting, older participants with greater difficulty are more likely to be living in supported care, whereas this population were able to live independently in the community. Also this study recruited a restricted age range; a younger sample may have produced difference results.

Co-morbidity

Co-morbid disease is common in stroke survivors and can have an impact on functional outcomes (Studenski, et al., 2004). For the stroke sample the most common co-morbid conditions were high cholesterol, coronary artery disease and angina, arrhythmia and atrial fibrillation/valvular heart disease, hypertension, and migraine respectively. Findings from this study are similar to (White, et al., 2007), who found that hypertension, cardiac conditions and high cholesterol were the most common conditions found in stroke patients. It is no surprise that the above mentioned disorders were more prevalent in the stroke sample as high cholesterol and cardio vascular disorders are risk factors associated with stroke (World Health Organisation, 2004). The higher frequency of migraine reported by stroke survivors has also been considered in the literature (Kurth, Chabriat, & Bousser, 2012; Tietjen, 2005), as well as an association between migraine and cardiovascular disease (Bigal et al., 2010). Given the overlap in symptoms and risk factors, as well as the treatment for migraine can increase the risk of stroke, this is understood to be a complex relationship and the clinical implications are still yet to be established (Kurth, et al., 2012; Tietjen, 2005).

For the control group, the most common co-morbid conditions were other, hypertension and high cholesterol. Rates of co-morbidity were found to differ between the two groups, with stroke survivors experiencing higher rates of high cholesterol, diabetes coronary artery disease and angina, arrhythmia and atrial fibrillation/valvular heart disease and migraine. Although the frequency of hypertension in the stroke sample was higher than the control, this was not significant.

The relationship between co-morbidity and functional outcomes was not considered in this study, however, given the higher frequency of co-morbid conditions reported both in the literature and in this study, the implications of co-morbidity post-stroke warrants consideration. Karatepe et al. (2008) reported that co-morbidity was a frequent occurrence post-stroke, and negatively impacted on both functional outcomes and functional gain post-stroke. Studenski et al. (2004) also explored the effects of co-morbidity on stroke recovery, and found co-morbidity to predict functional outcomes, particularly when taking into account baseline functioning and age.

Disability

Overall, the stroke group reported slight disability as measured by the mRS, and minimal dependency in ADL as measured by the BI. This is consistent with other studies, particularly those looking at long-term functional outcomes. Feigin (2010) found that at 5 years post-stroke, 68.6% of stroke survivors had a good outcome on the mRS with scores <3 , and reported a high score on the BI. At 5 years post-stroke, White et al. (2007) found that 73% of stroke survivors reported independency according to mRS which had increased from 63% at one year post-stroke. Wolfe et al. (2011) found that at 10 years post-stroke, 77.8% of sample reported independence according to the BI and 15.3% reported mild disability.

However, despite the favourable outcomes of the stroke group, in comparison to the control group, the stroke sample experienced significantly higher rates of functional impairment. High rates of disability in stroke survivors are consistent with the physical effects of stroke, and this becomes even more apparent when compared to those who are the same age and have not experienced a stroke (Gresham, et al., 1979). Disability has been shown to remain prevalent long-term following stroke (Patel, et al., 2006). In a 10 year outcome study, Wolfe et al. (2011) reported that 10-20% of stroke survivors were moderately to severely disabled. However, contrary to the findings from the present study, Gresham et al. (1998) found, when comparing long-term outcomes (20-38 years) with a control sample, the functional status of stroke survivors was more favourable than the age sex-matched control sample. Given length of time post-stroke, the survivors in the study would have experienced their stroke young and experienced better outcomes than the stroke participants from the original cohort who had died.

The qualitative data also indicated that disability was more prevalent in the stroke group compared to the control group. This was demonstrated through the participants' experiences with participating in employment, domestic, and leisure activities. The impact of post-stroke disability on participation in activities is documented in the literature (McKenna, et al., 2009; O'Sullivan & Chard, 2010; Robison, et al., 2009), and as such provides a pathway to better understand the ways in which stroke affects wellbeing (Clarke, 2003) and HRQoL (Kwok, et al., 2011).

When reporting on participation in activities, stroke survivors experienced greater physical limitations and restrictions as a consequence of their stroke, altering their ability to participate in various activities. This was most notable in employment, where only two participants reported that they were currently employed. The finding that impairment is a barrier to employment is consistent with many other studies. Hartke, et al. (2011) found that impairment as consequence of stroke was a common theme that prevented stroke survivors from returning to work. Robison et al. (2009) also found that at 12 months post-stroke, of 19 stroke participants only two were able to return to work.

The social consequences of returning to employment after stroke in younger stroke survivors has been considered in research (Daniel, et al., 2009), however for the older population, social and economic reasons also mean that many may also seek to retain the employed status for as long as possible (Hartke, et al., 2011). With age often considered as a barrier for employment as reported in this study, of the control group 16 (64%) participants were involved in some form of employment compared to 2 (8%) of the stroke group. Likewise, McKenna et al. (2009) reported similar rates with 15.4% of stroke survivors (mean age 74.2) participating in employment compared to 45.6% non-stroke survivors aged (>65 years).

Although this study did not explore the desire to return to work, returning to employment is often viewed as a basis for recovery, furthermore, being unable to return to work has been found to negatively impact on social participation (Daniel, et al., 2009). The desire to return to employment may not necessarily be financially motivated; employment also provides a way in which to participate in a meaningful activity. Being able to participate in employment provides a means by which someone is able to see themselves as a contributing member of society (Hartke, et al., 2011). Participating in employment was an area in which the

stroke and control groups in this study differed most considerably. For the stroke group this was often seen as a result of restricted functioning as a consequence of stroke, however, for some age was also reported to be a contributing factor.

For the stroke survivors, the theme of restrictions and limitations reflected the experience of a person who is dealing with the effects of stroke, and trying to compensate for their disabilities in everyday activities. The results from this study support previous findings that stroke survivors experience difficulty in domestic activities most commonly as a consequence of their disabilities (D'Alisa, et al., 2005; Gadidi, et al., 2011; Robison, et al., 2009). Despite difficulties, the stroke group continued to participate in domestic tasks with many demonstrating resilience as they accommodated their impairments by participating in a reduced capacity or developing innovative strategies. The shift towards adaption after loss of physical functioning has also been reported in other studies. Robison et al. (2009) found that in order to perform in activities, some stroke survivors were able to adapt their functioning accordingly, and others took up new activities. Salter et al. (2008) also found that for some stroke survivors, adaption and reconciliation became a key focus for recovery, rather than regaining physical functioning.

Responses from the control group however, echoed a theme of 'yes I can participate' when it came to reporting on their ability to be involved in activities such as employment, domestic activities, and leisure activities. When issues of difficulty were reported it was related to the more physically demanding tasks representing an increase in task difficulty rather than a reduced ability.

As their on-going effects of stroke restricted their ability to participate in various activities (O'Sullivan & Chard, 2010), the stroke survivors in this study were found to spend more time in less physically active, solitary activities such as reading, diary writing, puzzles and crosswords, than in activities such as walking, bowls, golf, and dancing as reported by the control group. This is consistent with McKenna et al. (2009) and O'Sullivan and Chard (2010), who found that stroke survivors spent more time at home participating in solitary activities than those without stroke. Furthermore, as also noted in this study, the ability to get around had the greatest impact on stroke survivors and as Danielsson et al. (2011) found, stroke

survivors continued to experience impairment in their ability to walk and participate in activities for many years after their stroke.

Findings from this study also indicated that many of the stroke group were unable to resume previous leisure activities after their stroke as a consequence of their disabilities. For some this was voiced as a loss, and for others it was necessary to participate in other activities in order to maintain physical functioning. Similarly, Robison et al. (2009) found that where stroke survivors were unable to resume previous activities, they either took up new activities or adapted themselves in order to accommodate disability. In contrast, in the control group only two participants reported no longer being able to participate in previous activities and most enjoyed a range of activities across various domains.

Social activities did however provide the opportunity for the stroke group to be involved in activities outside the home without being physically demanding. Furthermore, engaging in social activity has been shown to predict life satisfaction (Gadidi, et al., 2011). Findings from this study indicated that the stroke group were able to find opportunities to participate in social activities. This is somewhat consistent with McKenna et al. (2009) who found no difference between stroke and non-stroke groups in regards to participation in social activities, however the control group in the present study reported a higher rate of participation in social activities. In contrast, other studies (O'Sullivan & Chard, 2010; Salter, Hellings, et al., 2008) found reduced rate of participation in social activities in stroke survivors, and as a result they were more likely to experience social isolation. The different finding in this study is possibly due to many of the stroke survivors still retaining social networks with church groups, clubs and common interest groups; also a number of participants recruited for this study were involved with a stroke club which provides opportunities to socialise with other stroke survivors in an environment suitable for their disabilities.

Cognitive Impairment

Cognitive functioning as measured by the MMSE and the MoCa indicated that 2 (8%) of the stroke group meet the cut off score for cognitive impairment according to the MMSE, and 20 (80%) of the stroke group meet the cut off score for cognitive impairment according to the MoCA. In comparison, no

participants from the control group meet the cut off score for cognitive impairment according to the MMSE, and 15 (60%) meet the cut off score for cognitive impairment according to the MoCA. Overall, significantly more participants in the stroke group showed cognitive impairment according to both measures than the control group. The higher rates of cognitive impairment in the stroke group are consistent with consistent Nys et al. (2005) who detected cognitive impairment 47% of stroke patients compared to 8% of health control.

Research suggests that cognitive impairment is associated with poor long-term functional outcomes (Patel, et al., 2002) and difficulties in daily activities (Rasquin, et al., 2004; Viscogliosi, et al., 2011). Despite cognitive impairment being higher for the stroke group, the data from the qualitative findings suggests that this was not considered a concern. Although no questions were orientated towards deficits in cognitive functioning, when reporting on difficulties, physical impairment was more salient. Also, as only two participants in the stroke group were currently employed, there was an absence of situational triggers that could possibly draw attention to any cognitive decline. However, in a study by Viscogliosi et al. (2011), deficits in cognitive functioning post-stroke, particularly in the areas of memory, visual perception, and language functioning were found to impact on participation most notably in social roles. Therefore, although there was an absence of concern about deficits in cognitive impairment, a more comprehensive analysis of cognitive functioning may have yielded different findings. Cognitive functioning however was not found to be associated with HRQoL as measured by the SF-36 for either group; this is inconsistent with Barker-Collo et al. (2010) who found that neuropsychological deficits were associated with HRQoL and disability, although Barker-Collo et al. (2010) applied a more comprehensive cognitive assessment.

Cognitive impairment after a stroke frequently occurs (Gottesman & Hillis, 2010), however rates of cognitive impairment after stroke vary within the literature. Cognitive impairment in the stroke group as measured by the MoCA is similar to Pendlebury, et al. (2010) who detected cognitive impairment in 70% of stroke survivors who were either 6 months or 5 years post-stroke. However, Dong et al. (2010) detected cognitive impairment in 32% of stroke survivors, (as measured by the MoCA). At 3 months post-stroke, Patel et al. (2002) detected cognitive impairment in 38% of stroke survivors according to the MMSE. At 1

year post-stroke, Apprelros (2005) detected cognitive impairment in 29% of stroke survivors according to the MMSE. At 5 years post-stroke, White et al. (2007) reported 7% of stroke survivors demonstrated cognitive impairment, and at 10 years post-stroke Wolfe et al. (2011) found 18% of stroke survivors demonstrated cognitive impairment as classified by the MMSE.

Discrepancies in rates of cognitive impairment in the literature may be explained by factors associated with short-term and long-term outcomes. Rates of mortality are highest within the first month of stroke (Hardie, et al., 2003), with long term survival after stroke representing more favourable outcomes. Patel et al. (2002) found at 4 years post-stroke, case-fatality was higher in the cognitive impaired than the cognitively intact. Deficits in functioning after stroke (i.e., aphasia or neglect) can also affect an individual's performance on cognitive measures (Gottesman & Hillis, 2010) as found with a participant who had aphasia in this study and was unable to say 'watch' when prompted, or as seen with another participant with hemiplegia who was unable to copy a diagram. Also, as demonstrated in this study, rates of impairment can vary according to which measures are used. This has been noted within literature (Aggarwal & Kean, 2010; Dong, et al., 2010; Nasreddine, et al., 2005; Pendlebury, et al., 2010), and as a result the sensitivity of the MMSE in comparison to the MoCA for detecting cognitive impairment has been identified as a concern. It is also unknown if any of the stroke group were cognitively impaired prior to their stroke.

Sensitivity of the MMSE and the MoCA

Cognitive decline ranging from mild cognitive impairment through to dementia is frequently detected in stroke survivors (Gottesman & Hillis, 2010) and the MMSE is the most common measured used as a brief screening tool for cognitive impairment (Nys, et al., 2005). The results from this study demonstrated poor concurrent validity between the MMSE and the MoCA, suggesting there is very little relation between the two measures. Furthermore, the MMSE is not as sensitive at detecting cognitive impairment as the MoCA. Of the 23 stroke participants with unimpaired MMSE scores, 20 were found to have impairment according to the MoCA. This finding is consistent with Aggarwal and Kean (2010) who found that of the 43 patients with unimpaired MMSE scores, 25 scored as cognitively impaired according to

the MoCA. Similarly, Dong et al. (2010) found that 57 patients who were unimpaired according to the MMSE, 18 were cognitively impaired according to the MoCA.

The MMSE and the MoCA were developed for slightly different purposes and these purposes should be considered when looking at these findings. The MMSE were developed as a cognitive screening measure to detect severity of impairment (Folstein, et al., 1975), whereas the MoCA was developed to detect mild cognitive impairment in those where cognitive impairment was not detected with the MMSE (Nasreddine, et al., 2005). Thus, the MMSE is more orientated towards detecting severe cognitive impairment, whereas the MoCA is capable of detecting the presence of mild impairment.

The poor sensitivity of the MMSE may be due to its bias towards orientation and language, whereby executive skills, visuospatial and construction skills are underrepresented (Appelros, 2005). The superiority of the MoCA is credited to its more demanding tasks, for example, the memory test has fewer learning trials and longer delay for recall items (Nasreddine, et al., 2005). Neither the MMSE nor the MoCA were specifically designed for use on a stroke population, however currently there is no standardised cognitive assessment for stroke (Gottesman & Hillis, 2010). With deficits in functioning occurring as a consequence of aphasia, hemispatial neglect, and hemiplegia, tasks that require verbal responding and motor function have the potential to bias the performance of stroke survivors. Findings should be interpreted with caution and where necessary alternative measures should be used.

Depression and Anxiety

There were no significant differences between the stroke and control groups' levels of depression. Studies have found a decrease in symptoms of depression over time after stroke (Morrison, et al., 2005; Patel, et al., 2006; Teoh, et al., 2009). This reported trend in depressive symptoms could explain the comparable rates of depression between the two groups given the average length of time post-stroke is 9.88 years. When looking at mental health scores on the SF-36 there was also no difference between the groups for the domain of mental health which measures feelings of nervousness and depression. However, for the mental component summary, which measures the occurrence of psychological pain and the effects of

emotional distress on social and role, there was a significant difference. A possible reason for this is that the mental health component summary includes the multi-domains of vitality, social functioning, role-emotion, and mental health.

Rates of anxiety were significantly higher for the stroke group compared to the control group. This finding is also in line with other research in this area (Åström, 1996; Morrison, et al., 2005), where rates of anxiety were found to remain stable long-term post-stroke. Although post-stroke anxiety is not as extensively researched as post-stroke depression, Åström (1996) found the long-term clinical implications for post-stroke anxiety to not only negatively impact on functional recovery, but also social networks. Although findings from this study indicated anxiety was more prevalent in the stroke group, no stroke survivors scored in the probable range of anxiety. Furthermore, the qualitative data indicated that social activities were, for the stroke group, an area in where they were able to accommodate their physical limitations, and most were able to participate. Those that expressed the greatest difficulty in social activities were participants who experienced difficulty communicating as a consequence of aphasia.

Interestingly, although only 4% of the control group reported symptoms of anxiety, this was in the probable range, whereas of the stroke group 20% reported symptoms of anxiety in the possible range. So although anxiety was more prevalent in the stroke group, symptoms were more severe in the control group. However, 12% of stroke survivors reported symptoms of both anxiety and depression whereas this was not reported by the control group. Similarly, Bergersen et al. (2010) found high rates of both anxiety and depression in stroke survivors. Morrison et al. (2005) also found that anxiety was a clinical variable that predicted depression three years after stroke. Furthermore, Shimoda and Robinson (1998) found that co-morbid anxiety and depression greatly impaired ADL and social functioning more than depression or anxiety alone. The current study found no association between anxiety or depression in ADL. The small sample size in this study requires caution when interpreting findings, it should be noted that participants were not asked if they were taking medication for mood disorders. Finally, depression items on the HADS such as: 'I feel as if I am slowed down' and 'I still enjoy the things I used to enjoy' could be interpreted in terms of physical functioning rather than mood items and answered accordingly.

Health Related Quality of Life

HRQoL measures evaluate an individual's perception of their physical, social, psychological and emotional health status (Doyle, 2002; Salter, Moses, et al., 2008). HRQoL was found to be lower for the stroke group compared to the control group as measured by the SF-36 and the EQ-5D. Significant differences between the groups were demonstrated in all domains of the SF-36, aside from mental health and role emotion. The physical component summary and mental health component summary were also lower for the stroke group compared to the control group. The stroke group saw themselves worse off in the areas of physical functioning, difficulties in ADL, bodily pain, belief that health will deteriorate, energy, social activities, psychological distress, and restrictions in physical functioning than those in the control group.

Findings from this present study also indicated that higher levels of disability and limitations in ADL were associated with a reduced HRQoL for the stroke group. Disability has frequently been associated with a reduced HRQoL (Almborg, et al., 2010; Aprile, et al., 2006), and continues to impact on the recovery process long-term. At 3 years post-stroke, Patel et al. (2006) found disability was still prevalent and demonstrated a graded relationship with HRQoL.

Further exploration into the domains of the SF-36, indicated that higher disability was associated with the domains of physical functioning, vitality, and mental health for the stroke group. This suggests disability negatively impacts on how stroke survivors perceive their physical capabilities, energy levels, and psychological distress. Limitations in ADL were associated with the domains of physical functioning, role physical, and mental health suggesting that difficulties in ADL are associated with physical functioning, perceived ability in daily activities, and psychological distress.

The relationship between disability and the SF-36 physical and mental health domains found in this study is consistent with other research in this area. Aprile et al. (2006) reported that physical functioning and emotional distress was associated with greater disability and reduced ADL in stroke survivors undergoing rehabilitation. At 3 years post-stroke, Patel et al. (2006) found reduced physical functioning was associated with impairment in ADL, however mental health was considered satisfactory.

In comparison, for the control group, disability was associated with SF-36 domains of physical functioning, general health, and mental health component summary. Unlike the stroke group, the control group's belief that their health was likely to deteriorate was associated with greater disability. Overall, the control group reported little to no difficulty in ADL, and therefore the BI was not associated with any of the other measures. Interestingly, although the stroke group demonstrated lower scores in general health, and greater disability, their general health score suggests the stroke group did not see themselves as getting worse as a result of their disability.

A possible explanation for this, is overtime the stroke survivors have adjusted to the residual effects of their stroke (Eilertsen, et al., 2010; Kirkevold, 2002). This was observed in the qualitative data when exploring perceptions of health and wellbeing. For the stroke group, most reported favourable health outcomes, despite their post-stroke impairment. This suggests that the effects of stroke had been accommodated and were now a part of everyday functioning, and no longer viewed as residual disabilities of stroke.

A reduced HRQoL in stroke survivors compared to those who have not experienced a stroke is consistent with other long term outcome studies. Hackett et al. (2000) found that at 6 years post-stroke, stroke survivors reported lower scores than both their control group and New Zealand norms in SF-36 physical functioning and general health domains, and also, similarly to this study there were no differences in the mental health domain. Haley et al. (2011), when comparing scores from the SF-12 at 9-12 months post-stroke, reported a reduced HRQoL compared to the control group. At 4 years post-stroke, Haacke et al. (2006) completed a follow up study on stroke survivors and reported a reduced HRQoL as measured by the EQ-5D. Similar to this study, Haacke et al. noted that independence in ADL was associated with a more positive perception of health. In comparison, the control group in the present study demonstrated an association between health difficulties and greater disability, but this did not influence how they perceived their overall health.

Not all studies have found a reduced HRQoL following stroke, for example Wolfe et al. (2011) reported little variation in HRQoL from 3 months to 10 years post-stroke, and despite reduced activity and

participation, HRQoL was comparable with non-stroke scores. Similarly, Anderson et al. (2004) found that at 21 years post-stroke, HRQoL in stroke survivors was comparable to the New Zealand standardised norms for the SF-36, suggesting stroke survivors were effectively managing their disabilities. However, populations in long-term outcome studies represent those with more favourable outcomes, who have had more time to adjust to the long-term effects of stroke, and subsequently scores are more likely to be comparable to general populations. As suggest by Wolfe et al. participants who engaged in long-term follow-up studies are healthier participants and those of greater economic means. Also Anderson's et al. study, included <1 in 10 of the original stroke cohort of the study, demonstrating that risk of mortality is greater in those with poorer outcomes, and those who have experienced subsequent strokes.

The qualitative data in this study suggests that despite the on-going effects of stroke, the stroke group saw themselves as experiencing good health, and although they were aware of the impact their stroke had on their lives, their disability was not seen as synonymous with ill health. Similarly, the control group also saw themselves as living with good health, which at times was interrupted by episodes of ill health before returning to a state of good health. Although this comparison was not apparent in the HRQoL scores, it reflects how subjective experiences cannot always be so outwardly predicted by quantitative functional outcome measures. Also as seen in this study, the process of adaption is central in reducing the effects of disability (Clarke, 2009). As suggested by Kirkevold (2002), this occurs through the process of integrating the stroke into their life while trying to minimise the effects, and to move forward into a new era of 'normal' life. As demonstrated by the stroke survivors in this study, their view of their health reflected the adjusted perception of what they considered to be their experience of 'good' health. Similarly, Darlington et al. (2007) found that quality of life after stroke was determined by the ability to pursue certain goals or adjusting one's goals accordingly.

Although both groups presented with similar views of their health, some of the stroke group struggled to reconcile the outcome of their stroke with their life trajectory schema. Clarke (2003) found that more profound disability predicted a reduced wellbeing when the residual effects of stroke prevented engagement in activities. Similarly for the stroke group in this study, the effects of their stroke prevented

them from engaging in previous activities leaving them with a sense of loss over the life they thought they would have. Other stroke survivors expressed a more stoic view and were resigned to the effects of their stroke. Eilersten et al. (2004) also reported a similar view in stroke survivors, finding that some choose not to focus on worries and uncertainty.

This view was not completely separate from the control group's experience of their health related difficulties. The participants of the control group were not insusceptible to physical difficulties which were mostly reported in terms of bodily pain. Although the stroke group reported significantly higher levels of bodily pain on the HRQoL measures than the control group, pain was considered an issue that most felt that had to endure in their everyday life.

Support and Services

After considering the stroke group's experiences with participating in activities and the view of their health and wellbeing, and given that rehabilitation is also an integral part of recovery, the stroke survivors experiences with support and services were also explored. Most participants received inpatient care and rehabilitation after their stroke and expressed positive regard for the care they received. Many felt their rehabilitation was instrumental in regaining functioning, however for some the transition from the supportive clinical environment to home proved difficult. This process has been reported in other studies. Eilersten et al. (2010) identified a similar response, suggesting that a challenging time for stroke survivors is when they return home are no longer receiving the inpatient support. Kirkevold (2002) also noted how upon returning home, the stroke survivor faced a new set of challenges different from practical and personal tasks they focused on in hospital.

For some, the reintegration into home life was a struggle as they tried to generalise the skills they had acquired in the inpatient setting to their home environment. Bouffioulx et al. (2011) also reported a similar finding suggesting that life satisfaction decreased when health professionals focused on basic needs such as washing and dressing, but neglected ADL and other life situations that occur in both home and social environments. As a consequence many stroke survivors felt abandoned in the process, particularly

when left to cope with their acquired deficits in a new setting. As Darlington et al. (2006) suggested, although it is necessary for coping strategies to be modifiable and adjust overtime to context and situation, the authors found that coping did not adjust with time, instead it occurred when physical functional failed to improve, and the effects of stroke became part of everyday living.

It was not only the stroke survivor who was left to cope with the effects of stroke, the burden of stroke extended to family as they were also expected to make adjustments according to the needs of the stroke survivor. Spouses were at times expected to give up employment and take on a new role of unpaid caregiver with no training and assuming the identity of 'us' with the stroke. Kwok et al. (2011) also identified changes in the spousal relationship after stroke, and suggested that in order to improve family functioning interventions needed to focus on reducing caregiver stress, as well as promote independence and HRQoL in stroke survivors.

When reflecting back on their initial experience of life after stroke, it was apparent that many stroke survivors were unprepared for the actual impact the stroke would have on both their life and others around them. When exploring whether there was anything they felt was missing in regards to support and services, there was a distinct response to the perceived lack of information regarding the actual impact stroke would have on their life. Although this was not expressed in terms of an apparent lack of information, it was more in response to information that helped them more accurately understand how their disabilities would affect their life, and what this meant for them in terms of the realistic long-term outcomes they could expect. Kirkevold (2002) explains this in terms of the initial focus of stroke being a medical event in which, as information is gradually received, optimism shifts in response to a gradual adjustment of expectations. When this information is not forthcoming, is inaccurate, or does not fit within the stroke survivor's expectations, this results in significant distress as reported by the stroke group in this study.

Another factor to be considered is the timing of when expected outcomes were shared with the stroke survivor. Eilersten et al. (2010) noted that health professionals should not assume that a lack of enquiry from the patient in the early stages means the stroke survivor does not require any further information. For the stroke survivor, the pursuit of knowledge about their stroke needs to reflect their stage of recovery.

Overall, engagement with support was considered positive with most acknowledging the positive influence their rehabilitation had on their recovery. As many of the stroke participants were also involved in Stroke Club, there was also the opportunity for peer support from others both for the stroke survivors and the caregivers. Support seemed to fall short when it came to the burden and expectations on the caregiver, and the appropriateness of information regarding post-stroke outcomes.

Strengths and Limitations

The strength of this study was in the study design. The use of an age sex-matched non-stroke control sample enabled a comparison of outcomes highlighting areas of life that are affected by stroke. Also, the use of both qualitative and quantitative methodology provided a more comprehensive understanding of how the effects of stroke are experienced in everyday life. As Clarke (2003) suggests, qualitative analysis assists in illustrating aspects of stroke which are not accounted for by the quantitative data. Finally, by looking at long-term outcomes in a community setting, this study was able to explore how stroke impacted on life in both home and social settings, once short-term recovery has occurred.

A number of limitations have also been considered in this research. The sample size is relatively small and is predominantly European. A larger sample size which is inclusive of other cultural groups that reflects the wider New Zealand population would be useful to extend on these findings. A larger sample size would have meant also that multiple regression analyses could have been carried out which would have enabled the exploration of predictive factors associated with HRQoL, as well as increased reliability of the findings. Also, the stroke participants were predominantly recruited through their association with the Stroke Club in Hamilton and Te Awamutu, therefore the sample may be biased towards those with better outcomes due to their association with stroke clubs. Although this did not necessarily mean that this sample was more physically capable, just that it reflected a sample that was more inclined to socialise.

Severity of stroke was not assessed and was not included as a criterion; therefore the stroke group included severe to relatively mild stroke survivors who would have experienced very different functional outcomes. However, despite the inclusion of mild stroke survivors, differences were still apparent between

the stroke and control group. It also would have been useful to know the type of stroke and lesion location; however this study relied on self-report and although most stroke survivors were aware of what type of stroke they experienced, most were unsure of the location.

The study was cross-sectional and measures in this study were taken at one single time point. As a result is difficult to assume causality of effects of stroke where participants had experienced decline or improvement since their initial stroke. Also, although the measures that were used in this study are widely applied to a stroke population, aside from the mRS, they were not developed specifically. There is recommendations in the literature for a more standardised cognitive assessment (Gottesman & Hillis, 2010), and for comprehensive health status assessments (Doyle, 2002) for stroke to include not only functional outcomes in a range of areas affected by stroke, but also the extent to which stroke impacts on participation in activities. Further research into the long-term effects of stroke would benefit from this future analysis.

The qualitative component consisted of an interview developed by the researcher. Upon reflection, the semi-structured design of the interview would have benefited from less structure and a more open ended line of questioning which would have yielded more comprehensive findings.

Conclusion

When considering both qualitative and quantitative data and comparing outcomes to an age sex-match sample, it is apparent that the residual effects of stroke continue to restrict participation and functioning long-term after stroke. Furthermore, the challenges faced by stroke survivors impact on their HRQoL significantly more than difficulties experienced as a consequence of the ageing process.

As demonstrated by the outcomes measures used, the stroke group reported higher levels of disability, more limitations in ADL, greater impairment in cognitive functioning, higher rates of mood disorders, and a reduced HRQoL than the control group. Exploring participation in activities provides further information about the impact of stroke in everyday life (Gadidi, et al., 2011). The qualitative data reiterated disparities between the two groups, with the stroke group experiencing greater restriction and limitations in employment, domestic and leisure activities. However, when adjusting to accommodate their

disability the stroke group were able to continue engagement in activities. The comparable perception of health and wellbeing between the two groups provided evidence of the unobserved process of the how stroke survivor alters their perception of their impairments in relation to how they view their overall health and wellbeing.

In regards to the sensitivity of the MMSE compared to the MoCA as a brief cognitive screening measure, the MoCA was found to be more sensitive at detecting cognitive impairment in both the stroke and the control groups.

Implications of the Research

This study provided evidence that the effects of stroke continue to impact on the lives of stroke survivors long-term after stroke, restricting their ability to participate in activities. Rehabilitation that focuses on functional outcomes in relation to home, leisure and social settings will assist in generalisation of strategies outside the clinical environment, and enhance the ability to participate in activities.

Findings from this study also emphasise the adaptability of stroke survivors. Despite the effects of stroke, as demonstrated by some of the stroke survivors in this study, the potential exists to effectively adapt to deficits in functioning. This process may also require an adjustment of expectations, however focusing on what the stroke survivor can do, promotes independency and encourages the development of new skills that can be incorporated into both home and social settings.

As indicated by the stroke survivors in this study, there is a need to provide timely information about the realistic long-term outcomes of stroke. Furthermore, there is a need for carers to be more aware of how stroke will impact on their lives, as well as training and support to help with the role transition from spouse to carer.

Finally, this study highlighted the positive effects of social activities as well as the benefits of attending a peer supported group, such as stroke club. Social activities for most provided an opportunity to be involved in activities outside of the home, without being restricted by impairment in functioning. The benefit of participating in social activities is that not only it promotes and strengthens support networks;

it also enables the stroke survivor to associate with others who have like-minded interests and goals. The shared experience of stroke may be the common interest, as seen with those who attend stroke club, or it could be the continuation of involvement in activities they enjoyed prior to their stroke, such as church groups or garden clubs. Overall, the benefit of social activities is that it increases both health and wellbeing, thus increasing the HRQoL of the stroke survivor and their families.

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APPENDICES

Appendix A

Eligibility Screening

Have you experienced a stroke at least 2 years ago?	Yes/No Stoke group/non-stroke group
Are you aged between 55-85 years?	Yes/No
Do you live independently?	Yes No

Date of Assessment:	
Signed Informed Consent:	Yes/No

Section 1

1.0 Demographic Information:

Date of Birth:	
Male/Female:	M/F
Ethnicity:	
Marital Status:	
Current Living Arrangement:	
What is or was your prior occupation: (specify type of work/industry/organisation)	
Were you the main income earner:	
If No what is (was) the lifetime occupation of the main (other income earner in the family/household?	
What is you highest qualification:	

1.1 Has a doctor or medical person ever told you that you have any of the following:

Stroke/TIA: What type of stroke: Lesion site:	Present/Not Present
Elevated blood lipids(cholesterol)	
Diabetes	
Coronary artery disease, angina (heart attack)	
Irregular pulse (arrhythmia), atrial fibrillation/valvular heart disease	
Heart failure	
Epilepsy/seizures	
Migraine	
Head Injury	
Hypertension	
Have you received any other previous Diagnosis	

Section Two

2.0

Modified Rankin Scale

SCORE	DESCRIPTION
0	No symptoms at all
1	No Significant disability despite symptoms: able to carry out all usual duties and activities.
2	Slight disability: unable to carry out all previous activities, but able to look after own affairs without assistance.
3	Moderate disability: requiring some help but able to walk without assistance.
4	Moderate severe disability: unable to walk without assistance and unable to attend to own bodily needs without assistance.
5	Severe disability: bedridden, incontinent and requiring constant nursing care and attention.
6	Dead

Total (0-6) _____

2.1

Barthel Index

Activity	Score
FEEDING 0 = unable 5 = needs help cutting, spreading butter, etc., or requires modified diet 10 = independent	_____
BATHING 0 = dependent 5 = independent (or in shower)	_____
GROOMING 0 = needs to help with personal care 5 = independent face/hair/teeth/shaving (implements provided)	_____
DRESSING 0 = dependent 5 = needs help but can do about half unaided 10 = independent (including buttons, zips, laces, etc.)	_____
BOWELS 0 = incontinent (or needs to be given enemas) 5 = occasional accident 10 = continent	_____
BLADDER 0 = incontinent, or catheterized and unable to manage alone 5 = occasional accident 10 = continent	_____
TOILET USE 0 = dependent 5 = needs some help, but can do something alone 10 = independent (on and off, dressing, wiping)	_____
TRANSFERS (BED TO CHAIR AND BACK) 0 = unable, no sitting balance 5 = major help (one or two people, physical), can sit 10 = minor help (verbal or physical) 15 = independent	_____
MOBILITY (ON LEVEL SURFACES) 0 = immobile or < 50 yards 5 = wheelchair independent, including corners, > 50 yards 10 = walks with help of one person (verbal or physical) > 50 yards 15 = independent (but may use any aid; for example, stick) > 50 yards	_____
STAIRS 0 = unable 5 = needs help (verbal, physical, carrying aid) 10 = independent	_____
TOTAL (0-100):	_____

Mini-Mental State Examination
 Folstein, Folstein, and McHugh (1975)
 Folstein, Folstein, and Fanjiang (2000)

Date of examination _____/_____/_____ Examiner _____

Name _____ Age _____ Years of School Completed _____

Instructions: Words in boldface type should be read aloud clearly and slowly to the examiner. Item substitutions appear in parentheses. Administration should be conducted privately and in the examinee's primary language. Circle 0 if the response is incorrect, or 1 if the response is correct. Begin by asking the following two questions:
Do you have any trouble with your memory? May I ask you some questions about your memory?

ORIENTATION TO TIME	RESPONSE	SCORE <small>(circle one)</small>	
What is the... year?	_____	0	1
season?	_____	0	1
month of the year?	_____	0	1
day of the week?	_____	0	1
date?	_____	0	1

ORIENTATION TO PLACE*

Where are we now? What is the... state (province)?	_____	0	1
county (or city/town)?	_____	0	1
city/town (or part of city/neighborhood)?	_____	0	1
building (name or type)?	_____	0	1
floor of the building (room number or address)?	_____	0	1

*Alternative place words that are appropriate for the setting and increasingly precise may be substituted and noted.

REGISTRATION*

Listen carefully. I am going to say three words. You say them back after I stop. Ready?
Here they are...APPLE [pause], PENNY [pause], TABLE [pause]. Now repeat those words back to me.
 [Repeat up to five times, but score only the first trial]

APPLE	_____	0	1
PENNY	_____	0	1
TABLE	_____	0	1

Now keep those words in mind. I am going to ask you to say them again in a few minutes.
 *Alternative word sets (e.g., PONY, QUARTER, ORANGE) may be substituted and noted when retesting an examinee.

ATTENTION AND CALCULATION [Serial 7s]*

Now I'd like you to subtract 7 from 100. Then keep subtracting 7 from each answer until I tell you to stop.

What is 100 take away 7?	[93]	_____	0	1
<i>If needed say: Keep going.</i>	[86]	_____	0	1
<i>If needed say: Keep going.</i>	[79]	_____	0	1
<i>If needed say: Keep going.</i>	[72]	_____	0	1
<i>If needed say: Keep going.</i>	[65]	_____	0	1

*Alternative item (WORLD backward) should only be administered if the examinee refuses to perform the Serial 7s task. —>

Substitute and score this item only if the examinee refuses to perform the Serial 7s Task

Spell WORLD forward, then backward.

Correct forward spelling if misspelled,
but only score the backward spelling.

____ (D = 1) ____ (L = 1) ____ (R = 1) ____ (O = 1) ____ (W = 1) ____ (0 to 5)

RECALL

RESPONSE

SCORE

(circle one)

What were those three words I asked you to remember? [Do not offer any hints.]

APPLE	_____	0	1
PENNY	_____	0	1
TABLE	_____	0	1

NAMING*

What is this? [Point to a pencil or pen.] _____ 0 1

What is this? [Point to a watch.] _____ 0 1

*Alternate common objects (e.g., eyeglasses, chair, keys) may be substituted and noted.

REPETITION

Now I am going to ask you to repeat what I say. Ready "NO IFS, ANDS, OR BUTS." Now you say that.
[Repeat up to 5 times, but score only the first trial.]

NO IFS, ANDS, OR BUTS. _____ 0 1

Use the upper half of the next page (blank) for the Comprehension, Writing, and Drawing items that follow. Use the lower half of the page as a stimulus form for the Reading ("CLOSE YOUR EYES") and the following page for Drawing (intersecting pentagons) items.

COMPREHENSION

Listen carefully because I am going to ask you to do something.

Take the paper in your right hand [pause], **fold it in half** [pause], **and put it on the floor** (or table).

TAKE IT IN RIGHT HAND	_____	0	1
FOLD IN HALF	_____	0	1
PUT ON FLOOR (or TABLE)	_____	0	1

READING

Please read this and do what it says. [Show examinee the words on the stimulus form.]

CLOSE YOUR EYES _____ 0 1

WRITING

Please write a sentence. [If examinee does not respond say: **Write about the weather.**] 0 1

Place the blank piece of paper (unfolded) in front of the examinee and provide a pen or pencil. Score 1 point if the sentence is comprehensible and contains a subject and a verb. Ignore errors in grammar or spelling.

DRAWING

Please copy this design. [Display the intersecting pentagons on the stimulus form.] 0 1

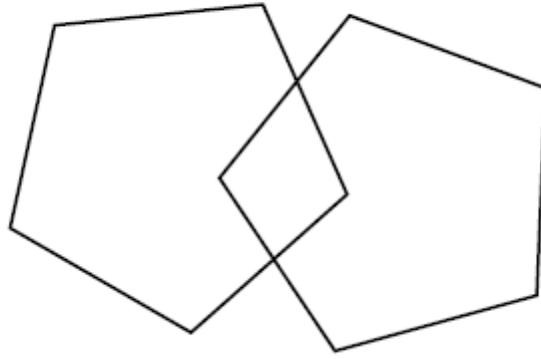
Score 1 point if the drawing consists of two 5-sided figures that intersect to form a 4-sided figure.

Assessment of level of consciousness.

Total Score = _____
(Sum all item scores) (30 points max.)

Alert/ Responsive	Drowsy	Stuporous	Comatose/ Unresponsive
----------------------	--------	-----------	---------------------------

CLOSE YOUR EYES



3.1

MoCA TESTING

Please perform the test in the following order:

1. Naming (animals)
2. Visuospatial/executive
 - a. Clock
 - b. Cube
 - c. Trail Test

Please record the following additional information from the MoCA during testing:

Verbal fluency Number of words beginning with f generated in the first 15 seconds	
Delayed recall (category cue) Number of words recalled with category cue (if patient does not spontaneously recall all the words)	
Delayed recall (multichoice cue) Number of words recalled with a multichoice cue (if patient fails to recall the words with a category cue)	
Start and finish time for testing Please record in the boxes on the testing sheet on the following page. Similarly, please record start and finish time for the MMSE at the end of the follow-up.	
Problems with cognitive testing Please record any problems with testing at the end of the MMSE using the boxes provided	

For further information, please see the information sheet (and please refer to this each time you perform the MoCA to ensure consistency of administration)

Please Note:

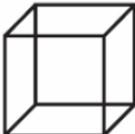
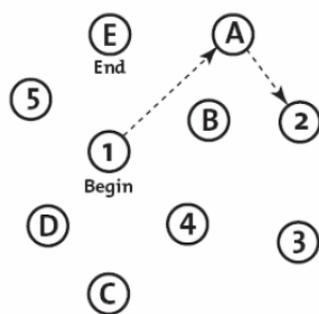
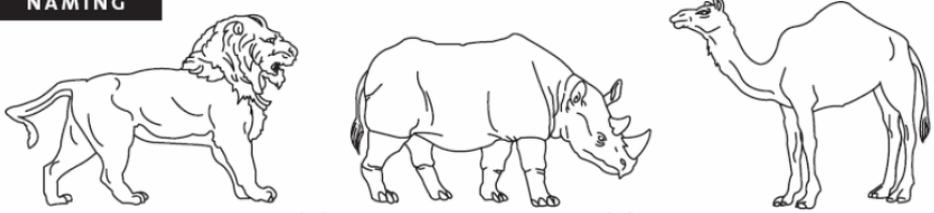
When conducting the assessment face to face please ask subject to answer all MOCA questions (max score:30).

When conducting the assessment over the phone only those MOCA questions marked "PHONE" should be asked (max score: 12).

MOCA	Full test*	Short test*	Not done
START TIME:			

MONTREAL COGNITIVE ASSESSMENT (MOCA)

NAME : _____
 Education : _____ Date of birth : _____
 Sex : _____ DATE : _____

	VISUOSPATIAL / EXECUTIVE		Copy cube	Draw CLOCK (Ten past eleven) (3 points)	POINTS																	
	 [] [] []			[] [] [] Contour Numbers Hands	___/5																	
	NAMING	 [] [] []			___/3																	
PHONE	MEMORY	Read list of words, subject must repeat them. Do 2 trials. Do a recall after 5 minutes.	<table border="1" style="width:100%; text-align:center;"> <tr> <td></td> <td>FACE</td> <td>VELVET</td> <td>CHURCH</td> <td>DAISY</td> <td>RED</td> </tr> <tr> <td>1st trial</td> <td></td> <td></td> <td></td> <td></td> <td></td> </tr> <tr> <td>2nd trial</td> <td></td> <td></td> <td></td> <td></td> <td></td> </tr> </table>		FACE	VELVET	CHURCH	DAISY	RED	1st trial						2nd trial						No points
	FACE	VELVET	CHURCH	DAISY	RED																	
1st trial																						
2nd trial																						
	ATTENTION	Read list of digits (1 digit/ sec.). Subject has to repeat them in the forward order [] 2 1 8 5 4 Subject has to repeat them in the backward order [] 7 4 2			___/2																	
		Read list of letters. The subject must tap with his hand at each letter A. No points if ≥ 2 errors [] FBACMNAAJKLBAFAKDEAAAJAMOF AAB			___/1																	
		Serial 7 subtraction starting at 100 [] 93 [] 86 [] 79 [] 72 [] 65 4 or 5 correct subtractions: 3 pts, 2 or 3 correct: 2 pts, 1 correct: 1 pt, 0 correct: 0 pt			___/3																	
	LANGUAGE	Repeat : I only know that John is the one to help today. [] The cat always hid under the couch when dogs were in the room. []			___/2																	
		Fluency / Name maximum number of words in one minute that begin with the letter F [] _____ (N ≥ 11 words)			___/1																	
	ABSTRACTION	Similarity between e.g. banana - orange = fruit [] train - bicycle [] watch - ruler			___/2																	
PHONE	DELAYED RECALL	Has to recall words WITH NO CUE	<table border="1" style="width:100%; text-align:center;"> <tr> <td>FACE</td> <td>VELVET</td> <td>CHURCH</td> <td>DAISY</td> <td>RED</td> </tr> <tr> <td>[]</td> <td>[]</td> <td>[]</td> <td>[]</td> <td>[]</td> </tr> </table>	FACE	VELVET	CHURCH	DAISY	RED	[]	[]	[]	[]	[]	Points for UNCUED recall only	___/5							
FACE	VELVET	CHURCH	DAISY	RED																		
[]	[]	[]	[]	[]																		
	Optional	Category cue																				
		Multiple choke cue																				
PHONE	ORIENTATION	[] Date [] Month [] Year [] Day [] Place [] City			___/6																	
© Z.Nasreddine MD Version 7.0		www.mocatest.org		Normal ≥ 26 / 30	TOTAL ___/30																	
Administered by: _____		Add 1 point if ≤ 12 yr edu																				

**** Please staple a copy of the printed report to this form**

Section Four

Hospital Anxiety Depression Scale (HADS)

Below are a list of questions which are designed to let me know how you have been feeling. Please choose from one of the four responses which come closest to how you have been feeling during the past week. Don't take too long over your reply; your immediate reaction to each item will probably be more accurate than a long thought out response.

(A) I feel tense or 'wound up':

Most of the time	3
A lot of the time	2
From time to time, occasionally	1
Not at all	0

(D) I still enjoy the things I used to enjoy:

Definitely as much	0
Not quite as much	1
Only a little	2
Hardly at all	3

(A) 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

(D) I can laugh and see the funny side of things:

As much as I always could	0
Not quite as much now	1
Definitely not so much now	2
Not at all	3

(A) Worry thoughts go through my mind:

A great deal of the time	3
A lot of the time	2
From time to time, but not too often	1
Only occasionally	0

(D) I feel cheerful:

Not at all	3
Not often	2
Sometimes	1
Most of the time	0

(A) I can sit at ease and feel relaxed:

Definitely	0
Usually	1
Not often	2
Not at all	3

(D) I feel as if I am slowed down

Nearly all of the time	3
Very often	2
Sometimes	1
Not at all	0

(A) I get a sort of frightened feeling like 'butterflies' in the stomach:

Not at all	0
Occasionally	1
Quite often	2
Very Often	3

(D) I have lost interest in my appearance:

Definitely	3
I don't take as much care as I should	2
I may not take as quite as much care	1
I take just as much care as ever	0

(A) I feel restless as if I have to be on the move:

Very much indeed	3
Quite a lot	2
Not very much	1
Not at all	0

(D) I look forward to enjoyment to things:

As much as I ever did	0
Rather less than I use to	1
Definitely less than I use to	2
Hardly at all	3

(A) I get sudden feelings of panic:

Very often indeed	3
Quite often	2
Not very often	1
Not at all	0

(D) I can enjoy a good book, or radio, or TV programme:

Often	0
Sometimes	1
Not often	2
Very seldom	3

4.1

EQ-5D

By placing a tick in one box in each group below, please indicate which statements best describe your own health state today.

Mobility

I have no problems in walking about

I have some problems in walking about

I am confined to bed

Self-Care

I have no problems with self-care

I have some problems washing or dressing myself

I am unable to wash or dress myself

Usual Activities (*e.g. work, study, housework, family or leisure activities*)

I have no problems with performing my usual activities

I have some problems with performing my usual activities

I am unable to perform my usual activities

Pain/Discomfort

I have no pain or discomfort

I have moderate pain or discomfort

I have extreme pain or discomfort

Anxiety/Depression

I am not anxious or depressed

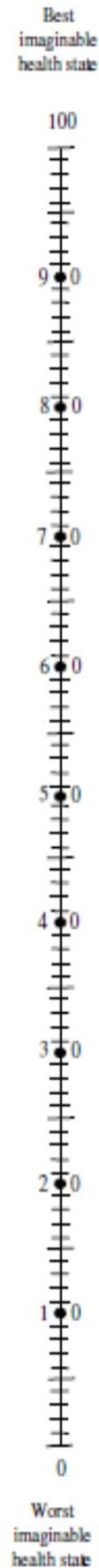
I am moderately anxious or depressed

I am extremely anxious or depressed

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

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

**Your own
health state
today**



Form (SF-36) (Australia/New Zealand, Version 1.0)

INSTRUCTIONS: This questionnaire asks for your views about your health, how you feel and how well you are able to do your usual activities.

Answer every question by marking the answer as indicated. If you are unsure about how to answer a question, please give the best answer you can.

1 In general would you say your health is:

(circle one)

Excellent	1
Very good	2
Good	3
Fair	4
Poor	5

2 Compared to one year ago, how would you rate your health in general now?

(circle one)

Much better now than one year ago	1
Somewhat better now than one year ago	2
About the same as one year ago	3
Somewhat worse now than one year ago	4
Much worse now than one year ago	5

3 The following questions are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

(circle one number on each line)

Activities	Yes Limited A Lot	Yes Limited A Little	No, Not Limited At All
a. Vigorous activities , such as running, lifting heavy objects, participating in strenuous sports.	1	2	3
b. Moderate activities , such as moving a table, pushing a vacuum cleaner, bowling, or playing golf.	1	2	3
c. Lifting or carrying groceries	1	2	3
d. climbing several flights of stairs	1	2	3
e. Climbing one flight of stairs	1	2	3
f. Bending, kneeling or stooping	1	2	3
g. Walking more than one kilometre	1	2	3
h. Walking half a kilometre	1	2	3
i. Walking 100 metres	1	2	3
j. Bathing or dressing yourself	1	c	3

4. During the past 4 weeks, have you had any of the following problems with your work or regular daily activities as a result of your physical health?

(circle one number on each line)

	YES	NO
a. Cut down on the amount of time you spent on work or other activities	1	2
b. Accomplished less than you would like	1	2
c. Were limited in the kind of work or other activities	1	2
d. Had difficulty performing the work or other activities (for example, it	1	2

took extra effort		
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5. During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

(circle one number on each line)

	YES	NO
a. Cut down on the amount of time you spent on work or other activities	1	2
b. Accomplished less than you would like	1	2
c. Didn't do work or other activities as carefully as usual	1	2

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

(circle one)

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

7. How much bodily pain have you had during the past 4 weeks?

(circle one)

- No bodily pain 1
- Very mild 2
- Mild 3
- Moderate 4
- Severe 5
- Very Severe 6

8. During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?

(circle one)

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

9. These questions are about how you feel and how things have been with you during the past 4 weeks:

For each question, please give one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks –

(circle one number on each line)

	All of the Time	Most of the Time	A Good Bit of the Time	Some of the Time	A Little of the Time	None of the Time

a. Did you feel full of life?	1	2	3	4	5	6
b. Have you been a very nervous person?	1	2	3	4	5	6
c. Have you felt so down in the dumps that nothing could have cheered you up?	1	2	3	4	5	6
d. Have you felt calm and peaceful?	1	2	3	4	5	6
e. Did you have a lot of energy?	1	2	3	4	5	6
f. Have you felt down?	1	2	3	4	5	6
g. Did you feel worn out?	1	2	3	4	5	6
h. Have you been a happy person?	1	2	3	4	5	6
i. Did you feel tired?	1	2	3	4	5	6

10. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc)?

(circle one)

All of the time	1
Most of the time	2
Some of the time	3
A little of the time	4
None of the time	5

11. How TRUE or FALSE is each of the following statements for you?

(circle one number on each line)

	Definitely True	Mostly True	Don't Know	Mostly False	Definitely False
a. I seem to get sick a little easier than other people	1	2	3	4	5
b. I am as healthy as anybody I know	1	2	3	4	5
c. I expect my health to get worse	1	2	3	4	5
d. My health is excellent	1	2	3	4	5

Section Five

5.0. I would like to ask you a few questions in regards to your ability to participate in various activities

- a. Are you able to participate in employment?
 (If yes) what do you do and what are your current duties?
 Have you changed your area of work due to health reasons?
 (If no) are you unable to work due to health reasons?
- b. Are you able to participate in household chores and yard work?
 (If yes) Which chores are you able to do?
 (If no) Is this due to health reasons?
 (both) Which chores do you find a struggle?
 (both) Which chores are you unable to do?
- c. Do you participate in any sporting/physical activities?
 (If yes) what are they?
 (if no) are you unable to do due to health reasons?
- d. Do you participate in any hobbies, leisure or social activities?
 (if yes) what are they?
 (if no) are you unable to do due to health reasons?

5.1. I would like to ask you some questions in regards to your health and wellbeing

- a. Can you describe to me how your health is currently?
- b. Have you experienced any difficulties/problems due to your health? (*for example emotional problems, physical problems, ability to do things*)
- c. (if yes) Where have things been difficult for you?
- d. What do you attribute your difficulties to?

5.2 (If participant has experienced a stroke)

- a. After your stroke what services or support did you find most helpful?
- b. What would you have liked to have known but were not told?
- c. What services or support do you feel were missing?

Appendix B

Factors Impacting on Lifestyle



Information Sheet

What is this study about?

Stroke is a major cause of disability in the adult population and has a huge impact on people's lives physically, psychologically and financially. Having a stroke affects a person's performance in everyday living and as such impacts significantly on their lifestyle. To enable a better understanding of the actual impact a stroke has on a person's life it helps to be able to compare those who have experienced a stroke to a similar group of people who have not experienced a stroke. This will provide a better picture of the areas of difficulty people face.

This study is being conducted as a Masters Thesis at the University of Waikato and aims to find out what impact a stroke has had on a person's lifestyle and their how they believe their stroke has affected their life.

Am I eligible to take part?

There are **two** groups needed for this study.

For the **stroke group** you are eligible to take part in this study if you are between 55-85 years of age, can speak and read high school English, have experienced a stroke as least two years ago and live independently in the community.

For the **non-stroke group** you are eligible to take part in this study if you are between 55-85 years of age, can speak and read high school English, have not experienced a stroke and live independently in the community.

What am I being asked to do?

If you agree to take part in this study, it will involve one session of approximately 2 hours. You will be asked to answer some questions about you, complete some simple puzzles, and complete an interview looking at your participation in activities and your experience and access to health related support. You can be seen in your own home or at the University of Waikato, whichever is most convenient for you.

What will happen to my information?

Be assured that no one will be able to identify you and all forms will be stored in a locked cabinet. The research team will conduct the analysis of the data. At the end of the study the paper-based forms will be destroyed. We will send an electronic summary of our findings to the participants who have indicated they would like to receive this information. The study has received ethical approval from the Department of Psychology Ethics Committee (ethics contact person Robert Isler, email r.isler@waikato.ac.nz).

What can I expect from the researchers?

If you decide to participate in this project, the researchers will respect your right to:

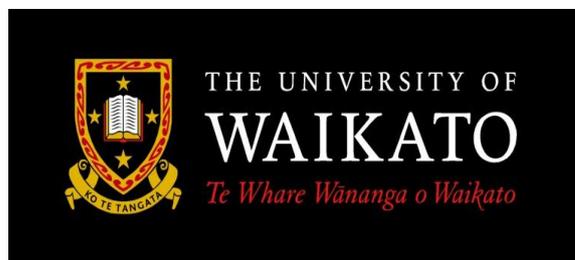
- ask any questions of the researchers about the study at any time during participation;
- decline to answer any particular questions or carry out any of the tasks;
- withdraw from the study;
- provide information on the understanding that it is completely confidential to the researchers. All forms are identified by a code number, and are only seen by the researchers. It will not be possible to identify you in any articles produced from the study;
- be given an electronic summary of the findings

Who can I speak with about my participation in this project?

If you, or anyone you know is interested in taking part in this research please contact **Kirstin Thomson** (Study

Co-ordinator) on ph 843 6865, or mobile 021 1763360, or via email at kmw20@waikato.ac.nz

Or contact Dr Nicola Starkey on 07
or email at nstarkey@waikato.ac.nz
HAMILTON STROKE CLUB



8562889 ext 6472

I would like to receive a summary of the results after the study.

Name.....

Address

Email

Appendix C

School of Psychology
CONSENT FORM

PARTICIPANT'S COPY

Research Project: Factors Impacting Lifestyle in a Community Based Stroke Population

Name of Researcher: Kirstin Thomson

Name of Supervisor (if applicable): Nicola Starkey

I have received an information sheet about this research project or the researcher has explained the study to me. I have had the chance to ask any questions and discuss my participation with other people. Any questions have been answered to my satisfaction.

I agree to participate in this research project and I understand that I may withdraw at any time. If I have any concerns about this project, I may contact the convenor of the Research and Ethics Committee (Dr Robert Isler, phone: 838 4466 ext. 8401, e-mail r.isler@waikato.ac.nz)

Participant's Name: _____ Signature: _____ Date: _____

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University of Waikato
School of Psychology
CONSENT FORM

RESEARCHER'S COPY

Research Project: Factors Impacting Lifestyle in a Community Based Stroke Population

Name of Researcher: Kirstin Thomson

Name of Supervisor (if applicable): Nicola Starkey

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